

“WITH SOME CARE, WE CAN GO ON”: EXPERIENCES OF PEOPLE WITH OSTOMY¹

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ABSTRACT: The aim of this study was to learn how care takes place in the lives of people with ostomy in a municipality in the countryside of the state of Rio Grande do Sul. A qualitative, descriptive study was conducted. Six people with definitive intestinal ostomy, who were registered in the municipality's program, participated in the study. Semi-structured interviews were used for gathering data. The obtained data were subjected to a thematic content analysis, from which the following categories emerged: "I am really well treated, everyone helps"; "My life is a little different"; and "It is necessary to go on, stopping is out of question". The study revealed that care is present in the daily lives of people with ostomy; changes in their lives are clear, related to social interactions, to how they take care of themselves and to eating habits. Ostomized patients learned how to live with these changes, aiming to going back to daily activities and getting involved with chores in their routines.

DESCRIPTORS: Ostomy. Nursing care. Nursing.

“COM UM POUCO DE CUIDADO A GENTE VAI EM FRENTE”: VIVÊNCIAS DE PESSOAS COM ESTOMIA

RESUMO: O estudo teve como objetivo conhecer o cuidado que permeia as vivências das pessoas com estomia de um município do interior do Rio Grande do Sul. Trata-se de uma pesquisa qualitativa descritiva. Participaram do estudo seis pessoas com estomia intestinal definitiva, cadastradas no programa do município. Para a coleta dos dados utilizou-se a entrevista semiestruturada. Os dados obtidos foram submetidos à análise de conteúdo temática da qual emergiram as categorias: "Eu sou muito bem cuidado, todo mundo ajuda"; "É um pouco diferente a minha vida"; e "É preciso andar, parar não dá". O estudo revelou que o cuidado está presente no cotidiano das pessoas com estomia; as alterações em sua vida são evidentes, relacionadas à convivência social, à maneira de cuidar-se e aos hábitos alimentares. Os estomizados aprenderam a conviver com essas mudanças, buscando retornar às atividades diárias envolvendo-se com afazeres no cotidiano.

DESCRIPTORIOS: Estomia. Cuidados de enfermagem. Enfermagem.

“CON UN POCO CUIDADO VAMOS ADELANTE”: EXPERIENCIAS DE PERSONAS CON ESTOMÍA

RESUMEN: Objetivo: conocer el cuidado que se respira en las experiencias de las personas con estoma de una ciudad del interior de Rio Grande do Sul. Se trata de un salto cualitativo, descriptivo. Los sujetos fueron seis personas con estomía intestinal definitiva registrado en el programa de la municipalidad. Para la recolección de datos se utilizó una entrevista semiestructurada trabajado a través de análisis de contenido temático de las categorías que surgieron: Yo soy muy cuidadoso, todos ayudan; "Es un poco diferente de mi vida"; y "Hay que caminar, no se detiene". El estudio reveló que el cuidado está presente en la vida cotidiana de las personas con estomía, los cambios en su vida son evidentes en relación con su vida social, la forma de cuidar de sí mismo y los hábitos alimentarios. Aprendieron a vivir con estos cambios, tratando de volver a sus actividades diarias y participar en las tareas diarias.

DESCRIPTORIOS: Estomía. Enfermería de cuidado. Enfermería.

INTRODUCTION

The increase in life expectancy in recent years has been contributing for the increase in the incidence and prevalence of chronic diseases throughout the world. Therefore, the needs of people who came to live under this condition are significant and affect many aspects of their lives, incorporating new habits as well as revisions and adaptations of social roles.¹

The World Health Organization (WHO) considers chronic health conditions the problems that demand care for an extended period of time, including people with definitive intestinal ostomy. It is an extremely wide group of harms, which are defined by chronicity and the need for continuous care.¹

Intestinal ostomies are built through surgical procedures, having the aim of redirecting the bowel transit to the exterior. Many causes are attributed to this procedure, and the most frequent include trauma, congenital diseases, inflammatory diseases, tumors and intestinal and bladder cancer.² The surgery that produces the ostomy is referred to by the ostomized patients as traumatizing, causing deep changes in the way they live, which require specialized care,³ demanding different resources and specific measures.

