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Fragmented comprehensive health care for ostomized person in the health care network

Atenção integral fragmentada a pessoa estomizada na rede de atenção à saúde

Atención integral fragmentada a la persona ostomizada en la red de atención a la salud

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ABSTRACT

Objective: To identify the actions of multiprofessional care performed on the ostomized patient from the preoperative to the follow-up after hospital discharge. **Method:** Descriptive study with qualitative approach, developed in southern Brazil. Patients with a medical diagnosis of colorectal cancer who were using ileostomy or colostomy were included. Data collection was done in 2018 and through semi-structured interviews. The participants were randomly selected. Data analysis according to Minayo. Ethical aspects respected. **Results:** 15 individuals took part. It was identified that pre, postoperative and after discharge care are fragmented. Thus, the ostomized patient finds weaknesses in the care received in the Primary Health Care, being referenced to the specialized services. **Conclusions and implications for practice**: The individual does not receive adequate care in he new condition and it is in the specialized service where care is provided that the physical and psychological aspects are being cared. Results can contribute to health professionals and managers, in order to discuss and propose actions that ensure care continuity and quality in the health care network.

Keywords: Ostomy; Comprehensive health care; Primary health care; Health Services.

RESUMO

Objetivo: Identificar as ações de cuidado multiprofissional efetivadas ao estomizado do pré- operatório ao acompanhamento após a alta hospitalar. **Método:** Estudo descritivo de abordagem qualitativa, desenvolvido no Sul do Brasil. Incluem-se pacientes com diagnóstico médico de câncer colorretal, em uso de ileostomia ou colostomia. Coleta de dados em 2018, que se deu por meio de entrevista semiestruturada. Sortearam-se os participantes. Análise de dados de acordo com Minayo. Aspectos éticos respeitados. **Resultados:** Participaram 15 indivíduos. Identificou-se que os cuidados pré, pós-cirúrgico e após a alta hospitalar são fragmentados. Ainda, o estomizado encontra fragilidades no atendimento recebido na Atenção Primária à Saúde, sendo referenciado para o serviço especializado. **Conclusões e implicações para a prática:** O indivíduo não recebe assistência adequada em sua nova condição e é no serviço especializado que são realizados cuidados que contemplam aspectos físicos e psicológicos. Os resultados podem contribuir para os profissionais e gestores em saúde, no intuito de discutir e propor ações que garantam a continuidade da atenção e a qualidade do cuidado na rede de atenção à saúde.

Palavras-chave: Estomia; Assistência integral à saúde; Atenção primária à saúde; Serviços de saúde.

RESUMEN

Objetivo: Identificar las acciones de atención multidisciplinaria realizadas a los ostomizados en el período que se extiende entre el preoperatorio y el seguimiento después del alta hospitalaria. **Método**: Estudio descriptivo de enfoque cualitativo, desarrollado en el sur de Brasil. Se incluyeron pacientes con un diagnóstico médico de cáncer colorrectal con ileostomía o colostomía. La recolección de datos se realizó en 2018 a través de entrevistas semiestructuradas. Los participantes fueron elegidos por sorteo. Análisis de datos según Minayo. Se respetaron los aspectos éticos. **Resultados:** Participaron 15 personas. Se identificó que la atención recibida en el período pre y posoperatorio y después del alta es fragmentada. Además, se advierte un déficit en el servicio de salud brindado a personas ostomizadas en el ámbito de la atención primaria de salud, en lo que se refiere a servicios especializados. **Conclusiones e implicaciones para la práctica**: El sujeto no recibe asistencia adecuada en su nueva condición y es en el servicio especializado que se brinda la atención que abarca aspectos físicos y psicológicos. Los resultados pueden contribuir a que los profesionales y gerentes de salud logren debatir y proponer acciones que aseguren la continuidad de la atención y la calidad de la misma en la red de atención médica.

Palabras clave: Ostomía; Atención integral de salud; Atención primaria de salud; Servicios de Salud.

