

Distress in Cancer Patients in Brazil: Integrative Literature Review

doi: <https://doi.org/10.32635/2176-9745.RBC.2022v68n3.2402>

Distress em Pacientes Oncológicos no Brasil: Revisão Integrativa da Literatura

Distrés en Pacientes con Cáncer en Brasil: Revisión Integradora de la Literatura

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ABSTRACT

Introduction: Cancer patients experience a series of changes in their lives due to diagnosis and treatment and the emotional aspect is one of those affected by this process. The term “distress” was chosen to refer to the emotional suffering that cancer patients experience. **Objective:** To identify how distress in cancer patients has been addressed in studies carried out in Brazil. **Method:** An integrative review of the scientific literature on distress carried out in September 2020. To search the databases, the descriptor “Neoplasms” and the term “Distress” were used. Articles available in full published in Portuguese, English or Spanish were selected, with the subject Country/Region: Brazil, without time cut, in the LILACS, MEDLINE and BDNF databases. The critical reading step was conducted to analyze and synthesize the articles. The articles selected were organized and presented as a table and the interpretation of the results in categories. **Results:** The final sample of this review consisted of nine articles which pointed out instruments capable of identifying and/or measuring distress, discussed the factors associated with the presence of distress and the factors impacting its reduction. **Conclusion:** Cancer patients can experience distress at any stage of the disease. In view of the scarcity of articles about distress in the Brazilian scenario, it is recommended that more studies are developed in order to deepen and substantiate the theme.

Key words: neoplasms/psychology; psychological distress; review literature as topic; Brazil.

RESUMO

Introdução: O paciente oncológico vivencia uma série de mudanças em sua vida diante do diagnóstico e do tratamento, sendo o aspecto emocional um dos atingidos nesse processo. O termo “*distress*” foi escolhido para se referir ao sofrimento emocional vivenciado pelo paciente oncológico. **Objetivo:** Identificar como o *distress* em pacientes oncológicos tem sido abordado em estudos realizados no Brasil. **Método:** Revisão integrativa da literatura científica sobre o *distress* realizada em setembro de 2020. Para a busca nas bases de dados, utilizaram-se o descritor “Neoplasias” e o termo “*Distress*”. Foram selecionados artigos disponíveis na íntegra publicados em português, inglês ou espanhol, tendo como assunto país/Região: Brasil, sem corte temporal, nas bases de dados LILACS, MEDLINE e BDNF. Foi realizada a etapa de leitura crítica para análise e síntese dos artigos. Os artigos selecionados foram organizados e apresentados na forma de quadro e a interpretação dos resultados em categorias. **Resultados:** A amostra final desta revisão resultou em nove artigos que apontaram instrumentos capazes de identificar e/ou medir o *distress*, discutiram sobre os fatores associados à presença do *distress* e os fatores que impactaram na redução dos *distress*. **Conclusão:** O paciente com câncer pode vivenciar o *distress* em qualquer fase da doença. Diante da escassez de artigos acerca do *distress* no cenário brasileiro, recomenda-se que se desenvolvam mais estudos a fim de aprofundar e substanciar a temática.

Palavras-chave: neoplasias/psicologia; angústia psicológica; literatura de revisão como assunto; Brasil.

RESUMEN

Introducción: Los pacientes con cáncer experimentan una serie de cambios en su vida de cara al diagnóstico y tratamiento, siendo el aspecto emocional uno de los afectados en este proceso. Se eligió el término “*distrés*” para referirse al sufrimiento emocional que experimentan los pacientes con cáncer. **Objetivo:** Identificar cómo el sufrimiento en pacientes con cáncer ha sido abordado en estudios realizados en Brasil. **Método:** Revisión integradora de la literatura científica sobre *distrés* realizada en septiembre de 2020. Para la búsqueda en las bases de datos se utilizó el descriptor “Neoplasias” y la palabra “*Distress*”. Fueron seleccionados artículos disponibles completos publicados en portugués, inglés o español, con el tema país/Región: Brasil, sin corte de tiempo, en las bases de datos LILACS, MEDLINE y BDNF. Se realizó la etapa de lectura crítica para el análisis y síntesis de los artículos. Los artículos seleccionados fueron organizados y presentados en forma de tabla y la interpretación de los resultados presentados en categorías. **Resultados:** La muestra final de esta revisión resultó en nueve artículos que señalaron instrumentos capaces de identificar y/o medir el *distrés*, discutieron los factores asociados con la presencia de *distrés* y los factores que impactaron la reducción del *distrés*. **Conclusión:** Los pacientes con cáncer pueden experimentar *distrés* en cualquier etapa de la enfermedad. Dada la escasez de artículos sobre el *distrés* en el escenario brasileño, se recomienda que se desarrollen más estudios para profundizar y fundamentar el tema.