The process of caring has been called "humane care" and consists of a way of living, being and expressing oneself; it is defined as an ethical and aesthetical stand before the world. It is expressed through behaviors and actions that involve knowledge, values, skills and acts employed to favor the potentialities of people to maintain or improve human condition in living and dying. Care results from the process of caring.⁴

Care related to people with ostomies demands specific actions in many dimensions, considering that they suffer many losses in that moment, demanding individual and systematic care. Caring for people who underwent this type of surgical procedure, which changes gastrointestinal physiology, self-esteem, body image, in addition to other changes in their lives due to the presence of a colostomy/ileostomy, has been a challenge for the care administered by health professionals, especially for nurses.⁵

These professionals, through their scientific knowledge, have the competence to promote comprehensive care, thus contributing to the rehabilitation of the ostomized person in relation to his or her new health condition, reinsertion in

society, as well as the development of teaching/learning self-care.⁶

In this perspective, in disease situations, care helps the healing process, making it faster and less traumatic. Even in silence, it is interactive and promotes growth. In any situation, care involves a sympathetic presence and helps in difficult times, being a significant experience for all of those involved, caring about them, understanding their own needs, respecting limitations and stimulating potentialities.⁷

It should also be noted that, under chronic conditions, these dimensions become more present, since care should include, particularly, the learning process of taking care of oneself with safety and in a continuous and prolonged manner. This learning process must take place in a slow, gradual and careful manner, aiming to stimulate people's autonomy, with the nurses taking co-responsibility for such process.⁸

The adaptation of people with ostomies happens through the adjustment of life in a new context, in which important factors such as their way of life, social interactions and diet have to be frequently abandoned, substituted or reduced.⁹ Therefore, it is an individual process that develops over time and includes a series of aspects that go from the offered care to how people involve themselves in their own care.

This research was conducted with the aim of studying the experiences of people with ostomies, in relation to their care. It is considered necessary for nurses to know and value these types of care, with the aim of knowing its possible benefits, having the capacity to act in a humanized manner in the situation.

With that in mind, it is asked: how does care take place in the daily lives of people with ostomies in a small municipality in the countryside of the state of Rio Grande do Sul (RS)? Aiming to answer that question, the objective was to study the care that permeates the daily experiences of people with ostomies in this Brazilian municipality.

METHOD

This is a descriptive study with a qualitative approach, since it is considered adequate for the researched problem because it deals with the universe of meanings, reasons, beliefs and values from the analysis of reality from different angles to capture the experiences of people or the experience of a given phenomenon.¹⁰

The study was conducted in a municipality in the mid-western part of Rio Grande do Sul, having as subjects six people with ostomies registered at the Municipal Program for Ostomies of the mentioned city. The chosen inclusion criteria were the presence of permanent intestinal ostomy and being over the age of 18; and the exclusion criterion was: lack of clarity and orientation to answer the questions and participate in the study.

The users' addresses were recorded in the registration files at a previous contact with the nurse responsible for the program. All registered users were visited in order to be invited to participate in the program. Of the 11 registered individuals, three met the exclusion criteria, one passed away during the data gathering period and one did not accept to participate, resulting in six subjects for the research.

A semi-structured interview was used to gather data in order to categorize information in levels and depths that were adequate for the study's objective. The interviews were conducted in the subjects' homes because they are appropriate environments to understand the life practices of the subjects, since they are the social context in which these practices take place.¹¹

The collected data were submitted to thematic content analysis, which consists of understanding the themes that emerge from the subjects' reports.¹⁰ This process was organized in three phases: pre-analysis, exploration of the material, treatment of results, inference and interpretation.¹⁰ Pre-analysis consisted of the systematization of the first ideas, when there was the transcription of the interviews, representing the initial contact with the data. In sequence, a thorough reading was conducted in order to obtain a more direct relation with the reports. Afterwards, the corpus was built, which enabled the organization of the empirical material in a way that made it possible to reach a general outlook of the collected data.

