ORIGINAL ARTICLE

LIFE EXPERIENCES OF PEOPLE WITH ELIMINATION OSTOMIES: DISCOURSES FROM AN ADAPTATION PERSPECTIVE

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Highlights: (1) Diet, clothing, and work-related activities are the main adaptive stimuli. (2) Social, family, and professional support, as well as religiosity, contribute to adaptation. (3) Aversive or hopeful perspectives surrounding elimination ostomies are identified.

PRE-PROOF
(as accepted)
This is a preliminary and unedited version of a manuscript that has been accepted for publication in Revista Contexto & Saúde. As a service to our readers, we are making this initial version of the manuscript available as accepted. The article will still undergo review, formatting, and author approval before being published in its final form.

http://dx.doi.org/10.21527/2176-7114.2026.51.16833

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How to cite:
Alves D de A, Lima LGA, Bezerra JVS, da Cruz LG, Dias OS, Gregório RGD. et al. Life experiences of people with elimination ostomies: discourses from an adaptation perspective. Rev. Contexto & Saúde. 2026;26(51):e16833

ABSTRACT:

Introduction: In light of the biopsychosocial challenges posed by elimination ostomies, it is necessary to understand the adaptive processes associated with the use of these medical devices. **Objective:** To explore the narratives of people with elimination ostomies in order to understand, from the perspective of Roy's Adaptation Model, the stimuli and adaptive mechanisms constructed in response to this new reality. **Method:** This qualitative, descriptive, and exploratory study was conducted using lexical analysis of narratives provided by people with ostomies, supported by IRaMuTeQ software and Callista Roy's Adaptation Theory. **Results:** the analysis resulted in three thematic axes: "People with elimination ostomies and perceived stimuli," "Reported adaptive mechanisms," and "The phenomenon of adaptation and the elements of this process." With the aid of word cloud and similarity graphs, these axes demonstrated perceived adaptive elements, such as stimuli, adaptive modes, and the self-perceived effectiveness of adaptation processesThese findings revealed the impact of factors such as the need for adjustments in diet, clothing, physical effort, social relationships, and work. This process contributes to effective adaptation, which is influenced by individual cognitive patterns, sociocultural constructs, and perceived social support. **Conclusion:** Based on this analysis, some understandings regarding elimination ostomies were explored, revealing the complexity of the adaptive process and the congruence of these representations with Roy's concepts of Adaptation.

Keywords: Ostomy; Psychological Adaptation; Nursing Theory.

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INTRODUCTION:

With the advent of health technologies, many diseases and health conditions can be managed through interventions and medical devices, such as elimination ostomies, whose formation represents an alternative for managing potentially severe clinical conditions, including oncological and inflammatory diseases, as well as trauma and obstructions that may affect the intestine or the urinary system[1,2].

The ostomy has the clinical objective of diverting intestinal or urinary output through an opening that directs the flow from the intended site to the exterior of the abdomen, where a collecting pouch is responsible for storing the diverted content, thereby promoting increased survival as well as the possibility of improved well-being and health for these individuals[3].

However, whether temporary or permanent, living with an ostomy leads to significant changes in the lives of affected individuals. This, in turn, requires a set of biopsychosocial adaptations and coping strategies, implying the emergence of other possible complications arising from this new reality, depending on the responses constructed in this process[4,5,3].

Given the challenges associated with this context, which may result in positive or negative adaptive responses, it is incumbent upon health professionals to mediate this process by seeking, in a multiprofessional manner, means to promote overall well-being and health[6]. According to Roy's Adaptation Model (RAM)[7], this is inherent to care practice, given the correlation of this concept with the promotion and maintenance of health balance in these individuals.

From this perspective, in order to add knowledge to the discipline and provide insights that may generate theoretical support for professional practice in health, the importance of qualitative investigation into the meanings of being a person with an ostomy is recognized, as well as the multiple implications and possibilities involved in this process.

To this end, this study aimed to explore the narratives of people with elimination ostomies in order to understand, from the perspective of Roy's Adaptation Model, the stimuli and adaptive mechanisms constructed in response to this new reality

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METHODOLOGY:

This is a qualitative, descriptive, and exploratory study aimed at investigating adaptive aspects related to the realities surrounding the formation of elimination ostomies, focusing on understanding this biopsychosocial process through the rigor and contributions inherent to qualitative studies[8].