Palabras clave: neoplasias/psicología; *distrés* psicológico; literatura de revisión como asunto; Brasil.

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INTRODUCTION

Life changes physically or psychologically when an individual is diagnosed with cancer. Oncological patients are reluctant yet in revealing their emotional problems due to the stigma created around psychological issues and receiving psychosocial care. Like the word cancer, the words “psychological”, “psychiatric” and “emotional” are feared and stigmatizing¹.

Due to cancer-related myths, scope and popularity of the term “stress”, the National Comprehensive Cancer Network (NCCN) decided to adopt the term “distress” to address emotional suffering lived by the oncologic patient for being more acceptable and less stigmatizing than “psychiatric”, “psychosocial” or “emotional”; it appears to be “normal” and less embarrassing and can be defined and measured by self-report^{1,2}.

Distress is defined as an “emotional unpleasant and multifactorial experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that can affect the ability to deal effectively with cancer, its physical symptoms and treatment”¹.

Because of its importance and impact, distress was recognized as a core indicator of health and well-being of oncological patients, it is the sixth vital sign for this population³. The increase of distress may have a significant impact on the overall well-being⁴, and psychological support is a key item of full attention to the patient with cancer⁵.

Distress can be a reaction to the diagnosis and continues through the course of the disease, including the survival period. It needs to be recognized, monitored, documented and treated promptly at all stages of the disease and in any environment; screening should identify the level and nature of the distress. Overall, early detection and management result in better adherence to the treatment, better communication, less calls and visits to the oncologist, less anger and development of anxiety and depression¹.

The following question emerged in this scenario: “What are the available evidences of distress in oncological patients in Brazil?”. Despite the current guidelines to manage distress for these patients, there is low production of articles about the theme in Brazil and unfamiliarity of health caregivers.

The publication of the present article addressing the approaches to the theme may potentially expand the knowledge and help health caregivers to improve the management of distress and provide more effective care.

The objective of the article is to identify how distress in oncological patients is being addressed in studies conducted in Brazil.

METHOD

Integrative scientific literature review on distress was carried out with the following steps: elaboration of the research question, data collection, critical review of the studies included, discussion of the results and presentation of the integrative review⁶.

The strategy PIC – Population – oncological patient, Interest – distress, and Context – Brazil was utilized to elaborate the research question: “What is being written about distress of oncological patients in Brazil?”.

A literature search in September 2020 was conducted at the following databases: Latin American and Caribbean Health Sciences Literature (LILACS), Medical Literature Analysis and Retrieval System on-line (MEDLINE) and Nursing Database (BDENF). The term “Distress AND Neoplasia” formed by the descriptor “Neoplasia” from the Health Science Descriptors (DeCS) combined with the term “Distress”, through the Boolean operator “AND” was utilized for the search. “Distress” was chosen for the search because the descriptor “Psychological Anguish” produced few results.

The inclusion criteria were articles fully available in Portuguese, English and Spanish referred to Brazil with the objective to evaluate how the concept of distress is being absorbed by the Brazilian reality without limitation of year of publication. Articles repeated, review articles and that did not respond to the research question were excluded.

An instrument for data collection was utilized including the identification of the article, year, authors, database, journal, language, objective, population, description of the protocol, results, study design and level of evidence based in Melnyk and Fineout-Overholt evidences pyramid: Level I – Evidences-based systematic reviews or meta-analyzes of randomized clinical trials; Level II – Evidences-based well-designed randomized clinical trials; Level III – Evidences-based non-randomized well-designed clinical trials; Level IV – Evidences-based well designed cohort and case-control studies; Level V – Evidences-based systematic reviews and meta-analyzes of descriptive or qualitative studies; Level VI – Evidences-based single descriptive or qualitative study; Level VII – Evidences-based experts panel and/or authorities reports⁸.

