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PERCEPTIONS OF PEOPLE WITH OSTOMIES REGARDING THEIR LIFE JOURNEYS

PERCEPÇÕES DE PESSOAS COM ESTOMIA SOBRE SUAS TRAJETÓRIAS DE VIDA

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ABSTRACT

A stoma is a surgical procedure that creates a stoma - an opening in the abdominal wall or trachea - either permanently or temporarily, allowing communication between the body's internal environment and the external environment. The surgery is performed to ensure the patient's survival, and the most common cases involve intestinal stomas for elimination, indicated when a portion of the intestine exhibits dysfunction, obstruction, or injury. It is often perceived by the patient as mutilation incompatible with social, professional, and even family life. This study aimed to explore the potential contributions of psychology to the life trajectories of individuals who underwent the surgical procedure for the creation of an intestinal stoma for elimination. The research was conducted as an exploratory, descriptive, and qualitative field study. Six people with stomas participated. The results showed that the main difficulties encountered by the participants were related to adapting to the stoma and insecurity regarding the new physical and emotional situations caused by the use of the colostomy bag. In the social sphere, participants reported receiving support from their families and expressed satisfaction with the quality of care provided by public health professionals. It was found that ostomy leads people to experience significant emotional distress in the face of the changes and adjustments required by their new way of life. It was concluded that, despite the lack of psychological studies on the ostomy context, psychology can make a significant contribution to psycho-emotional support, psychoeducation, adaptation, and the empowerment of people with ostomies

Keywords: Colostomy; Person with Physical Disability; Psychology; Interpersonal relationships.

RESUMO

A estomia é um procedimento cirúrgico que cria o estoma, um orifício na parede abdominal ou na traqueia, de maneira definitiva ou provisória permitindo a comunicação do meio interno do corpo com o meio externo. A cirurgia é feita como recurso para proporcionar a sobrevida do paciente e os casos predominantes são as estomias intestinais de eliminação, indicadas quando alguma parte do intestino apresenta disfunção, obstrução ou lesão. Pode se apresentar, muitas vezes, ao paciente como uma mutilação incompatível com a vida social, profissional e até mesmo familiar. Este estudo teve como objetivo conhecer possibilidades de contribuição da psicologia na trajetória de vida de pessoas que foram submetidas ao processo cirúrgico de confecção de estoma intestinal de eliminação. A pesquisa foi desenvolvida a partir de um estudo de campo exploratório, descritivo e de abordagem qualitativa. Participaram seis pessoas com estomia. Os resultados

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encontrados demonstraram que as principais dificuldades encontradas pelos participantes foram quanto à adaptação com o estoma e insegurança sobre as novas situações físicas e emocionais ocasionadas pelo uso da bolsa de colostomia. No âmbito social os participantes referiram ter recebido ajuda de seus familiares e satisfação pela qualidade de atendimento dos profissionais de saúde da rede pública. Identificou-se que a estomização leva as pessoas a sentir grande impacto emocional diante das mudanças e adaptações para sua nova maneira de viver. Concluiu-se que apesar da carência de estudos psicológicos sobre o contexto da estomia, a psicologia pode contribuir muito no suporte psicoemocional, na psicoeducação, na adaptação e no empoderamento da pessoa com estomia.

Palavras-chave: *Colostomia; Pessoa com Deficiência Física; Psicologia; Relações interpessoais.*

INTRODUCTION

According to Administrative Order No. 400, dated November 16, 2009, a person with a stoma is defined as someone who, as a result of a surgical procedure involving the externalization of bodily systems (digestive, respiratory, or urinary), has a stoma - that is, an artificial opening that connects internal organs to the external environment **(**BRASIL, 2009**).**

It is estimated that there are more than 400,000 people in Brazil with a stoma, and stoma creation surgery is performed as a means of ensuring the patient's survival (SANTOS; CESARETTI, 2015). The main causes leading to the creation of an intestinal ostomy include inflammatory bowel diseases, such as ulcerative colitis and Crohn's disease, colon and rectal cancer, intestinal obstructions, and trauma resulting from stab wounds, gunshot wounds, or motor vehicle accidents (AGUIAR *et al*.**,** 2017**)**. Among these causes, rectal cancer has the highest incidence (36%), followed by colorectal cancer (24%) and intestinal obstruction (12%) (MARECO *et al*., 2019).

