



ORIGINAL ARTICLE

SOCIAL NETWORK IN CARE FOR THE PERSON OSTOMIZED DUE TO COLORRECTAL CANCER

REDE SOCIAL NO CUIDADO À PESSOA ESTOMIZADA POR CÂNCER COLORRECTAL
RED SOCIAL EN CUIDADO A LA PERSONA ESTOMIZADA POR CÁNCER COLORRECTAL

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ABSTRACT

Objective: to understand the influence of the social network on the care of people with colorectal cancer and to describe the type of support that the social network offers for these people. **Method:** This is a qualitative, descriptive study, with 11 people with colorectal cancer. The data were collected through a semi-structured interview, subjecting them to the technique of content analysis. The theoretical-methodological framework of Sanicola's social network was used. **Results:** it is observed that the primary social network was composed mainly of children, siblings, spouses and friends, who offered emotional support, material and care. The secondary social network, made up of professionals from outpatient clinics and hospitals, provided reception, guidance and material support. It reveals the fragility of primary health care units to meet the demands of care. **Conclusion:** it was demonstrated that the social network exerts a strong influence on the care of the person with ostomy and the importance of the support of the professionals of all levels of attention to health in the promotion of integral assistance, resolute and aiming at self-care supported. **Descriptors:** Social Networking; Social Support; Colorectal Neoplasms; Ostomy; Professional-Family Relations; Nursing.

RESUMO

Objetivo: compreender a influência da rede social no cuidado de pessoas com estomia por câncer colorretal e descrever o tipo de apoio que a rede social oferece para essas pessoas. **Método:** trata-se de estudo qualitativo, descritivo, com 11 pessoas com câncer colorretal. Coletaram-se os dados por meio de entrevista semiestruturada, submetendo-os a técnica de Análise de Conteúdo. Utilizou-se o referencial teórico-metodológico de rede social de Sanicola. **Resultados:** observa-se que a rede social primária foi composta principalmente por filhos, irmãos, cônjuges e amigos, que ofereceram apoio emocional, material e cuidados. A rede social secundária, composta pelos profissionais de ambulatórios e hospitais, proporcionou acolhimento, orientações e suporte material. Revela-se a fragilidade das unidades de atenção primária à saúde para atender as demandas de cuidado. **Conclusão:** demonstrou-se que a rede social exerce forte influência no cuidado à pessoa com estomia e ressalta-se a importância do apoio dos profissionais de todos os níveis de atenção à saúde na promoção de uma assistência integral, resolutiva e visando o autocuidado apoiado. **Descritores:** Rede Social; Apoio Social; Neoplasia Colorretais; Estomia; Relações Profissional-Família; Enfermagem.

RESUMEN

Objetivo: comprender la influencia de la red social en el cuidado de personas con estomia por cáncer colorrectal y describir el tipo de apoyo que la red social ofrece para esas personas. **Método:** se trata de un estudio cualitativo, descriptivo, con 11 personas con cáncer colorrectal. Se recolectaron los datos por medio de entrevista semiestructurada, sometiéndolos a la técnica de análisis de contenido. Se utilizó el referencial teórico-metodológico de red social de Sanicola. **Resultados:** se observa que la red social primaria fue compuesta principalmente por hijos, hermanos, cónyuges y amigos, que ofrecieron apoyo emocional, material y cuidados. La red social secundaria, compuesta por los profesionales de ambulatorios y hospitales, proporcionó acogida, orientaciones y soporte material. Se revela la fragilidad de las unidades de atención primaria a la salud para atender las demandas de cuidado. **Conclusión:** se demuestra que la red social ejerce una fuerte influencia en el cuidado a la persona con estomia y se resalta la importancia del apoyo de los profesionales de todos los niveles de atención a la salud en la promoción de una asistencia integral, resolutiva y visando el autocuidado apoyado. **Descriptor:** Red Social; Apoyo Social; Neoplasias Colorrectales; Estomía; Relaciones Profesional-Familia; Enfermería.