The material exploration phase consisted of the transformation of raw data, which were classified through cutting, numbering and gathering. Thus, through codification the found phenomena were named, each line of the testimonials was read and analyzed. The cores were underlined and copied from the data. After comparison they were grouped by similarities and differences, forming the cores of meaning, which emerged from the reports of the subjects regarding the theme at hand.

In attention to Resolution 196/96,¹² which standardizes research with humans, the subjects signed a Free and Informed Consent Term. In addition, as a way to ensure the subjects' privacy and anonymity, their names were substituted by the letter S, as in subject, followed by a number referring to the order of the interview. Special attention is drawn to the fact that this research was developed only after being approved by the Research Ethics Committee of the Federal University of Santa Maria (UFSM), with the n. 23081.017044/2011-82, and CAAE n°. 0361.0.243.000-11.

RESULTS AND DISCUSSION

The subjects of this research were six people with definitive intestinal ostomy, aged between 51 and 75, being five women, of which four were widowed and one was married; and one married man. They had between one and nine children. Two of the subjects lived in the rural area of the municipality and the other four lived in the urban area. As for the people who lived in their homes, one lived with her 11-year-old daughter; another one, with her daughter-in-law and granddaughter; one with her husband and a 12-year-old daughter; another one, with her only daughter; one lived alone; and the interviewed male subject lived, at the time, with his wife. Regarding occupation, they declared themselves to be: a housewife (3), a business owner (1), an agriculturist (1), and a cattle breeder and a business owner (1). All of them claimed to keep performing their daily activities at home or at their workplace.

The reasons that made them undergo surgery to build the ostomy were intestine cancer (4) and Chagas disease (2). Regarding the length of time with the ostomy, they were at four months, one year, three years, seven years, 11 years and 18 years.

When asked about their religion, all of them were Catholics, however, they attended other churches, had their own faith and their individual beliefs independently from religion. Incomes varied from 1.5 to 6 national minimum wages, depending on their occupation. All of them had their own household.

From the thematic analysis, the categories presented below emerged as thematic units: "I am really well treated, everyone helps"; "My life is a little different"; and "It is necessary to go on, stopping is out of question".

Thematic Unit I: "I am really well treated, everyone helps"

The subjects mentioned that care has a far-reaching meaning, from the simplest actions, words, forms of help given to them, to concepts of specific care, which are requirements because of the chronic condition, as they put it in their reports.

[...] when I go out [of the farm], my neighbor takes care of the house for me and I take care of hers when she goes out, because we are fellows and friends and we help ourselves to take care of each other's houses, she is good to me and I am good to her and her daughters. Because of that, we go out at peace (S1).

Back home, it is the woman that always changes the pouch and, here in the city, the daughters do it, up until I gather the energy to change it by myself. They have been changing it for me since forever. But I'll try to change it by myself (S5).

[...] one of my children is always around. They never leave me alone. Wherever I go, they are with me. They are my protectors, they take care of me. I think they are afraid I might leave them (S2).

From the reports, it can be noticed how care is present in most actions, practices and experiences that are part of their daily lives. Considering that, in the presence or absence of a disease and in the daily living of human beings, humane care is also crucial, both as a way of life and as a way to relate.⁴

Going through the reports, it became clear that they made relations among this care and the forms of help, support and companionship, in addition to feelings, such as affection, esteem and love that other people dedicated to them, both family, friends and people with whom they live. It is noted that these care actions resulted in relationships of trust and loyalty, making them feel safer and more protected.

The report of S5 calls attention to the fact that she is willing to self-care, which must be stimulated by family members and professionals involved in this context. Other authors have mentioned that some ostomized people, who were autonomous before surgery, went on to have dependent actions, transferring self-care actions to their family members, with women (daughters and wives) being the informal caregiver.¹³

In this context, considering the chronic condition, professionals and family have the role of educating for self-care, fulfilling individual needs, respecting limitations and awakening self-care for their own autonomy.¹⁴⁻¹⁶

Everyone really takes care of me [...]. When I needed blood during surgery, there was none, then everyone rallied to donate. My sister-in-law, my son, everyone went to another city, where I was, to help me. People were sensitive toward us, they move and really help. They traveled and donated blood for me (S1).