For elimination stomas - urostomies, ileostomies, and colostomies - a collection bag is used to collect stool or urine. An intestinal stoma may be temporary or permanent, depending on the patient's clinical condition (SANTOS; CESARETTI, 2015). The predominant profile of people with an ostomy for waste elimination consists of women over the age of 60, with colorectal cancer being the primary surgical cause. Most ostomies are colostomies and are permanent (MORAES *et al.,* 2013).

According to Decree No. 5,296, dated December 2, 2004, a stoma is classified as a physical disability (BRASIL, 2004). Thus, individuals who undergo this type of procedure become part of the group of people with disabilities, experiencing new dimensions of physical, emotional, and social life.

Legal knowledge provides the tools to demand and fight for your rights as citizens and people with disabilities (SILVA *et al.,* 2017). The implementation of healthcare services for ostomates throughout Brazil is regulated by Ministry of Health Ordinance No. 400, dated November 16, 2009 (BRASIL, 2009). Its purpose is to coordinate, develop, implement, monitor, and ensure compliance with public rehabilitation policies for people with ostomies. These services are provided through the SUS and consist of specialized health care facilities designed to serve people with ostomies (BRASIL, 2021).

In addition to the changes in their lives, people with stomas experience changes in their anatomy due to alterations in their bodily functions, specifically regarding the elimination of feces, which are now excreted through the abdomen. The presence of an intestinal stoma for waste elimination creates a sense of a diminished and stigmatized body. Consequently, the person begins to develop behaviors of alienation from their body, which leads to changes in body image (MARQUES *et al.,* 2018).

A stoma triggers a grieving process in response to bodily changes, the loss of sphincter function, and changes in body image (FONSECA *et al.,* 2019). The emotional and social impact of ostomy surgery can be exacerbated by feelings of shyness and inadequacy, which make social interaction difficult. The decline in self-esteem caused by this new physical condition can lead to the development of depression and even suicidal thoughts (DE SOUSA *et al.,* 2022).

The primary motivation for this study stems not only from my personal experience as a person with a stoma but also from the observation that there is a scarcity of research on the role of psychology in the field of stoma care. A search strategy was conducted using controlled descriptors and Boolean operators in the PePSIC, SciELO, LILACS, and CAPES Portal databases; however, no articles meeting the established inclusion criteria were retrieved. It is urgent to expand the scope of psychological research and practice in this context, considering both the subjective experience of the person with a stoma and their integration into family, social, and work settings.

Furthermore, it is essential to also provide support to family members and healthcare teams involved in the care process, promoting a more sensitive and comprehensive approach.

Recognizing the importance of health research, and in line with health research guidelines, this study aligns with the Ministry of Health's Research Priority Agenda (MSRPA), particularly Thematic Area 1 - Environment, Work, and Health, whose subitem 1.2 addresses the analysis of suicide occurrence associated with work processes, environments, and relationships (SAÚDE, SECRETARIA DE CIÊNCIA *et al.*, s.d.). Thematic Area 8 pertains to the management of work and health education, and its sub-item 8.1 focuses on analyzing the relationship between productivity and the employment status of SUS health professionals.

This study aligns with the Sustainable Development Goals (SDGs) proposed by the United Nations, particularly SDG 3 (Good Health and Well-being) and SDG 10 (Reduced Inequalities). Sub-target 3.d of SDG 3 calls for strengthening countries' capacity for early warning and the management of national and global health risks. Sub-target 10.2 of SDG 10 aims to empower and promote the social, economic, and political inclusion of all individuals, regardless of age, gender, disability, race, ethnicity, origin, religion, or socioeconomic status (BRASIL, 2018).

In light of the above, this study was warranted; its objective was to explore how psychology might contribute to the life trajectories of individuals who have undergone surgery to create an intestinal ostomy for waste elimination.

METHOD

This study was a field study involving data collection, focusing on the complexity of ostomy and its impact on the life course of people with ostomies. It was based on exploratory, descriptive research with a qualitative approach, which aims to clarify the problem under investigation through research, interviews, and data analysis, thereby facilitating new discoveries. (GIL, 2017).

Qualitative research aims to describe, understand, and interpret behaviors, experiences, interactions, and social contexts. It enables an exploration of the meaning behind actions, allowing for an investigation of human transformation. Qualitative research contributes to our understanding of experiences and phenomena, fostering an appreciation of each individual's subjectivity in relation to their values, beliefs, and the meanings they ascribe to a given experience (MINAYO, 2016).

