

The Social Representations of Oncological Patients in Radiotherapy

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As Representações Sociais do Paciente Oncológico em Radioterapia

Las Representaciones Sociales del Paciente Oncológico en la Radioterapia

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ABSTRACT

Introduction: One of the main approaches to cancer treatment is radiotherapy, which can cause irreversible consequences to the individual. Through the theory of social representations (TSR), professionals are able to identify and intervene in the adversities, providing quality of life for the patient. **Objective:** To identify and analyze the structure of the social representations of people living with cancer due to radiotherapy. **Method:** Social representation-based descriptive qualitative approach study conducted with 111 patients in a reference hospital for cancer treatment in Rio de Janeiro. Data collection took place between October and December 2019 through a sociodemographic questionnaire and the free recall technique for the inducing term “radiotherapy”, with analysis using Microsoft Excel and IRaMuTeQ software. **Results:** The evocations that make up the probable central nucleus are: “burning”, being the most frequent, followed by the term “treatment”, “aggressive”, “bad” and “light”. The element “burning” represents a common side effect on the skin, radiodermatitis. The term “treatment” corresponds to a modality to fight the disease. The dyad “aggressive” and “bad” may be associated with the side effects generated and “light” with the exposure to light they receive during irradiation. **Conclusion:** The research shows the possible side effects of radiotherapy and its associated elements and highlights the importance of a comprehensive approach to the individual, promoting individualized care.

Key words: Neoplasms/radiotherapy; Radiotherapy/adverse effects; Health Personnel; Social Representation; Demography.

RESUMO

Introdução: Uma das principais abordagens para o tratamento do câncer é a radioterapia, que pode causar consequências irreversíveis no indivíduo. Por meio da teoria das representações sociais (TRS), os profissionais conseguem identificar e intervir nas adversidades, proporcionando qualidade de vida ao paciente. **Objetivo:** Identificar e analisar a estrutura das representações sociais das pessoas vivendo com câncer frente à radioterapia. **Método:** Estudo descritivo, com abordagem qualitativa, fundamentado na TRS. A pesquisa com 111 participantes foi conduzida em um hospital de referência em tratamento oncológico, no Rio de Janeiro. A coleta de dados ocorreu durante o período de outubro a dezembro de 2019 por um questionário sociodemográfico e pela técnica de evocação livre ao termo indutor “radioterapia”, sendo a análise por meio dos softwares *Microsoft Excel* e *IRaMuTeQ*. **Resultados:** As evocações que compõem o provável núcleo central são: “queima”, seguida pelos termos “tratamento”, “agressiva”, “ruim” e “luz”. O elemento “queima” representa um efeito colateral comum na pele, a radiodermatite. O termo “tratamento” corresponde à maneira de combater a doença. A díade “agressiva” e “ruim” pode estar associada aos efeitos colaterais gerados e “luz”, à exposição à luz que recebem durante a irradiação. **Conclusão:** A pesquisa mostra os possíveis efeitos colaterais da radioterapia e os elementos atrelados e, com isso, evidencia a relevância de uma abordagem integral do indivíduo, promovendo um cuidado individualizado.

Palavras-chave: Neoplasias/radioterapia; Radioterapia/efeitos adversos; Pessoal de Saúde; Representação Social; Demografia.

RESUMEN

Introducción: Una de las principales aproximaciones al tratamiento del cáncer es la radioterapia, la cual puede causar consecuencias irreversibles en el individuo. A través de la teoría de las representaciones sociales (TRS), los profesionales son capaces de identificar e intervenir en las adversidades, brindando calidad de vida al paciente. **Objetivo:** Identificar y analizar la estructura de las representaciones sociales de las personas que viven con cáncer frente a la radioterapia. **Método:** Estudio descriptivo, con enfoque cualitativo, fundamentado en la TRS. La investigación con 111 participantes se llevó a cabo en un hospital de referencia en tratamiento oncológico en Río de Janeiro. La recopilación de datos se realizó durante el período de octubre a diciembre de 2019 mediante un cuestionario sociodemográfico y la técnica de evocación libre al término inductor “radioterapia”, con análisis a través de los programas *Microsoft Excel* y *IRaMuTeQ*. **Resultados:** Las evocaciones que componen el probable núcleo central son: “quemadura”, siendo la más frecuente, seguida por los términos “tratamiento”, “agresivo”, “malo” y “luz”. El elemento “quemadura” representa un efecto secundario común en la piel, la radiodermatitis. El término “tratamiento” corresponde a la forma de combatir la enfermedad. La díada “agresivo” y “malo” puede estar asociada a los efectos secundarios generados y “luz” a la exposición a la luz que reciben durante la irradación. **Conclusión:** La investigación destaca los posibles efectos secundarios de la radioterapia y los elementos asociados, evidenciando la importancia de un enfoque integral del individuo, promoviendo una atención personalizada.