In all services I go to, I am well received. Their doors are always open for me, they know me and it seems like everyone wants to help me, you know, in any city I go, here and everywhere I needed to be I have always been well cared by everybody from the health teams. I learn with them and they learn with me [laughter] (S3).

The mobilization of family members and friends in relation to the need for blood transfusion had a significant impact on the informant's life, because when she was questioned about examples of care in her experiences, she reported this fact with satisfaction. Family members are the most prominent people in the subjects' reports as a source of support, strength and care. The family plays a crucial role in the patient's recovery process, in the acceptance of their condition, creating mechanisms of union and strength among its members, and showing feelings of faith, hope and positive attitudes.¹⁵

Another subject felt comfortable at the health services, claiming that, regardless of the municipality where she looked for help, she was well received and felt supported and protected with this type of professional care, when referring to the health teams. In the report, special attention is called for how important it is for the health team to be well prepared to receive the ostomized person in any situation, with empathy, good communication, making this service resolute and complete.

The human being builds his or her social relations by being concerned and worried with people and things to the point of recognizing him or herself as a being in the world and with others and, with that, dedicating themselves to and introducing care in everything that has importance and value for them.¹⁶ It is important to highlight the fact that, in order to provide care, the nurse needs to build relations that establish closeness among the subjects and that result in mutual interactive processes, where dialog and contact are appreciated, always based on ethics and respect for the condition of the being as subject of rights, desires and knowledge.

The participants also mentioned the care that is dedicated to the pouch, which has specific needs, with which they learned to live through the contribution of people with whom they are related and of health professionals.

The girl takes care of me, she cleans the pouch for me during the day and my daughter-in-law does it at night [...]. I prefer that they do it, because I can't see very well and if it is not well fixed, it leaks. I am afraid of that (S2).

I have lived with the pouch for many years. [...] sometimes I clean it, other times my daughter does it and changes it, checks me up, takes care of my skin, applies these lotions, because I only change them. She is more careful with my skin and it seems like there is less smell when she does it (S6).

I am the one who always cleans it, since the beginning, in my way [...]. I use disposable pouches, which make my life easier, because I only have to remove them. [...] of course I learned it from the health people, I went there to learn [...] (S3).

It was hard in the beginning, my daughter helped me with everything because I didn't know [...]. One day, I decided to take care of myself, I could not depend on her forever. I cleaned it, changed it alone. [...] today it is so natural (S4).

It can be concluded that there is concern and a special care toward the pouch. Some subjects emphasized the existence of people who helped them with this process and others made it clear that they performed this care by themselves, with determination and assuredness. Those who had less time with the ostomy had more difficulties to handle it, in opposition to those who had a significant time with the ostomy and who reported being familiar with this care. They showed attention as to placing and fixing the pouch in order to avoid any leakage, unpleasant odors and cared for the peristomal skin.

A study shows that the biggest difficulties that people with intestinal ostomies face refer to the care dedicated to the collection device, including placing it and adapting, as well as fear for its lack.¹⁷

Special attention is called to the importance of the people with ostomy developing skills for self-care, because it generates independence and less exposure, which increase self-esteem.¹⁸ Therefore, they need constant monitoring and motivation to better adapt to the situation, promoting effective self-care.¹⁷

The presence of God in the lives of all subjects is mentioned in the reports. They say they are being taken care of by divine protection and by the feeling of faith that they had. It was an important part of their forms of support, of care, giving them strength and hope in moments of hardship, as can be perceived from the following reports.

I have faith, I am always saying that if it wasn't for God I would not be here. And the saints that help us. I always had a saint's image at home, it was given to me and I take it to the mass and the priest blesses it for me (S1).

I thank God every day for my life, because at moments I thought I would die, but today I have a lot of faith in God, even though before I was not very religious (S5).

