

Social Representation of the Life Quality After the Intestinal Stoma by the Patient with Colorectal Neoplasm

Representação Social da Qualidade de Vida Após o Estoma Intestinal pelo Paciente com Neoplasia Colorretal

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Abstract

The aim of this study was to analyze the social representation of life quality of after the preparation of an intestinal stoma by oncological patients, as well as to identify the structure of the social representations of life quality after the preparation of an intestinal stoma by cancer patients and to discuss the possible repercussions of these representations in nursing care planning in this social group. Descriptive study, of qualitative nature, based on the Theory of Social Representations. Eighty patients were approached and the technique for data collection was that of free evocation, with the terms "quality of life before colostomy" and "quality of life after colostomy", being treated by software *Ensemble de programmes permettant l'analyse of evocations* (EVOC). The Social Representation of life quality after the manufacture of a stoma showed negative elements, as well as the life quality before the stoma, showed positive elements. By making a brief comparison, it was clearly possible to see their differences, especially in relation to their feelings, limitations, eating habits, fears and stigmas. It is necessary the implantation and permanence of a multidisciplinary team that aims at social reintegration, providing strategies to better adapt to their new living conditions, reprioritizing values and goals.

Keywords: Social Perception; Colorectal Neoplasms; Colostomy.

Resumo

Objetiva-se analisar a representação social da qualidade de vida após a confecção de um estoma intestinal pelos pacientes oncológicos, além de identificar a estrutura das representações sociais da qualidade de vida após a confecção de um estoma intestinal pelos pacientes oncológicos e discutir as possíveis repercussões dessas representações no planejamento da assistência de enfermagem nesse grupo social. Estudo descritivo, de natureza qualitativa, pautado na Teoria das Representações Sociais. Foram abordados 80 pacientes e a técnica para coleta de dados foi a da evocação livre, com os termos indutores "qualidade de vida antes da colostomia" e "qualidade de vida após a colostomia", sendo tratado pelo *software Ensemble de programmes permettant l'analyse des evocations* (EVOC). A Representação Social da qualidade de vida após a confecção de um estoma mostrou elementos negativos, assim como a qualidade de vida antes do estoma, mostrou elementos positivos. Fazendo uma breve comparação, foi claramente possível ver suas diferenças, principalmente em relação aos sentimentos, suas limitações, seus hábitos alimentares, seus medos e estigmas. Faz-se necessário a implantação e permanência de uma equipe multidisciplinar que vise à reinserção social, fornecendo estratégias para melhor adaptação da sua nova condição de vida, repriorizando valores e metas.

Palavras-chave: Percepção Social; Neoplasias Colorretais; Colostomia.

Introduction

Since 1903, cancer is a worldwide public health problem. It should be noted that at this time there were no centers and specialized professionals for diagnosis and treatment of this disease, which made this health problem more serious⁽¹⁾.

Nowadays, with all the technology we have for early diagnosis and treatment, life losses associated with this disease still persist, with cancer accounting for 8.2 million worldwide deaths in 2012⁽²⁾. In the world, colon and rectum cancer is the third most common cancer type among men (10.0%), and the second in women, 9.2%⁽²⁾.

In the colon and rectum tumors' group, the treatment is usually surgical, being frequent the necessity of making an intestinal stoma. These stomas may be temporary or definitive and are basically indicated to prevent stool from passing through the gut region manipulated by the surgical procedure prior to complete anastomoses healing, thereby preventing infections or dehiscence at the sutured sites, or to serve as a via permanent stool elimination in surgeries where there is resection of the lower rectum or the anus⁽³⁾.

One in ten thousand people is ostomized in the world. In Brazil, it is estimated that 1.4 million people use the collecting equipment due to intestinal and urinary stomies⁽⁴⁾.

The cancer and a colostomy experiences permanently changes the subjects' daily life and is one of the most critical moments in a person's life, because it implies a complex system of analysis and reflection of the its biography, whose meanings were constructed throughout its trajectory, life experiences⁽⁵⁾.

Although it has been developed as a strategy to prolong survival and promote a better life quality for people, the stomies are aggressive and mutilating throughout the human living process, resulting in self-disgust and social deprivation feelings⁽⁵⁾.

This work arose from a restlessness generated during the people's care who had undergone a surgical intervention resulting in a stoma. Assistance is not only about guidelines for stoma care and equipment. Thus, in to better understand the stomized person daily life reality, analyzing their social representation about the life

quality after the stoma, which was proposed to carry out this research.

