

Nurses' Perceptions of Cancer Survivorship in Brazil

<https://doi.org/10.32635/2176-9745.RBC.2024v70n2.4556>

Percepções de Enfermeiros sobre a Sobrevivência ao Câncer no Brasil

Percepciones de las Enfermeras sobre la Supervivencia al Cáncer en Brasil

Antonio Tadeu Cheriff dos Santos¹; Fernando Lopes Tavares de Lima²; Maria Lúcia Magalhães Bosi³; Liz Maria de Almeida⁴

ABSTRACT

Introduction: In Brazil, there is an emerging discussion regarding care plans and concerns related to the needs of cancer survivors. **Objective:** This study aimed to understand the experience of oncology specialist nurses in providing care to cancer survivors. **Method:** This exploratory qualitative research was conducted through an exploratory approach with a qualitative focus, carried out in two public hospitals and two private hospitals located in Fortaleza and Rio de Janeiro. Data were collected through in-person focus group sessions in each city, with 11 and 8 participating nurses, respectively. Thematic analysis was employed to analyze the data. **Results:** The study revealed an understanding that having cancer impacts individuals and society across various dimensions. Notably, the interplay between physical, psychological, social, and economic well-being was highlighted. Additionally, challenges related to the unpreparedness of services and professionals to address these comprehensive needs were identified. **Conclusion:** These aspects should guide the reconstruction of policies and practices aimed at supporting people with cancer in Brazil, particularly in optimizing care processes and attending to the long-term needs of unsatisfactorily addressed survivor groups.

Key words: Cancer Survivors/psychology; Nursing Care; Health Services Needs and Demands; Oncology Nursing.

RESUMO

Introdução: No Brasil, há uma discussão incipiente acerca de planos de cuidados e/ou preocupações voltadas para as necessidades dos sobreviventes ao câncer. **Objetivo:** Compreender a experiência de enfermeiros especialistas em oncologia na prestação de cuidados aos sobreviventes ao câncer. **Método:** Pesquisa exploratória, com abordagem qualitativa, realizada em dois hospitais públicos e dois hospitais privados localizados em Fortaleza e no Rio de Janeiro. Os dados foram produzidos por meio de um grupo focal realizado presencialmente, em cada cidade, participando 11 e 8 enfermeiros, respectivamente. A análise dos dados foi realizada por meio da análise temática. **Resultados:** Identificou-se uma compreensão de que o adoecimento por câncer afeta os indivíduos e a sociedade em suas diferentes esferas, destacando-se as interações entre as necessidades de bem-estar físico, psicológico, social e econômico, e as dificuldades e o despreparo dos serviços e profissionais para o atendimento integral dessas necessidades. **Conclusão:** Tais aspectos devem servir como norteadores para reconstrução das políticas e práticas destinadas às pessoas com câncer no Brasil, em especial, na otimização dos processos de cuidados e atenção às necessidades dos grupos de sobreviventes de longo prazo.

Palavras-chave: Sobreviventes de Câncer/psicologia; Cuidados de Enfermagem; Necessidades e Demandas de Serviços de Saúde; Enfermagem Oncológica.

RESUMEN

Introducción: En el Brasil, hay una discusión que ha surgido sobre los planes de atención y las preocupaciones relacionadas con las necesidades de los sobrevivientes de cáncer. **Objetivo:** Comprender la experiencia de las enfermeras especialistas en oncología al brindar atención a los sobrevivientes de cáncer. **Método:** Investigación exploratoria, con enfoque cualitativo, realizada en dos hospitales públicos y dos hospitales privados ubicados en Fortaleza y Río de Janeiro. Los datos se recopilaron a través de sesiones de grupos focales en persona en cada ciudad, con 11 y 8 enfermeras participantes, respectivamente. Se utilizó el análisis temático para examinar los datos. **Resultados:** Se identificó una comprensión de que la enfermedad del cáncer afecta a los individuos y a la sociedad en diversas dimensiones. Se destacó especialmente la interacción entre el bienestar físico, psicológico, social y económico. Además, se identificaron desafíos relacionados con la falta de preparación de los servicios y profesionales para abordar estas necesidades integrales. **Conclusión:** Estos aspectos deberían guiar la reconstrucción de políticas y prácticas destinadas a apoyar a las personas con cáncer en el Brasil, especialmente en la optimización de los procesos de atención y en la atención a las necesidades a largo plazo de los grupos de sobrevivientes insatisfactoriamente atendidos.

