







Cancer survival expectations of patients admitted to inpatient clinical units

Expectativas sobre a sobrevivência ao câncer de pacientes internados em unidades de clínica

Expectativas sobre la supervivencia al cáncer de pacientes ingresados en unidades de hospitalización

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ABSTRACT

Objective: to analyze the expectations of hospital inpatients diagnosed with cancer as to the end of treatment and their surviving the disease. **Method:** in this qualitative, descriptive study of 32 inpatients at a university hospital, data were collected by semi-structured interview between April and June 2019 and treated by content analysis. **Results:** expectations for autonomy in performing daily activities predominated, i.e., for resuming social roles and changing habits after treatment. **Conclusions:** cancer survivors' expectations must be acknowledged in order to assist them towards taking the lead in decisions about their future life and treatment and to encourage autonomy in constructing their health process.

Descriptors: Nursing; Oncology; Neoplasms; Survival; Life Expectancy.

RESUMO

Objetivo: analisar as expectativas de pacientes internados devido ao diagnóstico de câncer sobre o término do tratamento e a sobrevivência à doença. **Método:** estudo qualitativo e descritivo realizado com 32 pacientes internados em um hospital universitário. A coleta de dados ocorreu entre abril e junho de 2019 por meio de entrevista semiestruturada e a técnica para tratamento dos dados foi a análise de conteúdo. **Resultados:** observou-se predomínio de expectativas sobre de autonomia para realizar atividades do cotidiano, relacionando à retomada dos papéis sociais e às mudanças de hábitos após o tratamento. **Conclusões:** é necessário reconhecer as expectativas do sobrevivente ao câncer para auxiliá-lo em direção ao protagonismo acerca de suas decisões sobre sua vida futura e tratamento, incentivando a autonomia na construção do seu processo de saúde.

Descritores: Enfermagem; Oncologia; Neoplasias; Sobrevivência; Expectativa de Vida.

RESUMEN

Objetivo: analizar las expectativas de los pacientes hospitalizados debido al diagnóstico de cáncer en cuanto al término del tratamiento y la supervivencia a la enfermedad. **Método:** estudio cualitativo y descriptivo realizado junto a 32 pacientes ingresados en un hospital universitario. La recolección de datos se realizó entre abril y junio de 2019 a través de entrevista semiestructurada y la técnica para el tratamiento de los datos fue el análisis de contenido. **Resultados:** Se observó que predominan expectativas sobre tener autonomía para realizar las actividades diarias, relacionado a la reanudación de los roles sociales y a los cambios de hábitos tras el tratamiento. **Conclusiones:** Es necesario reconocer las expectativas del superviviente al cáncer para asistirlo en el protagonismo sobre sus decisiones en cuanto a su vida futura y su tratamiento, incentivando la autonomía en la construcción de su proceso de salud.

Descriptores: Enfermería; Oncología; Neoplasias; Supervivencia; Expectativa de Vida.

INTRODUCTION

Currently, cancer is one of the main causes of mortality in the world, represented by a group of diseases in which there is disorderly cell growth, with an infiltration tendency to the adjacent tissues^{1,2}. Due to these characteristics, it has the stigma of an incurable disease, with the inevitable possibility of death, loss of physical independence, autonomy, vitality and even an increased risk for the occurrence of pain and mortality².

In 2018, more than 18 million new cancer cases were recorded, as well as more than 9.6 million deaths due to the disease. In Brazil, for each year of the 2020-2022 triennium, the National Cancer Institute (*Instituto Nacional de Câncer*, INCA) estimated an incidence of 625,000 new cancer cases, with the exception of non-melanoma skin cancer. The most incident types of cancer will be prostate (65.840) and breast (66.280), in addition to colon and rectal, lung, stomach, cervix, oral cavity, central nervous system, leukemia and esophagus¹.

Therefore, knowing the expectations regarding the survival of cancer patients is essential for the planning of Nursing actions that aim to adequately attend to their needs, understanding that the cancer survivor experiences feelings of anguish, for not being able to share the anxieties that cause them physical and mental

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discomfort. Consequently, in this context, the objective established was to analyze the expectations of the patients with a cancer diagnosis hospitalized in clinical wards about treatment conclusion and survival after the disease.

LITERATURE REVIEW

The demographic transition observed in recent years in developing countries demanded the structuring of prevention and health promotion public policies, for causing important impacts on the population's health and being associated with the increase in the prevalence and incidence rates of chronic non-communicable diseases, with emphasis on cancer¹.