The research was conducted at an enterostomal therapy outpatient clinic located in the Brazilian municipality of Crato, in the state of Ceará. This setting is dedicated to providing health care through direct assistance to patients with elimination ostomies and includes generalist professionals and enterostomal therapy nurses who work in a multidisciplinary manner, in addition to technical and academic support from students from partner institutions.

In addition, to compose the study sample, the following inclusion criteria were established: patients aged 18 years or older who had an elimination ostomy, linked to the enterostomal therapy outpatient clinic where the study was conducted, and in regular follow-up consultations. Patients who were not in clinical condition to participate in the interview were excluded from the sample.

Accordingly, data collection took place through interviews conducted between December 2023 and April 2024, using a semi-structured guide, which was applied individually and in a private setting in order to ensure participants' privacy and comfort, as well as greater freedom for patients to express their experiences, feelings, and perceptions.

To this end, six questions were asked, namely: what do you understand by an ostomy? what feelings or actions did you express upon learning that the physician decided to construct an ostomy? how did your family react when they learned that you became a patient with an ostomy? in your personal, family, and professional life, what types of changes and/or adaptations needed to occur for you to have a normal routine? and finally, in your opinion, is this ostomy a life-saving alternative or do you consider it the end of your condition?

The interviews were recorded, with the participants' free consent, using a voice recorder, and were subsequently transcribed into a text document in .txt format, which was processed using the IRaMuTeQ software (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires). This resulted in a statistical analysis that

demonstrated the frequency and correlations established by the content of the interviewed patients' responses[9], that is, the corpus, from which it was possible to generate multivariate graphical analyses using the "R" programming language.

The data analysis process was conducted through the interpretation of word cloud and similarity tree graphical analyses generated by IRaMuTeQ based on the frequency of terms cited in the textual corpus, as well as the correlations established among them. In addition, excerpts from the participants' transcribed narratives were used to support the interpretive and reflective process undertaken.

Accordingly, the investigation sought to be anchored in reflection on the adaptive stimuli and mechanisms discussed in Roy's Adaptation Model theory, with a view to understanding the meanings and modes of adaptation adopted by people with elimination ostomies assisted at the outpatient clinic.

In compliance with Resolution 466/12 of the Conselho Nacional de Saúde (CNS)[10],the study was approved by the Research Ethics Committee of the Universidade Regional do Cariri (URCA), under opinion number 4.262.824 (CAAE: 32323420.9.0000.5055), and included the express authorization of voluntary participants through the Free and Informed Consent Form (ICF), with due attention to the preservation of their identities by replacing their names in the dialogues with the letter "P," followed by a consecutive Arabic numeral.

RESULTS:

The study sample consisted of 19 people with elimination ostomies, of whom 52.63% (n = 10) were male and 47.36% (n = 9) were female. Regarding age, 5.26% (n = 1) were between 21 and 34 years, 57.89% were between 35 and 59 years (n = 11), 21.05% (n = 4) were between 60 and 74 years, and 15.78% (n = 3) were 75 years or older.

The sample comprised 68.42% (n = 13) of patients with colostomies, 21.05% (n = 4) with urostomies, and 10.52% (n = 2) with ileostomies. Of these, 57.89% (n = 11) were permanent, 26.31% (n = 5) were of indefinite duration, and 10.52% (n = 2) were temporary. The main reasons for ostomy use were malignant neoplasms (47.36%), followed by benign tumors (21.05%) of cases, and nodules, perforations, recurrent abdominal pain, constipation, and fistulas in 31.57%.

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After processing with the IRaMuTeQ software, a set of lexical analyses was obtained, generating word cloud and similarity tree graphs. These were organized according to their similarity to the thematic cores proposed by Roy's Adaptation Theory. This process resulted in the identification of two thematic axes:

Axis 1 – People with elimination ostomies and perceived stimuli:

Initially, in order to observe how the interviewed individuals perceived stimuli in the context of ostomies, participants were asked about their understanding of this process. The responses resulted in a set of meanings, in which the terms be (17), eat (15), know (12), understand (12), thing (10), how (10), and remain (10) appeared with higher frequency, as illustrated in Figure 1.

