

Intestinal ostomy: Adversities and care strategies after hospital discharge*

Ostomía intestinal: dificultades y estrategias de cuidado tras el alta hospitalaria

Estomia intestinal: adversidades e estratégias de cuidado após alta hospitalar

*This study derived from the research titled "Experiences of people with intestinal ostomy after hospital discharge."

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Abstract

Objective: To describe the difficulties and advantages encountered by people after undergoing an intestinal ostomy and being discharged from hospital services.

Materials and methods:

Qualitative, descriptive, and exploratory study conducted at a teaching hospital. The study included people with an intestinal ostomy who were discharged within 60 days from the beginning of data collection, which occurred from March and June 2018. Data collection involved a semi-structured interview and thematic content analysis, resulting in thematic categories.

Results: A total of 11 people participated in the study. Factors such as the delay in defining the diagnosis, difficulties in the continuity of care at home, misinformation, and fear were identified as adversities by participants. Care actions were related to the existence of a support network and hope for the reconstruction of intestinal transit.

Conclusions: The care of people with intestinal ostomy requires planning hospital discharge, health education, strengthening care strategies that involve social support, and the involvement of health professionals for the continuity of health care at home.

Descriptors: Ostomy; Patient Discharge; Patient Care Team; Nursing (source: DeCS, BIREME).

Resumen

Objetivo: describir las dificultades y ventajas en el cuidado identificadas por personas con ostomía intestinal tras el alta hospitalaria.

Materiales y métodos: estudio cualitativo, descriptivo y exploratorio desarrollado en un hospital universitario. La muestra estuvo compuesta por personas con ostomía intestinal que fueron dadas de alta hasta 60 días antes del inicio de la recolección de datos, lo cual ocurrió entre marzo y junio de 2018. La recolección de datos se realizó por medio de una entrevista semiestructurada y análisis de contenido, lo que dio lugar a la formulación de categorías temáticas.

Resultados: la investigación contó con la participación de 11 pacientes, quienes identificaron a modo de dificultades aspectos como un diagnóstico tardío, limitaciones para dar continuidad a los cuidados en casa, desinformación y miedo. Las estrategias de cuidados se relacionaron con la existencia de redes de apoyo y la esperanza de recuperar el tránsito intestinal.

Conclusiones: el cuidado de personas con ostomía intestinal requiere planeación para el alta hospitalaria, educación en salud, fortalecimiento de las estrategias de cuidado que involucran redes de apoyo social y la activa participación de los profesionales de salud, con lo cual será posible dar continuidad a las prácticas de cuidado desde casa.

Descriptoros: Ostomía; Alta del Paciente; Grupo de Atención al Paciente; Enfermería (fuente: DeCS, BIREME).

Resumo

Objetivo: descrever as adversidades vivenciadas e as estratégias de cuidado identificadas por pessoas com estomia intestinal após alta hospitalar.

Materiais e métodos: estudo qualitativo, descritivo-exploratório, realizado em um hospital de ensino. Foram incluídas pessoas com estomia intestinal, que tiveram alta hospitalar em um período de até 60 dias a partir do início da coleta dos dados, que ocorreu de março a junho de 2018. Foi utilizada entrevista semiestructurada e a análise foi de conteúdo, resultando em categorias temáticas.

Resultados: participaram 11 pessoas. Como adversidades, identificaram-se a demora na definição do diagnóstico, as dificuldades na continuidade dos cuidados no domicílio, a desinformação e o medo. As estratégias de cuidado se relacionaram à existência de rede de apoio e da esperança pela reconstrução do trânsito intestinal.

Conclusões: o cuidado às pessoas com estomia intestinal requer o planejamento para alta hospitalar, educação em saúde, fortalecimento de estratégias de cuidado que envolvem suporte social e envolvimento dos profissionais de saúde para continuar o cuidado no domicílio.

Descritores: Estomia; Alta do Paciente; Equipe de Assistência ao Paciente; Enfermagem (fonte: DeCS, BIREME).

Introduction

The effects caused by a gastrointestinal stoma bring physiological and physical changes that affect patients' emotional and social spheres (1). A stoma is an artificially created opening, surgically performed in the abdominal region to deviate from the usual path of elimination or feeding. The elimination ostomies, temporary and permanent, are performed from the gastrointestinal tract (2).

