

# Care in the Ostomates Programs: the multidisciplinary team's perspective

Assistência no Programa de Ostomizados: perspectiva da equipe multidisciplinar

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### ABSTRACT

**Objective:** to interpret the multidisciplinary team's perspective on care for ostomates. Methods: qualitative study involving five professionals from the multidisciplinary team of the Ostomates Program, based on the Social Model of Disability. To collect the data, a focus group, participant and non-participant observation were used, along with a field diary, interpreted using the thematic analysis method. Results: the experience of this team was interpreted based on the theme Challenges for the implementation of the Ostomates Program and the respective thematic nuclei: In search of teamwork and Specialized care demands for intestinal ostomates, which evidenced the influences on the work and the need for improvements in care, infrastructure and human resources. Conclusion: the health professionals' integration among different public healthcare levels and the ostomates and families' participation influence the care for ostomates. Descriptors: Ostomy; Disabled Persons; Health Personnel; Health Services; Public Health Policy.

## RESUMO

Objetivo: interpretar a perspectiva da equipe multidisciplinar sobre a assistência às pessoas estomizadas. Métodos: estudo qualitativo, com cinco profissionais da equipe multidisciplinar do Programa de Ostomizados, fundamentada no Modelo Social da Deficiência. Coletaram-se dados com grupo focal, observação participante e não participante, além do diário de campo, que foram interpretados pelo método de análise temática. Resultados: a experiência desta equipe foi interpretada ao partir do tema Desafios para implementação do Programa de Ostomizados e dos respectivos núcleos temáticos: Em busca do trabalho em equipe e Demandas de assistência especializada para pessoas estomizadas intestinais, os quais evidenciaram as influências no trabalho e a necessidade de melhorias assistenciais, de infraestrutura e recursos humanos. Conclusão: a assistência aos estomizados foi influenciada pela integração dos profissionais de saúde, de diferentes níveis de atendimento no sistema público, pela participação das pessoas estomizadas e famílias. Descritores: Estomia; Pessoas com Deficiência; Pessoal de Saúde; Serviços de Saúde; Políticas Públicas de Saúde.

## Introduction

The implementation of specialized care for ostomates, in line with the national guidelines of the Brazilian Unified Health System, was consolidated through the publication of Ministry of Health Decree 400, in 2009, regarding the organization of this service in all Brazilian states<sup>(1-2)</sup>.

In addition, the rights of ostomates gained strength when the condition of disability was recognized through the implementation of the National Care Program for People With Disabilities, which provided for accessibility to health, rehabilitation and work, to achieve independence and social reintegration, representing the state of Social Welfare<sup>(1,3-4)</sup>.

Therefore, integration was needed between the tertiary and secondary care levels, through the counter-referral of these patients from the hospital to the Ostomates Program, considered the gold standard as it ensures the legal right to specialized care and the receipt of collecting equipment and protective and safety devices<sup>(5-6)</sup>. In Brazil, this strategy for the continuity of care between the different levels was called responsible or qualified discharge.

To implement the responsible discharge, further investments have been necessary in hospital care for the health of these people, who have lacked professional training to demarcate the ostomy site in the preoperative period, and in teaching about the surgery and its consequences; and, in the postoperative period, for the preparation of hospital discharge, including the teaching of specific care, in addition to postoperative adaptations to daily activities for the family member and, when possible, for the patient<sup>(5-6)</sup>. To offer health care to these people, the interrelation among the different points of the public system has become indispensable.

The sociodemographic, clinical and therapeutic characteristics of these patients and of the collectors and adjuvant devices offered in different Brazilian regions have been used to dimension the extent to which the implementation of Decree 400 has benefitted the patients attended at these services<sup>(2,5-7)</sup>. The evaluation of this implementation in the country, as a public health policy, still lacks consistent data though on the progress, especially with regard to the allocation of resources and the achieved results<sup>(1-2)</sup>.

Thus, looking deeper into the experience of the multidisciplinary team may add aspects of care and management of material and human resources, aiming to strengthen the reflection on the challenges in the care practice of the team professionals, which are related to the targeting of actions, deriving from epidemiological data and the lack of evaluation parameters of the Ostomates Program<sup>(1-2)</sup>.

Thus, the objective was to interpret the multidisciplinary team's perspective on care for ostomates.