The current review gathered and synthesized the articles selected that were organized and presented in a table with the interpretation of the results in categories after critical reading.

RESULTS

The initial survey at the databases selected found 25 articles, eight from LILACS, 15 from MEDLINE and two from BDENF. After selection and eligibility, nine

manuscripts remained to be included in the synthesis of evidences shown in Figure 1.

Of the nine articles selected for the review, six were identified at MEDLINE, two at BDNF and one at LILACS, published between 2008 and 2018, standing out the years 2012 and 2014 with two publications in two different journals.

The journal *Psychooncology* published four articles, the “*Revista Enfermagem*” of the State University of Rio de Janeiro (UERJ) published two. The journals *European Journal of Cancer Care*, *Journal of Wound, Ostomy and Continence Nursing* and “*Revista da Escola de Enfermagem*” of the University of São Paulo (USP) published one each.

Six articles were published in English, five were observational, three, qualitative and one, cross-sectional descriptive.

Table 1 presents the results, author, objective and level of evidence.

The articles indicated instruments able to identify and/or measure distress in oncological patients and discussed the factors associated that impacted its reduction.

The studies were divided in three categories to analyze the results: 1) instruments to identify and/or measure distress; 2) factors associated with distress; 3) factors of reduction of distress. Some articles addressed more than one category.

The instruments indicated by the studies of the first category were reviewed^{9,11,14,17}. In two studies^{9,14}, distress was measured by the distress thermometer (DT) and in another study¹¹, in addition to DT, the instrument Hospital Anxiety and Depression Scale (HADS) was utilized. One study alone utilized the MD Anderson Symptom Inventory (MDASI) – core¹⁷.

The second category studies addressing factors associated with distress^{9-11,13-16} concluded that younger and female patients with a rare cancer are more propense to report high levels of distress; those evaluated during the phase of active treatment compared with the monitoring phase were associated with more distress⁹.

It was possible to identify in three studies^{10,11,14} that patients had more prevalence of clinically significant distress at the beginning of the treatment.

49.6% of the patients reported distress⁹. In the course of the treatment, the patients tend to report lower level of distress according to some studies^{11,14}. One study¹¹ evaluated the patients at the beginning, mid-cycle and at the last day of chemotherapy according to the respective protocol and 82% of them at the beginning of the treatment had a significantly high level of distress; at the mid-cycle evaluation, it dropped to 36.4% and at the last day of the treatment, 18.2% of the 77 patients still enrolled had distress.

