RESEARCH

STOMAS CHANGING LIVES: FACING THE ILLNESS TO SURVIVE

A ESTOMIA MUDANDO A VIDA: ENFRENTAR PARA VIVER

LA OSTOMÍA CAMBIA LA VIDA: CÓMO ENFRENTARLA PARA VIVIR

Amanda Rodrigues Coelho [1]
Fernanda Silva Santos [2]
Marica Tasso Dal Poggetto [3]

[1] Nurse. Iturama, MG – Brazil.
[2] Nurse. Clinical Hospital of Universidade Federal do Triângulo Mineiro – UFTM. Uberaba, MG – Brazil.
[3] Nurse. Professor at the Undergraduate Course in Nursing at UFTM. Uberaba, MG – Brazil.

Corresponding Author: Amanda Rodrigues Coelho. E-mail: amandicaarc@hotmail.com

Submitted on: 06/21/2011 Approved on: 02/28/2013

ABSTRACT

This paper is an exploratory and descriptive field research with a qualitative approach, aimed at describing the changes in the daily life of stomized people and identify their ways of coping with their illness. The sample consisted of individuals with a permanent intestinal stoma for at least two years and who were enrolled in the Multidisciplinary Assistance Program for Stomized Patients (PAMPO in Portuguese). Semi-structured interviews were used, to collect data, which were recorded and later transcribed verbatim, producing a text for content analysis, as proposed by Laurence Bardin. Most colostomized individuals made changes in their way of life after the stoma creation, such as physical, psychological, and social changes caused by the loss of sphincter control and changes in body image, which led to the need to adopt strategies to adapt to new circumstances. Some people adapted well to these changes, while others had difficulties in dealing with such changes, resulting in psychological and physiological imbalances. Therefore, the adjustment or not to the problem stressors, in this case the creation of the stoma, influence the quality of life of stomized individuals. It is commonly observed that shortly after undergoing a surgical process, patients become enormously involved with taking great care of themselves, which they did not feel confident enough to do before. This is due to the aid offered by nursing care. It is also important to note that it is the nurse's role to intervene exclusively in the perioperative period, aimed at achieving the best possible adaptation for stomized individuals, encouraging the patient to face the chronic and permanent intestinal stoma, which demands continuous and long-term care from both the healthcare group and the interdisciplinary team.

Keywords: Colostomy; Nurse; Qualitative Research.

RESUMO

Trata-se de uma pesquisa de campo, exploratória e descritiva, com abordagem qualitativa, tendo como objetivos descrever as mudanças ocorridas no cotidiano do estomizado e identificar quais as formas de enfrentamento utilizadas por ele. A amostra foi constituída por pacientes com estomia intestinal definitiva há pelo menos dois anos, cadastrados no Programa de Assistência Multidisciplinar ao Paciente Ostomizado (PAMPO). Para a coleta de dados utilizaram-se entrevistas semiestruturadas, que foram gravadas e, posteriormente, transcritas na íntegra, produzindo um texto com a finalidade de proceder à análise de conteúdo proposta por Laurence Bardin. A maioria dos colostomizados apresentou mudanças no seu modo de vida após a confecção do estoma, sendo essas mudanças provenientes de alterações físicas, psíquicas e sociais causadas pela perda do controle do esfíncter e alterações da imagem corporal, levando à necessidade de adotar estratégias para adaptar-se à nova realidade. Houve pessoas que melhor se adaptaram a essas alterações, enquanto outras manifestaram dificuldades em conviver com essa realidade, acarretando desequilíbrios fisiológicos e psicológicos. Portanto, a adaptação ou não aos problemas estressores, nesse caso a confecção do estoma, influencia na qualidade de vida do indivíduo estomizado. Cabe ressaltar que competem ao enfermeiro intervenções exclusivas no período perioperatório visando melhor adaptação à condição de estomizado, promovendo o enfrentamento à condição crônica estomia intestinal definitiva e exigindo cuidado contínuo e prolongado dos serviços de saúde, o que também não exime a atuação da equipe interdisciplinar.

Palavras-chave: *Colostomia; Enfermagem; Pesquisa Qualitativa.*

RESUMEN

Se trata de una investigación de campo exploratoria descriptiva, con enfoque cualitativo, llevada a cabo con miras a describir los cambios ocurridos en el cotidiano de la persona ostomizada e identificar cómo los enfrenta. La muestra estuvo compuesta de portadores de ostomía intestinal definitiva desde hacía por lo menos dos años, inscritos en el Programa de Atención Multidisciplinaria al Paciente Ostomizado (PAMPO). Para recopilar los datos se realizaron entrevistas semiestructuradas que fueron grabadas y posteriormente transcritas textualmente, produciendo un texto con el fin de hacer el análisis de contenido propuesto por Bardin Laurence. La mayoría de los pacientes ostomizados presentó cambios en su modo de vida después de la confección del ostoma debido a alteraciones físicas, psíquicas y sociales causadas por la pérdida de control del esfínter y modificación de su imagen corporal, llevando a la necesidad de adoptar estrategias para adaptarse a la nueva realidad. Algunas personas se adaptaron mejor a tales alteraciones y otras tuvieron dificultad en convivir con la realidad lo cual causó desequilibrios fisiológicos y psicológicos. Por lo tanto, la adaptación o no a los problemas estresores, en este caso la confección del ostoma, ejerce influencia en la calidad

DOI: 10.5935/1415-2762.20130021

de vida de la persona ostomizada. Se realza que en el período perioperatorio le corresponde exclusivamente al enfermero intervenir para que el ostomizado se vaya adaptando a esta nueva situación y enfrente la condición crónica de ostomía intestinal definitiva. Ello exige cuidados permanentes y prolongados de los servicios de salud y, asimismo, del equipo interdisciplinario.

