






## Impacts of a psychoeducational group on the self-care of people with ostomies

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### ABSTRACT


**Objective:** To analyze the perceptions of individuals with elimination ostomies regarding the repercussions of participating in a psychoeducational group aimed at strengthening self-care. **Method:** This qualitative, descriptive, and exploratory study included thirteen individuals with elimination ostomies who participated in a psychoeducational group developed in a specialized stomatherapy clinic affiliated with a public higher education institution in the state of Rio de Janeiro. Data were collected through semi-structured interviews conducted either in person or by telephone, according to participants' preferences, and were subjected to thematic content analysis. **Results:** Before joining the group, participants reported experiences marked by negative and traumatic feelings related to the ostomy, difficulties in managing collection devices and accessories, limitations in self-care, and limited psychosocial support. After participation in the psychoeducational group, positive transformations were observed, including increased knowledge, greater confidence in self-care, strengthened autonomy, reframing of the ostomy experience, and a perceived improvement in quality of life. **Conclusion:** Participation in the psychoeducational group proved to be an effective strategy for strengthening self-care and autonomy among individuals with elimination ostomies by promoting emotional support, exchange of experiences, and access to reliable information, thereby contributing to adaptation to the ostomy condition and to comprehensive care.

**DESCRIPTORS:** Enterostomal therapy. Self-help groups. Self-care. Colostomy. Ileostomy.

## Impactos de um grupo psicoeducativo no autocuidado de pessoas com estomias

### RESUMO

**Objetivo:** Analisar a percepção de pessoas com estomias de eliminação acerca das repercussões da participação em um grupo psicoeducativo voltado ao fortalecimento do autocuidado. **Método:** Trata-se de um estudo qualitativo, descritivo e exploratório. Treze pessoas com estomias de eliminação participaram de um grupo psicoeducativo desenvolvido em uma clínica especializada em estomaterapia vinculada a uma instituição pública de ensino superior no estado do Rio de Janeiro. A produção dos dados ocorreu por meio de entrevistas semiestruturadas, realizadas presencialmente ou por contato telefônico, conforme a preferência dos participantes. Os dados obtidos foram submetidos à análise temática de conteúdo. **Resultados:** Antes de ingressarem no grupo, os participantes relataram vivências marcadas por sentimentos negativos e traumáticos relacionados à estomia, dificuldades no manejo dos equipamentos coletores e adjuvantes, limitações no

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autocuidado e fragilidade do apoio psicoemocional. Após a inserção no grupo psicoeducativo, foram evidenciadas transformações positivas, com ampliação do conhecimento, maior segurança no autocuidado, fortalecimento da autonomia, ressignificação da experiência com a estomia e melhoria percebida na qualidade de vida. **Conclusão:** A participação no grupo psicoeducativo mostrou-se uma estratégia potente para o fortalecimento do autocuidado e da autonomia de pessoas com estomias de eliminação ao promover apoio emocional, troca de experiências e acesso a informações qualificadas, contribuindo para a adaptação à condição de estomia e para o cuidado integral.

**DESCRITORES:** Estomaterapia. Grupos de autoajuda. Autocuidado. Colostomia. Ileostomia.

## Impactos de un grupo psicoeducativo en el autocuidado de personas con estomías

### RESUMEN

**Objetivo:** Analizar la percepción de personas con estomas de eliminación sobre las repercusiones de la participación en un grupo psicoeducativo para el fortalecimiento del autocuidado. **Método:** Estudio cualitativo, descriptivo y exploratorio. Participaron trece personas con estomas de eliminación integrantes de un grupo psicoeducativo desarrollado en una clínica especializada en estomaterapia vinculada a una institución pública de educación superior en el estado de Río de Janeiro, Brasil. La producción de los datos se realizó mediante entrevistas semiestructuradas, llevadas a cabo de forma presencial o telefónica, según la preferencia de los participantes. Los datos obtenidos fueron analizados mediante análisis de contenido temático. **Resultados:** Antes de la participación en el grupo, los participantes relataron vivencias marcadas por sentimientos negativos y traumáticos relacionados con el estoma, dificultades en el manejo de los dispositivos colectores y adyuvantes, limitaciones en el autocuidado y fragilidad del apoyo psicoemocional. Tras la inserción en el grupo psicoeducativo, se evidenciaron transformaciones positivas, con ampliación del conocimiento, mayor seguridad en el autocuidado, fortalecimiento de la autonomía, resignificación de la experiencia de vivir con un estoma y mejora percibida en la calidad de vida. **Conclusión:** La participación en el grupo psicoeducativo se mostró como una estrategia potente para el fortalecimiento del autocuidado y la autonomía de las personas con estomas de eliminación, al promover apoyo emocional, intercambio de experiencias y acceso a información calificada, contribuyendo a la adaptación a la condición de estoma y al cuidado integral.