Palabras clave: Neoplasias/radioterapia; Radioterapia/efectos adversos; Personal de Salud; Representación Social; Demografía.

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INTRODUCTION

Cancer is a disease that has a major impact on morbidity and mortality worldwide, making it an extremely important public health issue. This repercussion directly affects several segments, such as countries' demographic transitions and social and economic aspects. In regions where resources are limited, the access to health services and preventive measures can be deficient, which may lead to a higher incidence of the disease, in addition to unfavorable outcomes. In view of this, variations in incidence are evident according to the development of the regions and the resources aimed at promotion, prevention, early detection and treatment used by them¹.

According to estimates by the National Cancer Institute (INCA)¹, in Brazil, 704,000 new cancer cases will be reported annually from 2023 to 2025. Breast, prostate, colon and rectum are among the most frequent cancer types, their predominance varying from one Brazilian region to another. Tumors can be identified based on their extension, which allows professionals to propose the most appropriate treatment for each type of tumor and staging. Among the options for treating cancer, surgery, chemotherapy and radiotherapy are the main approaches².

Radiotherapy is a local or locoregional treatment that uses equipment to irradiate the areas affected by the disease, with the target areas being marked on the patient's body by the health professionals in charge. This procedure has several purposes, such as curative, that aims to heal the patient; neoadjuvant, being performed before surgery to reduce the lesion and facilitate surgical intervention; adjuvant prophylactic, administered after surgery or chemotherapy, with the goal of eliminating small lesion focuses; palliative, whose main purpose is to reduce pain and control bleedings².

Despite scientific and technological advancements, the existing treatments can have consequences to the user's life, including physical limitation, emotional impacts, and body changes. These side effects vary according to the chosen treatment type. In radiotherapy, for instance, effects such as radiodermatitis, mucositis, fatigue, nausea, vomiting, anorexia, dysphagia, and diarrhea³ are common. That way, in addition to following the prescribed treatment, the patient with cancer must deal with adaptations and hardships that include new physical, emotional, and social issues, usually finding solace in the support of relatives and friends that actively participate in these challenging moments⁴.

With the advent of social media, several information sources reinforce the negative stigma in society around the word "cancer", associating it to an incurable disease, suffering, disfigurement, and even death. That information

negatively impacts the patients' perspective, as well as that of their caregivers, making the disease coping process even more challenging^{4,5}.

This negative perception of the disease has an association with the theory of social representations (TSR) developed by Serge Moscovici⁶. TSR is defined as a "particular knowledge modality whose function is the elaboration of behaviors and communication between individuals"⁶. This reinforces the description that social representations are shaped through communication with other people and interactions in the social environment⁵.

Social representations are built through daily social practice, dialogs, thoughts, cultures, relationships, and behaviors of people within society.

Thus, social representation is a psychosocial phenomenon whose concept is formed by individuals based on their interactions with others, stories, experiences, challenges, struggles and coping in life^{8,9}. In this context, adopting this theory allows health professionals to broaden their knowledge beyond the biomedical model, which is mainly based on scientific healing fundamentals. It also emphasizes the importance of understanding the representations that people who live with cancer project over their diagnoses, with the purpose of reducing negative feelings associated with them and providing cheer, courage, and strength to cope with this phase⁴. Following these principles, the objective of the present study is to identify and analyze the structure of social representations of people who live with cancer regarding radiotherapy.

METHOD

Descriptive qualitative approach study based on the theory of social representations (TSR) described by Serge Moscovici in 1978. The Abric¹⁰ technique of structural analysis of free evocation was used, which the author highlights as essential for structuring a representation. TSR is shaped by interpersonal, behavioral, cultural relationships, as well as by experiences and values^{11,12}.