This study can generate contributions that cover the developed work not only by the nurses, but also the multiprofessional team that assists him/her and, mainly, the client. As far as the subjects' representation on the life quality after the intestinal stoma preparation is better known, the possibility arises of proposing strategies to qualify care and to sensitize the other professionals of the multiprofessional team about the importance of rehabilitation sense understanding and the subjects' life quality.

In this way, the research aims to analyze the social representation of cancer patients' life quality after the intestinal stoma preparation, in addition to identifying the structure of social representations of cancer patients' life quality after the intestinal stoma creation and discuss the possible repercussions of these representations in nursing care planning in this social group.

Method

A descriptive study was chosen, of a qualitative nature, based on the Social Representations Theory, which according to Moscovici⁽⁵⁾, is "a particular knowledge form whose function is the behavior elaboration and communication between individuals".

The research was carried out at the stomatherapy outpatient clinic of a national public reference research, teaching and Oncologic care institution in the city of Rio de Janeiro, while the patients waited for care. In the period between March and October 2016.

The population was composed of patients followed in the stomatherapy sector. To understand the social representation structure, 80 patients were stomized as a result of colon and rectum neoplasia in follow-up at the unit. The inclusion criteria were: to be definitively stomized for colorectal cancer; older than 18 years-old; accept to participate in the research.

To perform the data collection, a sociodemographic questionnaire was used to characterize the participants and to use the free evocation technique. This technique allows the subject to speak and write words, adjectives or expressions that occur to them, after being

stimulated by an inductor term and thus to allocate them in the order that comes to mind. For this study, two inducing terms "quality of life before colostomy" and "quality of life after colostomy" were applied, which were asked to associate five words⁽⁶⁻⁷⁾.

The analysis was made through the simple statistical treatment of sociodemographic data by Excel Software and free evocations' analysis by the Ensemble de programs *permettant l'analyse et des evocations* (EVOC), which is an informatics program that organizes the evoked frequency words evoked and evocation average, which allows the four-house framework construction that will facilitate the data organization for later analysis and discussion⁽⁷⁾.

This study was submitted to the ethics and research committee, being approved by the opinion 1,529,624 and the same is in agreement with the established in the Resolution No. 466/12 of the National Health Council and its complementary ones. Participants were advised about the research objectives and about the Free and Informed Consent Term (FICT) signing, which was guaranteed anonymity.

Results and Discussion

A seguir serão apresentados os resultados encontrados através das interviews with 80 stomized patients, atendidos no ambulatório de estomaterapia.

Table 1. Stomized patients' distribution according to sociodemographic characteristics. Rio de Janeiro, RJ, Brazil, 2016.

| Sex | F | % |
|------------------------|----|-------|
| Feminine | 42 | 52,5 |
| Masculine | 38 | 47,5 |
| Age Group | | |
| 18 – 35 | 05 | 6,25 |
| 37 – 49 | 14 | 17,5 |
| 50 or more | 61 | 76,25 |
| Marital Status | | |
| Single | 20 | 25 |
| Married | 38 | 47,5 |
| Separated | 7 | 8,75 |
| Widower | 15 | 18,75 |
| Education Level | | |
| Functional literacy | 3 | 3,75 |
| Elementary School | 35 | 43,75 |
| High School | 34 | 42,5 |
| Higher education | 7 | 8,75 |
| Póstgraduate studies | 1 | 1,25 |
| Religion | | |

| | | |
|-------------|----|-------|
| Catholic | 43 | 53,75 |
| Evangelical | 28 | 35 |
| Messianic | 1 | 1,25 |
| Spiritist | 2 | 2,5 |
| No religion | 6 | 7,5 |

Source: survey data.

This table shows that the men and women's percentage is balanced, being feminine, 52.5%, and 47.5% masculine. According to NCAI estimates⁽²⁾, women are at an increased risk of developing this neoplasia type, with an estimated risk of 17.10/100,000 women and 16.84/100,000 men.

Regarding age, 76.25% are 50 years-old or older, while 17.5% are between 37 and 49 years-old and only 6.25% are between 18 and 36 years-old. In this way, it can be seen that the population with advanced age is the most affected by this neoplasia, corroborating with research that says that in individuals over 50, the increase in incidence may be exponential⁽⁸⁾.

About marital status, 47.5% are married, followed by 25% singles, 18.75% are widowers and 8.75% are separated. These data become important when we consider the partner as a support for facing the current state and for emotional security, since the life quality is linked to the emotional state of any person⁽⁹⁾.

