Technology Journal of Management , Accounting and Economics (TECH)
ISSN: 2311-3995

Vol. 12 No. 3 (2024)

SOCIAL AND FAMILY ADJUSTMENT OF OSTOMY PATIENTS: A QUALITATIVE CASE STUDY

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Abstract

Objective: To understand the coping and adaptation of a colostomized person over a period of two years.

Methodology: Qualitative case study. The case of a patient with a colostomy due to rectal cancer is illustrated. Data were collected through semi-structured interviews with the patient and family at two different times, during hospitalization and two years later. The four interviews were recorded, transcribed and analyzed according to the Taylor-Bogdan method.

Results: During hospitalization, coping strategies aimed at alleviating negative emotions by delegating stoma care to their family member prevail. Two years later, a greater concern for practical matters is observed, finally achieving autonomy. The aspects that have contributed to this adaptation and the changes caused by the ostomy in their life are discovered.

Conclusions: The need for individualized care that considers the ostomate in their biopsychosocial dimension is evident.

Keywords: Adaptation, Coping, Ostomy, Social reintegration.

Introduction

Digestive ostomies, that is, emptying the intestine into the abdominal wall for excretory purposes, constitute an aggression to functionality and body image. Different studies on quality of life confirm this fact, showing the different facets affected by the new situation. Hygienic habits, diet, eating behavior, leisure, way of dressing, sexuality or social and work life undergo modifications. [1] On the other hand, qualitative research offers a complementary vision showing the perception and experiences that derive from the change generated in their organism. The ostomized person interprets the otomy as "a before and after", as a gap in their lives from which not only their routine changes, but also the conception they have of themselves. [2,3]

These changes require a cognitive and behavioural adaptation process. The process begins in the hospital environment, the moment when the person really becomes aware of their condition and must first confront the situation.

Coping involves a wide range of behaviours aimed at restoring the lost balance. Some strategies are aimed at alleviating the negative emotional burden, while others act directly on the problem, trying to solve it or to perceive a certain degree of control over it ·

However, not all strategies are effective. Adapting to the ostomy requires the presence, to a greater or lesser extent, of strategies aimed at solving problems. This group includes behaviors such as seeking information, going to professionals for technical help, learning how to manage the stoma, getting involved in self-care or analyzing the problems that may occur in one's routine, looking for solutions for them. When these types of attitudes are completely dispensed with, the person delegates care to another person, altering their degree of autonomy and tending toward social isolation. [5]

Adaptation is a dynamic process that begins with the placement of the stoma and must continue when leaving the protected environment of the hospital. The return to the social and family environment of each individual imposes new challenges for adaptation and new sources of stress. A long road then begins for the person with an ostomy, during which he or she must take on the care of the stoma alone, return to social life, resume sexual activity, leisure activities or start working. All of this requires an effort to readjust in order to overcome the difficulties imposed by the new condition.

The aim of this study is to illustrate the coping and adaptation process of an ostomate over a period of two years.

Methodology

The qualitative methodology, in its phenomenological aspect, has been chosen to address the objective of the study. This is a case study in which, through the informant's life narrative, the aim is to understand the peculiarities of his process. To do so, the method proposed by Amezcua et al. [6,7] has been followed.

A person who had undergone a permanent colostomy due to rectal cancer was selected by intentional sampling. This person is José, 62 years old, a graduate, shy but good speaker and communicator. His wife, Carmen, is 60 years old and they have been together for almost 40 years, so her story helped to understand José's story, providing new information or corroborating what he offered.

José underwent surgery in February 2008 in a specific colorectal surgery unit. A low anterior resection was performed, leaving him with a permanent colostomy. The postoperative period was uneventful and he was discharged after nine days.

The researchers were part of the nursing team assigned to the unit. The data were collected through semi-structured interviews with the patient and the closest relative in two stages: on the fifth postoperative day in the hospital and one and a half years later at home. The interviews were recorded for later transcription and qualitative analysis. Data from the first interviews were added to those from participant observation carried out during the care of the patient-informant, collecting both verbal and non-verbal information. The latter provides information regarding the attitude towards the ostomy, an aspect that is difficult to explore with other methods because it has a non-voluntary component.