Palabras clave: Sobrevivientes de Câncer/psicología; Atención de Enfermería; Necesidades y demandas de servicios de salud; Enfermería Oncológica.

^{1,2}Instituto Nacional de Câncer (INCA), Divisão de Pesquisa Populacional, Núcleo de Pesquisa e Estudos Qualitativos. Rio de Janeiro (RJ), Brasil. E-mails: cheriff@inca.gov.br; flima@inca.gov.br. Orcid iD: <https://orcid.org/0000-0002-3577-0772>; Orcid iD: <https://orcid.org/0000-0002-8618-7608>

³Universidade Federal do Ceará, Faculdade de Medicina, Departamento de Saúde Comunitária. Fortaleza (CE), Brasil. E-mail: malubosi@ufc.br. Orcid iD: <https://orcid.org/0000-0001-9742-9230>

⁴INCA. Rio de Janeiro (RJ), Brasil. E-mail: lalmeida@inca.gov.br. Orcid iD: <https://orcid.org/0000-0002-2359-0651>

Corresponding Author: Antonio Tadeu Cheriff dos Santos. Rua Marquês de Pombal, 125, 7 andar – Centro. Rio de Janeiro (RJ), Brasil. CEP 20230-240. E-mail: cheriff@inca.gov.br



INTRODUCTION

In the context of social sciences, cancer is understood as a constitutive aspect of contemporary social life¹. Characterized by anthropologist Lochlann Jain as a total social fact, according to the concept by anthropologist Marcel Mauss, cancer is an event whose clinical, social, economic, and biographical effects intersect with apparently different areas of human life, intertwining them in a complex and pungent way¹. Individually, such effects that follow a cancer diagnosis can directly impact patients and their families in the physical, psychological, and socioeconomic spheres².

Such a process, nowadays called “cancer survivorship”, is a public health challenge affecting a heterogeneous population with complex needs, from the diagnosis to the post-treatment phase and, eventually, end of life care^{3,4}. Though there are recommendations and survivorship care proposal plans in the USA and Europe to help coordinate care in the specialized and primary care spheres^{4,6}, the actual effectiveness and reach of these measures still lack adjustments and substantiation⁷.

In Brazil, though there are studies on the theme^{2,8,9}, those are still incipient regarding a broad and systematized discussion on care plans and/or concerns regarding needs of cancer survivors, especially long term and late needs. Due to the health system’s epidemiological and organizational factors in this country, the focus of interventions and policies for cancer control are more targeted to the promotion of health, early diagnosis, and treatment of new cases, while the needs for structured and integral follow-up in the post-treatment phase is set aside^{2,9}.

Considering the importance and possibility of multiple views on this issue, this article will help understand it through the perspective of oncology specialist nurses who work directly in the different phases of cancer treatment and post-treatment. Thus, the objective of this study is to understand and interpret the experience of oncology specialist nurses in providing care to cancer survivors.

METHOD

Exploratory research with a qualitative approach guided by interpretive tradition^{10,11}. This approach was preferred as it enables the understanding of subjective narratives and experiences of participants¹².

It is worth noting that this study is a framing of a much broader research, aimed at understanding cancer survivorship in Latin America, whose first stage was published in 2020². The chosen field of study were two public hospitals and two private hospitals located in Rio

de Janeiro and Fortaleza where the oncology nursing teams that took part in the study worked.

The discursive material was elaborated through an in-person focus group on each city. The focus group is a data collection and production technique that uses the synergistic effects of elaborating ideas through discussions that may not arise in individual interviews¹³. The discussions were especially useful to explore complex issues and problems involved in identifying needs and providing care to cancer patients in the post-treatment phase.

The two focus groups were mediated by researchers with extensive previous experience in qualitative health research. An open questions script guided the focus groups’ discussions. The script was based on the literature regarding needs and issues of cancer’s post-treatment phase^{5,14,15}, with adaptations to the Brazilian context made by the authors. The chosen procedures allowed the researchers to stimulate free verbalization and gather personal testimonies. The data production was carried on until the desired power of information was obtained¹⁶. To increase reliability, field notes were also taken to better understand the interactions in the group sessions.

In Rio de Janeiro, the group was formed by eight nurses and had a duration of 1 hour and 40 minutes. In Fortaleza, the focus group was composed of 11 nurses and had a duration of 1 hour and 35 minutes. The number of participants was chosen following the literature’s recommendations¹³ and recruiting was based on convenience sampling, with the inclusion criteria being professionals with at least two years of experience in nursing and one year working in the oncology ward in one of the selected hospitals. The participants were identified and contacted directly by the researchers through email and phone, with no pre-existing relationships between them.

