

ORIGINAL RESEARCH

Feelings and expectations of permanent colostomy patients

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Abstract

Objective: Original article, based on field research that sought to describe the challenges that persons face when adapting to a permanent colostomy. Design: Data were collected through a semi-structured interview and analyzed using the technique of Content Analysis proposed by Bardin. Subjects and Setting: five participants in the Ostomy Program of the City Health Department of Capão do Leão, Brasil.

Methods: Qualitative descriptive study, conducted from July to September of 2005, in the city of Capão do Leão, State of Rio Grande do Sul/Brazil.

Results: The categorization of the data led to identification of three thematic units. The first we described as “Experiencing the consequences of illness as a disorder”. The second was “Restoring a sense of order to life”, and the third was “Living with the new condition”. Reflections illuminated by the complex thought were pointed out as possibilities of a care for the human being, capable of making choices and of actively participating of its process of health and illness.

Conclusion: We concluded that a having permanent ostomy was difficult for the subjects and restoring the sense of an orderly life was complex.

Key words

Colostomy, Nursing care, Psychosocial impact

1 Introduction

The most frequent disorders leading to creation of a colostomy are trauma, congenital diseases, inflammatory diseases, tumors and intestinal cancer. Both temporary and permanent intestinal ostomies results in changes in the user's life such as in gastrointestinal function, as well as psychosocial factors including self-esteem and body image. In addition to the profound changes arising of ostomy, the person must also cope with the physical and psychosocial impact of the underlying disorder^[1, 2].

The adaptation to these changes requires specialized nursing care, which is anticipated to be life-long for the person living with a permanent ostomy. Psychosocial responses during the immediate postoperative period include fatigue or weakness,

a sense of mutilation or violation, grief, revolt and depression. The characteristics and severity of these psychosocial responses vary from person to person ^[2, 3]. Several studies point out that support from both professional health care and family or lay caregivers enhances recovery following stoma surgery and adaptation to the new life situation resulting from a new ostomy ^[2, 4, 5].

Health professionals, including the Wound, Ostomy and Continence Nurse (WOCN), play a decisive role in the physiological, functional, and psychosocial adaptation of patients and their families that are learn to manage and cope with an intestinal ostomy. Optimal management uses a holistic approach, incorporating psychological support, education about the ostomy, and development of the ability for self-care ^[2]. Therefore an interdisciplinary approach that defines the patient as an integrated is indicated when caring for persons learning to cope with a colostomy ^[6].

Unfortunately, not all patients have access to a WOC in ostomy nurse specialist, resulting in suboptimal care and an increased risk for difficulty adjusting to life with an ostomy ^[1]. Therefore, our study sought to describe the challenges that persons face when adapting to a permanent colostomy. Specific research questions were: 1) What are the feelings and expectations of permanent colostomy patients facing the process of adaptation? 2) How can nurses and other health care professionals minimize the problems of colostomy patients?

2 Methods

This descriptive and qualitative study was performed in the City Health Department of the City of Capão do Leão, in the State of Rio Grande do Sul/Brazil. The approximate population assisted by this City Health Department is around 27,000. The criteria for the selection of the study participants were: all users with permanent colostomy belonging to the Ostomy Program of the City Health Department. All data were collected through semi-structured interviews. For this study an individual interview per subject was conducted and the approximate duration of each interview was of about an hour and a half. The interviews were recorded and afterwards transcribed for analysis. The data were categorized and analyzed using the technique of Content Analysis proposed by Bardin ^[7]. We extracted the central ideas and the data led to identification of three thematic units by classification and grouping of elements by the frequency in which they appeared, with the objective to deduce the meaning of the responses logically, with justifications complementing and validating the results of the interpretation ^[8].

The study was conducted in accordance with Resolution 196/6 of the National Health Board of Brazil related with research involving human beings ^[9]. The research project was approved by the Ethics in Research Committee of the Hospital of Santa Casa de Misericórdia of Pelotas. Written consent from the City Health Department was obtained and all participants signed the Free and Clarified Consent and the anonymity and privacy of the participants were guaranteed. The name of participants (such as *Rosa* or *Azaléia*) used to identify the participants' speech on the results of this article are not their real name.

3 Results

Five patients from the Department's Ostomy Program participated in the study. Three lived in the area of Jardim América (the most populated area of the city), one was from Bairro Teodósio and the other from the downtown area. All subjects had a permanent colostomy; their ages varied from 42 to 75 years of age, with the average of age being 62. Three were women and two were men. The time since ostomy surgery varied between 14 months and 25 years. The average time since an ostomy surgery was 9.3 years.

Three underwent ostomy because of intestinal cancer, one owing to uterine cancer, and one due to accidental trauma. All received ostomy pouches provided by the State. All subjects were independent with care of their ostomy with the exception of one participant who received help from his wife, due to other health problems. He was the only patient who

did not go to the City Health Department to receive his ostomy supplies. The other four users, and the wife of the home bound patient, went to the Health Department monthly for supplies and for a nursing consultation with the author (M.T.S.B.). During this consultation with the nurse, the users cleared up their doubts, presented their complaints, received orientations and also talked about themselves and their families and received technical/professional and emotional support from the nurse. While the participants expressed a positive relationship with their nurse, they also expressed complaints about delivery delays, lack of supplies or inadequate ostomy supplies provided by the State. All subjects were interviewed during visits to the City Health Department with the exception of the home bound male subject who was interviewed in his home.