The analysis was carried out following the methodology proposed by Taylor and Bogdan.[8] These authors consider four phases in the analysis: data preparation; discovery of emerging themes and ideas through detailed reading of the information; coding, gathering and studying all the data that refer to the same theme; relativizing these data by interpreting them in the context of the participants.

Data triangulation was carried out by obtaining the information through two different methods. Researcher triangulation was also carried out, so that each interview was analyzed individually by the two researchers, who then pooled the data and arrived at the resulting thematic categories. These two methods give greater credibility and consistency to the research ·

The ethical principles of information, voluntariness and confidentiality were ensured through oral and written consent of the informants and by using fictitious names throughout the article.

Results

1. Meaning that José gives to his stoma. The process of coping and adaptation begins with an assessment of the situation. In this sense, it is important to point out the meaning that the ostomy has for the informant. His stoma is in a context of cancer, which from the first moment becomes the centre of his concerns and the stoma becomes secondary "my assessment is first alive, then ready" (J1). His wife corroborates this view by dealing with the subject in these terms: "we give more importance to life than to those little things that we have to put up with" (C1).

This way of interpreting the stoma is understood from the seriousness and severity of cancer and from José's particular experience with this disease. His first son died at the age of five as a result of leukemia, his second son suffered and overcame Hodgkin's lymphoma, and his wife underwent a hysterectomy at the age of 39 due to uterine cancer.

Two years later, having overcome the illness, the meaning remains the same, but with a connotation of gratitude for having survived. "For me it is a gift. If they give you a gold rifle, how can it bother you if it has a scratch? Well, it has a scratch. Why should it bother me if I had to be in PARCEMASA a year and a half or two years ago?" (J2).

For José, the ostomy is nothing more than a reminder of an illness he has overcome. "I can say that I left there with a sign that I was there" (J2).

2. First contact with the stoma. Coping during hospitalisation. The first time he saw the stoma did not seem to impact him, despite not knowing any ostomates and lacking information on the subject. He even had completely erroneous preconceived ideas about its anatomical location: "I had a mistaken idea that it was a back opening, not that it was in the front" (J1).

From this point, José focuses on emotions. In the interview, we can see how the main thread of the story is his feelings, which he openly shows and lets off steam. His speech, as well as the information gathered through observation, allow us to identify different attitudes whose purpose is to reduce the anguish generated by the situation:

- Focuses on aspects of his life that may help him adapt to the stoma. He interprets his way of dressing, not working, the character of his friends, not being very sexually active or his leisure preferences as advantages for living with the stoma. This helps him to live in a less threatening way with his new condition.
- He tries to make the stoma seem normal. He uses behaviours such as showing it to people, talking about it, or using irony and humour. In this way, the colostomy is made less important and is perceived as something natural, not shameful and not necessary to hide. "When I showed it to others (...). Obviously I don't have to hide it. It's mine, I have to live with it. I'm not going to publish it in ABC, but those around me do have to know what it is" (J1).
- He relies on faith to overcome the problem. José is a believer with strong religious convictions, which helps him understand and interpret the problem, while providing emotional relief from knowing that he is protected by a paternalistic

God. "What has helped me the most is faith and the people who have prayed for me" (J2).

- Accepts and seeks family and social support. Perceiving the empathy and unconditional help of those around him makes him feel emotionally comforted. "I am protected, right now, by my family and friends. [He gets emotional, cries and waves his hands, remains silent" (J1).

On the other hand, the situation he faces, illness and ostomy, imposes new emotional needs that José expresses in numerous passages of his story:

- Need to feel socially accepted as he is, an ostomy patient and incontinent. "Look, I have this [points to the stoma , and I'm incontinent, you either take me or leave me. If the portable toilet bothers you, you go your way and I'll go mine" (J1).
- Need to maintain his role within the family. He feels the responsibility of knowing how to face and overcome a situation that different members of his family have already gone through. "It's complicated, you see [he gets emotional, his eyes get wet, silence . My wife has come out [he refers to uterine cancer and has shown more balls than the horse of Espartero, my son has come out [he refers to Hodgkin's Lymphoma and has shown more balls than the horse of Espartero, I can't be a "waxy", be less. [Silence " (J1).
- Need for security. Although the subject of noise, smell and detachment from the body are also included in his speech, the perception of vulnerability with respect to the stoma is the most addressed aspect and the one that worries him the most. This interpretation is maintained in the second interview, two years later. "I am worried about a blow, a bad blow. Since there are many sharp, blunt things" (J1), "now it is true that if I am in a crowd I put my hand in the place [on the colostomy " (J2).