The data were analyzed by content themes based on the interpretivist paradigm through an interactive process composed of five steps^{13,17,18}. In the first step, a professional transcriber transcribed all the Portuguese audio recordings. To ensure reliability, the transcriptions were compared to the audio recordings. The generated texts were independently read by the researchers to identify recurring ideas and provide an immersion in the whole material.

In the second step, researchers manually coded all transcriptions independently, summarizing the outstanding characteristics of the data produced. Later, in the third step, researchers gathered to discuss the coding and identify and solve disagreements. In the fourth step, the coded texts with similar ideas were grouped and classified to identify emerging topics and subtopics and select expressive excerpts for citations. The fifth step



consisted of a meeting with all the researchers to review and confirm the decisions made on the previous step. The objective of this meeting was to present and review the results emerged and define the final themes, increasing the analysis' credibility.

The study has been approved by the institution's Research Ethics Committee, (CAAE (submission for ethical review): 22698713.2.0000.5274), approval report number 792.271 in compliance with Resolution n. 466/2012¹⁹ of the National Health Council. The participants signed the Informed Consent Form (ICF) in the same day of the focus group meeting. To ensure anonymity, the participants were coded randomly by sequential numbers, differentiating only the focus group in Fortaleza with codes "F1" to "F11" and that in Rio de Janeiro with codes "R1" to "R8".

RESULTS AND DISCUSSION

All participants were females, with a mean age of 40 years old and on average 13 years' experience in oncology. Most of them (16 nurses) worked in the public and private sectors (11 nurses) as well as in different oncology wards (8 nurses), which helped to reach power of information^{16,20}.

The synthesis of meanings presented by the nurses demonstrates an understanding that having cancer impacts individuals and society across various dimensions (biographical, social, cultural, technological, and economic), approaching it to the concept of total social fact¹ presented earlier. The highlights included the existing interrelationships between physical, psychological, social, and economic needs and the unpreparedness of services and professionals involved in providing necessary care for addressing those needs. Thus, though each need is presented in a thematic section in this article, they must be understood in relation to each other, knowing that the body dimension includes issues related to psychic suffering, access to social support network and the socioeconomic context of patients, vital elements for any successful cancer control and integral care approach.

THE BODY DIMENSION

From the focus groups narratives', it was possible to observe that nurses are used to witnessing the physical alterations caused by cancer or its treatment. These alterations involve body image, sexuality, and pain.

For alterations in the body image, they specifically highlighted those affecting skin, hair, and nails. These alterations are due to the treatment and cause a negative impact in the aesthetic self-perception of some of the survivors, which directly affects their self-esteem.

They can present skin and nail color alteration, or have nails fall off [...]. They come in with their nails quite darkened, asking if it's normal, showing that their nails are black, their skin is black (F7).

The body image in cancer patients is a complex and diverse topic as, together with the physical-clinical aspects involved, it carries a series of emotional, psychological, and social meanings that merge and affect the journey and experience of being ill and the treatment of oncological patients. Thus, body alterations caused by the oncological treatment not only activate physical-clinical changes, but also directly harm self-image, which can negatively impact the emotional and social lives of patients^{21,22}.

Another physical alteration highlighted by the participants is the difficulty that cancer survivors find in maintaining an active sexual life, especially those diagnosed with cervix and prostate cancer. Due to the great impact these issues have in the psychological and social aspects of the survivor, the qualification of care provided to minimize these issues was considered extremely relevant.

We clearly notice that the patient's return to an active sexual life is heavily impacted by radiotherapy (R1).

They will always have skin issues, women will have issues with waxing, [...]. So, all this changes women's sensibility. It affects their life (R8).

They keep returning to the nursing ward because they feel more at ease talking to a nurse about these issues than to a doctor. Specially because doctors will be like: 'Look, you're healed, you don't have cancer anymore, this is what you should focus on, go easy on everything else, just take it easy, you'll adjust, there's always a way.' But what is that way? [...] They have to tell them (R8).

This absence of integral care reflects the hegemony of the biomedical model in health care training²³, in which the subject is excluded, and consequently, their sexuality, race, gender, and social class. Sexual dysfunction in cancer patients remains underdiagnosed and undertreated. The focus is on the biological dimension of the base disease, which affects the sick biomedical body. The constitution of specialized multidisciplinary services to cater for the intimacy and sexuality issues arising from treatments provided should also be seriously considered²⁴. It is imperative that health professionals, especially gynecologists, oncologists and urologic oncologists review their references and include a broad assessment of sexual health as part of their routine evaluation of these patients.