***Palabras clave**: Colostomia; Enfermería; Investigación Cualitativa.*

INTRODUCTION

Stoma and stomate are terms of Greek origin that mean 'mouth' or 'pore', used to indicate the exteriorization of any form of hollow internal organ in the body, due to a variety of causes, redirecting the normal bowel movement.[1] The stoma takes on the functions of the organ that has undergone surgical damage in which an opening is created to connect the organ to the outside environment.[2]

The naming of the stoma varies according to the affected body cavity. Thus, there are terms such as tracheotomy, which is the opening of the trachea; gastric stoma, called gastrostomy; urinary stomas, urostomas that can be classified as pyelostoma, ureterostomy, and vesicostomy; as well as intestinal stomas, which include the jejunostomy, ileostomy, and colostomy.[3]

The intestinal stomas are specifically classified as regards the time that they remain as permanent or temporary. The temporary stomas, once the problem that called for the creation of the stoma has been remedied, allow for the reconstruction of the bowel movement. By contrast, the permanent stomas are those which present the distal segment of the blocked intestine, hindering the reestablishment of the normal bowel movement.[4]

The permanent colostomy is used when a portion of the large intestine is compromised, with a loss of the sphincter function. This generally occurs in patients with Crohn's disease and a compromising of the rectum, in unspecific ulcerative rectocolitis and in neoplasias of the rectum, in which this segment and the anus are amputated. The permanent ileostomy results from the full colectomy, without the possibility of ileorectal anastomosis.[3]

Individuals who undergo the formation of a stoma undergo changes in their body image and lose control of their own bodily functions, provoking diverse changes in their perspective of life. They can pass through the stages of grief, as defined by Kübler: denial, anger, bargaining, depression, and acceptance. In the first stage, denial serves as a kind of "shield" in which the stomized patients try to find any possible explanation other than acceptance. The second stage, anger, is characterized by the anger that overwhelms the patients due to the new reality imposed by their diagnosis and their condition as a stomized patient. In the third stage, bargaining, patients seek alternatives to increase their life expectation. The next stage of depression is characterized by the moment in which there occurs the "loss of strength" to fight against the reality of the condition. The final stage of grief is that of acceptance. In this stage, there are no longer feelings of depression, but there is also no happiness. It is important to note that each person that goes through these stages does so in a unique manner.[5] In this sense, stomized individuals need to review their moment of struggle and loss in order to find the strength to accept their condition and work on their perspectives and possibilities after surgery.[6]

The intestinal stoma does not only alter the biological system, but also affects the individual both emotionally and physically, harming their own social relations. The absence of the anus and the consequent presence of a device attached to the abdomen to allow for the collection of effluents generates a feelings of inferiority, indifference, and exclusion in relation to other members of the community. These feelings are reinforced by the environment and the culture in which these individuals are inserted, leading the individual, throughout their lives, to construct a stereotype of their own body. Thus, it is necessary to show the individuals the customs and values that favor their own social inclusion.[7]

Due to the anatomical changes in their body, the majority of stomized individuals change their lifestyles. Many begin to use looser clothing so that the collection bag is not seen by others, take on new eating habits, and even distance themselves from their jobs. Sexual relations and leisure activities are also impacted, leading the stomized individual, in some cases, to social isolation. These facts are only a few examples that demonstrate that the patient's quality of life is compromised.[8]

Upon discovering the diagnosis that imposes the creation of an intestinal stoma, people can react in many ways. When they assume the attitude of not giving into the condition, of doing everything possible to achieve the best possible rehabilitation, of searching for information to face the disease, they tend to increase their feeling of confidence and to have a better adaptation to the treatment, which demonstrates a positive facing of the illness itself.[9]

Adapting to a given event, facing similar situations in many ways, depends on innumerous factors that involve not only personal characteristics, but also emotional and cultural aspects and previously lived experiences.

This entire context of the illness and the imposed therapy can cause stress, causing the individual to resort to *coping*.[10] The process in which the individual controls the demands generated by their relationship with their environment to satisfy what is demanded by society and, simultaneously, maintains a stable physical, psychological, and social state is called *coping*, which occurs when the individual is able to control the stressor before it becomes a threat.[11]

In Brazil, *coping* has no specific translation, and can be understood as an attempt to overcome that which is causing the stress, that is, strategies to face the illness. These strategies may not be effective when the threatening situation is conducted in an inefficient manner, resulting in crisis and bringing about physiological and psychological imbalances.[11,12] The illness, as it is a stressful event, demands that the individuals produce answers to face the condition, which impact the their health, generating significant changes in their lifestyle.[9]

The changes that occur in the daily routines of stomized people generate intense emotional disorder, resulting in periods of suffering, which demands the search for specific strategies to face this new condition.[13] It is important to note that the reactions caused by these changes depend on personal mechanisms to face the condition, which can be more or less intense and can be accompanied by feelings of denial, rage, aggressiveness, grief, among others.[14]

The facing of the condition has the objective of increasing, creating, or maintaining the perception of personal control when faced with a stressful situation. This can be learned, used, and adapted, regardless of the stress agent; it is a dynamic process, which can be evaluated and reevaluated. This is directly related to the individual repertoire and lived experiences, which can focus on the problem or the emotion. Depending on the moment and the situation, the two forms can be used by the same individual.[15,16]