Regarding the education level, the table shows that 43.75% of the interviewees have primary education, 42.5% have elementary school, 8.75% have higher education,

3.75 are functional illiterates and only 1, 25% have a postgraduate degree. It is important to point out that a low education level is an important fact, because the lower subject's education level, the greater the difficulty related to knowledge access about the disease process and its treatment⁽¹⁰⁾.

Therefore, regarding religion, 53.75% of those interviewed said they were Catholics, 35% evangelicals, followed by 7.5% who said they had no religion, 2.5% declared themselves spiritists, and 1.25% were messianic. Thus, we perceive that values, beliefs and attitudes are important concepts that guide the life and behavior of the ostomized patient, helping to return to the daily life activities and favoring the rehabilitation process⁽¹¹⁾.

Table 2. Stomatal patients' distribution according to the health situation after ostomy. Rio de Janeiro, RJ, Brazil, 2016.

| Surgery Time | F | % |
|---------------------|----------|----------|
| 1 – 7 years | 70 | 87,5 |
| 8 – 19 years | 9 | 11,25 |
| 20 years or more | 1 | 1,25 |
| Stoma Type | | |
| Colostomy | 68 | 85 |
| Ileostomy | 12 | 15 |

Source: survey data.

In relation to surgery time, 87.5% of the interviewees were between 1 and 7 years-old, 11.25% were between 8 and 19 years-old and only 1.25% were 20 years-old or over. The more recent the surgery to perform the stoma, the greater the difficulties encountered by this population, to handle the new needs and the greater the embarrassments suffered by the people⁽¹²⁾.

As for the ostomy type, 85% have a colostomy and 15% have an ileostomy. The intestinal stoma accomplishment is closely related to the proposed surgery for the causal factor treatment, in this study the predominant cause was colorectal neoplasia⁽¹¹⁾.

Based on the four houses analysis with the EVOC 2005 Software support with the inducer term "quality of life before colostomy",

it was possible to identify the possible central, contrast and peripheral elements of the social representation of life quality before the stoma by the patient with colorectal neoplasia.

800 words were evoked, being 115 different. The average order of evocations (AOE) mean, that is, the score was 2.8, while the average frequency was set at 13 and the minimum at 12. The combined analysis of these data resulted in four households presented below (Chart 1).

Chart 1. Social representation structure of the life quality before the colostomy. Rio de Janeiro, RJ, Brazil, 2016.

| AOE (n=80) | | | | | | |
|-------------------|-------------------|----|-------|-------------------|----|-------|
| < 2,8 | | | | ≥ 2,8 | | |
| Average frequency | Evoked terms | F | AOE | Evoked terms | F | AOE |
| | Central elements | | | First periphery | | |
| ≥ 12 | Good | 35 | 1,943 | Joyful | 17 | 3,471 |
| | Best | 21 | 2,524 | Family support | 17 | 3,588 |
| | Normal | 57 | 2,772 | Recreation | 16 | 3,188 |
| | Work | 23 | 2,304 | Go out more times | 18 | 3,222 |
| | | | | Health | 13 | 4,538 |
| | | | | Active life | 30 | 3,633 |
| Average frequency | Evoked terms | F | AOE | Evoked terms | F | AOE |
| | Contrast elements | | | Second periphery | | |
| < 12 | Did everything | 7 | 2,571 | Housework | 6 | 2,833 |
| | Bad eating habits | 6 | 2,667 | Self-Care | 6 | 3,667 |
| | | | | Good nutrition | 8 | 3,250 |
| | | | | Happiness | 7 | 3,143 |
| | | | | Unlimited | 11 | 3,273 |
| | | | | Freedom | 11 | 4,273 |
| | | | | No pain | 6 | 3,500 |
| | | | | | | |

Note: Average order of evocations (AOE)

Source: survey data.

Considering the Central Nucleus Theory statement, the words grouped in the upper left quadrant are those that had the highest frequencies and were more readily evoked, thus forming, by hypothesis, the representation central nucleus. These words characterize the most consensual and constant part of the representation, as well as less conducive to changes in function of the external context or the subjects' daily practices. This shows the most spontaneous discourses of the research participants, since the evocation act brings out the imagination of something that is spontaneously present in the individual's memory and which are equivalent to the belief systems, values and ideas of these subjects⁽¹³⁾.