In addition to issues related to alterations in the body image and active sexual life, participants also reported the need for pain management, presented as the main complaint of people that suffer from cancer. According to the participants, despite the impact that oncological pain has on survivors, the subject is usually minimized by the responsible doctors. Such management should then be conducted in a more caring way by the multi-professional team.

In gynecology, pain is expected, but very poorly managed, unfortunately. It is minimized by the medical professional. I'm afraid I have to say it, because the patients turn to their doctors exactly due to the medication issue [...]. It's not just that doctors don't acknowledge their pain, they're just not prepared to manage this kind of pain (R1).

They present peripheral neuropathies, which can be quite limiting. Patients get that feeling of stepping on barbed wire, that's why they don't want to walk. Some drugs give the feeling of, when they ingest some food, [it seems like], they're ingesting shards of glass, which leads them to not want to eat, you see? (F8).

Pain is not exclusive to a category, I cannot prescribe a medication, but I can tell the patient what to do to seek pain relief, I can guide them [...]. I do and I guide them in writing (R8).

The adverse effects of oncological pain are complex and highly individual. In some cases, patients suffer from anxiety or depression, or lose their ability to perform work, hobbies, or other tasks due to their unmanaged pain²⁵. Though pain management is considered one of the essential well-being needs for cancer survivors, there is still lack of a structured line of integral care for early identifying and managing oncological pain that considers emotional, sociocultural, and economic issues in a standard approach to adequate pain management²⁶.

THE PSYCHIC SUFFERING

To the participants, in association with the physical, social, and economic aspects, cancer survivors suffer a great psychological impact, living with expressive psychic suffering that runs from the diagnosis to the post-treatment phase. They highlighted low self-esteem and anxiety related to the different forms of fear and insecurity about the diagnosis and treatment. According to the participants, this situation makes it difficult to accept the illness and interferes with adhesion to treatment and the quality of care provided.

Cancer significantly increases the risk of developing depressive symptoms and anxiety²⁷. Population data suggest that cancer survivors are twice more likely to have debilitating psychological issues when compared to adults that don't have cancer, specially up to the third post-treatment year²⁸.

In addition to this impact, participants reported that the experience of having cancer and undergoing treatment are loaded with social stigma, especially in relation to imminent death, which can contribute to anxiety development in survivors. Though there have been several advances in cancer diagnosis and treatment, receiving a cancer diagnosis still sounds like an imminent death sentence.

So much crying, despair, wanting to die, abandoning treatment [...]. There are the phases of denial, acceptance. Right after comes depression [...]. Because what is cancer related to? Suffering, pain, and death [...]. The stigma is still too strong (F3).

Proximity to death is not the only source of fear that generates psychological suffering in survivors. According to the interviewees, beyond death, there are other worries shared by the survivors, like the possibility of recurrence after what it seems to be the end of treatment.

We deal with a lot of young patients when they're hematology patients, like, this patient has a great anxiety, most of them know more about the disease than us. They know about their exams, their platelets, their hematocrit, they know when they need and don't need transfusion, so this fear of disease recurrence is too big, it generates great anxiety. Recurrence is their worst fear (R2).

The possibility of cancer recurrence is a common cause of late anxiety in survivors²⁹. As much as every treatment has satisfactory results, a cancer survivor is never really healed, technically. They will constantly be in fear of a possible recurrence, a ghost that will be present for an uncertain amount of time³⁰. Thus, anxiety is observed to be a significant condition and constitutive part of the cancer survivorship experience from the diagnosis onwards. The simple recollection of facts related to the diagnosis and/or treatment periods, or even the need for scheduling routine exams, or experiencing light clinical symptoms, such as fever, are enough to cause intense anxiety²⁹.

All this psychological process, when not properly cared by the professional, in addition to the suffering itself, contributes to the non-acceptance of the sick condition, which interferes in the patients' adhesion and in the quality of the oncological care provided.

You can offer a nice rehabilitation guidance for the patient [...], but if they don't accept it, if they don't want to accept it, they won't adhere well to it [...]. This directly affects the quality of the treatment, the patient sometimes [...] interrupts the radiotherapy cycle due to not caring (R7).