## Methods

Qualitative study involving the multiprofessional team of the Ostomates Program in a city in São Paulo State, composed of the nurse, nursing assistant, nutritionist and physician, as well as the voluntary psychologist of the Ostomates' Association, who were experienced in care for ostomates, complying with the selection criterion.

The five professionals were contacted personally and meetings were arranged, being one in March and another in April 2017, according to the participants' availability. Data collection took place through an interview using the focus group technique<sup>(8)</sup>, with the five professionals, during the two meetings, held in a private room at an outpatient clinic. The participants were identified as professional (P1 to P5), according to the order of participation in the first focus group. Each meeting lasted one and a half hours and was recorded on an audio device.

One moderator conducted the focus group, using participant observation during the meetings. The three observers were responsible for non-participant observation and the individual field diary during the two meetings. The non-participant observation and the field diary were fundamental to identify behaviors, consistency and possible inconsistencies in the reports of each participant, essential for data triangulation in the analysis and interpretation of a qualitative study<sup>(9)</sup>.

We used a guide, prepared with specific objectives for the first meeting, using the questions: in your opinion, how should self-care for the intestinal ostomy and collecting equipment be approached for these patients and family members? Have you been able to work on this out with the patient and the family? For the second meeting using the guide, the guiding question was focused on: How do you participate in the rehabilitation and, for you, what is the function of self-care for these patients and families? The participants validated the data through the synthesis at the end of each meeting.

The data were interpreted through inductive content analysis, according to the proposal of thematic analysis, which followed the recommended steps for the transcription of the data set, in text form, by the leading researcher, reading to categorize the data, establishing themes and interpreting the participants' experience, based on the reference framework of the Social Model of Disability<sup>(10)</sup>.

The study complied with the Brazilian requirements for research involving human beings. Approval by the Research Ethics Committee of the proposing institution was obtained in opinion 896,782/14.

## Results

The five professionals who constituted the team of the Ostomates Program participated in the professional focus group. Their average age was 45.4 years, with a predominance of women, length of experience in the specialized service between four and 20 years, specialization degree and only two professionals had background experience with intestinal ostomates, prior to the current relationship.

The experience of these professionals was categorized based on the theme Challenges for the implementation of the Ostomates Program, composed of two thematic nuclei: In search of teamwork; and Demands for specialized assistance for intestinal ostomates.

### In search of teamwork

The Ostomates Program had existed for more than 20 years in the Unified Health System in the city surveyed and consisted of a coloproctologist, a stomatherapist nurse, a nursing assistant and a nutritionist. The nursing team worked exclusively in the program, while the other members provided care in certain periods of the week according to a schedule (Field diary).

The continuous bond with the ostomate and family members was considered one of the important points for the team's specialized work: *The meetings here are sporadic* (Field diary: Ostomates Program), *they pass by every three months and we always instruct them, whether they experience difficulty or not, but the nurse has the closest contact... We do not interfere in the treatment, I cannot be antiethical, but the response to guidance by means of letters to the team staff is good* (P4).

On the other hand, the nutritionist indicated that her role depended on the clients' acknowledgement that nutritional monitoring is important: *1* think that the problem is the patient's lack of accountability, understanding of the importance of the nutritionist and those who comply and come to me, they notice a big improvement, particularly with respect to flatulence and very loose bowels, where the bag gets loose and doesn't last, you change it several times and it hurts the skin (P3).

The Ostomates Program, like others at the specialty outpatient clinic under investigation, had a psychologist, with a very busy agenda for appointments, which made it unfeasible to attend to everyone. Hence, to make it possible to attend to newly registered patients, when difficulties were observed to cope with the novel condition as an intestinal ostomate, the nurse asked the psychologist to attend, who is a volunteer at the Ostomates Association and experienced with these clients: *Psychology's work is to raise that patient's awareness on the acceptance and her responsibility* (Field diary: self-care for the ostomy and the collector device), *because that is impor-*

tant, for you to take care of yourself... in the case of the ostomy... if he accepts the ostomy, if he does not feel guilty (P5).

