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# Perception of people with intestinal ostomy about their quality of life

Percepción de las personas con ostomía intestinal sobre su calidad de vida

Percepções de pessoas com estomia intestinal acerca da sua qualidade de vida

## ABSTRACT

**Objectives:** to know the perception of intestinal ostomized people about their quality of life. **Methods:** Exploratory and descriptive study with a qualitative approach. Performed at a Stomatherapy Service. Twenty-six people with permanent or temporary intestinal stoma aged 18 years or older participated in the study. Data were collected in October and November 2019, after approval by the Research Ethics Committee, under opinion No. 253/2019, through a sociodemographic and clinical questionnaire and semi-structured interview. The data were submitted to Content Analysis. **Results:** The quality of life of people with intestinal ostomy is affected by complications of the ostomy and changes in their social roles, as well as the emotional and physiological changes resulting from ostomy. **Conclusions:** It is noteworthy that the positive effects on quality of life may be associated with the way people react to their own ostomy. Most participants reported having a good quality of life.

**DESCRIPTORS:** Quality of Life; Ostomies; Medical-surgical nursing.

## RESUMEN

**Objetivos:** conocer la percepción de las personas ostomizadas intestinales sobre su calidad de vida. **Métodos:** Estudio exploratorio descriptivo con abordaje cualitativo. Realizado en un Servicio de Estomaterapia. Participaron en el estudio 26 personas con estoma intestinal permanente o temporal de 18 años o más. Los datos fueron recolectados en octubre y noviembre de 2019, previa aprobación por parte del Comité de Ética en Investigación, bajo dictamen No. 253/2019, mediante cuestionario socio-demográfico y clínico y entrevista semiestructurada. Los datos se enviaron a Content Analysis. **Resultados:** La calidad de vida de las personas con ostomía intestinal se ve afectada por las complicaciones de la ostomía y los cambios en sus roles sociales, así como por los cambios emocionales y fisiológicos resultantes de la ostomía. **Conclusiones:** Es de destacar que los efectos positivos sobre la calidad de vida pueden estar asociados con la forma en que las personas reaccionan a su propia ostomía. La mayoría de los participantes informaron tener una buena calidad de vida.

**DESCRIPTORES:** Calidad De Vida; Estomas; Enfermería Médico-Quirúrgica.

## RESUMO

**Objetivos:** conhecer a percepção de pessoas estomizadas intestinal acerca da sua qualidade de vida. **Métodos:** Estudo exploratório e descritivo de abordagem qualitativa. Realizado em um Serviço de Estomaterapia. Participaram do estudo 26 pessoas com estoma intestinal definitivo ou temporário com 18 anos ou mais. Os dados foram coletados em outubro e novembro de 2019, após aprovação do Comitê de ética em Pesquisa, sob parecer nº 253/2019, por meio de questionário sociodemográfico e clínicos e entrevista semiestructurada. Os dados foram submetidos à Análise de Conteúdo. **Resultados:** A qualidade de vida de pessoas com estomia intestinal é afetada por complicações da estomia e as mudanças nos seus papéis sociais, bem como as alterações emocionais e fisiológicas decorrentes da estomização. **Conclusões:** Destaca-se que os efeitos positivos na qualidade de vida podem estar associados à forma como as pessoas reagem à sua própria estomia. A maioria dos participantes refere ter boa qualidade de vida.

**DESCRITORES:** Qualidade de Vida; Estomias; Enfermagem médico-cirúrgica.

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**INTRODUCTION**

**B**ecoming an intestinal ostomy can provoke feelings of revolt, sadness and deconstruction of the self-image, due to the embarrassing experiences and circumstances resulting from the ostomy, as well as due to complications such as prolapse, dermatitis and others,<sup>1</sup> changing the quality of life (QL). It is observed that the intensity of this situation can particularly affect each individual according to their adaptive and emotional capacity. The way of coping with this condition can lead to feelings of exclusion, embarrassment and rejection, with a possible decrease in the QoL of these people.<sup>2</sup>

The concept of QoL is linked to the individual's perception of their health status in relation to social, physical, psychological, economic and spiritual domains.<sup>3</sup> For people with intestinal ostomies, QoL is also dependent on other factors, such as psychological adaptation to the new change, self-image, self-esteem, stoma complications, adaptation to collecting equipment, in addition to adequate support received from qualified professionals.<sup>4</sup>