Feelings of disgust and insecurity about the intestinal stoma in the postoperative period are common and bring challenges for those who live with this new condition. Family support and the bond created with the health team are factors that help in the struggle to understand living with an intestinal stoma (3). Abdominal pain, bowel dysfunction, physical mobility, and impaired home maintenance become obstacles for adaptation and contribute to the denial of the process and hopelessness towards future improvement (4). There is evidence that people with an ostomy have insufficient knowledge about self-care strategies and the complications that the ostomy and the deficient maintenance of the collection bag can cause, further stressing their lives (3). These impasses result in the worsening of the quality of life of these people, who can develop anxiety and depression symptoms (5).

In this context, the health care provided to people with an ostomy becomes essential and must be aimed at providing interdisciplinary care in both primary care and specialized services in order to encourage health promotion, the prevention of complications, and enhance self-care, whenever possible (6, 7).

However, assistance to people with an ostomy in Brazil differs from the national proposal and does not meet all the necessary demands of these patients (8). This problem is closely related to the lack of training and information by health professionals on the care required for the ostomy, which weakens the guidelines for hospital discharge and impairs the adaptation process of patients to their new reality (1).

The low number of studies on the topic makes the re-adaptation process difficult, which directly interferes with the construction of an adequate discharge plan for these patients (9). Thus, we observe the gap between hospital and home care, revealing the need to characterize the aspects that contribute to and

hinder the adaptation of patients with an ostomy to their new life, also reformulating the care strategies deployed based on the results of this research.

Therefore, the research question we propose is: What are the adversities experienced and the care strategies identified by people with an ostomy in their adaptation process after hospital discharge? The objective was to describe the difficulties and advantages encountered by people after undergoing an intestinal ostomy and being discharged from hospital services.

Materials and methods

Qualitative, descriptive, and exploratory research, carried out in a teaching hospital whose services are 100% offered within the Unified Health System (SUS, in Portuguese), and which counts on 403 inpatient beds. All participants met the inclusion criteria, which established having an intestinal ostomy and having been discharged from the hospital within a period of up to 60 days from the start of data collection, phase that took place from March to June 2018. People under 18, individuals with a previous diagnosis of cognitive deficit that could compromise the understanding of the issues addressed, and those with some restriction or clinical symptom that could hinder answering the research questions, such as pain or some type of discomfort, were excluded from the sample.

In order to select the participants, who were hospitalized at the institution, we had to access the information system called "Management Application for University Hospitals," in which the people who had undergone the intestinal ostomy surgical procedure and the corresponding inpatient unit were listed. With this information, we read patients' medical records to gather data on the date of the procedure, previous diagnoses, and their age, required to meet the inclusion criteria. From this, sampling was performed, with an option for the convenience sample. Later, visits were made to the patients' beds to provide information about the return appointment after hospital discharge, to invite them to participate in the study, and to clarify whether participation was voluntary. For those who agreed to participate in the research, the consultation and the interview would take place on the same day, which would be informed by telephone call.

A student in the last year of nursing education performed data collection. This person also participated in meetings in research groups and had experience

in qualitative data collection. The technique used for this process was the semi-structured interview, consisting of a script prepared by the student and a professor tutor. This instrument comprised four questions aimed at understanding participants' point of view on the research subject. We carried out a pre-test with people who did not meet the inclusion criteria in order to verify the feasibility of the questions, which asked information about the following aspects: tell me about your return home after surgery; guidelines received for hospital discharge; facilities and difficulties at home; implications of the ostomy for your family, social and work life.

We finished the interviews with the data saturation, that is, from the preliminary analysis of the data—carried out by the student and the professor who supervised the study—no new information was evidenced by the participants. Therefore, the collected data were considered sufficient to understand the phenomenon under scrutiny. No one refused to participate in the research and the sample consisted of 11 participants.

The interview was audio-recorded, prior consent of participants, carried out individually in a private room at the institution, and lasted from 30 to 40 minutes. The student and another member of the research group entirely transcribed interviews. Data analysis considered the proposal of content analysis technique (10), consisting of three stages: pre-analysis, through floating reading of the data; exploration of the material; and the treatment of results, inferences, and interpretations. After a detailed analysis of the organized material, the coding and organization of the results by thematic categories were carried out.