When the focus is on the problem, individuals tend to concentrate on making direct changes to their environment, which is more often used when the condition is able to be changed, intended to control the cause of stress through the solution or minimization of the problem. To resolve the situation, the individuals attempt to use information about the stress factor, analyzing the alternatives of action that are available to them and opting for that which they believe to be the most appropriate.[15,17,18]

By contrast, focusing on the emotion has the intention of reducing the sensation of emotional discomfort, which is more commonly used in unchangeable situations; the individual tends to control and manipulate the emotional response related to the situation that has caused the stress. The strategies employed contain a high emotional load and derive from processes of personal self-defense; they include mechanisms of distancing, escape, and sidestepping, intended to avoid a possible confrontation between the individual and the stress agent, aimed at modifying the reality and the unpleasant sensations arising from this.[15,17,18]

Both strategies to face the condition, whether focused on emotion or reason, are employed to dominate, tolerate, reduce, or minimize stressful events. Facing the illness involves thoughts and behaviors used to manage the internal and external demands of the stressful situations. According to Krouse et al. (*apud* Silva),[9] men tend to use a strategy of facing the illness that is focused on the problem, such as the excessive valorization of the collection bags, while the women tend to focus on the emotion.

In addition to the difficulty of facing the illness, as they are find themselves incapable of exercising their roles, patients endure feelings of impotence and inferiority, which can unleash emotional conflicts and psychological reactions associated with beliefs and behavioral patterns that inhibit their active participation in the treatment.[19]

Facing the illness refers "to the cognitive and behavioral efforts geared toward the handling of both external and internal demands, which are evaluated as an excessive strain upon personal resources".[20]

The strategies to face the condition intend to minimize the effects of the stressful situations and maintain the well-being of the patient, and can change according to the evolution and maturity of the patient.[21]

Therefore, the detection of certain diseases triggers deep changes in the daily routine of the affected people and compromises the quality of life, as they must adapt to their own capacity to carry out daily activities. Changes in their anatomy, dependence, compromised sexuality, feeling of inferiority, suffering, alterations in self-esteem, and biopsychosocial imbalances all occur. The compromising of the patients' well-being provokes abrupt changes in their own quality of life.[22]

Considering that presented above, this work aims to describe the changes that occur in the daily routine of people with permanent intestinal stoma and identify in what ways the studied patients face their illnesses.

METHODS

The present study was an exploratory and descriptive field research with a qualitative approach and was developed in one single stage. It was carried out in the city of Uberaba, MG, Brazil, during the second semester of 2009.

All subjects of this research were people who had permanent intestinal stomas for at least two years and who were enrolled in the Multidisciplinary Assistance Program for Stomized Patients (PAMPO in Portuguese), were 18 years of age, were capable of taking part in an interview, and agreed to participate in this research project.

PAMPO is a program that attends to patients with stomas, both in the intestine and the urinary tract, as outpatients, aimed at preventing complications and promoting health, based on the care and education system. In this sense, nursing care aims to understand the patients and their needs, respect their limitations, and stimulate their potential. The assistance provided particularly favors the learning process as regards safe and long-term self-care. This learning process occurs in a progressive manner, based on incentives toward the autonomy of the stomized patients and/or their family or caretaker.

As of the first moment in which the patient/family and/or caretaker are attended to by the nursing staff, they are automatically enrolled in the program. The subsequent medical care is carried out by appointment. In these appointments, the conditions and needs of the patient are evaluated and the collection bags are distributed (materials provided by the Department of Health of the State of Minas Gerais).

Through this contact, it was possible to define the sample for this study. The patients who reported having a permanent intestinal stoma for at least two years presented greater possibilities of adaptation to this condition and, therefore, greater possibilities to express their experiences concerning their processes of facing the illness.

The data were collected after having received approval from the Ethics Committee on Research in Human Beings from Universidade Federal do Triângulo Mineiro (UFTM), respecting all recommendations set forth in Resolution 196/96 (protocol number 1200/08).[23]

Individual interviews were carried out in the patients' homes to clarify the aims and explain the development of this research project, at which time the Free and Clear Consent Form was signed by the participants and data were collected.

To collect the data, semi-structured interviews, formulated by the researchers, were used and consisted of the patients' personal information and three guiding questions: "Were there changes in your way of life after having contracted the stoma?", "What were these changes?", and "How did you react to these changes?".

The interviews were recorded and later transcribed verbatim, producing a text with the aim of analyzing the content as proposed by Laurence Bardin. Next, the study continued to the pre-analysis or organization stage, aimed at formulating indicators that provide a basis for the interpretation and inference of an expression that is representative. The second stage, called the material exploration stage, contemplates the codification by means of units of meaning. In the final stage – analysis of results and interpretation – the categorization was performed, which consists of the classification of the elements according to their similarities and differences, with a later regrouping of these according to common characteristics.[24]

To identify the interviewed patients, the letter "P" was adopted, followed by Arabic numbers from 01 to 23 (P1, P2, P3,...), corresponding to the chronological order of the interviews.

The discussion was based on two theoretical references: stages of grief, as defined by Kübler, and *coping*. The first reference, proposed by Elizabeth Kübler-Ross[5] was introduced with the intention of identifying attitudes and reactions of the patients when faced with the creation of an intestinal stoma. For this, it is essential to recognize the patients' values, beliefs, feelings, and how they deal with this experience.

By contrast, the reference to *coping* was used so as to recognize how the functions of managing or changing the stressor (in this case, the creation of the stoma) appeared, classified as concentrating on the problem and, when they seek to control, reduce, or eliminate the emotional responses to the stressor, classified as concentrating on the emotion.[11] This group of processes used by the patients are aimed at dominating, tolerating, or diminishing the impact of the stressor on their own physical and psychological well-being.

