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RESEARCH

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CONJUNCTURE OF COLOSTOMIZED CLIENTS OF AN INTEGRATED HEALTH CENTER, REFERENCE IN THE STATE OF PIAUÍ

Conjuntura de clientes colostomizados de um centro integrado de saúde, referência no estado do Piauí

Conjuntura de clientes colostomizados de un centro integrado de salud, referencia en el estado del Piauí

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ABSTRACT

Objective: to analyze the real situation of colostomized clients in terms of knowledge about the importance of the colostomy, the changes that occurred in their life and the difficulties faced in the quality of life. **Method:** this is an exploratory, descriptive study with a qualitative approach performed at the Integrated Health Center in the state of Piauí, with 17 clients using a colostomy bag. The data were collected in the months of March and April of 2015. For the analysis of the data, the Discourse of the Collective Subject was used. **Results:** people who used the colostomy bag developed forms of coping, such as reflection, knowledge about the health problem, social isolation and adaptation. **Conclusion:** it is necessary to orient and strengthen coping strategies, since they contribute to reduce the complications related to the physical and psychological changes of the patient.

Descriptors: Quality of life; Colostomy; Colonic pouches; Adaptation, Psychological; nursing care.

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RESUMO

Objetivo: analisar a real conjuntura de clientes colostomizados quanto ao conhecimento sobre importância da colostomia, as mudanças ocorridas na sua vida e as dificuldades enfrentadas frente à qualidade de vida. Método: trata-se de uma pesquisa exploratória, descritiva com abordagem qualitativa realizada no Centro Integrado de Saúde referência no estado do Piauí, com 17 clientes que utilizavam bolsa de colostomia. Os dados foram coletados nos meses de março e abril de 2015. Para a análise dos dados, utilizou-se o Discurso do Sujeito Coletivo. Resultados: as pessoas que utilizavam a bolsa de colostomia desenvolveram formas de enfrentamento, dentre essas se destacaram a reflexão, o conhecimento sobre o problema de saúde, o isolamento social e a adaptação. Conclusão: é necessário orientar e fortalecer as estratégias de enfrentamento, pois as mesmas contribuem para diminuir as complicações relacionadas às mudanças físicas e psicológicas do paciente.

Descritores: Qualidade de vida; Colostomia; Bolsas cólicas; Adaptação psicológica; Cuidados de enfermagem.

RESUMEN

Objetivo: analizar la real coyuntura de clientes colostomizados en cuanto al conocimiento sobre la importancia de la colostomía, los cambios ocurridos en su vida y las dificultades enfrentadas frente a la calidad de vida. Método: trata de una investigación exploratoria, descriptiva con abordaje cualitativo realizada en el Centro Integrado de Salud referencia en el estado de Piauí, con 17 clientes que utilizaban bolsa de colostomía. Los datos fueron recolectados en los meses de marzo y abril de 2015. Para el análisis de los datos, se utilizó el Discurso del Sujeto Colectivo. Resultados: las personas que utilizaban la bolsa de colostomía desarrollaron formas de enfrentamiento, entre ellas se destacaron la reflexión, el conocimiento sobre el problema de salud, el aislamiento social y la adaptación. Conclusión: es necesario orientar y fortalecer las estrategias de enfrentamiento, pues las mismas contribuyen a disminuir las complicaciones relacionadas con los cambios físicos y psicológicos del paciente.

Descriptores: Calidad de vida; Colostomía; Reservorios cólicos; Adaptación psicológica; Cuidados de enfermería.

INTRODUCTION

Colorectal cancer (CRC) is one of the leading causes of morbidity and mortality in the world. It is the third most common malignancy and the fourth leading cause of deaths from cancer worldwide. CRC is responsible for approximately 1,400,000 new cases and about 700,000 deaths worldwide. In recent decades, there has been a significant increase in the incidence of CRC, especially newly-diagnosed CRC cases. In Brazil, according to the *Instituto Nacional do Câncer* (INCA) [National Cancer Institute], 36,360 new cases were estimated to occur in 20218: 17,380 among men and 18,980 among women.

