

# Physical, Emotional and Socioeconomic Needs in the Post-Treatment of Head and Neck Cancer: a Qualitative Study

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*Necessidades Físicas, Emocionais e Socioeconômicas no Pós-tratamento do Câncer de Cabeça e Pescoço: um Estudo Qualitativo*  
*Necesidades Físicas, Emocionales y Socioeconómicas en el Postratamiento del Cáncer de Cabeza y Cuello: un Estudio Cualitativo*

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## ABSTRACT

**Introduction:** Head and neck cancer patients are a group with complex needs barely studied in the post-treatment phase. **Objective:** To understand the experience and needs of the head and neck cancer survival phase from the perspective of the patients themselves, their families, and health professionals from oncology services. **Method:** Qualitative, exploratory, and descriptive study, using the hermeneutic-dialectic methodological framework. Semi-structured interviews and focus group were adopted as data production techniques. **Results:** The empirical material was organized into three categories of needs *physical, emotional and socioeconomic* and structured in three broad senses involving the consequences of the biological, psychological, and socioeconomic impact of the disease and its treatment. The aspects related to the adaptations of eating habits, communication and management of the treatment effects stand out for the first; emotional support for patients and families in the second, and information about social benefits for the third impact. **Conclusion:** The physical, emotional, and socioeconomic needs of the disease and its treatment are intertwined to form a complex network of challenges for public cancer control policies in Brazil.

**Key words:** Needs Assessment; Health Services Needs and Demand; Head and Neck Neoplasms; Medical Oncology; Survival.

## RESUMO

**Introdução:** Os pacientes com câncer de cabeça e pescoço constituem um grupo com necessidades complexas pouco estudadas na fase de pós-tratamento. **Objetivo:** Compreender a experiência e as necessidades da fase de sobrevivência ao câncer de cabeça e pescoço a partir da perspectiva dos próprios pacientes, seus familiares, e profissionais de saúde de serviços de oncologia. **Método:** Pesquisa qualitativa, exploratória, descritiva, tendo como referencial metodológico a hermenêutica-dialética. Adotaram-se, como técnicas de produção de dados, a entrevista semiestruturada e o grupo focal. **Resultados:** O material empírico foi organizado em três categorias de necessidades *físicas, emocionais e socioeconômicas* e estruturado em três abrangentes sentidos envolvendo as consequências do impacto biológico, psíquico e socioeconômico da doença e seu tratamento. Destacam-se, para o primeiro, os aspectos relativos às adaptações do hábito alimentar, comunicação e manejo dos efeitos do tratamento; o apoio emocional para pacientes e familiares no segundo; e as informações sobre benefícios sociais para o terceiro. **Conclusão:** As necessidades físicas, emocionais e socioeconômicas da doença e seu tratamento se entrelaçam para formar uma complexa rede de desafios para as políticas públicas de controle do câncer no Brasil.

**Palavras-chave:** Determinação de Necessidades de Cuidados de Saúde; Necessidades e Demandas de Serviços de Saúde; Neoplasias de Cabeça e Pescoço; Oncologia; Sobrevida.

## RESUMEN

**Introducción:** Los pacientes con cáncer de cabeza y cuello son un grupo con necesidades complejas poco estudiadas en la fase postratamiento. **Objetivo:** Conocer la experiencia y necesidades de la fase de supervivencia del cáncer de cabeza y cuello desde la perspectiva de los propios pacientes, sus familias y los profesionales sanitarios de los servicios de oncología. **Método:** Investigación cualitativa, exploratoria y descriptiva, utilizando el marco metodológico hermenéutico-dialéctico. Se adoptaron las entrevistas semiestructuradas y el grupo focal como técnicas de producción de datos. **Resultados:** El material empírico se organizó en tres categorías de necesidades *físicas, emocionales y socioeconómicas* y estructurado en tres amplios sentidos que involucran las consecuencias del impacto biológico, psicológico y socioeconómico de la enfermedad y su tratamiento. Los aspectos relacionados con la adaptación de los hábitos alimentarios, la comunicación y el manejo de los efectos del tratamiento destacan por el primero; apoyo emocional a pacientes y familiares en el segundo; e información sobre beneficios sociales para el tercero. **Conclusión:** Las necesidades físicas, emocionales y socioeconómicas de la enfermedad y su tratamiento se entrelazan para formar una compleja red de desafíos para las políticas públicas de control del cáncer en Brasil.