The words located in the upper right quadrant and the lower left are considered intermediate elements and can approach central elements or peripherals. The ones located in the lower right quadrant are part of the peripheral system. These have a lower evocation frequency, but as a higher average order, constituting the prepared thought, that is, the subjects can prepare them intentionally before evoking them. Chart 1 shows the following words distribution: in the upper left quadrant we have the words good, better, normal, work, these being the possible central elements of representation; in the upper right quadrant are the first periphery words, they are joyful, family support, recreation, go out more times, health and active life; among the contrast elements, which are located in the lower left quadrant, stand out doing everything and poor food; in the lower right quadrant we have the words that constitute themselves as probable peripheral elements of representation (second periphery), housework, self-care, good nutrition, happiness, unlimited, freedom, and no pain.

Regarding the possible elements of the central nucleus it is important to emphasize that the normal word presents the highest evocation frequency. Thus, this term was summed up in all, 57 times. As for the other words, good has 35 evocations and the lowest score (1,943), indicating his citation more readily, the word work was quoted 23 times and better 21 times. These elements express the group common sense and direct their behaviors and attitudes towards the

life quality before the ostomy. The observation of this quadrant leads us to understand that this group saw their life quality positively before the ostomy.

The word "normal" means, among other definitions, everything that is allowed and socially accepted and is said of the person who has no defects or physical or mental problems⁽¹⁴⁾. Therefore, this term refers us to a positive view before this group is submitted to an ostomy.

As well as the word "good", the ostomized people saw their life quality as being good, without physical or emotional changes that caused them to feel bad, and other sensations.

Whereas the word "work", which means, professional, regular, paid or salaried activity⁽¹⁴⁾. Work is all physical and cognitive activity performed by man, with the producing wealth purpose, serving as the basis for social relations. It acts as a social bond of living outside the family environment, providing relationships of friendship, companionship, and even competition, which unite individuals and keep them in constant social participation⁽¹⁵⁾.

Thus, before the stoma, people felt satisfied in their profession, without any problem. In the moment after ostomy, most feel unable to return to work, causing her often to experience feelings of herself clear rejection, sometimes even as an early defense of rejection⁽¹⁶⁾.

The word "better", which means something that is superior, by comparison with another, in kindness, quality, character, importance and value⁽¹⁴⁾, leads us to think in comparison between the life quality before and after the stoma. It is better in the period before the stoma.

We understood the reason for this evaluation, since the patient did not feel harassed and ashamed as currently, having to undergo several restrictions, as if he were not even after the stoma. The peripheral system of social representation is organized around the central nucleus, constituted of more accessible, more alive and more concrete elements, that have three primordial functions, which are: concretization, regulation and representation defense⁽¹³⁾.

The periphery elements that were "housework", "self-care", "good food",

"happiness", "unlimited", "freedom" and "no pain" presented less frequency and higher AOE. This means that they were quoted words that contained a more elaborate thought. The term "housework", much used by the female sex, shows us that these people had no difficulty in performing their daily tasks, nor did they need help for this. As a collection bag use consequence, these activities have become more difficult, with limitations imposed by the stoma, which end up bothering and influencing the social role, making him choose the activity he is able to do⁽¹⁶⁾.

Orem⁽¹⁷⁾, conceptualizes self-care as being the performance or practice of activities that individuals perform in their benefit to maintain life, health and well-being. In these people self-care was very visible, at the evocations' time, they reported that they took better care of themselves and felt good about themselves.

The term "good food" reveals that they once believed that their food was good, without restrictions, could eat everything they wanted without worrying. Nowadays their main preoccupation is with the foods that can cause gazes and odor or that are of fast digestion, being many foods vetoed. Food is a very important aspect, as it interferes with the stomized persons' life quality⁽¹⁶⁾.

The term "happiness" means the state of mind of those who are happy or satisfied⁽¹⁴⁾. Respondents stated that they were quite satisfied with their life quality prior to the stoma, and that this life quality should be seen as a greater good to be maintained and/or recovered, so that they can live happily and in harmony in their life context⁽¹⁸⁾.

The term "unlimited", along with the term "freedom", refers us to reflect on what was the person's life quality, without restrictions and limits, and can do everything without worry. The stoma process proves to be a traumatizing experience in people's lives not only because of the limitations mentioned above but also because of the dreaded constraints that are associated with living for a lifetime with a stoma⁽¹⁶⁾.

The term "no-pain" means that this person did not feel the pain he feels now, leading us to believe that the pain arose at the diagnosis time was revealed, because the impact was great, to find that having cancer and need for the stoma⁽¹⁹⁾.

The intermediate elements can approach the central nucleus or the periphery, they are: joyful, family support, recreation, go out more times, health and active life. The term "joyful", which means that feels, has or expresses joy; happy, approaches the happiness terms, as previously said these people had more reason to rejoice, this was notoriously perceived at the interview time. For many, life ended there, at the colostomy time, where they totally lost their will to live and rejoice.

