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RESILIENCE IN FAMILIES OF PEOPLE WITH CANCER COLOSTOMY: A LOOK FROM THE BELIEF SYSTEM

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ABSTRACT

The objective was to identify the facilitating and restrictive beliefs of resilience in families of people with cancer colostomy. This is a descriptive study, with a qualitative approach, carried out with seven families, totaling 15 people. Data collection took place at a hospital in the interior of Rio Grande do Sul/Brazil, through an open interview. The data were submitted to thematic content analysis. The results show that resilience-facilitating beliefs relate to believing that people, even the sick ones, do their best to move forward and that they can count on the family. Restrictive beliefs arise from the fact that they feel weak and think that they cannot count on the family. When experiencing the illness of a member, the family acts from what they believe, in order to give meaning to the lived experience and gather forces to follow the walk.

Keywords: Family. Ostomy. Neoplasms. Psychological Resilience. Nursing.

INTRODUCTION

Cancer is one of the major causes of mortality and morbidity worldwide, affecting, among other organs, the large intestine, being colon and rectum one of the most incident neoplasms in the country(1). The indicated treatment is a deviation surgery from the intestinal tract to an opening in the abdominal wall, called colostomy(2).

Chronic diseases, such as cancer, require changes in family dynamics and a longer adjustment period when compared to acute-onset diseases. In this context, some families are better prepared to deal with change, exchange clearly defined roles with flexibility, solve problems efficiently, and use external resources(3).

The ability to deal with adversity and resist the disruptive challenges of life, reborn from them, can be defined as resilience. The term "resilience" relates to physics and corresponds to the property by which the energy stored in a deformed body is returned when the tension causing an elastic deformation ceases. In a figurative sense, it would be a "shock resistance"(4).

However, being resilient does not mean staying immune to experience through painful experience, but rather gaining strength from that experience. Therefore, resilience is forged by adversity, not despite it(5). The lens of resilience shifts the perspective of looking at families in distress and in trouble, seeing them as challenged to ratify their potential for repair and growth(5:59).

Thus, it is important to consider the uniqueness of families and their forms of expression against adverse conditions, since the whole family operation focuses on the belief system, considered powerful forces to resilience(5). Beliefs are "the lens through which we view the world we live in, and they influence what we see or what we do not see and what we do to our perceptions"(5:62).

Belief systems widely include values, beliefs, attitudes, trends and assumptions that blend to form a set of basic assumptions that trigger

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emotional reactions, inform decisions and guide actions. Beliefs can be either facilitative or restrictive. Facilitating beliefs increase the options for solving problems, for healing and growth, while restrictive beliefs perpetuate the problems and restrict options(6).

A study of beliefs and resilience in survivors of leukemia has identified that, among the beliefs that facilitate resilience, there are optimism, the will to overcome, hope, family forces, faith and trust in health professionals, while restrictive beliefs are linked to the idea of invulnerability to illness, to the feeling of being threatened by the stigma of illness, low self-esteem and family crises(7).

For nursing, the application of the concept of resilience creates possibilities for reflection, as well as an increase in ways of seeing and doing care(8). For this, it is important to clarify that resilience is not an innate gift; people and families can learn, promote and develop it(5). The understanding and apprehension of its meaning and promoting factors in specific contexts of illness become essential for nursing, since professionals can guide their actions, reinforcing the beliefs that facilitate resilience and contributing to the re-signification of the restrictive beliefs(7-8).

Given the exposed, the study aims to identify the facilitating and restrictive beliefs of resilience in families of people with cancer colostomy.

METHODOLOGY

The study consisted of descriptive research, with qualitative approach, in which seven families of cancer-ostomized people (15 people - seven with colostomy and eight relatives) participated in the oncological follow-up at the University Hospital of Santa Maria, Rio Grande do Sul/Brazil.