The research was conducted in a federal public hospital of reference in oncological treatment located in the city of Rio de Janeiro, Brazil. The inclusion criteria were patients with cancer diagnosis confirmed through biopsy, who were clinically able to participate in the study, aged 18 or over, male or female, willing to voluntarily take part in the study. The exclusion criteria were patients with improper clinical conditions, that could compromise the understanding of the objective of the study and their understanding of questions.

The study had a non-probabilistic sample by convenience composed of 111 participants. A sociodemographic questionnaire and the technique of

free evocation were used for data collection. The data were collected from October to December 2019, when the participants were invited to mention the first words, at least three and up to five, that came to their minds after being presented with the inductive term “radiotherapy” by the interviewer. The participants signed two copies of the Informed Consent Form (ICF).

The sociodemographic data of participants and their evocations were organized and analyzed in a Microsoft Excel database. This approach allowed for the creation of graphs, simple and percentage tables, as well as a dictionary, with the purpose of standardizing the evoked terms. Of the 518 words evoked, 146 were unique.

The software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ)¹³ was used to analyze the evocations with the purpose of grouping the evoked terms in a four-house table, creating connections among them.

This table is divided in four quadrants: in the upper left quadrant there is the probable central nucleus, which comprises the most frequently evoked elements. The bottom left quadrant is the contrast zone, which houses the less evoked terms, but considered important by the participants. In the upper right quadrant are the most relevant elements of the representation, forming the first periphery. Lastly, the bottom right corner forms the second periphery, which contains the less relevant elements^{11,14,15}.

From the evocations obtained in the four-house table, another technique was used to assess the data, called similitude analysis or maximum tree. That way, the strength of connections between the words spontaneously evoked by the participants was analyzed, resulting in the maximum tree of similitude¹⁶.

This study followed the guidelines and recommendations of Resolutions 466/2012¹⁷ and 510/2016¹⁸ of the National Health Council related to research involving human beings^{17,18}. This study has been approved by the Research Ethics Committee, report number 5593306 (CAAE (submission for ethical review): 19774719.1.0000.5274).

RESULTS

Sociodemographic characterization involves determining the profile data of the study participants, which consists of 111 individuals diagnosed with cancer after confirmation by biopsy. The group was mainly represented by the male sex (69.4%), in the 50-59 age group (24.3%), followed by the 60-69 age group (33.3%). As to their education level, most of the participants had completed high school (37%), while 31.5% had incomplete elementary school. Regarding their marital

status, 52% were married and 31%, single. As to religion, 45% were catholic, while 55% followed other religions.

Regarding their current treatment, 52.3% of the studied group had undergone surgery, 41.4% had chemotherapy, 5.4% had radiotherapy combined with chemotherapy, and 0.9% had radiotherapy. Most patients had been diagnosed less than a year ago (53.0%), followed by one to two years ago (21%). Regarding a family history of cancer, most patients reported having had some relative (first to third degree) diagnosed (54.1%).

The free evocations of the study participants were processed in the IRaMuTeQ software, resulting in a total of 518 words and expressions evoked, 146 of those being unique words. To organize and analyze those evocations, the following criteria were employed: minimum frequency of words (6), mean frequency 12.46; and mean evocation order (MEO) equal to 2.74, representing the average of the position of each evoked term in the studied population. Based on these criteria, the software generated a four-house table with the respective contents (Table 1).

The elements located in the probable central nucleus correspond to the words more frequently evoked by the participants, that is, the most significant to them. In this quadrant, the following words are found: “burning”, “treatment”, “aggressive”, “bad” and “light”. The most frequent term was “burning”, with a frequency of 33, possibly related to the recurring effect on the skin after radiotherapy, known as radiodermatitis. The second most evoked term, with a frequency of 32, was the element “treatment”, indicating the method of treating the illness, as is the case for cancer radiotherapy.

The “aggressive” and “bad” evocations occupy the third and fourth positions, with a frequency of 20 and 17, respectively, which can be associated with the side effects of radiotherapy. In fifth place is the term “light”, with a frequency of 14, being related to the exposure to light the patient receives during the irradiation.

