








## Social representations attributed to prostate cancer by men undergoing follow-up at an in-hospital oncology service\*

Representações sociais atribuídas ao câncer de próstata por homens em acompanhamento no serviço hospitalar de oncologia

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### ABSTRACT

**Objective:** to understand the social representations of prostate cancer by men undergoing follow-up at an in-hospital oncology service. **Methods:** a qualitative study, developed using the Collective Subject Discourse method, with 30 men over the age of 18 undergoing treatment for prostate cancer. The data were collected through semi-structured interviews and analyzed using the Theory of Social Representations. **Results:** the most shared central ideas in the studied community were as follows: A curable disease; Worry, fear, annoyance and sadness; Loss/Impairment of sex; Nothing, something normal/common; A minor ailment that doesn't shake/shook me, it was faced head on, without fear; Something/Disease that is bad, difficult, serious, intense, dangerous, that ends life and kills. **Conclusion:** the social representations found in this study denoted intense and difficult experiences in dealing with the disease and treatment, but also showed coping, with potential for overcoming/resilience. **Contributions to practice:** understanding these representations enables the implementation of integrated and interprofessional education, assistance and management actions.

**Descriptors:** Prostatic Neoplasms; Nursing; Oncology Nursing; Qualitative Research; Social Representation.

### RESUMO

**Objetivo:** compreender as representações sociais sobre o câncer de próstata por homens em acompanhamento no serviço hospitalar de oncologia. **Métodos:** estudo qualitativo, desenvolvido pelo método do Discurso do Sujeito Coletivo, com 30 homens na faixa etária superior a 18 anos, em tratamento para o câncer de próstata. Dados coletados por entrevistas semiestruturadas e analisados pela Teoria das Representações Sociais. **Resultados:** as ideias centrais mais compartilhadas na coletividade estudada foram: uma doença curável; preocupação, medo, aborrecimento e tristeza; perda/comprometimento do sexo; nada, algo normal/comum; doencinha que não abala/abalou, foi encarada de frente, sem medo; algo/doença ruim, difícil, sério, intenso, perigoso, que acaba com a vida e mata. **Conclusão:** as representações sociais encontradas nesse estudo denotaram experiências intensas e difíceis para lidar com a doença e o tratamento, mas também demonstraram enfrentamento, com potencial para superação/resiliência. **Contribuições para a Prática:** a compreensão dessas representações possibilita a implementação de ações integradas e interprofissionais de educação, de assistência e de gestão.

**Descritores:** Neoplasias da Próstata; Enfermagem; Enfermagem Oncológica; Pesquisa Qualitativa; Representação Social.

## Introduction

Among the neoplasms that most affect the male population, prostate cancer has been responsible for high morbidity and mortality rates. This type of cancer exerts a considerable epidemiological impact since, in 2020, it ranked fourth in terms of incidence worldwide and second among men of all ages. In Brazil, it is the type of tumor that most affects men, regardless of region, with an estimated 71,730 new cases expected for the three-year period from 2023 to 2025<sup>(1)</sup>.

Although statistics indicate high incidence, prostate cancer has a good prognosis when diagnosed early in time. The available therapies are broad and indicated according to evolution of the disease, the general clinical condition and life expectancy, highlighting the importance of men's participation in the therapeutic decision-making process<sup>(2)</sup>.

Thus, as in other types of cancer, diagnostic and therapeutic interventions offer indispensable benefits for prognostic success<sup>(3)</sup>. However, these interventions can have repercussions in the physical, psychological, social, cultural and spiritual dimensions<sup>(4-7)</sup>. As a chronic condition and singular event in the male imagination, prostate cancer exerts a strong impact on the way of thinking and living with illness, as it is a culturally constructed experience<sup>(8)</sup>.

From this perspective, the theoretical framework adopted for this study considers Social Representations as ways of understanding, which imply that subjects share common language, values and memories, which, in turn, shape reality and modify behaviors concerning this reality. Thus, knowledge is constructed in search of familiarity with what is presented about the reality undergone, conveyed through communication, which nuances behaviors and practices, which are also forms of expression of these meanings<sup>(9)</sup>.

Therefore, studies that seek to understand the meanings attributed to prostate cancer by men oftentimes point out negative aspects that compromise search for care, adherence to therapy, quality of life

and self-perception<sup>(4,8)</sup>. In the literature, the results of studies that highlight meanings capable of stimulating effective coping with prostate cancer are still limited.