The inclusion criteria were the participation of, at least, two people from the family, one being the patient; being 18 years old or more; being without pain or other discomforts and with verbal communication and comprehension skills. The exclusion criteria were being a patient without the company of a relative and not having colostomy of neoplastic origin. For the anonymity of the participants, the F1 code was used to identify Family 1, and so on, to F7; and the letter E, to identify the Interviewee (entrevistado, in Portuguse), followed by the number of interviewees in the family.

The data collection used an open interview, recorded and later transcribed. The analysis followed the recommendations of content analysis(9) and based on the Family Belief System(5). The data collection was closed when the questions were answered and the objectives, reached.

Respecting the ethical aspects, the research obtained the approval of the Research Ethics Committee, according to Certificate of Presentation for Ethical Assessment (CAAE) No. 00528112.7.0000.5346. All participants signed the Informed Consent Form.

RESULTS AND DISCUSSION

The study participants with colostomy (seven) were aged between 63 and 75 years, were retired and from Santa Maria/RS/Brazil. There were five women, three married, three widowed and one separated; six had incomplete Elementary School. The time of diagnosis of cancer varied between two months and four years, and the time of colostomy, between two months and three years, being most of temporary character. Regarding the relatives (eight), they were all married, aged between 27 and 76 years, coming from urban area. There were five women, there were three patient's spouses and five children, four had Elementary School.

The analysis of the content of the participants' statements enabled to group the results into two themes related to the facilitator beliefs and the restrictive beliefs of resilience and their respective categories, described below.

Theme 1. Perspectives that strengthen resilience-facilitating beliefs

Theme 1 refers to aspects consistent with the facilitating beliefs presented by families regarding the colostomy. In that context, **believing they are doing what is possible** refers to the belief of the family in relation to the referrals made by them and the professionals to the resolution of the requirements arising from cancer illness.

> The important thing is that she did what she had to do for her health, and the rest, we get by, doing whatever is possible. (F4 E3)

> The important is to be fine, it would be worse if undergoing the colostomy did not work out. (F5 E2)

The family believes that the proposed treatment was what made possible to preserve the health and considers that the colostomy is the reason for the patient to be alive. The family becomes more resilient when valuing decisions and giving positive meaning to what they are living. In this sense, a study found that people who underwent colostomy considered the procedure as an alternative to stay alive. Despite the changes and adversities of the condition, they were thankful that they were alive and perceived the colostomy as the possibility of overcoming the disease(10).

Therefore, believing there **is always someone else who is in a worse condition** is a way of thinking that strengthens the family belief in their capacity to move on, because it refers to the was the families see themselves in the face of the illness.

> He got sad, but there are so many people who are in a worse condition, who get better and live the rest of their life they have to live. (F1 E2)

> If you get to see at the hospital, and we see out there, there are people who are much worse, with much more difficulties than he is. Lacking one leg, I think it is too difficult! (F7 E2)

The family seems to seek to understand and give meaning to their experience, seeking resources that help them overcome adversity, seeing beyond themselves. The perception of their situation as less painful than that of other people has important significance because it strengthens them in some way and helps them maintaining hope and confidence, enabling resilience. It can be called "positive illusion" and acts as a buffer against extreme stress, promoting strong mental health(5).

In the trajectory experienced because of the illness, families can find strength by seeing the example of others, which relates to the ability to perceive the world around them.

> There is an old lady we know who has used a little bag for 31 years. She goes to parties, weddings, mass, everything. Her mother feels ashamed. Even at home, with us. (F3 E2)

> I have a sister who has a cancer problem and she has been in treatment for 18 years and is living. She has already undergone five surgeries. (F5 E1)

People who have gone through similar situations and become referrals may be from their own family, friends or acquaintances. The way those people dealt with and faced their illnesses, or still face it, influences the family's way of thinking about their own condition. If the observed reality is positive, consequently the influence will also be positive, strengthening and encouraging the family to believe in their capacity and possibility of success, inspiring them(5).

In the search for a sense for the sickness and trying to find the strength to deal with adversity, the belief **that there is a greater force**, evidenced in the faith and in the spirituality of the family, constitutes a resource that promotes resilience.