José thinks vaguely about the practical aspects, not using this type of strategy and expressly stating his decision to delegate the management of the stoma to his wife. "My wife is going to do this for me, among other things because I am a bit of a disaster with my hands, with manual skills and because I am fat I have poor access to the area" (J1).

Participant observation allows us to detect this lack of interest on the part of the informant in the practical aspects of the ostomy. During health education he does not pay attention, looks away, talks about other subjects and even answers phone calls. Carmen knows that she will have to take care of the stoma and assumes it with total normality. "I will have to help him because he is lazy, I think that with time he might know how to manage by himself but I will have to collaborate. I think that will be my turn" (C1).

During this first period, José has adapted to the situation by developing behaviours and attitudes that comfort him emotionally. On the other hand, he has resolved the issue of managing the stoma by making his wife responsible. This type of attitude leads to a change in the person's degree of autonomy and to compromising family dynamics and social reintegration. It is therefore considered to be an ineffective or non-adaptive coping method.

3. Two years have passed, the adaptation. "I don't know what will happen in six months in an environment that may be less understanding with people... My biggest difficulty is that I am now speaking with fear of an immediate event and also in a protected environment, I don't know what will happen in six months, then it will be more real experiences, not based on a theory or on my way of thinking" (J1). This is how José expressed during his hospitalization his fears,

uncertainty and expectations about returning and adapting to his social-family environment.

Almost two years later, the narrative line of the discourse has changed considerably. José integrates numerous technical aspects of the stoma into his narrative; he talks at length about the devices he uses, explains how he anticipates problems that may arise, how he has resolved the difficulties, and how he has adapted his clothing and social life. The strategies he now uses in the adaptation process are basically focused on problem solving. He acts directly on the cause of the conflict, his ostomy, trying to resolve the problems it generates and thus perceiving a certain degree of control over the situation.

We also observed how this person, who left the hospital with total dependence for the elimination function, has become autonomous again by performing self-care.

The question arises: What has caused this change in José's behaviour? The story allows us to objectify how this has not been a gradual change in attitude, but rather it was motivated by the indication of a different device than the one that had been recommended to him at the Hospital Centre. "You see, she [referring to his wife has been doing it for as long as I have used the three pieces, when I have used one piece, no. Also, one piece is very simple, I was encouraged to do one piece basically with an ATS who, speaking to me, said "try with one piece", I tried it and I see that I am more autonomous with one piece than with the three" (J2).

4. How the stoma affects my life. José and Carmen's stories allow us to see which aspects of their lives have been most affected. José has had to slightly adapt his clothing in order not to damage the stoma and to hide the collecting device. "It has led me to change the way I dress" (J2).

The diet has also been modified, restricting certain foods, especially those that caused the most gas. "There was a time when he told me that cauliflower, Brussels sprouts, cabbage, I shouldn't eat them because of the gas" (C2).

Sex life has changed dramatically, making full sexual relations impossible. "I see that he wants to, but nothing, he gets close, caresses me, but nothing" (C2). However, as Carmen explains in her interview, this limitation does not derive from emotional aspects related to the stoma, but from the intervention carried out.

The impact on social life is the aspect most discussed by the informants. Relationships with others outside the home generate feelings of insecurity caused by the fear of the bag being loud, the collection bag being full, part of the contents coming out or the bag being detached from the body. Many people with ostomies find in ostomy associations an environment of understanding and refuge in which they feel safe and accepted. José, although he states that his personality is not very given to corporatism, does express the need to be surrounded by people who know his condition as an ostomate as a strategy to feel safe. On the other hand, it is observed how he has had to adapt his social relationships by restricting the time he spends outside the home or the activities he carries out. "I can participate in something that lasts two, three, four hours and return home. But an activity that can take up eight hours makes me feel uncomfortable. Maybe nothing happens to me, but I feel uncomfortable with the growth of the bag, it makes noise" (J2). Furthermore, the perception of vulnerability has contributed to limiting some activities with crowds, or the simple fact of using urban transport. "When I take the bus I usually sit at the back, which means there is less contact, less friction, I protect myself" (J2).