This research followed the ethical principles established by Resolution 466 and 510, under the opinion of the Ethics Committee at the Federal University of Santa Maria number 2,481,723. All participants signed the corresponding informed consent form.

Results

Sociodemographic characterization

Eleven people participated in the research. More than half (63.6%) were male, single (54.5%), and in the age range 48 to 81. The hospital stay was between 5 and 20 days. Cancer and other pathologies without a confirmed diagnosis were the main causes of the creation of a stoma. The time from the surgical procedure to hospital discharge was from 10 to 60

days. Table 1 shows participants' sociodemographic characteristics.

Data analysis enabled the construction of two thematic categories: Adversities experienced by people with an ostomy before and after hospital discharge and Care strategies identified by people with an ostomy after hospital discharge.

Table 1. Participants' sociodemographic characterization. Santa Maria, Rio Grande do Sul, Brazil (2018)

| Variables | No. (%) |
|------------------------------|----------|
| Gender | |
| Female | 4 (36.4) |
| Male | 7 (63.6) |
| Education level | |
| Incomplete elementary school | 7 (63.6) |
| Complete high school | 3 (27.3) |
| Complete higher education | 1 (9.1) |
| Marital status | |
| Single | 6 (54.5) |
| Married | 5 (45.5) |
| Income | |
| Retired | 7 (63.6) |
| Pensioner | 1 (9.1) |
| Illness benefit | 2 (18.2) |
| No remuneration | 1 (9.1) |

Source: authors.

Adversities experienced by people with ostomy before and after hospital discharge

In this category, patients described the adversities they experienced before hospital discharge that had a major impact on their health, and which include inadequate care and the obstacles found in the health system related to delays in the diagnosis and structural problems, such as lack of beds, as verified in the speeches below.

[...] to enter the system you have to enter the emergency care unit, where I stayed for six days until the surgery took place. I spent about four days in the hallway [...]. P09

[...] and it was all because of a hemorrhoid, which was hurting a lot and bleeding, so they sent me there

from City X but they never called me, until the disease got worse and one day I had to come here quickly because it was bad [...]. P10

Upon hospital discharge, patients should be instructed about the right to receive via sus the materials needed to exchange the collection bag at home and the documentation needed to access this equipment, such as the medical report. There were reports of problems in releasing the medical report necessary to remove the materials from health units. The bureaucratic process imposed by the health system on people with an ostomy in order to receive collection bags is an obstacle to access their rights and therefore reveals a load of logistical problems.

[...] they said that I had to have a report signed by the doctor who operated on me so that I could receive this bag. When I came from my brother's, I arrived here and explained to them and said "look, I couldn't be seen in City Z. They didn't want to give me the material because of this report." P10

Another situation reported was the patients' lack of information after hospital discharge. Guidance on procedures for changing the collection bag and peristomal skincare is insufficient to promote adequate health care at home. They registered the feeling of helplessness regarding health professionals.

[...] a lot of allergies, it was filled with little balls, it turned red. You know? Like when it's at the point where it's well chapped that it even looks like blood is going to come out [...]. P04

[...] at the health center, after I went there so many times, they asked me if I couldn't change [the bag] myself, with an unwillingness to provide assistance. And so, I decided not to go back there and change myself [...]. P10

There were reports of feelings of fear related to the painful experience of touch and contamination. These feelings may reflect insufficient information.

[...] I was afraid of touching there and hurt myself, of doing a deeper cleaning, of touching [...]. P02

[...] I think it's very scary, it seems like something very alive is there. You're afraid to touch it, of what's going to happen, of getting infected, of getting infection inside, something [...]. P04

Another feeling expressed was insecurity about the functioning of the stoma, which enhances the distancing of people with a stoma from their social life.

[...] we are afraid of inviting a person for dinner and that it suddenly starts to make noise. Even when we receive invitations to dinners, parties, we don't go because receiving them at your house is uncomfortable, now imagine you're going to someone's house, and suddenly your bag is full. How are you going to clean that at someone else's house? [...]. P03

The reports reveal that the adversities go from bureaucratic issues to define the diagnosis, through the continuity of care after hospital discharge and receiving misleading information, ending in feelings of fear.

Care strategies identified by people with an ostomy after hospital discharge

Regarding the care strategies required to face a new reality, some participants reported the hope of rebuilding the intestinal transit. We noticed that they understand the need to have the collection bag for their survival, but they want to improve their health status to go back to their routine.

