Revista de Enfermagem UFJF

https://periodicos.ufjf.br/index.php/enfermagem

ORIGINAL ARTICLE

Knowledge of patients with advanced cancer about their diagnosis and treatment modalities

Conhecimento dos pacientes com câncer avançado sobre seu diagnóstico e modalidade de tratamento

Conocimiento de los pacientes con cáncer avanzado sobre su diagnóstico y modalidades de tratamiento

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Article information:
Received: 11/20/2024
Accepted: 12/26/2024

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ABSTRACT

Objective: To assess the knowledge of patients with advanced cancer regarding their diagnosis and pharmacological and non-pharmacological treatment modalities. **Method:** A cross-sectional study conducted in a university hospital in southern Brazil, including patients diagnosed with advanced cancer. Data collection took place from October 2022 to February 2024. Sociodemographic and clinical data were collected, along with questions related to knowledge of prognosis and treatments. **Results:** A total of 101 participants were included, with a mean age of 56.8 years; 73.3% were women ($p<0.05$), 38.6% had breast cancer ($p<0.05$), and multiple metastases; 49.5% were aware of the advanced cancer diagnosis ($p<0.05$), 30.7% were unaware of the disease stage, 37.6% did not understand the treatment objectives, and 33.7% believed the treatment was curative; 94.1% had not been advised on non-pharmacological therapy by a healthcare professional ($p<0.05$). **Conclusion:** Patients showed limitations in understanding the stage of the disease, treatment objectives, and the use of non-pharmacological therapies.

DESCRIPTORS: Neoplasm Metastasis; Quality of Life; Integrative Palliative Care; Complementary Therapies; Oncology Nursing.

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RESUMO

Objetivo: Avaliar o conhecimento do paciente com câncer avançado, sobre o seu diagnóstico e modalidade de tratamento farmacológico e não farmacológico. **Método**: Estudo transversal realizado em um hospital universitário do sul do Brasil, inclusos participantes com diagnóstico de câncer avançado, sendo a coleta realizada de outubro de 2022 a fevereiro de 2024. Foram coletados dados sociodemográficos, clínicos e questões relacionadas ao conhecimento do prognóstico e tratamentos. **Resultados**: Foram 101 participantes, com média 56,8 anos; sendo a 73,3% mulheres (p<0,05), 38,6% com câncer mama (p<0,05) e múltiplas metástases; 49,5% eram cientes do câncer avançado (p<0,05), 30,7% desconheciam o estágio da doença, 37,6% o objetivo do tratamento e 33,7% acreditavam que o tratamento era curativo; 94,1% não tiveram indicação de terapia não farmacológica por profissional de saúde (p<0,05). **Conclusão**: Os pacientes apresentaram limitações quanto à compreensão do estágio da doença, objetivos do tratamento e uso de terapias não farmacológicas.

DESCRITORES: Metástase Neoplásica; Qualidade de Vida; Cuidados Paliativos Integrativos; Terapias Complementares; Enfermagem Oncológica.

RESUMEN

Objetivo: Evaluar el conocimiento de los pacientes con cáncer avanzado sobre su diagnóstico y las modalidades de tratamiento farmacológico y no farmacológico. **Método:** Estudio transversal realizado en un hospital universitario del sur de Brasil, incluyendo pacientes con diagnóstico de cáncer avanzado. La recolección de datos se llevó a cabo desde octubre de 2022 hasta febrero de 2024. Se recopilaron datos sociodemográficos y clínicos, así como preguntas relacionadas con el conocimiento del pronóstico y los tratamientos. **Resultados:** Participaron un total de 101 pacientes, con una edad promedio de 56,8 años; el 73,3% eran mujeres (p<0,05), el 38,6% tenía cáncer de mama (p<0,05) y múltiples metástasis; el 49,5% eran conscientes del diagnóstico de cáncer avanzado (p<0,05), el 30,7% desconocía el estadio de la enfermedad, el 37,6% no comprendía los objetivos del tratamiento y el 33,7% creía que el tratamiento era curativo; el 94,1% no había recibido indicación de terapia no farmacológica por parte de un profesional de la salud (p<0,05). **Conclusión:** Los pacientes mostraron limitaciones en la comprensión del estadio de la enfermedad, los objetivos del tratamiento y el uso de terapias no farmacológicas.