**DESCRIPTORES:** Estomaterapia. Grupos de autoayuda. Autocuidado. Colostomía. Ileostomía.

## INTRODUCTION

Elimination ostomies constitute a chronic health condition that imposes significant changes in individuals' lives, affecting physical, emotional, social, and cultural domains. The need to adapt to the use of collecting devices, changes in body image, challenges related to autonomy and self-care, as well as coping with social stigma, may compromise quality of life and psychosocial well-being. In this context, self-care emerges as a central element for adaptation to the new life condition, requiring not only technical skills but also emotional, informational, and social support<sup>1</sup>.

Nursing, especially in the field of stomatherapy, plays a fundamental role in supporting individuals with ostomies through educational actions that promote autonomy, empowerment, and comprehensive care. However, traditional educational strategies, focused exclusively on the transmission of information, may be insufficient to encompass the complexity of experiences associated with ostomy. Thus, approaches that value listening, the sharing of experiences, and the collective construction of knowledge become relevant in addressing the demands imposed by this condition<sup>2</sup>.

In this sense, psychoeducational groups are presented as an important healthcare strategy. These groups are aimed at understanding the emotional, cultural, and cognitive dimensions of individuals, considering feelings, beliefs, values, and knowledge, with the objective of stimulating reflection and promoting transformation through educational and communicative strategies. Such interventions enable the conversion of vulnerabilities into strengths and contribute to coping with health and illness situations, strengthening participants' capacity for adaptation and protagonism<sup>2</sup>.

The literature shows that participation in psychoeducational groups is associated with benefits such as improved psychosocial well-being, reduction of adverse symptoms, prevention of relapses, and strengthening of individuals' social integration<sup>3</sup>. In addition, when grounded in active teaching-learning methodologies, these spaces foster the active participation of individuals in the educational process, promoting critical reflection on their life trajectories, recognition of limitations and potentialities, and the development of strategies for self-care<sup>3</sup>.

Despite the advances observed, studies that explore, from the perspective of the participants themselves, the repercussions of psychoeducational groups on the self-care of individuals with elimination ostomies are still incipient. Understanding these perceptions may contribute to improving health education practices, supporting the work of stomatherapy nurses, and strengthening scientific production aimed at the comprehensive care of this population<sup>3</sup>.

Given this context, the present study focuses on the perceptions of individuals with elimination ostomies who participated in a psychoeducational group regarding the repercussions of this experience on self-care. The group, named ESTOUBEST, aims to promote discussion circles with a holistic approach, enabling the exchange of experiences related to ostomy care, the experience of health situations, and the pursuit of autonomy in self-care. In addition, the group seeks to provide support to participants and to articulate with extension and research projects, enhancing health education actions, fostering comprehensive care, and contributing to strengthening scientific production in the field of nursing in stomatherapy.

## OBJECTIVES

The objective of this study was to analyze the perception of individuals with elimination ostomies who participated in a psychoeducational group, particularly with regard to the repercussions of this experience on the strengthening of self-care.

## METHODS

This is a qualitative, descriptive, and exploratory study, grounded in thematic content analysis as proposed by Bardin. Data production was carried out through semi-structured interviews conducted with patients with ostomies who participated in a psychoeducational group developed in a specialized stomatherapy clinic.

The study was conducted in a stomatherapy clinic linked to a public higher education institution located in the state of Rio de Janeiro, part of a health complex that serves users from different municipalities within the state. Access to services occurred through a national health regulation system, which organizes the referral of users across different levels of care. In this context, a psychoeducational group aimed at patients with ostomies followed at this unit was developed, which constituted the setting in which the study participants were included.