> We cannot surrender! I believe in God and, one day, we will get there. Getting there is what matters. (F1 E1)

> We have faith in the Almighty and we think it has worked out because we managed to get here. (F4 E2)

The faith and religiosity manifested by patients and family members, as the force that helps them to continue the struggle and overcome the challenges, corroborate what the literature describes, in which transcendence and spirituality promote comfort, help to give meaning to experience and guide in moments of adversity(5), strengthening them to face difficulties with confidence and hope for the future.

A study of cancer patients has identified manifestations of spirituality-related beliefs in expressions that faith moves mountains and offers strength, help and support when one can no longer advance(11). In this perspective, beliefs that transcend the limits of experience and knowledge offer comfort in situations of distress and, in the circumstances of facing the disease, in which people perceive threat to their life, religiosity guides them to live, and that external force helps to channel internal forces so they can react to physical disorder(5).

Thus, once the families give meaning to the experience, accepting that the colostomy is **now part of it**, it is evident the willingness to accept that characteristic as part of the family, their routine and their life.

> Now I am changing it more times, because it gets dirty, and I do not like it. I learnt it. I am the one who cleans and changes it. I got used. It is part now. (F3 E1)
>
> It kept going on and on, and now (she/he) is used to it, it seems it is not there. (She/he) got used to it. (F5 E2)

The family, when understanding the changes that have occurred and assigning meaning, starts to see the colostomy as something that is part of the family context. That perspective enables to normalize and contextualize adversity, generating a sense of coherence that redefines the situation as a controllable, resolvable challenge(5). Normalization helps to deal with the situation and to accept it, making families stronger and more cohesive, helping to identify strategies that allow controlling what is possible and gradually adapting to new demands, reorganizing and carrying out the required care.

> Yes, in the beginning, it was hard. Until she got used to it, she tore everything apart. Not now, everything is fine. (F3 E2)
>
> I am the one who cleans, washes everything, takes care of it. Only when I have to change it, she does it for me. It cannot stay for many days because the silicone starts to rot, and it starts to itch and scratch. It seems an infection. Then she comes and changes it for me. (F5 E1)

Family members are not always able to control the results of events, but they can make choices in order to actively participate in the process and outcomes, and, thereby, feel encouraged to discover aspects to which they can contribute. It causes the family to direct efforts to what is possible(5).

In this perspective, the family can also be strengthened by the certainty of **having someone to count on**, which strengthens the family's beliefs about the family themselves, friendships and support network. During sickness, a time marked by difficulties and confrontations, participants report believing that their strength comes from the family because they can count on the help and support of their families.

> What has been helping me? It is the family! Family is everything. When we want to fall, the wife do not let us. (F1 E1)
>
> I sought strength, but I cried around the corners, alone so that no one could see it. I sought strength in my wife, and then the things moved on, trying to find strength to move on. (F2 E2)

The interviewees consider the time of sickness as difficult to live. Thus, they believe that the family is supportive, encourages them to move on and allows overcoming difficulties. When they realize that they can count on family members, they feel empowered and able to cope with illness and treatment. However, that support extends to people with whom the family maintains affective bonds and solidarity.

> Actually, we talk a lot about the family, but you cannot choose your family and, sometimes, people who do not have the same bloodline are the ones who are more willing to help you. So, we have some relatives who are always available, willing to help you, but we also have other good relationships with friends, who, over the years, are more available than your own family. (F2 E2)

Although prior experiences intensify the belief that a new process may be similar to the previous one(12), the encouragement and support offered by family members and friends provides a safety condition for the patient and stimulates him/her to construct positive attitudes towards the patient in the illness process(13). Nevertheless, they are fundamental for coping with adverse situations, for rehabilitation after colostomy and for returning to daily life activities(14). A study reinforced that perception when identifying as important for ostomized people, among other aspects, the support and dedication of people involved in their relationships, such as family, friends and neighbors(15). When they provide care, it results in relationships of trust and fidelity(15), making people feel more secure and protected, which can contribute to resilience.