**Palabras clave:** Evaluación de Necesidades; Necesidades y Demandas de Servicios de Salud; Neoplasias de Cabeza y Cuello; Oncología Médica; Sobrevida.

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## INTRODUCTION

Head and neck cancer is the 5<sup>th</sup>. leading cause of cancer by incidence in the world<sup>1</sup>. In Brazil, for each year of the triennium 2020-2022, considering lip, oral cavity, pharynx, larynx, nasal cavity and thyroid tumors, the estimates indicate the occurrence of 36,620 new cases, representing the third highest incidence among men and women<sup>2</sup>.

In the world, due to the increase of the incidence in younger patients, improved diagnosis and more effective therapeutic choices, survival rates are improving significantly. However, in the long term, the survival carries morbidities and sequelae, mainly because of the types of treatment applied<sup>3</sup>. This scenario is similar in Brazil, although aggravated because the diagnosis occur late, increasing the possibility of morbidities and physical, psychological, and social sequelae<sup>4</sup>.

Patients with head and neck cancer are a group with post-treatment complex necessities. The experience of survival of these and other patients should be understood as a journey, not only in pursue of cure and/or treatment, but also of understanding and mitigation of the clinical, emotional, and social impacts of a complete process of treatment since diagnosis until end-of-life care<sup>5</sup>.

As chronic patients, these individuals require a complex and long-term therapy with the participation of health professionals of multiple formations. For postoperative patients, chronicity is not related to cancer history alone, but to toxicity of the treatment administered<sup>6</sup>.

The main social, emotional and physical comorbidities affecting this group are: depression and social isolation by alteration of the self-image, eating and drinking difficulties (including dysphagia, dental problems, trismus and sensorial disorder), hypothyroidism, more possibility of incidence of second malignancy, relapses, alcohol and nicotine dependency and financial burden<sup>6-8</sup>. The strategies to minimize these complications and optimize their management in the long term are increasingly necessary<sup>3</sup>.

Although there are recommendations and proposals of developing researches and plans to identify the necessities and care coordination to the survivors both in primary and specific attention<sup>9-12</sup>, a more thorough analysis of the efficacy and scope of these measures is of essence<sup>13-16</sup>. Yet, studies related to socioeconomic factors<sup>6</sup>, information and researches about the needs and quality of the long-term care and support are required<sup>15,16</sup>. In Brazil, regardless of the existing studies addressing clinical and therapeutic protocols and quality of life<sup>4,17</sup>, there is no ample and systematic discussion about care plans, public policies and lines of study directed to the long-term necessities of head and neck cancer survivors.

In view of this scenario, the aim of this study is to understand the experience and needs of the survival phase of head and neck cancer based in the perspectives of the patients themselves, their families and oncology health professionals.

## METHOD

Exploratory, qualitative study guided by the methodological-theoretical referential of dialectic-hermeneutic in its double function: configuration of the categories and questions related to the object and as procedure of analysis of the empirical material<sup>18-20</sup>.

The union of hermeneutic with dialectic was prolific to conduct a process at the same time comprehensive and critical of the symbolic attributions to the experience of cancer survival both in the perspective of patients and their families who live through the sickening, of the forms of treatment and medical services in addition to health professionals who apply the clinical and caring programs and manage the public health policies.

Purposive and convenience sample of six head and neck cancer survivors with confirmed diagnosis for at least 12 months, three family members of head and neck cancer survivors, five nurses with at least one year of professional experience and two physician-managers of clinical or surgical oncology for head and neck cancer treatment.

The choice of patients and family members was based in the rates of four types of head and neck cancer most incident in Brazil<sup>2</sup>, being one thyroid, one, larynx and oral cavity for the remaining. The patients who joined the study had physical-clinical conditions and ability to express themselves orally. Survivors and relatives had no blood kinship.

The Institutional Review Board approved the study, number 660.486. All the participants were instructed about the objectives and methods and signed the Informed Consent Form (ICF). They were assigned codes for anonymity: (S) survivors; (F) family; (E) nurses; and (G) for physician-managers.

