Assessment of Spirituality in Cancer Patients Receiving Palliative Care: Qualitative Study

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Avaliação da Espiritualidade de Pacientes Oncológicos em Cuidados Paliativos: Estudo Qualitativo

Evaluación de la Espiritualidad en Pacientes con Cáncer que Reciben Cuidados Paliativos: Estudio Cualitativo

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ABSTRACT

Introduction: Spirituality is an intrinsic component of human experience, with the manifestation of religious beliefs or experiences often observed in the health context. In palliative care, spiritual assessment seeks to understand the patient's relationship with these beliefs and the community, in an attempt to identify suffering inherent to the end-of-life condition. **Objective:** To analyze whether the assessment of spirituality is relevant for patients under oncological palliative care. **Method:** Observational, cross-sectional, and qualitative study conducted with oncological patients in palliative care, assisted by the Integrated Oncology Center and Home Care Service. Data collection was carried out using a semi-structured questionnaire, utilizing the FICA Spiritual History Tool and the American College of Physicians' Spiritual History instruments, followed by Thematic Content Analysis as proposed by Bardin. **Results:** Twelve patients were interviewed, identifying four thematic categories that express the participants' spiritual experience: faith/belief, importance of faith; community, spiritual history, and therapeutic approach. **Conclusion:** The results showed heterogeneity in patients' expectations regarding the approach to spirituality in the SUS, reinforcing the need for individualized care and its role as a coping resource.

Key words: Spirituality; Palliative Care; Spiritual Therapies; Neoplasms/psychology.

RESUMO

Introdução: A espiritualidade é um componente intrínseco da experiência humana, sendo a manifestação das crenças ou vivências religiosas frequentemente observadas no contexto da saúde. Nos cuidados paliativos, a avaliação espiritual busca compreender a relação do paciente com essas crenças e a comunidade, na tentativa de identificar sofrimentos inerentes à condição de terminalidade. **Objetivo:** Explorar o significado da espiritualidade e as expectativas de pacientes em cuidados paliativos oncológicos quanto à sua abordagem na prática clínica no Sistema Único de Saúde (SUS). **Método:** Estudo observacional, transversal e qualitativo, realizado com pacientes oncológicos em cuidados paliativos atendidos pelo Centro Integrado de Oncologia e Serviço de Atenção Domiciliar. A coleta de dados foi realizada por meio de questionário semi-estruturado, utilizando os instrumentos FICA *Spiritual History Tool* e *Spiritual History* do *American College of Physicians*, seguida da Análise de Conteúdo Temática proposta por Bardin. **Resultados:** Foram entrevistados 12 pacientes, identificando-se quatro categorias temáticas que expressam a vivência espiritual dos participantes: fé/crença, importância da fé, comunidade e abordagem terapêutica. **Conclusão:** Os resultados evidenciaram heterogeneidade nas expectativas dos pacientes quanto à abordagem da espiritualidade no SUS, reforçando a necessidade de cuidado individualizado e seu papel como recurso de enfrentamento.

Palavras-chave: Espiritualidade; Cuidados Paliativos; Terapias Espirituais; Neoplasias/psicologia.

RESUMEN

Introducción: La espiritualidad es un componente intrínseco de la experiencia humana, siendo la manifestación de las creencias o vivencias religiosas frecuentemente observadas en el contexto de la salud. En los cuidados paliativos, la evaluación espiritual busca comprender la relación del paciente con estas creencias y la comunidad, en un intento de identificar sufrimientos inherentes a la condición de terminalidad. **Objetivo:** Analizar el significado de la espiritualidad y las expectatvas de los pacientes bajo cuidados paliativos oncológicos respecto a su enfoque en la práctica clínica en el Sistema Único de Salud (SUS). **Método:** Estudio observacional, transversal y cualitativo, realizado con pacientes oncológicos en cuidados paliativos, atendidos por el Centro Integrado de Oncología y por el Servicio de Atención Domiciliaria. La recolección de datos se realizó mediante un cuestionario semiestructurado, utilizando los instrumentos FICA *Spiritual History Tool* y *Spiritual History* del *American College of Physicians*, seguida del Análisis de Contenido Temático propuesto por Bardin. **Resultados:** Se entrevistaron a 12 pacientes, identificando cuatro categorías temáticas que expresan la vivencia espiritual de los participantes: fe/creencia, importancia de la fe, comunidad, historia espiritual y enfoque terapéutico. **Conclusión:** Los resultados evidenciaron heterogeneidad en las expectativas de los pacientes respecto al enfoque de la espiritualidad en el SUS, reforzando la necesidad de una atención individualizada y su papel como recurso de afrontamiento.