As seen earlier, cancer has become one of the diseases responsible for a large number of deaths worldwide. Even in countries with greater access to health services, one of the main problems is late diagnosis, hindering treatment and survival. Early detection and effective treatment provide the possibility for the individuals to continue working and supporting their family members, reducing the impact of the disease on quality of life and because treatment effectiveness is greater in the early stages³.

According to the National Coalition for Cancer Survivorship, cancer survivors are those individuals who are diagnosed at some point in their life⁴. The National Cancer Institute defines, in addition to the person with cancer, the family and the caregivers themselves as survivors³.

With this information, it must be considered that, as difficult as surviving cancer it is to overcome the stigmas and stereotypes that the disease carries, which emotionally affects the people who experience it, as well as their family members. In this sense, cancer diagnosis causes several feelings, concerns and worries in people, for being a life-threatening disease. Having cancer goes beyond physical pain and emotional discomfort, requiring differentiated understanding for care. Providing assistance to the person with cancer requires concern with the emotional, social and psychological aspects from the health professional, in order to maintain the patient's quality of life⁵.

Cancer survivors represent a new reality in the health services. Thus, in order to provide adequate care to this growing population, health professionals must know their needs to develop appropriate interventions. In this context, the demand directed at health professionals is expanded, suggesting interventions targeted at educational processes and at psychosocial support, person and family, aiming at well-being and quality of life after cancer treatment.

The literature describes the need, from the therapeutic protocol implementation phase, to guarantee effective communication between a multidisciplinary health team, patient and family/caregivers, in order to facilitate the understanding of the health situation, promote autonomy during treatment, and allow for the construction of the future perspective⁴.

METHOD

A descriptive research study, with a qualitative approach, which aimed to capture information from patients diagnosed with cancer and to portray the essence of the expectations after treatment conclusion, from a perspective that includes their feelings, values and perceptions about their activities and the repercussions on their quality of life⁶.

The study was carried out in three general clinical hospitalization units of a university hospital in the municipality of Rio de Janeiro. In the data collection period, between April and June 2019, nearly 648 people were hospitalized in the units surveyed, with different reasons for hospitalization and predominance of cardiovascular, gastrointestinal, hematological and oncological disorders. The choice of non-oncological clinical units was precisely due to the presence of these patients "outside the clinic", which leads us to reflect on the need for the formal preparation of the professionals who provide assistance to them. The sample included individuals diagnosed with cancer and aware of the clinical condition, and with their consciousness and orientation levels preserved. Patients with a reduced level of consciousness or change in orientation were excluded, according to the daily assessment recorded in the medical chart by the Nursing team, as well as those who demonstrated ignoring their own diagnosis, and those who had difficulty understanding the study.

After the participant accepted and signed the Free and Informed Consent Term in two copies, data collection took place at the bedside, by means of a semi-structured interview with the help of a sociodemographic and clinical characterization instrument (age, gender, schooling, profession/occupation, income, absence from work activities, support network, and diagnosis) and containing the following guiding question: *What activities, commitments or relationships do you expect to resume at treatment conclusion?* The answers were recorded in a list format in a printed form by the lead researcher.

The analysis of the sociodemographic and clinical data was performed by means of simple descriptive statistics, with the aid of the *Microsoft Office Excel*® and the *Statistical Package for the Social Sciences*® (SPSS v.20.0) software programs. The diverse information reported about the activities and expectations was listed and subjected to analysis

following the content analysis methodology: Pre-analysis: with organization of the material and composition of the study *corpus*; Exploration of the material: where the data are systematically transformed and aggregated into registration units (RUs) that had characteristics in common, and later grouped and classified into units of meaning (UMs) or themes; Treatment of the results: with inference and interpretation, seeking to support the analyses and make sense of the interpretation⁷. Thus, after reading the answers, it was possible to delimit 103 UMs that were grouped into three categories: Performance of the social roles, Autonomy to carry out activities of daily life, and Changes in habits to improve health and coexistence.

The research protocol was approved by the Research Ethics Committee under CAAE No. 06240919.0.0000.5282, observing the current Resolutions of the National Health Council.

RESULTS AND DISCUSSION

A total of 32 patients aged from 26 to 82 years old participated in the study. Predominance of men was observed (56.3%), with complete elementary school (56.3%). The majority stated that they were away from their work activities (78.1%), with 12.6% indicating that they had no income at the time of the study. Predominance of leukemia (25%) and lymphoma (18.8%) diagnoses stands out. All reported having family support, with 21.89% and 9.38% recognizing friends and work colleagues as support networks, respectively.