Semi-structured interviews were conducted with the survivors, family, and managers. For the nurses, a focal group was created to understand the consensus and dissensus about the study object.

The interviews and the focal group were conducted by three investigators with previous experience between June and October 2014 in an oncology center in Rio de Janeiro. The construction and collection of the data followed the order: survivors, family, managers, and nurses.

Both for the interviews and focal group, a script with topics about the experiences, difficulties and necessities of the head and neck survival phase was adopted. The average time of each interview was 50 minutes with survivors and

family members and 30 minutes with physician-managers. The focal group lasted 90 minutes. The whole process of construction and collection of the data was recorded and transcribed for analysis.

The dialectic-hermeneutic analysis followed the guidelines of Minayo<sup>18</sup> and Gomes<sup>19</sup>. Hermeneutics is the pursue of comprehension of the meaning occurring in the communication among human beings whose core is the language. Dialectic seeks in facts, in language, in symbols and culture the obscure and contradictory ideas to criticize them.

The content of the narrative of each participant was analyzed based in the experience of cancer survival that implies in interconnections of the biological, emotional, economic and social dimensions<sup>21</sup> and requires an interpretive and critical approach to the phenomenon<sup>19,22,23</sup>. This process involved the co-construction of meanings, since the participants' narratives and the interpretation of the investigators were inserted in an hermeneutic circle of critical understanding and interpretation of the language and writing<sup>20,24-26</sup>.

The analysis followed the five steps recommended<sup>18,22</sup>: (a) comprehensive reading; (b) identification of the subjacent feelings to the participants' narratives; (c) problematization of the ideas and feelings found in the narratives and articulation with sociocultural meanings; (d) elaboration of the synthesis among the empirical data and the information extracted from studies about the theme of sociology of cancer, cancer survival, specially head and neck cancer offering theoretical inputs; (e) elaboration of schemes of process of interpretive analysis containing empirical categories and their correlations with theoretical categories, generating synthesis of feelings.

The dialectic-hermeneutic interpretation of the study content was shared among the investigators who, in weekly meetings, read thoroughly the transcriptions and identified the subjacent meanings of the empirical material, in addition to configuring and comparing the empirical and theoretical categories which formed the hermeneutic and critical schemes utilized for the interpretive analysis.

The empirical categories and subcategories were elaborated as a mosaic which, although splitting and identifying the participants' perspective was assembled into an integrated and comprehensive vision about the necessities of the survivors of head and neck cancer.

The theoretical referential of analysis selected were: (1) Gadamer's<sup>24</sup> hermeneutic of health as reflection about the subjacent elements of the complexity of health; (2) Mullan's idea of survivorship as precursor of the rupture with the biomedical approach; (3) orientations and guides of treatment about the care to be offered to the survivors

of head and neck cancer<sup>7,9-11</sup>; and (4) Habermas<sup>27,28</sup> dialectic hermeneutic as a methodological proposal of social investigation.

Three empirical categories resulted from the analysis based in the principle of theoretical saturation and configured from the assemblage of narratives and extraction of their respective interpretations of meaning<sup>18,19,23</sup>.

## RESULTS

In its great part the group of survivors participants was formed by men between 64 and 79 years of age, married, retired, having completed elementary school with relatives as financial dependents. Mostly, the treatment consisted of the association of surgery and radiotherapy (four participants). All the patients were still in treatment (between 15 days and two years) and two of them were treating a relapse.

The three relatives, aged 34, 50 and 53 years of age were wives of patients with diagnosis of oral cavity cancer.

The group of nurses consisted of skilled oncology professionals, with experience between three and 30 years and aged 28 and 56 years old. The group of the physicians-managers was formed by surgeons of head and neck with professional experience between 30 and 35 years and aged between 58 and 60 years old.

The results of the interviews and of the focal group were organized in three empirical categories: *physical needs*; *emotional needs* and *socioeconomic needs*. Each category includes subcategories respectively listed and defined in Chart 1. Charts 2, 3 and 4 complement the results of the study and present for each category the set of subcategories and their respective extracts of the narratives selected.