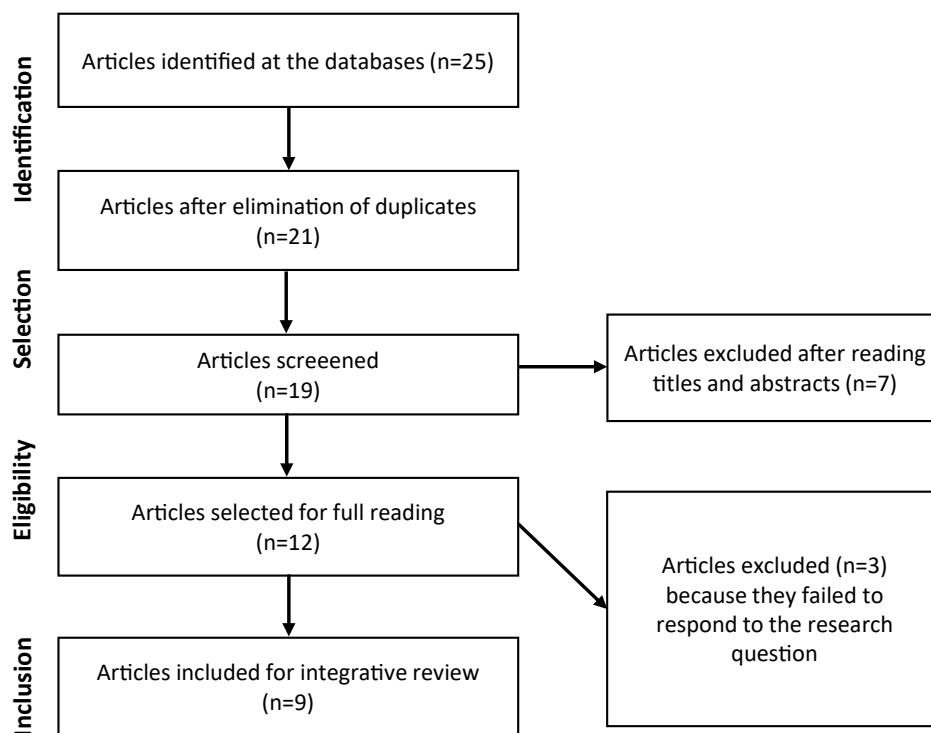


Figure 1. Flowchart of search and selection of articles at the databases. Fortaleza, 2021

Chart 1. Synthesis of the articles per author, year, objective, results and level of evidence. Fortaleza, 2021

Number	Author/year	Objective	Results	Level of evidence
1	Bergerot et al., 2018 ⁹	Investigate the quality-of-life and prevalence of distress in a cohort of patients diagnosed with rare cancer classified by the RARECARE (Information Network on Rare Cancers) definition	In total, 49.6% of the patients reported moderate to severe distress according to DT scale. The level of distress was related to physical (92.7%) and emotional problems (73.7%)	VI
2	Bergerot et al., 2016 ¹⁰	Describe the process and pilot implementation of the distress screening program (DS) and initial analyses to understand the investigation about this key aspect of cancer treatment	Patients receiving DS + Psychosocial Care Meeting Group showed significantly lower distress and depression/anxiety upon chemotherapy initiation compared to the group receiving DS. Emotional and physical problems were the main problematic areas reported	IV
3	Decat et al., 2011 ¹¹	Measure distress at three time points during the course of chemotherapy: beginning, middle and the last day of therapy in a private cancer center in Brazil	At the beginning of the treatment, 82% of the patients presented significant level of distress. In the middle of the treatment, of the remaining 88 participants, 36.4% had distress. On the last day of the treatment, 18.2% of the 77 patients still enrolled scored above 4 by the Distress Thermometer (DT). Emotional and physical problems were the most important at the three timepoints	IV
4	Paiva et al., 2012 ¹²	Obtain preliminary information on the effectiveness of a palliative care outpatient programme in improving cancer-related symptoms, identify and correlate symptoms that changed (improved or worsened) together	Palliative outpatient programme was effective in promoting significant improvements in the evolution of the symptoms evaluated through reduction of symptoms and TSDS	IV
5	Lopes et al., 2012 ¹³	To explore the psychosocial meaning and repercussions on lifestyle associated with erectile dysfunction and urinary incontinence (UI) in men following radical prostatectomy	Men reported difficulties in dealing with treatment-related physical and emotional impotence. Urinary incontinence and erectile dysfunction affected the body, reinforcing the conflicts associated with masculinity, triggering subjective feelings of powerlessness and psychological distress	VI
6	Bergerot et al., 2014 ¹⁴	Investigate the relation between distress and demographic and health characteristics and elaborate a percentile curve reference chart with distress scores of a large sample of patients of a private cancer hospital in Brazil	More than half (n=269, 53.8%) of the participants reported clinically significant distress at some point in the course of the treatment with high percentage at the beginning of the treatment (n=254, 50.8%). Problem-related distress reduced progressively in time. Physical and emotional problems were the most commonly reported all through. Distress diminished along the time from a mean of 4.0 in T1 to 2.0 in T3	IV

to be continued

Table 1. continuation

Number	Author/year	Objective	Results	Level of evidence
7	Caetano et al., 2009 ¹⁵	To know what the reactions of women receiving the diagnosis of breast cancer are and how they coped with the disease and treatment	Breast cancer diagnosis brought up symptoms of despair and anguish (distress), that were minimized while hoping for cure from God and medicine and with this, started to value more their lives and simple things of the daily life	VI
8	Cascais et al., 2008 ¹⁶	To understand the social representations about cancer of the individuals affected by the disease	Social representations of cancer are still strongly based in death, suffering, impairment, dread, fear and despair (distress)	VI
9	Kolankiewicz et al., 2014 ¹⁷	Review the reliability and validity of the psychometric properties of the Brazilian version of MDASI	Fifty percent (50%) of the interviewees reported concerns (distress) at level 2 of intensity. The prevalence was 54.5%, mean of 3.36 (± 3.64)	VI

Captions: DT = distress thermometer; TSDS = total symptom distress score; MDASI = MD Anderson Symptom Inventory – core. Levels of Evidence: VI – Evidence-based single descriptive or qualitative study. IV - Evidence-based well-designed cohort and case-control studies.