The family was another aspect reported, which favored the work of the multidisciplinary team, because it is considered a fundamental support network in the rehabilitation of intestinal ostomates. The family was important to the patient, to enhance the action of social support, despite the fact that some ostomates go through this experience lonely (Field diary): *I don't think the family is as important as the patient, I think the patient is responsible for him-/herself, and the family also helps a lot, but the main responsible for him-/herself is the patient, I think that the main work has to be done with the patient, the family as this support. We cannot charge the family with the responsibility, I have to do a lot of work with this patient, because he will be responsible for changing the bag, for his illness, his emotional state, so the main focus is the patient* (P5).

In these reports, the professionals were clear about the functions in the health program investigated, acknowledging the responsibility and complexity of care for the intestinal ostomate, which required specialized care, with emphasis on the patients and family members' participation (Field diary).

Each professional performed his/her own function, but had greater expectations about the work of the team which, due to the members' different bonds and hour loads, had difficulties to hold meetings in which all members participated. This was evidenced as an important and immediate demand: *The professionals who work on behalf of the ostomate should exchange more information, because each works in an individualized way, I do this, you do that, there, no one communicates, so sometimes I do one thing, the doctor does something else ... and it does not match! There should be more communication... I really miss that* (P5).

As verified, each of the team professionals understood the particular importance of each member and believed in the need to complement the other professional's action but, yet, they had not been able to accomplish specialized care with a comprehensive vision. Despite the recommendation for ostomates and family members to be attended by the multidisciplinary team, the health program under study still persisted in a juxtaposition of individual actions, as it was not always possible to meet all the demands (Field diary).

In addition to the absence of a psychologist in the program, the lack of a social worker was identified. Previously, when the nurse identified the need for a social worker to attend, this professional, who also attended another health program, was summoned. Despite the transfer to another service, this professional was not replaced. Since then, the nurse became responsible for registration in the Ostomates Program, which served 90 cities, resulting in a burden for this professional, who was also responsible for registering these patients' socioeconomic issues (Field diary).

The concreteness of the multidisciplinary team professionals' work in promoting the patient's independence was related to the fact that the patient actively assumes the new condition: *But, it is hers* (Field diary: ostomate), *she needs to assume what is hers... then, psychology enters, the nurse let's assume what's yours... touching it is like a private part!!! It's yours, we'll take care of what's yours... you do not wash yourself, brush your teeth, clean your ears, let's take care, assume what is yours. We need to address the patient's independence and not his dependence, we grant the initial support and work with this independence!* (P5).

#### Specialized care demands of intestinal ostomates

The different participants reported on the specialized care demands for intestinal ostomates, linking them with professional actions. For the nurse, teaching self-care for the ostomy and the collector devices, as well as the adaptations to a new situation, were fundamental actions, since the start of care for this clientele: *The guidance we give to the patient about self-care is the basis he has in the reality, which is a new situation, different from what he has already experienced and as we have already discussed… full of mysticism, so, the issue of us guiding this patient, demystifying situations and guiding… it is fundamental, so that he can live with the bag more appropriately later on, much less traumatic, the adaptation process, in the first months, it is a little more difficult for him and we end up staying on top a bit more (P1).* 

For the psychologist, the ostomate's acceptance of the situation favored the care in the program: In fact, it is the patient who should accept it first, but it is difficult ... because you agree that our feces is the ugliest thing we have, so if you'll see the ugliest I have and if you accept it without problem, I'm calm, now if you don't accept it, how am I going to expose this as it comes. So the way you handle it, it changes everything! (P5).

For the physician, the ostomy was a mutilation that restricted some of the patient's living activities, however, this was justified by the goal of saving lives. The scope of psychosocial rehabilitation depended on the ability to cope with the ostomization process though, approaching the physical disability as part of this: You realize that, no matter how adapted you are, there is a restriction of social, family, affective, sexual life, it changes the person's life. It's a mutilation, but we don't tell them that, it's incontinence ... urinary and fecal (P4).

This professional acknowledged that patients treated in hospital institutions, who received specialized care, generally did not present greater rehabilitation problems. Patients who had not received this care though, and even patients who had difficulties in accessing the program, presented problems to assimilate information and needed customized follow-up: *Even in large services, with a good structure and support from stomal therapists, you see that when the patient arrives here, he heard, but he did not understand, he heard, understood, but he did not want to do it, I think this is individual, you have to work on this part more, give more assistance ... but, those who come from another city, where there is no service and stomal therapist, it is complicated* (P4).