The category *physical needs* encompass the assemblage of necessities resulting from the biological impact of the pathology and repercussions in the physical body and respective demands for management and clinical follow-up (Chart 2).

The *emotional needs* address the assemblage resulting from the psychic impact of the pathology and its treatment with repercussions in behavior, emotions and demands for psychological follow up (Chart 3).

The *socioeconomic needs* result from the socioeconomic impact of the pathology and its treatment with repercussions in finances and social conviviality of patients and relatives (Chart 4).

## DISCUSSION

The feelings of different groups of interviewees in the three categories converged towards a configuration of the same scenario of necessities.

Chart 1. Empirical Categories and subcategories - Definitions

Empirical Category	Subcategories	Definition of empirical subcategories
<b>Physical needs</b>	Adaptation of eating habits	Assemblage of adaptations of eating habits and forms determined by the biological impact of the pathology and its treatment with repercussions in the digestive process
	Adaptations of oral communication	Assemblage of adaptations of oral communication determined by the biological impact of the pathology and its treatment with repercussions in the phonatory process
	Clinical interventions related to the physical effects of the disease and its treatment	Assemblage of clinical interventions related to the management of effects of the pathology and its treatment
<b>Emotional needs</b>	Strategies of coping with potential relapse	Assemblage of strategies to be implemented through clinical follow-up and psychological support to cope with potential relapse
	Psychological support for the diagnosis	Assemblage of actions of psychological support to be implemented when the positive diagnosis is announced
	Psychological support for survivorship	Assemblage of actions of psychological support focused to overcoming emotional traumas and obstacles for motivation and appreciation of life during survival
<b>Socioeconomic needs</b>	Resuming social living	Assemblage of necessities resulting from the social impact of the pathology and its treatment with repercussions in the daily social relations and its respective demands of resuming conviviality among different social groups
	Information and accessibility to social rights	Assemblage of necessities resulting from the economic impact of the pathology and its treatment on the survivor with repercussions in its citizenship and its demands for available information and actual access to social rights and equity

## PHYSICAL NEEDS

The category of *physical needs* addresses the meaning of the necessities as consequence of the disease's biological impact and its treatment, encompassing the compromise and disarray of organic functions and anatomic structures resulting from the disease itself or the therapeutic interventions.

Survivors and their families verbalize the strong and acute impact of sickening and the result of the treatment in the life of everyone involved. The narratives reveal changes in the lifestyle, eating habits, communication, and social relations.

The speeches of nurses and physicians-managers within a technical-descriptive approach are similar while exposing the complexity and depth of the physical alterations and necessity of specialized and continuous support for eating disorders, speech rehabilitation, control of the chemical dependency of smokers and pain management.

The improvement of oncologic treatments and the resulting expansion of patients' survival time<sup>29</sup> bring

new challenges to health services. The patients still at the oncologic attention units even after the end of the treatment demand specific actions to value their quality of survival that go beyond the mere clinical boundaries of disease monitoring.

Among the physical demands the participants addressed, stand out the necessities of adaptations of eating habits and ability of oral communications and control of chemical dependence and management of the effects that the disease and its treatment have provoked.

The *adaptations of eating habits* occur in the act of eating and nourishment experience due to the repercussions of the disease and its treatment. The act of eating is a complex function involving the biological necessity and gustative, esthetic, emotional and social satisfaction. These dimensions are affected and impacted. The meanings of the narratives indicate that because of dysphagia, the survivors experience difficulties to eat and drink<sup>15</sup>. Other complications and dental problems, trismus, sensorial disorders, and taste changes affect the

Chart 2. Narratives of the subcategories of the empirical category “physical needs”