The social representation of cancer is still strongly grounded in death, suffering, impairment, dread, fear and despair¹⁶.

Men submitted to radical prostatectomy had high treatment-related distress as difficulty to cope with urinary incontinence and erectile dysfunction¹³.

A study classified as third category^{10-12,14} to develop and implement a comprehensive psychosocial screening programme reached results indicating reduction of distress in patients in oncologic treatment who received the Distress Screening Programme and the Psychosocial Support Care Meeting. The significant differences encountered are attributed to multidisciplinary collaboration, attention to distress screening and care provided in the course of the treatment including former management of distress.

In addition, the outpatient follow-up by a palliative care interdisciplinary team eventually reduced the suffering of patients with advanced cancer¹².

Two studies^{11,14} measuring distress have also demonstrated that during the treatment the patients tend to present low level of distress.

DISCUSSION

INSTRUMENTS TO IDENTIFY AND/OR MEASURE DISTRESS

DT is a specific tool to measure cancer-related distress developed by the NCCN Distress Management Panel, similar to the scale utilized for pain⁴.

In 2009, DT was adapted and validated to Portuguese. The study results indicated a sensitivity of 82% and specificity of 98%, being possible to conclude that DT is viable and effective to evaluate psychological distress. Due

to its simplicity and effectiveness, it can be applied by any health caregiver and included in the oncology routine¹⁸.

DT identifies the level of distress and possible causes referred to the week before, including the day when the evaluation is occurring. It is an easy-to-evaluate tool consisting in two instruments; one detects the level of distress and the other identifies possible causes. The first is presented as a thermometer and allows the patient to sign-off the level of distress starting from zero (no distress) to ten (extreme distress). The second called List of Problems has 35 items to recognize possible causes of distress related to the diagnosis, treatment and other factors^{2,14,18}.

Another instrument utilized was the Hospital Anxiety and Depression Scale (HADS) validated to Brazil which covers 14 items to measure anxiety, depression and distress¹⁹, it is also considered a distress screening instrument for individuals with cancer⁴.

A study¹⁸ noticed the convergence of DT and HADS to identify psychological distress and potential problems reinforcing that both are comparable with each other.

Clinical oncological treatments create innumerable symptoms as fatigue, pain, sleeping disorders, lack of appetite, tribulations that can vary in the course of the treatment, which requires a correct identification of the symptoms for early identification of problems and minimize likely alterations of the patients' functioning ability¹⁷.

Symptoms measuring scales are essential to detect and classify the severity and efficacy of the treatment²⁰. MDASI is an important tool in clinical practice and research to evaluate multiple symptoms the patients present and report as a result of the disease and treatment¹⁷. It can

be utilized to assess the severity of the symptoms and interference in the patients' daily life²¹ and easily applicable by most of them²⁰.

MDASI-core has two components: 13-items measuring the intensity of the symptoms and 6-items for symptoms interfering in the daily life. The 13 main items are those more frequent and highly severe for patients with several types of cancer and treatments: pain, fatigue, sleeping disorders, distress, dyspnea, difficulty to remember, lack of appetite, somnolence, dry mouth, sadness, vomit, tingling/numbness evaluated in a 0-10 scale, zero being without symptoms and ten, as strong as possible. The second component (6-items) addresses symptoms interfering in the daily life also with a 0-10 scale, zero, being no interference and ten, full interference: general activity, mood, work, relationships, walking and joy of living. It is possible to utilize the mean of the items of interference to represent distress of general symptoms^{17,21,22}.

The routine screening tends to individualize the treatment to address specific needs and allow the patients and health caregivers team to recognize the problems and report them easily to ensure fast access to the available resources¹⁰.

Distress screening is essential to detect specific needs of the oncological patient and better management.

FACTORS ASSOCIATED WITH DISTRESS

Oncological patients experience several levels of distress associated with cancer diagnosis in the course of the disease and as a result of its effects and treatments⁴.