[...] when I found out what I had, I wanted to get rid of it right away

[from the stoma]. What I want is to take it out at once and get everything back up and running and don't have to be changing and chasing these things [referring to collection bags] [...]. P10

The specialized sector was also reported as a resource that helps and facilitates the care of people with an ostomy. The support of health professionals and the relationship of trust built between them proved to be essential for patient's recovery, both physically and emotionally.

[...] Specialized sector X helps me in this part of changing the bag and instructing me at looking for other professionals I need, such as a psychologist, nutritionist, physiotherapist. I am well taken care of there. The professional is well trained, so he does everything right and guides me too [...]. P08

[...] if I could give a grade, I would give it a ten. A public service, SUS and everything else were very good, they were very attentive, the staff is very kind. I felt so well watched over there [...]. P11

The organization at home and the support of those who live with people with an ostomy favored coping with this moment of vulnerability and adaptation.

[...] we have the hygiene materials all separated; everything was purchased in order to clean. We have a sterilized basin, glove, cloth to put underneath, and a place to wash. We have all this preparation. What they were doing at the hospital, they are doing it here [...]. P06

[...] Ah, the adaptation was very difficult in the first days. The first

few days I had to be monitored by my wife. She is on vacation to be with me until I adapt, to clean... because for me this is new [...]. P03

[...] I couldn't do it alone, without the woman together... Alone I don't think I can. As I told you, we come home dizzy, we are weakened [...]. P05

The reported care strategies showed the importance of having a support network during the acceptance and rehabilitation process and the hopes put for the reconstruction of the intestinal transit. Despite the difficulties, these strategies can be considered the driving force that mobilizes patients in the process of adapting to a new reality.

Discussion

The testimonies regarding the adversities and strategies before and after hospital discharge were very important. As evidenced in participants' speeches, disagreement with the altered body image brings turbulence of thoughts and emotions related to the treatment and rehabilitation, which influences the adaptation to the new lifestyle (11). This process of learning how to take care for the ostomy is time-consuming and affects not only the patient, but also their family members. They are all affected in different ways, which makes learning and appropriation difficult, especially in the first months after the procedure (12).

The statements also showed the fear and concern of people with an ostomy to perform self-care because they do not know how to proceed. This insecurity increases when these patients are discharged from the hospital and encounter obstacles to access health services and obtain information (1). This is particularly evident in getting access to collection bags, since bureaucratic impasses make patients look for care in different places, thus putting themselves in charge of providing care and the immediate obtainment of materials for the sanitation of the stoma (8).

Hospital discharge is a delicate moment, as when leaving the hospital all physical and personal resources will no longer be available. At this point, care will start to be performed at home with the available resources. The first days at home become a challenge for the patients who will face the objectification

of their limitations, their new body image, and changes in routine and physiological habits, which generate feelings of sadness and insecurity due to the new physical condition (13, 14). Coping with this new reality could be less troubled if patients were informed and oriented about the functioning of the stoma. Therefore, it is urgent to optimize the health education provided to ostomy patients at hospital discharge.

In agreement with patients' statements, we identified in the literature that the lack of information provided during the hospitalization period about the continuity of care after hospital discharge is something common (8). Failures in health management such as the gigantic waiting lists for medical appointments and the lack of resources and trained professionals are examples that increase the feelings of sadness and despair by those who need care. The lack of information and qualified assistance can also generate health problems (1), such as dermatitis on the peristomal skin or accidents such as the rupture or detachment of the collection bag, thus leading to leakage of fecal content (15, 16).

Based on the above, we recommend educational activities in the postoperative period to inform about the care and functioning of the stoma, in addition to provide training on the hygiene required by the collection bag. This way, patients will be adequately prepared for home care and facing a new reality (17, 18). We also need to expand health care networks for these people, speed up diagnostic results, reduce waiting times for surgeries, and increase access to specialized care. Health professionals need to be trained and qualified to be able to properly guide patients and prepare them for hospital discharge, thus promoting autonomy and well-being.

The distancing from social activities pointed out in the interviews may be related to factors such as the physical restrictions resulting from the surgery, changes in body image and self-esteem, and the fear of social stigma related to having an ostomy, which also affect the acceptance process (19). Consequently, health professionals can act by developing awareness actions about the new body reality, informing the limitations and possibilities of living with an ostomy (20).