The changes caused by ostomy can be so significant that the feelings experienced can lead to moments of depression,

**The changes caused by ostomy can be so significant that the feelings experienced can lead to moments of depression, fear, sadness, social isolation, in addition to withdrawal from work.**

fear, sadness, social isolation, in addition to withdrawal from work.<sup>5</sup> Still, it is necessary to consider the presence or absence of associated multimorbidities, the maintenance of relationships and social interactions, positive and hopeful feelings, in addition to the facilities and obstacles in accessing health services and specialized support and family support.<sup>6</sup>

The QoL of the person with ostomy is the result of a set of facilitating factors in this process of change that is so relevant in these people's lives. Therefore, nursing care allows people with a stoma to learn about health care, the stoma and how to improve QoL through self-care.<sup>7</sup>

Thus, it is questioned how the person with a stoma perceives their QOL? Given the above, this article aims to know the perception of people with ostomy about their QOL. This knowledge becomes essential as it allows nursing care to be carried out in a broader way, based on the perception of the person being cared for about their QOL.

**METHOD**

This is a qualitative, descriptive and exploratory research carried out with people with intestinal ostomies treated at the Stomatherapy Service (SS) of a

University Hospital in a city in southern Brazil. The inclusion criteria of the participants were: being 18 years old or more, having an intestinal stoma, having an active registration in the SS, having the physical and mental conditions to answer the study questions. Exclusion criteria were limited to absence from nursing consultations at the ES, being undergoing chemotherapy and/or radiotherapy.

The number of participants was defined by saturation 8 data, that is, when there were no new elements, the collection was interrupted. Thus, 26 people with intestinal ostomy aged between 29 and 80 years participated, 14 were men and 12 women, mostly due to colorectal cancer.

Data collection took place in October and November 2019 at the SE office, after a favorable opinion from the Ethics Committee in Research in the Health Area of the Federal University of Rio Grande Certificate of Presentation of Ethical Appreciation No. 20012819.4.0000.5324, the CNS Resolution - 466/12. We used a questionnaire with sociodemographic and clinical information about the person with an ostomy and a semi-structured interview, applied during nursing consultations. In the semi-structured interview, participants were asked about their perceptions of their QoL. The script is based on a literature review about the aspects that interfere in the QOL of people with intestinal ostomy. The interviews were recorded and later transcribed in full.

All participants signed the Informed Consent Form. Data were analyzed through Content Analysis, developing the pre-analysis steps; exploration of the material and treatment of results and, finally, inference and interpretation.<sup>9</sup>

## RESULTS

QOL is built from people's perception of their social, physical, economic, but also psychological and spiritual domains. Thus, the participants of this study demonstrate in their speeches the impact on QoL when living with an ostomy.

### Bodily transformations impacting QOL

The ostomized physical body transforms the self-image and its functionality, affecting their QOL.

*When you have an ostomy, you have to wear loose pants. (P6)*

*In the beginning it is difficult, until the person adapts, he/she loses weight. (P12)*

*It causes an inconvenience, because I'm not perfectly as I was, I can't push, I can't squat down to pick up weight, a lot has already changed. (P14)*

The continence is altered and may cause distrust regarding its odor, as well as painful injuries by the effluent in contact with the skin that impacts QOL.

*I can't hold the gas, but it doesn't stink because it doesn't come out of the bag. Then everyone starts laughing. (P2)*

*It felt like I was always stinking, but that's just our impression. (P5)*

*I have very sensitive skin and right now I'm all bruised all around [because of the stoma]. It even hurts to walk. (P20)*

### Between isolation, fear, hopelessness and happiness

Isolation is observed, as well as hopelessness and fear in the face of changes in living with a stoma.

*For the first few months I was pretty disoriented. I was very nervous, I hardly spoke to anyone. (P11)*

*What's the use of staying, living with it? I don't live, I'm vegetating. I often preferred death to living with it. (P13)*

*I don't communicate with anyone, I isolated myself. I think so, the cross is heavy. Here comes that word again: But you're alive. And I wonder sometimes how much it's worth seeing me like this. I think by the time I die, I'll rest. (P15)*

*But this is how it is, that I get a little depressed at times. Because I want to go places and I don't get excited, I get scared. (P20)*

The scholarship becomes the materiality of suffering due to limitations and the fear of setbacks with it.