It is estimated that there are about 50,000 stoma patients in Brazil. Concerning the meaning of the word "stoma", it is derived from Greek and means an opening of any hollow viscera through the body. In various situations, it receives specific names according to the segment to be exteriorized so that waste can be diverted out of the human body.

This orifice, which can be oval or round, aims to establish the functionality of the damaged organ.⁵

The intestinal stomas, in particular, are classified as definitive or temporary, i.e., they can be performed and then closed, or maintained for the rest of life. Intestinal stomas are classified as colostomy, ileostomy, and jejunostomy. A colostomy is the surgical creation of an opening in the colon. It is used when a portion of the large intestine is compromised. Surgery is considered the main treatment for most colon and rectal cancers.⁶

The history of stomas began in the seventeenth century. Nonetheless, from the twentieth century to the present day there has been a great evolution in surgical techniques, equipment, and devices available. As a result of this technological evolution, there is a growing concern with the quality of life of stoma patients, especially regarding psychosocial aspects.⁵

Surgeries for constructing intestinal stomas are performed in the colon, ileum, or jejunum and consists in making an opening on the abdomen to eliminate waste, which consequently causes physical changes. This type of procedure involves physical issues related to loss of body integrity, violation of hygiene rules, loss of sphincter control with impairment of fecal control, involuntary elimination of gases, and odors. Additionally, other consequences may occur, such as self-esteem and self-concept changes, feelings of uselessness, depression, disgust, non-acceptance. As a result, negative feelings and physical appearance are among the main obstacles to be faced by these patients, who will need professional support to establish a good quality of life.⁵

Most of these patients experience loss of intestinal continence, resulting in a constant outflow of intestinal elimination through the stoma, which leads to the constant use of a colostomy bag. However, these clients do not always have a collection bag (stomas cannot be controlled voluntarily due to their characteristics) adequate to avoid the inconveniences resulting from this change. This compromises their social relationships and has a significant impact on their quality of life.⁷

In relation to collection equipment for intestinal stomas, they are disposable bags (which are attached to the peristoma skin through the use of adhesives) of single or compound systems. They are attached to the skin around the stoma with the aim of collecting waste, being of fundamental importance for the biopsychosocial rehabilitation process of the stoma patient.⁸

It is interesting to note that people who will undergo ostomy surgery should receive care at the time of diagnosis. The continuity of this process in the late postoperative period requires the constant maintenance of physical, social, and psychological support by all members of the health care team through general and specific care. Moreover, it requires the application of preventive and therapeutic measures if

necessary, in addition to the support from the health care or self-help team in order to facilitate coexistence with the stoma and thus improve the quality of life of stoma patients.⁹

Regarding the quality of life of these clients, this concept refers to the well-being that individuals and the community find in family, love, social, and environmental life. Sociology defines it as the pattern that society has or mobilizes to conquer individual and collective freedoms and positive changes in the way of life through public and social policies that induce and guide human development.¹⁰

Stoma care requires a reflection on the rehabilitation aspects, which means a great challenge for the health care workers, especially nurses. Hence, knowledge of these patients' needs through their extensive and constant questioning is indispensable. Nurses have a key role in understanding the patients' emotions and they seek to determine the conduct to be applied to each case based on conversations.

This study is justified by the necessity of identifying these clients' profiles since their quality of life is closely related to the strategies adopted to live with these biological, physical, and psychological changes. Therefore, knowing their profile will imply in the systematization of quality care for them.¹¹

Bearing in mind the aforesaid, the following research question was developed: "what is the real situation of colostomy patients in an Integrated Healthcare Center?" This study is aimed at analyzing the real situation that the colostomy patients attending an Integrated Healthcare Center are facing. To this end, this study considers the understanding of the importance of colostomy, the changes in the patients' lives, and the difficulties they face in relation to their quality of life.

METHODS

This is a descriptive-exploratory study with a qualitative approach that was performed at an Integrated Healthcare Center, which is a referral institution in the *Piauí* State, Brazil. The Assistance Program for Stoma Patients is one of the programs implemented by the Integrated Healthcare Center. This program seeks to guide users, as well as to distribute bags and devices needed by people with stomach problems throughout the State. Until 2015, 1,682 patients were registered to receive these bags.

