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ORIGINAL ARTICLE

A qualitative approach to the experience of patients from the diagnosis of cancer

Uma abordagem qualitativa acerca da vivência de pacientes a partir do diagnóstico de câncer

Juliana Soares Cândido da Silva , **Rayane Tavares da Silva*** , **Josinaldo Furtado de Souza**
João Pessoa University Center, UNIPÊ. João Pessoa, Paraíba, Brazil.

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KEYWORDS
Cancer
Psychological adaptation
Psychosocial Support Systems

ABSTRACT

Objective: to understand the experiences of cancer patients based on the diagnosis and the strategies adopted.
Methods: this is a qualitative and transversal research, exploratory and descriptive. The sample consisted of 10 women with cancer assisted by a support association for cancer patients in João Pessoa/PB, selected by non-probabilistic convenience sampling. To collect data, a sociodemographic and health questionnaire was used, as well as a semi-structured interview based on the life history method. Sociodemographic data were analyzed using descriptive statistics (frequency and percentage), and data from the interview were analyzed using the Thematic Content Analysis technique proposed by Bardin. The average age of the women was 61.8 years. Four categories and 12 subcategories emerged.
Results: the diagnosis of cancer caused negative impacts on the lives of patients and their families. Having a support network is an essential coping strategy used by patients due to the suffering caused by cancer.
Conclusion: The importance of strategies for coping with the suffering of cancer patients was highlighted, especially concerning the support network, this being the most prominent category among all those found.

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*Corresponding author:
Centro Universitário de João Pessoa-UNIPÊ.
Addr.: Usina Central Olho D'água, Vila do Campo, 70. Camutanga, PE, Brasil.
Phone: +55 (81) 9292-5602
E-mail: rayanetavaresdasilvartds@gmail.com (Silva RT)

This study was conducted at the University Center of João Pessoa-UNIPÊ.

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PALAVRAS-CHAVE

Câncer
Estratégias de enfrentamento
Sistemas de apoio psicossocial

RESUMO

Objetivo: compreender as vivências de pacientes oncológicos a partir do diagnóstico e as estratégias adotadas.
Métodos: trata-se de uma pesquisa de natureza qualitativa e transversal, de caráter exploratória e descritiva. A amostra foi constituída por 10 mulheres com câncer assistidas por uma associação de apoio a pacientes com câncer em João Pessoa/PB, selecionadas por amostragem não probabilística por conveniência. Para a coleta dos dados utilizou-se um questionário sociodemográfico e de saúde, e a entrevista semiestruturada, pautada no método História de Vida. Os dados sociodemográficos foram analisados através de estatística descritiva (frequência e porcentagem), e os dados provenientes da entrevista foram analisados pela técnica de Análise de Conteúdo temática, conforme proposta por Bardin. A média de idade das mulheres foi de 61,8 anos. Surgiram 4 categorias e 12 subcategorias.
Resultados: o diagnóstico de câncer provocou impactos negativos na vida dos pacientes e na vida dos seus familiares. Ter uma rede de apoio é uma importante estratégia de enfrentamento utilizada pelas pacientes, devido ao sofrimento causado pelo câncer.
Conclusão: Evidenciou-se a importância de estratégias de enfrentamento do sofrimento do paciente oncológico, sobretudo com relação à rede de apoio, sendo esta a categoria de maior destaque ente todas as encontradas.

INTRODUCTION

Receiving a cancer diagnosis implies several modifications in the patient's life, with significant consequences in the way of living, ranging from physical and emotional changes due to discomfort, pain, disfigurement, dependence, and loss of self-esteem to stigma linked to cancer and associated finitude. After all, cancer is a disease considered by many to have no possibility of cure[1]. Therefore, in addition to the fears and desires that the diagnosis awakens, the patient needs to deal with worries about pain and the treatments to be performed, chemotherapy and radiotherapy, and the fear of death[2].

Considering the subjectivity and the characteristics within us, each patient will find strategies that best help them cope with the suffering caused by the diagnosis. One of these strategies is religious experience, which often influences treatment adherence, coping with pain, and the search for an explanation for the current situation, in addition to reducing anxiety and stress arising from the process of coping with the disease[3].