Figure 1. Word cloud no. 1, Juazeiro do Norte, Ceará, 2024

In this context, this analysis enables an initial understanding of the representations surrounding ostomies and their stimuli, that is, the numerous factors that may interfere with

adaptation to this process and that are identified through words from the corpus, as well as through the transcribed accounts:

> *It was a means provided by God to the doctor to save my life, because it is through this surgery with this ostomy bag that life is saved, because if it were not for this bag, I don't know what would have happened to me. [...] It is not easy, but I thank God because I am alive, I am feeling well, taking care of my family, being able to do my tasks, whatever I can do, I do it* (P6).
>
> *First of all, a miracle, because given the situation she was in [...] if I were not using this bag right now, where would I be? Under the ground, right. And thanks to God, to this day I do not feel anything about this bag. I don't feel ashamed* (P18).
>
> *It is an annoying thing, very annoying, it bothers a lot because we cannot wear tighter clothes. We always have to wear loose clothing because it shows a lot. It is annoying* (P2).

Axis 2 – Reported adaptive mechanisms:

When questioned about adaptations in personal, family, and professional life, the aim was to understand the adaptive mechanisms adopted by these individuals. Numerous aspects related to this process were identified, as described in Figure 2, which illustrates the connections established by the textual data based on a lexical similarity analysis of the reports:

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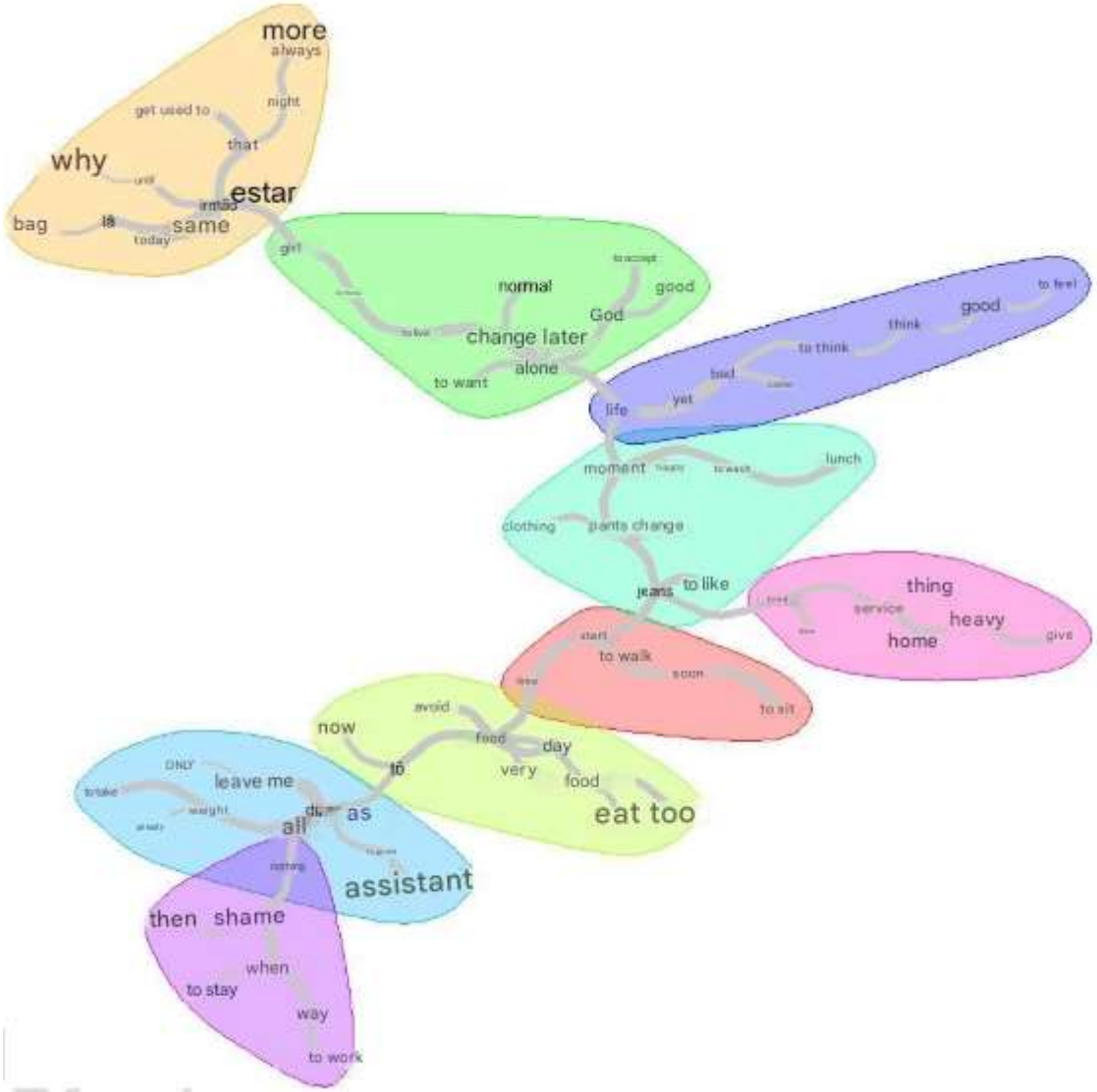

Figure 2. Similarity analysis no. 1, Juazeiro do Norte, Ceará, 2024.