Seventeen clients using colostomy bags provided by the Integrated Healthcare Center participated in this study. The clients were approached randomly as they sought the service to receive colostomy bags. This first contact had the purpose of signing and officializing the invitation to participate in the research. Furthermore, participants were selected by considering their availability and interest to participate in the research after removing any doubts about the proposed objectives.

Inclusion criteria were clients with temporary or definitive colostomy from 18 to 65 years of age, who were willing to

participate in the study and answer the questions based on the proposed objectives. Exclusion criteria were clients who were unable to participate in the study, such as clients who indicated that they were not in a healthy condition to answer the questions at the time of the interview.

The data were collected by means of semi-structured interviews containing open questions to identify changes in the patient's life in face of the new physical condition, which may be temporary or not, and closed questions to characterize the participants. This data was important to characterize the patient's daily life and which changes occurred after the surgery.

The interviews were carried out in a private, air-conditioned room with good lighting. The researcher recorded the participants' statements through a mobile phone. Later, these records were transferred to a pen-drive for further analysis and full transcription. Each interview lasted approximately fifteen minutes. Data collection took place in March and April 2015. In order to identify the study participants, the interviews were ordered numerically and increasingly.

An official letter was sent to the Municipal Health Foundation so that it could become aware of the scientific-methodological content of this study. After its authorization, the study was submitted to the Brazil Platform and the Research Ethics Committee of a Higher Education Institution and was approved under the *Certificado de Apresentação para Apreciação Ética* (CAAE) [Certificate of Presentation for Ethical Appreciation] No. 40827015.0000.5210 and Legal Opinion No. 946.386. This study was conducted in accordance with all the principles stated in the Resolution No. 466 from the National Health Council, which regulates research involving human participants.¹²

For data treatment, three aspects of the Collective Subject Discourse (CSD) were used: Key Expressions (KEs), Central Ideas, (CIs), and the CSD.

The data obtained from the interviews were analyzed and later discussed. The participants' statements that met the objectives proposed by this study were selected. Later, the statements were analyzed in light of two theoretical references: Kübler's process of dying and coping. Proposed by Elizabeth Kübler-Ross, the first reference was used with the aim of identifying the attitudes and reactions of clients to the placement of an intestinal stoma. ¹⁴

The objective of the second reference was to know the processes used by the clients in order to dominate, tolerate, or reduce the impact of the stressor on their physical and psychological well-being. The coping referential was used to understand how patients performed the functions of managing and changing the stressor. In this case, these functions are problem-oriented if their focus is on the placement of the stoma, or emotion-oriented if their objective is to control, reduce or eliminate emotional responses to the stressor.¹⁵

RESULTS

Assessing the characterization of the interviewees, they were aged 50.1 years old on average. Considering the marital status, 52.9% of the participants were single and 47.1% were married. Observing the interviewees, 88.24% were from cities of the *Piauí* State and 11.76% were from cities of the *Maranhão* State. *Teresina* city was the most prevalent with 35.3%. Regarding the type of colostomy, 64.7% were definitive and 35.3% were temporary. The most predominant time since colostomy creation was >1 year (76.5%).

The following central themes and ideas emerged from the interviews, which together formed the CSD: "Creation of stomas and use of colostomy bags", "Daily life changes resulting from colostomy", "Patient's attitudes toward and responses to the use of colostomy bags according to Kübler", and "Management of the situation of living with the colostomy bag – coping strategies".

I. Creation of stomas and use of colostomy bags

Central Ideas:

- Signs and symptoms;
- Diseases;
- Lack of self-care;
- Late diagnosis;
- Feelings associated with the final condition of the colostomy bag.

Abdominal pain, diarrhea, melena, flatulence, a stomach infection, and intestinal obstruction, these were some of the initial signs and symptoms of the diseases that led to the need to undergo ostomy surgery. Colorectal cancer, anus cancer, cervical cancer, stomach cancer, and ulcerative colitis were the causes of this need. By the time I realized I was already sick because many are the tasks we have and we neglect health. Routine exams are neglected, there are late diagnoses, and, at times, they are inaccurate, which ends up delaying treatment and leaving only one option, the definitive use of a colostomy. The use of the colostomy bag is a condition for us to try to improve our quality of life, but we are not always one hundred percent sure.