Descriptive studies are designed to describe the characteristics of a given population or phenomenon. They may be conducted to identify potential associations and to investigate the opinions, attitudes, and beliefs of a given population. Some descriptive studies go beyond simply identifying the existence of relationships between variables; they also aim to determine the nature of those relationships (GIL, 2017).

Exploratory research aims to provide a better understanding of the problem, to make it more explicit, or to develop hypotheses. Its design tends to be quite flexible, as it seeks to consider the various aspects related to the fact or phenomenon under study. Data collection can occur in various ways, but generally involves: a literature review, interviews with people who have had a specific experience, and analysis of examples that facilitate understanding (GIL, 2017).

Considering the methodological approaches enabled by the conduct of qualitative studies of a descriptive-exploratory nature, the design of this research facilitated an understanding of the lived experiences of individuals with an intestinal ostomy and answered the research question. It also enabled the exploration of a topic that remains understudied in the field of psychology, broadening the understanding of the research subject.

The study participants are adults with stomas residing in a city in the interior of Rio Grande do Sul. Participants were invited in person at one of the meetings organized by the Association of Ostomates in a city in Rio Grande do Sul. Publicity and invitations to participate in the research only occurred after approval by the Research Ethics Committee. Regarding the number of participants in the sample for this study, non-probabilistic, convenience sampling was used. The inclusion criteria for participant selection were as follows: a) men and/or women who had undergone a stoma creation procedure; b) aged 18 years or older; c) residing in a city in Rio Grande do Sul. In addition, the exclusion criteria were individuals with cognitive impairment and minors.

Regarding ethical procedures, this study was submitted to Plataforma Brasil and the Research Ethics Committee. It was approved under CAAE 76638523.4.0000.5306 and received a favorable

opinion under case number 6.659.229. Participants were guaranteed confidentiality, the freedom to choose whether or not to participate in the study, and the option to withdraw or revoke their consent at any time during the study.

Data collection consisted of a sociodemographic questionnaire and a semi-structured interview and took place in the integrated psychology study room of a college located in Rio Grande do Sul.

Participants individually completed the sociodemographic questionnaire and the semi-structured interview. The questionnaire collected data regarding the participant and their family, such as age, marital status, education level, occupation, family income, religion, and number of children. The semi-structured interviews used a script, developed specifically for this study and administered by the researcher, a psychology student, to facilitate the process and ensure that the study's objectives were met.

Participants were guaranteed confidentiality, the freedom to choose whether or not to participate in the study, and the option to withdraw or revoke their consent at any time during the study. These aspects were guaranteed by the Informed Consent Form (ICF).

The participants' statements were recorded using a cell phone and transcribed in full, with their permission. Data analysis was conducted according to Bardin's (2016) content analysis, which consists of a qualitative data analysis technique that enables the interpretation of discourses, texts, statements, or other types of material. According to Bardin (2016), content analysis comprises three phases: pre-analysis, exploration of the material, and treatment of results and interpretation. The pre-analysis phase consists of selecting the material and formulating hypotheses and objectives. The material exploration phase refers to coding - that is, the assignment of codes - and floating reading, which involves the selection of words and phrases.

Analysis of the data obtained allowed for an understanding of the history of individuals who underwent the surgical procedure for an intestinal ostomy, beginning with the identification of the first signs of the disease that led to the creation of the stoma. For this study, three thematic categories were developed based on the decoding of the interviews.

RESULTS

Participants were identified using codes - P1, P2… P6 - to ensure confidentiality and anonymity.

The participants are all over the age of 54. Regarding marital status, two are married, two are widowed, one is single, and one is divorced. The average household income is three times the minimum wage. Regarding religion, three are Catholic, one is an Evangelical Methodist, one is an Umbanda practitioner, and one identified as a Spiritist. Four participants are retired, while one practices law and another serves as a priest. The length of time since the participants underwent ostomy surgery and have lived with the stoma ranges from three months to 26 years.

All have a colostomy, which is an intestinal ostomy for elimination, and have a permanent stoma - that is, one that cannot be reversed - except for one participant, whose stoma's permanence is still under evaluation.

For this study, three thematic categories were developed. The first referred to receiving the diagnosis that led to the creation of the stoma. The second focused on the life trajectory after the stoma, and the third concerned healthcare for people with a stoma.

FROM DIAGNOSIS TO STOMA CREATION

All participants had been diagnosed with colorectal cancer, which led to the creation of a stoma - in this case, a colostomy.