This study was developed after identifying knowledge gaps that aim at understanding the social representations of men affected by prostate cancer from a perspective that contributes to reframing the illness process. The objective was to understand the social representations of prostate cancer by men undergoing follow-up at an in-hospital oncology service.

## Methods

This is a qualitative research study anchored in the Theory of Social Representations<sup>(9)</sup>. The Consolidated Criteria for Reporting Qualitative Studies (COREQ) guide was used to write the manuscript.

The research context was a hospital service for cancer treatment in the southern region of Minas Gerais, a reference for 26 municipalities. The participants were men who met the following inclusion criteria: aged 18 years and over, diagnosed with prostate cancer (ICD C61), at different stages of the disease, and followed-up by the in-hospital Oncology service. People who had difficulty answering at least two of the following questions were excluded: What is your full name? What month are we in? What day of the week is today? What is the name of the city we are in now? No non-inclusion criteria were used in this research.

Fifty five (55) men with prostate cancer were contacted; however, 23 were unable to remain until the end of the interview due to appointment times and intercity transportation, and two refused to participate. Thus, 30 men took part in this study. The number of study participants does not need to be limited for the Collective Subject Discourse (CSD) method<sup>(10)</sup>.

The data were collected between July 2019 and January 2020. The men were approached personally in the waiting room of that institution and invited to participate in the study by the main researcher, who was an MSc student in Nursing with experience in qua-

litative data collection. After consent, they were taken to a reserved room to carry out the interview, with the sole presence of the researcher and the interviewee, this being the first contact with the participants.

The participants were informed about the study objectives and the importance of their experiences with the illness, and were informed that there would be no judgment of values, and that an interview was going to be being carried out with each participant.

The data were collected through access to medical records (clinical data: diagnosis, treatment and staging) and semi-structured interviews. To this end, an instrument consisting of two parts was used: the first one was related to sociodemographic and clinical characterization and the second, to the guiding question. The question was formulated aiming to get closer to the social imaginary, in which the following was asked: If in a conversation with someone you knew well, that person asked you "What is prostate cancer, or what did it mean to you?", what would you answer?

The information regarding the participants' clinical characterization was collected from medical records under supervision of the professional in charge of the archives sector. The testimonies were recorded using a digital recorder and a cell phone with a recording app and transcribed in accordance with the spoken word. Each interview lasted a mean of twenty-seven minutes, and the set of interviews totaled 13 recording hours, transcribed with the help of *Microsoft Word 2010* and totaling 166 pages in font 12.

Each interview was transcribed immediately after it was conducted and was not subsequently shared with the participants. The interviewees' characterization data were analyzed in *Microsoft Excel 2010* using descriptive statistics (absolute and relative frequencies).

The qualitative data were read horizontally and vertically, and the following instruments were used for analysis: Discourse Analysis 1 (IDA1) and 2 (IDA2)<sup>(11)</sup>. After analyzing the data and Key expressions, equal, similar and complementary Central Ideas were grouped; emerging meanings were listed, the participants

who contributed to the process with each representation were described; and, subsequently, the CSD<sup>(10)</sup> was prepared. This stage included the participation of three researchers with expertise in the method.

CSD is a method for tabulating and organizing qualitative data that allows researchers, based on a systematic analysis, to understand the representations of a community on a topic. This method associates, in each category, contents of similar meaning contained in different testimonies, assembling a summary statement written in the first person singular, which represents the Collective Subject Discourse<sup>(10)</sup>.

The participants' identity was preserved, with their names replaced by the letter "I", meaning Interviewee, followed by an Arabic number. Example, I1, I2, I3... I60. The ethical principles established in Resolution 466/12 were complied with and the research was approved by the Research Ethics Committee of *Universidade Federal de Alfenas*, under opinion No. 3,199,866/2019 and Certificate of Presentation of Ethical Appraisal: 08784919.7.0000.5142.08784919.7.0000.5142.

## Results

The interviewees' age varied from 53 to 87 years old, with predominance of 70 to 79 years old (46.6%). Regarding skin color, 43.3% declared themselves of mixed race and 33.3% as white-skinned. In relation to other characteristics, the majority stated being married (60%) and having Incomplete Elementary School (60%), as well as being Catholics (70%), retired (80%) and earning monthly incomes of one to three minimum wages (83.3%). Among the participants, (46.6%) perceived their financial situation at the moment as good and fair. Regarding lifestyle, 63.3% did not consume alcohol and 50% denied the smoking habit; however, 50% were former smokers.