Empirical subcategories	Extracts of the narratives
<b>Adaptations of the eating habit</b>	<ul style="list-style-type: none"> <li>✓ To me, the form of eating is the toughest part (S-03)</li> <li>✓ Well, a patient who undergoes a radical treatment for head and neck cancer (...) will certainly develop or experience a series of physiological alterations, great part of them related to deglutition and eating (G-02)</li> <li>✓ Overall, our patients have dysphagia (E-05)</li> <li>✓ No, I was just on pasty food, was unable to swallow, have difficulties in chewing (S-01)</li> </ul>
<b>Adaptations of the capacity of oral communication</b>	<ul style="list-style-type: none"> <li>✓ I rarely leave my house. If I go to a noisy place, I can't talk. Outdoors, even with a device, I can't talk because of the noise. I only go to my daughters' place (...) I only go to places where I don't have to talk (S-04)</li> <li>✓ (...) the speech therapist is being well accepted by my brother. He was depressive because he was unable to talk with the others, he had to write (F-02)</li> <li>✓ I'm feeling a little, just hoarse, can't talk much (S-01)</li> <li>✓ The great obstacle for most part of our clients is the difficulty of communication, this is unquestionable (E-04)</li> </ul>
<b>Clinical interventions related to the physical effects of the disease and its treatment</b>	<ul style="list-style-type: none"> <li>✓ You can't do much. I try, but I get tired (S-02)</li> <li>✓ It is with talking, because of the radiotherapy, I have problems, even to swallow something is sort of tough (S-05)</li> <li>✓ (...) many (patients) have neuralgic pain because the tumor is close to the nerves and involves nerves and the pain is intense, very intense (...) (E-02)</li> <li>✓ (...) these patients will need support from the team of speech therapists, occasionally they will also need certain medication that helps to humidify the mouth, reduces the irritation of the mucosa, facilitates food intake (...) (G-02)</li> </ul>

Chart 3. Narratives of the subcategories of the empirical category “emotional needs”

Empirical subcategories	Extracts of the narratives
<b>Strategies of coping with potential relapse</b>	<ul style="list-style-type: none"> <li>✓ I'm not afraid, but God forbid! Don't want it back, but if it does, I will ask the doctor to cut again (S-02)</li> <li>✓ There are those who completed the treatment and after 1 or 2 years, it came back and say the disease is back and they cry together with us (E-02)</li> </ul>
<b>Psychological support for diagnosis</b>	<ul style="list-style-type: none"> <li>✓ I thought I was going to die soon. This is what came to my mind. Didn't even want to seek treatment (S-05)</li> <li>✓ I thought it was not necessary, but we need help. Sometimes, one word can change our path. A word from a well-meant person changes our direction (S-04)</li> <li>✓ Not the fear of the treatment, but I was afraid to die because I believe everybody is afraid of dying (S-03)</li> </ul>
<b>Psychological support for survivorship</b>	<ul style="list-style-type: none"> <li>✓ The anguish never abandons me, but I'm feeling stronger (S-05)</li> <li>✓ (...) these ill persons start to receive some support, some counseling from a psychologist or psychiatrist only when they have an important behavioral disorder detected, identified by the assistant physician. But in my opinion, this should be routine for all these patients who are enrolled here (G-02)</li> <li>✓ (...) I wanted some psychological treatment. A support group (F-01)</li> </ul>



Chart 4. Narratives of the subcategories of the empirical category “socioeconomic needs”

Empirical subcategories	Extracts of the narratives
<b>Resuming social living</b>	<ul style="list-style-type: none"> <li>✓ The difficulty is only in the relationship with the persons (S-04)</li> <li>✓ You have a guest, and you can't talk (...) some persons are impatient (S-04)</li> <li>✓ (...) Brazil is still an impoverished country and we find illiterate patients, if this patient loses the ability to communicate, it is isolated from everyone, doesn't know to read, to write, is illiterate and can't talk (G-02)</li> <li>✓ Because we are dealing with tracheostomy, but there are the amputees, quite invisible, who are (...) Remove the eye, the nose, part of the tongue, of the ear, maxillary, mandible, you understand? They are disfigured. There is prejudice (E-02)</li> <li>✓ (...) he enjoyed walking around his house in the neighborhood. This is over! (F-01)</li> </ul>
<b>Information and accessibility to social rights</b>	<ul style="list-style-type: none"> <li>✓ I believe we failed in social support (G-01)</li> <li>✓ It needs to mention only the financial allowance for disease [benefit granted to the patient by the Brazilian government]; everything else was good (S-05).</li> </ul>

form, type, and social ritual of feeding, which require new forms of nutritional, culinary and gastronomy orientation for these patients and their families<sup>8,30</sup>.