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INTRODUCTION

It is estimated that in Brazil the occurrence of colorectal cancer in 2018 was 36,360 new cases, 17,380 of which were men and 18,980 among women, representing the third most common malignant neoplasm among men and second type among women.¹

It is explained that the modality of the therapy of this type of cancer will depend on the type of tumor, dissemination of the disease and clinical condition of the patient, however, the surgical treatment will always be present as a curative or palliative form and in this case the need for an opening in the abdomen for the exteriorization of a small portion of the intestine to the outlet of the fecal effluent, which is called the stoma or ostomy.²⁻³

It is known that the stomies resulting from colorectal cancer can have a great impact on a person's life, such as concern about quality of life in the face of biopsychosocial changes and situations of embarrassment and vulnerability.^{4,5} It is believed that the network and social support play a relevant role in coping with the difficulties arising from chronic diseases and in the success of treatment.⁶⁻⁸

The term social network is understood as a set of interpersonal relations that determine the characteristics of the person, such as: habits, customs, beliefs, values; being that of this network the person can receive support of the emotional, material and informative type or can receive negative influences, since not always the presence of several members of the social network in the life of a person results in positive emotional and/or behavioral effects.⁹

Social network is classified into two main categories: primary network and secondary network. Primary network is characterized by the relationship between family members, friends, neighbors or colleagues, and the secondary network by the relation that the person establishes with members of the public institutions of health care, education, social assistance or other.⁹

It is observed that in the area of oncology the biomedical and epidemiological aspects related to the different types of neoplasias reflect in the advance of the knowledge on the subject.^{1,10-11} It is observed, however, in the national and international scientific literature that there is still a gap in the production of research aimed at understanding the social network of people with colorectal cancer.^{4-7,12-13}

It is believed that this investigation amplifies the understanding of the determinants and social determinants involved in the daily life of the person with the ostomy^{2,13} and attends one of the priority areas of health research in Brazil,

regarding the evaluation of social support networks and life dynamics of people with chronic diseases.¹⁴

OBJECTIVE

- Understanding the influence of the social network of people with colorectal cancer and describing the type of support that the social network offers for these people.

METHOD

It is a qualitative descriptive study, based on the theoretical-methodological framework of Sanicola's social network,⁹ which made possible the identification of the social network, as well as the understanding of the type of support offered by this network.

11 people with oesophageal cancer were interviewed, who met the following inclusion criteria: being over 18 years of age, diagnosed with colorectal cancer, and having undergone surgery that made the elimination intestinal ostomy less than a year ago. People who had cognitive problems and did not have the conditions to participate in the interview were excluded from the study.

The data was collected through a semi-structured interview, recorded in the second semester of 2014, in a reserved room of a Service of Care to the Ostomized Person in Rio de Janeiro, Brazil.

An interview script composed of sociodemographic questions and the following guiding questions was used: - Tell me about the people who are present in your life at this stage of your life (relatives, neighbors, friends, colleagues, people associations, institutions or place of work); "At some point did you need help or did you have a hard time taking care of the ointment?" Who did you tell? - What kind of support do you get from members of this social network?

Participants were asked to assist in drawing up a design that would be representative of the people and institutions present in their social context, as well as the type of link established in this network, following the methodological framework of Sanicola.⁹

Interviews were terminated in the 11th participant, when repetitions of ideas emerged and saturation of the findings that generated the categories about the meanings of social relations and the type of support received by members of the social network were reached.

It was attempted to transcribe in full the testimonies obtained in the interviews and the data were analyzed according to the technique of content analysis that is based on operations of dismemberment of text in units, that is, in discovering the different nuclei of meaning that constitute the communication, and then to

regroup them into classes or categories.¹⁵ Two categories emerged: Daily family support and (In) Availability of professionals from health institutions.