> But when the doctor gave me the diagnosis, it was just me and him in the room. And then he said: "The news I have for you isn't good. You have carcinoma. [...] You have a seventy to seventy-five percent chance of not surviving, because I'm going to open you up and I don't know what I'm going to find in there (P1). From the very beginning, when the doctor told me I'd have to undergo radiation therapy and chemotherapy, they already told me the cancer was aggressive. You know, they already prepared me for the fact that if it didn't work - if, let's say, the radiation therapy and chemotherapy didn't have the expected effect - the procedure would be this: an amputation and the creation of a colostomy (P3). Right away, I only knew I had a tumor; I didn't know I was going to have a colostomy bag.

It was found that the participants were unaware that their surgery would involve the placement of a colostomy bag, which had a significant impact on them:

> *When it comes to the people who undergo surgery, what's missing is for the media and public sectors to provide more information on the subject, because it's almost a taboo. Nobody talks about it, right? You only find out when you go through it yourself; otherwise, you don't know (P4). Because, you see, the word "cancer" is already scary - it causes panic. Then there's the ostomy - people don't even know what that is. It's hard (P3). So he tried radiation therapy. We did 40 sessions of radiation therapy, but it didn't work. It just made things worse, so there was nothing else to do, right? It was either the ostomy or life (P4). So, as soon as he said I'd have to use (the bag), I refused. Because I thought it was just awful. No, I couldn't imagine myself with a colostomy bag (P4). Then I had to live with it forever. He (the doctor) amputated the rectum [...] it was all removed because it (the cancer) was deeply rooted. [...] I had radiation, I had chemo (P5).*

Upon receiving the diagnosis, there was initially a sense of denial until the situation worsened and it was seen as the only way to continue living

> *When he said it was definitive, I asked a second specialist for their opinion, and that's exactly what happened. Of course, we're not exactly jumping for joy, but I took it in stride. I thought to myself: if there's a chance, we're still going to try - why not? (P3)*

The participants' accounts highlighted the impact the family experienced upon being informed of the diagnosis:

> *We were really moved, and things went smoothly with the doctor, but then we hugged each other and cried - really hard, all together, you know? (P6). Oh, and my oldest son was really shocked at first, but then as they saw things, they came together, you know [...] my kids used to fight a lot, but now it seems like they don't - they're a lot calmer [...] maybe seeing these difficulties helps the family too, you know. It helps the family reflect (P2). I think at first it was a shock; my father wasn't dead at the time. He didn't even want me to have (the surgery) (P4).*

Participants described their feelings about the surgical procedure:

> *That's when I found out I had a tumor in my intestine, in my rectum. Then they referred me for surgery, and I started chemotherapy [...] the cancer (the metastasis) spread from the rectum to the peritoneum [...] and it reached my lungs as well. It affected my vision (P6). I fell into depression; I had to undergo treatment, and it was really hard to accept. We face prejudice because back when I had the surgery (ostomy procedure), people didn't talk about it much, you know. Today there are celebrities who talk about this, so people know a little more about it. But back when I had it done, people didn't talk much about it. I didn't know anyone myself, I didn't even know you could live like that, you know (P4).*

The participants spoke about their experiences with ostomy surgery and their confrontation with mortality:

> *And here I am, just taking each day as it comes, and after a year and eight months, it turned out that the cancer cells were winning (P6).*

Participants shared their feelings about life after surgery:

> *I also have a different perspective on life, on day-to-day things, on some of the things we used to want. Today, I don't care anymore [...] I know I have to always look ahead and live. The simplest thing in the world: living. So, what is living? It's just day-to-day life, right? One day after another, and life is simple (P6). When I opened my eyes, I was born again. Every day I'm being reborn. [...] I had two chances to die, and He (God) didn't let me die. It's so I can stay... My mission isn't over (P1). It's a limitation, but one that, well, we just have to live with and learn from, too (P2).*

LIFE AFTER A STOMA

It was observed that the participants noted changes in their way of life following their ostomy. Most participants expressed uncertainty and had questions about the new physical and emotional situations brought about by the use of the colostomy bag:

> *It felt like I was going to spend my whole life focused solely on that, right? Ugh, now my life is over, and I - I like going to the beach, I like going to parties, and I like doing everything - so how is that going to work out? But that was right at the beginning (P5). So I didn't*

> *have any bad impressions; I was, actually, I was afraid to touch it, afraid of hurting myself, afraid of those kinds of fears - which I think are normal - because it's something totally new. Imagine a hole in your belly (laughed) (P3).*

Based on the data collected, it was possible to identify other impressions among the participants.