Regarding the clinical characteristics, it was found that the referrals to the Oncology service were made by the Unified Health System (86.7%), diagnosed more than a year ago (80%), did not present me-

tastasis (76.7%) and underwent radiotherapy or chemotherapy treatments (66.7%).

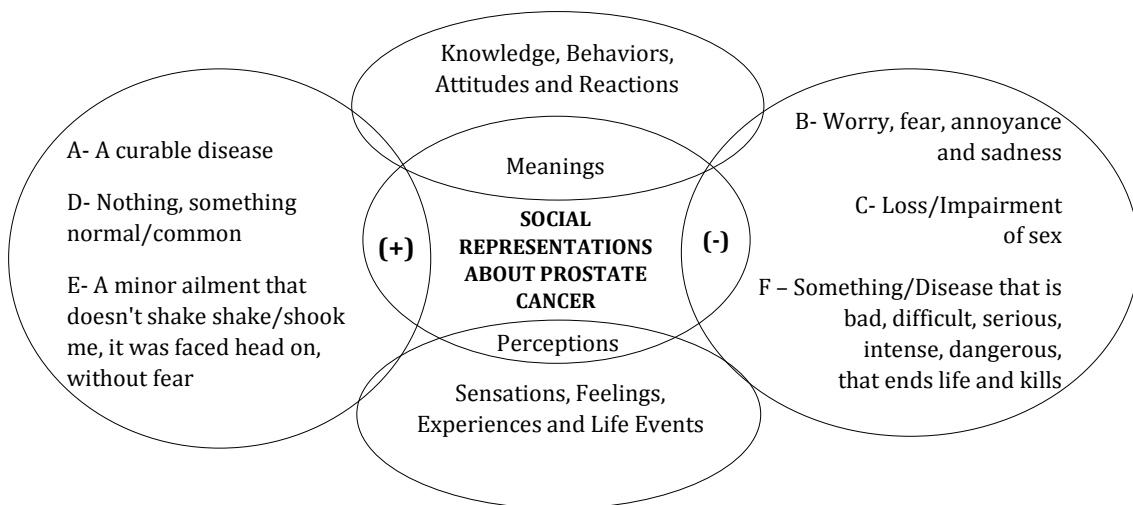
The most shared central ideas in the studied group were the following: “A curable disease”; “Worry, fear, annoyance and sadness”; “Loss/Impairment of sex”; “Nothing, something normal/common”; “A minor ailment that doesn’t shake/shook me, it was faced head on, without fear”; “Something/Disease that is bad, difficult, serious, intense, dangerous, that ends life and kills”.

The groupings of Central Ideas that constituted the prostate cancer representations and the participants’ descriptions are presented in Table 1.

It was understood that the representations were related to perceptions, sensations, experiences, life events, feelings, knowledge, behaviors, attitudes and reactions towards prostate cancer. The men described these elements in a more painful and impactful way, represented in the image by a negative sign (-) referring to Central Ideas B, C and F. On the other hand, in Central Ideas A, D and E, they showed better coping/resilience perceptions regarding prostate cancer, represented by a positive sign (+). This interpretation guided the discussion and is presented in Figure 1.

**Table 1** – Central Ideas about prostate cancer, study participants and frequency (n=30). Alfenas, MG, Brazil, 2020

Central Ideas	Participants	Frequency (%)
A – A curable disease	I04, I08, I10, I11, E15, I21, I24 and I29	8 (26.7)
B – Worry, fear, annoyance and sadness	I02, I05, I07, I11, I15, I24, I25, and I26	8 (26.7)
C – Loss/Impairment of sex	I02, I04, I05, I06, I11, I18, I19, I25 and I29	9 (30.0)
D – Nothing, something normal/common	I02, I03, I11, I14, I17, I19, I27, I28 and I30	9 (30.0)
E – A minor ailment that doesn’t shake/shook me, it was faced head on, without fear	I08, I09, I12, I14, I15, I16, I18, I21, I22 and I27	10 (33.3)
F – Something/Disease that is bad, difficult, serious, intense, dangerous, that ends life and kills	I07, I08, I11, I12, I15, I17, I18, I24, I25, I26 and I29	11 (36.7)



**Figure 1** – Illustrative synthesis of the social representations about prostate cancer based on the meanings of the collective subject(n=30). Alfenas, MG, Brazil, 2020

Subsequently, the CSD of Central Ideas A, D, E, B, C, E and F are presented, according to the grouping represented in Figure 1, referring to the social representations emerging from the studied group.