*Estou debilitada nesse momento e é muito sofrimento para mim. (P13)*

*There are difficult moments. There are still things to be overcome. (P1)*

*My whole day to day has changed, I have to take care of this bag here 24 hours a day. (P10)*

*Affects. I don't go shirtless in summer, I haven't had a bath in the beach for 3 years, I don't sleep on my stomach, some limitations. (P23)*

*Nowadays if I have to travel, I won't be able to. Or I will, but I'll have to prepare a lot of things to be able to travel and fit into it. So, it means that it's not just simply going. It is not quite easy for you to reconcile one thing with the other. (P10)*

*I have a discontent with the fear of expelling gas at an inappropriate time. (E15)*

There is a lack of characterization of the person prior to ostomy, the bag being something that imprisons and consumes the person who uses it.

*We can't do what we used to do. You always have that concern. We are no longer free, just to have this obstacle. It's always here [the bag]. You go out, you are over there and it is loose. (P11)*

*You're a normal person and in a little while, you'll have a bag. In reality it represents as if it were a parasite stuck to you. It is not normal. (P12)*

Apesar das falas negativas, há pessoas que se sentem felizes com o novo contex-

to de vida por perceberem ter mais QV com a estomia e a bolsa coletora.

*If it affected me in any way, it was in a positive way, because I think in my head that I traded cancer for a bag so I think I won. (P9)*

*It's changed for the better, there are people who feel disgraced with a bag. I don't feel that way, I'm a very happy person, very, very happy. (P7)*

*Look, I think I have quality of life, I don't lack anything, I have everything. (P26)*

### Adaptations and restrictions due to the new context for improving QOL

Participants report having adapted or restricted some activities in view of new health needs, a fact that can reduce their QOL.

*In certain places, we can no longer be. I used to participate in tournaments, so it became more difficult. (P16)*

*I only go to the beach wearing a shirt and I don't take a swim in the pool or the sea anymore. (P18)*  
*I don't travel, I can't travel. To go out in the morning, I can't have coffee, because of the bowels, the stools are soft. So I try not to drink coffee. (P20)*

*The only thing I used to do a lot and don't do anymore is playing football. (P21)*

*I feel embarrassed when I'm with other people and I happen to get gas. I avoid having dinner at acquaintances' houses because right when we're eating is the time they go out. (P23)*

Despite the statements above, there is a possibility of having QoL and a less difficult confrontation, but this depends on the subjectivity of each person and the construction made about their life context.

*I'm just like that, I'm talking and: "Oh, wait a minute, I'm going to see my bag, which is very full of air." (P7)*

*I live normal with everyone, I've never had any relationship problems because of the ostomy and there are people who don't even know I have it. I don't speak either, because it has nothing to do, but I think I live well with it and so do people. (P9)*

*Nothing has changed. It didn't change my relationship with other people, or with my family. (P17)*

*I never let it interfere with relationships. This is an individual issue, quite the opposite, I had relationships, I went out, walked a lot, because I understood that I had to be well to face the disease. (P24)*

### Hope and faith in a new chance to live

Faith improves QoL by strengthening and comforting the person to face the daily life of ostomy with more lightness.

*The doctor was terrified that I reacted very well. I have a lot of faith in God! God to me is everything. (P2)*

*I believe in God and let's go. I usually joke that I'm in profit. (P11)*

*I've always had faith in God and it's still that way today. (P12)*

*It's having faith in God and moving forward. It's no use wanting to be traumatized that it won't lead to anything, it will only be harmed even more. So you have to go your way. (P16)*

They report gratitude for being alive because they perceive the ostomy as a second chance, which makes them live with more quality.

*I'll repeat to you: "I'm alive! I went through several things, but the 'old man upstairs' still doesn't want me there. I don't take any*

*medicine. Thank God I don't have anything. What am I going to complain about? (P4)*

*Why don't I come back to life after colostomy? I saw that it was better, I saw that I was losing life. Thank God He gave me one more chance to live. (P7)*

*I think it has the hand of God, I was supposed to die. What caused me the most was the faith in God, of being able to survive through an ostomy because there would be no way out. (P6)*

*I have a lot of faith, I already had it and there's even more. It was significant for me. I believed it was a way for me to live and I created faith. I promised, paid, all that. I thought I was going to die before, but no, thank God! (P17)*

*Improved, improved a lot. It increased even more. I got much closer to God. I'm not strong, strength comes from God for sure. To have gone through everything I've been through in the last few months and to be here laughing with you. (P19)*

*I started praying more. (P26)*

There is the hope that medical advances will help them to live without the collection bag and, consequently, with better quality.