All these emotional and psychological descriptions indicate that cancer is probably one of the most difficult experiences that one can go through, as the disease exposes the individual to a myriad of experiences, emotions and affections related to life and death drives and metaphors³¹. To provide integral support to the oncological patient, psychological support should be included as a relevant aspect of the disease and its treatment³².

SOCIAL SUPPORT NETWORK

The participating nurses described a series of immediate and late social issues which are extremely important for maintaining the quality of life of survivors. The important role of family and other players of the social network of the cancer survivor in meeting intense care demands were particularly highlighted. Despite this essential role, due to difficulties inherent to the care process, nurses experience and report frequent stories of social abandonment suffered by some of the survivors, in addition to difficulties in finding institutional alternatives to remedy the situation.

The family, as the basic organizational structure of contemporary society, is usually thought to provide the sick person with basic support^{2,33}. The participating nurses agree to this premise, but considering their large professional experience in the field, they highlighted that this is not always true. Sometimes, the painful process of dealing with cancer ends up pushing families away from the care process. Moreover, a previous condition of precarious family organization tends to worsen this scenario.

Family support is essential, they become the patient's foundation, if they don't have family support [...] half their treatment is already impaired. At some point, be it in the beginning, or during survival, whether they're rid of the disease or not, that patient will weaken, due to the fear of a recurrence, or the treatment's side effects, or because they went through all of that, radiotherapy, chemotherapy, surgery [...]. The family needs to provide this support, (but) the family gets sick with the patient. The oncological disease is not just one person's disease, it's a family disease (R9).

We have patients here that [...] are treating cancer. She has a drug addict son, an alcoholic husband, so her family has other problems that affect her, not just her physical health (F11).

As the physical and psychological needs previously presented and discussed generate care demands that are often not limited to the professional spheres, the survivor needs to follow a series of care actions prescribed by professionals at home, which demands the support of a caregiver, usually a family member or neighbor. The prescribed care is not always simple and may be uncomfortable for the caregiver to provide.

We see that a lot in home care. Families that don't want to, specially of patients of head and neck. There really is a fetid part [...] of the tumor [...]. We try to raise awareness in the family that the patient needs this care, that there is a person there, that they are alive, regardless of that part, right? And we have to do it. Sometimes we can, sometimes we can't (F7).

These difficulties families find in providing care, associated with the other needs discussed in this article, contribute to a sad phenomenon of social abandonment of the cancer survivor.

The current focus is abandonment because we have many cases of people being abandoned (F4).

It's pure exclusion, because families exclude the oncological patient, they leave them aside, build a room for them in the back of the house, they don't want the oncological patient inside with them (F9).

This phenomenon was highlighted due to its seriousness and recurrence which, besides being an individual choice by a family member, should be understood as a complex social phenomenon¹, therefore, this abandonment demands further studies to be more broadly understood.

It's usually the wives, the female partners that we see there, keeping company during treatment, every single day with their spouse. The husband usually abandons the wife during her treatment. It's very common (F3).

Sometimes a husband gets in the hospital, and he seems so supportive, so loving that he even shaves his head together with his partner, but during the treatment he just ends up abandoning the patient (F6).

This imbalance of responsibilities towards their partner, described by the participants, may partly be explained by the gender issue that puts women in charge of caring for their family members³⁴. Such dimension is an object that refers to the social division of labor and gender analysis³⁵.



Thus, identification and appreciation of the support network offered by the professionals become essential in the process of caring for cancer survivors. It is known that as the patients' social support levels increase, so does their quality of life, which in turn decreases their loneliness levels³⁶. Moreover, it is important to acknowledge that the family, and not only the individual diagnosed, experiences the demands and contingencies of cancer. Everyone is affected by the illness experience, and as such, will demand referral to appropriate support programs³³.

THE SOCIOECONOMIC CONTEXT

The participants in the focus group were seriously concerned with the impact of cancer in the economic sphere of survivors and their families, especially in relation to difficulties that can impair treatment continuity. These issues aggravate even more when there are financial difficulties prior to the diagnosis, since cancer survivorship also results in a significant economic burden, known as "financial toxicity"³⁷.

Even with the gratuity of treatment granted by the public service, or private health insurance, participants noticed that there is a worsening of the survivor's financial conditions, related to a reduction in income due to the absence from work activities and an increase in treatment-related expenses, such as commuting to and from health facilities, feeding, temporary housing and some medications.