Furthermore, the role of the family in this process becomes invaluable, as it is through family assistance that the patient can find understanding, support, and emotional support, which are extremely necessary to cope with this disease less painfully[4]. In addition, a support network made up of people beyond the family circle, such as friends, neighbors, and co-workers, is of great relevance in this scenario because it favors the process of adaptability experienced by the patient during this process[5].

Given the above, the present study sought to understand how patients with cancer have lived since their diagnosis to plan interventions that promote health, quality of life, and well-being, especially considering the gaps regarding this life-oriented theme and how it continues after confirmation of the diagnosis.

METHODS

This is a qualitative, transversal, exploratory, and descriptive study. Participants were selected by non-probabilistic convenience sampling, consisting of patients diagnosed with cancer and assisted by an association that serves cancer patients in João Pessoa, Paraíba. Through donations, the association promotes work to help cancer patients who cannot afford exams, medications, and other treatment-related needs. Furthermore, it is a space where patients share their experiences through the meetings and workshops offered. Although the target audience is cancer patients of both sexes, females are the most common. Given this scenario, the association's president was contacted to authorize the necessary interviews, and after approval, days and times were scheduled in which the patients would already be in the association due to activities they would have later. We explained the study's objective and how data collection would be conducted on the participants, and we began individual interviews with those who agreed to participate. Only female patients were present on the days available to us researchers, totaling 10 women between 48 and 73 years old, with an average age of 61.8 years. The interview saturation criterion was used to delimit the number of participants. The following inclusion criteria were used: patients aged 18 years or over who voluntarily agreed to participate in the research and signed the Informed Consent Form and the Voice Recording Authorization Term. At the time of the research, patients who were suffering from any acute or chronic condition that limited their ability to participate were not included in the study, making this a limitation.

Participants were informed about the objective of the research, risks and benefits, and the non-obligation of participation. This study was conducted considering the ethical aspects pertinent to research involving human beings, following resolution No. 466/2012 of the National Health Council and the Declarations of Singapore and Hong Kong. This study was approved by the Ethics Committee in Research at the João Pessoa University Center - UNIPÊ, according to decision no. 5,535,331. The names mentioned are fictitious to protect the participants' identity and confidentiality.

Data collection occurred from 8/15/2022 to 9/15/2022, and analysis was from 9/16/2022 to

9/30/2022. The interviews and data collection occurred individually, between 2:00 pm and 4:00 pm, in an isolated and specific room, conducted by researchers JSCS and RTS. The participants did not receive any help or cost to attend the interview, as they took place on days when the interviewees usually attend the association, only specifying the time we could conduct the interviews.

A sociodemographic and health questionnaire and a semistructured interview were used to collect data. The questionnaire aimed to characterize the participants using variables such as age, family income, level of education, marital status, profession/occupation, level of religiosity, and type of cancer. The semi-structured interview was based on the Life History method. Initially, participants were asked to tell their story through the evocation: "I would like you to tell a little of your story from the moment you were diagnosed with cancer". Other questions were introduced throughout the interview to better analyze the participants' life stories. This method develops through the relationship created.

Sociodemographic data were analyzed using descriptive statistics (frequency). The data from the interviews were analyzed using the Thematic Content Analysis technique[6].

RESULTS

Among the ten participants, nine lived in João Pessoa/PB, and eight had incomplete primary education or completed secondary education. The majority were brown or black, married or living together, had three to four children, were housewives, and had a family income of one minimum wage. All women reported having a religious orientation, and the majority considered themselves on a scale of 8 to 10 in the degree of religiosity (Table 1).

Most participants did not take psychotropic medication, and the most prevalent cancer was breast cancer. Furthermore, most of these participants received their cancer diagnosis more than three years ago and mentioned having someone in their family who had or has a cancer diagnosis (Table 2). The categories, subcategories, and content units are listed in Table 3.