In addition to the presence of friends, the family’s beliefs that they have someone to count on is strengthened, also because they are counting on a support network. When receiving help from institutions, the family has the possibility to reorganize some of their demands, directing their resources to other needs.

> The mother is receiving some things from

> AAPECAN [Support Association for People with Cancer], which is helping us too. Because, every day, there is a medication, a diaper, a thing or another, and we started to spend and had no one to count on. Now we are getting almost everything we need from AAPECAN. (F2 E2)

The guidelines received in the pre- and postoperative period and the certainty of being able to count on the care, guidelines, answers to doubts and courtesy of health professionals are aspects that give concrete possibility of support for the family.

> I underwent chemotherapy and radiotherapy. I had to wait for a long time because the radio machine was broken. However, the service was great, both in here as in there, it gives us strength. (F3 E1)

> The physicians and the nurses we had were great, they gave us hope. The girls who treated him, I do not even know what to say. They were great to us. (F7 E2)

When receiving the attention they need and when being well attended, both the patient as the family have their belief that they have someone to count on strengthened, their hopes are renewed, they feel stronger, protected, and supported. The relationship of trust established between professionals and patients is fundamental to promote resilience, and the information provided by health professionals, in the same way as it may represent a difficulty, in the case of omission, can represent an important support(14).

The work of health professionals, especially nursing professionals, includes information that facilitate the adaptation of the family unit to the new life condition, encourage self-care and are the link between family members and the person with colostomy, in order to facilitate rehabilitation(16).

In the context of the family belief system, the perspective adopted by families regarding life events, which reveal an optimistic attitude in interpreting reality and seeking conditions to overcome adversity, is a force that drives walking, gives confidence, strengthens hope and fosters resilience.

Theme 2. Aspects that reinforce resilience-restrictive beliefs

Theme 2 refers to aspects related to the resilience-restrictive beliefs presented by families regarding the colostomy, but which involve the illness as a whole. In this context, the feelings manifested by the participants reveal elements that strengthen restrictive beliefs and weaken the family to deal with illness and colostomy.

Thus, the belief of **not being able to count on the family** comes from the movements undertaken by relatives during the period of illness. The lack of collaboration for the demands of care and the lack of support for the difficulties and complexity of cancer and colostomy management, identified in the detachment and non-commitment by some family members, added to the difficulty of communication and the exacerbation of problems of intra-family relationship, reinforce the perception of not being able to count on the family.

> My sisters came to the hospital once. They only think about the inheritance. They did not help to take care of our father; they are not helping to take care of our mother. One sister called only once to our mother three months ago. She never came to visit our mother. We cannot count on them. (F3 E2)

The unwillingness to cooperate in care and lack of communication increase animosity among family members, favoring negative feelings of mistrust and anger on the part of those who are engaged in the caring process. Moreover, discomfort, insecurity, fear and guilt may be present. That context of disunity increases the family's stress and likelihood of disorganization, weakening them as a whole.

Trust, empathy and respect are essential for open communication, mutual understanding and problem solving(5). Therefore, when not feeling confident to speak, people tend to postpone decisions, isolate themselves and suffer alone.

> In the beginning, I had a blood disorder, but I kept moving on. Then my husband fell ill, he suffered a stroke. He got bad and deceased. Then, I waited for 30 days. I did not tell anyone. I did not want to disturb. Then living blood started to come out. I forced myself to go to the doctor. I was a little weak, white, pale. (F3 E1)

> If she had come before, when the first bleedings started, maybe she would not have to put the little bag. If she had warned...the mother never told

> anything for anyone, not even the deceased father knew about it. (F3 E2)

The reluctance to share fears and concerns can denounce the difficulty of communication in the family, but also the members' desire for protection, which, regardless of motivation, extend the problem. Chronic illness is characterized as a great mobilizer of energies and family resources, especially when they are responsible for the necessary care, generating varied affectations, which need to be elaborated according to the possible conditions of each entity, family and of each situation lived by them(17).