RESULTS AND DISCUSSION

The sample consisted of 23 people, 16 men (69.5%) and 07 women (30.5%, between 40 and 85 years of age; 10 were married (43.5%), 01 separated (4.5%), 06 widowers (26%), and 06 single (26%). As regards their occupations, 18 were retired (78.4%), 02 were housewives (8.7%), 01 was a painter (4.3%), 01 was a machine operator (4.3%), and one was a telephone card salesperson (4.3%). As regards their level of education, 07 had no formal education (30.5%), 08 had an incomplete elementary school level (34.7%), 01 had completed elementary school (4.3%), 04 had completed high school (17.5%, and 03 had an undergraduate degree (13%). As regards the illness that led to the creation of the stoma: 08 presented a neoplasia in the rectum (34.8%), 05 presented a chagasic megacolon (21.8%), 02 presented a neoplasia of the colon (8.7%), 02 presented a perforated acute abdomen (8.7%), 02 presented Crohn's disease (8.7%), 02 presented ulcerative rectocolitis (8.8%), 01 presented a gastric neoplasia (4.3%), and 01 presented diverticular bleeding (4.3%). The time that the individuals live with the stoma in their body varied between 02 and 28 years. Regarding the manner in which the patients faced the illness, 17 claimed to be facing the illness positively (74%), while six were unable to adapt to living with the stoma (26%). Concerning the changes in their daily routine, 17 reported that changes had occurred in their way of life (74%), while six alleged that there was no change (26%).

It is important to note that, during the period of data collection, seven people who fit the inclusion criteria were out of town, five were unable to participate in the interviews, and three died; all were therefore excluded from this study.

Through the transcription of the recordings and reading of their statements, four thematic categories arose: changes in the daily routine due to the stoma, denial, acceptance, and facing the illness.

CATEGORY 1 – CHANGES IN THE DAILY ROUTINE DUE TO THE STOMA

This category groups statements from the interviewed patients concerning the main changes resulting from the stoma, given that the patients' lifestyles changed due to physical, psychological, and social changes caused by the loss of sphincter control and changes in their body image.

To present this in a didactic manner, this category was divided into six subcategories, as follows:

SUBCATEGORY 1 – CHANGES IN EATING HABITS

This subcategory includes the statements on the patients' changes in eating habits after the formation of the stoma.

The eating habits and the intestinal functioning have an important relationship, since the quality and quantity of food intake interferes directly in the volume and consistency of the feces, in the formation of gas, and in the appearance of a bad small.[8,25]

The following answers demonstrate that the eating habits interfere in intestinal evacuation:

> *[...] you have to eat a lot of fiber, a lot of vegetables... sometimes, when I have a lazy intestine [...] (P5).*
>
> *[...] orange, kale, for example, don't go down well, I push them aside... green pepper is like that too [...] (P23).*
>
> *[...] drinking milk is the same thing as taking a laxative [...] (P5).*

Stomized patients, over time, are able to identify the foods that cause intestinal problems, such as gas and diarrhea. Multidisciplinary medical care, which provides information and healthcare during the period of adaptation to the colostomy, can minimize these limitations and difficulties.[26]

On the other hand, for some, the construction of the stoma led to their nutritional rehabilitation, demonstrating that the stoma contributed to remedying difficulties in eating habits: "[...] before, I didn't even eat, today I eat too much [...]" (P4); "[...] it was different, what made me sick before, now makes me feel good [...]" (P10).

Over time, the colostomized patients come to understand their own bodies better and associate their food intake with the formation of gases and the consistency of the feces. Another important piece of data is that the choice of diet is also related to the patients' available financial resources.[27]

SUBCATEGORY 2 – CHANGES IN THE WAY ONE DRESSES

This subcategory gathers reports about the changes in the patients' style of clothes, aimed at preventing people from seeing the collection bags.

The stomized people change their entire wardrobe in an attempt to hide the collection bag, avoiding the appearance of the volume caused by the elimination of feces and/or gases.[8]

What can be observed in the statements is the concern over the volume caused by the collection bag and over the possibility of it being noticed by other people: "[...] now I only use looser clothes [...]" (P3); "[...] I have to have a bigger shirt now [...]" (P17); "[...] for me, the clothes have to ones that don't show it [...]" (P8).

In some statements, it is easy to see that the location of the stoma impedes the use of certain clothes and accessories:

> *[...] I don't use them only because they rub up against the collection bag, they're a bit heavy, so I use more formal pants, which are lighter [...] (P6).*
>
> *[...] I always use the elastic ones that you tie up. Unfortunately, science has found that the only place to make a colostomy was in the exact place where the elastic string goes [...] (P19).*
>
> *[...] I wear shorts under the bag [...] (P22).*

The need to change the way in which one gets dressed, symbolizes the way the patients are able to stay normal within social circles and be accepted by them, since what is different should be hidden.[27]

SUBCATEGORY 3 – ACTIVITIES THAT AFFECT ONE'S DAILY ROUTINE

This subcategory presents units of measure that demonstrate the change and the interruption of one's daily routine after the creation of a stoma.

After the initial shock caused by the creation of the stoma, it is possible to see the individuals passing through moments of depression and sadness, almost always caused by the loss of the pleasure to carry out activities that used to be valued.[28]

The lifestyles of stomized patients undergo changes according to the changes in their anatomy and their physiological functions, imposing limits and restricting their capacity.