I think the main factor is socioeconomic, having a precarious socioeconomic situation. Most of them don't have the money to even buy food, let alone medication, which is so expensive (...). They already lack money to pay for adequate nourishment, they need supplementation. A sustenance rich in carbohydrates, proteins, that they won't be able to afford (F11).

The impact of people with cancer leaving work has been the subject of studies around the world. According to a cohort from the United States, 88% of male survivors and 78% of female survivors were employed at the time of diagnosis. Of those, 41% and 39%, respectively, stopped working during treatment³⁸. This reduction in the ability to work throughout the treatment is related, particularly, to the physical and emotional needs of the survivor, mainly those related to the effects of treatment that cause high levels of fatigue and prostration³⁹.

How can the patient go back to work, how can they make an appointment if they need to perform self-catheterization, how will they know if there are hygienic conditions to do so in the workplace.

This is something doctors don't contemplate in the reports about treatment results. Most of our female patients are the breadwinners in their families [...]. In addition to being rejected by their partners, they are responsible for providing for their family and usually have young children and all, and still have to worry about the disease and providing a living for their family (R1).

The process of returning to work follows a non-linear path that varies among individuals, their stories, and infirmities. Among the survivors, reports about not receiving enough support from treatment teams and insurance companies are common. Many have reported the lack of professional referral to an adequate process of returning to work³⁹. In this sense, studies indicate that multidisciplinary interventions involving physical, psychological, and vocational components result in higher rates of return to work for cancer survivors compared to usual care^{40,41}.

Finally, it is worth highlighting that, in addition to the impact of cancer and its treatment on household finances, the impact on the economy of society as a whole cannot be ignored, as cancer is a significant cause of absence from work, unemployment, retirement and precocious death⁴². Therefore, defining measures that facilitate the survivor's return to work can benefit society, in addition to them and their family.

CONCLUSION

The nurses participating in the research, based on their experiences in caring for cancer survivors, reported the interrelationships between the needs for physical, psychological, social, and economic well-being. By highlighting aspects that surpass biological limits, they demonstrate the influence of different sociocultural processes that directly interfere in the process of caring for people with cancer.

Such results enable a better understanding of the challenges faced by patients and their families in the search for care. This study revealed the gap in planning and service structures to offer the necessary care to fully meet these needs. The qualification of managers and professionals is urgent, such as restructuring the lines of care, in search for the desired and necessary comprehensiveness of integral oncological care.

CONTRIBUTIONS

Antonio Tadeu Cheriff dos Santos and Fernando Lopes Tavares de Lima have contributed to the study design, analysis and interpretation of the data, wording,



and critical review. Maria Lucia Magalhães Bosi has substantially contributed to the study design, planning, acquisition, analysis, and interpretation of the data, as well as the wording. Liz Maria de Almeida has contributed to the study design, planning, fund-raising, project administration, wording, and critical review. All the authors approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

FUNDING SOURCES

The Mexican Health Foundation (FUNSALUD) with financial support by Sanofi. The referred institutions had no role in the study design, data collection and analysis, publication decision or drafting this manuscript.

ACKNOWLEDGMENTS

To Rildo Pereira da Silva, Márcia Marília Vargas Fróes Skaba, Maria de Fátima Batalha; Joecy Dias Andrade; to the teams of professionals from the institutions where the research was carried out; as well as to Alessandra Durstine and Heitor Arreola Ornelas for the support provided during organization and data production; to FUNSALUD for administrative support.