Table 1 — Profile of women according to sociodemographic variables.

Variables	n
Living city	
João Pessoa	9
Bananeiras	1
Education	
Incomplete Elementary	4
Complete School	4
Graduated	2
Skin color	
White	2
Black	4
Brown	4
Marital status	
Single	1
Married/Living together	7
Separated/Divorced	
Widow	1
Number of children	
None	1
1-2 children	4
3-4 children	5
Work/Occupation	
Housewife	6
Beneficiary	2
Pensioner	2
Family income	
< 1 Minimum wage	2
1 Minimum wage	6
1-2 Minimum wages	2
Religious orientation	
Catholic	3
Evangelical	7
Degree of religiosity	
5-7	1
8-10	9

*Minimum wage in force in 2022: R$ 1,212.00

Table 2 — Profile of women according to health variables.

Variables	n
Practice physical activity	
Yes	5
No	5
Psychotropic Medication	
Yes	8
No	2
Type of cancer	
Breast	8
Colorectal	1
Breast, Ovaries and Bones	1
How long	
1-3 years	1
> 3 years	9
Has anyone in the family ever had or has cancer	
Yes	8
No	2

Impact of the disease on life

The *Impact of the Disease on Life* category comprises three subcategories, corresponding to 33.1% of the content units.Among the reports in this category, the subcategories *Initial Impact/Acceptance Process* stand out, as well as statements that highlight frequent content related to the initial shock, crying, and the acceptance process, as found in the reports below.

> Ah, it was a huge shock. For me, the house would fall down... (Elizabete, 73).
> It wasn't easy, you know, because it was a blow, it was a shock, but even so, I still had hope that it wouldn't be... (Francisca, 67).

Table 3 — Categories, subcategories and content units.

Categories	Subcategories	Content Units (f)	Content Units (%)
Impacts of the disease on life	Initial impact/acceptance process	16	33.1
	Repercussions on routine	13	
	New way of seeing life	16	
Family	Initial impact of family members upon receiving the news	9	12.5
	Concern for family members	5	
	Concern of family members	3	
Reactions to treatment	Reactions to chemotherapy and radiotherapy	12	12.5
	Significant losses	5	
Support networks	Family and friends	15	41.9
	Faith/Religiosity	21	
	Cancer Association	11	
	Health professionals	10	
Total		136	100

The reports in the subcategory *Repercussions on Routine*, portrayed by the participants, show significant changes in how to live the new reality installed.

> We left a well-structured house and moved to a much smaller apartment. Very difficult. (Ruth, 48).
>
> Yes, I had to stop working, so it was just my husband working, right... (Germana, 70).

Regarding the new ways of seeing life and living, through the subcategory *New Way of Seeing Life*, statements such as:

> But I kept going, you know, and so far, thank God I'm doing so well, it's not easy because the journey changes everything, the trajectory of our lives, you know, the family changes, the child's mind changes, the person's head changes, it really changes, and the people grow and I grew through my diagnosis. (Francisca, 67).

Family

Regarding the F*amily* category, which comprises three subcategories and corresponds to 12.5% of the content units, issues related to family members stand out, from the impact generated to the concern on their part. In the subcategory *Initial Impact of Family Members upon receiving the news*, this shock of family members can be seen in the following statement.

> It was very difficult, they suffered a lot, my daughters cried , they couldn't look at me because the tears came, they suffered a lot, I had to be strong so they wouldn't fall, they suffered a lot, but they had support from their husbands, that was luck also. (Miranda, 63).

In addition, giving rise to the subcategories *Concern for Family Members* and *Concern of Family Members* present in this category, this reality can be seen from the statements made by the participants, as demonstrated below.

> I asked God a lot for the grace to make me stronger, if I was strong everyone would be strong, if I was strong it was up to them, so they don't know (Cristina, 64).
>
> They started to not want me to walk alone, and I showed them that I had to walk alone, because not every time I need to go out and sort things out do I have someone to go with me, no, I'm going to walk alone, there's no problem, not even every time I need someone, that person will be available to me, so little by little they got used to me. (Cristina, 64).