> *[...] I would stay a while without eating so that I could go out [...] (P18).*
>
> *[...] we can't do anything [...] [...] to begin with, I don't go out [...] (P9).*
>
> *[...] I stopped lifting heavy things, making any physical effort [...] (P3).*
>
> *[...] I do everything alone, I am not so meticulous about cleaning the house as I used to be, I do as much as I can take... (P6).*
>
> *[...] I used to work with farming. I had to stop working. [...] (P14).*

These statements indicate the repercussions caused by the stoma from the aspect of work, and the limits and loss of capacity to work. It could be observed that the physiological and anatomical changes and the care taken with the collection bag make the colostomized patients perceive their limitations, thus altering their daily routine according to the imposed reality.[2,5] In addition to the physical problems, there is also the fear of being exposed and embarrassed in the work environment, which can bring about the desire to quit work altogether, through retirement, which brings about subsequent changes in the family dynamic and socioeconomic losses .[26]

SUBCATEGORY 4 – LEISURE

This subcategory consists of statements that identify restrictions in the patients' leisure activities due to the existence of the stoma.

The underlying reason to abandon moments of leisure is due to the insecurity related to the quality of the device, difficulty with hygiene, physical problems, embarrassment, and fear of gastrointestinal disorders.[30]

> *[...] I felt safer about going out, going for a walk, now I feel more uncomfortable [...] (P1).*
>
> *[...] before, at the beach I would go into the ocean, now I don't swim anymore [...] (P20).*
>
> *[...] even the UAI (Medical Clinic for the Elderly) I used to go to, I don't go anymore [...] [...] now I don't travel anymore [...] (P16).*

These statements show changes in the patients' lifestyles, affecting their leisure activities and social interaction.

More significant changes can be noted in the leisure activities considered to be active, such as travelling, practicing sports, and going to recreational clubs, due to the physiological changes and the lack of confidence in the adherence of the collection bag. These same difficulties were mentioned by Cassero and Aguiar[26] in their research.

SUBCATEGORY 5 – RELATIONSHIP WITH PARTNER

This subcategory emphasizes the damage caused to relationships with the patients' partner, caused by the physiological and bodily changes, making sexual intercourse difficult.

The majority of stomized people present difficulties in relating to sexuality, caused by changes in their body image and, at times, because they present a physiological dysfunction, such as the loss of sexual drive and impotence, in addition to the sensations of feeling dirty and repulsion.[7,31]

After the formation of the stoma, the sexual function is harmed due to this stress, due to the feelings of inferiority, feeling dirty, depression, anxiety, and especially embarrassment in the presence of their partner.[32]

> *[...] I don't even try, I avoid it because I think that a boyfriend, when they find out I have one of these, he won't want to [...] I've stopped dating [...]. (P9).*
>
> *[...] I always used to want to find another girlfriend, but I don't want it anymore, because to understand this here is difficult [...] (P2).*
>
> *[...] I wanted to separate the beds because my wife is not obligated to have to live with this slaughter [...] (P14).*
>
> *[...] living together, the girlfriend, it's all difficult, you have to have your head on straight, if not, the person won't want to date you [...] (P8).*

Analyzing the above statements, it is clear that the sexuality of the stomized patients is affected, as the individuals almost always have the sensation of feeling dirty, feeling embarrassed by the changes in their body image, and are afraid of being rejected by their partner, making sexual intercourse nearly impossible.[31]

The lack of psychological help, the clarification about sexuality, the insecurity to assume a new sexual relationship, and the fear to expose their body to their partner are limitations that are present in the life of a colostomized patient.[28,32]

Of the interviewed individuals that cited having difficulty to have sexual relations, only one pointed out the physiological dysfunction as a hindrance: "[...] it doesn't get hard anymore, only if the doctor implants a new one to get hard [...]" (P10).

The stomized patients have their sexuality altered more due to their own self-esteem than because of a physical limitation, since, in addition to having their body image affected, they are afraid and anxious, also presenting the influence of preconceived ideas concerning sexuality.[33] One factor that accentuates the difficulty in exercising this function fully is the heavy pressure from society on individuals as regards having the perfect body. When the stomized patients are faced with this new condition, they feel excluded, unfit for the standardized and stigmatized normality, which can bring about the loss of attractiveness to the opposite sex.[34]

SUBCATEGORY 6 – PHYSIOLOGICAL CHANGES

This subcategory represents the harm in the physiological realm caused by the new reality imposed upon stomized patients.

Changes in the physiological activities due to the loss of sphincter control reinforces the feeling of mutilation, seen as a body that is out of control and, therefore, dysfunctional.[27,32]

> *[...] when I am in the middle of others, of society and dirty, there's that bad smell [...] (P18).*
>
> *[...] it's a thing of no confidence [...] [...] you're sleeping [...] [...] you wake up with it full [...] (P11).*

> *[...] I can't get dirty because I get worried, I want to take it off, I want to change it, it's just the worst thing there is [...] (P21).*
>
> *[...] there's no limit, there's no time, there's no confidence, there's nothing. Without confidence you're dead! [...] (P13).*

It could be observed that the interviewed individuals have an altered view of their body, without sphincter control and without confidence, which can lead to a psychological imbalance, making it necessary to adapt to the imposed condition to survive this new reality.

A collection bag for effluents triggers feelings of impotence, loss of control, reduction or absences of competence and self-value, that is, this represents the violation of the body image, causing, in this manner, deep changes in one's own self-esteem.[11,33,35]

CATEGORY 2 – DENIAL

This category demonstrates attitudes of the denial of the subject when facing the formation of the stoma.