"Family support" was the only term present in the same quadrant, before and after the stoma, showing us how important and essential this support is before diagnosis. The family is the first patient social group, playing a fundamental role of support in all phases faced by the same⁽¹⁹⁾. Thus, the family members' support and the complicity between patient and family are the basis for dealing with any experienced situation⁽²⁰⁾.

The terms "recreation" and "go out more times" were used to express the activities they did to be entertained, referred to by them as fishing, embroidering, traveling, swimming, running among others, being very difficult to do again after the stoma. These activities provide the individual with distraction and social reintegration, helping him to feel normal as those around him. The stomized person looks for ways to resume social, interpersonal and recreation activities, prior to surgery that contribute to their rehabilitation and social reintegration⁽¹⁵⁾.

Regarding the word "health", patients reported that they felt healthier in the period before the stoma, when they reported being in perfect health, which was suddenly transformed into a new reality full of restrictions⁽²¹⁾. With the diagnosis the individual's health condition is characterized as being a chronic situation, throughout its life, making it necessary that it develop strategies that allow it to improve self-care skills, social coexistence, to learn how to live and to manage the health-disease process situation⁽¹⁶⁾.

The expression "active life" refers to the affective relationships they had, the fact of leaving, having an encounter, among others. With the stoma advent these interests ended up being left in the background initially. Not only because of sexuality, it exceeds the physiological need and is

directly related to the desire and attraction symbolization⁽²¹⁾. In most of the patients with stomas, sexual activity and sexuality are difficult due to surgery and changes in body image. People with stable relationships perceived it positively, as physical and emotional need to be shared, and those in which relationships had problems prior to the stoma attributed negative meanings, denying or avoiding it⁽²²⁾.

The contrast elements are "did everything" and "bad eating habits". And they are elements that can approach the central elements or the peripherals. Regarding the "did everything," the interviewees referred to the fact that they had no restrictions on any activity type, they could do

everything without worrying about health or physical effort. "Bad eating habits" leads us to reflect on their eating habits, the habits of eating fast foods, high salt intake, foods with few fiber, and suddenly found themselves forced to change their eating habits⁽¹⁶⁾.

On the other hand, the life quality after the stoma analysis showed 800 evoked words, with 115 different ones. The average order of evocations (AOE) was 3.3, and the minimum frequency was 13, with the following four houses frame structure.

Chart 2. Social representation structure of the life quality after colostomy. Rio de Janeiro, RJ, Brazil, 2016.

| AOE (n=80) | | | | | | |
|-------------------|----------------------|----|-------|------------------|----|-------|
| < 3,3 | | | | ≥ 3,3 | | |
| Average frequency | Evoked terms | F | AOE | Evoked terms | F | AOE |
| | Central elements | | | First periphery | | |
| ≥ 13 | Fear | 22 | 3,227 | Acceptance | 23 | 3,609 |
| | I do not do anything | 25 | 3,240 | Adaptation | 13 | 3,308 |
| | | | | Family support | 24 | 4,125 |
| Average frequency | Evoked terms | F | AOE | Evoked terms | F | AOE |
| | Contrast elements | | | Second periphery | | |
| < 13 | Difficulty | 11 | 1,818 | Good | 10 | 4,300 |
| | Uncomfortable | 11 | 2,818 | Ache | 10 | 3,700 |
| | Limited | 12 | 2,667 | I am alive | 08 | 3,875 |
| | Change of life | 11 | 3,000 | Overcoming | 10 | 3,500 |
| | Nothing changed | 10 | 2,100 | Sadness | 10 | 3,700 |
| | Normal | 09 | 1,778 | Shame | 12 | 3,333 |

Note: Average order of evocations (AOE)

Source: survey data.

Chart 2 shows the following words distribution: in the upper left quadrant we have the words fear, I do nothing, these being the possible central elements of representation; in the upper right quadrant are the words of the first periphery, they are acceptance, adaptation, family support; Among the elements of contrast, which are located in the lower left quadrant, stand out difficulty,

uncomfortable, limited, change of life, nothing changed, normal; in the lower right quadrant, we have the words that constitute themselves as probable peripheral elements of representation (second periphery), good, ache, I am alive, overcoming, sadness, shame.

Regarding the possible elements of the central nucleus it is important to emphasize that

the expression does not do anything presents the greater evocations frequency. Thus, this term was quoted in all, 25 times. As for the other words, fear has 22 evocations and the lowest score (3,227), indicating that it was quoted more readily. As previously mentioned, these elements express the common sense of the group and direct their behaviors and attitudes towards the life quality before the ostomy.

