

## Nursing team's operation in dealing with elimination stoma terminal ill patients with in a Public Stomatherapy Service

### *Atuação da equipe de enfermagem frente ao paciente terminal com estomia de eliminação em um serviço público de Estomaterapia*

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Paczek RS, Luz JM, Tanaka AKSR, Duro CLM, Carvalho KP, Limberger JJ, Micheletti VCD, Durante K. Nursing team's operation in dealing with elimination stoma terminal ill patients with in a Public Stomatherapy Service / *Atuação da equipe de enfermagem frente ao paciente terminal com estomia de eliminação em um serviço público de Estomaterapia*. Rev Med (São Paulo). 2023 Nov-Dec;102(6):e-216740.

**ABSTRACT: Introduction:** the most frequent cause for the creation of an elimination stoma is colorectal cancer, which has consequences from individual's biopsychosocial spectrum and causing impacts on their self esteem, self image and life quality related to health. **Objective:** to report the experience in assisting terminal phase ill people with elimination stoma. **Method:** experience report type study on the care of terminal phase ill people with stoma, treated in a public stomatherapy service located in south of Brazil in 2023. **Results:** the majority of patients treated require care to replace the collection equipment or treatment of lesions on the peristomal skin. An increase in the number of patients in the terminal phase was observed, where some of them even facing difficulties in locomotion, using oxygen therapy, pain, dyspnea, still demonstrated great determination when attending the regular consults. **Conclusion:** terminal phase ill ostomized patients face significant challenges in their treatment, experiencing debilitating symptoms, pain, bodily changes and quality of life, as well as profound psychosocial impact and, often, difficulty in accepting not only the ostomized situation, but also the terminality situation itself, where the nursing team plays a crucial role in the process of guiding and supporting those patients.

**DESCRIPTORS:** Critical Illness; Nursing; Ostomy; Enterostomal Therapy.

**RESUMO: Introdução:** o câncer colorretal é a causa mais frequente para confecção de estoma de eliminação, o que traz consequências ao espectro biopsicossocial do indivíduo causando impactos em sua autoestima, autoimagem e qualidade de vida relacionados à saúde. **Objetivo:** relatar a experiência na assistência às pessoas com estomia de eliminação em fase terminal. **Método:** estudo tipo relato de experiência sobre o atendimento a pessoas com estomia em fase terminal, atendidas em um serviço público de estomaterapia no sul do Brasil em 2023. **Resultados:** a maioria dos pacientes atendidos necessita de atendimento para troca do equipamento coletor ou tratamento de lesões na pele periostomal. Observou-se um aumento no número de pacientes em fase terminal, onde alguns mesmo enfrentando dificuldades de locomoção, utilizando oxigenoterapia, dor, dispnéia, ainda assim demonstravam grande determinação ao comparecerem às consultas para acompanhamento. **Conclusão:** os pacientes estomizados em fase terminal enfrentam desafios significativos no seu tratamento, experienciando sintomas debilitantes, dor, mudanças corporais e de qualidade de vida, bem como impacto psicossocial profundo e, muitas vezes, dificuldade de aceitação não apenas da situação de estomizado, como também da própria terminalidade, onde a equipe de enfermagem desempenha um papel crucial no processo de orientação e apoio a esses pacientes.

**DESCRITORES:** Estado terminal; Enfermagem; Estomia; Estomaterapia.

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## INTRODUCTION

Several causes lead to the making of a stoma, among them neoplastic diseases, inflammatory bowel diseases, trauma, and congenital diseases, where colorectal cancer is the most frequent malignant neoplasm of the gastrointestinal tract, with surgery as the main treatment, depending on the extent of the procedure and the location and size of the tumor<sup>1,2</sup>.

Therapy is often not limited to surgery alone, but also includes additional treatments such as chemotherapy and/or radiotherapy. Although chemotherapy is an essential tool in the fight against cancer, it can have significant side effects, among the most common being hair loss, nausea, fatigue, loss of appetite, and low immunity. In addition, patients undergoing chemotherapy can experience long-term effects on their health, such as heart problems, organ damage, and cognitive difficulties<sup>3</sup>.

For those who have already undergone ostomy surgery, chemotherapy can represent a further challenge, affecting not only the body but also their emotional health and adapting to their new reality. These patients must receive holistic care, covering both cancer treatment and the support needed to cope with the physical and psychological changes resulting from the presence of the stoma and the effects of chemotherapy<sup>3</sup>.