When going through the suffering, the pain and the stress of illness, family members may feel distressed and have difficulty to accept and cope with the disease. When not knowing how to deal with the disease, the colostomy, other relatives and their own feelings, some may move away from family life as a resource to overcome the encountered obstacles, reinforcing, with attitudes of that nature, the belief that it is not possible to count on the family. That perception can be considered as restrictive of resilience, since it makes that the family do not visualize sources of support and does not find a meaning for the experience of illness.

The feeling of loneliness, present throughout the process of illness by the distancing of the family, explains the vulnerability and the helplessness of who is responsible for the person who is sick.

> There was a moment when I got tired, because I was a little lonely. That way, pretty alone. The an old lady saw me, an old lady I had never seen, but who was going through the same problem as my mother, and started to talk to me, and told me that a single swallow does not make summer, that I needed to ask for help. (F2 E2)

During illness, the family experiences a difficult period of pain, suffering and uncertainty about the future and what needs to be done. When seeing themselves alone, without having someone to share the anguish, the family may feel weakened, lacking sufficient strength to move on, which may interfere with the ability to mobilize resources and overcome adversity. That context of instability can be temporary, until the family recognizes they need help and mobilizes to share concerns, feelings and tasks.

The family is the main care provider, but there is a great demand in the occurrence of chronic situation. In this context, it is important to recognize that the family takes care of the their strategies; however, in situations of vulnerability, those potentials are depleted, as long as such situations prolong and/or impact considerably on their concrete possibilities of caring for(17).

Not being able to perform the care refers to the difficulties often faced by the family when not being able to perform the specific care of colostomy.

> For a time, they kept coming to my house to make the changes, because no one knew how to do it, it always kept leaking. (F1 E1)

> After the surgery, she stayed a time with me, because she could not handle the bag. They taught how to put it, clean it, and she was even learning, but then there was the surgery, with the stitches and everything else, which hindered it a little. (F6 E2)

> I change it sometimes, because now, with the special bag thing, I have been doing it at the outpatient care. If it is the simple one, I can do it myself, I do it correctly. (F2 E1)

During hospitalization, the family receives guidelines on bowel stoma surgery and how to use the device. However, the development of home care may seem complicated and frustrate the initiative of family members, generating feelings of incompetence, especially when the family member does not have help.

The exchange and cleaning of the colostomy bag are tasks initially shared among the family members. In order to overcome the difficulties related to the procedure and the possible complications, the family searches for the means they think are necessary to solve their doubts. Thus, the individual and the family need to develop some abilities and potentialities that confer autonomy and independence in the care process, showing that they are capable of doing something for themselves(18).

Regarding the collecting bag, a study identified that ostomized people mentioned that the managing the bag requires specific care, with which they learned to live with the contribution of the people of their relationships and health professionals(15).

The ostomization has repercussions in the process of people's living and the difficulties, in some way, can result in damages to the ostomized person and his/her family. Research evidenced that the preoccupations in acquiring the materials for self-care frightened the families by the possibility of being without the essential devices to maintain the quality of life of the ostomized member, being the absence the cause of stress and commitment of the living. In this way, the frequent search for material made the respondents of the mentioned research become dependent on the health service(18).

The context of intra-family relationships, the difficulties to develop care for the sick person and the colostomy, and the limitation of options and sources of help and material resources can put the family in the face of factors that restrict their ability to face difficulties, feelings of hopelessness and pessimism that reinforce resilience-restrictive beliefs.