Treatment reactions

The *Treatment Reactions* category has two subcategories corresponding to 12.5% of the content units. This category refers to the effects of the treatment, which came to light very explicitly, as shown in the following report, and belongs to the subcategory *Reactions to Chemotherapy and Radiotherapy*.

> The reactions to chemotherapy, you know, I had a lot of them, vomiting, a lot of nausea, it's... total discomfort, it was a lot, I felt sick a few times, I felt like I was going to die, I thought I was going to die, but I got over it (Miranda, 63).

Regarding the *Significant Losses subcategory*, it was possible to notice the suffering resulting from the treatment and the related losses.

> I suffered a lot during the treatment, the surgery also removed my entire breast, it was

> very difficult, we women know that it is difficult, you know, to be without a breast, and I'm here, thank God I'm here. (Miranda, 63).
>
> (...) I wouldn't admit that I was going to lose my breast, because we get mutilated, right? (Janete, 53).

Support networks

The *Support Networks* category has five subcategories, corresponding to 41.9% of the content units, where a large part of the main reports are related to the position of *family/friends* in this process.

> I have had it all my life. From my husband, my two daughters (Germana, 70).
> I had, I had my friendships. I always said I had cancer and everyone came to my house to visit me (Elizabete, 73).

Within this category, there is also the *Faith/Religiosity* subcategory of the participants, which is very prominent in the participants' statements, as can be seen in the speech below.

> No, I need to live, I have things to resolve, it's not my time, and then your faith and your insistence on living, your will to live, will speak much louder than a diagnosis. Why? Because you will create means, right? (Rute, 48).

Still, within this category of support networks, there is the *Cancer Association* subcategory, in which patients participate to this day, and in their statements, they bring great relevance to this support.

> The support from here at the NGO was very important, because, because of the other women, there was a lot of friendship (Miranda, 63).

Finally, in the last subcategory referring to the support of *Health Professionals*, its importance can be highlighted from the statement below.

> I was followed up with a psychiatrist; I was followed up with a psychologist... Excellent psychologist, because you tell me, sometimes you share things that you don't want to share with your husband, you don't want to share with your child, but there are decisions that we need to make, you understand (Ruth, 48).

DISCUSSION

Regarding the initial impact on their lives, the patients, upon receiving the cancer diagnosis, were completely surprised and impacted. It is possible to propose that this occurs because the stigma of the disease itself causes this impact, putting them in contact with the finiteness of life, which is still a fearful event. Because of this stigma, cancer shows the patient that their world and their previous life no longer exist, giving rise to uncertainty and insecurity as to what will happen, still under the impact of the diagnosis[7]. The process of accepting the disease is an important step. In seeking to accept their new health condition, patients adhere to coping strategies that can help in the coping process, thereby reducing the impact of the diagnosis[8].

Regarding the repercussions on their routine, patients reported considerable changes in their daily lives, redefining their social roles and causing significant consequences in how they live. These changes range from physical and emotional to dependence. This study highlighted the repercussions on work, mostly leading to their absence due to oncological treatment[1].

It is possible that the patient, being ill, can develop a positive review of some concepts of life, producing a new meaning, meaning that the illness can be viewed less painfully. After diagnosis, it is observed that this series of changes, especially in the way of living and facing life, is sometimes so profound and significant that it begins to transform the lives of those around them[9]. Given this, the patient must find strategies that make it possible to find a meaning for this suffering because, in any situation, even in the last moment of life, there is the possibility of finding a new meaning for suffering, even in the face of what is called the "tragic triad" - pain, guilt, and death[10].

The reports also demonstrated the initial impact of family members upon receiving the news and how affected they were after confirming the diagnosis, validating what authors Pio and Andrade (2020) bring when they point out how the cancer diagnosis causes shock to the families of patients diagnosed with cancer, and how members experience this within their uniqueness[11].