High prevalence of distress at the beginning of the treatment may be related to the impact of the diagnosis and patient's anticipation of the chemotherapy treatment. Cultural differences of adaptation to cancer in Brazil may be associated with levels of distress from moderate to severe and how the diagnosis of advanced disease can impact the outcome of distress¹⁰.

Because of the diagnosis, oncological patients experience distress as a circumstance permeated by insecurity, denial, impotence and fear of pain and death, anxiety, despair and even depression^{16,18}.

Cancer is stigmatized and continues to be a fearing disease, even with the increasingly effective therapeutic possibilities of the treatment, inducing fear and emotionally affecting the individuals. The idea that something grows and destroys the vitality, the uncertainty of the cure, possibility of imminent death allied to great suffering is attributed to cancer and associated with punishment in many cultures^{16,23}.

Distress in oncological patients is usually associated with physical and emotional problems^{9-11,14}. In a study with oncological patients utilizing distress screening instruments, physical problems as memory/concentration, sleeping disorders, constipation, nausea, appearance,

fatigue, pain and sexual problems were reported as major causes of distress. The emotional problems, fear, concern, sadness and loss of interests in daily activities were the items the patients reported at the most¹⁸.

Screening with DT offers a wide spectrum of emotional and physical symptoms, but support services still need to go beyond physical complaints of the patients. The development of studies with interventions to improve the general well-being of the patients through educational materials helps patients to report the symptoms effectively and minimize emotional and physical problems⁹.

It is quite clear the extent the impact of the diagnosis and cancer treatment has on the outcome of distress, reinforcing the importance of a distress routine screening by health caregivers who are part of the care to the oncological patient, with emphasis at the diagnosis and during treatment.

FACTORS OF DISTRESS REDUCTION

With the development and implementation of psychosocial screening programs, it is possible to let the patient report its experience, improving the communication among patients, family and health team and encourage the patients to become the protagonists of their treatment. They begin to be more aware of their physical symptoms, feelings and thoughts and immersing in their own care. During the implementation of the program, constant discussions among the health team were held, ensuring the opportunity to develop strategies to improve the psychosocial attention in the course of the treatment¹⁰.

It also allows the health team to expand their understanding and appreciation of the psychosocial issues the patients face, in addition to providing the perspective of the patients to cope with cancer and treatment; they provide evidences-based practical recommendations that can be incorporated in their clinical routine¹⁰.

Similarly, another study¹² with patients with cancer followed-up by a multidisciplinary team in an outpatient palliative care programme concluded that the team was able to bring palpable improvements in the evolution of the symptoms and eventually reducing the suffering with the symptoms. The main focus of palliative care is to relieve the symptoms and improve the quality-of-life through pain control and other stressful symptoms.

The programme developed by the team resulted in improvements of the Total Symptom Distress Score (TSDS) of the instrument Edmonton Symptom Assessment System (ESAS), being feasible to reduce the symptoms for patients in palliative care.

Studies have identified that treatment-related distress reduces as the treatment nears its ending^{11,14}. It can be related to the patients' adjustment to the treatment, feeling of relief with the end of the treatment or correct management by the health team¹⁴.

NCCN's panel encourages the creation of interdisciplinary committees to monitor distress and prompts the institutions to offer a structure prepared to deal with psychosocial care for better management of distress¹.

The action of the interdisciplinary team is essential to manage distress with visible impact on the patient, family and the team itself through the correct approach to psychosocial issues, going beyond the physical complaints, with clear improvements for the patients and health caregivers.

The focus of the article preferred by the authors was the Brazilian scenario alone, which is a possible limitation of the study.

CONCLUSION

The results indicated that instruments able to identify and/or measure distress in oncological patients are utilized, in addition to factors associated which reduce patients' distress.

It is possible to conclude that distress was detected in patients with cancer, the necessity and importance of screening with consistent instruments, the attention required by health caregivers to manage distress and minimize the adverse effects through patient-centered actions in the course of the disease.

The paucity of studies was the main motive to investigate how distress is being managed by health caregivers. More studies are necessary to expand the scope of future investigations.

CONTRIBUTIONS

All the authors contributed equally 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 interests to declare.

FUNDING SOURCES

None.

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Recebido em 14/10/2021

Aprovado em 9/3/2022