The ethical precepts of Resolution 466/12 were respected with regard to research involving human beings. The research project was approved by the Ethics and Research Committee of the Anna Nery School of Nursing and the São Francisco de Assis School Hospital, under the number 491,991 / 2013. Consent was requested for participation in the research, as well as the permission to record the interviews, through the Informed Consent Form. Anonymity of the participants and their speeches were guaranteed by identifying them with the letter "E" followed by an Arabic number corresponding to the order of the interview.

RESULTS

It was observed that among the participants six were male and five female, the age range ranged from 60 to 73 years, the average being 58.3 years. It is stated as to the marital status that nine participants were married or lived in a stable union. It was noticed the level of schooling that seven had until elementary school, three completed high school and one completed higher education, and as for the occupation, six participants had some kind of paid work.

It was revealed that the primary social network was composed of children, siblings, spouses and friends, these being pointed out as the most present people and who offered support during the treatment of colorectal cancer and care with the stompy. It was found that the secondary social network was composed mainly of professionals from health institutions of medium and high complexity in Oncology.

The statements about the relation of the participants with the members of the primary network were analyzed, emerging the following category:

- **Daily family support**

It is presented in this category that the participants received the support of their relatives when they had access to the health service for the diagnosis of colorectal cancer, during the hospital stay for the surgery and the preparation of the ostomy and later in their homes. It is pointed out that the type of support offered was focused on emotional, material support and daily care, as can be seen in the following statements:

[...] *joined everyone to expedite my examination, because my physical condition was very critical. The woman here, modesty part is well loved [...].* (E3)

[...] *M. (cousin) always asks if I'm in need of anything if I'm in need of money. She gives me many things. [...].* (E7)

[...] *every day, he (husband) does something in the blender for me [...].* (E4)

It is observed that in the same way that the participants had family support, they also mentioned the presence of their friends from the moment of diagnosis to the period after discharge from the hospital, who offered them emotional and financial support, as expressed in the speeches:

[...] *I was thrilled when, at first, I spoke with my friend L .. I got there and I said that I had rectal cancer and we cried together [...].* (E8)

[...] *my colleagues from the Barracks gave me support, even financial [...].* (E10)

It is evident that the relations of friendship with the people of the Church also provided spiritual support through manifestations of words of consolation, prayers and strength through faith:

[...] *the greatest support I have had is the friends of the Church who are going to my house, visiting me, consoling and praying for me [...].* (E9)

It reveals itself in the analysis of the statements about the meaning of the relation of the participants with the members of the secondary network to the following category:

- (In) **Availability of professionals from health institutions**

In the second category, the participants were able to count on the professionals' support in the hospital environment, which was referred to as the caring, attentive and helpful manner with which they were treated by: receptionists, security, and concierge, cleaning staff; doctors, nurses and other staff members.

[...] *the receptionist, is very good, very friendly, helpful, everyone there is helpful. The security at the door is very good, it helps us and treats us very well. [...]. I was treated very well by everyone from the janitor to the director and all the nurses. [...]. I had that strong bond because I spent a lot there with them [...].* (E10)

[...] *They showered me with respect, apologizing. [...] This has a value for me that you can not imagine. Because you see the professionalism in those people. Respect, affection, the way people talk to you. This makes us eternally grateful. [...].* (E11)

It is evident that in the institutions called Service of Care to the Ostomized Person, the support offered by the professionals was centered in the humanized reception, orientation on the treatment; care with the stompy and in the material support through the reception of the collecting equipment.