The physician noted that the demarcation of the ostomy in hospital care influenced the work in the programme, despite recognizing that, in some cases, the surgeon could not make the ostomy in the established site, due to the patient's clinical condition and physical characteristics or for other reasons, such as the lack of training of the physician, and the lack of integrated work with the stomal therapist nurse: *And there's the detail of the team making the ideal ostomy and, some times, the location of the ideal ostomy is not good for that patient, not marking the abdomen, being unable to bring up the handle and, often, who does this at home is the student and, nevertheless, the tu*- tor cannot advise or you're on your own in the morning and have to manage, do it and later, they come back to scold you because you did it wrong. Regarding the demarcation, the nurse said it, but that's not where I demarcated ... but, the handle did not come, so the ideal is not possible (P4).

The professionals who worked in perioperative care were appointed as responsible for welcoming the patient and relative, for the teaching that addressed the health status, the surgery and the consequences of this (ostomy) and care for the ostomy and collector device, nutritional aspects, follow-up with the psychologist, as well as the need for possible adaptations to the life changes. Upon the hospital discharge, when the counterreferral to the Ostomates Program was performed for the sake of registration, acquisition of collector devices and adjuvants, this was a condition that permitted the continuity of specialized multiprofessional care (Field diary): And when he arrives here, we try to talk with the family for guidance, we try to see things from the other side, try to make him think that it is not a big deal as he is imagining, we try to make the person understand ... that's our role. Now, sometimes, it also depends on the family's acceptance, sometimes the family does not accept it, but we try to do this work with them (P2).

The ostomates returned monthly, to get collector devices, which were dispensed by the nursing assistant and, every three months, they returned for medical consultation to maintain their registration active (Field diary). There was one report about the care offered in the program that involved the managers: *I* think we even do global work, even multidisciplinary... to optimize the patient's acceptance of the bag, see what guidelines have been provided and know how he is doing, the fact of placing the bag, dealing with it, the routine ... I think not only in relation to the patients, but to try and explain to the administration that does not want to spend and on the need to have quality bags, which is ideal and necessary for the patient (P4).

From the participating professionals' perspective, despite the reported difficulties, the ostomate achieved the rehabilitation: *That is when he returns to normal life* (P5). *Rehabilitated is when you get rid of the role of victim!* (P3).

For the professionals in the health program

surveyed, the intestinal ostomates demanded specialized and customized care, teaching and evaluation of the ostomate's self-care capacity, the supply of collector devices, according to the need presented, in addition to the professionals' acknowledgement on the importance of the multidisciplinary team's action in the clients' rehabilitation.

# Discussion

The limitation of this study was the participation of professionals from a single regional hub of ostomates in the Unified Health System, which could be expanded with perspectives of professionals from other regions in future studies on the implementation of care for ostomates.

The goal of the results presented is to contribute to the improved implementation of care in the Ostomates Program and in the different levels of health care, providing comprehensive care to intestinal ostomates and their relatives, as well as with the ongoing education of the multiprofessional team.

Specialized care planning for ostomates should involve an interdisciplinary team, with joint actions to stimulate the ostomate's ability to cope with the illness and its repercussions, for the sake of making decisions that fit the needs, in view of the physical disability's limitations. In this perspective, the teaching of self-care presupposes going beyond the implementation of a procedure, including psychosocial aspects for the purpose of adaptation and the adoption of a new lifestyle<sup>(2,5-6)</sup>.

The joint work of the nursing team and the psychologist helped the ostomates with the physical and psychosocial adaptation, stimulating the understanding of the need for the ostomy, which favored the adaptation to the new lifestyle and the accomplishment of self-care. When the independence for the development of the ostomate's capacity for self-care was strengthened, gradually, the internal time and limitations were respected, for the purpose of adaptation and adoption of the new lifestyle as a person with a physical disability, enabling physical and psychosocial rehabilitation in everyday life<sup>(2,11)</sup>.

After the surgery, teaching self-care for the ostomy and collector equipment to the patient and family was fundamental to permit greater independence and increase the self-confidence of the family member, until the ostomate person was able to perform it alone. Feelings of insecurity, fear and doubt marked this phase. The teaching of self-care by the specialized intra-hospital team was essential for the achievement of rehabilitation, as well as the counter-referral to the specialized health program for the continuity of care<sup>(2,5-6,12-15)</sup>.

