RESEARCH

PERCEPTION OF ONCOGERIATRIC PATIENTS ON FAMILY FUNCTIONALITY

PERCEPÇÃO DE PACIENTES ONCOGERIÁTRICOS SOBRE A FUNCIONALIDADE FAMILIAR PERCEPCIÓN DE PACIENTES ONCOGERIÁTRICOS SOBRE LA FUNCIONALIDAD FAMILIAR

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ABSTRACT

The objective of this study was to learn how oncogeriatric patients perceive family functionality. It is a descriptive-exploratory study, of a qualitative nature, developed with 21 elderly people. Data were collected from October to December 2016 using the APGAR Family Scale and semi-structured interviews performed at an oncology outpatient clinic. The interviews were transcribed in full and submitted to content analysis in the thematic modality. The results show that the majority of the elderly perceive a good family functionality, even referring the disease has promoted approximation between the members. Some elderly, however, feel dissatisfied with the time shared with the family, with the need to receive care and with the authoritative behavior of some relatives regarding the treatment. Health professionals should recognize and value the family relationships of oncogeriatric patients, since these directly affect the proposed therapeutics and coping with the disease.

Keywords: Family; Nursing; Neoplasms; Geriatrics.

RESUMO

O objetivo do estudo foi apreender como o paciente oncogeriátrico percebe a funcionalidade familiar. Trata-se de um estudo descritivo-exploratório, de natureza qualitativa, desenvolvido com 21 idosos. Os dados foram coletados no período de outubro a dezembro de 2016, mediante aplicação da Escala APGAR de família e entrevistas semiestruturadas realizadas no ambulatório de Oncologia. As entrevistas foram transcritas na íntegra e submetidas à análise de conteúdo, modalidade temática. Os resultados mostram que a maioria dos idosos percebe boa funcionalidade familiar, inclusive refere que a doença promoveu a aproximação entre os membros. Alguns idosos, no entanto, sentem-se insatisfeitos com o tempo partilhado em família, com a necessidade de receber cuidados e com o comportamento impositivo de alguns familiares em relação ao tratamento. Considera-se importante que os profissionais de saúde reconheçam e valorizem as relações familiares dos pacientes oncogeriátricos, já que estas comprometem diretamente a terapêutica proposta e o enfrentamento da doença.

Palavras-chave: Família; Enfermagem; Neoplasias; Geriatria.

RESUMEN

El objetivo del presente estudio fue descubrir cómo el paciente oncogeriátrico percibe la funcionalidad familiar. Se trata de un estudio descriptivo, exploratorio, de naturaleza cualitativa llevado a cabo con 21 adultos mayores. Los datos fueron recogidos de octubre a diciembre de 2016, utilizando la Escala de Apgar familiar y entrevistas semiestructuradas realizadas en la consulta de oncología. Las entrevistas fueron transcritas en su totalidad y sometidas al análisis de contenido, modalidad temática. Los resultados muestran que la mayoría de los adultos mayores percibe buena funcionalidad familiar, incluso que la enfermedad promovió la aproximación entre ellos. Algunos, sin embargo, se sienten insatisfechos con el tiempo compartido en familia, con la necesidad de recibir atención y con el comportamiento autoritario de algunos familiares en cuanto al tratamiento. Es importantes que los profesionales de la salud reconozcan y valoren las relaciones familiares de los pacientes oncogeriátricos porque tales relaciones influyen directamente en el tratamiento propuesto y en el combate de la enfermedad.

Palabras clave: Familia; Enfermería; Neoplasias; Geriatría.