The *adaptations of the ability of oral communication* address the repercussions in the process of verbal communication. The participants indicate difficulties in the ability of verbal expressions in daily processes of social interactions. These limitations call for new solutions because the extended perspective of survival yields a new survivor who, even with the active disease, is alive in the world, trying to resume his daily living and plan the future, despite the uncertainties in relation to the cure. The inclusion of palliation<sup>31,32</sup>, physiotherapy, and speech therapy rehabilitation<sup>3,32-34</sup> are alternatives to minimize the condition.

The participants emphasized the importance of the *management of the effects provoked by the impact of the disease and its treatment*. Head and neck cancer therapy have debilitating physical effects<sup>7</sup> and the management of these patients is complex, requiring continuous care provided by a robust and skilled multi-professional team. Although the acute toxicities related to the irradiation and chemotherapeutic agents may diminish soon after the cessation of the therapy, its duration can be significant. In addition, late and long-term effects compromising the quality of life may occur such as radiation-associated vascular diseases, xerostomia, fibrosis of deglutition muscles, scars, dental deterioration, loss of gustative and olfactory sensations, hearing loss, dysphagia, pain, chronic aspiration, nutritional depletion, and overall well-being, in addition to functional difficulties affecting the appearance<sup>4,34-36</sup>.

Another aspects of management and follow-up include the high risk of disease recurrence and incidence of the metastatic disease in the first two years after the treatment of the primary disease. The core focus of care in this period is the early identification of new cancers, management

of the toxic and late effects of the treatment and offer of health primary care as prevention and early detection of pulmonary and cardiovascular diseases<sup>34</sup>.

For physical necessities, the intervention in the global scope of survivorship focused only to clinical issues is barely enough. The care to be implemented must address the complex relations established among social and clinical necessities. Therapeutic should be singular and plural. Personalized and humanized in its approach, matched to the specific needs of the survivor and plural in its inter-disciplinary construction utilizing technologies and considering the individual's<sup>37,38</sup> integrality and diversity.

### EMOTIONAL NEEDS

The category *emotional needs* introduces the meaning of the necessities as consequence of the psychic impact of the disease and its treatment. The necessities of emotional aid reported by the interviewees are related to issues of psychological support in face of the diagnosis, psychological guidance for survival and strategies of coping with possible relapses.

According to Salz et al.<sup>36</sup>, 50% of the cancer survivors are diagnosed with some psychological alteration. Panwar et al.<sup>3</sup> indicate that one third of the patients has long-term significant psychological disorders. Regardless of this, severe psychiatric disorders are uncommon among cancer survivors.

Compared with the general population, head and neck survivors have a slightly higher risk of presenting depression or post-traumatic stress disorder although studies defining them as long-term effects are scarce<sup>36</sup>.

The *psychological support after the diagnosis* can minimize the impact of the announcement. The anguishing experience after a diagnosis and during cancer treatment is not unexpected or uncommon. In these cases, basically, stress results of an existential threat of a potentially fatal disease and of the uncertainties involving

the decision taking about the course and results of the treatments applied<sup>39</sup>. Considering that the emotional suffering can impact the adherence to the treatments and worsen the evolution of the disease<sup>40</sup>, the psychological support becomes a long-term important measure for the care and quality of survival of patients with head and neck cancer.

The *psychological support for survivorship* is required because of the disease's late impacts. According to Stein et al.<sup>39</sup>, the identification of the factors influencing the trajectory and the psychological balance of the cancer survivor is challenging. The authors believe that the response and the psychological adjustment to the experience of cancer are influenced by the stress, the burden of the sickening by cancer and the available resources for its treatment. As bigger the stress and burden, higher the risk of negative psychological effects in the short and long-term. Additionally, as great the resources available, lower is that risk. Understanding the risk of an individual in relation to the negative psychological effects should not be limited to the objective report of the stressors related to its experience of cancer but explain its subjective response to the presumed stressors. Psychological follow-up can stimulate, consequently, the resilience and help the individual to learn to live as survivor<sup>40,41</sup>. These actions should include the family because they share the same suffering.