The participants in this study were individuals from the psychoeducational group who voluntarily agreed to contribute to the research. The inclusion criteria were: being 18 years of age or older; having had an elimination ostomy for at least six months (a condition that favors a more consolidated understanding of living with an ostomy); and having participated in at least two group meetings, in order to ensure sufficient basis to report their experiences in greater depth.

Patients who did not have cognitive conditions to describe their experiences in the group, those whose ostomy care was performed exclusively by family members or caregivers, as well as those who, due to emotional issues, were not able to discuss their health-illness process were excluded from the sample. At the end of the screening process, 13 participants fully met the established criteria and were included in the study. All selected participants agreed to take part in the study by signing the Informed Consent Form.

The data collection technique was the semi-structured interview, whose script consisted of two parts. The first aimed to capture participants' social and clinical characteristics: age, biological sex, gender, duration of the elimination ostomy, duration of participation in the group, and reason for the construction of the ostomy.

The second part aimed to apprehend aspects related to the object of study; for this purpose, three questions were developed:

1. How did you care for/deal with your ostomy before joining the group?
2. How do you care for/deal with your ostomy as a result of your participation in the group?
3. Describe your experience participating in the group, highlighting positive or negative aspects of this participation.

No pilot test was conducted.

The interviews lasted, on average, 20 minutes and were conducted either in person, at the stomatherapy clinic, or remotely, via telephone, according to participants' availability and preference. Of the 13 interviews conducted, eight took place in person and five remotely. The study employed audio recording as a data collection strategy. The records obtained were stored digitally, under the custody and responsibility of the researcher, and will be kept for a period of five years after the completion of the study. Throughout the entire process of data storage and handling, technical and ethical procedures were adopted to ensure the confidentiality of information and the preservation of participants' privacy.

Data were collected in May 2023. Field notes were taken during the interviews in order to record important statements and the sequence of the conversation, thus ensuring accuracy and the capture of immediate contextual details. Transcriptions were typed in Microsoft Word, and the transcribed interviews were sent to participants for validation; no feedback indicating the need for corrections or changes to the content was received. To ensure anonymity, participants were identified by a code generated after the consent process. Data saturation was considered during the data collection process and was reached when the interviews began to show recurring information without the emergence of new elements relevant to the study objectives, indicating the sufficiency of the empirical material obtained. This condition was observed from the tenth interview onward, when the content began to repeat consistently.

For data treatment, the content analysis technique was used, which aims not only to understand the explicit meaning of communication but also to identify underlying meanings, revealing implicit messages of a psychological, sociological, political, or historical nature<sup>4</sup>.

Through the application of this technique, four empirical categories emerged:

1. Dialectical feelings regarding the ostomy prior to participation in the psychoeducational group;
2. Self-care prior to participation in the group: limitations, lack of information, and challenges;
3. Transformations experienced in the psychoeducational group; and
4. Facilitators and barriers to participation in the psychoeducational group: perceptions regarding personal engagement.

It is important to highlight that, upon agreeing to participate in the study, the Informed Consent Form was provided in two copies, with one copy retained by the participants and the other by the researcher, in order to clarify the purpose of the study and the possible risks associated with participation. The present study was approved by the Research Ethics Committee through Plataforma Brasil, under CAAE: 68696923.8.0000.5282 and approval opinion number: 6.011.173.

## RESULTS

The mean age of the participants was 52 years, with the majority being of the female biological sex (11 out of 13 interviewees). The average duration of living with an ostomy was approximately six years. Among the participants, eight reported having lived with an ostomy for more than 35 years, while five others had an ostomy for a period of six months, having undergone reversal after this interval.

The causes attributed to the creation of the ostomies were: colorectal cancer (eight participants), inflammatory bowel disease (three participants), abdominal trauma resulting from a work-related accident (one participant), and postoperative complications (one participant). All participants attended two or more meetings and had been involved in the group for more than one year.