2. Daily life changes resulting from colostomy

Central ideas:

- Affected daily life activities;
- Feeding changes;
- Difficulty in using the colostomy bag.

The day-to-day activities have become more difficult to perform, especially when you have to make the physical effort, get down and up, stand for a long time, shop, clean the house. We don't stop doing all the activities, but some are avoided. The habit of standing near the stove had to be changed, as well as the feeding. Adapting to a healthier diet is not easy, as it requires family and financial support. It is necessary to pay more attention to quality, hygiene, and the types of food so as not to cause any intestinal discomfort and, to help with this attention, we find ourselves dependent on others. The colostomy bag is a nuisance, you can no longer sleep carelessly, you may need to change the bag early in the morning, even sitting in the toilet is difficult, because they are low. Handling the bag is a matter of adaptation, first, it is necessary to know how to put it so that it does not leak, hurt or irritate the skin, then handle the bag to know how to use it, time to change, how to make it comfortable under the clothes we use, in the sleeping position, etc. We have to feel safe with the bag so as not to be embarrassed when we have to leave home or receive a visit, these are details, but they make the difference in our self-esteem.

3. Patient's attitudes toward and responses to the use of colostomy bags according to Kübler

Central ideas

- Negation;
- Anomaly;
- Relationship with the partner;
- Difficulty in connecting with people;
- Acceptance;
- Adaptation.

Life changes. Embarrassment is inevitable, it is not possible, no matter how much effort, it is not possible that the bag is the cause. It makes noise, it makes the abdomen look bigger, people stare at me. So, I consider it an anomaly, I started to feel like this, a person with an anomaly, an abnormal person, and people don't stop noticing this. The relationship with the partner is complicated. Things change when you get sick and the people close to you can't always cope. In the beginning, they are still there for us, but then they lose interest, they move away and we have to hold on, move on, but life is no longer the same. It is very difficult to get close to someone as before, we're not the same anymore. Life goes on, after a while, you get used to it. In the first days, everything is different, you get upset, you don't know how to use the bag, you're afraid to squeeze your belly, hurt, but then you adapt yourself to it. Adaptation.

Management of the situation of living with the colostomy bag – coping strategies

Central ideas

- Social isolation;
- Fear:
- Embarrassment;
- Sadness:
- Adaptation over time.

Even if I want to go out, I'll keep myself as safe as I can. I avoid staying in meetings, in small groups, or birthdays only when it is extremely necessary. I feel fear and shame when I have to go out to places with many people because we have no control, the gases are constant and uncontrollable. To avoid embarrassment, I prefer to stay at home. When it comes to friendships, things are not like before. People are distancing themselves, because close friends are far away when you notice it. You feel sad, they seem to think that this disease is contagious. But we go on, I do my activities, I help at home and I live. You adapt yourself over time, today I already do it and guide several people. Time is in charge of fixing everything and this adaptation is also related to the way you use the bag, you gain experience while you use it, for you to go out, it is an adaptation. You and whoever is by your side have to accept a lot of life-changing things, but, within a normal context, if you have a good head, there is no problem at all, normal, normal.

DISCUSSION

This study made it possible to understand the patients' view of the use of the colostomy bag. Feelings associated with the placement and use of the bag, daily life changes, attitudes, and reactions while using it and the management of the situation of living with the colostomy bag.

With regard to the placement and use of the bag, the patients' medical records of the illness are almost identical to each other. Also, the initial symptoms, such as melena and intense abdominal pain, are similar. Initially, many patients were diagnosed with cysts located in the intestine or rectum. Later, they were diagnosed with cancer.