> *Before, I wanted to embrace everything. Then I had to worry a little bit about the disease. Of course I didn't want it to happen, but I can handle it and say that I have a normal life. [...] I say that I'm a happy guy despite everything (P6). There was that... that shock, but it passed like that. I took it step by step (P3). Every day is a new day for me; it's as if I were born again (P1).*

Participants mentioned difficulties in adapting to their new way of life as people with ostomies

> *"Look, it was kind of hard at first, because right from the start I was actually afraid to eat, you know. So that was the period when I lost weight, because I was afraid to eat. And I wondered how that bag was going to work, if it was going to fall off, how I was going to manage down there. So I'd go to the clinic to have it changed." (P3). I still haven't learned how to change (the bag). My son is the one who learned how to change it. I don't know if it's just me having trouble, but I think that soon I'll know how to clean and change it too, you know. We have to learn as we go (P2). At first - well, actually, I still haven't changed it. I couldn't change the bag by myself. My wife or my daughter - usually it's my wife who changes it (P6).*

In social settings, ostomates may face embarrassing situations due to rejection and prejudice, as reported by the participants:

> *We face prejudice from family members and neighbors. I had a tenant who stopped drinking mate with me when she found out I had a stoma (P4). When I got home (after being discharged from the hospital), there was a plate painted with enamel just for me, a spoon, a knife, a saucer, a cup, a glass - everything was marked, everything (P1).*

As for spirituality, the participants in this study reported following a religion, and their beliefs played a significant role in this process:

> *So, I believe in God, you know. I know there's a higher power guiding us. Tomorrow is another day (P6). The prayer chain was really powerful. That was a really good thing for me, too. It helped me a lot to get through it. I give glory to God, you know. I was given a second chance at life (P1).*

The presence of family members makes the process less complicated, as the participants explain below:

> *I don't really do anything around the house, you know. I don't even carry a grocery bag. They're always welcoming me and helping me, and that extra strength I have is really important - the fact that we're always together. And I think that helped a lot. Knowing that I have a foundation in my family and that we're all together. That unity... (P6). Look, for me, I think part of my acceptance came from my family. That's really important (P5). "I told her: look, my daughter, if I'm going to get through this, I'll do everything in my power, because*

> *I can see that I'm getting support (P2). My husband, yes, he's passed away now, right? He passed away in 2020. He really was, wow, a warrior, you know, to me. He took me to every radio show, every single one; for all 40 days I was hospitalized, he was there (P4).*

Support for people with ostomies can be provided by the public health system and through their social network, such as family, friends, support groups, and others

> *Like I said, the strength that comes from friends and family. So yeah, I lead a normal life. The only thing I've lost is soccer. These are just things (P6). At the clinic, they were amazing. [...] they were always so responsive. So much so that they were my safety net. I realized I was almost dependent on them because the service was so good, everything was so convenient. [...] It was convenient; I didn't need to switch, I'd go there to get things done. So that's how I felt... I'd make an appointment, I'd get there, and I'd be seen even before my time, sometimes (P3).*

Quality of life for ostomates involves meeting their needs in their new living situation, such as providing adapted physical facilities:

> *For me, the biggest challenge is always that I have to prepare myself before I even know if there will be a bathroom I can use. For me, that's the worst part - the issue with the bathroom, an accessible bathroom (P3).*

HEALTH CARE FOR PEOPLE WITH OSTOMIES

The responses provided by the participants made it possible to assess their satisfaction with the quality of care provided by public health care professionals:

> *Oh, it was really great. At the clinic, they were amazing [...] they were always so responsive (P3). So, I didn't know there was a specialized department there, you know, just for our disability, and I was made to feel very welcome there (P1). Look, I found so much support, you know, from the team there [...] they're very attentive, they're... you know... you feel like they're people who welcome you, you know, they help you (P2).*

As for the demand for psychological care, it was found that prior to the ostomy procedure, only two participants expressed an interest:

> *I've been through psychoanalysis. I've been in therapy with a wonderful psychoanalyst, and she's been working with me since 2020, so she's been an old acquaintance of mine for a while now (P1). It was only back in college that we actually took psychology courses, you know. And any kind of follow-up like that, even for my education [...] was always meant to help me in my daily life (P3). Not before. Before, I lived a good life. [...]. But after that, yes. After that, yes. After that, I had to seek help (P4).*