Based on this graphical representation, it is possible to identify groups that reflect both specific stimuli and the adaptive mechanisms developed in response to them, such as the connections formed around words such as change, shame, home and eat, shame, way, stay and work, and thing, service, heavy and home. These point to adaptations that occur in diet and clothing, as well as in daily life and work and domestic activities.

With regard to the physiological adaptive mode, the contours related to physical effort and diet are observed in particular, such that the correlation among the lexical items avoid, food,

much, and eat makes it possible to denote the impacts of ostomy use on eating:

> *I cannot eat everything like I used to, I cannot eat just anything anymore, I am overweight, and the nutritionist has already advised me to reduce my weight, I cannot reduce my weight because I cannot stop eating* (P4).

> *Food as well, right? We need to think a lot about what we are going to eat, about the quantity. And particularly, if I have something to do where I cannot leave to go to the bathroom, then the day before I already avoid a lot of food, many foods, and sometimes even the intake itself* (P15).

> *I used to eat all kinds of things, like fried foods, now I can no longer eat things like that* (P3).

In addition, a connection is also observed between the items shame, way, stay, and work, as well as thing, service, heavy, and home, which point to a possible need to interrupt domestic or external work activities due to physical effort:

> *What worried me most was work, because I liked to work. [...] If I were healthy, I would be there working. On my little farm. I just watch people planting their little farms and I wait for the selling day so I can go there to pay more (P4).*

> *We are no longer the same person, right? As I said, it is not easy, but we have to adapt, we have to get used to going out with the ostomy bag. I cannot anymore. I have to avoid going to the fields, avoid the sun, avoid lifting weight, avoid many things. You have to avoid it (P6).*

> *It changed. I used to work and now I am stopped, but I am accepting it, because that is the way it is, to accept it. It is not good, but what am I going to do? I have to stay at home, wait to recover to see what God will do (P8)*

The importance of the social systems in which individuals are inserted for this adaptation process is emphasized, such that maintaining these bonds through receiving and offering support constitutes one of the strengths in the face of the stimulus and the adaptive process established by the elimination ostomy.

> *And so it is about seeking moments to be happy. Having a moment. I get sad sometimes, sometimes people leave us aside. They think that because we have a the ostomy bag, we have cancer. Sometimes just being invited to something already makes us feel happy. Go, I will go, I will go with pleasure, I know I will feel good, I will go. I get sad when they do not invite me (P6).*
>
> *If it were not for my children helping me like that, right? I do not know how it would be (P17).*
>
> *I stopped everything, right? I am even staying at my sister's house, this sister's house, I am at her place. I am not at mine because I am not able to take care of myself (P14).*

When questioned about the family relationship and this new reality, connections were observed among the lexical items bag, sad, hospital, and support, whose community is associated with the terms child, always, speak, help, and everything, and likewise the items accompany, brother, doctor, and take, as shown in Figure 3:

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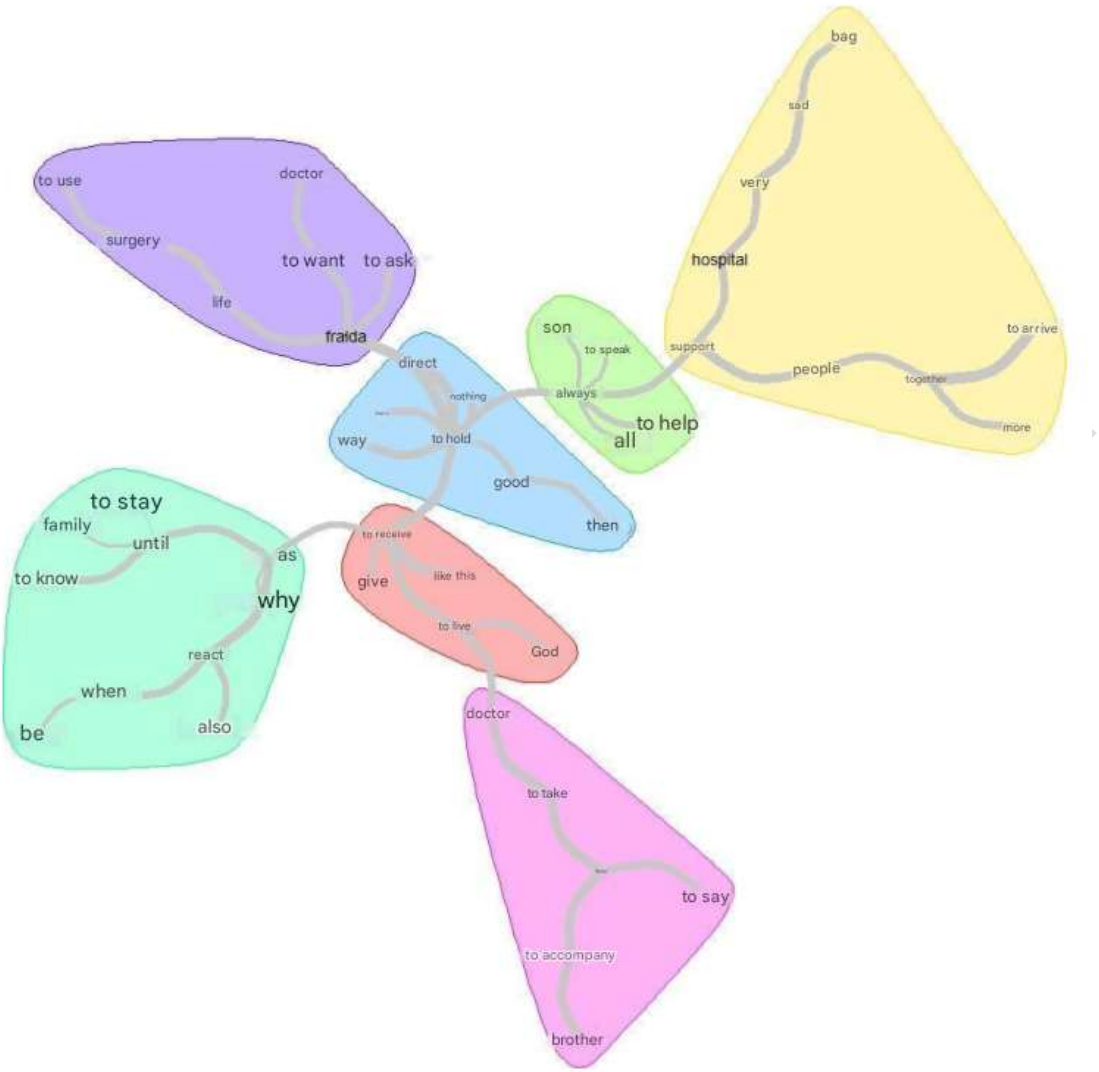

Figure 3. Similarity analysis no. 2, Juazeiro do Norte, Ceará, 2024.

Thus, these narratives are corroborated by the accounts evoked by these individuals when asked about the family's reaction to this new reality following the construction of the elimination ostomy:

> *Sad, very sad. Everyone supported me, everyone gave me strength. I spent one month and one day in the hospital, with two sisters accompanying me at the hospital* (P2).
>
> *They always support me. Always whatever is best for you. My children are a*

> *young woman and a young man, they are good people, they help me with everything. My husband also always gives me support. Family is the foundation, right? When they are there to give strength, we feel stronger. I had the support of my family, then of my community. Everyone came together, do you need it? Let's do a bingo, a raffle, to help with her exams, and everything happened quickly* (P6).

> *No. No one even said anything about it. No one. My daughter was the one who changed the bag, helped me. She always helped me, always with changing the bag, but today I am the one who does everything, I change the bag, she only cuts it. The family is always by my side, all my children* (P13).