DESCRIPTORES: Metástasis de la Neoplasia; Calidad de Vida; Cuidados Paliativos Integrativos; Terapias Complementarias; Enfermería Oncológica.

INTRODUCTION

Cancer is an important global public health problem, the estimates for 2050 show that there will be 35 million new cases in the world, and 704 thousand will be in Brazil by 2025. In 2022, approximately 20 million new cases and 9.7 million deaths were registered, respectively 627,193 cases and 278,835 deaths in Brazil. Thus, the country has one of the highest incidences in South America[1,2].

Advanced cancer is characterized by the presence of metastasis, being responsible for 90% of deaths, which may be related to recurrence of the disease, unlike primary tumors that recede or heal after a line of treatment[3]. Its discovery in the advanced phase is related to several factors, which include limitations of financial and human resources, low search for preventive examinations, patients' lack of

knowledge about early signs and symptoms, fears and low health literacy[4].

Also characterized as progressive and incurable, the emergence of advanced cancer results in a decline in functional capacity, increased symptoms and negative quality of life[5]. At this stage, the patient may present physical symptoms that are difficult to manage, such as pain, nausea, vomiting, loss of appetite, fatigue, as well as changes in the emotional (anxiety and depression) and social aspects, such as difficulties in role performance[6,7].

The proposed treatment for advanced cancer is Palliative Therapy (PT), directed to promote comfort, but its purpose is not curative. The different systemic or localized modalities aim at reducing distressing symptoms, promoting quality of life and survival. It can be administered with other treatments, both pharmacological and non-pharmacological, concomitant from diagnosis to the end of life[8]. It is highly recommended to associate PT with Palliative Care (PC). Although this is original and has evolved, given its relevance in Oncology, it remains poorly understood, with frequent misinterpretations by professionals in the provision of care. The complexity of PC is heterogeneous and highly contextual, which results in limitations on its integration and indication for patients with advanced cancer[9]. In the last decade, there is consensus among researchers and organizations on the need for early integration of PC in the care of cancer patients, which associated with PT can optimize the person-centered care[10].

Non-pharmacological therapies (NPT) are also increasingly being used as complementary treatment in palliative action. When combined with PT and PC, they can increase the benefits due to worsening of clinical performance and progression of symptoms produced by therapies already performed[11]. They are defined as non-invasive, non-drug-based health interventions, based on science, through various methods, products, programs and services that act on biological and psychological mechanisms[12]. The integration of NPT with TP or PC, besides improving quality of life, can promote autonomy, regardless of survival time.

In the situation of patients with advanced cancer, there emerges the importance of being informed about their diagnosis, therapeutic path and options for improving quality of life. Comprehensive communication about treatment and prognosis is important for decision-making, indication and acceptance of the best care. It allows patients to assess the risks and benefits of treatment and collaborate in the formulation of person-centered care plans. The occurrence of such misknowledge are often related to the communication of doctors or other health professionals and minority to patients who prefer not to know, since in the era of informed decision, the protective function of misknowledge is easily ignored[13].

Regarding the professionals who work with patients with advanced cancer, the recognition of the real needs of patients to be assisted in PT, through socioeconomic and clinical characterization, allows directing campaigns and promotion and prevention actions, early diagnosis and treatment, along with the essential role of nursing. The possibility of understanding the profiles of patients who are in PT allows the

team to evaluate them individually, develop care plans to minimize physical, psychological, emotional, social and spiritual anguish and suffering during this period[14].

In the context of the importance of clarifying the patient about their diagnosis, types of treatment and options for improving quality of life, the following research guiding question emerged: does the patient with advanced cancer know the objectives and modalities of treatment and make use of non-pharmacological therapies to improve their quality of life during their therapeutic journey?