Palabras clave: Espiritualidad; Cuidados Paliativos; Terapias Espirituales; Neoplasias/psicología.

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INTRODUCTION

Spirituality, in the context of healthcare, is understood as a dynamic and intrinsic aspect of human experience, to which individuals seek meaning, purpose, and transcendence[1]. This dimension has been acknowledged as an important coping resource from the past century[2] onwards, given that several studies demonstrate its influence on health decision-making[3], clinical results[4], and improving patients' quality of life[5-9].

The importance of this dimension becomes even more evident when we verify its association with reducing mortality and relieving psychological suffering[10,11], and even improving the efficacy of medical interventions[5,12]. In contexts of potentially fatal illnesses or severe clinical conditions, patients have expressed a desire to discuss their beliefs with healthcare professionals in a way that is sensitive to individual values[13-16].

Despite their relevance, the spiritual needs of patients often remain neglected in clinical contexts, especially in advanced illnesses, in which spirituality may be a source of comfort and hope[14]. In 1990, the World Health Organization (WHO) defined palliative care as " the active total care of patients whose disease is not responsive to curative treatment", highlighting that pain control and other symptoms, as well as psychological, social, and spiritual aspects, are essential to integral care[17].

In this context, the main objective of palliative care is to prevent and alleviate suffering, promoting the best possible quality of life for the ill and their families, regardless of disease progression or continuity of other therapies. This humanized approach necessarily involves including the spiritual dimension in the therapeutic plan, respecting cultural, religious, and spiritual specificities of each individual[16,18,19].

To ensure the spiritual needs of patients are properly addressed, it is necessary to resort to instruments such as FICA, HOPE, and FAITH, which help in identifying and guiding clinical care[20]. In health investigation, these systematized approaches have fostered the analysis of constructs, such as spiritual well-being, meaning of life, religious practices, and coping strategies, as well as their association with clinical outcomes, including quality of life, coping with disease, and decision-making in health[6,16,21].

In Brazil, this dimension gains relevance in the context of palliative care, especially with the recent organization of public policies aimed at integral care for people with grave illnesses within the National Health System (SUS)[22-24]. The CIT Resolution N. 41/2018 and Ordinance GM/MS N. 3,681/2024 provided guidelines and instituted the National Policy for Palliative Care, in accordance with Law N. 14,758/2023[22-24]. In this scenario, assistance must fully contemplate the physical, emotional, social, and spiritual dimensions of suffering[25]. Recent Brazilian studies associate spirituality with quality of life, hope, and disease coping mechanism for oncological patients in palliative care[13,18], although its systematic incorporation into care practice still represents a challenge[21].

In the public network context, Integrated Oncology Centers (IOC) are favorable environments for exploring this more integral approach, given that they provide multiprofessional care, including doctors, nurses, psychologists, and nutritionists, according to the Ministry of Health's guidelines[22]. Moreover, the Home Care Services (HCS) of the *Programa Melhor em Casa* (Better at Home Program), instituted by the Ministry of Health in its Art. 30, item X of Ordinance N. 825, of April 25, 2016, also promotes multiprofessional assistance at home for patients in palliative care who are clinically stable and need a higher level of complexity[26].

Despite the robust literature on the relevance of spirituality in health[6,16] and national guidelines recommendations[25], there is still a gap between the theoretical knowledge of this dimension and its effective integration into the assistance practice of SUS. Incorporating this knowledge into clinical practice requires advancing the conceptual plan to analyze patients' actual experiences and explore how they want this dimension to be considered by healthcare teams.

Considering the recent National Policy for Palliative Care[24], investigating this gap can contribute to aligning spiritual support with the expectations of public network users. Therefore, the objective of this study is to explore the meaning of spirituality and the expectations of patients who receive oncological palliative care regarding how it is addressed in clinical practice within the SUS.

METHOD

Qualitative, observational, cross-sectional, and descriptive-exploratory study. This methodological framework is used in healthcare research due to its pragmatism and focus on obtaining rich, direct, and low-interference descriptions of participants in their own language[27]. Unlike other qualitative approaches, such as phenomenology or grounded theory[28], the descriptive qualitative method does not seek to develop complex theories or explore the essence of a phenomenon, but to provide an encompassing and detailed report of an event or perception, ideal for answering direct questions on the experiences of patients[27].