Axis 3 – The phenomenon of adaptation and the elements of this process:

When questioned about hopes surrounding the ostomy and whether it can be considered an alternative or a final condition, the aim was to observe the effectiveness of the adaptive process and how it occurred. The similarity analysis illustrated in Figure 2 allows visualization of these established correlations:

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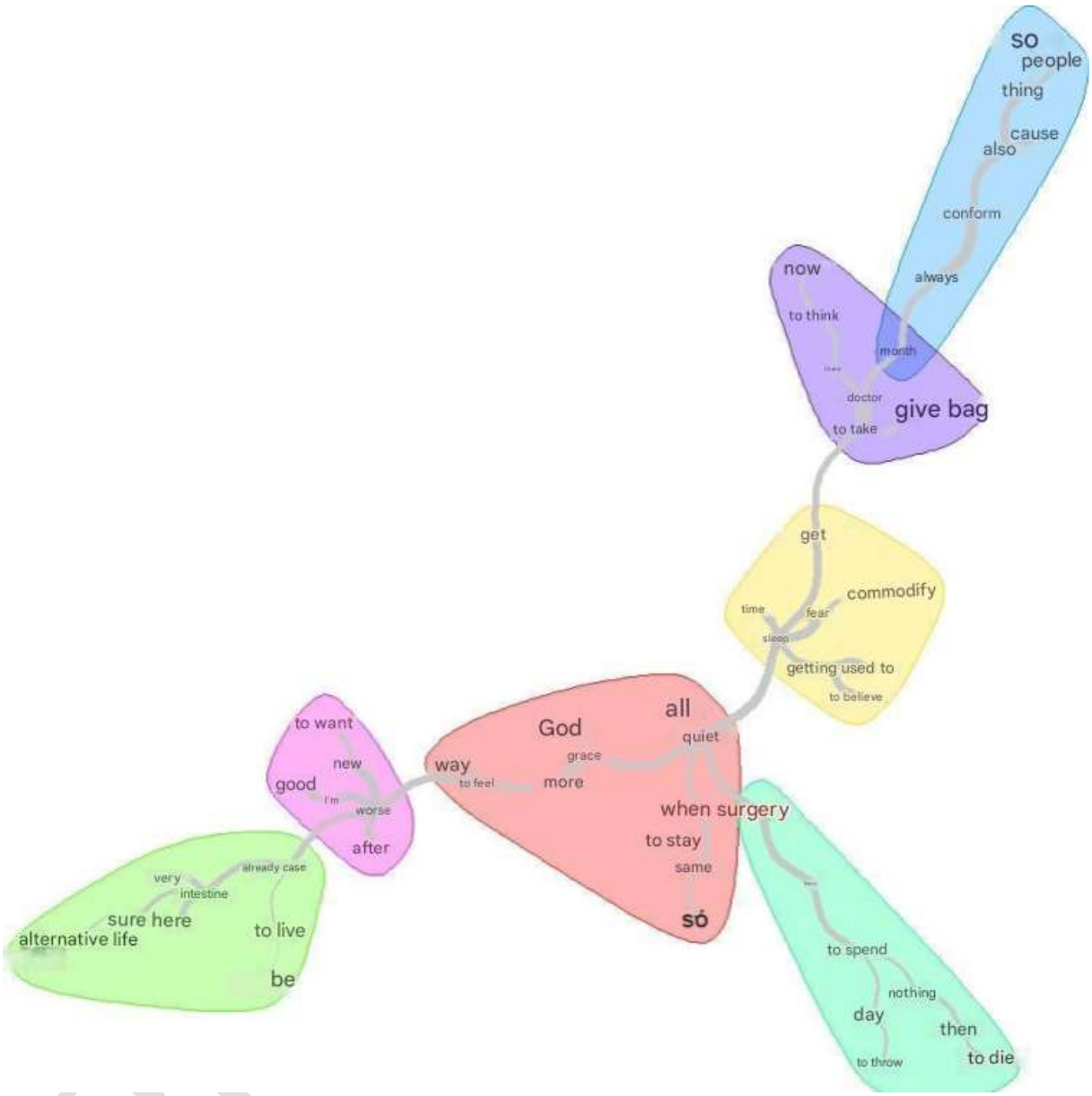

Figure 4. Similarity analysis no. 3, Juazeiro do Norte, Ceará, 2024.

In this context, connections are also observed among the items “God”, “grace”, “feel”, “stay”, and “calm”, which reflects the evocation of the strong religiosity that characterizes the sample population. In addition, it is possible to visualize a correspondence among the terms certainty, alternative, and life, which corroborate the positive viewpoint regarding the ostomy.