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INTRODUCTION

The worldwide increase in life expectancy is an important phenomenon for public health.¹ In 2012, the elderly population in Brazil corresponded to 11.5% of the general population and it is estimated that by 2025 Brazil will already be the sixth country in the world in the number of elderly people.^{1,2}

Aging is an inherent process of life and involves changes in the biological, psychological and social aspects that reflect in morbidity and mortality, functional capacity and quality of life.³ In this context, there is the need to promote healthy behaviors throughout life in order to reduce, prevent and delay the onset of chronic noncommunicable diseases (CNCD), which are the main causes of death in Brazil.⁴

Cancer is an expanding CNCD that can reach anyone in different age groups, but its incidence increases after 60 years of age. In this sense, both cancer and aging are seen in a stigmatized manner, which brings the need for specific attention to the complexities combined.⁵

In Brazil, in 2011, the specific mortality rate due to neoplasms among the elderly population was 78.8%.⁶ In addition to high mortality, cancer affects the functionality of the population, the performance of daily activities and, consequently, the quality of life.⁷ In turn, aging associated with the impairment of functional capacity, often resulting from chronic diseases, affects the daily life of the whole family.⁸

The family is a complex social system made up of people who relate and are influenced by the social and cultural environment in which they live; it presents different behaviors due to their specific characteristics in their way of being and the need for adaptation.^{9,10}

Even though it is recognized as a primary source of support and care for the sick person, the family may not be prepared to take over the necessary care and may find difficulties in the face of stressors related to care for the elderly with cancer, compromising family functionality.^{9,11}

Family functionality is understood as the way in which its members harmonize the essential functions in an appropriate manner to the identity of its members and in agreement with the reality that prevails in the social environment. Thus, the classification of the family system into functional or dysfunctional is based on the way in which the relations and adaptations happen through the necessity of a family adjustment during, for example, the period of illness of one of its beings.¹²

From this perspective, the collection of information about the family functionality of the elderly with cancer enables the nursing team to know the seniors' satisfaction with regard to the care provided by the members of their family. The identification of dysfunctions allows the development of intervention strategies that enable the strengthening of family relationships that consequently reflects in the therapeutic response and the qual-

ity of care provided. Thus, the present study aims to know how the oncogeriatric patient perceives the familiar functionality.

METHOD

This is a descriptive and exploratory study, of a qualitative nature, carried out with 21 elderly people with cancer attended at an oncology outpatient clinic in the interior of São Paulo. Participants of the study were subjects of 60 years of age or older, of both sexes, with a confirmed diagnosis of oncological disease and who knew about this condition and had the capacity to answer the questions.

Data were collected from October to December 2016 in the institution's outpatient clinic through a semi-structured interview, which aims to collect sociodemographic information and on the family's functionality. To that end, an instrument was used to measure respondents' satisfaction about their family in relation to five basic components of family functioning, from the acronym APGAR: Adaptation (satisfaction with the attention received), partnership (satisfaction with family communication in problem-solving), growth (satisfaction with the freedom available in the family environment), affection (satisfaction with emotional interactions and intimacy in the family) and resolution (satisfaction with the time shared with the family).¹³

The answers are presented on a five-point Likert scale (0 = never, 1 = rarely, 2 = sometimes, 3 = almost always and 4 = always). A score of zero to eight indicates high family dysfunction; from nine to 12, moderate family dysfunction; and from 13 to 20, good family functionality.¹³

In order to know the elderly's perception about the functioning of the family before and after the onset of cancer and how they see themselves in the family scenario, the interviewee was asked to justify the answer given in each item of the family APGAR and, in the end, they should answer three other questions: Did you notice changes in your family relationships with the onset of cancer? Talk about it. Is there anything you would like to be different in your family relationships? How do you feel about needing care from your family members?

The interviews were transcribed in full and later submitted to content analysis, consisting of the phases of pre-analysis and data exploration, categorization of data in record units and treatment and interpretation of the results according to their similarities.¹⁴

The development of the study was in accordance with the guidelines of Resolution 466/2012 of the National Health Council. It was approved by the Standing Committee on Ethics in Research with Human Beings of the State University of Maringá (opinion no. 1,808,932). All participants signed the Free and Informed Consent Form in two copies and were identified by the letter P for patient, followed by the interview number,

letter M, referring to male, and F to female, and finally the age. Ex: P1, M, 71 years old.