REFERENCES

- Jain SL. *Malignant: how cancer becomes us*. Berkeley: University of California Press; 2013.
- Santos ATCD, Silva RPD, Almeida LM, et al. Cancer survivorship needs in Brazil: patient and family perspective. *PLoS One*. 2020;15(10):e0239811. doi: <https://doi.org/10.1371/journal.pone.0239811>
- Shapiro CL. Cancer Survivorship. *N Engl J Med*. 2018;379(25):2438-50. doi: <https://doi.org/10.1056/nejmra1712502>
- Manthri S, Geraci SA, Chakraborty K. Overview of cancer survivorship care for primary care providers. *Cureus*. 2020;12(9):e10210. doi: <https://doi.org/10.7759/cureus.10210>
- Hewitt M, Greenfield S, Stovall. *From cancer patient to cancer survivor: lost in transition*. Washington, DC: National Academies Press; Institute of Medicine and National Research Council; 2006. doi: <https://doi.org/10.17226/11468>
- Keesing S, McNamara B, Rosenwax L. Cancer survivors' experiences of using survivorship care plans: a systematic review of qualitative studies. *J Cancer Surviv*. 2015;9(2):260-8. doi: <https://doi.org/10.1007/s11764-014-0407-x>
- Halpern MT, Argenbright KE. Evaluation of effectiveness of survivorship programmes: how to measure success? *Lancet Oncol*. 2017;18(1):e51-9. doi: [https://doi.org/10.1016/s1470-2045\(16\)30563-0](https://doi.org/10.1016/s1470-2045(16)30563-0)
- Oliveira RAA, Zago MMF, Thorne SE. Interaction between professionals and cancer survivors in the context of Brazilian and Canadian care. *Rev Lat Am Enfermagem*. 2017;25:e2972. doi: <https://doi.org/10.1590/1518-8345.2253.2972>
- The Economist Intelligence Unit [Internet]. London: The Economist Newspaper Limited; 2017. Cancer survivorship country profile Brazil. 2017 [acesso 2019 dez 10]. Disponível em: <https://worldcancerinitiative.economist.com/pdf/BMS-Global-cancer-survivorship/Brazil.pdf>
- Renjith V, Yesodharan R, Noronha JA, et al. Qualitative Methods in Health Care Research. *Int J Prev Med*. 2021;24:12-20. doi: https://doi.org/10.4103/ijpvm.ijpvm_321_19
- Pope C, Mays N. *Qualitative research in health care*. 4. ed. London: Wiley-Blackwell Publishing; BMJ Publishing Group; 2020.
- Launer J, Wohlmann A. Narrative medicine, narrative practice, and the creation of meaning. *Lancet*. 2023;401(10371):98-9. doi: [https://doi.org/10.1016/s0140-6736\(23\)00017-x](https://doi.org/10.1016/s0140-6736(23)00017-x)
- Backes D, Colomé J, Erdmann R, et al. Grupo focal como técnica de coleta e análise de dados em pesquisas qualitativas. *Mundo saúde*. 2011;35:438-42. doi: <http://doi.org/10.15343/0104-7809.2011354438442>
- Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med*. 1985;313(4):270-3. doi: <https://doi.org/10.1056/nejm198507253130421>
- Feuerstein M, Nekhlyudov L, editores. *Handbook of cancer survivorship*. 2. ed. Springer Cham: Gewerbesraße; 2018. doi: <https://doi.org/10.1007/978-3-319-77432-9>
- Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*. 2016;26(13):1753-60. doi: <https://doi.org/10.1177/1049732315617444>
- Graneheim UH, Lindgren BM, Lundman B. Methodological challenges in qualitative content analysis: a discussion paper. *Nurse Educ Today*. 2017;56:29-34. doi: <https://doi.org/10.1016/j.nedt.2017.06.002>
- Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. *Afr J Emerg Med*. 2017;7(3):93-9. doi: <https://doi.org/10.1016/j.afjem.2017.08.001>
- Conselho Nacional de Saúde (BR). Resolução nº 466, de 12 de dezembro de 2012. Aprova as diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. *Diário Oficial da União, Brasília, DF*. 2013 jun 13; Seção I:59.
- Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet*. 2001;358(9280):483-8. doi: [https://doi.org/10.1016/s0140-6736\(01\)05627-6](https://doi.org/10.1016/s0140-6736(01)05627-6)