The subjects mentioned God in this moment as the one responsible for giving them life again, in these situations, because the disease that caused the ostomy was cancer. Therefore, they believed that the ostomization surgery gave them another opportunity to live, now free of tumors. The search for spirituality/religion is very common, even among those who "were not very religious". Confidence in the divine, in prayer and oaths makes these people feel more at ease, with faith, hope for the future, giving sense to their lives.¹³

Faith is an important tool to ease the pain of the human being. The search for divine help and faith makes the individual move toward resources for dealing with their daily struggle.¹⁹

I believe in God and I have him in my own way [...]. I think there is only one God and He is the one who will always take care of me (S3).

What I do believe in is God [...]. I am a firm believer in God, that God helped me a lot through this. [...] even the doctor told me, after I recovered, that God was with him during the surgery (S2).

It can be noticed that each one has his or her religious faith, his or her belief. Religious faith, along with science, can help the patient trust the team and can give them hope regarding the treatment of the disease and overcoming fears and anguishes. The security of being able to trust in God comes from the fact that they may have overcome hardships in the past. Certainly, this type of feeling is important for people who live with diseases that may lead to death at any time.¹⁵

Therefore, attention to religious and spiritual aspects becomes even more necessary in the practice of health care. The importance and greatness of religiosity in the human being's dimension becomes increasingly clear.¹⁹

Thematic Unit II: "My life is a little different"

Here, there is an emphasis on the changes in the way of life of people with ostomy, which emerged from the interviews. The subjects claimed

they had changes in their lives related to their way of life, of living with other people, of taking care of themselves and receiving care from others. In conclusion, in their entire daily lives from the moment they began living with the ostomy.

[...] yes, my life changed a little, it is more difficult now, I don't like going out of the house too much [...]. I didn't use to go out a lot, now with the pouch [...] I almost never go out. I only go to where I feel good, where people already know me (S2).

Of course it changed my life a lot, but I got used to it over time [...], I can say I came back to normal activities, however, with more care because if I didn't carry on normally, I think I'd get even sicker (S1).

The first report makes it clear that the user did not feel comfortable leaving the house because of shame and insecurity in relation to the pouch. People who undergo this type of intervention face changes in their daily lives, which happen not only due to physiological issues, but also emotional and social ones.³ A research shows that users who undergo an ostomy surgery went through many concerns, from learning how to handle their ostomies to self-esteem and body image conflicts. They frequently perceive the ostomy as invasive and disfiguring.²⁰

They end up with these fears related, in most cases, to loss of fecal control and gas elimination, leading to social isolation. Some people with ostomy reveal that it changed their way of life, especially bringing difficulties related to work, leisure, social interaction and family life, sexuality and diet, and feelings of shame and insecurity in face of their new condition.⁹

The second deponent reported that she changed her habits and routines, but that over time there was adaptation, with normal activities being resumed eventually. Most interviewees mention this difficulty in the beginning, probably related to the acceptance of the use of the pouch and especially the adaptation to it. The building of the ostomy causes problems in the initial phase, because they face both physical and psychological problems, which are a consequence of the need to include changes in their daily lives.²¹

The process of adaptation happens with the adjustment of an entire life, in a new individual context that develops over time and includes a series of aspects that go from the offered care, the quality of the devices that are employed, to the way a person engages in his or her own care. The devices available in the market go through an evolution. They lessen these anguishes, improving the

social living of ostomized patients, making them more confident to perform their daily activities.¹⁷

Regarding changes in their way of life, an aspect that was emphasized by the people participating in the research was eating habits:

after learning everything about it, I completely changed my diet. I eat very little, in small portions, and only food that does not cause gas nor bloating [...]. I don't starve myself, but I frequently have anemia issues (S3).

when I am preparing a meal near people who are not close, like, who are not from my home, I avoid eating almost everything. I fear what might happen afterwards, passing gas or blowing up the pouch [...] sometimes I come back hungry (S5).