**CSD of Central Idea A - A curable disease:** *When this disease is discovered early on, there is a cure! Fifteen to 20 years ago, I began visiting the doctor for every little issue, people might say I'm soft, many men say: whoever looks for it finds it! I say, if we find it in the beginning, there is a cure for it. The doctor said: if I were to have cancer, I would want to have prostate cancer, prostate cancer is one of the easiest to cure. I believe that God heals, but gave us doctors, God blesses that medicine and I drink it with faith, then it heals. God gave the disease, God heals! Yes, there is a cure* (I04, I08, I10, I11, I15, I21, I24 and I29).

**CSD of Central Idea D - Nothing, something normal/common:** *I think this is very normal today, especially in people aged 50 and over, it is such a common disease among men, it is the same as breast cancer in women, isn't it, cervical cancer. I expected this, almost everyone in my family faced cancer. I'm here for whatever God sends; I don't torment myself with anything For me it was nothing* (I02, I03, I11, I14, I17, I19, I27, I28 and I30).

**CSD of Central Idea E - A minor ailment that doesn't shake/shook me, it was faced head on, without fear:** *For me, this is a minor ailment, the simplest thing ever! I faced it head on, hard, firmly, I fought it, without being afraid at any time and, to this day, I don't let the guard down. It wasn't very sad. God wanted it this way, we will get through it, I'm calm, I was very conscious, I went and said: I have the problem, but I have to find a way, so I didn't despair so much! It doesn't affect me, this little illness, it's just a little thing!* (I08, I09, I12, I14, I15, I16, I18, I21, I22 and I27).

**CSD of Central Idea B - Worry, fear, annoyance and sadness:** *For those who have never had an illness, it's very sad, it causes worry, a lot of annoyance and harm... There's that worry about visiting the doctor every month, having that treatment. It means fear, I don't want to suffer, two of my friends suffered a lot, they died skin and bones because of the prostate, this disease is very sad* (I02, I05, I07, I11, I15, I24, I25 and I26).

**CSD of Central Idea C — Loss/Impairment of sex:** *It really interfered with sex, it determined the sexual aspect, it was the heaviest burden, because sex is something that's good for your health, and losing something you're used to doing is always terrible. We feel down as men, a lot of people talk nonsense, that those*

*who have prostate cancer are no longer men! Men are reproducers, to a certain extent it is men's animal instinct and they don't have much control over it, I think that a healthy man losing his potency is the same thing as losing his life! And doctors aren't too worried about men's sex life, the doctor said: what you had to do, you already did. Men suffer so much from this!* (I02, I04, I05, I06, I11, I18, I19, I25 and I29).

**CSD of Central Idea F — Something/Disease that is bad, difficult, serious, intense, dangerous, that ends life and kills:** *Prostate cancer only meant bad things for me, because it was very difficult, it was intense, it was terrible! It's a very serious disease, you can't joke around, this disease really kills! I don't want this to happen to anyone, I made the family suffer too much! I wanted to kill myself! When I found out, I just kept crying, I worried about saying: "cancer" is the worst disease that exists so far! Six of my family members died, it runs like the wind. There are many who don't accept it, but if it came to me, it has to touch me, which is not good, it's not, it's very difficult, it brings me down so much* (I07, I08, I11, I12, I15, I17, I18, I24, I25, I26 and I29).

## Discussion

In CSD A — A curable disease, men said that, among other types, prostate cancer is a curable disease, and that treatment in the early phase is related to this favorable outcome. Removal of the prostate, the reduction of clinical manifestations and professional guidelines may have contributed to the foundation of these social representations.

It is understood that healing is seen as something to be achieved by those who aim for preventive health care, such as early diagnosis, and that this attitude is not well received in the male universe, as they can be called "soft", which goes against the precepts of hegemonic masculinity.

Thus, men point out that this attitude may not be well regarded by the group, as they violate conduct standards established by the concepts of invulnerability, which may show certain dissociation from this universe of belonging. Additional results were observed in which the participants faced the dilemma between following what they thought was cor-



rect, moving away from the precepts of masculinity, or following what “others” said and not taking care of themselves, thus affecting their own health<sup>(4)</sup>.