Categorization of the data led to identification of three thematic units. The first we described as “Experiencing the consequences of illness as a disorder”. The second was “Restoring a sense of order to life”, and the third was “Living with the new condition”.

3.1 Experiencing the consequences of illness as a disorder

The disorder in the lives of patients after an ostomy involves physiological, functional and psychosocial transformations affecting their wardrobe, diet, medications, body image, and fecal elimination functions. One respondent stated,

“It changes, changes. Certain kinds of clothes that I used to wear I don’t wear anymore. For example, I don’t wear a tight pair of jeans anymore, it’s bad, uncomfortable. I started wearing pants with elastic on the waist. Another participant reported, “... there’s a piece missing. I feel normal, feel well. The holes were changed (laughed).” One participant described dietary changes in detail stating that there are “some things I can’t eat: corn, beans, and peanuts. I have to always take medicine. Three kinds of medicine: fluoxetine, omeprazol and aprazolan. I take medicine for depression. I have chronic gastritis. I took a lot of dolantina and morphine in the hospital. And now, once in a while, I eat something that doesn’t go down well, then I take dolantina in the... (Azaléia-ostomized 10½ years before the interview). Another subject commented on perceptions of odors generated by the ostomy, “I always had the impression that I had a bad smell next to people.”

This sense of disorder in the lives of participants also impaired social function that including the perceived ability to work outside the home, or participate in certain social or recreational activities. One respondent stated, “I can’t go out for a ride, [or] on a picnic where there isn’t a bathroom. It’s already uncomfortable for me).” Another participant stated, “I couldn’t work anymore, I was a phone operator at....I don’t go to all the places I used to go to, parties, the beach...”

This sense of disorder also influenced participants’ emotional lives, resulting in feelings of inferiority, social isolation, and depression. One participant reported that *“First I was very angry. I didn’t want to accept. I felt inferior to other people. I didn’t like to leave home. I didn’t leave home for a year and a few months.”* A second subject noted *“I take medicine for depression . I have chronic gastritis, it doesn’t go away.”*

3.2 Restoring a sense of order to life

This section illustrates and demonstrates through the statements of the participants how they have been able to restore their lives while people, despite their condition of vulnerability and shaken feelings and uncertain perspectives after undergoing the ostomy surgery.

“Hah! First I was very angry. I didn’t want to accept. I felt inferior to other people. I didn’t like to leave home... The support of the family is very important. At a time like that it is very important. My daughter used to say to me to think that I hadn’t lost an arm or a leg, that I had received something extra, that had increased but wasn’t visible, I was the only one who knew about it. People were not going to look at me and know I was using it. That’s how I conformed myself and today I accept it. Today I go out, I travel. I think that’s it. I’ve even been to Rio de Janeiro after I had the operation (...).” (Rosa – ostomized five years before the interview).

“I think the colostomy is not meant to suffer, not a problem, but a problem solves. I think the doctors should prepare us first. Of course sometimes this is not possible, they have to open up and do a colostomy. But the second time around there would have been time and he lied and said it was a hernia. I told him (doctor): never lie to me again. I think the patient has to be prepares for everything. When you wake up from the surgery, you feel mutilated” (Azaléia-ostomized 10½ years before the interview).

This last participant of the study faced a series of difficulties of adaptation. However, her participation in the group of ostomized in a neighboring city has helped her a lot to overcome her problems and the depression associated to it. In this group, this user has already been treasurer and also expressed that during the lectures conducted by the health professionals she was usually used for demonstration to the others and told her story to the other participants of the group, what makes us think that with this she felt valued for and capable of overcoming her difficulties and still was able to help the others. She complemented:

“I’ve participated in Pelotas and whenever there is a birthday of ostomized I always go and also to the monthly meetings... I think it’s great. There’s the Nurse there who explains everything about the ostomized. Sales representatives go there to show the bags. It’s a lot of good things. We used to rent a van to go on field trips, always on birthdays” (Azaléia-ostomized 10½ years before the interview).

As to the question made to the subjects about what they think about having an ostomized groups in their own city and if they would like to participate, another interviewed answered:

“I think that would be a good thing. I don’t know... Not that it’s lacking for me. It would be good for a greater orientation about hygiene. But I can participate, I don’t see any problems. You have already taught me everything” (Lírio – ostomized 14 months before the interview).

It is worth mentioning that up to this moment this user had used colostomy bags for only 14 months and was able to adjust well. He had never participated in the group of ostomized and also did not know about the existence of these groups.

3.3 Living with the new condition

The participants of the study express clearly that the beginning was difficult for them to accept their new condition and to adjust them selves to the use of colostomy bags. However, as time passed by, they became conformed and accepted the new condition, especially with the support of their family. They inclusively speak about a new meaning of life after undergoing a situation of illness, in the case of cancer, also verified by Santos ^[10].