After the stoma was created, however, all participants acknowledged the need for psychological care to support them in their new way of life:

> *It's essential, right? For me, it was a real turning point because when you have the surgery,*

> *you feel like an alien - like you're unique, you know, like no one else has it. Then you really need it (P4). Oh, I think we have the support of a professional who's prepared. The psychologist knows how to guide you. They know how to boost your self-esteem (P1).*

Regarding the psychological care they received through the public health system, the participants reported:

> *The psychologist there (at the Basic Health Unit) tried to start a group. I went twice. [...] Then the group ended. They said there wasn't a room available (P6). I didn't really need it, you know. [...] I started living what I told others to live. It was very peaceful. [...] I think psychological counseling is necessary, every now and then, so we can always be well, so you can have new horizons too. Especially because I work with people. I help people. The priest is the psychologist of the poor, right? (P3).*

Understanding the social support network is important for the care of people with ostomies. Therefore, participating in meetings of ostomy associations is of great help to people with ostomies and their families:

> *I really like it so much that I go to the group meetings there regularly. I only miss them when I can't make it (P4). Yeah, since I'd never even been to one of these group meetings before - it was my first time last year - it was a good experience, because I needed it [...] so it was interesting that we could share some questions and practical tips [...] someone who's been through it knows. So, I think we help each other a lot more when we talk to someone who's already going through it (P3).*

DISCUSSION

The use of a colostomy bag causes feelings of insecurity and raises questions about the new physical and emotional challenges the individual faces. It is a condition that can affect people's lives, their social interactions, and have direct consequences for their quality of life. It entails changes in lifestyle, and a multidisciplinary and/or interdisciplinary approach is of great importance in cognitive, psychoeducational, and emotional interventions (HENRICH; CALVETTI, 2019).

It was observed that a lack of knowledge about the ostomy procedure and the subsequent placement of the colostomy bag exacerbated the impact of receiving the diagnosis. The process of accepting the ostomy among the participants in this study began with receiving the diagnosis, progressing from rejection to acceptance as it was perceived as the only option for survival.

This aspect was also observed in the reactions of family members, who experienced feelings of distress. However, attitudes that strengthened emotional bonds were also identified. Thus, the importance of family support was recognized, as it promotes the self-esteem of the person with a stoma and their reintegration into their social environment.

After surgery, the person with a stoma faces a significant rupture with their previous experience of bodily identity. The postoperative period requires not only physical recovery but also time

and support to develop emotional coping strategies. Feelings such as distress and fear are common, accompanied by defense mechanisms such as denial, anger, bargaining, and anxiety. The loss of sphincter control and the dependence imposed by the collection pouch can profoundly compromise the sense of security, self-confidence, and autonomy (DOS SANTOS REIS; VIEIRA, 2021).

The emotional and social impact of ostomy can intensify with the emergence of feelings of shyness and inadequacy, which hinder social interaction. (DE SOUSA *et al.*, 2022). According to Cetolin *et al.* (2013), living with a stoma is highlighted as a source of fears, embarrassment, discomfort, and doubts, as most people who undergo the surgical procedure to create a stoma experience changes in their lifestyle after surgery. They state that these changes stem from physical, psychological, and social alterations, as well as changes in body image, which necessitate the search for strategies to adapt to the new reality.

It is important to highlight the experience of grief due to the mutilation and alteration of body image. In this adaptation process, it is common for the individual to experience symbolic grief for the body they had before stoma creation. This grief involves the deconstruction of the previous identity and the need to reconstruct a new self-image. Grief encompasses a process of adaptation to loss, in which the individual must perform psychological tasks to reorganize their life (WORDEN, 2013). Given this, psychological care is of great importance, as it can assist in the processing of grief and the individual's adaptation to the resulting changes.

According to Saunders (1991), cancer patients experience what is called "Total Pain," meaning that the disease, in addition to causing physical suffering, brings about social, psychological, financial, and spiritual suffering, as well as repercussions for their family members and the healthcare team involved in their care. The concept of Symbolic Pain of Death, derived from this premise, encompasses psychological and spiritual pain. The former refers to the fear of suffering, anguish, and guilt arising from loss, while the latter involves reflections on the meaning of life, guilt before God, and fear of death.