The convenience sample included oncological patients in palliative care cared for by the IOC and HCS in the municipality of Indaiatuba (São Paulo, Brazil). The interviews

were conducted by three healthcare researchers, duly trained to address patients and family members as well as to use assessment scales in the clinic and home care settings. The study followed the Standards for Reporting Qualitative Research (SRQS) to ensure methodological rigor[29].

The inclusion criteria were oncological patients in palliative care, cared for by the IOC or HCS, 18 or older, capable of communicating in Portuguese, and who voluntarily agreed to participate in the study. Patients with cognitive limitations and/or significant linguistic barriers that compromise the proper understanding of questionnaires and interviews, as well as those who did not meet the inclusion criteria, were excluded.

The potential participants were identified by the IOC/HCS medical teams. Next, the investigators reached out to confirm the eligibility criteria and obtain informed consent. The interviews occurred in the clinic (IOC) and home (HCS) environments, conducted by three researchers.

The collection was centered on patients, with the previously defined possibility of collecting data from caregivers who were directly involved in patient care, according to the assistance context. The researcher mediated the interview with a focus on the patient, directing questions to the patient, and redirecting the speech when needed, preserving their perspective as the unit of analysis.

Seventeen patients were eligible at first; 5 were later excluded for presenting previously established exclusion criteria, such as cognitive and language deficits that compromised verbal communication. Therefore, 12 patients were interviewed: Ten in the presence of family caregivers (5 spouses, 4 adult children, and 1 sister) and 2 without a companion.

Initially, a semi-structured questionnaire was applied to collect sociodemographic and clinical data, followed by the FICA Spiritual History Tool[30,31] and the American College of Physicians (APC)[32] Spiritual History instruments. The functional state, assessed using the Palliative Performance Scale/Karnofsky Performance Status (PPS/KPS)[33] and Eastern Cooperative Oncology Group Performance Status (ECOG)[34] scales, was obtained from the medical records. These instruments were chosen for being validated and recommended in oncological clinical practice[35], enabling the team to systematically investigate spirituality and its influence in coping with the disease[21].

The questionnaires were verbally applied by the researchers, with an average duration of 9.2 minutes (Min=5.5; Max=24.4), in person and audio-recorded, ensuring precision and integrity of the collected information. The recordings were later fully transcribed into text documents with access restricted to the research team, ensuring personal data protection.

The interview data was processed using the Thematic Content Analysis[36] technique. The analysis followed a deductive approach, in which the analysis initiates with a previous framework for the initial codes[37]. In this context, the categorization was guided by the four dimensions of the FICA instrument – Faith, Importance, Community, and Address –, applied during data collection[30].

As a theoretical premise, the consensus was adopted that spirituality corresponds to the search for meaning, purpose, and connection with the transcendental, not restricted to institutional bonds[1,36]. Whereas religiosity was defined as its organized expression, through shared beliefs and practices[12,38].

Based on these constructs, the instrument was analyzed following the dimensions: Faith (F), referring to the key beliefs and sources of meaning; Importance (I), the role of these beliefs in coping with the disease; Community (C), the formal and informal support networks; and Address (A), the expectations of patients regarding the consideration of this dimension in healthcare[1,34].

The three steps proposed by Bardin[36] were then applied in this context, with a pre-analysis conducted, followed by reading the data in an exploratory manner for familiarization, initial organization, and definition of analysis categories, in addition to the formulation of preliminary hypotheses. In the second step, exploration of the material, the content was systematically encoded and allocated into the four pre-defined FICA[30] categories. In the third step, regarding the treatment of results, the encoded data was interpreted and discussed using relevant scientific literature on spirituality and palliative care as technical elements of support, allowing the articulation of data with existing knowledge[34] (Figure 1).