## Dialectical feelings regarding the ostomy prior to the psychoeducational group

Considering the data obtained, it was found that the majority of participants (69.2%) reported that, prior to participating in the group, they had negative feelings about the ostomy and experienced difficulties with self-care:

*I was lost; I didn't know how to cut the pouch properly, use the spray, or that paste. I didn't know anything about the ostomy. (C6)*

The ostomy and, consequently, the use of the collecting device were associated with suffering and shame:

*Dealing with an ostomy is quite frightening; it causes a lot of fear, shame, and sadness. I was very scared. I received almost no guidance on how to manage the ostomy during hospitalization. (C3)*

However, there were mentions of positive perceptions and feelings regarding the ostomy, especially in relation to how it was accepted after surgery:

*My urostomy has never been a hindrance in my life, even though I didn't know what an ostomy was. (...) I love my pouch, and that's what I try to convey to others. It saved my life. (C9)*

## Self-care prior to participation in the group: limitations, lack of information, and challenges

This category allows for an understanding of how participants performed self-care prior to their experience in the group, analyzing the prior knowledge they possessed, regardless of their participation in the initiative. It also highlights the limitation of practical knowledge related to self-care, mainly attributed to the scarcity or absence of guidance from the healthcare team.

Participants reported difficulties in managing the ostomy, especially with regard to hygiene, as well as the selection and proper use of collecting devices and adjuvants:

*It was horrible; I would get so nervous, not knowing how to cut things, [the colostomy], and my skin would become irritated. (C1)*

*Before participating in the group, I would wash my abdomen, then apply egg white and put the pouch on top, and that was it. (C8)*

*I was afraid to handle it; I didn't have the confidence to clean the ostomy. (C12)*

## Transformations experienced in the psychoeducational group

This category made it possible to understand the positive changes promoted by the psychoeducational group in the participants' lives, as well as to identify situations perceived as unfavorable or challenging. In addition, suggestions for improvements in certain practices and educational dynamics used during the meetings were captured, while actions already implemented and considered effective and beneficial were highlighted.

Participation in the group contributed to several advances, such as greater ease in handling the ostomy, better acceptance of one's condition, and the adoption of a lighter, more autonomous, and healthier lifestyle:

*Now it's better; I already change the collecting device, perform hygiene on my own, and I'm more adapted. I used to do this with my daughter's help, but now I do it by myself; the group helped me a lot. (C3)*

*Currently, I get along very well with the ostomy, taking good care of the pouch and being more independent. Participating in the group was beneficial. (C5)*

*After participating in the group, I teach at the clinic to the women who are training how to perform the treatment, including bowel irrigation. (C6)*

*I adopted all the nutrition guidelines and care practices I learned in the group into my life. I gained confidence in them. I felt that it benefits me, and it really does. (C12)*

## Facilitators and barriers to participation in the psychoeducational group: perceptions regarding personal engagement

In this category, the impacts of participation in the psychoeducational group on patients' self-care are discussed, highlighting several positive aspects resulting from this experience. However, some factors that acted as barriers to engagement with the group were also identified.

Among the elements that hindered participation, embarrassment in exposing oneself in a collective environment stood out, especially among more reserved or shy individuals. This discomfort was intensified by the way the sessions were conducted, when professionals adopted a more assertive approach in attempting to encourage these participants to speak. This approach may have generated discomfort at certain moments, interfering with participants' full adherence and interaction throughout the meetings.

*Each person says something. When it's my turn, I tell the [nurse], "I'm not going to say anything," and she says, "No, speak!" I say I'm not going to speak, just listen. I feel a bit embarrassed. (C2)*

*I wish people would share more information about their problems—what they are feeling, what they can do. I don't see that much in this group; people don't seem to have many doubts. They are more experienced. There should be more interaction, especially with those who are just joining. (C12)*

However, the positive aspects significantly outweighed the reported challenges. Participants emphasized that the group contributed to improving quality of life by providing information on care technologies, nutrition, hygiene, work-related activities, and sexual activity, among other topics. These contents were identified as fundamental for promoting autonomy and facilitating the social reintegration of individuals with an ostomy:

*After I started attending the group, I learned many things. (C1)*

*After I went there, [the nurse's name] was there, a very special person. She guided me in many ways. That's where I learned how to deal with a colostomy. (C6)*

*I found it interesting to participate in this group. The comments from other colleagues who have the same problems, because I am alone and have no one to exchange ideas with. So it is a way to help me without bothering other people. (C7)*