We found that people with an ostomy find it difficult to return to their occupational activities due to the feeling of loss or reduction in their productive capacity (21). Obstacles related to work activities and social integration are associated with insecurity towards the collection bag adhered to the abdomen

regarding leaks, odors, discomfort, and gases (21). In this sense, we observed once more the importance of health professionals in the development of educational actions, including guidance on food, clarifying which products are well tolerated or increase the production of gases and odors, so that these people can better manage their condition and return to their daily activities.

Although the literature highlights that health units are crucial mechanisms for comprehensive care in the health care network for ostomy patients (8, 22), the findings of this study showed that this type of services did not fulfill their function, particularly because they neglected providing care for the person with an ostomy. Professionals should offer a high quality attention that promotes self-care and prevents complications. Due to the characteristics of these health centers, they are closer to people's reality, which favors the bond with the patient and the effectiveness of health actions (22).

Living with an ostomy is, in many cases, having to reinvent oneself. People go through phases such as denial, fear, shame, insecurity, seeing their body changed, and all their routines transformed, since they now depend on other people to continue care at home. However, the support found after hospital discharge could contribute to the autonomy of the person with a stoma and the continuity of self-care.

The interviews mentioned the support of the specialized sector and the presence of the professional stoma therapist nurse in post-discharge care, which is the key to the qualified care of people with an intestinal stoma, both for the care required and for the information and guidance these professionals provide (23). The literature shows that nursing intervention in stoma therapy started in the preoperative period and continued in the postoperative period, promoting the construction of new knowledge and skills in the management of stoma care and favoring psychosocial adaptation to the stoma and a new quality of life (24).

People with an ostomy consider nurses essential in health care, feel calm knowing they can count on these professionals in times of weakness, and consider their presence important until they reach the autonomy that constitutes a key point for the acceptance of the stoma (23). Developing a mutual relationship between professionals and patients is important to resolve doubts and concerns, in addition to helping to face and accept the new reality (1, 4, 23).

The possibility of reconstituting the intestinal transit is also a factor that contributes to better cope with the situation, and patients do not mind undergoing a new surgery or the time it takes for it to occur. What really matters is knowing that their current situation will be reversed, although they may recognize the ostomy as an alternative that provides them with quality of life, minimizes suffering, and prevents health problems (11).

Living with an ostomy permeates physical, psychological, and social dimensions, in addition to the loss of autonomy and discouragement of self-care. Educational actions and support from family members help in the recovery of autonomy and the continuity of care after hospital discharge. Family support, together with the bond between nursing professionals and other team members, and educational activities enable the construction of knowledge for self-care with the active participation of patients, providing opportunities for them and their families to reflect on the situations in which they are involved, and demystify the ostomy process (25). These actions are considered essential and, if initiated during the hospitalization process and constantly performed in health care networks services, they will enable continuous and longitudinal care (26).

From the above, we could perceive that the adversities and the care strategies experienced by patients contemplate situations that people with intestinal ostomy face before and after hospital discharge, and that both of them are susceptible to transformation when health professionals are engaged and concerned with the health of the population. The presence of the nursing team, especially the stoma therapist nurse, is essential for strengthening care and for the quality of life of people with an ostomy.

The qualitative research method, which does not favor the quantitative sample nor the generalization of data, is not a limitation of the study. However, for this research, the self-reported data constitute a limitation since they contain potential sources of bias.

The results showed that the delay in defining the correct diagnosis and certain difficulties in the continuity of care after hospital discharge, due to misinformation and fear, are adversities experienced by people with an intestinal ostomy. Care strategies were related to the existence of a support network and hope for the reconstruction of the intestinal transit.

We expect to contribute to the reflections by health team workers regarding the care provided and to the planning of strategies that provide a more qualified care practice for people with an ostomy.

Conclusions

Adversities such as the delay in diagnosis and the lack of information received by patients with intestinal ostomy require the development of actions that allow these barriers to be eliminated. In addition, care strategies such as social support and access to surgery procedures to reconstruct the intestinal transit must be enhanced, hence qualifying health care.

We conclude that the care of people with intestinal ostomy requires knowledge and involvement of health professionals in order to overcome the adversities experienced before and after hospital discharge. Social support from people in close contact, specialized professionals, and the provision of services for the continuity of home care are also essential.

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