OBJECTIVE

To evaluate the knowledge of the patient with advanced cancer about their diagnosis and modality of pharmacological and non-pharmacological treatment.

METHODOLOGY

Quantitative, cross-sectional study, guided by the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) tool[15].

The research was developed from October/2022 to February/2024 and had as scenario the Hematology and Oncology Outpatient Clinic of a university hospital with exclusive care by the Unified Health System (UHS), reference in the southern region of Brazil in high complexity treatment in different clinical and surgical specialties; it promotes different actions of teaching, research, extension and human resources training in its multiprofessional residency programs.

This is a non-probabilistic sample survey and all patients who underwent different types of palliative therapy during the study were invited to participate in the study. Inclusion criteria: age over 18 years, diagnosed with any type of advanced cancer (stage IV) that were performing any modality of PT. Patients with inability to maintain verbal or written communication were excluded.

The instruments for data collection were predominantly applied during systemic treatment in the infusion room or waiting room before medical consultation, guaranteeing privacy and confidentiality of information. An objective questionnaire was used, structured with sociodemographic (age, sex, income, marital status, race, schooling) and clinical information (location of the primary tumor, metastasis site and current treatment) previously used in previous studies for a similar population[5,14]. The variables related to the research question were also collected (patient knowledge about advanced cancer, purpose, treatment objective, indication and use of NPT), which is an instrument built by the researchers themselves and not yet validated for this population.

The sociodemographic data and information related to the research question were collected directly with the patient. Clinical data were collected in the patient's electronic medical record. All the collection occurred with the use of an electronic data capture tool RedCap® and subsequently analyzed

in Microsoft Excel® 2023, with descriptive statistics expressed in simple and absolute frequency (%). Statistically significant results were obtained from the application of the Chi-square test (or Fisher's exact test in case of small frequencies).

Concerning the ethical aspects, it is noteworthy that the research was approved by the Research Ethics Committee under opinion n. 5.204.355. All patients signed the ICF and ethical precepts were respected.

RESULTS

The study included 101 participants, with an average age of 56.8±12.6 years, 73.3% (n=74) women (p<0.001), 50.5% (n=51) were married or in a stable relationship (p<0.001), predominantly 76.2% (n=77) were retired or pensioners (p<0.001) and had income of 1 to 3 minimum wages (p<0.001) (Table 1).

Table 1 - Sociodemographic characteristics of patients with advanced cancer. Curitiba, PR, Brazil, 2024.

Variables	n	%	*p-Value*
Age in years (mean±Standard Deviation)	56.8 ±12.6		
Sex	n=101		
Female	74	73.3	< 0.001*
Male	27	26.7	
Race			
White	68	67.3	< 0.001*
Brown	22	21.8	
Black	9	9.9	
Yellow	1	1.0	
Marital Status			
Married/stable union	51	50.5	< 0.001*
Separated/divorced	22	21.8	
Single	16	15.7	
Widowed	12	11.9	
N. of children (mean)	2.3		
Schooling			
Illiterate	3	3	
Elementary education	48	47.5	0.02
High school	32	31.7	
Higher education	18	17.8	
Occupation			
Retiree/Pensioner	77	76.2	< 0.001*

Employed/Own-account worker	9	8.9	
Housekeeper	10	9.9	
Unemployed/Others	5	5	
Income			
<1 minimum wage	7	7	
1 - 3 minimum wages	68	67.3	< 0.001*
4 - 10 minimum wages	23	22.8	
>10 minimum wages	3	3	

*p values statistically significant

Regarding the clinical data (Table 2), a prevalence of 38.6% (n=39) with breast cancer diagnosis (p=0.002) was observed. Among the different metastases identified (n=219), almost all have more than one site, with lymph nodes, bone, liver, lung and peritoneum sites being statistically significant (p <0.05). Palliative chemotherapy was the most used treatment 73.4% (n=91), since many patients performed more than one modality simultaneously and only 6.4% (n=8) were concomitantly accompanied by the specialty of PC, although all participants had advanced cancer.