The presence of a stoma has significant consequences for the biopsychosocial spectrum of the individual who, often after being diagnosed with a terminal illness, sees their chances of staying alive tied to a bag attached to their abdominal wall, causing impacts on their self-esteem, and self-image and health-related quality of life<sup>4</sup>. These patients end up facing transformations in their body's functioning, which often have a negative impact on their quality of life and well-being, potentially affecting them biologically and psychologically, making it extremely important to provide emotional support to minimize the difficulties of adapting to their new reality<sup>5</sup>.

Nurses are one of the health professionals who have a great deal of interaction with the feelings of insecurity, frustration, impotence, and emotional distress that terminal patients experience. Given the above, these professionals are subject to emotional distress and anguish as a result of this interaction. Death, despite being a natural fact, can be perceived as a process and not an end, and care in the last days of life can also be demonstrated by listening to, understanding, and respecting the patient<sup>6</sup>.

Terminality is understood as the onset of a situation where death will be the outcome, despite the therapeutic measures used, where the measures adopted are designed to alleviate suffering, as the search is no longer for a cure for the disease<sup>7</sup>.

Considering the impact of the stoma on the individual, the aim is to present the experience of professionals working in a public stomatherapy service in southern Brazil in assisting people with terminal stomas. In this way, it seeks to make the issue visible, as there has been an increase in the number of patients with terminal illnesses being monitored in the service in recent years, which has made the authors reflect on terminality and how they can help patients and the multi-professional team when faced with this scenario.

The study covers the cases of five terminally ill patients

with an elimination stoma who made an appointment with a nurse at the Stomatherapy Service in 2023. The patients were emaciated, had difficulty walking, and all used opioids for pain control. One of the patients also used a wheelchair and oxygen therapy. Most of them had intact skin and were using two-piece collection equipment. During the visits, we realized that the search for our services went beyond the clinical aspect; the patients were looking for a space to talk, to be listened to, and to receive attention from the nursing team. We then implemented specific treatment plans, promoted open and transparent communication, and sought to improve the patient experience during consultations, with the intention of strengthening their trust in our team.

## METHOD

This study is a report on the experience of nurses and nursing students in caring for people with terminal stomas in a public stomatherapy service in southern Brazil in the first half of 2023.

The specialized public service where the study was carried out treats patients with stomas from Monday to Friday, from 8 am to 3:30 pm. The stomatherapy service's team includes a nurse stomatherapist, two nursing technicians, a coloproctologist, a psychologist, a nutritionist, an administrative assistant, and a receptionist. It serves around 650 users with elimination stomas, of both sexes and different age groups, living in the catchment area of the city where it is located.

## RESULTS

Appointments with the nurse, to begin follow-up in the service, are scheduled via the municipality's computerized system by the primary health care units to which the users are linked in the territory where they live, or when they register with the stoma therapy service. The stoma sector has six appointments a day, two of which are for new patients and four for return and follow-up appointments. Even so, extra appointments are made almost daily to meet the demand of patients who come to the service without an appointment for urgent reasons, such as a bag detaching, a leaking bag, changing the bag ahead of schedule, doubts, and clarifications.

During the first consultation, the patient's anamnesis is taken, as well as an assessment of the stoma, an indication of the most suitable collection equipment for the type of stoma, and guidance on the use of materials and changes at home, when necessary. The stomatherapy service acts as a training ground for nursing students and residents, so the initial consultations and daily care almost always involve the participation and work of a graduate student or specialist. Most of the stomatized patients in our care have an elimination stoma as a result of neoplastic disease, and some of these patients need weekly care to help change the collecting equipment or treat lesions on the peristomal skin.

The motivation for carrying out this study was due to the significant increase in the number of patients with neoplastic diseases in an advanced stage or terminal phase who came for

care. Some of the patients, even though they have difficulty getting around and/or are using oxygen therapy, complain of pain and are using opioids, have dyspnea, difficulty eating, and have lost a lot of weight, and yet these patients show great determination when they attend follow-up appointments. They show confidence in the service and report that they feel safe changing their bags at the referral service, often more so than with family care, caregivers, or other professionals. A bond was established with these patients, as their bags were changed once a week or more. As a result, the nursing team was able to closely follow the suffering they face when dealing with the disease, which causes anguish for professionals when they are faced with the continuous progression of the disease at each consultation/service.