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INTRODUCTION

Currently, intestinal cancer contributes to the increase in abdominal surgical procedures, including colostomy and ileostomy. Estimate from the National Cancer Institute[1] predicts 36,360 thousand new cases of colorectal cancer (CCR), with 17,380 in men and 18,980 in women. This pathology corresponds to 36% of the most frequent reasons for performing intestinal stoma surgery.[2]

The term "ostomy" originates from the Greek *stómae*, which means opening and exteriorizing a hollow viscera, through the surgical act. These can be temporary, or definitive, depending on the possibility, or not, of reconstructing intestinal transit.[3]

In this sense, this condition demands articulated and multiprofessional care from health services. Fact that may be related to the different needs of the ostomized patient, with a view to adapting to the new condition.[4] In order to ensure that the patient has his autonomy and adaptation established, it is up to the health professionals to carry out educational actions, such as care guidelines in the preoperative period and, especially, in the postoperative period, as the patient and family need information that give them the ability to care for the ostomized at home. The effectiveness of these actions is essential for the rehabilitation of the patient and care at home. However, the authors infer that this occurs partially, which compromises the care.[5]

In addition, after hospital discharge, Primary Health Care (PHC), as well as the specialized service, which make up the HCN, must carry out planned assistance and include physiological and psychological aspects of the patient and his family, with a view to ensuring health integrality.[6] Therefore, it is essential that all professionals participate effectively in the care process, in order to guarantee its continuity and comprehensive health care.[7] However, evidence points to communication failures between the primary and secondary levels of health care.[8]

Among the weaknesses, it is observed that health services operate in an articulated way in the care network, still in an incipient process, which results in fragmented care, especially when caring for the ostomized patient. The need to strengthen the HCN is highlighted, which aims at comprehensive care, which will allow for continuous assistance, responding to the needs and particularities of each subject. Another aspect also refers to the incipience of studies about the theme and this population group that discusses the health care offered to these subjects in the HCN. In view of these aspects, it was established as a research question: What care is provided to the ostomized patient in the HCN? And, as the objective of the study, to identify the multiprofessional care actions performed on the ostomized patient from preoperative to follow-up after hospital discharge.

METHOD

This is a descriptive study, with a qualitative approach, which integrates a master's dissertation entitled "Knowledge and practices of care for ostomized patients in the health care network", developed in a municipality in the south of Brazil, with an estimated population of 83,173 people .

A nominal list of individuals registered in the Disabled Users Management (DUS) System with a CRC diagnosis was requested from the Municipal Health Department, in order to settle the participating population, where 29 users were obtained. Inclusion criteria are: Over 18 years old, with medical diagnosis of CRC, using ileostomy or colostomy. Individuals were randomly selected to participate in the study, with replacement of participants in case of refusal, thus, 15 participants were obtained.

Data collection took place during the first half of 2018, through semi-structured interviews (conducted by the first and third author). It includes closed questions that made it possible to characterize the study participants and open questions about the topic on screen, which allowed for dialogue and reflection on the studied theme.

The interviews were conducted at home, by prior appointment by telephone, in which the date and time of the interviews were established by the participant. It is important to highlight the difficulties encountered in this stage, due to incompatible addresses, recent deaths of participants, difficulties in accessing the home, etc.

First, it was suggested to the participant that the conversation be held in a quiet and private place, so that he could explain about his condition. Then, the objective of the study was clarified and, afterwards, it was explained that participation was voluntary and could be interrupted at any time. When the participant's acceptance was obtained, they signed the Free and Informed Consent Term (FICF) in two counterparts, one counterpart being for the study participant and the other, for the researcher.

Sequentially, the interviews began, lasting an average of 15 minutes, being fully recorded and transcribed. In order to guarantee anonymity, the study participants were identified by the letter p, followed by the sequential number corresponding to the interview, that is, from P1 to P15.

Data analysis was performed as recommended by Minayo,[9] in three steps: Ordering the data through the transcription of recorded interviews, reading, organization of interviews and identification of themes; classification of data based on the rereading of texts and material obtained, to identify common themes and, subsequently, to group them into categories according to the theme; and final data analysis, considering the theoretical basis and relating the data referring to the simple observation of the data, referring to the proposed objectives.

Ethical aspects were respected according to the Resolution of the National Health Council 466/2012,[10] and the project was approved by the Research Ethics Committee (CEP), under CAAE 80479417.2.0000.5322.