*Yes it has! The hope is that, with the advancement of medicine, we will no longer need to use a bag, but that they will create something else that will improve our quality of life. That's what I support myself every day. (P1)*

### Reduction in standard of living and quality of life

The economic domain was affected by the absence from work due to ostomy. This fact compromises QOL by reducing access to services, in addition to the feeling of being unproductive and dependent.

*The part that affected me the most was the professional. It did have a financial impact, it reduced my income. When I was normal, I worked, I used to earn a good salary, had a normal professional life and after the ostomy it reduced a lot. (P6)*

*I was a woman who made frozen foods, worked until Sundays, Christmas, New Year, and now I depend on others. (P13)*

## DISCUSSION

The participants' perception is that ostomy impacts all QOL fields. On the physical side, the ostomy transforms the image and functionality of the body. The image is built up by the shape and contours and dissatisfaction with the body can generate negative feelings and even lead to depression.<sup>10</sup> This phenomenon still occurs even in cases where the person is aware of the situation and accepts the new condition without difficulties in adapting.<sup>11</sup>

Bodily issues influence the psychological aspect, generating isolation, fear and disgust with life. Although this fact is frightening, dissatisfaction with the new living conditions and the doubt regarding the choice for ostomy in favor of survival are not surprising, since, when experiencing the impact that surgical treatment entails, they even consider the death itself, even though the performance of the ostomy represents the difference between living and dying.<sup>7</sup>

Although impactful, this desire becomes understandable when considering the challenges that a stoma can add to these people's lives, as the wounds from surgery and concerns about skin irritation, risk of hernia, fear of leaks, and discomfort to others people make people with an ostomy feel unable to remain physically active and lack the confidence to participate in regular activities.<sup>12</sup>

Generally, these feelings are associated with social restrictions and intru-

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sive thoughts, in addition to concerns about the ostomy patient's social life and insecurity when trying to recover previous social roles and functions.<sup>13</sup> The changes resulting from ostomy also involve self-esteem and interpersonal relationships, thus emerging the fear of rejection, the block in the construction of new relationships, the shame of one's own body, the embarrassment of using the collection bag and, with that, the difficulty in talking about their new condition of life.<sup>14</sup> Facts that corroborate the perception of study participants about the social domain reduced to their QoL.

Social isolation is perceived at various times in the speeches, even if partial, such as when the person maintains social contacts, but does not talk about the ostomy or hide it from others, and isolation ends up compromising social, religious and leisure activities. The merciless, stigmatizing and excluding gazes end up pulling people away from social life and making them hostage to public perception.<sup>15</sup>

It is evident that the participants have difficulties in talking about aspects of their lives related to the ostomy. Sometimes, they are introverted and evasive, others emotional and destabilized. It is common for people with ostomies to prefer to live in a very inconvenient environment, have high scores of depressive state and dissatisfaction with leisure activities.<sup>16</sup>

The QoL in the economic aspect is perceived as affected by reducing the standard of living, by the feeling of unproductiveness and dependence on the ostomy. Thus, the loss of sphincter control is considered an obstacle to returning to activities.<sup>17</sup> In addition, fear of exposure and embarrassment lead to permanent withdrawal from work activities. Situation that changes family and socioeconomic dynamics.<sup>15</sup> The impact of this can be intense, as these people are unlikely to be able to return to their previous occupation and will need to readjust to a new role.<sup>4</sup>

Despite the negative perception in the



aforementioned domains, it is observed that the construction of the ostomy's subjectivity can influence better confrontations and, consequently, a better perception of their QoL. In addition, faith, gratitude and hope are aspects of the spiritual that elevate the QoL by helping to reframe ostomy and comfort in times of difficulty, keeping people focused on their health care.<sup>1</sup>

## CONCLUSION

People with a stoma notice changes in their QOL. Physical, psychological, social and economic domains are perceived negatively, especially due to the influence of changes in image, functionality and dependence on the collection bag. The spiritual proved to be a field that improves QOL by bringing

comfort, hope and faith.

The research has the limitation of being carried out in only one stoma-therapy service. It is suggested that new qualitative research be carried out in favor of the QoL of people with ostomy to provide new subsidies for nurses to develop therapeutic actions that improve QoL and promote the health of people and their families. ■

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