Throughout this process, a deep respect and empathy were developed for patients facing this challenging condition. Accompanying their suffering reaffirms the purpose of the nurse's work on a daily basis, encouraging them to look for ways to provide even more humane and welcoming care. Despite their anguish in the face of adversity, they find inspiration in the courage and determination they show with every visit. The dedication to creating an environment of trust and mutual support between the nursing team and the patients grows stronger every day, in the constant search to offer the best possible support, in the hope of making their lives more comfortable and meaningful during this challenging period.

Among the team, conversations and discussions about the cases are held at the end of each service, in which each professional and student expose their knowledge, perceptions, and feelings related to the patient's history, seeking a better understanding of the clinical and psychosocial situation of each service user.

## DISCUSSION

The main causes of colorectal cancer described in the literature are associated with ethnic or hereditary factors; behavioral factors such as diet, physical inactivity, alcohol, and tobacco use; and health-related factors such as depression, colonization by multidrug-resistant microorganisms, ulcerative colitis, Crohn's disease and familial adenomatous polyposis<sup>8,9</sup>.

Worldwide, colon/rectum cancers are the third most common cancer in men and the second most common in women, behind lung and prostate carcinomas in men and breast cancer in women<sup>9</sup>. Despite advances in diagnosis and treatment, this form of cancer continues to be one of the main causes of mortality worldwide because it is often diagnosed late, which can be explained by the asymptomatic state of the individual or by the manifestation of non-specific symptoms<sup>10</sup>.

It can also be seen that the human development index (HDI) of each region, which measures the degree of economic development and quality of life in countries, has an influence on the types of cancer and the incidence rates of cases, and there is a relationship between regions with a higher HDI and a higher incidence of colorectal cancer, for example<sup>9</sup>. In more developed regions, it is common for the population's eating habits to change, with an increase in the intake of red meat, fats, ultra-

processed foods, and total calories<sup>11</sup>.

This is in line with the reality in Brazil, where there is a notable disparity in both the incidence and mortality figures for colon/rectum cancer between the states, with the highest figures concentrated in the Southeast, Midwest, and South regions, which have the highest HDI in the country<sup>9,11</sup>. The National Cancer Institute (INCA) has an estimated incidence of 45,630 new cases of colon and rectal cancer in the current year<sup>12</sup>.

The prognosis of this type of cancer is related to the existence of problems during the course of the disease, including intestinal obstruction, colon perforation, gastrointestinal bleeding, anemia, weight loss, fistulas, intussusception, and ischemia<sup>10</sup>. Given that these symptoms are present in more advanced cases of the disease and are often the complaints that lead patients to seek medical attention, it is natural that they are also the main problems that trigger the surgical procedure to make the stoma, which consists of externalizing part of the digestive system, diverting the normal transit of physiological needs<sup>8,10,12</sup>.

A stoma can be temporary or permanent, depending on the characteristics and extent of the disease in the body. However, it is a very invasive procedure that brings significant changes to the user's life<sup>8</sup>. Acceptance of the stoma patient's new condition is often not an easy process and some social roles come into question when that individual, who used to be a totally independent person, suddenly finds themselves stuck with a collection bag to dispose of their waste<sup>4</sup>.

A number of factors can make it difficult for people with ostomies to adapt to using a pouch, including the volume of the pouch, which cannot be easily disguised by clothing, lack of control over bowel function, gas, and unwanted odors. Many people with stomas go through states of denial, anger, isolation, and depression until they begin the process of accepting their new health condition; these phases vary for each person and can last for different lengths of time<sup>4</sup>.

Inadequate care of the intestinal stoma can lead to various complications, especially on the stoma mucosa and peristomal skin, such as skin lesions, abscesses, hernias, infections, stenosis, prolapse, retraction, folliculitis, peristomal varices, hemorrhage, necrosis, among others. The occurrence of these complications is multifactorial and may involve the way the stoma was made, its location, the age of the individual, as well as inadequate care for the procedure<sup>13</sup>.