This study identified the existence of rejection and prejudice experienced by some participants due to their status as ostomates, factors capable of affecting self-esteem and personal identity. Law No. 13,146, dated July 6, 2015, known as the Statute of Persons with Disabilities, constitutes the Brazilian Inclusion Law (BIL) and was drafted with the purpose of ensuring the full exercise of the rights of persons with disabilities, promoting their participation and social inclusion (MINISTRY OF HEALTH, 2021). As provided for in Brazilian law, people with ostomies are legally recognized as people with disabilities (PWD). This is, however, a physical disability of an invisible nature, hidden by clothing, yet highly significant.

The Social Model of Disability, developed by and for people with disabilities, including those with stomas, proposes a break with the biomedical conception of disability, conceiving it not as a biological sentence or personal failure, but as a mode of existence that demands recognition, rights, and participation (MAIOR, 2017). This new paradigm has underpinned significant changes in

international legislation, such as the International Classification of Functioning, Disability, and Health (ICF) and the Convention on the Rights of Persons with Disabilities (CRPD), to which Brazil is a signatory. Both view disability as the result of the interaction between physical impairments and exclusionary social contexts that do not embrace human diversity (SANTOS, 2016).

Despite legislative advances, significant barriers to the sociocultural participation of people with disabilities persist, primarily due to prejudices and discrimination still present in various sectors of society. Even in the face of legal recognition of their rights, these individuals continue to face situations of exclusion, invisibility, and oppression (JESUS *et al.*, 2024).

Knowledge about the social support network is important for the care of people with stomas. This care should be directed toward the exchange of experiences and the identification of individuals' needs, aiming to establish strategies to improve the quality of life for all involved (CARVALHO, *et al.*, 2013).

Health care must be provided in a comprehensive manner, taking into account the various biopsychosocial, pathophysiological, nutritional, psychological, social, and spiritual aspects of the person with a stoma (SILVA *et al.*, 2017). The multidisciplinary team plays a crucial role in informing and improving the quality of life of the patient and their family (CETOLIN, *et al.*, 2013).

Health services and professionals must be prepared, through care planning that includes psychological support and health education, to develop the person's self-care skills, thereby contributing to a significant improvement in these individuals' quality of life (CARVALHO *et al.*, 2013).

According to Santos (2017), people who undergo surgery for a stoma experience changes in their identity. In this regard, Family Health Strategy teams, in conjunction with the social and family support network, need to address the expectations that arise in the ostomized person (CETOLIN *et al.*, 2013).

Regarding psychological care for people with a stoma in the hospital setting, its importance can be highlighted at every stage. Psychological care strategies should be developed from the preoperative period through preparation for discharge. These strategies include: review of the medical history, identification of the patient's psychological needs in the preoperative period, team meetings to discuss cases and develop a therapeutic care plan, guidance for family members, psychological support at the bedside, and assessment of the patient's psychological needs during the surgical procedure and ostomy creation, as well as patient guidance and evaluation of their psychological state, with a view to preparing for hospital discharge (SILVA *et al.*, 2019).

Within the public health context, the work carried out by the Health Care Network (RAS) stands out. It is essential to have trained teams capable of caring for individuals with stomas in primary and specialized care, as well as in secondary and tertiary care. It is equally essential to have a variety of interventions and services to better manage care for any health condition, including for individuals with stomas (TRAMONTINA *et al.*, 2019).

According to the results of the study conducted by Louis *et al.* (2023), it was found that health education initiatives for patients with stomas in primary care units are essential, as they promote autonomy and improvements in various aspects, including social, physical, environmental, and cultural dimensions. Health promotion and rehabilitation care for people with stomas are therefore critical needs. Joint efforts by multidisciplinary teams in the health sector yield positive outcomes for both the professionals involved and the patients served (DORNELAS, 2022).

Regarding the quality of care received in the public health system, the responses provided by the participants in this study allowed us to assess their satisfaction with the quality of care provided by public health professionals. With regard to the psychological support offered to people with ostomies, it was found that it is provided through the public health system, in a specialized ostomy unit, primarily through sessions based on the clinical model of individual psychotherapy.

With regard to the role of psychology in healthcare services, progress has been made in establishing its presence, particularly within the public healthcare system. Existing studies confirm that individuals with ostomies can lead normal lives and emphasize the crucial role of the multidisciplinary team within the healthcare system (NASCIMENTO, 2018).

Emotional support is essential and of great help to ostomates. The most commonly observed change in ostomates who receive pre-surgical and/or post-surgical psychological counseling is a reduction in anxiety, fear, and sadness (MORAES *et al.*, 2013).