Denial occurs shortly after the diagnosis, given that the patients can search for other healthcare professionals to deny the result that they refuse to accept.[6]

The psychosocial aspects of colostomy influence their answers when facing the illness and their search for help or denial of this new condition

> *[...] It's horrible, even today, I still haven't accepted this thing [...] (P2).*
>
> *[...] it was the same thing as killing me [...] (P22).*
>
> *[...] we don't get used to it, it's already been 20 years, it's impossible to get used to it [...] (P15).*
>
> *[...] I've even thought about committing suicide because of this [...] (P7).*

These statements show the depressing feelings that are a part of the stages of grief presented by Kübler.[6]

The intestinal stoma, specifically, leads to personal transformation, since, even when the collection bag is hidden under their clothes, the new reality breaks with the previous experience, values, and habits of daily life. They refer to the collection bag by substituting other words in an attempt to minimize the condition of the stomized patients and/or their suffering.[5]

CATEGORY 3 – ACCEPTANCE

This category consists of actions that highlight the acceptance of the subject when facing the creation of a permanent colostomy.

Acceptance is a final product of the strategies to effectively face the illness; favor the rehabilitation of the stomized patients, aimed at their reintegration in activities of normal social life; and improve their quality of life after the formation of the stoma.[36]

For the stomized patients, the means must be established to understand that their stoma was constructed with the objective of preserving their health; therefore, accepting the stoma is essential to adapting to the new condition. The more the subjects are able to adjust themselves to these changes in a positive manner, accepting the condition, the better off they will be in facing the limitations imposed by it, not to mention the improvement in their state of health, without devaluing themselves.[37]

> *[...] I take life as it comes, thank God, I go everywhere, to the beach [...] (P2).*
>
> *[...] I do everything perfectly, it doesn't get in my way at all [...] (P8).*
>
> *[...] life now is wonderful [...] (P1).*
>
> *[...] I feel good, it doesn't even feel like I have one [...] (P4).*

Acceptance, when done efficiently, reflects physical and psychological behavior, which lessens the feeling of discomfort. Individuals, when facing their own inability to resolve their condition as a stomized patient, react in a gradual manner, accepting the situation, according to their own adaptation to living with the stoma.[38,39]

In this sense, reports from ex-healthcare professionals can be observed among the interviewed participants. The following excerpts demonstrate that these subjects are more susceptible to adapting to the illness itself, since their own experience contributed to a better acceptance and understanding of their treatment.

> *[...] I worked in a pharmacy for 39 years, I agreed because I helped a lot in operations, even to open up the corpse, I saw how the organism worked [...] (P23).*
>
> *[...] for us who work in the hospital, it's much easier, it seems like we are better prepared, nothing shocks us, for us it's more normal [...] (P11)*

CATEGORY 4 – FACING THE ILLNESS

This category represents the adaptation of the colostomized individuals when facing the changes that occur after creating the stoma.

With the stoma, the individuals go through a deep transformation in their lifestyles, which provokes intense emotional disorder and, consequently, suffering, fear, and anguish, thus demanding the search for strategies to face this new reality, focusing either on the emotion or on the problem.[13,31]

To facilitate the understanding of this category, it was divided into three subcategories, with the first two presenting the act of facing the condition, focusing on the emotion, while the third focuses on the problem.

Subcategory 1 – Social Isolation

This subcategory includes the statements on changes in social relationships due to the difficulties faced by the stomized patients. When facing this stress, the individuals provide emotional responses.

After the creation of the stoma, the patients are confronted with the changes in their body and physiological image; present feelings of fear, solitude, and impotence; isolate themselves from social interaction; and begin to avoid public places.[13,29]

> *[...] when I see a lot of people around me, I find a way to get out [...] (P5).*
>
> *[...] if I go to a birthday party, I don't get in the middle of a lot of people because there are some people that don't understand that we are like this [...] (P22).*
>
> *[...] I don't go anywhere, I don't sleep at anyone's house [...] (P13).*

According to these statements, the majority of stomized patients stop participating in social events, since they are worried about keeping their need to use a collection bag secret, distancing themselves from the people that are a part of their social environment.[31]

In addition to the social isolation, it is important to consider that the loss of control of the elimination of gas and feces, a condition that is highly valued for life in society, also leads to psychological isolation. The changes make it difficult for the colostomized patients to fully exercise their interpersonal relationships, which hinders their social reinsertion.[40]

Subcategory 2 – Adaptation over time

This subcategory approaches the forms of adaptation to the stoma over time. In this case, the answer given to face the illness is also emotional.

The stomized patients suffer abrupt changes in their lifestyles, provoking intense emotional disorder, bringing about periods of suffering. For this reason, they need time to reflect and adapt themselves to this new reality.[11]

This adaptation may occur slowly and depends on the lived experiences. Sometimes, even living with the stoma doesn't help the stomized people fully understand their new condition of life.

> *[...] in the beginning, I didn't accept it very well [...] [...] now I forget I even have it [...] (P7).*
>
> *[...] I think we deal with it, we end up thinking of it as an accessory [...] (P15).*
>
> *[...] little by little you get used to it because there's just no other option [...] (P9).*
>
> *[...] ah, it's a day-to-day adaptation, because there's just no other way to live [...] (P18).*

The colostomized individuals tend to believe that living with the stoma provides the motivation to overcome the difficulties.[28] It is crucial that the family and the partner offer help and incentives to the stomized patients so that they can develop positive attitudes to face the new situation, accelerating and facilitating the adaptive and rehabilitative process, as well as the activities of daily life.[41]

Subcategory 3 – Way of using the bag

This subcategory gathers the statements concerning the ways of facing the illness by focusing on the problem, which are created by the stomized patients in an attempt to feel more adapted to the use of the collection bag.