RESULTS

The 21 subjects under study were in the age range from 60 to 80 and were distributed almost equally between the sexes; 17 of them declared themselves Catholics, 11 were married and they referred themselves as of brown skin color.

Regarding schooling, 13 had incomplete elementary education. In relation to the occupation, 16 were retired, with a family income of one to three minimum wages and 10 declared that two people are dependent on their monthly income. In face of financial need, more than half (13) sought the children for help, followed by loans in banking institutions (seven). Although on the day of the interview eight of them were accompanied by their spouse, when asked about who they could count on to help with their care, 10 of them mentioned the children, seven the spouse, one a brother, one a niece and one a neighbor.

Prostate cancer (six) and breast cancer (six) were the most prevalent among participants, with a prevalence of time since diagnosis of less than six months and the most commonly used treatment was chemotherapy. When asked about other health problems, the most cited were hypertension, arthrosis and diabetes.

Through the score obtained with the APGAR scale, most (19) of the patients presented good family functionality and the other two, moderate family dysfunction.

From the data analysis the following categories emerged: a) family functionality perceived after illness; and b) feelings about the need for family care, which will be described below.

FAMILY MEMBERS BECAME CLOSER AND HAVE SHOWED MORE CONCERN

The majority of respondents revealed to be satisfied with the family support related to the APGAR components of family, adaptation and partnership:

I can always count on my family. Today I came here with my son, he brought me. The car made available by the city council was full and it was going to be too late, so he has a car and I asked him to take me here (P5, F, 74 years old).

[...] they kept supporting me, doing everything they could do for me, arranging things in a rush to do the treatments I need. My son-in-law who lives here with me accompanied everything. After the diagnosis of prostate cancer he arranged everything because I used to work, I

did not have time; I could not leave my work [...] He was a great support [...] (P8, M, 65 years old).

It was observed that even in situations where the elderly lives alone, habits and routines created by family members are able to favor satisfaction with the family relationship:

I live alone, but my children have meals at my house. They always stop to listen to me; they always support me [...] (P11, F, 64 years old).

[...] Every once in a while we meet. When we are not together, we call each other. I call and they talk: you take care, do not forget to take the medicine (P1, M, 71 years old).

However, one of the participants states that he is rarely satisfied with the support relationship offered by his sons:

My daughter is the one who helps me the most; the others I do not even say anything to them, because my sons, oh. They would only say: it is up to you, dad [laughs]. I am the one who makes the decision (P9, M, 68 years old).

In addition to family support, most interviewees highlight other sources of support:

I count on my family, but I also count on the prayer group. We are like a family formed in a prayer group that prays the rosary. I feel good with the group because everyone around me asks for strength [...] (P6, F, 67 years old).

I talk about my problems to my friends, because my daughter already has her problems [crying]. These friends of mine, we had lived together for seven years when we went to college in Bauru. We spent 40 years without seeing each other. And I never thought I would get so much help. The one who has a friend has a treasure (P20, F, 69 years old).

The time shared with their families after illness was also highlighted as a reason for satisfaction by the participants:

[...] every five o'clock in the morning my son goes to see me, and the other who is not working does everything [...] they are very nice (P14, F, 67 years old).

I go to their house, they come to mine. They invite me to have lunch at their house; I do not go because I do not want to [...]. They treat me well; they tell me not to be alone (P16, F, 68 years old).

However, dissatisfaction was also mentioned, although it was justified by the recognition of the many obligations of family members with social life, work and studies:

[...] I miss spending more time together. When they arrive all together, I'm telling you, it's a pleasure I have (P7, M, 78 years old).

[...] I miss my grandchildren, they have been absent these days [...] I have four grandchildren [...] I have one with ten years old, this one is still affectionate; he is in that phase of affection with the grandma. He hugs me and kisses me, but the other two [...] already have other places to go, to have fun (P18, F, 73 years old).