Table 2 - Clinical and therapeutic characteristics of patients with advanced cancer. Curitiba, PR, Brazil, 2024.

Variables	n	%	*p-Value*
Location of the primary tumor	n=101		
Breast	39	38.6	0.002*
Colon and rectum	19	18.8	
Gastric (Esophagus and Stomach)	8	8	
Ovary	8	8	
Trachea, bronchus and lungs	7	7	
Pancreas/biliary tract	6	6	
Gynecological (Cervix and body of the uterus)	4	4	
Prostate	4	4	
Bladder	2	2	
Other locations	4	4	
Metastases	n=219		
Lymph nodes	41	40.5	< 0.05*
Bone	40	39.6	< 0.05*
Hepatic	33	32.6	< 0.05*
Pulmonary	29	29.7	< 0.05*
Peritoneum	27	26.7	< 0.05*

Pleura	8	7.9	
Central nervous system	7	6.9	
Skin	6	5.9	
Adrenal	3	2.9	
Gastrointestinal	1	0.9	
Renal	1	0.99	
Other locations	23	22.7	
Current treatment	n=119		
Palliative Chemotherapy	91	90	< 0.001*
Hormone Therapy	10	9.9	
Palliative Care	8	7.9	
Immunotherapy	6	5.9	
Palliative Radiotherapy	2	1.9	
Palliative Surgery	2	1.9	

*p values statistically significant

When the participants were asked about their knowledge of their disease, it was observed that regarding the stage of the disease, 49.5% (n=50) assumed to be advanced (p <0.01) and 16.8% (n=17) patients believed that their stage was initial. When asked about the objective of their treatment, 37.6% (n=38) of participants were unaware of it (Table 3).

Table 3 – Knowledge of patients with advanced cancer about the disease and treatment. Curitiba, PR, Brazil, 2024.

Variables	n	%	*p-Value*
Disease stage	n=101	%	
Advanced	50	49.5	< 0.01*
Unknown	31	30.7	
Initial	17	16.8	
Terminal	3	3.0	
Treatment objective			
Curative	34	33.7	
Unknown	38	37.6	0.45
Palliative	29	28.7	

*p values statistically significant

In relation to the use of non-pharmacological therapies, it was observed that only 5.9% (n=6) of patients had some indication of NPT by some health professional, and, as for the most indicated modalities, Yoga for 30% (n=3) participants, however 12.1% (n=12) patients used NPT without the advice of a health care professional (Table 4).

Table 4 - Characteristics of the indication and use of non-pharmacological therapies in patients with advanced cancer. Curitiba, PR, Brazil, 2024.

Variables	n	%	*p-Value*
Indication of NPT by healthcare professional	n=101		
No	95	94.1	< 0.001*
Yes	6	5.9	
Type of NPT indicated by the professional	n=10		**
Yoga	3	30	
Acupuncture	2	20	
Plants/phytotherapy	2	20	
Aromatherapy	1	10	
Reiki	1	10	
Flower therapy	1	10	
Use of any NPT	n=101		
No	89	88.1	< 0.001*
Yes	12	11.9	
NPT used	n=16		**
Plants/phytotherapy	5	31.3	
Reiki	3	18.8	
Aromatherapy	2	12.5	
Homeopathy	2	12.5	
Massages	1	6.3	
Meditation	1	6.3	
Flower therapy	1	6.3	
Yoga	1	6.3	

*p values statistically significant

** p value not calculated, number of variables is small enough to require significance testing.

DISCUSSION

The study is relevant for the understanding of health professionals about the patient's knowledge and understanding about the stage of the disease, type of treatment and the use of non-pharmacological therapies. Both disease and treatment require supports for maintenance and promotion of quality of life, and professionals attentive to the patient's lack of knowledge can develop interventions aimed at minimizing this gap and possibly increasing adherence to palliative therapy.