This fact is explained when considering that almost 70% of the sample population began

using an elimination ostomy as a result of previous neoplasms or tumors. In addition, in the discourses, this alternative occupies a place of solution for the health condition in which these individuals found themselves. From the reports, it is possible to extract narratives that corroborate this meaning, demonstrating that ostomies provided the possibility of reducing pain, enabling the maintenance of physiological activities, and above all ensuring well-being:

> *It is a life-saving alternative for sure, because the way I was, God forbid. I was very bad indeed. I was not living, I was just surviving* (P5).
>
> *It is a life-saving alternative, because if I had continued the way I was, maybe I would be worse, it would have become more difficult later. I am feeling well, it is a new life, I am feeling well thanks to God* (P3).
>
> *It was the beginning, I will not even say the end, because as I said, it is not the end. What I am afraid of, the end for me that I am afraid of, is the disease coming back. But if God grants me the grace to live ten years or more, He is the one who knows the time, right?* (P6).
>
> *I felt lost, I thought I was going to go crazy. It affected my mind a lot, I could not get used to it, I thought all of that was suffering. [...] I used to go everywhere, I walked, did everything, now I can even do it, but I feel ashamed, because when the bag fills up, it becomes visible under my clothes, so I am afraid it will get heavy and open. We feel embarrassed. So I stay at home. I hardly leave the house* (P11).

Likewise, aversive views regarding the ostomy are also observed in the subjects' discourses, often generating denial of the use of these devices, as well as the construction of a negative value judgment.

> *No, for me, my wish is that the day comes when I can take this bag off [...] just ask God that the day comes when we can remove it* (P17).
>
> *I have no life. I prefer death. Even today I prefer it. Whenever it comes, I will be happy. It is really over for me. It did not change, it ended* (P10).

Constructions surrounding self-concept are observed to oscillate between acceptance and revolt, as well as the impacts on self-esteem that this condition may generate:

> *I felt lost, I thought I was going to go crazy. It affected my mind a lot, I could not get used to it, I thought all of that was suffering. [...] I used to go everywhere, I walked, did everything, now I can even do it, but I feel ashamed, because when it fills up the bag shows on the clothes, so I am afraid it will get heavy and open. We feel embarrassed. So I stay at home. I hardly leave the house* (P11).
>
> *It is an annoying thing, very annoying, it bothers a lot because we cannot wear tighter clothes. We always have to wear loose clothing because it shows a lot. It is annoying* (P2).
>
> *It does not stop me from going to mass, I go out, to a small party. I will not stay locked inside the house because of an ostomy, because of a the ostomy bag, I will not stay at home crying. I want to get ready, I want to go out, enjoy the moment that I can enjoy. I see that I can do it, I will go. It is not something for us to stay trapped inside the house and say no, I will not go out. I am not ashamed. People ask, when will the doctor remove it? I say, he did not say, and I will not keep asking. I want to know if I am well. What matters is that I am well* (P6).
>
> *I have no life. I prefer death. Even today I prefer it. Whenever it comes, I will be happy. It is really over for me. It did not change, it ended* (P10).

DISCUSSION:

People with ostomies as open systems exposed to stimuli:

Despite the positive clinical aspects resulting from the construction of elimination ostomies, this process generates a set of stimuli which, like any other that leads to a change in body functionality or original appearance, constitutes a major impact, requiring a series of care measures and an effective adaptation process[11].

Understanding the health status and the pathways of professional practice in relation to the people with ostomies is a process that begins with the assessment of the external and internal stimuli that these individuals, as an open system, receive[7,5]. Therefore, health care focused solely on physical aspects, such as pain, possible inflammation, or the correct management of the collecting pouch, is not sufficient[4].

Moreover, from the perspective of Roy's Adaptation Theory, promoting comprehensive health implies recognizing the variability of stimuli triggered by this new context through a dynamic and continuous process, whose challenge consists of gaining control over events, emotions, and negative perceptions that may affect quality of life[12,13].

Adaptation to an elimination ostomy is shaped by stimuli that go beyond focal stimuli, that is, those immediately related to the construction of the medical device itself, resulting in circumstantial and subjective aspects that are also evoked. From this perspective, this context reflects, in addition to the need for clinical care, a series of factors such as the role of family members, friends, and the community, as well as socioeconomic support and health services[5,14].

Furthermore, it also influences more subjective aspects, which in turn constitute residual stimuli that may not be objectively measured or recognized but directly affect the adaptive process, mediating its effectiveness through culturally and socially internalized constructions and representations, especially those that view illness and dependence on medical devices as synonymous with weakness or loss of the body's original form[3].

In a more detailed manner, these stimuli end up shaping perceptions and, consequently, adaptive responses to ostomies, and include aspects such as self-esteem, representations, and stigmas constructed from previous individual experiences, as well as cultural norms and worldviews that may hinder acceptance and coexistence with the ostomy condition[15,16].