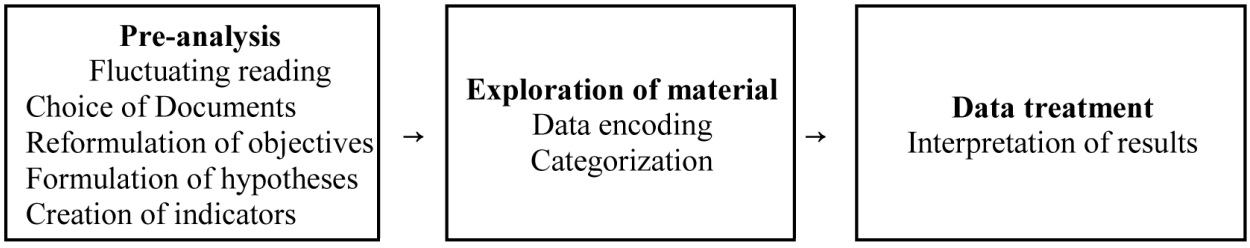

Figure 1. Data analysis flowchart
Source: adapted from Bardin[36].

The software Atlas.ti[39] was used as a supporting tool for organizing and managing data, helping with encoding and categorization. The thematic analysis was conducted by the researchers, and the categories were discussed and validated by consensus among the research team.

The study followed the Brazilian ethical norms for research with human beings, according to Resolution 466/2012[40] of the National Health Council. The Research Ethics Committee of the *Instituto de Ensino Superior de Indaiatuba-SP* approved the research, approval report number 7312089 (CAAE: 85319424.6.0000.0241). Participation was voluntary and granted by signing a Free and Informed Consent Form, ensuring all rights.

RESULTS

The analyzed sample was composed of 12 patients, 6 male and 6 female. The age of participants presented a mean of 66 years (SD=12.0; min=38; max=79), revealing a predominantly elderly profile, with 75.0% of the sample in the age group of 60 to 79 years, most of whom were married (75.0%). Regarding education, incomplete elementary school (66.7%) predominated, followed by complete higher education (25.0%). Regarding religious identification, the sample was heterogeneous: 33.3% self-identified as Catholic, 33.3% declared following no formal religion, 25.0% were Evangelical, and 8.3% were Spiritist.

Half the patients were assisted by the HCS and the other half by the IOC, and the average follow-up time for patients in palliative care was 6 months (SD=8.1; Min=0; Max=27). There was a diversity of oncological diagnoses, with the most frequent being colorectal, tongue, and kidney cancer (16.7% each). The sociodemographic and clinical profile of participants is detailed in Table 1.

Most participants classified their health status as severe (33.3%) or very severe (41.7%). Despite that, 66.7% reported feeling physically and mentally well at the time of assessment, in line with the good functionality observed, with 66.7% presenting PPS/KPS between 80–90 and a predominance of ECOG 1 (66.7%). The scenario analysis showed differences between the care contexts: in IOC, 100% of patients presented ECOG 1, with PPS/KPS between 70–90; in HCS, 66.7% were classified as ECOG 2 or 3, with PPS/KPS between 40–80.

The application of the APC[28] instrument highlighted that 83% of patients reported faith as a strong element in previous phases of life. Additionally, 58.3% declared having someone to talk to about spirituality, although only 33.3% demonstrated interest in deepening this conversation in the context of treatment. Moreover, 33.3% reported overcoming problems or diseases through faith; 25.0% highlighted believing in a higher entity; and 16.7% expressed trust in both medical care and spiritual support. Less frequent manifestations included reflections about rituals, hope in the absence of suffering after death, and subjective experiences with spirituality (8.3% each).

Table 1. Sociodemographic and clinical characteristics of the sample of oncological patients in palliative care in the Home Care Service and in the Integrated Oncology Center

Variables	Patients (n=12)	
	n	%
Age		
30 to 39 years	1	8.3
50 to 59 years	2	16.7
60 to 69 years	4	33.3
70 to 79 years	5	41.7
Sex		
Male	6	50.0
Female	6	50.0
Marital status		
Married	9	75.0
Divorced	2	16.7
Widower	1	8.3
Education		
Incomplete elementary school	8	66.7
Complete elementary school	1	8.3
Complete higher education	3	25.0
Diagnosis		
Colorectal cancer	2	16.7
Stomach cancer	1	8.3
Larynx cancer	1	8.3
Tongue cancer	2	16.7
Ovarian cancer	1	8.3
Prostate cancer	1	8.3
Kidney cancer	2	16.7
Leukemia	1	8.3
Multiple myeloma	1	8.3

The data organized in thematic categories is presented as follows:

CATEGORY I: FAITH AND BELIEFS

Upon investigating the participants' spiritual identification and whether their beliefs helped coping with problems, 75.0% identified as religious or spiritualized, and all participants expressed that practicing faith is a resource for dealing with hardship. This perception can be illustrated in the following testimonies:

> Oh, I think faith in God is everything to us, you know? I have much faith in God, yes (Patient 1).