RESULTS

The study included 14 individuals who had an intestinal colostomy and one with an ileostomy, but all had definite stoma. Of these, 80.1% (12) were in the age group between 51 and 80 years old, 53.3% (8) were female, 40% (6), widowed and 33, (5) married. As for the occupation, 46.7% (7) were retired, and 53% (8) had incomplete elementary education. Still, 86.7% (13) of the respondents had an ostomized from one to five years.

The analysis of the testimonies allowed the identification of two categories of analysis: Multiprofessional care provided to ostomized patients from preoperative to follow-up after hospital discharge; Therapeutic itinerary and centralized care for the ostomized patient.

Multiprofessional care provided to ostomized patients from preoperative to follow-up after hospital discharge

A surgical procedure consists of several stages, which are called pre, trans and postoperative. It has its beginning established after the evaluation of the indication for the procedure, when the consent is obtained, and the surgical preparation begins. It appears that the guidelines in the preoperative period are fundamental, but it is observed that it often does not occur, as evidenced in the reports:

> *I was not advised before the procedure (P5, P6, P10, P12, P15).*
>
> *I was not guided, nobody ever said anything to me, I had no idea. And this is very important, because I never went through this and we need to be guided and explained what will be done (P13).*

In this sense, the guidelines aim to clarify the reasons that led to the need to make the stoma, whether it is temporary or definitive, its possible complications and the care that must be taken in handling and maintaining it.

It is also noteworthy that, in greater numbers, the study participants reported having received guidance from the multiprofessional team, as reported below:

> *Before the procedure, I was guided by the doctor (P2).*
>
> *[...]I was guided there at the hospital, it was from nursing (P3, P8, P14, P9).*
>
> *I was guided by the doctor, psychologist, and nursing at the hospital (P7, P1).*

Therefore, the importance of surgical guidelines is observed, in order to clarify doubts and facilitate the acceptance/adaptation process. In order to obtain humanized and qualified assistance, the participation of different professionals is necessary. The guidelines must be carried out independently of the professional in charge, therefore, they are not linked to a professional class. However, it is important to emphasize that the nurse, among all professional categories, is the one who stays the longest with the patient.

> *After the procedure, the nursing team helped and guided me (P8).*
>
> *After I had the surgery, yes, they told me, they guided my daughter (P9).*

Performing the guidelines requires professional competence, as well as knowledge, skills and attitudes to carry out this action. In addition, the actions must be individualized and consider the individual's prior knowledge, in order to answer questions and meet the needs of each patient. This aspect was also mentioned in the report of a study participant:

> *They changed the bag and showed me, but I didn't understand anything, I couldn't assimilate any of that, nobody told me when I had to clean, change, cut it (P12).*

In addition to the pre-operative guidelines, the post-operative guidelines are also decisive for the self-care, acceptance and quality of life. Therefore, health professionals need to be present in the postoperative period, offering constant support. In this sense, study participants expressed guidelines received in the post-surgical period:

> *I was instructed on hygiene, that I had to control what I ate, then I would control my intestines, [...]how to change the bag [...] (P10, P11).*
>
> *They explained to me what could happen, what it was for [...]they showed a lot about the bag, like what they had to do to wash and empty it, [...]that exchanges were done every 7 days [...] (P2, P3 P8, P13, P14).*

It is important to involve family members, as in many situations they will be the ones who will carry out the first care at home, such as changing the bag, cleaning, among other cares, therefore, they also need to be able to provide them. A fact that is also identified in the statements of the participants:

> *They told my family how to clean, change the bag, use all the products, how to cut, showing the models (P4, P5).*
>
> *My daughter was oriented at the hospital, I can't say (P9).*

Furthermore, the transfer of knowledge to the ostomized patient and his family can be carried out in numerous ways, which facilitate the apprehension of information. The use of booklets, guides, *folders* positively influences learning, a method that was also identified in the participant's speech:

> *They explained it to me, gave me a paper and read saying how to clean and change it (P7).*

All these actions favor teamwork as they contribute to qualified health care and standardize it.

Therapeutic itinerary and centralized care for the ostomized patient.