[...] *when you have a rectal cancer, finding someone who gives you that support, that support, is very important. [...] I left the Pole (Care to the Ostomized Person) delighted. ... not only for the human service there they gave me the material, they explained everything to*

me, how I should do it, what care I should have [...]. (E8)

It is revealed in this same category that, contrary to the way in which the study participants felt welcomed and accompanied by the health services of the secondary and tertiary levels, in the relationship with the professionals of the Primary Health Care network, they did not receive the support or support needed for the care of the ostomy:

[...]I went there (at the Health Post) at the time, for them to look at the ostomy. No one was capable. It is a specific case that should be treated more carefully, right? But they neither look, nor give importance, nor appear. We ask receptionist 'nurse like I wanted to deal with such a subject', they do not even appear to pay attention. [...] Sometimes I go there to ask for materials to clean, they say they can not give. Do not even look to say 'then I do. They treat me coldly. It seems that it is one more that has passed by [...] these things are revolting the people. (E2)

Thus, in this category, in the relationship with primary health care professionals, especially nurses, participants reported not having found the availability of these professionals and demonstrated their fear that they did not have adequate technical knowledge to perform the care with the ostomy.

DISCUSSION

It was verified that the person who lives with a colostomy bag due to the treatment of colorectal cancer belongs to a relational context and seeks the support of its primary and secondary social network, to cope with the situations resulting from illness and help in the face of the need to adapt to their new living conditions.

Among the components of the primary social network were children, siblings, spouses and friends; being these fundamental in the emotional support, material and in the daily tasks.

The findings of this research are corroborated by studies that point to the family as the main source of support when one of their members falls ill, especially when it is a chronic disease and needs chronic daily care.^{4,6,8-9,16-17} The same phenomenon can be seen in the research on the social network of the family that had one of its members submitted to the preparation of the stom- omy, which revealed the strong support of family members during difficult times during hospitalization and home care.^{2,7,12}

It is important to note that the relevance of the centrality of family support is evidenced both in the national and international scientific literature, where studies show that the greater the social support received by the family, the better the adjustment of the person in relation to the coexistence with cancer and posterior care of the

ostomy^{5,7,12-13}. It is identified in a study conducted in Poland that people with colostomy who had higher quality of life received greater social support from the family and the types of support received were: emotional, material and information.⁶

It is revealed in an investigation about the relationship between social support, social isolation, adaptation to the ostomy and satisfaction with life performed with adults in the United States and the United Kingdom, that people with greater social interaction with their relatives presented a higher level of support emotional state and greater level of adaptation to ostomy care. The opposite was observed among people living in social isolation who had low levels of life satisfaction and emotional support, indicating the negative effect of theostomy on their lives.¹¹

It is highlighted, in this study, that the presence of friends also meant companionship to confront fears and anxieties, as well as financial support and help to experience spirituality.

It is noticed that the person with chronic illness needs to share their living and experiences, and the presence of friends constitutes an empathic environment, which favors the reduction of the anxiety of the person with the ostomy, through the manifestations of affection, understanding and solidarity.^{4,12,18} In the presence of friends, a facilitator is available so that the person with a ostomy can gradually achieve security in order to return to their social activities and continue the goals of their life.

The socioeconomic situation is one of the emerging concerns in the participants' lives, when they were in the postoperative period, away from their work activities. It is considered in this case that the financial support received can be a significant support for the adjustment to this new condition of life, due to the increase in expenses with medicines, supplies for the care of the ostomy, among others.¹⁹

It is emphasized that besides the opportunity to receive from the friends the emotional and material support^{2,6-8,12, 17-19} counting as spiritual support is another fundamental aspect for people living with a cancer or an oedematum, because they can find in spirituality relief for suffering and assistance to face the adversities of everyday life, through the comfort of words of faith and hope.^{7,20}

It corroborates with these findings research on the social network of support for men with prostate cancer that showed belief in God as an important factor for overcoming the negative feelings arising from illness and for cancer survival.⁷

It was verified that the professionals of the network of attention of the secondary and / or tertiary level, independent of the professional

function or category, offered to the participants: attention, welcome, affection, respect, orientations and materials for the care with the stommy, which can contribute to ease the fear, anxiety and clarify the doubts related to self-care.^{5,11,13,17}

Nevertheless, it was emphasized that the same was not identified in the contact with the professionals of the primary health care network, because in the perception of the participants, the professionals of this level of attention, especially the nurses, were not present in the life of these people who live with the problem of cancer and in this way did not perceive the support or support with regard to the necessary care.