According to the study results, of the 17 participants, 64.7% had a definitive colostomy and 35.3% had a temporary colostomy. Moreover, it is inferred that the patients' intestinal content had to be diverted in most of the cases. Nevertheless, regardless of whether a stoma is temporary or definitive, it causes profound changes in people's way of life, considering that their gastrointestinal physiology is modified, as well as their body image, self-esteem, etc. ¹⁶

In regard to the stoma patients' profiles, they are middle-aged and elderly men with cancer. Moreover, the reason for the placement of the stoma was colon and rectal cancer. These results are in line with those of a study carried out in *São José do Rio Preto* Region, *São Paulo* State, Brazil. Of the 252 stoma patients who participated in the study, 51.1% were women and 48.9% were men. The 68-78 age group had the highest proportion of cases (26.3%) with an average age of 73 years old.¹⁶

Regarding the reason for undergoing surgery, the study results corroborate the literature. In fact, intestinal obstructions caused by agenesis and atresia, cancer, diverticular disease, ischemic colitis, cancer-related colon punctures and inflammatory bowel disease (Cröhn's disease, ulcerative colitis), and penetrating traumas (melee or ranged weapon) are indications for colostomy.¹⁷

Most of the participants reported not knowing about what disease led them to undergo surgery. The person's knowledge about the severity of the disease that led him/her to use the colostomy bag is of fundamental importance for better acceptance because if the patient understands that this bag will improve his/her physiological condition, he/she will be able to adapt himself/herself better to it.¹⁸

It was observed that most of the participants mentioned only the diagnosis, not showing familiarity with the subject. Not knowing the possible causes may make the patient even more concerned about his/her future. This diagnosis, which is not easy for the patient to accept, brings about a reality in which the patient has difficulty in accepting the "physical changes". For example, technical knowledge to handle the collecting bag and professional help to learn and understand the process of change is needed. In this way, challenges arise from diagnosis to the adaptation to the new life condition. After the diagnosis and the communication of the need for ostomy surgery, many patients experience life-changing feelings and emotional unbalance. 18

Concerning the patients' life changes, intestinal stomas not only changes the biological system but also affect patients emotionally and physically, impairing their social relationship. Colostomy brings about body restrictions and life-changing habits. This was corroborated by another study in which these limitations were regarded as factors that increase the individual's perception of disability. The patient is unable to perform movements such as standing or squatting for a long time, or go down quickly, which may cause displacement of the bag.¹⁹

Feeding changes were also cited by the interviewees. There is an important relationship between diet and intestinal function, as the quality and quantity of ingested food interfere directly with the volume and consistency of feces, the formation of gases, and bad smell. However, the placement of the stoma also allowed the patients to think about a healthier diet, because over time people get to know their bodies better and adapt themselves to a healthier diet, avoiding risks and intestinal discomfort.¹⁹

Changes in daily life activities, such as cleaning the house, physical barriers, feeding, clothing, and the necessity of requiring the relatives' help to perform some of these activities, were also emphasized by the participants. It is perceived that, in attempting to adapt to the changes, people with colostomy adjust their lives to a new context. It was also reported sleep changes such as fear of the bag leaving its place, fear of getting dirty. Even clothing changes were reported, such as the replacement of tight clothes with loose ones, or the fact that the participants disguise the abdominal volume.

Handling the colostomy bag would be the main difficulty expressed by the study participants. Because it is a new device that causes changes in peoples' lives, it is regarded as a nuisance, causing fear and frequent concern with the elimination and smell of the gases and feces. There is a constant feeling of shame, insecurity and a negative view of oneself.¹⁴

To care for the person with an intestinal ostomy, it is necessary to use nursing technologies developed to handle the collection bag properly, which requires theoretical and practical knowledge. The reason is that a correctly connected device can ensure more security and tranquility in social relations and daily activities.²⁰

Regarding the patient's attitudes toward and responses to the use of the colostomy bag, Kübler¹⁴ highlights that individuals may go through the stages of death (denial, anger, bargaining, depression, and acceptance). Of them, negation, depression, and acceptance were identified in the interviewees' statements. Denial was evidenced by the difficulty of accepting the condition. The patients cannot accept the colostomy bag and when they see it, they view themselves as anomalous people.