During the first month after the ostomization, the person and family should be monitored and supervised closely, as they would not yet be fully adapted to the new health condition, a crucial stage for lifestyle change. This professional support was important for self-confidence and for them to assume the care at home more independently. On the other hand, in those people who were unable to assume self-care, this was generally due to the non-acceptance of the health condition or the family member who did not permit the opportunity to assume it, keeping the patient more dependent on the professionals or the family caregiver, even with accommodated or passive behavior<sup>(5-6,11-16)</sup>.

Decree 400 focused on the regulation of care in the Ostomates Program. The Type I Service consisted of a clinician, nurse and social worker, involving actions like teaching self-care, prevention of complications in the ostomy and peristomal skin, supply of collector equipment, protective and safety adjuvants; Type II minimally consisted of a clinician, nurse, social worker, psychologist and nutritionist, which defined the actions of Service I, including the treatment of complications in the ostomy and peristomal skin and the training of public health professionals<sup>(1-2,5-6)</sup>.

For the implementation of these actions, there is a need for integration with the primary and tertiary health care institutions of the Unified Health System, but the service where the study was conducted, despite being a type II service, was unable to provide training to public health professionals. Therefore, the challenge was to maintain the continuity of specialized care, defining actions for each professional on the specialized team, in the different spheres of health care, with a hierarchy of care.

In this sense, the daily challenges of the multidisciplinary team were related to the implementation of Decree 400<sup>(1-2,5-6)</sup>, especially in relation to the operational aspects of this health program. Indicators of the dimensions of these challenges included the lack of replacement of the social worker and psychologist, different bonds of the team professionals, hardly efficient strategies for the patients and family members' compliance with comprehensive self-care, inefficient hospital counter-referral, which compromised the rights of these clients, in line with other studies<sup>(2,7,11-17)</sup>.

On the other hand, the need was evidenced for the professionals to adopt theoretical frameworks in the implementation of actions that could broaden the understanding of the situation these people face, as well as effective permanent education, with the participation of the health managers<sup>(1-2)</sup>.

In the planning of care for the ostomates and their family, in health institutions, the perspective of the Social Model of Disability favors the implementation of comprehensive care because, in addition to including specific care for the intestinal ostomy and collector equipment, the psychosocial aspects, the adoption of a new lifestyle, in view of the physical disability, and the removal of social barriers for social reintegration are considered. This enhances the scope of physical and psychosocial rehabilitation for the ostomates<sup>(2,5,10,13-17)</sup>.

Hence, establishing a line of care for ostomates in the public healthcare system, based on the Social Model of Disability, can benefit specialized care, with a focus on teaching self-care for the ostomy and the collector equipment, for the patient or family member. This can also address the concept of physical disability in the fight against stigma and prejudices, rupturing social barriers, thereby increasing the scope of rehabilitation, which involves the continuing education of the healthcare professionals who provide care to this group, in the different levels of care in the Unified Health System<sup>(1-2,5-6,10,17)</sup>.

The evaluation of the Ostomates Program, as a health policy, runs through the dynamics of interrelations between the profile of the people attended, the perspectives of the actors in this context of care, the actions of the multidisciplinary team, with the establishment of parameters for the evaluation of results, based on a theoretical model, adding quantitative and qualitative aspects<sup>(1-2,18)</sup>.

The challenges of the multiprofessional team, analyzed in this study, can contribute to the definition of each professional's interventions and to the discussion of evaluation parameters of the Ostomates Program, aiming to strengthen the Care Network for Disabled People in the Unified Health System.

## Conclusion

The interpretation of the multidisciplinary team's experience in the Ostomates program showed the challenges to implement care for ostomates in the Unified Health System, in view of the need to teach self-care and supply collecting devices, as well as the urgent integration of the different health care levels, indicating improvements in hospital care, in the counter-referral of this clientele and communication between professionals, aiming to favor the effectiveness of this service, involving both the ostomates and their family.

## **Collaborations**

Sasaki VDM, Teles AAS and Sonobe HM cooperated with the design and project, data analysis and interpretation. Russo TMS, Aguiar JC and Paraizo-Horvath CMS contributed to the formulation of the article, relevant critical review of the intellectual content and final approval of the version for publication.

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