They pointed out that medical treatment, associated with divine providence, would be capable of leading to a cure. Thus, it is understood that the social representations, learned through religious practices, can guide and orient behaviors and contribute to adherence to the treatment and to the hope of curing the disease. A similar result was observed in a study where religiousness/spirituality was seen as a source of support and hope for a cure in the face of the challenges experienced when diagnosed with prostate cancer<sup>(12-13)</sup>.

In CSD D — Nothing, something normal/common, it is observed that men perceive prostate cancer as something natural, possibly because they are in the age group of 53 to 87 years old, which corresponds to the high incidence of this type of cancer<sup>(1)</sup> and also due to family history of the disease. This naturalization can be related to identity representations, in which subjects seek to familiarize themselves with their “group of equals”.

A family history of cancer can motivate behaviors that are in line with prostate cancer preventive actions; on the other hand, those who did not have this history did not realize this need<sup>(14-15)</sup>.

When relating prostate cancer to breast and cervical cancer, the subjects showed knowledge about the cancer specificities according to sex<sup>(16)</sup>. These representations suggest that women and men should wait for these diseases, as they constitute problems that may affect their groups. It is up to health professionals to appropriate these representations that place subjects in their social environment, examining whether they are factors that encourage or discourage care, thus adding support to the planning of their actions.

In CSD E — A minor ailment that doesn't shake/shook me, it was faced head on, without fear, the men reported prostate cancer using the diminutive form of the word disease/ailment to signify this problem as

something minor. By attributing this meaning, it is understood that they place themselves in a position of superiority in relation to cancer. They said that they faced prostate cancer with “hardness”, a word that anchors symbolic concepts related to the paradigm of hegemonic masculinity, which may indicate that they consider themselves unshakable in the face of illness<sup>(17)</sup>.

Although these men feel “stronger” in the face of the disease, which contributes to coping, health professionals need to consider the minimizing meanings of the disease in their work process, as this can contribute to low adherence to the therapy and exert impacts on the treatment and, consequently, on the clinical outcome.

This position of superiority can refer to the concept of invulnerability and guide representations and behaviors of non-adherence to the treatment and preventive exams for prostate cancer<sup>(15)</sup>. Recognizing this context and the challenges arising from these behaviors, it is considered that involvement in Primary Care services is crucial to develop in the male population a sense of belonging to spaces for health promotion, protection and recovery, in accordance with the National Policy for Comprehensive Men's Health Care<sup>(18)</sup>.

Innovative educational actions can contribute to bringing men closer to health services from a longitudinal perspective, to minimize male prejudice towards rectal exams and, consequently, to demystify the ideal of male invulnerability<sup>(14)</sup>. In this context, Nursing care in the promotion and prevention of prostate cancer is as necessary as fundamental.

In CSD B — Worry, fear, annoyance and sadness, the men showed sadness, fear and concern regarding the illness, as well as apprehension towards the permanent need for monitoring by health professionals. Representations of pain and suffering attributed to cancer, strongly present in common sense<sup>(8)</sup> and associated with negative experiences, seem to have favored these feelings.

Longitudinal monitoring in the health service

was a reason for concern for men, which they considered the “bad side of the disease”<sup>(19)</sup>. The results showed that the prostate cancer diagnosis raised existential thoughts in the participants about the survival prospect in the face of a potentially lethal disease and the possibility of the treatment causing lifelong suffering<sup>(20)</sup>. Negative feelings attributed to prostate cancer converge in the literature, in which men expressed sadness, fear, low self-esteem and social isolation<sup>(7-8,21)</sup>.

In people with cancer, anguish and well-being were associated with perceptions of the disease and coping behaviors<sup>(22)</sup>. Health professionals must act in a comprehensive and sensitive manner, contributing to acceptance of the disease and adherence to the treatment. From this perspective, it is essential to look at the biopsychosocial, cultural and spiritual dimensions, recognizing that any person experiencing a chronic condition presents weaknesses and care demands in these dimensions<sup>(23)</sup>.

CSD C — Loss/Impairment of sex reveals that, for the participants, having compromised sexual activities represents one of the worst impacts of prostate cancer, as it affects their identity as men.

It is clear from these statements that the principles of hegemonic masculinity permeated men’s social imagination due to the fact that sexual vigor is considered inseparable from being a man, in which loss of this capacity leads them to feel less of a man and, therefore, no longer belonging to their identity group.