Regarding the desires of the patients, the family was satisfactorily referenced:

My children respect my wishes and encourage me. They even ask me to go for a walk, because I live alone. [...] (P3, M, 74 years old).

They tell me what is good for me to do, but I have never done it against my will; I have autonomy of my life, I always do what I want and they do not say anything to me. If I say, it goes (P8, M, 65 years old).

However, when the decision-making power is related to the treatment of cancer, some elderly people feel dissatisfied with the authoritative position of the family members:

[...] they [daughters] will not like it very much if I say I do not want to do treatment anymore (P13, M, 63 years old).

[...] no one interferes when I want to do something. Only in the treatment, I think they would even abandon me if I say I do not want to do it. Sometimes I stop and think: I'm going to quit everything, but I have never talked to them about it [...] (P21, F, 60 years old).

The elderly also stressed that the illness increased the concern of family members:

[...] After cancer it seems they [...] are afraid of losing the "old man". It's something crazy. They get more worried because when I go out they say "dad, be careful"; the grandchildren say "grandpa, take care" [...] And when I get home, my great-granddaughter comes up to meet me, "hey, are you okay?" (P1, M, 71 years old).

[...] they stay like this, very concerned [...] They became more worried. I have a daughter, the oldest daughter, she worries a lot, oh my god, all week long she's in my house. [...] (P5, F, 74 years old).

This concern has sometimes been identified from concrete care actions offered by family members:

[...] They have been visiting us more, this has changed. They have gone there more often, called more often. They have accompanied us more; every day they call to know about us. This issue of concern has changed. They have been more concerned. They see if I'm doing everything right, taking the right medicines, it has changed for a positive aspect (P10, M, 69 years old).

Oh, it has changed, changed a lot. I see they have been more affectionate to me. [...] It has changed our relationship a lot; I feel more loved (P11, F, 64 years old).

Besides the concern, they also pointed out a closer relationship among the family members after the illness:

I have noticed that my family members got closer. They already were close, but now they want to see me more. But not my daughters; they have always been the love of my life. My daughters have always been worried about me. But my son became more concerned; they did not even want me to work. [...] I am much loved, I love and I am loved [...] (P12, F, 63 years old).

[...] I noticed that it has had more union, more support from my family (P21, F, 60 years old).

THE NEED TO BE CARED FOR AROUSES POSITIVE AND/OR NEGATIVE FEELINGS

Most individuals manifested positive feelings with the need for care, as can be observed in the following statements:

[...]I feel good because sometimes I'm not even looking for help, then they [children] arrive and say "dad, do you need something?" [...]This does not bother me at all. Sometimes I do not even talk and they're already volunteering. My daughter came with me once here on radiotherapy [...] (P1, M, 71 years old).

[...] It does not bother me at all, because they [daughters] have never showed that I give trouble; they always

like it. Even when I'm at home, they call me all the time; they call me all week long [...] (P4, M, 80 years old).

These feelings are favored by the family relationship established throughout life:

[...] I feel good because my children themselves say "dad, do you want me to accompany you?" [...] Then I say: "You do not need to do it for now, I'm fine" [...]. They all work, but when I need, because I stayed here one day, when I did the surgery, they took turns. One stayed at night and the other during the day; they stayed controlling like this. They all came happy, both the sons and the daughters. The whole life it has been like this [...] (P7, M, 78 years old).

I feel good. When I did chemotherapy, he [husband] would come with me, help me go to the bathroom, hold the saline solution, help me go down and raise my shorts. My sister-in-law would prepare the lunch. This did not bother me. (P15, F, 68 years old).

However, some elderly people experience the process of illness and the need for care permeated by the feeling of discomfort caused to family members:

We get a little annoyed [...]. My son was trained to handle the bag (colostomy) and he does it normally. He says that's the way it is, that we have to be patient, but I keep thinking I'm giving trouble, you know? (P14, F, 67 years old).