The creation of the stoma obligates the patients to organize a number of measures to adapt and readjust to daily activities, including the learning of self-care and the handling of the devices.[26] The individuals, upon assuming this condition as a stomized patient, begin to be concerned with the collection bag, which becomes an extension of their own bodies.[42]

> *[...] I use medical tape so that the bag doesn't fall [...] (P20).*
>
> *[...] I change or wash out the bag before leaving home [...] (P12).*
>
> *[...] I use a plastic bag so that the collector bag doesn't weigh so much [...] (P14).*
>
> *[...] I only use a dark bag, I don't like the clear bags because they give me the sensation of being dirty [...] (P12)*

These statements present the artifices used by the colostomized patients to guarantee confidence in using the collection bag, preventing the leaking of effluents and gases, as well as a way to hide the feces.

It is important to note that culture, beliefs, lifestyles, as well as physical and emotional aspects influence the development of abilities for the patients' self-care, and each patient deals with this in their own unique way.[27]

CONCLUSION

The present study aimed to identify the changes in the colostomized patients' way of life and the strategies of facing the illness adopted by them to overcome the stress caused by the stoma. This study also sought to produce new knowledge on the challenges faced by stomized patients in an attempt to supply aid to nurses so that they can act effectively during perioperative care, minimizing the suffering of the patients and possible negative consequences, which can facilitate the patients' adjustment to living with a stoma.

It was frequently observed that, after the surgical procedure, the patients assumed the difficult task of taking care of themselves in ways that they had not done previously, without help from the nursing staff. It is important to emphasize that it is the nurse's role to intervene exclusively in the pre-, trans-, and post-operative periods, aimed at achieving the best possible adaptation of the individual to the condition of a stomized patient, encouraging the patient to face the illness to achieve a better quality of life for those who are today living a chronic condition (the permanent intestinal stoma), which demands continuous and long-term care from both the healthcare group and the interdisciplinary team.

After having analyzed the data, it could be observed that the majority of stomized patients suffered abrupt changes in their lifestyles, mainly in their eating habits, in their way of getting dressed, in the activities of their daily life and leisure, as well as in their self-esteem. Also identified were damages to social relationships and relationships with their partners, caused by physiological and bodily changes.

-As regards the acceptance of the stoma, most of the individuals adapted to the presence of the permanent colostomy, adopting certain strategies to face the illness, such as social isolation, adaptation over time, and the creation of alternative ways of using the collection bag, which helped this population to better accept the device, as well as achieve a better quality of life and well-being.

In addition, some stomized patients were unable to adapt to the stress factor related to the colostomy and the use of the collection bag, adopting attitudes of denial, damaged social and sexual relationships, and alterations in self-esteem, thus generating depressive feelings and emotional, social, and psychological disorders.

Although many authors have mentioned faith and religion as strategies to face the illness, none of the interviewed individuals in the present study cited this as an adaptive response.

During the development of this work, it was possible to conclude that the quality of life of the stomized patients is intimately related to the strategies adopted by them to live with these biological, physical, and psychological changes, in the same way that their experience of life contributed to their acceptance or denial of living with a stoma.

For this reason, nurses, due to their proximity generated by the greater contact with patients, can aid in discovering available strategies to better face the condition of being a stomized individual, given that, as of the construction of the dialogic link, they can aid their patients in the adaptation process of living with a permanent intestinal stoma.

REFERENCES

1. Santos VLCG. A bolsa na mediação "Estar Ostomizado"-"Estar Profissional": análise de uma estratégia pedagógica [dissertação]. São Paulo: Escola de Enfermagem da Universidade de São Paulo; 1996.
2. Gemelli LMG, Zago MMF. A interpretação do cuidado com o ostomizado na visão do enfermeiro: um estudo de caso. Rev Latinoam Enferm. 2002; 10(1):34-40.
3. Júnior AM, Rocha JJR. Tipos de estoma. In: Crema E, Silva R. Estomas: uma abordagem interdisciplinar. Uberaba: Ed. Pinti; 1997. p 43-4.
4. Brasil. Ministério da Saúde. Secretária Nacional de Assistência à Saúde. Instituto Nacional do Câncer. Estimativas da incidência e mortalidades por Câncer no Brasil. Rio de Janeiro: INCA; 2008.
5. Kübler-Ross E. Sobre a morte e o morrer. São Paulo: Martins Fontes; 1987.
6. Sonobe HM, Barichello E, Zago MMF. A visão do colostomizado sobre o uso da bolsa de colostomia. Rev Bras Cancerol. 2002; 48(3):341-8.
7. Silva AL, Shimizu HE. O significado da mudança no modo de vida da pessoa com estomia intestinal definitiva. Rev Latinoam Enferm. 2006; 14(4):83-90.
8. Dal Poggetto MT. Temáticas de aprendizagem de clientes colostomizados: estratégias norteadoras da assistência de enfermagem [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2002.
9. Silva G. Processo de enfrentamento no período pós-tratamento do câncer de mama [dissertação]. Ribeirão Preto: Escola de Psicologia de Ribeirão Preto da Universidade de São Paulo; 2006.
10. Lorencetti A, Simonetti JP. As estratégias de enfrentamento de pacientes durante o tratamento de radioterapia. Rev Latinoam Enferm. 2005; 13(6): 944-50.
11. Lazarus RS, Folkman S. Stress, appraisal and coping. New York: Springer Publishing; 1984.
12. Barnabe NC, Dell'Acqua MCQ. Estratégias de enfrentamento (coping) de pessoas ostomizadas. Rev Latinoam Enferm. 2008; 16(4):712-9.
13. Silva AL, Shimizu HE. A relevância da rede de apoio ao estomizado. Rev Bras Enferm. 2007; 60(3): 307-11.
14. Martins LM. Ensinando e aprendendo em grupo a enfrentar situações enfrentadas como ostomizado [dissertação]. Florianópolis: Departamento de Enfermagem da Universidade Federal de Santa Catarina; 1995.
15. Ravagnani LMB, Domingos NAM, Miyazaki MCOS. Qualidade de vida e estratégias de enfrentamento em pacientes submetidos a transplante renal. Estudos Psicol. 2007; 12(2):177-84.
16. Andolhe R, Guido LA, Bianche ERF. Estresse e coping no período perioperatório de câncer de mama. Rev Esc Enferm USP. 2009; 43(3):711-20.
17. Seidl EMF, Trócolli BT, Zannon CMLC. Analise fatorial de uma medida de estratégia de enfrentamento. Psicol Teoria Pesq. 2001; 17(3):225-34.
18. Pereira APS, Pelá NTR. Atividades grupais de portadores de estoma intestinal definitivo: a busca da aceitação. Rev Enferm UERG. 2006; 14(4):574-9.
19. Bellato R, Maruyama SAT, Silva CM, Castro P. A condição crônica ostomia e as repercussões que traz para a vida da pessoa e sua família. Ciênc Cuidado Saúde. 2007; 6(1):40-50.
20. Folkman S, Lazarus RS, Gruen RJ, De Longis A. Appraisal, coping, health status and psychological symptons. J Pers Soc Psychol. 1986; (50):571-9.
21. Santos JR, Enumo SRF. Adolescentes com Diabetes Mellitus Tipo1: seu cotidiano e enfrentamento da doença. Psicol Reflex Crít. 2003; 16(2):411-25.
22. Michelone APC, Santos VLCG. Qualidade de vida de adultos com câncer colorretal com e sem ostomia. Rev Latinoam Enferm. 2004; 12(6):875-83.