The new eating habits are acquired when searching for well-being, not eating or avoiding the intake of foods because of the enormous attributes conferred to them, such as gas, liquid feces, among others. Feeding is an important factor to be taken into account by ostomized patients, since some foods produce gas and unpleasant odors in the feces, reinforcing apprehension among them.¹⁷

Cabbage, kale, beans, I can't even think about eating them [...]. I removed them from my diet myself (S3).

This statement takes us back to common knowledge, where the person uses his or her own knowledge in addition to a search for their own well-being, and decides what the best methods of care are. In this case, this can be harmful for other aspects of their health.

The popular conceptions and practices related to diet can cause benefits and harms to health, according to type, occasion and frequency with which foods are used. In addition to that, psychosomatic manifestations of non-acceptance of foods are numerous, which may cause diet errors and symbolisms. The practice of diet selection based on popular beliefs may cause a nutritional imbalance, leading to the abnormal function of the human body.²²

Therefore, it is essential for the nurse and the health team to understand the changes that happen in the lives of people with ostomy, as well as reports of living through this whole process, clearing doubts and minimizing fears, creating comprehensive and quality care.

Thematic Unit III: "It is necessary to go on, stopping is out of question"

In this category, the interviewees brought forward the ways they lived through the adapta-

tion to the ostomy. The adaptation process is what leads to acceptance and a harmonic living with the new situation.

[...] today I have a normal life [...] coming and going, between highs and lows, because I went through many surgeries, hospitalizations, but I took them very well, trying to go on as usual [...] because I strive to feel well. [...] it is like there is nothing else (S3).

Almost nothing has changed. [...] I adapt myself little by little [...]; What I can do, I do. That's because it's very recent (S2).

Bah! In the beginning I felt very bad, I felt enraged, scared, I didn't know what to do, [...] but today I'm another person, I started noticing that life is beautiful, that I had my children to raise. [...] I learned a lot, I overcame a lot and I live normally (S1).

[...] I want to do everything outside, like if everything is the same [...], but then I remember that I can't strain so much, because I had always been active, I did everything outside [...], but I live very quietly, inside my limits (S5).

As observed, they tried to live normally with the ostomy. Some still with specific care, others adapting, but they all showed they were reaching to overcome this situation every day. These people's experiences are in constant transformation as time goes by.

In the beginning, they cannot elaborate their feelings or reactions regarding this reality. As time goes by, depending on the evolution of their diseases and the possibilities of adaptation that are found, they develop coping strategies with which they deal with the problems or daily changes that happened because of the ostomy. Therefore, the person needs some personal time to think and adapt to this condition, which may take days, weeks or months.⁷

Some ostomized people revealed that they had already overcome the losses when they mentioned some adaptation, probably because of the time since they underwent surgery, because of social support, evolution of the disease and type of coping strategies. It is important to remain hopeful, to give oneself time to adjust to the new conditions, with support from family members and cohabitants.¹³

In this context, special attention should be given to how the informants saw their daily activities.

I do all my house chores, [...] I take care of my pets, of my vegetable garden, [...] I go dancing, I love it,

[...] I get involved and I don't think about stupid stuff. I take my life very easily (S1).

[...] I love to see my house clean, I clean it, I function a lot outside [...] I have chickens, pigs, I feed them, I put the chickens inside their coop and I even take care of my mother-in-law, who lives close by (S4).

I am always involved with something. I take courses, I visit my neighbors, go to the market, downtown, everything normally, [...] that's because it's been many years with the pouch (S6).

It is possible to perceive that they tried to get involved with their activities in an optimistic way, looking for a normal life. They claimed that, with that fact, they could live well. The presence of a strengthened social support network can be noticed in the reports. It is fundamental for the overcoming of feelings of loss and, simultaneously, for gaining a better perspective for their lives.