The higher number of cases in males corroborates the data found by the National Cancer Institute (INCA)¹. With regard to this data, the need to pay special attention to this group stands out, since many men are ashamed to seek help, due to the influence of cultural issues, myths or taboos, delaying the diagnosis of diseases⁸. The predominant schooling level of the interviewees was elementary school, confirming the profile of patients seen at another public chemotherapy service, and acting as a potential delaying factor in the early identification of cancer, as it hinders access and assimilation of information on prevention, diagnosis, control and treatment⁹.

Due to the impairment by diseases of the musculoskeletal system and connective tissue, pain was presented as the main reason for many of the hospitalizations. Pain is one of the most frequent complaints in patients diagnosed with cancer, and is responsible for their suffering and that of their family. Other studies have shown that cancer patients were admitted to general wards and that pain was the most common symptom¹⁰.

The high rate of distancing from the activities of daily life by most of the respondents stands out, even though it was expected due to hospitalization. Some participants reported not being able to return to work or having lost their jobs due to cancer, treatment or side effects. In addition to that, they stated having difficulties finding a job due to the treatment schedule and its effects.

Cancer survivors report professional loss because of the disease due to the inability to continue their careers, to postponing graduation plans or to the inability to travel for work¹¹. In this sense, the importance of discussing the family's economic and social situation in team meetings is emphasized, in order to consider better support possibilities and specific referral to support services.

Through open-ended questions, the participants were also asked regarding their expectations in relation to activities, commitments or relationships that they expected to resume after treatment conclusion. There was a wide range of answers listed, analyzed and categorized as: Performance of the social roles, Autonomy to carry out activities of daily life, and Changes in habits to improve health and coexistence. The answers are shown in Figure 1 and the categories are discussed below.

Performance of the social roles

Regarding performance of the social roles, most of the participants expressed the desire to be and/or live with the family, in addition to being able to raise grandchildren or other dependents.

The literature shows that the family has a great effect on the improvement and quality of life of the patients undergoing treatment, often being the main source of social, emotional and affective support, essential in the health-disease process¹¹. A recent study evaluated the quality of life of cancer patients in different treatment periods and demonstrated that quality of life is directly related to the social support offered¹².

It is noteworthy that impairments in functional capacity resulting from the disease or its treatment can affect the ability to perform in the activities of daily life and in practical activities, which includes social relationships¹³.

The family has a major effect on the improvement and quality of life of the patients who undergo treatment for any type of cancer. Its support and presence is essential, due to its importance that is not restricted only to emotional and affective support, but also in assisting health care¹⁴.

Answers	N	f(%)	Classification
Being/Living with the family	8	25.0	Performance of the social roles
Raising children/grandchildren/ dependents	5	15.62	
Studying	2	6.30	
Getting married	1	3.16	
Directing	1	3.16	
Being happy	1	3.16	
Working	19	59.38	Autonomy to perform activities of daily life
Practicing physical/leisure activities	14	43.75	
Attending church/religious practices	13	40.63	
Taking care of the house	5	15.62	
Socializing with friends	4	12.50	
Health self-care	2	6.30	
Taking care of pets	1	3.16	
Independence	1	3.16	
Paying bills	1	3.16	
Proof of life in the bank	1	3.16	
Managing to retire	1	3.16	
Traveling	4	12.50	Changes in habits to improve health and coexistence
Quitting smoking	3	9.36	
Cultivating a vegetable garden/plants	3	9.36	
Understanding people	1	3.16	
Having peace	1	3.16	
Saying no to people	1	3.16	
Stopping drinking	1	3.16	
Moving out of Brazil	1	3.16	
Participating in a Non-Governmental Organization (NGO)	1	3.16	

FIGURE 1: Activities, commitments or relationships that the patients expected to resume after treatment conclusion. Rio de Janeiro, RJ, Brazil, 2019.

In addition to that, cancer patients have concerns about their roles as parents, both to carry out usual practical activities for their children, as well as concerns about the emotional consequences for the children¹⁵. A previous study found that most of the patients (60%) considered that they were extremely capable of carrying out their parental responsibilities before diagnosis, dropping to 11% after the diagnosis¹⁶.

Autonomy to perform activities of daily life

The diagnosis of cancer, a disease with so many stigmas, which carries suffering and concerns both for those affected and for everyone around them, is a destructuring situation that often generates behavioral changes, leading the patients to approach or to distance from those around them. It is possible to suppose that the diagnosis alone will lead the subject to triggering reflections and feelings, with the possibility of being influenced by their own and others' experiences, which will result in adaptation behaviors, whose purpose is to cope with the stress and anxiety caused by this moment^{17,18}.