This implies recognizing that the adaptive process is gradual. It is constructed through social support from family members and health professionals, as well as through accumulated experiences that influence effective adaptation[17]. This, in turn, makes it necessary to understand the dynamic interaction constituted by these stimuli and how this cycle can affect the effectiveness of the adaptive process.

Constructed adaptive modes as support for care delivery:

Recognizing the influence of stimuli on the adaptive process, this study reveals the adaptation mechanisms developed by the analyzed patients. In this regard, beyond the physiological mode, which is configured through daily care with the skin, the collecting device,

diet, and physical effort, responses aligned with the self-concept, role function, and interdependence modes are also identified[15,11].

In the analyzed accounts, diet and physical effort are seen as the most frequently cited components of the physiological mode, as observed in the literature. There is an emphasis on heightened attention to care such as constant hydration and dietary modifications, which are necessary for controlling odors, discomfort, stool consistency, and preventing complications[16,4].

Within this new context, the reduction of physical effort is also considered a physiological adaptive mode, largely due to fear of complications such as irritation, leakage, or even parastomal hernias. This points to the need to promote a healthier lifestyle through practices that balance sedentary behavior and excessive physical effort[18,19].

It is necessary that the resulting physiological needs do not become barriers to the exercise of social functions. However, as revealed in the narratives, this ends up occurring in some cases, potentially generating repercussions in the adaptive mode of role performance, often distancing individuals from their social, family, marital, and work-related functions and activities[11,17,12,20,4,21,22].

This aspect is explained, in addition to physiological modes, by the self-concept mode of the people with ostomies, which in some cases becomes an imperative that prevents engagement in work, religious practices, socialization, and even sexual functions. This is due to rejection associated with body image, the presence of the collecting pouch, possible intestinal or urinary output and leakage, or even feelings of impurity evoked by the use of the ostomy procedure[17,20,15].

In line with this observation, a Saudi study[20] conducted with Muslim patients describes how the new reality imposed by ostomies affected religious practices, such as annual pilgrimages to Mecca or even individual and group prayers, due to fear of effluent leakage or the sensation of impurity even after ablution prior to practices.

Effluent leakage, possible odors, and the presence of the ostomy pouch are also factors that interfere with social practices, such as attending gatherings and events, hindering social functioning[4,23]. Similar effects are observed in work and sexual practices, which may also be affected at a notable level[17,11,24].

This set of factors corroborates the negative mental health outcomes among ostomized individuals identified in the literature, which may be linked to these aspects. A high prevalence of negative feelings associated with body image, disease perception, and inadequate coping with the new reality is observed, which may lead to the development of depressive or anxiety disorders[25].

In this regard, a study conducted by Baykara, Demir, and Karadağ (2020)[26] shows that greater perceived social support is associated with better adaptation, highlighting the relevance of the adaptive mode of interdependence, that is, the one strengthened by interpersonal relationships and family and social support.

This perspective, in addition to converging with the literature, is widely reflected in the analyzed accounts, which demonstrate the importance of social alignment for the promotion of hope and quality of life. This can be achieved through cohesion within the family, as well as through support groups and broader social networks[27,13].

FINAL CONSIDERATIONS:

Based on this analysis, it was possible to investigate some of the understandings of people with ostomies regarding these medical devices, as well as the complexity of the adaptive process involved in living with elimination ostomies and the congruence of these representations with the concepts of Roy's Adaptation Theory.

This study highlighted adaptive stimuli related to elimination ostomies and how they are manifested, generating focal, contextual, and residual impacts associated with elements such as new needs for skin and ostomy pouch care, as well as impacts on diet and clothing, and on family, professional, and social relationships.

Accordingly, adaptive mechanisms were identified as variable, and may constitute positive responses, such as interpreting the ostomy as a new chance at life, as well as a condition that implies strengthening faith and family support. In addition, negative adaptive responses were also identified, such as shame, isolation, and suffering experienced by these individuals during this process.

A limitation of this study is its small sample size, which highlights the importance of further studies that may explore this topic from a broader perspective, particularly including a larger number of participants.

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Submitted: December 11, 2024

Accepted: July 9, 2025

Published: January 2, 2026

LIFE EXPERIENCES OF PEOPLE WITH ELIMINATION OSTOMIES: DISCOURSES FROM AN ADAPTATION PERSPECTIVE

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All authors approved the final version of the manuscript.	
Conflict of Interest: The authors declare no conflict of interest.	

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Funding:	This study received no funding.

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