It was observed, however, that only half of the participants in this study reported having sought psychological care after hospital discharge. Key factors contributing to this finding include the lack of contact with a licensed psychologist and the absence of such support within the hospital setting at the time of the ostomy surgery. According to Almeida (2016), although interprofessional collaboration is a topic addressed in academia, it is rarely practiced in educational settings and healthcare institutions. Health services and professionals must be prepared, through care planning that includes psychological support and health education, to develop individuals' self-care skills, thereby contributing to a significant improvement in these individuals' quality of life (CARVALHO *et al.*, 2021).

All participants reported receiving a great deal of help from their family members, which greatly contributed to their acceptance of the stoma, social reintegration, and alleviation of distress. The family serves as a source of support and sustenance for the person with a stoma. Family support can foster a new identity for the person with a stoma, enabling the restoration of lost self-esteem and social reintegration. However, the family may face challenges, as, like the patient, they also undergo this rehabilitation process and therefore also need support to be prepared to assist with care (SANTOS *et al.*, 2021). It should be emphasized that the family, just like the patient, also undergoes this rehabilitation process; therefore, it is the responsibility of the professional psychologist - preferably in an integrated manner with the interdisciplinary healthcare team - to provide psychoeducational interventions that promote the empowerment and autonomy of people with stomas (SILVA *et al.*, 2017).

However, the lack of academic training on ostomy care constitutes an obstacle to adequate psychological intervention at the interprofessional level.

Furthermore, in addition to the scarcity of specific psychological studies addressing the needs of people with stomas, it is evident across various healthcare fields that care practices are outdated. The Brazilian healthcare sector still adopts practices based on a biological approach. In the context of stoma care, individuals undergoing stoma creation experience changes in their body image. Complications with the stoma may occur, such as inadequate surgical technique, age, diet, premature physical exertion, poor self-care, infections, weight gain, improper stoma placement, and incorrect use of devices (DE OLIVERIA; DOS SANTOS MAIA, 2020).

Given this situation, there is a need for multidisciplinary technical guidance from professionals to work with ostomy patients, providing information, support, confidence, and a better quality of life. The professionals who care for them should always aim for comprehensive and early rehabilitation, initiated in the preoperative period and continued throughout the duration of the stoma, to help them cope with daily challenges (DOS SANTOS REIS; VIEIRA, 2021; NEIVA *et al.*, 2020).

It is necessary to adapt the current training model in undergraduate health programs, including, in the case of this study, the Psychology program. Studies point to interprofessional education as an important strategy for building collaborative and interprofessional work. This perspective can help professionals engage in dialogue with their team, sharing knowledge focused on interprofessional care in comprehensive health (COSTA, 2016).

However, curricular gaps in undergraduate psychology programs, which do not address the context of ostomy, pose a challenge to interprofessional practice. The scarcity of studies focused on the interface between psychology and ostomy highlights a theoretical and practical gap that needs to be addressed.

CONCLUSION

This study sought to understand the potential contributions of psychology to the life trajectories of individuals who have undergone surgery to create an intestinal ostomy for waste elimination. Furthermore, it identified aspects of these individuals' experiences as ostomates and their perceptions of the care they received both within their social and family circles and within the public health system.

The lack of prior knowledge about colostomy, loss of sphincter function, and the consequent use of a collection bag can have a significant emotional impact on patients.

The discovery of the diagnosis, combined with a lack of understanding about the context of the stoma, were the key triggers of the perceptions experienced by the participants. Receiving the

diagnosis and learning of the need to use a colostomy bag can give rise to various emotions and feelings of distress and fear, which are also reflected in the dynamics of the family system.

The participants reported changes in their way of life following ostomy, in the sense of seeking adaptive strategies in the face of sphincter loss and their new body image.

This study aims to contribute to the body of knowledge for professional psychologists in their work addressing the needs of this large population. Furthermore, it is essential to also offer support to family members and healthcare teams involved in the care process, promoting a more sensitive and comprehensive interdisciplinary approach. Psychology can contribute through psychoemotional support, psychoeducation, adaptation, and the empowerment of individuals with stomas.

The scarcity of studies focused on the interface between psychology and stoma care characterized the limitations encountered in developing this research, highlighting a theoretical and practical gap that needs to be addressed. This important approach is not yet present in the academic training of future psychology professionals. It is urgent to expand the field of psychological research and practice in this context, considering both the subjective experience of the person with a stoma and their integration into family, social, and work settings.

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