The observation of the central nucleus' words expresses negative positions of the subjects about the life quality after the ostomy.

The expression "do not do anything" reflects that this patient does not feel able to perform any activity, and may also be a fear consequence. People subjected to the stoma have difficulties returning to their daily activities, causing them to spend much of their time at home, idle and feeling invalid and therefore unable to perform any activity⁽²⁸⁾.

Throughout the process, inferiority and incapacity feelings also appear, which can interfere in the daily development process, forming social isolation, which can affect both work and leisure⁽²³⁾.

Uselessness, inferiority, disgust, loss of self-esteem and social status feelings, as well as causing changes in family dynamics, cause psychological impact, nourish the idea that they will lose their productive capacity, causing them to express feelings such as sadness, repulsion and fear⁽²⁴⁾.

The word "fear" is related to the insecurity that this patient feels, for dealing with a totally new and different situation for him, and for fearing some kind of rejection for the other. The person who goes through this process feels insecure about the collecting device handling and the ostomy care, a feeling that is associated with the possibility of leakage of the pouch and odors exhalation⁽¹⁷⁾.

The experience of being cancerous and having a stoma causes impacts and suffering due to the values and beliefs present in society. To live this experience is to confront the values and beliefs of the group with personal values and beliefs⁽⁵⁾.

The periphery elements were: good, ache, I am alive, overcoming, sadness and shame presented lower frequency and higher AOE. This means that they were words little mentioned by

the patients, but with a greater evocation order, constituting a more elaborate thought.

The word "good" shows that, despite all this change in life, the stomates still consider good life quality, reacting differently, recognizing the stoma as a normal thing, a factor that will help and not to minimize suffering, demonstrating acceptance and habituation to the current condition⁽²³⁾.

The term "pain", which means unpleasant or distressing sensation, caused by an anomalous state of the organism or part of it⁽¹⁴⁾, make us realize what this patient feels, whether it is a physical pain resulting from a surgical intervention and/or an emotional pain of seeing his body mutilated and having a different way to eliminate the feces.

The sequels, treatments and complications resulting from surgery end up leading to symptoms such as pain, vomiting, headache, malaise, infections, influencing the person's non-return to active life⁽¹⁵⁾. The patient's pain has special characteristics, in this sense, the pain added to the condition transforms the experience into something that favors the affliction and suffering, surpassing the physical dimension, thus affecting the psychological and social spheres⁽²⁴⁾.

The pain caused by the rash, induced by the contact of the excretion with the skin, adding anxiety and insecurity feelings, related to the fear of taking off, "bursting" the bag in a public place, restricts a lot the stomized person's life quality. The best treatment form is prevention, with the need of the specialized professionals participation contributing in the complication reduction⁽²³⁾.

In this sense, nursing can contribute to the care given to these patients by monitoring the ostomy to detect possible complications, evaluate the efficacy of the placed device, observe signs of irritation or lack of adherence, teach self-care and deal with the ostomate reactions⁽²³⁾.

The expression "I am alive", which had the least evocations frequency of this quadrant, makes us understand that despite all the situations that it has passed, it is still alive, being a positive element of evaluative dimension. These patients accept the stoma for lack of choice, emphasizing that even though it is difficult to live with the handbag, they

are alive and do not feel more sick, with pain or with the impending death possibility⁽¹⁹⁾.

There is a balance between what has been lost and what has been gained, in which an intestinal deviation and all the difficulties felt are somewhat ameliorated, because they are alive and with some life quality⁽¹⁶⁾.

The term "overcoming", which is also an evaluative dimension element, makes us understand that for the overcoming process it was necessary to use coping tools such as religion, family and others. Over time, depending on the disease evolution and the possibilities of adaptation encountered, the ostomized person creates tools that will help him to face this new way of living, to overcome the challenges and to accept his new reality, to adapt and achieve the best life quality for them.

The existence of people who are able to face even more difficulties makes them believe that it is possible to overcome their own adversities⁽²³⁻²⁴⁾.

The word "sadness" which projects itself as a negative element of an evaluative dimension reinforces the idea that the reactions and feelings of the stomized persons are strongly influenced by the aspects valued in our culture as health, the perfect body valuation and life. These principles are the references for the feelings of sadness, depression, suffering, fears and uncertainties and, mainly, for the impotence before the life's finitude declaration, that accompanies these people⁽¹⁵⁾.

These people, besides having to live with intense pain as a result of the surgical procedure, still needed to live with the suffering of their relatives, which intensified even more their sadness feeling⁽¹⁶⁾.