In the contrast zone in the bottom left quadrant are the least frequent terms, though considered relevant by the study participants, once they were evoked with no hesitation. In this quadrant, the following terms are found: “good”, “pain”, “necessary”, “unknown”, “improvement”, “horrible”, “machine”.

In the upper right quadrant is the first periphery, which contains peripheral elements more relevant to the representation, like: “cure”, “God”, “have faith”. This triad represents aspects related to the radiotherapeutic treatment, showing the belief in a cure through this treatment.

Finally, in the lower right corner is the second periphery, composed of terms with a lower frequency, considered of low relevance by the research participants.



Table 1. Four-house table from the inductor term “radiotherapy” by people diagnosed with cancer and treated at a Cacon. Rio de Janeiro, RJ, 2021 (n=111)

MEO	≤ 2.74			> 2.74		
Mea Freq.	Evoked term	Freq.	MEO	Evoked term	Freq.	MEO
≥ 12.46	Burning	33	2.2	Cure	21	3.2
	Treatment	32	2.2	God	15	3.7
	Aggressive	20	2.2	Have faith	14	3.6
	Bad	17	2.5			
	Light	14	2.4			
< 12.46	Good	12	2.7	Sequelae	12	3.0
	Pain	11	2.7	Suffering	11	2.8
	Necessary	9	2.7	Hard	9	3.0
	Unknown	7	2.1	Hope	9	3.1
	Improvement	6	2.7	Medicine	8	3.0
	Horrible	6	1.5	Joy	7	3.9
	Machine	6	2.3	Life	7	3.6
				Fear	7	3.1
				Cancer	6	3.7

Captions: Cacon = High-Complexity Oncology Center; MEO = mean evocation order.

These elements include: “sequelae”, “suffering”, “hard”, “hope”, “medicine”, and “joy”. Most of these elements have a negative nature in the context of the treatment, however, they were considered less important by the participants according to the four-house table analysis.

Continuing the analysis of the social representation of radiotherapy for oncology patients using the four-house table method, it was decided to use the similitude analysis technique, resulting in the maximum tree (Figure 1).

By analyzing the maximum tree of similitude, the elements “treatment”, “burning” and “cure” can be seen as possibly central, due to the broad halo and interconnections established, corroborating the four-house table previously shown. Moreover, other interrelations can be observed between the elements.

The words “burning”, also central to the four-house table, is strongly associated to the terms “bad”, “horrible” and “unknown”, possibly related to the side effects and the lack of dialog between health professionals and patients to improve understanding. This evocation is also connected to “light”, “fear”, and “machine”, suggesting possible effects of the exposure to radiation, potential side effects, treatment effectiveness and impact in the quality of life.

The term “cure”, a probable component of the central nucleus, has a direct connection to the elements “God” and “have faith”, promoting comfort, emotional and spiritual support, during the treatment and recovery process.

As to the term “treatment”, this is related to the evocations “aggressive”, “sequelae”, “cure”, and “medicine”, showing the consequences of this kind of approach. Moreover, this vocabulary also connects to the other evocations, such as “joy”, “improvement”, “pain”, “suffering” and “hope”, revealing the complexity of the experience of a person with cancer throughout their therapeutic process.

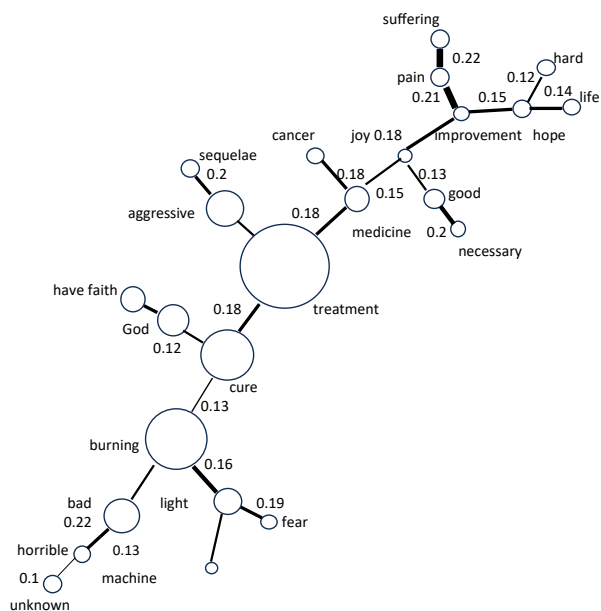


Figure 1. Maximum tree of similitude of evocations to the inductor term “radiotherapy”. Rio de Janeiro, RJ, 2023 (n= 111 subjects)

DISCUSSION

According to the theory of social representations (TSR), the representation of radiotherapy may vary due



to the different perspectives and cultural contexts. These representations are shaped by factors such as personal experiences, available information, individual and collective perceptions and beliefs^{5,19}.