The sociodemographic and clinical characteristics of cancer patients may be factors of vulnerability to the course of the disease, the lack of understanding about the disease stage and treatment options significantly influence the prognosis and health-related quality of life of these patients[16]. Professionals, knowing these characteristics, can provide holistic assistance, directed to the real needs that may positively influence patients' adherence to treatment.

In the present study, there was a predominance of women, close to 60 years. This may possibly be related to the higher frequency of breast cancer diagnosis. These data corroborate a previous study, carried out at the same institution in 2018[5]. Nevertheless, the data differ from a Spanish study, where the diagnosis was most frequent in men, with an average age of 65 years, married and not working[16].

The clinical data of this study indicated a higher frequency of breast cancer, with the presence of metastases in lymph nodes and bones, as well as during palliative chemotherapy treatment. These data are partially dissenting from the prospective research conducted in Spain on patients with advanced cancer (n=863); lung, bronchial and non-colorectal digestive cancers were the most frequent. However, the data are consistent with palliative chemotherapy treatment, which was the most frequent. Patients with advanced cancer still have chemotherapy as the most prescribed treatment, regardless of the type of tumor. Therefore, they end up presenting greater toxicity and decline in clinical performance. In 59% of cases, treatment is suspended, dose adjustments or cycle delays occur; 87% of patients have a high risk of death[17].

A survey of (n=1,030,937) North American patients with advanced cancer highlighted that 82.6% of deaths are related to the evolution of metastatic disease or treatment complications, while 17.4% died from concurrent causes. The sites with the highest probability of dying from metastatic cancer are lung, pancreas, esophagus and stomach, while those with prostate and breast disease have a lower probability, with an average survival time limited to 10 months[18].

In the present study, attention was drawn to the imprecision of patients' knowledge about the stage of their disease. Only half of them had clarity about the advanced disease and just over 30% were unaware of the stage, with consequent misunderstandings about the objectives of treatment. This fact was also corroborated by a cross-sectional study carried out in the oncology hospital of Barretos/SP - Brazil, with dyads of outpatients with advanced cancer and their oncologists, the agreement between both on perceptions regarding treatment objectives and curability was small[19].

In Asian cultures, there are beliefs that information about the current stage of disease can harm health; the study investigated this fact in (n=195) patients with advanced cancer (stage IV) and highlighted that 74.9% were aware of the stage and 41% preferred to know about life expectancy, although 75% did not know the intention of treatment. The results of the study indicated that there was no association between the level of knowledge about the extent of the disease and the psychological suffering of patients.

Nonetheless, those who were aware of the advanced condition had significantly higher scores for quality of life in the social welfare aspect[20].

Prognostic awareness depends on how patients attach value to health information, expected survival and quality of life, impact on significant life events, uncertainty and affection with the professional. Patients highlight knowledge as a way of coping, important in decision-making and maintenance of normality despite the prognosis[21]. Understanding the prognosis of patients with advanced cancer is important in planning better care, although a systematic review indicates that 50% of patients had no knowledge of the prognosis, and this awareness was not significantly associated in 48% of the participants or 40% with worse results, which may be variably associated with quality of life[22].

Our results are predominant in pointing out the lack of knowledge of patients about NPT, the non-indication by health professionals and their low use concomitant to cancer treatment. Although Brazil has a National Policy of Integrative and Complementary Practices (PICS – *Política Nacional de Práticas Integrativas e Complementares*) inserted in the Brazilian Unified Health System (UHS) since 2006, these are not routinely prescribed to cancer patients[11].