It is revealed that not always the social network components can meet the total care needs of the person with chronic disease, which compromises the integrality of attention. Thus, the fragility of the primary health care units to meet the care demands of cancer patients, characterized by the lack of emotional, instrumental, informational and material support,^{6,16,18} and the lack of articulation among the different levels of the network.²¹

It is known that knowledge of the profile and social network of the population with oncological disease residing in the territory of the basic units allows the nurse to perform actions aimed at the rehabilitation, adaptation and improvement of the quality of life of this population group.^{20,22-23}

Nurses' lack of knowledge about the care provided to the users of cancer and management of the stomies reflects the need for permanent education actions aimed at qualifying the entire primary care team, in order to acquire competencies to enable effective interventions and ensure the coordination of the care provided to cancer patients and their relatives.^{22,24-25}

It is worth mentioning the fragility of the relationship of the participants of this study with the professionals of the primary care network, which is similar to other investigations, regarding the difficulties of the teams of basic health units in the monitoring of people with chronic diseases in partnership with professionals of medium and high complexity services, establishing the effective practice of reference and counter-reference.²¹⁻²² There is a negative impact on the quality of comprehensive care provided to people with cancer, which often requires continuous care of the various components of health services.

It is a problem of network governance, the lack of articulation among the different levels of health care, since primary health care should be the care provider, by welcoming the users' needs, guaranteeing access to services, strengthening of social networks, as well as of intersectoral relations.^{24,26}

It was verified in an investigation carried out in the United Kingdom that the articulation between

the nurses of the diverse levels of attention to the health guarantees the continuity of the care and integrality of the health care of the person with ostomy.¹¹

It is considered fundamental that the nurse of the primary health care level be articulated to the other professionals of the cancer care network and in their care practice consider the psychosocial, emotional and spiritual needs of the individuals, in addition, from the knowledge of the social context of the person with colorectal cancer, this professional may influence the person's self-esteem, confidence and safety during their rehabilitation,^{4,6,10,12,17,20,24} as well as in the adjustment of everyday life to issues arising from chronic disease.^{22,25-26}

The restricted number of participants is limited to this study, which may not guarantee the generalization of the results for all people with colorectal cancer who live with an estomy. However, it is possible to understand the influence of the social network of support, whether primary or secondary, involved in the daily care actions and the care provided to the stomized persons at the different levels of the health care network.

CONCLUSION

It is understood that the members of its primary and secondary social network exerts a strong influence in the care to people with estomia due to colorectal cancer.

Family members, especially their children, siblings and spouses, are presented as essential for the follow-up of the participants during the search for health services and during the period in which they were in their homes. It is evident that these members offered emotional support, material and daily care, which influenced the self-esteem and coping with adverse situations.

It was found that the support of friends characterized by presence, affection, concern, financial assistance, word of comfort and faith, contributed to the relief and spiritual well-being of people with stomies, generating strength and tranquility in daily living.

It was found that the relationship with professionals in secondary and tertiary health care services was marked by reception, orientation and material support, while the relationship with professionals from basic health units was weak due to a lack of linkage, preparation and availability of these professionals for the follow-up of cancer treatment and care of the ostomy.

It is understood that, despite advances in the expansion of the Family Health Strategy teams, access and integrality of care to people with oncological diseases is a challenge for professionals working at this level of primary health care. It was verified in this context the need of the health team, especially the nurses, to

participate in training courses on the management of patients with colorectal cancer who live with the stomies and thus be part of the social support network of these people.

It is concluded that the knowledge of the social network of people with colorectal cancer constitutes an important subsidy for professionals of all levels of attention to promote comprehensive, articulated, resolute care and self-care supported.

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