Similar meanings were evidenced, in which the subjects reported that a real man is one who keeps the reproductive organs functioning, expressing regret for the loss of sexual performance or for sexual impairment. Thus, sexual capacity constitutes a social determinant of masculinity<sup>(4,16,24)</sup>. In addition to that, the participants reported that health professionals have difficulties dealing with issues related to sexual capacity, pointing to an unmet care need<sup>(25)</sup>.

In view of the harms resulting from erectile dysfunction, which impacts on the biopsychosociocultural dimensions and male identity, it becomes necessary for health professionals, from an interdisciplina-

ry perspective, to create conditions that favor dialog and offer support to face these difficulties, collaborating so that men can attribute new meanings to their role in society<sup>(18)</sup>.

In CSD F — Something/Disease that is bad, difficult, serious, intense, dangerous, that ends life and kills, the subjects showed that prostate cancer exerted an intense impact on their lives, reporting it as a serious disease that can kill. It was very difficult, intense and terrible for the men, which denotes the experience of individual and family distress.

In addition to that, as a result of the suffering experienced, the men expressed representations that can be related to suicidal ideation. The impact on these men’s mental health is significant, and depressive, anxious and suicidal symptoms were common<sup>(26-27)</sup>. In this understanding, the importance of knowing these perspectives and understanding the causes that can lead to suffering is valued, with the aim of providing care that meets these demands<sup>(7)</sup>.

The participants recognized the seriousness of cancer through the representation that associates it with death, that is, a negative outcome. By associating the disease with the “wind”, they represented the rapid evolution of the disease with a terminal outcome. Some authors present similar results, in which the participants associated prostate cancer with a disease without a cure, which causes fear and can kill quickly<sup>(13,15)</sup>.

In relation to the reactions to cancer diagnosis, the impact on men’s lives was perceived, due to the severity with which they symbolize the disease. The externalization of feelings and the fact that they verbalized their fears and concerns when faced with the prostate cancer diagnosis reveal a break in the hegemonic masculinity standards, understood as a perception that men demonstrate authority and supremacy, guided by the ideals of invulnerability, such as strength, success, capacity, confidence, dominance, control and virility, still striking and present in the current context<sup>(4,17)</sup>.

Similar testimonies mentioned the impact of

receiving a prostate cancer diagnosis, reporting that men cried a lot and that the belief that “men don’t cry”, socially understood from the perspective of hegemonic masculinity, has no strength at these moments<sup>(28)</sup>. Men with prostate cancer reported negative experiences in relation to words and attitudes at the time they received the diagnosis, which highlights the existence of gaps in the information provided by health professionals and in communication skills to meet their needs<sup>(29-30)</sup>.

Guidelines that help understand the illness and the treatment course are essential for comprehensive care and satisfaction with the Nursing assistance received<sup>(16)</sup>.

## Study limitations

Although the qualitative approach adopted for this study does not allow generalizing the results to other groups of men with prostate cancer, researching men belonging to different age groups and stages of the disease and treatment resulted in understanding unique experiences of the illness process of the researched group.

## Contributions to practice

As a care science, and by appropriating interdisciplinarity and understanding the meanings surrounding illness due to prostate cancer, Nursing contributes to promoting resilience and coping, more empathetic and person-centered care, the exercise of dialog, knowledge feedback, understanding of health demands and sociocultural contexts, with a view to implementing assertive and coherent care actions.

## Conclusion

It is understood that men’s social representations in relation to prostate cancer denote intense and challenging experiences regarding the illness and treatment. In addition to that, they showed the ability to

cope and overcome, indicating resilience. It is also inferred that these representations played a significant role in shaping the men’s individual concepts, values, beliefs and behaviors. Therefore, this study provides insights that can improve the Oncology Nursing practice by promoting holistic, person-centered care.

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## Authors’ contributions

Conception and design or data analysis and interpretation; writing of the manuscript or critical review of the intellectual content; final approval of the version to be published; agreement to be responsible for all aspects of the manuscript related to accuracy or integrity to be appropriately investigated and resolved: Peloso-Carvalho BM, Nascimento MC, Fava SMCL.

Writing of the manuscript or relevant critical review of the intellectual content and final approval of the version to be published: Lima RS, Silva JV, Dázio EMR. Conception and design or data analysis and interpretation; final approval of the version to be published; agreement to be responsible for all aspects of the manuscript: Sawada NO.

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