The term "shame" is used to express the loss of the body connotation to be intact, to have a different configuration and dirty appearance. The stoma's presence causes changes in the person's body image, thus manifesting the shame of an altered and mutilated body, fearing to return to the familiar and social life, thus interfering in the activities performed before the stoma⁽¹⁸⁾.

The intermediate elements can approach the central nucleus or the periphery, they are: acceptance, adaptation and family support.

The word "adaptation" approaches both the central nucleus and the periphery elements, can be defined as the action or effect of adapting; to learn to live with an unusual situation resulting, in this case, from a health problem aimed at the health rehabilitation. Adaptation, therefore, is based on the process by which the person adjusts to the environment conditions, perceived by the latter as adverse, to guarantee their physical, psychological and social integrity⁽¹⁹⁾.

The patient undergoing an ostomy will need to go through adaptation periods, because with the loss of control of his body, which previously operated autonomously, the same will experience different feelings and often frightening in the face of this new situation. This patient's view on the collecting bag use implies on issues related to drastic changes in his daily life, and represents a challenge for his adaptation to this new reality⁽²⁴⁾.

The word "acceptance", which means the act or effect of accepting/agreeing⁽¹⁴⁾, approximates the periphery overcoming element, starting from the principle that in order to be overcome, it must first pass through acceptance.

The changes that occur in the patient's life are many and also difficult to accept, mainly because they are unpleasant situations and that alter the patient's daily life, such as the inconvenience caused when there is leakage, gas elimination and feces' odor. Undoubtedly, this represents a great challenge, as they need to find alternatives to minimize unpleasant situations. Thus, from the stomized person, the innumerable measures of adaptation and readjustment measures adoption in daily activities, including learning the stoma and the peristaltic skin self-care actions to avoid or minimize possible problems⁽¹⁸⁾.

At times, the patient shows difficulties in accepting himself and in the adaptation process, requiring an internal time to live his mourning moment, that is, reconsidering his concepts, reassessing his losses and finding the strength to accept and work on his new possibilities after the colostomy bag use⁽²³⁾.

Acceptance is a continuous process between the person and his new life condition. It is a particular medium, which varies from person to person, being more or less prolonged, depending on the available resources for each to face the

individual condition⁽²⁵⁾. There are factors that are determinant for the acceptance, among them the family support and the multidisciplinary team assistance contribution⁽²²⁾.

The term "family support" stands out as fundamental to face the disease. The family is perceived as a care unit in which solidarity bonds are tightened. It is the help source that contributes to the well-being and better being of the person with ostomy. They may have blood or emotional attachments, whether they share the same environment or not, and are influenced and influenced by the experience of living with their stomized family member. The family, perceived as the first social nucleus of the individual exerts a profound influence on the reactions that he may have in crisis situations or those that determine changes in the life's routine⁽¹⁹⁾.

Family support, demonstrated through proper physical, psychological, and social care, accurately assists in the ostomized person's recovery. Positive reactions are also essential at this stage, as well as their reintegration into social and daily activities⁽²⁹⁻²⁰⁾.

Therefore, it is believed that the family support given to the ostomized person is fundamental, being very important for the ostomy acceptance and, consequently, for its process of rehabilitation and adaptation, offering protection, comfort and affection to the patient⁽¹⁹⁾.

The contrasting elements are: difficulties, uncomfortable, limited, life changing, nothing changed and normal. They are elements that can approach the central elements or the peripherals. The word "difficulties" has a nature meaning of what is difficult; difficult situation. We can relate these difficulties to lack of information, practical the different devices types demonstration for ostomy, withdrawal from social relationships, incapacity for self-care, economic and financial constraints in obtaining social resources and emotional support⁽¹⁶⁾.

Although the ostomy is performed with the saving lives purpose, it can also generate several difficulties for individuals subjected to it, such as: physical and social changes, food, clothing, role performance and sexuality, and can cause psychological disorders leading to anxiety, anguish,

depression and shame, thus causing a social isolation of the individual⁽¹⁵⁾.

The limits and difficulties brought on by living with the stoma are also present and are related to: skin rash and irritation, food restriction, physical restraints, fear of taking off and "bursting" the bag in a public place⁽¹⁹⁾.

There are also difficulties regarding the return to recreation activities, which in many cases these patients do not resume their activities and when they do it is only partially, due to insecurity related to the devices' quality or gastrointestinal problems' fear. Difficulties also related to return to work, because they feel insecure to continue taking care of the stoma and still work. As a result, some end up asking for disability retirement, which is an economic problem because these people are often the family providers, a fact that causes an imbalance and changes in the living standard, besides being a factor that causes problems for the patient⁽²¹⁾.