[...] I feel sometimes cheerful, sometimes sad because we do not expect such a thing [...]. I feel sad because when we depend on others, it seems that we are bothering. My daughter has her concerns and I do not want to give trouble because I see that she suffers because of my problem [crying] (P21, F, 60 years old).

DISCUSSION

The predominance of the female sex corroborates the Brazilian patterns of greater female representation within the elderly population.² On the other hand, low schooling may be related to restricted access to education for individuals over 60 years old and to female predominance, since women, due to cultural patterns, used to be prevented from studying and had responsibility for domestic activities and childcare.^{2,15}

In the speeches of P5 and P8 one can observe the contentment of the interviewees with the family support, which facilitates the satisfaction of material and affective needs of the individual. A functional family has more flexibility to solve the

problems of the family group and is more apt to deal with situations of vulnerability, such as in case of illness.¹⁵ In addition, good family functionality favors the adoption of habits and routines capable of favoring satisfaction with the family relationship even in cases where the elderly lives alone, as can be observed in the speeches of P1 and P11.

However, sometimes the cultural pattern, in which there is the appointment of a main caregiver, who is most often represented by the wife or daughters of the elderly, may cause dissatisfaction with the support offered by male children,¹⁰ as recognized by P9. In addition, fragile family relationships compromise the support offered in face of chronic situations of one of its members. In this way, extra-family relationships become an important alternative or a complementary means of support, both for coping with the disease and for the re-significances necessary for the aging process.¹⁶

In this context, extra-family relationships can be considered as a strategy to improve the quality of life, especially for the elderly, both physically and psychologically. These support networks have the function of contributing to the well-being and encouraging self-care attitudes, which collaborate to monitor health and search for new possibilities in the case of chronic illness.¹⁷

For some elderly, as referenced by P7 and P18, the absence of family members causes solitude and isolation. Although most of them perceive the family as the main source for dealing with changes arising from illness, when the family does not offer support in the expected way there is the need to seek other sources that increase resilience to face obstacles in life and situations of suffering.¹⁸

Therefore, the nurse should to encourage the elderly, either they are ill or not, to establish new bonds, such as participation in living groups, so that this alternative can contribute to the stimulation of self-care and emotional strengthening, which will consequently increase the adaptive competence towards the aging process accompanied by the disease.⁹

Other aspects that contribute to the quality of life of the elderly include autonomy, independence and freedom of decision, which need to be stimulated and respected in family relationships. A study carried out with 665 elderly people attending two geriatric outpatient clinics in the city of São Paulo revealed that the majority of the elderly with cancer had high self-esteem, even in the condition of illness, which was related to the independence and feeling of usefulness they had.¹⁹

However, when the decision-making power is related to the performance or not of the treatment, some elderly people feel dissatisfied with the imposition of the family. Oncologic therapy causes physical and emotional changes in the individual, which may influence the decision to continue it. However, the family acts on developing the patient's conviction that, even in the face of side effects and complications,

treatment is a strong and powerful ally for curing cancer.²⁰ The choice of not continuing the treatment is associated by the family members to choosing the death, therefore, most of the time they do not respect the autonomy of the elderly in relation to this decision. The statements of P13 and P21 show that the decision to continue treatment is influenced by the desire of family members not to abandon care. It is important that health professionals can identify whether adherence to treatment is voluntary or imposition of family members, as this can cause much suffering for the patient.

When experiencing the process of illness, the family experiences numerous uncertainties. From the moment of diagnosis, relatives are at a time of extreme emotional fragility, especially when the disease is cancer, because it is linked to the idea of imminent risk of death. However, in some situations, experiencing the illness process strengthens and approximates the relationship between family members.²¹

As verified in the statements of P10 and P11 and reiterated in the literature, a care that does not mischaracterize the figure of the elderly as a member of the family and holder of autonomy makes them realize that the increase of the family concern in relation to their care is synonymous of affection and attention. In addition, it can be a factor of approximation between the familiar members. A study carried out in Pernambuco with 33 individuals with cancer reported that after the illness the individuals perceived more support, concern and presence of the family; the families presented a flexible behavior in complex situations, adapting to the new demands imposed by the disease and reorganizing to provide adequate help.²

In view of these findings, we can state that cancer is a disease stigmatized by fear and that good family functionality is perceived by the elderly in a positive way regarding the care received, provided that their autonomy and decision-making power are respected. In addition, the establishment of extrafamily relationships is an important source of social support and coping with the disease. Finally, the family approach contributed positively to the experience of this moment in the life of the elderly, allowing commitment to the proposed treatment and more involvement in coping with cancer.