Radiotherapy is a technologically improved treatment, seen as highly sophisticated and advanced for treating cancer, which emphasizes the effectiveness and healing potential of this therapy. However, it is a difficult and challenging treatment, due to possible side effects and physical, emotional and psychosocial impacts that can affect the patients³.

The sample of this study is mainly composed of male individuals, which is in line with the findings of other studies^{20,21}. This predominance of men with a positive diagnosis for malign neoplasm can be justified by the fact that women tend to seek early medical treatment, usually avoiding the need for high complexity hospital treatment and allowing for less invasive interventions through routine screenings^{22,23}.

The most affected age group includes people over 50 years old, which is in line with oncology-related research results. This age group presents greater exposure to carcinogenic factors, increasing the chances of mutations and cell alterations^{1,2}. It is worth noting that most participants have some religious affiliation, corroborating the findings of previous studies. Religiosity plays an important role in coping with the disease, offering courage and cheer to the afflicted, contributing to greater adhesion to treatment⁵.

In this research's possible central nucleus are the most frequently evoked words, "burning" being the most frequent, followed by the terms "treatment", "aggressive", "bad", and "light", respectively. The association between "burning" and radiotherapy occurs due to a common effect caused by the irradiation on the skin, known as radiodermatitis, which can vary from light erythema to ulceration or bleeding. This effect can be associated to the increase in the number of oncological diagnoses, the absence of preventive protocols and institutional treatments, in addition to associated risk factors²⁴.

The term "treatment" follows the term "burning" in frequency, as radiotherapy is one of the main intervention modalities for healing and prolonging the life of patients with cancer diagnosis². Moreover, one of the most frequently seen side effects of radiotherapy is different degree burns in the irradiated area. The dyad "aggressive" and "bad" may be related to the common side effects experienced after radiotherapy and to people's beliefs regarding the stigmatization of the word "cancer"^{4,5,25}. Finally, the evocation of the term "light" is related to the light beam generated by the equipment that irradiate the afflicted body parts that have been previously marked by professionals.

By analyzing the terms that compose the central nucleus, it was possible to verify that they mostly translate the informative dimension of the social representation. This dimension portrays the social representations created from a knowledge the person acquires throughout time about a certain topic, configuring a type of socially elaborated knowledge essential for building a shared reality.

In the contrast zone in the bottom left quadrant are the less frequent terms, though evoked by the participants with no hesitation. The triad formed by the evocations "good-necessary-improvement" can be related to the expectation of tumor reduction and/or disappearance through this treatment, disease control, and even the search for a cure²⁶. The evocation "unknown" reflects the lack of accessible and simplified information about the subject on social media, facilitating understanding of the theme by the patients and lay readers. The term "machine" is related to the equipment that emits the ionizing radiation in radiotherapy. In this zone, the affective dimension is highlighted since the participants express, mostly, feelings, emotions, and affections regarding the treatment.

The frequent presence of the word "pain" in previous studies can be related to the physical limitations resulting from radiodermatitis, reducing patients' quality of life and, consequently, causing a negative impact. This can justify the inclusion of the term "horrible" in this quadrant^{24,27}. It is worth mentioning the importance of professionals managing this symptom together with the patients, using medication, complementary therapies or self-care strategies to promote well-being and quality of life²⁸.

The triad "cure-God-life", found in the upper right quadrant of the first periphery is relevant to the representation. As mentioned in some studies, religiosity, spirituality and faith are essential mechanisms that cancer patients use when coping with the disease. These dimensions offer emotional support, comfort, and strength, helping them deal with the stress and anxiety associated to the treatment²⁸. In addition, they help developing resilience to cope with the challenges of the treatment, strengthening determination, hope, spirituality, and bringing purpose and meaning to life^{25,29-31}. Health professionals should respect and support the spiritual beliefs and needs of each person, integrating this dimension to their care in a holistic way²⁵.