Stoma patients feel apprehension because just one look is enough to make them uncomfortable. Consequently, they feel as if they are being judged, impairing their social relationships. In the face of certain situations, they try to distance themselves and even try to hide the bag. ¹⁴

The study participants described depression as a feeling of sadness, uselessness, and "loss of strength" to fight against reality. Depression was also associated with relationships. The participants reported having difficulty in establishing new relationships or maintaining an existing one. These findings are corroborated by a study, which pointed out that stress due to the presence of a stoma impaired sexual performance due to feelings of inferiority, dirt, depression, anxiety and, above all, shame in front of the partner.²¹

People do not experience derogatory feelings nor joy during the acceptance and adaptation stages. Living with the colostomy bag brings about a whole new context of adaptation because there are different ways of reconciling life with a given event. This adaptation will depend on numerous factors, such as personal peculiarities, cultural and emotional aspects, and previous experiences.

Both the disease and the therapeutic proposal can cause stress for patients, forcing them to implement coping strategies. In Brazil, coping strategies are those seeking to overcome, dominate, and overcome the stressor. Effective coping strategies lead to physical and emotional balance as much as possible, while the ineffective ones result in crisis, as well as psychological and physiological imbalances.²²

Coping strategies are based on stress theory and are intended to create, increase, or maintain the conception of personal control in the face of a stress situation. Coping strategies are dynamic and can be evaluated and re-evaluated since they are closely associated with personal experiences. There are problem-focused and emotion-focused coping strategies.²²

The changes in social relationships are a consequence of the stress that is the colostomy bag, as evidenced by the participants' statements. Thus, the individuals reported experiencing an emotional response when faced with this stress.

The presence of intestinal elimination equipment constitutes a threat to the physical and psychic integrity of the colostomy patient due to changes in gastrointestinal physiology, which have family and social implications. These changes make socially impaired colostomy patients have feelings of insecurity and discrimination. So, they prefer to stay at home to avoid frustration and embarrassment.²³

When it comes to friendships, VIOLIM²⁴ points out that the illness can bring people together or separate them, as well as make them reflect on their existence, attitudes, and behaviors according to their choices. It is a time of transformation in which they often give value to little things that were once insignificant. The care involves solidarity and help in difficult moments. Gaining experience in a given subject is very significant for those involved. Recognizing their importance, understanding their needs, and respecting their limitations are very important as well.

Regarding the adaptation over time, it was found that this is also a strategy for coping with emotions. The stoma patients' suffering is alleviated after a few months. Moreover, their social life improves, as well as their body over the years. In other words, patients find a way to adapt themselves over time.²⁵

In this study, it was observed that the people who use a colostomy bag developed problem-focused and emotion-focused coping strategies, such as reflection, knowledge of the health problem, social isolation, and adaptation over time.

It is important to stress that health care workers should be concerned with the physical and psychological well-being of the ostomy patients, with the aim of an adequate quality of life. Therefore, nurses should guide these people so that they will understand and deal with the changes caused by the disease. In addition, they should inform the patients about body and

functionality changes, help them, and encourage support networks for help and information by strengthening coping strategies. Such strategies will help them in living with the disease and transforming or abandoning ineffective strategies.²⁵

CONCLUSIONS

Using a colostomy bag is considered as something that impacts the patient's life, also bringing discomfort and stigma. Hence, guiding them and strengthen their coping strategies is of utmost importance, contributing to reducing complications due to physical and psychological changes.

Therefore, it is recommended that the care for colostomy patients should be initiated, preferably, in the hospital environment because adaptation to the new lifestyle is a continuous process and, sometimes, time-consuming. It is necessary to implement a multidisciplinary care plan that includes the participation of stoma-therapist nurses, social workers, psychologists, nutritionists, surgeons, and assistant physicians so that quality care could be attained. Promoting health education aims to facilitate changes in the way these patients think and act. These changes will be necessary for their self-care.

Concerning the limitations of this study, it is worth mentioning that it was conducted only in one hospital. Furthermore, some colostomy patients reported not being able to answer the questions due to their weakened health condition. Nonetheless, the development of the study was not compromised because these situations were included in the exclusion criteria.

The relevance of this study is evident due to their contribution to the knowledge of and discussion on the issue of the colostomy patients' quality of life. It is essential to carry out such studies, which seek to further understand the patients' experience of using a colostomy bag and identify their coping strategies, their understanding of the diagnosis, their life changes, and the difficulty of adapting themselves. As a result, they make it possible to ease the understanding, resolution, and implementation of strategies aimed at providing care for these clients in a holistic and humanized way.

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