The aging process accompanied by cancer leads to unavoidable changes in the condition of the elderly. In this context, the care provided by the family has the purpose of preserving the quality of life of the patient and adapting it to the possibilities of the environment where they live.²³ Faced with the need to receive care, the majority of individuals expressed positive feelings of affection and kindness.

However, there are situations in which the need for care generates in the elderly the fear of disturbing and overloading their family members, making them ashamed. In addition, the aging process itself can cause a reversal of roles and a restruc-

turing in the family environment, i.e., the elderly person who used to be the caregiver is now the person who needs help, which creates feelings of inferiority and low self-esteem.²⁴

Dependency, even partial, experienced by the elderly with cancer can cause feelings of annoyance, dissatisfaction, sadness and discomfort because they believe that their condition causes physical and emotional wear to the life of their caregivers. They feel uncomfortable when their family members need to manage devices, face economic difficulties and spend time with them due to treatment, as demonstrated in the statements of P14. P20. and P21.

Given this, the family must be prepared in relation to the necessary care activities to be developed in a daily basis until they feel safe to assume them. In addition, health professionals need to emphasize and stimulate the importance of engaging the oncogeriatric patient considering the specific possibilities of the different cases in this care process so that they do not experience the care provided in a negative way.²²

In this category we conclude that the changes resulting from illness affect the individual in his/her biopsychosocial aspects and have as consequence the need for care performed by the family members, either they are partial or total. Such care can be felt by the patient as a demonstration of affection or frustration and uselessness. These feelings will depend on the family dynamics in which the elderly is inserted and the preparation of the family to perform the care.

CONCLUSION

Knowledge of familiar functionality in the perception of the oncogeriatric patient allowed identifying some needs and desires to be explored by the nurse during the care process to the family and the patient.

Even though the majority of the elderly have evaluated the functionality of their family as "good", some are dissatisfied with the time shared with their relatives, being important to elaborate strategies to favor the quality of time spent between the patient and the family and to encourage the participation of the elderly in social groups, strengthening extra-family relations.

When referring to the patient's wishes, it is necessary to encourage family communication because when it comes to the possibility of not performing the treatment, the elderly person perceives that his/her autonomy is weakened. The patients of the present study, although experiencing conditions of chronicity, are mostly independent. However, when they need care from their family members, they report feeling uncomfortable. It is necessary, therefore, that health professionals work together with families, reinforcing the importance of preserving the elderly's autonomy and decision-making power as a factor to promote quality of life.

The nurse should advise the patient and the family on the changes related to the diagnosis of cancer so that the situation of dependence, although it is accentuated at the beginning of the treatment, starts to, over time, undergo adaptations that favor the confrontation of the new situation in a peaceful way for the patient and his/her family.

The present study may contribute to expand the understanding of the impact of cancer and the interference of this condition in the family context under the perception of the elderly. However, a limitation of this study was the time spent with each interviewee. We assume that if this time was longer, a relationship of trust would be established, allowing the verbalization of other feelings that may have been omitted by the patients.

Health professionals should recognize the family relationships of the patients followed in the service, since these relations affect the proposed therapy and the coping with the disease. From this point, they will be able to plan actions directed to each reality in order to insert the family in the provision care to the patient in a positive way, recognizing the established links and the support networks used and whether they are weakened or broken. The patient and the family should be prepared to deal with the changes and difficulties imposed by cancer and its treatment so as to contribute to quality care.

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