In Italy, a cross-sectional survey conducted with patients (n=283) with advanced cancer at home, predominantly male and average age of 73 years, only 4.2% were using any NPT, similar to this survey; However, 50% of the therapies were prescribed by a health professional in different modalities, which differs from our study[22]. In another context of populations with advanced cancer, a survey conducted in Atlanta/USA with (n=100) African-Americans without health insurance, sample composed mostly by men, with an average age of 64.2 years, elementary school and almost all unemployed. Some knowledge about NPT was presented by 22% of the participants, 16% made use or 4.2% were in use of some modality, with higher prevalence of meditation, herbal therapies, yoga and acupuncture, either alone or often combined, 70% would like to receive information about NPT from health professionals[23].

The NPT in cancer treatment are under development, clinical and integrative oncology societies support the indication of modalities with strong evidence in specific clinical conditions: mindfulness, cognitive therapy and tai chi or qigong in the management of fatigue and stress; mindfulness, yoga, hypnosis, relaxation therapies, music therapy, reflexology, acupuncture, tai chi and essential oils of lavender for anxiety control; mindfulness during active treatment of depression[24]. Despite this, there are still limited publications with robust methods and systematic reviews that prove the evidence of various NPT in different populations and integrated into tertiary care[11].

NPT can help in the quality of life of patients, both by alleviating the symptoms of chemotherapy and the effects of cancer. A review study highlighted that different NPT, such as yoga practice, acupressure, acupuncture, reflexology, aromatherapy massage and medical Qigong positively influence emotional disorders (such as depression and anxiety), pain, physical conditioning, sleep disorders and

quality of life[25].

The Integrative Oncology Society (*Sociedade de Oncologia Integrativa*) recommends the development of research on NPT, which were considered safe and effective to be integrated during conventional treatment, although there are several barriers in training, lack of knowledge and receptivity of health professionals, low production of evidence, lack of funding and implementation in clinical practice[26-27].

Study Limitations

This study had limitations. The number of participants, although significant, was recruited in only one institution, which implies limited generalization of results, although they are inspiring. In addition, the questionnaire on prognostic knowledge and non-pharmacological therapies used in the study was not a previously validated research tool in our population, which could be further explored.

Contributions for Nursing, Health or Public Policy

This research is relevant because it allows health professionals to understand how patients with advanced cancer perceive the objectives of palliative treatment and use of non-pharmacological therapies during the therapeutic itinerary. It can help in the articulation and training of professionals regarding communication with patients about palliative treatment and the use of non-pharmacological therapies.

CONCLUSION

The study investigated the knowledge of patients with advanced cancer about diagnosis, treatment objectives and use of non-pharmacological therapies during their therapeutic path. In summary, when the patient's knowledge regarding advanced cancer and the objective of its treatment were evaluated, it was shown that there are limitations in participants' understanding of the disease stage and palliative treatment objectives. In relation to non-pharmacological therapies, the scenario is aggravated, besides the lack of knowledge by patients, the non-indication by their professionals and the low use of different existing modalities were identified.

Given the above, it is urgent that health professionals develop compassionate and assertive communication skills in the care of people with advanced cancer, especially regarding the dialogue on diagnostic, prognostic and therapeutic information, as well as to clarify and undertake efforts to implement the different modalities of non-pharmacological therapies with available evidence for the management of different clinical conditions in this population with the aim of promoting a better quality of life.

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Acknowledgments: National Council for Scientific and Technological Development (CNPq – *Conselho Nacional de Desenvolvimento Cinetífico e Tecnológico*), through notice 09/2022 – Research Productivity Grant and through CNPq grant code 001.

Funding: None.

Authors' contributions: Conception and design of the research: Leonel dos Santos Silva; Acquisition of data: Leonel dos Santos Silva, Ana Paula Felicio de Lima and Cleo Watanabe Pisaia; Analysis and interpretation of the data: Lourdes Maria Rosinski Lima Gomes and Paulo Ricardo Bittencourt Guimarães; Writing of the manuscript: Natália Naome Oshiro, Ana Paula Felicio de Lima and Cleo Watanabe Pisaia; Critical review of the manuscript for intellectual content: Luciana Puchalski Kalinke, Luciana de Alcantara Nogueira.

Editor-in-Chief: André Luiz Silva Alvim