In this sense, the expectation for quality of life and the return to work point to the hope of returning to a normal life and as a way to face the disease and hospitalization. The experience of cancer for the study participants caused moments of uncertainty and frustration; however, from the speeches, the hope of believing in the cure of the disease and the return to their activities can be perceived. However, fear of relapse and metastases was frequent, putting individuals on alert for what can be faced in the future, leading them to adapt and survive this disease.

In relation to work, the most cited element in this category, it is highlighted that the financial issue is something that worries cancer survivors due to the impact on the family's economy. In this study, most of the participants reported distancing from their work activities, assuming that probably many had to give up their jobs due to the disease. The social situation and the inability to maintain the job are issues that can generate some kind of harm to cancer patients and challenges for their family members¹⁹. Thus, it is important that, during the service, the health team is attentive not only to the symptoms, but also to addressing the socioeconomic aspects in order to expand the health care provided to the person.

The desire to practice physical activities and to follow religious practices also stood out among the answers that emerged as expectations of autonomy resumption. It is known that the practice of regular physical exercise, of moderate intensity, is related to the improvement in functional capacity as well as it has anti-inflammatory and immunostimulatory effects, contributing to a better prognosis of the cancer patient¹⁹.

Spirituality and religiousness are resources widely used by cancer patients, as religious and spiritual well-being, in most cases, provides positive coping, changing the way of dealing with the diagnosis and adherence to the cancer treatment²⁰. Positive thinking related to the disease was present among the participants, through the mention of faith in God and in the search for a cure, a behavior that has also been observed in other studies²¹.

Changes in habits to improve health and coexistence

Changes in habits to improve health and coexistence were especially highlighted when it came to the desire to travel (5 UMs) and to changes in habits, such as quitting smoking (5 UMs).

The change in habits seen as harmful to health, negative emotions and unhealthy eating, and in oncogenic ones such as smoking, can express a behavior directed by the social anti-cancer pressure and psychological defense mechanisms. This change in conduct in their daily lives is considered adequate in the process of overcoming the health problem. However, it can also be considered as part of the disease denial process²².

As it is a process permeated by doubts, fear and insecurity, assistance to patients diagnosed with cancer requires special attention and comprehensive care from a well-trained multi-professional team with specific knowledge of this population, in order to meet their biopsychosocial and spiritual demands. There is a need for a proactive role of the Nursing professionals in assessing the basic needs of these patients²².

In view of the results, it is perceived that the subjects become active when they participate in decisions about their own life and, thinking about the scope of health autonomy, when they become a central element in the construction of their health process, differently from the logic that designates a person for their pathology, overshadowing their personality and their ability for decision-making or participation – “a patient”. The reflection on the legitimacy and respect for the patient's/user's autonomy raises the question about the appreciation of the patient's will in search of humanized assistance. Many professionals approach patients diagnosed with cancer as fragile individuals, with a rapid decline in their general condition and with difficulties accepting the diagnosis, especially if the patients are aged¹².

In this sense, the need is highlighted that, since the period of professional training, the future nurse develops a view of individuals as biopsychosociospiritual beings, seeking to understand their dimensions and to provide well-being. The search for autonomy by the patient is part of the humanized care that respects and promotes the fulfillment of the patient's needs.

Study limitations

It is acknowledged that one of the study limitations is related to the reduced number of participants, due to the particularities of the clinical units, which are not specific for cancer patients. In addition to that, the study was developed in a single health service, limiting generalizations to patients hospitalized in institutions which are similar to the setting of this study. It is believed that it would be appropriate to conduct other studies, establishing comparisons with other services, mainly those specialized in cancer with hospitalized patients and undergoing outpatient treatment and/or follow-up.

CONCLUSION

The results reflect the perception of the cancer survivors about their expectations, as well as hope in relation to their autonomy after treatment conclusion. The patients' reports indicated the need to promote quality of life and the return to their activities, also indicating the subjectivity of these choices, linked to personal values and influenced by the repercussions of the health-disease process.

In addition to that, resumption of the social roles, giving visibility to family issues and to the financial impacts related to the disease, and changing habits to improve health, demonstrate the need to return to life and to relieve the suffering caused by the deprivation of activities due to the disease.

In this context, it becomes necessary to know and recognize these expectations of cancer survivors in relation to the treatment and to life in the future, for individualized and higher quality Nursing care. Thus, professional support for the patients and their family members is considered important, ignoring pre-judgments and assumptions and allowing them to listen, based on attentive and welcoming listening in order to promote humanized care and to provide well-being.

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