“(…) I learned a lot after the operation. My life was just work, work, and work. Today I value life much more. What God sends us, we have to accept. Getting angry only makes it worse. Thank God my family is very good, my children are very good to me. They do no let me sink (become depressed). There is a friend of mine who has been operated four times, because he doesn’t accept it. On the third surgery he went through they perforated the large intestine and he almost died. And they couldn’t take it out. He’s with the bag. Is it a comfortable thing? No, no it isn’t. But it’s something to which we have to adapt, it’s the only way out.” (Rosa – ostomized five years before the interview).

“Hah! In the beginning it was very difficult, but now I have more experience. Everything is normal. My hygiene is a-ok. I’ve gotten completely used to it.” (Lírio – ostomized 14 months before the interview).

“First it was that regular bag (disposable). It took me a long time to adapt to that. Afterwards I got used to it. Today there is no problem. I don’t feel anything. I’ve gotten used to everything. In the beginning it was very difficult. I’ve already adapted...” (Cravo – ostomized 25 years before the interview).

4 Discussion

Disorder not only opposes order, it cooperates with it to create organization. The disorder present in the origin of the organizations threatens them incessantly with disintegration. Therefore, the self-organization behaves as a permanent process of disorganization, which is transformed in a permanent process of reorganization^[6, 11].

The implantation of a ostomy provokes diverse alterations in the lives of the ostomized, related to the gastro-intestinal physiology, the corporal image and the self-esteem, which end up influencing and conditioning the affective, family and labor life of these individuals, as already evidenced also by other studies^[2, 4, 5, 12, 13].

Dialogue is a vital part of the complex care needed to help ostomy patients regain a sense of control and order in their lives. The dialogue doesn't make the difficulties go away, but it does help the patient evolve principle of coping with their new reality^[6]. In face of the countless limitations experienced by the ostomized, family support and professional medical support become fundamentally necessary, essential for the acceptance of the ostomy, a faster and more efficient rehabilitation and a good adaptation of the person to his/her new condition^[2, 4, 5].

The use of the colostomy bag represents a challenge as to the adjustment to the new condition of life and the ostomized needs some time to live his moment of losses, of grief and to find strength in the sense of elaborating and accepting his new condition. The resolution of the difficulties found by the ostomized is related to the internal disposition of the actual ostomized, the support of his family, of the health professionals and the structure of the attendance offered^[4]. The users with definitive ostomy feel the need to adjust to it, and, after some time passed, start to believe that this is possible, mobilize themselves to conduct the self-care and seem motivated to overcome the difficulties related to the ostomy and reconstruct their lives based on this new condition^[5].

The sense of disorder must be replaced with a sense of possibility. In this sense the disorganization of life caused by the disease needs to be reframed as the opportunity for valuable reorganization^[6]. For the health care team, this means recognizing the person as a communicative subject, endowed with conscience, autonomy, desires and expectations, and not definable as passive entity whose role is to treated and directed by professionals. The health team facing the choices of what to do and how to do it, must discuss and negotiate the choices with the patient^[14, 15].

Therefore, one of the current challenges related to the assistance and care for ostomized individuals to the need of a greater competence and autonomy of the nursing professional specialized in stomal therapy, concerning leadership and work quality of the interdisciplinary work and proven cost-use relationship, based on "the practical, aesthetic, ethnic, empirical and social-political knowledges, constantly updated and based on evidence – and focused on a group of clients with diverse needs but singular in its humanity"^[12].

Although the number of participants in this study was only five patients with permanent colostomy, this was the total number of patients who were using permanent colostomy in the municipality at the time of data collection. Each participant experienced the process of adaptation to a colostomy in a unique way. However, there were several similarities between the study participants, such as family income and living conditions. Even with differences in age and gender, the adjustment process with permanent colostomy was similar at all. The only difficulty the study participant ostomate there 25 years ago was his health condition at the time of the interview, because it had difficulty in speaking due to respiratory failure.

5 Conclusion

The implantation of an ostomy provokes diverse alterations in the lives of ostomized individuals, related especially to the gastrointestinal physiology, the corporal image and the self-esteem. The ostomized individual, as well as his family, need to be prepared by the health team, because it is the family who remains the closest to the users and who supports him, her

role being essential for the acceptance of the ostomy and for a faster and more efficient recovery. The supply of information and necessary orientations, the interdisciplinary work, among others, are important strategies to be used to help and support the patients that are submitted to ostomies, because these individuals are usually not prepared to face this new condition in their lives. However, even though not being prepares, after their process of adaptation as carriers of an ostomy, they start to conceive life in another manner, especially when the base illness is cancer.

We emphasize that it is essential and necessary that the health team prepare and guide the patient and his family before installing the ostomy for the adaptation process with the same is not so painful. Furthermore, we suggest the formation of groups of ostomates in the city, to be nurtured interaction, exchange of experiences and coping among patients with colostomy. Also we recommend to do another study in which are incorporated a larger number of patients users of permanent colostomy in which the patterns of the similarities and differences may emerge more convincingly.

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