This new situation asks for some adaptation in the daily lives of people with ostomies, with the time and social support factors being fundamental for coping with and accepting the ostomy. In addition to that, despite the limitations, the person can perform their activities and keep social interactions.²³ In a bibliographic analysis, it became clear that the main social support networks for people with ostomies were related to family, associations and groups of people with ostomies, in addition to health professionals, among them the nurses.²⁴

Thus, it is necessary for nurses to know and value the social support network for taking care of people with ostomy, helping to improve quality of life and enabling them to cope with this situation, having a complete picture of the person with ostomy and his or her social context.²⁴ In addition, the presence of the nurse represents support and security for ostomized patients.²⁵ Only three reports in a study with 20 subjects indicate the perception of the nurses' action, a low number, even though qualitative research does not focus on numerical expression. This situation can be a strong point of reflection, even for new research, regarding the role of nurses in the rehabilitation process of ostomized patients.²⁵

It is worth noting that, in addition to seeking involvement with some activities in their lives, the research subjects made it clear that they had dreams, aspirations, motivations to carry on.

[...] I can't stay put just thinking, because that makes us think about too much stupid stuff, and really get sick. What I can do, I do. I get involved with

everything and everybody. The more people around, the better I feel (S2).

[...] I think it is my self-esteem, my strength of will [...] I accepted everything, with support from my children and husband, who was alive at the time [...]. I didn't bow down to anything [...]. For me, it was a problem that I would carry for my whole life, like, very normal. It would be worse to lose a leg (S3).

Look, you have to go on, stopping is out of question, you have to carry on. Of course, with care, now [...]. Trying to get involved with everything, doing what you can and in the middle of people, friends, neighbors, family members (S5).

They make it clear that they had strength of will to face the challenges of their day-to-day life and this considered that they had overcome their stigmas in relation to the ostomy. It is observed that, by their excitement during the reports, they really believed that this involvement in their activities and self-esteem are fundamental, thus contributing for their support as healthy human beings.

[...] that's what keeps us going. You have to have dreams, you have to dream, to go after stuff, having chores, helping people, paying attention to other things. That's when you live well and forget you have problems, which is not actually a problem, some things are much worse (S3).

[...] I am young. Now I can see that life is so beautiful, [...] I take the bus, I travel, I go to dances, I love dancing! I live a normal life [...]. I want to fix my house, expand some parts (S1).

The presence of dreams, of the search for something better, of aspirations in the lives of people with ostomy show that it is possible to live in a healthy and normal way with a colostomy, all it takes is believing and overcoming the acceptance and denial phase, which usually happens soon after surgery. People with ostomy have the possibility of living a normal life, in an environment with friends, of enjoying the pleasures in life, and discrimination can be overcome over time.²³

Therefore, care for patients with ostomy demands reflection from professionals regarding the rehabilitation aspects, becoming a true challenge, because knowing the needs of the users is essential, since they are many and change continuously. It is necessary to give more attention to people with ostomy, looking, in their universe, to know them and understand them through their feelings, giving them the change to be sensibly heard.²⁶

Therefore, it is important to understand the meaning of care, the changes in the way of life

of people with ostomy and how they face these changes, with special attention to the fact that this process of becoming closer to the world of the subjects creates a link between the nurse and the user, improving the quality of the care that is offered to them.

FINAL CONSIDERATIONS

The development of this study made it possible to understand that care is present in the daily lives of people with ostomy, from the simplest actions directed at them to the most specific actions related to living with the chronic condition. Presented in this process of care are the support and dedication of the people involved in their relationships, such as family and friends, as well as divine support, the belief in God expressed as protection.

The changes in their ways of life are clear, related to their social living, to how they take care of themselves and to eating habits. However, after some time it can be seen that most subjects learned to live with these changes, seeking to come back to their normal daily activities and getting involved in daily chores.

They also made it clear that they had dreams and goals for the future. They believed that they could not stop and surrender to the disease, because by "going on" they felt involved, inserted in a normal life context, ensuring an important improvement for their quality of life.

Therefore, it was noted, through research, that it is crucial to understand the forms of care that permeate the daily living of people with ostomy, as well as the changes that happen in their lives and how they handle these situations. It is believed that this knowledge brings the nurse closer to the reality in which these people live, creating a necessary link for comprehensive, quality and resolute care.

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