21. Martins AM, Nascimento ARA. Representações sociais de corpo após o adoecimento por câncer na próstata. *Psicoestud.* 2017;22(3):371-81. doi: <https://doi.org/10.4025/psicoestud.v22i3.31728>
22. Junqueira LCU, Santos MA. Atravessando a tormenta: imagem corporal e sexualidade da mulher após o câncer de mama. *Rev Fam Ciclos Vida Saúde Contexto Soc.* 2020;8(Suppl 1):562-74. doi: <https://doi.org/10.18554/refacs.v8i0.4669>
23. Kim Y, Matthew J. Loscalzo. *Gender in Psycho-Oncology.* Oxford: Oxford University Press; 2018. doi: <https://doi.org/10.1093/med/9780190462253.001.0001>
24. Del Pup L, Villa P, Amar ID, et al. Approach to sexual dysfunction in women with cancer. *Int J Gynecol Cancer.* 2019;29(3):630-4. doi: <https://doi.org/10.1136/ijgc-2018-000096>
25. Strada A, Portenoy RK. Psychological, rehabilitative, and integrative therapies for cancer pain. Teerão: Uptodate; 2021.
26. Gomes P, Lima FLT, Santos ATC. Significados da dor crônica na sobrevivência ao câncer de mama. *Rev Bras Cancerol.* 2021;67(1):e-071143. doi: <https://doi.org/10.32635/2176-9745.RBC.2021v67n1.1143>
27. Niveau N, New B, Beaudoin M. How should self-esteem be considered in cancer patients? *Front Psychol.* 2021;12:763900. doi: <https://doi.org/10.3389/fpsyg.2021.763900>
28. Naughton MJ, Weaver KE. Physical and mental health among cancer survivors: considerations for long-term care and quality of life. *N C Med J.* 2014;75(4):283-6. doi: <https://doi.org/10.18043/ncm.75.4.283>
29. Berry-Stoelzle MA, Mark AC, Kim P, et al. Anxiety-related issues in cancer survivorship. *J Patient Cent Res Rev.* 2020;7(1):31-8.
30. Cupit-Link M, Syrjala KL, Hashmi SK. Damocles' syndrome revisited: Update on the fear of cancer recurrence in the complex world of today's treatments and survivorship. *Hematol Oncol Stem Cell Ther.* 2018;11(3):129-34. doi: <https://doi.org/10.1016/j.hemonc.2018.01.005>
31. Pelaez Doro M, Pasquim R, Medeiros CR, et al. O câncer e sua representação simbólica. *Psicol cienc prof.* 2004;24(2):120-33. doi: <https://doi.org/10.1590/S1414-98932004000200013>
32. Daniel E. Revisión sistemática sobre la intervención del psicólogo en el abordaje de los pacientes con cáncer. *CdVS [Internet].* 2023[acesso 2024 jan 25];16(2):81-101. Disponível em: <http://revistacdvs.uflou.edu.ar/index.php/CdVUFLO/article/view/392>
33. Lewis FM. Strengthening family supports. *Cancer and the family.* *Cancer.* 1990;65(Supl3):752-9. doi: [https://doi.org/10.1002/1097-0142\(19900201\)65:3+%3C752::aid-cncr2820651320%3E3.0.co;2-d](https://doi.org/10.1002/1097-0142(19900201)65:3+%3C752::aid-cncr2820651320%3E3.0.co;2-d)
34. Meira EC, Reis LA, Gonçalves LHT, et al. Vivências de mulheres cuidadoras de pessoas idosas dependentes: orientação de gênero para o cuidado. *Esc Anna Nery.* 2017;21(2):e20170046. doi: <https://doi.org/10.5935/1414-8145.20170046>
35. Skinner D. The gendering of cancer survivorship. *Health Cul Soc.* 2012;3(1):64-76. doi: <https://doi.org/10.5195/hcs.2012.83>
36. Çamlıca T, Koç Z. Loneliness, social support level, quality of life and symptom management among turkish oncology patients. *Omega (Westport).* 2022;302228221086057. doi: <https://doi.org/10.1177/00302228221086057>
37. Jiang H, Lyu J, Mou W, et al. Association between financial toxicity and health-related quality of life in cancer survivors: a systematic review. *Asia Pac J Clin Oncol.* 2023;19(4):439-57. doi: <https://doi.org/10.1111/ajco.13901>
38. Short PF, Vasey JJ, Tunceli K. Employment pathways in a large cohort of adultcancer survivors. *Cancer.* 2005;103(6):1292-301. doi: <https://doi.org/10.1002/cncr.20912>
39. Urquhart R, Scruton S, Kendell C. Understanding cancer survivors' needs and experiences returning to work post-treatment: a longitudinal qualitative study. *Curr Oncol.* 2022;29(5):3013-25. doi: <https://doi.org/10.3390/currenol29050245>
40. Boer AG, Tamminga SJ, Boschman JS, et al. Non-medical interventions to enhance return to work for people with cancer. *Cochrane Database Syst Rev.* 2024;3(3):CD007569. doi: <https://doi.org/10.1002/14651858.cd007569.pub4>
41. Feuerstein M. *Work and Cancer Survivors.* New York: Springer; 2009. doi: https://doi.org/10.1007/978-0-387-72041-8_2
42. Pearce A, Sharp L, Hanly P, et al. Productivity losses due to premature mortality from cancer in Brazil, Russia, India, China, and South Africa (BRICS): a population-based comparison. *Cancer Epidemiol.* 2018;53:27-34. doi: <https://doi.org/10.1016/j.canep.2017.12.013>

Recebido em 31/1/2024
Aprovado em 2/4/2024