The word "nuisance" can be understood as something that bothers, that does not offer comfort. Therefore, the concerns of this population focus on the pouch use and the discomforts arising from it, such as gasses elimination, leakage and feces' odor⁽¹⁵⁾.

The term "limited" gives us the idea of limits, something with restricted limits, and in this sense, this is how the person with the stoma lives, limited in several life areas⁽¹⁶⁾. The stoma can represent a limitation to the life project of these people and being the big life change impact, because they were in a good health state and unexpectedly are forced to radically change their life habits⁽²¹⁾.

These limitations end up bothering and influencing the social role, because these barriers impair in different life areas, such as food, clothing, sexuality and social life, causing the individual to select the activities that can be performed or making you stay at home most of the time. They are exposed to contact with the physical deformation, they experience feelings of low self-esteem, and also, it is the moment that the person becomes aware of the limitations in their daily life activities, generating a nonconformity feeling⁽²²⁾.

The word "life change" is related to changes in the patient's life after the stoma. The

ostomized person experience is related to the change that occurs in his life, in his health, in social relationships and in environments. All this process requires that the person incorporate new knowledge, change behaviors, attitudes and also the concept of himself. Living with an ostomy determines permanent life changes in the daily life of the person and family, thus being one of the most critical moments in the life course⁽¹⁶⁾.

Several times the individual does not know how to cope with these changes that occur, especially with the corporal appearance, as is the case of the abrupt and pronounced weight decrease, since it undergoes strict dietary restrictions, being indispensable the family support in those occasions⁽¹⁵⁻²¹⁾.

The term "nothing changed" shows itself to be a positive element, making us realize that even with all the changes that have occurred throughout the process, many patients view life in the same way when they do not use the colostomy. It is a recognition process that involves feeling what has changed or not, and the differences that have occurred during the transition process, reflecting on your well-being⁽¹⁶⁾.

The word "normal", just as the term "nothing has changed", is also shown as a positive element, its meaning, according to the online dictionary, is said of the person who has no defects; everything that is permitted and accepted socially. After the initial shock, and after the adaptation period, the patient is ostomized, can and should lead a normal life, always respecting some fundamental points and using appropriate materials to achieve the security that needs⁽²³⁾.

It is also possible to observe a determination on the part of some people to resume normalcy in their lives, in the same way as previously lived, taking into account, however, the specificities resulting from the stoma presence⁽¹⁸⁾.

Making a comparison between the before and after of the stoma, it was clearly possible to see their differences, especially in relation to their feelings, limitations, eating habits, fears and stigmas. For many, life really ends with the stoma, for others life begins in a different way, full of willpower and overcoming, and that means being resilient, that is, they were able to face and

respond positively to adversities and its potentially negative consequences⁽²³⁾.

Nursing, as well as other professionals have important participation in this adaptation process, each one will act integrally, adding benefits to the main target of our care, the ostomized. In this way, their rehabilitation is facilitated, as well as the new body image acceptance and the self-care realization⁽²⁰⁾.

Conclusion

Throughout the course, the individual is faced with several changes in his daily life, such as those that are not reached at the physiological level, but also at the psychological, physical, spiritual, social and sexual levels, which radically affect the life quality. Therefore, lack of attention and understanding in their aspects, considering the entire rehabilitation period. This attention must be provided from the preoperative period, encompassing the meanings and conceptions of the individual, his family and his social reforms.

Nursing in this case is important to assist both physically and psychically in accepting this new reality, guiding and training the individual and family in the choice of appropriate equipment, informing them about diets, discussing and making doubts related to the stoma, collaborating to a gradual life quality improvement and aiding in the self-care teaching, thus promoting health and preventing other diseases.

For the stomized, life quality will be the well-being maximum range and autonomy. Therefore, it is necessary to establish and maintain a multidisciplinary team that aims at social reintegration, providing strategies to better adapt to their new living conditions, reprioritizing values and goals.

These people are able to resume their activities always respecting the limits inflicted by their new condition. We hope that this study will promote knowledge about the patient's life quality, contributing to a complete and satisfactory relationship.

The initially proposed objectives for this work were achieved insofar as they allowed the understanding of the representations of the life quality of the person living with a stoma due to cancer.

Knowing the patient's life quality representation was and will be an important way for nurses' professionals to better understand those to whom care will be given, thereby collaborating in their qualification and attendance to all with efficiency and in a humanized way, enabling future studies on this population to be carried out.

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