*I think there is nothing to improve or worsen; for me, it is great. When the women talk about the pouches, how to clean them, those kinds of things—I find that most interesting. I learned many things from the group. For example, about diet, how to handle things better, the proper care. It was very good; if it weren't for this group, I don't know what would have become of me or how I would have learned to do these things. (C10)*

## DISCUSSION

The results indicate that the mean age of the participants corresponds to an age group that is still productive, both for work and for activities of daily living, not characterizing an elderly population. This finding is consistent with the literature, which points to an increase in the number of individuals of economically active age undergoing ostomy construction, expanding the impacts of the condition beyond the clinical sphere and reaching social, occupational, and relational dimensions. In this context, the relevance of guidance actions for self-care is highlighted, aiming at the prevention of complications and the promotion of social reintegration, including work, social interaction, leisure, and sexuality, which are fundamental aspects for quality of life at this stage of the life cycle<sup>5</sup>.

There is an increasing prevalence of younger individuals with ostomies, revealing a shift in the epidemiological profile previously characterized by a predominance of older adults. The literature supports this transition, attributing it to factors such as the increase in urban and traffic-related violence; the rise in the incidence of noncommunicable chronic diseases, especially colorectal cancer; changes in nutritional profiles; the occurrence of occupational accidents in precarious work environments, particularly in the construction sector; and advances in diagnostic and therapeutic medicine, which have expanded the possibilities of intervention and survival in the face of various pathologies<sup>6</sup>.

Regarding biological sex, a greater participation of women was observed in the study. This result is supported by epidemiological data indicating colorectal cancer as the main cause of intestinal elimination ostomies, in addition to being the second most incident neoplasm among women, reinforcing the association between oncological diagnosis and ostomy construction<sup>7</sup>.

Furthermore, it is necessary to consider that the male population, due to sociocultural gender constructions, tends to seek healthcare services less frequently and avoids exposing vulnerabilities. Studies indicate that this behavior negatively impacts access to specialized care, leading many men to remain confined to the home environment, being cared for by family members, which compromises their autonomy and limits the appropriation of self-care strategies<sup>8</sup>.

Regarding the duration of the ostomy, a diversity of experiences was observed, with reports ranging from months to decades. The literature highlights that this temporal variability directly influences the level of mastery of care practices, as, over time, individuals acquire greater familiarity with handling devices, as well as the ability to identify changes in the stoma and peristomal skin. It is noteworthy that care for individuals with ostomies is a continuous and dynamic process, requiring systematic educational actions from hospitalization to post-discharge, aiming at maintaining quality of life<sup>6</sup>.

Corroborating these findings, studies indicate that many patients demonstrate anxiety about returning home after surgery, which hinders the retention of guidance provided in the hospital environment. This overload of information, combined with emotional distress, compromises the assimilation of knowledge essential for self-care. Therefore, it is recommended that guidance begin in the preoperative period, allowing for greater understanding and preparation to cope with the new life context<sup>9</sup>.

It is equally essential that patients receive physical educational materials, such as booklets and guidance manuals, which serve as reference tools in moments of doubt or insecurity. These printed materials allow practical and continuous access to information, reinforcing the guidance provided by the healthcare team<sup>10</sup>.

Another critical aspect concerns the under-dimensioning of the network of specialized services aimed at the care of individuals with ostomies. The literature indicates that the lack of appropriate referral compromises continuity of care, restricting access to essential resources such as the distribution of equipment and multiprofessional follow-up that ensures comprehensive rehabilitation<sup>11</sup>.

Regarding the underlying pathology, cancer represents the most prevalent condition among participants. This finding is widely described in studies that associate oncological diagnosis with feelings of finitude, suffering, and stigmatization, even

when there is a prospect of cure. The bodily changes imposed by the ostomy intensify psychophysical suffering, requiring emotional support and qualified professional care<sup>12</sup>.

The importance of humanized and empathetic psychosocial follow-up is evident, with special attention from the nursing team, which plays a central role in conducting care and strengthening patients' autonomy during the process of adapting to the new health condition<sup>13</sup>. Although it represents a stigmatized condition, the ostomy may be perceived as a therapeutic procedure capable of providing relief from suffering and even saving lives. In certain cases, it is experienced as a resource that restores well-being and functionality, being accepted with less resistance<sup>13,14</sup>.