The care for patients with CRC starts at diagnosis and requires a trained professional team to prepare them for a probable surgical procedure, or another type of treatment, and this should start at the PHC. Having in view that they are assigned to this unit, and that the multiprofessional team knows their health/disease process and the bond that the patient has with the professionals of the unit. It is inferred, even though, even though the patient is referred to other parts of the HCN, such as a hospital, this care must be coordinated by the PHC.

In this sense, after the ostomy has been done and the patient discharged, the adaptation of the ostomized patient begins at home. It is enhanced after one realizes being at home, with no health professionals to perform the cares. Thus, before hospital discharge, professionals from the multiprofessional team must refer patients and family members to the PHC, with a view to continuing care. However, the participants revealed weaknesses in the counter-reference, as observed in the reports.

> *I was not referred to the neighborhood reference unit (P1, P2, P3, P4, P6, P7, P8, P9).*
>
> *I was instructed to go to the reference unit to get the colostomy bags (P10, P11, P12, P14, P15).*

It is noteworthy that the secondary care level must carry out the counter-referral to PHC, since effective communication between the different levels of care is important for the rehabilitation of the patient. However, the fragility is explicit in the reports of some of the study participants.

> *I had no follow-up from the referral health unit (P1).*
>
> *My wife looked for it, but they didn't want to see me that day (P3).*
>
> *I only go to the health unit for other things, but not to receive care for the colostomy (P14*).

The PHC is the gateway to health services and the originator of care in the HCN. However, study participants experienced difficulties made explicit in their reports:

> *[...]the nursing told my wife what the ostomized was, but they knew almost nothing [...] (P1).*
>
> *I only go to the health unit for other things, but not to receive care for the colostomy, because they don't know (P14).*
>
> *I am registered with the FHS of the neighborhood, but I go to the central post, because here in the unit nobody knows about it (P7).*

In this sense, it is highlighted that, in the municipality where the study was carried out, there is a specific space that performs care for ostomized patients. In it, a stomatherapist nurse and nursing technicians work. These professionals register the ostomized patients in a specific system, so that patients receive stoma care materials, free of charge, in addition to performing stoma care (skin, devices, nutrition, psychological support), as recommended by the National Guidelines for Health Care of People with Ostomized.

However, this does not take away the responsibility of the health professionals of the unit where the user is assigned to assist them. In addition, the assistance provided in the PHC must be resolute in the demands of individuals at home and, when necessary, the PHC team can seek support from the specialized team, however, there must be communication between the services. However, as noted in the reports:

> *I had no follow-up at the referral health unit, only the professionals at the center unit came twice (P1).*
>
> *The doctor said that any doubt was there at the central unit that they were going to help [...] (P12).*
>
> *I went to the neighborhood unit, but they instructed me to look for the downtown unit, because my bag had been released and I had diarrhea, then they sent me there, saying that they didn't know how to deal with it (P14).*

The highest percentage of respondents indicated that they only received adequate/specialized guidance and care when they contacted a specialized service. As evidenced in the reports of the participants in this study.

> *I received guidance, I was treated very well in the specialized service (P2).*
>
> *In the central unit it was 100%! There I learned everything (P8).*
>
> *The nurse at the specialist service showed me how to clean and change the bag, gave me some papers, and now it goes smoothly. After the nurse taught me, I had no more problems (P7).*
>
> *The nurse showed me how to clean and change the bag, gave me some papers, and now it goes smoothly. After she taught me, I had no more problems (P14).*

Therefore, one of the strategies carried out by the reference unit is the group of ostomized patients. Such aspects are explained in the statements:

> *[...]I started to go with the group, so I was guided by some food things (P15).*
>
> *[...]when I went to remove the bags at the center, I heard about a group of ostomized patients, so I started to participate (P15).*

In this way, the group is perceived as an effective and necessary intervention for the consolidation of self-care for the ostomized patient, as information about food, care for the stoma is made available, in addition to allowing social interaction. However, the occurrence of groups and a specialized center does not exempt the PHC from its responsibility towards these individuals.