FINAL CONSIDERATIONS

The study allowed identifying that, in the experience of families who had a family member with cancer and colostomized, the perspective adopted before the event strengthens the beliefs that facilitate resilience, because it develops an optimistic context that strengthens and mobilizes to seek alternatives and overcome difficulties, accepting the situation. Among the aspects that can reinforce the restrictive beliefs of resilience, there are the negative feelings and animosity among family members that promote disunion, separation and difficulty to solve problems. The feelings of impotence, frailty, and helplessness limit family initiatives and, if persisted for a long time, reduce the possibility of positive responses and expectations of overcoming challenges. The beliefs can be individual or common to the family unit.

The resilience-facilitating beliefs, which predominate in the families participating in the study, enable finding the means to make the family feel more secure and confident in the face of adversities. They renew the internal forces of the family and, thereby, favor the acceptance of the new condition, making cancer and colostomy events with which the family can cope.

During the illness process, the family goes through different moments in which restrictive and facilitating beliefs coexist and alternate within the same family. It means that the resilient promoters or restraints are provisional and circumscribed to the environment and the context of the experience. For nursing, knowledge of family beliefs regarding the specific context of cancer illness and colostomy allows, when identifying resilience facilitators, strengthening the family's potentialities and capacities and, in the face of possible restrictive beliefs, adopting strategies that contribute to re-signify them and regain confidence.

The results of this study, considering the limits of the analysis that is restricted to the family belief system as promoters or restrictors of resilience, point to the need for investigations that consider other factors that may influence that context. On the other hand, they show that the identification of family beliefs can contribute to quality care, since that knowledge can bring the nursing professional closer to the reality of families, generating collaborative bonds and helping them find coherence and hope in the face of the complexity they are living.

RESILIÊNCIA EM FAMÍLIAS DE PESSOAS PORTADORAS DE COLOSTOMIA POR CÂNCER: UM OLHAR A PARTIR DO SISTEMA DE CRENÇAS

RESUMO

O objetivo foi identificar as crenças facilitadoras e as restritivas da resiliência em famílias de pessoas portadoras de colostomia por câncer. Trata-se de estudo descritivo, de abordagem qualitativa, realizado com sete famílias, totalizando 15 pessoas. A coleta de dados ocorreu em um hospital do interior do Rio Grande do Sul/Brasil, por meio de entrevista aberta. Os dados foram submetidos à análise de conteúdo temática. Os resultados revelam que as crenças facilitadoras da resiliência relacionam-se a acreditar que as pessoas, mesmo doentes, fazem o possível para seguir em frente e que elas podem contar com a família. As crenças restritivas decorrem do fato de sentirem-se enfraquecidas e pensarem que não podem contar com a família. Ao passar pela experiência de adoecimento de um membro, a família age a partir daquilo em que acredita, para, assim, dar sentido à experiência vivenciada e reunir forças para seguir a caminhada.

Palavras-chave: Família. Ostomia. Neoplasias. Resiliência Psicológica. Enfermagem.

RESILIENCIA EN FAMILIAS DE PERSONAS PORTADORAS DE COLOSTOMÍA POR CÁNCER: UNA VISIÓN A PARTIR DEL SISTEMA DE CREENCIAS

RESUMEN

El objetivo fue identificar las creencias facilitadoras y las restrictivas de la resiliencia en familias de personas portadoras de colostomía por cáncer. Se trata de un estudio descriptivo, de abordaje cualitativo, realizado con siete familias, totalizando 15 personas. La recolección de datos ocurrió en un hospital del interior de Rio Grande do Sul/Brasil, por medio de entrevista abierta. Los datos fueron sometidos al análisis de contenido temático. Los resultados revelan que las creencias facilitadoras de la resiliencia se relacionan a creer que las personas, aunque enfermas, hacen lo posible para seguir adelante y que ellas pueden contar con la familia. Las creencias restrictivas se deben al hecho se sienten debilitadas y piensan que no pueden contar con la familia. Al pasar por la experiencia de enfermedad de un miembro, la familia actúa a partir de aquello que cree, para, así, dar sentido a la experiencia vivida y reunir fuerzas para seguir el camino.

Palabras clave: Familia. Estoma. Neoplasias. Resiliencia Psicológica. Enfermería.

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