The stomatherapist or trained nurse is the main professional responsible for guiding the person with the stoma towards self-care, assessing the condition of the stoma, the peristomal skin, the aspect of the effluent, also advising on existing equipment, and choosing together with the patient which will be the best equipment to use<sup>14</sup>. The care provided by the health team to the person with the stoma will help them adapt to their new living conditions, and strengthen the bond with family members and professionals, which will have repercussions on the rehabilitation process and strengthen their self-esteem, stimulating self-care. For this to happen, health professionals need to be properly prepared to guide people with stomas<sup>15</sup>.

Various tools and technologies help the work of the stoma nurse or nurse who works with stomas. These

technologies range from hygiene products and skin and stoma care to teleconsultations and the use of apps. The use of apps by health professionals is growing in Brazil and around the world, as they are formulated with a scientific foundation, in order to improve the clinical assessment of the stoma and peristomal skin and provide accurate guidance on the prevention and treatment of complications, while also giving terminal patients a better quality of life. These technologies should be used increasingly, as they provide greater support and safety for nurses who work with stomas<sup>16</sup>.

Terminality represents a critical stage in a patient's healthcare journey, which demands a compassionate and specialized approach from the nursing team in a public Stomatherapy service. When a patient with an ostomy faces a terminal condition, they are faced with a series of emotional, physical, and psychological challenges. The nursing team, in this context, plays a fundamental role in promoting the patient's quality of life, offering comprehensive support to deal with the complex issues surrounding terminality. This includes not only the proper management of the stoma but also the provision of palliative care aimed at relieving symptoms, reducing suffering, and providing dignity to the terminally ill patient<sup>17</sup>.

The nursing team plays a crucial role in the process of guiding and supporting these patients since in the specialized outpatient clinic they are the closest professionals and therefore end up strengthening bonds, providing strategies for regaining self-esteem, self-care and helping throughout the stages of acceptance. It should be recognized that these professionals also suffer from the complexity of terminality, often facing emotional challenges related to the journey of the users they accompany.

Nursing professionals are constantly dealing with terminality in their work environment, so the process of death becomes a trigger of anxiety for nurses. Faced with this situation, they strive to cure the patient, but the outcome is often a prolongation of the patient's suffering and that of everyone involved: patient - family - professional, and this inevitably

forces them to face situations related to the finitude of the human being<sup>18</sup>.

Funes, et al. (2020)<sup>19</sup> identified in their study that the majority of nursing staff who deal daily with issues related to terminality perceive death as a complex, painful, and difficult-to-accept phenomenon, especially when it comes to oncology. In the teams' day-to-day work, this approach is still precarious, and it is necessary to address the issue with the multi-professional teams, providing space for dialogue and with a view to easing professionals' suffering when faced with such situations.

## CONCLUSION

This study highlights the fundamental importance of care and support provided to patients with neoplastic diseases, with a focus on colon and rectal neoplasms, predominantly seen at the clinic where the study took place and with a notable increase in cases in recent years, and especially to those patients who are in an advanced or terminal stage of the disease.

Both in direct care and in the literature, it can be seen that stoma patients living through the terminal phase of their illnesses face significant challenges in their treatment and care journey, experiencing debilitating symptoms, pain, bodily changes, and changes in quality of life, as well as a profound psychosocial impact and, often, difficulty accepting not only the situation of being a stoma patient but also terminality itself.

Finally, this study highlights the complexity of the issues surrounding terminality and the quality of life of patients with advanced or terminal carcinoma. For these cases, the optimal approach is multidisciplinary, comprehensive, and empathetic, seeking to provide comprehensive care and constantly seeking best clinical practices. In addition, it is important to look for more inclusive public health policies that help in the search for more humanized care and guarantee these patients a better quality of life.

**Authors' participation:** Rosaura Soares Paczek: literature review, data analysis, writing, and final review of the manuscript. Jessica Martins da Luz: literature review, data analysis, writing of the manuscript. Ana Karina Silva da Rocha Tanaka: analysis, writing, and final review of the manuscript. Carmen Lúcia Mottin Duro: literature review, analysis, and final review of the manuscript. Jordana Jahn Limberger: literature review, writing, and final review of the manuscript. Vania Celina Dezoti Micheletti: analysis, writing, and final review of the manuscript. Karla Durante: literature review and final review of the manuscript.

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Received: 2023, October 03

Accepted: 2023, December 22