DISCUSSION

The CCR covers tumors of the large intestine and rectum, and most of them affect the rectum and anus. In such cases, surgery is the treatment and maintenance option for life, which results, in most cases, in the construction of an intestinal stoma.[11]

However, it is observed that, sometimes, the performance of the surgical intervention can cause negative experiences, emotionally and physically, especially in surgeries in which an intestinal stoma is made. Thus, many individuals experience feelings of anxiety or fear due to the unknown, anesthesia, mutilation and even the possibility of death, when undergoing the procedure.[7]

In this sense, the monitoring of this patient in PHC may contribute to easing such feelings, because, based on the support received from the team, the patient can be better prepared to face this new condition. Thus, it is essential that the PHC multiprofessional team assist in the process of coping with the disease and subsequent phases.

According to authors[12], the preoperative phase comprises the moment of the patient's decision to undergo the procedure, until his transfer to the operating table. In it, the professionals of the multiprofessional team must carry out educational actions, in order to clarify doubts about the intervention, reduce the anxiety, stress and fears that the surgical intervention imposes.[5]

In addition, the guidelines in this phase contribute positively to avoid future complications, with a view to the patient's recovery, their quality of life, in addition to contributing to the acceptance of body change, and collaborate for the professional-patient interaction.[12]

It is noteworthy that a considerable number of participants in this research reported not having received guidance. And study[5] corroborates the results of the study on screen, as it highlighted that many of the participants did not receive guidance and/or did not remember if they had been guided.

When the patient does not receive guidance in the preoperative period, they are vulnerable to significant changes and the performed intervention may be perceived as traumatizing, since the individual is shaken by the information on the diagnosis, the surgical intervention and the construction of a stoma.[13]

Furthermore, the greater the stress and tension in the pre-surgical period, the greater the difficulties will be in facing the limits that the surgery imposes on the patient's daily life.[7] Regarding stoma cares, the author[14] points out that it is important to show images and intestinal stomas with and with no collection bag, to allow for the patient and their family to manipulate the materials they will be using, offer direct and real contact with the materials, to facilitate the acceptance of the new condition.

In this way, the effective educational actions have a positive influence on self-care techniques, acceptance of the new condition and adaptation to it. In the same measure, they allow patients to learn to take care of themselves, feel safe in the face of the situation and come to better understand what they are experiencing.[15]

Multiprofessional interaction is necessary and fundamental, as it encourages work integrated with a view to the well-being of the user and promotes the exchange of knowledge, the articulation of actions and integration between team members.[16]

In a study[11], the interviewees did not mention having received guidance from a nurse, related it to the doctor, and were directed to the surgical procedure, excluding self-care guidelines. In addition, in another study, 75% of the interviewees stated that they received guidance in the preoperative period, the majority being by nurses.[5]

The nurse is present since the diagnosis, before, during and after the surgical procedure, as well as in rehabilitation. Therefore, it is up to him to carry out educational actions aimed at the patient's autonomy, as he is responsible for the guidelines of self-care, mainly related to the handling of the stoma and the collection equipment.[15]

Authors[4] corroborate, when inferring that the teaching-learning actions are the function of the nurse and allow self-care and autonomy, consequently, they collaborate for the quality of life, living with their families and social reintegration, actions that can be identified in the statements.

The guidelines should be given in a continuous and systematic way, as they are effective for the acquisition and sharing of information, in addition to being an essential tool to obtain quality assistance.[5] The moment after surgery must be worked out in a specific way and using methodologies that guarantee the subject's understanding and involvement in self-care. [17]

In this phase, the guidelines should focus on skin care of the peristoma and exchange of collection bags, regarding eating habits, stoma hygiene and the collection device, in addition to encouraging self-care, which positively influences the adaptation process stoma and prevents complications.[18]

It is important to emphasize that, during this learning process, the family must be included. She intervenes as an important support network, as she acts as a mediator to face the situation experienced before and after hospital discharge, exercising care at home and providing emotional support.[2,4]

The family caregiver, in addition to stoma care, is responsible for emotional support, through dialogues, listening, explanations, advice, providing comfort and safety, reducing fears and anxieties of the person with intestinal ostomized.[2,4]

In this perspective, the use of educational materials is a mediator between the professional and the patient/family member, because, in addition to helping to assimilate the guidelines through texts and figures, they also represent an available resource so that they can consult you at the time of doubts.[19]