23. Brasil. Ministério as Saúde. Conselho Nacional de Saúde. Comitê Nacional de Ética em Pesquisa em Seres Humanos. Resolução nº196 de 10 de outubro de 1996: diretrizes e normas Regulamentadoras de Pesquisa Envolvendo Seres Humanos. Brasília: MS; 1996.
24. Bardin L. Análise de conteúdo. Lisboa: Ed. 70; 1985.
25. Cezareti IUR. Ostomizado: reabilitação sem fronteiras? Ponto de vista do enfermeiro. Acta Paul Enferm. 1995; 8(1):11-7.
26. Cassero PAS, Aguiar JE. Percepções emocionais influenciadas por uma ostomia. Rev Saúde Pesq. 2009; 2(2): 23-7.
27. Dázio EMR. O significado do estoma intestinal entre homens: um estudo etnográfico. [dissertação]. Ribeirão Preto: Escola de enfermagem de Ribeirão Preto da Universidade de São Paulo; 2008.
28. Farias DHR, Gomes GC, Zappas S. Convivendo com uma estomia: conhecendo para melhor cuidar. Cogitare Enferm. 2004; 9(1):25-32.
29. Costa SPR. Perfil de qualidade de vida dos portadores de colostomia [dissertação]. João Pessoa: Programa de pós-graduação em enfermagem da Universidade Federal da Paraíba; 2007.
30. Souza SMA. Qualidade de vida em clientes ostomizados. Texto Contexto Enferm. 1999; 8(1):121-50.
31. Cascais AFMV, Martini JG, Almeida PJS. O impacto da estomia no processo de Viver Humano. Texto Contexto Enferm. 2007; 16(1):163-7.
32. Carvalheira C, organizador. Ainda posso levar uma vida normal? 2ª ed. Rio de Janeiro: News Eventos e Promoções; 1999.
33. Santos VLCG, Sawaia BB. A bolsa na mediação “Estar Ostomizado”-“Estar Profissional”: análise de uma estratégia pedagógica. Rev Latinoam Enferm. 2000; 8(3):40-50.
34. Santos FS, Dal Poggetto NT, Rodrigues LR. A percepção da mulher portadora de estomia intestinal acerca de sua sexualidade. REME Rev Min Enferm. 2008; 12(3):355-62.
35. Freitas AAS, Peres MF, Pereira L, Menezes MFB. Cuidando e promovendo a adaptação do cliente com estoma na perspectiva da concepção de Roy. Nursing. 2008; 11(125):461-7.
36. Bellato R, Maruyama SAT, Silva CM, Castro P. A condição crônica ostomia e as repercussões que traz para a vida da pessoa e sua família. Ciênc Cuidado Saúde. 2007; 6(1):40-50.
37. Gianini MMS. Câncer e gênero: enfrentamento da doença [dissertação]. São Paulo: Pontifícia Universidade Católica de São Paulo; 2007.
38. Martins G, Cunha S, Coelho R. Estudo da aceitação da incapacidade em doentes com Insuficiência Renal Crônica: comparação de duas escalas. Rev Port Psicossomática. 2005; 7(1-2):53-8.
39. Menezes APS, Quintana JF. A percepção do indivíduo estomizado quanto a sua situação. Rev Bras Prom Saúde. 2008; 21(1):13-8.
40. Krouse RS, Grant M, Rawl SM, *et al*. Coping and acceptance: the greatest challenge for veterans with intestinal stomas. J Psychosom Res. 2009; 66:227-33.
41. De Paula MAB, Takahashi RF, De Paula PR. Os significados da sexualidade para a pessoa com estoma intestinal definitivo. Rev Bras Coloproct. 2009; 29(1):77-82.
42. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: A theoretically basede approach. J Pers Soc Psychol. 1989; (56):276-83.