Still, regarding the family, there is concern that patients have with their family members, as some end up needing to take time away from routine activities and sometimes even from professional life to dedicate themselves to the patient's care. In this sense, it is common for a cancer patient to be accompanied by someone close to them, such as parents, siblings, children, or spouse. Therefore, there is a significant loss in the lives of these companions and in their routine because of the absence of their daily activities[12]. The discovery of a disease such as cancer has repercussions on the entire family context, making it necessary to reorganize daily life to implement the necessary care that the disease requires as well as its treatment[13]. Therefore, there is a change in family habits.

Cancer has a painful treatment that results in uncomfortable reactions and small daily losses in terms of health, hair that begins to fall out, the body that suffers from the consequences of the treatment, separation from family life, and life plans that have been postponed or lost due to the installation of fears related to death[14]. The sample for this study comprised women assisted by a non-profit association that assists needy people with cancer. The absence of a male audience was due to their non-existence during the interviews.

The most feared effect is hair loss, as it is a more visible representation of femininity than the breast itself15. Given that the public most present at the time of data collection was female, the type of cancer that was most evident was breast cancer. This is the most common occurrence in women worldwide, with approximately 2.3 million new cases estimated in 2020, representing 24.5% of new cancer cases in women[16].

Going through the process of confirming a cancer diagnosis is quite painful, as can be seen in the reports, as is facing the necessary treatments to be carried out. Therefore, the speeches highlighted the importance of having a support network at this time.

During the reports, it was noticed that family and friends were essential as a support network, with the family being a source of emotional support. This confirms what Alecrim, Miranda, and Ribeiro (2020) highlight, claiming that the role of the family during this coping process is vital, where the patient can find support, understanding, and emotional and psychological support, helping them to cope with the disease[4]. However, a support network made up of people beyond the family circle, such as friends, also proved to be necessary, as they strongly contribute to the adaptation process that the patient experiences[5].

Faith/religiosity was a frequent point reported by patients, proving to be an essential coping strategy. Therefore, it presents itself as an important experience in the lives of cancer patients, as it helps in coping with this process, providing relief in difficult times, strength to overcome emotional impacts, and can help in the search for well-being, providing cancer patients with a healthy confrontation with the new context they will face, helping them elaborate and give new meaning to their experiences, relationships, and the meaning of their life[17].

The participants also demonstrated the importance of having received support from the cancer association of which they are part, as they were in a group sharing experiences related to cancer. In this regard, the group format provides favorable conditions for dialog to share and exchange experiences and catharsis, which are important support elements for psychosocial rehabilitation[18].

From the perspective of a support network, health professionals were presented as relevant actors during the disease course. Multidisciplinary support is vital, operating based on actions and strategies that cover the physical and psychosocial state of patients, such as the presence of psychologists and therapists, who can contribute significantly to this process, from the initial moment of diagnosis, making it necessary to manage negative reactions that may arise in coping with the disease[19].

Therefore, the initial impact of the disease is quite significant, not only on the patient's life but also on their support network. There is currently a more significant insertion of psychologists in the health area, but many achievements can still be made, seeking greater integration between different professionals to offer better care to patients and their families. Therefore, it is crucial to have a more significant association between hospital psychologists working in oncology, being attentive to the needs of patients, not only while they are undergoing treatment in the hospital but also being able to refer them so that they continue to be monitored when the treatment ends.

The small number of participants is a limitation of the study and cannot, therefore, be generalized. Through the results obtained, the aim is to expand this theme from a social and scientific point of view, giving visibility to a perspective that looks at life in its continuous process after the confirmation of a cancer diagnosis.

CONCLUSION

This experience is permeated by individual and subjective characteristics that lead to transformations in these people's lives and their support network, from the moment they discover the disease to the adaptation of a new way of living. However, the importance of having a support network is noted from the time the diagnosis is confirmed until later. Patients who receive this support tend to face the diagnosis and treatment journey in a significantly less painful way. One of the main coping strategies used by the patients who participated in this study was faith/religiosity. It was observed that it already played an essential role in the patients in question. Nevertheless, because of the diagnosis, faith/religiosity was further boosted, thus becoming one of the most positive ways of coping with the disease.

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