As for leisure, travel is perceived as problematic, and many inconveniences are found in it. "This makes me reluctant, because I don't like going through the arch of the planes at the airport (...), I am also afraid of going on a plane because of the pressurization problems" (J2).

However, although they expose all these limitations, it is observed that they give them a non-conflictive meaning. Their stories are imbued with optimism and gratitude. They have sought solutions to the problems associated with the ostomy, having a positive vision of the whole process. José and Carmen interpret these limitations as small adjustments that do not incapacitate family life, social life or leisure, not posing a problem in their lives. José is also able to extract a benefit from his ostomy by using it on occasions to hide his own limitations. "What I have noticed is that I use this procedure to do what I want, if I don't want to go somewhere or don't want to do something, I have problems and of course, I can certify it [points to the stoma and laughs , you can't and I have used that sometimes" (J2).

Discussion

José's experience has allowed him to expose the adaptation to the ostomy as a dynamic process in continuous evolution. At first, the informant focuses almost exclusively on alleviating the negative emotional burden. This attitude leads him to modify his degree of autonomy and alter the socio-family dynamics. After two years, the situation has changed drastically, evidencing a different and more effective behavior. Harmony in the adaptation process occurs when the person is able to combine strategies directed at emotions and problem solving. Within this second group, self-care is essential for adequate social reintegration.

Various studies confirm that coping methods that promote autonomy are the most effective. [5,10,11] In the multi-centre study carried out by Piwonka [12] a series of factors predicting adaptation were identified, with self-care being the most determining variable. Along with this, other decisive factors are also considered, such as social and family support, the time elapsed since the ostomy was performed or the non-tragic perception of the bodily change.

José's interpretation of his ostomy has helped him in this adaptation. Even in the hospital, it is clear that he is focused on his illness, on the cancer, with the stoma being a small inconvenience to overcome. Haugen's study [13] confirms this view by objectifying how people with neoplastic disease obtained better results on the adaptation scale.

As for family and social support, it is present throughout the study. Already during the postoperative period, we can see how José tries to seek social acceptance from his environment and how, after two years, he has managed to resume his social and leisure activities. The support of his family is even more palpable; the interviews carried out with Carmen show the same line of thought as her husband, as well as unconditional support, both technical and emotional. The References places this type of help as essential in adaptation. [12,13] Perhaps in Spain, where the family has strong cultural roots, this aspect is even more decisive.

The analysis of the interviews reveals a clear turning point from which José's attitude towards his stoma changes: the change of device. This fact allows José to perceive management in a less complex way, allowing him to take charge of self-care and thus break his dependence on Carmen.

Prescribing devices is not easy; it requires knowing all the available products, being clear about their indications, advantages and disadvantages. On the other hand, it requires a comprehensive assessment that takes into account the physical, emotional and social dimensions of the person. For this reason, it cannot be limited to a mere anatomical examination of the abdomen; other factors such as manual dexterity, visual acuity, clothing, family support, lifestyle, personality, cognitive ability or the patient's preferences must also be assessed. In addition, this assessment must be contextualized taking into account the life stage in which the ostomate is (childhood, adolescence, maturity or old age) and the specific moment in relation to the coping and adaptation process.

This requires healthcare professionals to have an aptitude and attitude that is in line with the needs felt by patients. Knowledge is not enough; empathy, active listening, presence and creating a climate of trust that allows them to express their perception of the problem are necessary.

The in-depth interview is seen as the ideal technique to approach the experience of these people, obtaining other benefits apart from the informative one, such as emotional relief or strengthening the nurse-patient relationship.

It can be concluded by stating that care for ostomates requires individualized care that goes beyond the technical aspects to also encompass more humanistic aspects such as coping and adaptation; only in this way will we be able to provide effective help for these people.

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