Since the surgical intervention and the hospital discharge, the individual will have the challenge of acquiring skills to live with the altered body and will experience a psychosocial transition.[7] In this sense, the ostomized person will live with significant changes in life, due to physical changes, which directly interfere with their lifestyle and require adaptation to their new condition.[2]

It is important that these patients counter-referral, in order for family health teams to provide care continuity. Which must meet the health demands of users assigned to a defined territory, with a view to developing comprehensive care, so that it may positively impact the health and autonomy of the individuals.[6]

However, according to the authors,[8] there are difficulties in the continuity of assistance determined by the lack of communication between the care systems. The same authors[8] emphasize the need for dialogue between the team at the primary and secondary care levels, with the patient and his family, in order to guarantee comprehensive and continuous care at home.

It is noteworthy that the PHC is considered the coordinator of care, with the role of ordering the HCN, in addition, it aims to facilitate the access of the population and is the gateway for health services, thus, it is up to the professionals working in the to carry out actions for the promotion, prevention, protection, diagnosis, treatment, recovery and rehabilitation of health[6]

Under a study[20] conducted with 16 PHC nurses, it was found that six of them had incipient knowledge about ileostomy and two were unaware of the theme, which shows a deficit in the training of this professional. Such findings are in line with a study[21] that identified insecurity and inadequate responses regarding the description of the equipment replacement procedure, showing the need for nurses to take over this topic.

Thus, in the face of these weaknesses, it is clear that the ostomized patient is not fully assisted by the team in PHC, which causes this individual to be unassisted in the HCN. In this perspective, the National Guidelines for the Health Care of People with Ostomy[22] guarantee comprehensive health care for people with stoma, which includes the provision of materials that favor self-care.

The discontinuity and disarticulation of the care networks allow the centralization of care and do not allow comprehensive health care.[23] A study infers that, when the ostomized patient arrives at the referral center, he has already gone through several points of the HCN, a fact justified by ineffective care, the occurrence of frustrating situations that explain the current fragility, represented by the experiences of ostomized patients who seek answers to their concerns from the professionals for their anguishes and, at some times, face the precariousness of information, as well as care.[23]

Most ostomized users only receive adequate guidance and care when they contact a specialized service.[24] Specialized assistance for people with a stoma aims at rehabilitation, with an emphasis on self-care guidance, by developing skills for carrying out their daily activities, preventing complications in stomies and providing collector equipment and protection and safety aids.[25]

The support group provides interaction between the participants, contributes to the sharing of experiences and favors social interaction. Living with other ostomized people is a method of acquiring knowledge through the exchange of experiences, as each participant faces adversity with a different perspective and, when these experiences are exchanged, the bond of trust is strengthened, making there is motivation to face the challenges.[18]

The authors[18] point out that this educational strategy makes it possible to unveil several challenges, bringing to the fore new perspectives on their physical condition, allowing greater autonomy and social participation. The ostomized patient requires different care and these have an impact on his life. Therefore, the attention of the multiprofessional team is important throughout their therapeutic itinerary,[26] care aimed at guaranteeing comprehensive care in the HCN.

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

Results allow to infer that the care actions offered in the pre and postoperative period are incipient, as well as the follow-up of these patients after hospital discharge, which weakens the comprehensive care, expected in the HCN. When accessing their reference BHU/FHS, ostomized patients are referred and oriented to seek care at the specialized service.

This service should be understood as supporting the assistance provided at the health unit where the user is registered, however, it is he who provides physical and psychological care to these users and their families. In this sense, it is important that the multidisciplinary BHU/FHS staff seize knowledge to meet the needs of ostomized individuals through continuous care actions, in order to develop skills and knowledge.

In this perspective, it is suggested that health professionals and managers rethink their work process, in order to respond to the users' care needs, given that the BHU/FHS should be the priority access and should solve most of the problems for the enrolled population. It is still necessary to carry out permanent education actions in order to enhance care practices and care management to respond to the demands arising from ostomized patients and their families.

The consolidation of comprehensive care for ostomized patients requires matrix support actions by the specialized service team for PHC teams, with a view to offering specific technical support to multiprofessional teams, which will qualify the care provided to the ostomized patients.

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