The *strategy of coping because of possible relapse* is required since a deep and persistent fear can significantly affect the quality of life, reduce the functional capacity, and increase the risk of tobacco addiction<sup>3,39</sup>. Seeing that the future may not be real is the core element that expresses the fear of cancer recurrence. Many survivors without active disease live the fear and anxiety of this possibility, requiring, for control purposes, the correct screening and therapy to help reducing the symptoms<sup>42,43</sup>.

## SOCIOECONOMIC NEEDS

The category *socioeconomic needs* presents the meaning of the necessities as result of the socioeconomic impact of the disease and its treatment. The narratives of the survivors demand the expansion of the scope of social rights with initiatives of socioeconomic aid and reinsertion in the labor market in order to reestablish and support its social and individual life. The nurses' and physician-managers' speeches corroborate these pledges and necessities.

The feelings that emerged in this category reveal the complexity of the survivor's social and economic necessities, calling for actions and policies of resuming the social conviviality, access to information and social rights.

*Resuming the social conviviality* involves a double coping: the limitations imposed by the disease and its

treatment combined with the identification, mediation, and promotion of the circles of the survivors conviviality. Coping with stress that the diagnostic and treatment of cancer brings, improves when the individual is accepted and interacts with its social group. Social support improves the psychological adjustment of the patients and cancer survivors in the short and long term<sup>44,45</sup>. In Brazil, this type of support is addressed in the National Policy for Cancer Control and Prevention (PNPCC)<sup>46</sup>, which proposes the rehabilitation of the oncologic patient as part of the full care. However, it did not include specificities of social rehabilitation necessities of this patient.

The *necessity of information and access to social rights* is justified due to the heavy bureaucracy, poor communication channels and bad quality and/or missing information about clinical treatment in addition to the application and achievement of social security and social rights. For patients with cancer and survivors, the access to accurate and clear information about the disease, its prognosis, options of treatment and side effects, availability and local of the support services and counseling about social and social security rights are invaluable<sup>15,47,48</sup>.

There are initiatives in this area in Brazil. The National Cancer Institute José Alencar Gomes da Silva (INCA) has a primer addressing "Social rights of the individual with cancer"<sup>49</sup>, attempting to promote easy orientation and comprehension to its patients about the theme. However, other initiatives and teaching materials with social and economic information and including the necessities and sociocultural level of the target-public are required. Nevertheless, the set of social benefits and rights granted by public policies address only oncologic patients with active disease in the phases of diagnosis and treatment. They still do not encompass the peculiarities of the survivors and their family who continue to be socially and economically vulnerable.

## CONCLUSION

Cancer survivorship is being increasingly recognized as a distinct entity within the *continuum* of cancer care and control. As the transition from the immediate treatment to a long-term follow-up, this phase is an important period to plan a set of preventive measures related to the screening of new types of cancer, such as management of late and long-term comorbidities, rehabilitation, promotion of health, emancipation, and social empowerment.

Brazilian head and neck cancer survivors face various challenges posttreatment. This scenario consists of a wide assemblage of physical, emotional, and socioeconomic necessities that not only affect them but their relatives and

caretakers as well. The most urgent necessities to be met are: psychological counseling for patients and relatives and more specific information about social and social security benefits to the individual.

More national-based studies are needed to expand the knowledge of the specificities of the Brazilian population. In despite of this, even with lack of information, it was noticed a paramount necessity of creation and improvement of public policies focused to cancer posttreatment capable to address, beyond the physical issues, the urgent dimensions of the emotional and socioeconomic necessities.

The main limitation of this exploratory and descriptive study was the narrow scenario where it was carried out. Regardless of being possible to conduct qualitative studies with small samples, they are unable to be generalized. The results obtained, although significant due to the power of the information contained in the narratives, indicate the necessity of additional studies that include, preferentially, more individuals with time of diagnosis and treatment among five and ten years before the interviews. This initiative will allow to widen the understanding and correct evaluation of the care to this group.

### CONTRIBUTIONS

Carolina de Menezes Rabello contributed substantially for the study conception and design, collection, analysis and/or interpretation of the data and wording. Rildo Pereira da Silva and Antonio Tadeu Cheriff dos Santos contributed substantially for the study design, analysis and/or interpretation of the data and critical review. Fernando Lopes Tavares de Lima and Liz Maria de Almeida contributed substantially with critical review. All the authors approved the final version to be published.

### DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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