The inferior quadrant corresponding to the second periphery is characterized by the less frequent elements, being considered less relevant by the patients. The triad "sequelae-suffering-hard" may be associated to the physical, emotional, or cognitive effects that radiotherapy can cause, including scars, fatigue, gastrointestinal



issues and skin marks and even consequences in the organ functions. In addition, emotional issues, such as anxiety, depression, and emotional stress may impact the individual at this time. Such sequelae may affect the quality of life in the short and long-term^{28,32}.

These considerations about the possible radiotherapeutic treatment sequelae directly connect to the patient's experience, indicating that physical and emotional aspects can be affected. Moreover, in some cases, displacement and exhaustion may be important factors. Since the radiotherapeutic treatment usually requires daily planning, having the patient show up to the health service during the treatment days can be challenging, especially when the treatment unit is located far away from their home, which incurs in logistic and financial hardships^{33,34}.

Associated to that, it can change the patient's routine and impose significant restrictions to their daily life, including work and physical workout, and affect their social life, as patients can sometimes need to skip social events or face difficulties in interaction due to the side effects or their health status³⁵.

The dyad "hope-joy" may represent optimism and positivity that many patients seek during this process, since radiotherapy can be seen as a hopeful approach to fighting the disease and improving their quality of life, in addition to seeking activities that bring joy and celebrate the small victories along the way³⁶. Finally, the word "medicine" may be associated to the radiotherapeutic treatment that, in some cases, involves combinations with other treatments, such as chemotherapy.

In certain regions and developing countries, radiotherapy may not be broadly available or accessible, resulting in social representations that reflect inequities in the scope of health and access to treatments. This reality sometimes creates significant expectations on patients regarding therapy, considering that radiotherapy is usually associated to the hope of recovery and cure of serious illnesses.

By adopting the theory of social representations (TSR), health professionals can benefit from their practices, since they acquire a more precise understanding of their perceptions, knowledge, disinformation and individual beliefs related to the understanding of the patients' clinical condition, the proposed treatments and their possible side effects. This can be reached by implementing more effective communication strategies to inform the patients, using a more adequate and easily understood language, in addition to tools that facilitate this understanding. Such an approach allows professionals to establish a more effective and confident communication with their patients²², in addition to helping them tailor the care and treatment according to the individual needs and expectations, thus

improving adhesion to treatment and, consequently, reaching the expected results²².

Another topic to be considered is the active engagement of patients in their self-care, considering their specific needs. This promotes a more collaborative partnership between health professionals and patients, resulting in better outcomes and a more satisfactory care experience. Thus, by adopting TSR, the professional may potentially offer a more optimistic perspective, mitigating negative factors associated to the therapy, as well as promoting positive emotions and improving patients' quality of life.

CONCLUSION

This research highlights the duality of radiotherapy in the cancer treatment, showing its therapeutic benefits and associated hardships. Though it is a crucial tool in oncology, offering the hope of cure, its potential side effects and physical, emotional, and social impacts demand a holistic approach to meet the complex needs of each patient. The understanding of social representations of radiotherapy becomes essential for professionals since, by using the theory of social representations (TSR), they can customize care, intervene and communicate more effectively, and integrate the patients' beliefs into treatment, promoting a patient-centered approach.

In addition, it highlights the importance of the health professionals involved, including the nurses who act in radiodermatitis prevention and control through appointments of the radiotherapy ward. This approach not only offers guidance and clears doubts but plays a key role in assessing the degree of severity of this common side effect, as demonstrated in this study, avoiding treatment interruptions. The active engagement of patients in their self-care is emphasized, promoting a collaborative partnership that improves adhesion to treatment and offers a more satisfactory care experience. Finally, adopting TSR promotes substantial improvements to patients' quality of life and well-being, empowering them to cope with the challenges of the cancer treatment with hope, support, and efficacy.

This study is limited by the fact it was conducted in a specialized center and, additionally, with patients that were not necessarily in radiotherapy treatment. Future studies involving patients from other institutions that are actively receiving radiotherapy are relevant to corroborate this social representation.

CONTRIBUTIONS

All the authors have substantially contributed to the study design, acquisition, analysis and interpretation of the data, wording, and critical review. They approved the final version for publication.



DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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