However, this acceptance is not immediate; it requires time, support, and appropriate strategies. It is a gradual process of re-signifying identity and constructing new meanings for life, based on trust relationships with healthcare professionals and on the empathy that guides care practices. Among the feelings most frequently reported at the initial moment of ostomy creation are fear, shame, and insecurity, intensified by the lack of prior knowledge. For most participants, the ostomy was an unprecedented and unexpected experience, lived in a context of health crisis. Therefore, continuous support from the nursing team is essential to mitigate psychosocial impacts and promote the development of self-care<sup>13,15</sup>.

Support from family and social networks is fundamental for rehabilitation. The literature highlights that, in the immediate and intermediate postoperative periods, individuals are physically and emotionally vulnerable, requiring welcoming, affection, and practical assistance to absorb guidance and adapt to the new care routine. Family members play a decisive role by providing support and contributing information to the construction of an individualized care plan<sup>12</sup>.

Considering the complexity and multiplicity of demands involving individuals with ostomies, it is necessary to implement diverse support strategies. Among these, psychoeducational groups, telenursing, telemonitoring, in-person consultations, and the use of digital platforms stand out as fundamental for social reintegration and the promotion of self-care<sup>11</sup>.

Psychoeducational groups, in particular, demonstrate great potential to promote the exchange of experiences among participants, strengthen social bonds, expand the sense of belonging, disseminate information about the health-disease process, foster empowerment, prevent complications, and promote health in its biopsychosocial dimension. Nursing care should be grounded in ethical, technical, and scientific principles and, above all, in a humanized approach. Respect for the individuality of individuals with ostomies requires recognition of their physical, emotional, social, familial, and cultural specificities. Nursing professionals should adopt practices based on empathy and clear communication, ensuring comprehensive, person-centered care<sup>11,16</sup>.

Finally, another relevant aspect concerns participants' awareness of their rights as political subjects. The literature shows that living with an ostomy may encourage engagement in social movements, strengthening the collective struggle for public policies that ensure dignity, inclusion, and social justice. Initiatives such as the State Association of People with Ostomies of Rio de Janeiro (AEPORJ) and Municipal Centers for People with Disabilities play an essential role in promoting rights and building a more inclusive society by offering support, representation, and channels for social participation for this population<sup>17,18</sup>.

## Study limitations

Some limitations of this study should be considered, such as the small number of participants and the fact that the study was conducted in a single institutional setting. These aspects limit the generalizability of the findings. In this sense, further investigations are recommended in different regional contexts and with larger samples. Such initiatives may deepen the understanding of the contribution of psychoeducational groups to the self-care process of individuals with ostomies.

## Recommendations

Based on the findings, it is recommended to continue and strengthen psychoeducational groups aimed at individuals with ostomies, ensuring methodologies that promote both the collective sharing of experiences and respect for the individuality of those who prefer not to expose their difficulties. It is suggested to expand the provision of qualified guidance on self-care, encourage the creation of support networks, and integrate strategies that promote psychosocial well-being and participants' engagement in advocating for their rights.

## CONCLUSION

The results allow us to infer that, prior to participating in the psychoeducational group, the process of ostomy creation was experienced as negative and traumatic. Factors identified as intensifying psychophysical suffering included inadequate ostomy management; difficulty in using and handling collecting devices and adjuvants; the absence or low quality of guidance on self-care; and the fragility of psychosocial support offered to this population.

In contrast, participation in the group proved to be a significant differential in promoting effective self-care and in the development of autonomy. Within the group, guidance on the use of care technologies was provided, and topics relevant to the well-being of individuals with ostomies were discussed. In addition, a sense of belonging, the expansion of support networks, political engagement in the defense of rights, and the exchange of experiences were highlighted as strategies for coping with the challenges of daily life with an ostomy.

The group played a relevant role in participants' lives by enabling the sharing of experiences, recognition of similar situations, access to qualified information, and clarification of doubts regarding the care process. The need to improve the methodology adopted is emphasized, especially with regard to preserving the individuality of those who prefer not to publicly expose their difficulties, fears, and insecurities.

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