> I think everything we've got to have is faith, you know? If we don't have faith, we can't move forward (Patient 7).

> Oh, I think I can answer both, see? Religious and very much spiritualized. I trust very much in God, you know? (Patient 12).

CATEGORY II: IMPORTANCE AND INFLUENCE

When questioned about the importance of faith and its influence, all participants reported that spirituality played a relevant role in their coping with cancer. Most (91.7%) stated that their beliefs helped them deal with the stress and weaknesses imposed by the illness. Regarding the influence on medical or treatment decisions, 75.0% declared that their beliefs do not interfere, 16.7% pointed to some influence, and 8.3% associated it with a lack of hope in a cure. Since most of the interviewees did not tie faith to biomedical restrictions, the testimonies show that spirituality acts indirectly in therapy: providing a basis for trust and adherence to the care plan and surrender to medical treatment.

> People surrender to [religious] institutions. I surrender myself to a divine power. Divine power knows what to do. It's not me who's going to say what the doctor does or doesn't do. When I go to surgery, I place it in the hands of God and the doctor (Patient 3).

> Faith in the sense of believing, persisting in something, I think it's very important. […] I understand faith as this: persistence in what you need to do, or have to do, or think is necessary to do (Patient 4).

> I think faith is what moves me. What moves my life. One certainty is that God is with me, guiding me at every step, and can heal me of this infirmity if it's his will (Patient 9).

CATEGORY III: COMMUNITY

When inquired about participation in religious or spiritual communities, 41.7% of patients declared having bonds with spiritual groups, 8.3% reported involvement in prayer groups, while 50.0% reported having no connection with any community. The most mentioned support network was family (83.3%), followed by references to higher entities (8.3%), and bonds of friendship (8.3%). Spiritual support was described through prayers (41.7%), home visits from religious groups (16.7%), support from associations aimed at fighting cancer (16.7%), and, in 25%, lack of direct support. Among the reports, we highlight the following:

> I have several reports from people that sometimes have nothing to do with my daily life. You see? For example, some people showed up to me out of nowhere [...] after 20 years of not seeing them. […] And when you tell them what you're going through, they start to support you, welcome you. And then, they include you in a spiritual circle they attend. […] It's not me who's asking for those things. They are the ones doing it, that's why I say it's out of nowhere (Patient 3).

> Oh, but they gave me an incredible support. […] The people came here, talked, [...] supported us. In the sense of bringing you some soup, talking, and sending you communications. So, perfectly, yes (Patient 4).

> She talks a lot to me, people come and talk to me. On the subject. Some people went through this. So, they talk to me about [...] So, it's a way of saying: do not give up. Fight until the end (Patient 6).

> So, when talking, when you're like that, kind of thrown away here and there and don't know what to do, the person comes, talks to you, explains things. To me, it's already very good, see? (Patient 12).

CATEGORY IV: THERAPEUTIC ADDRESS

Regarding expectations on how spirituality must be considered in medical care, six different demands emerged: maintenance of neutrality (25.0%), care and reception (25.0%), respect to personal beliefs (16.7%), clarification about integration between spirituality and treatment (16.7%), demand conditioned to professional competency (8.3%), and a patient answered that their doctors were excellent (8.3%). In the testimonies, different perspectives emerged:

> I think that Medicine is also like that. Let's give an antibiotic, but also try to listen to this side that also makes up the whole (Patient 3).

> I even prefer to leave it out, because the doctor sometimes has their own beliefs, right? […] He does his technical job and conveys it to me. But I expect him to be considerate, if I say something, right? […] But if I say something, [I expect] that he has, you see, some consideration, respect, and doesn't invade too, right? (Patient 4).

> I don't have much to complain about this part. Because they have all respected me. I also try to respect, because everyone is different. […] I think people must be respectful, that's all. About each one's religion. And they always were, to me, normal (Patient 6).

DISCUSSION

The interpretation of the findings, in light of the conceptual framework adopted, reinforces spirituality as a key dimension in the experience of illness, understood as a search for meaning, purpose, and connection with the transcendental, not restricted to formal religiosity[20,41]. In this context, the results are organized coherently with the FICA instrument's categories, allowing a structured analysis of the spiritual experience in palliative care[1].

In the Faith (F) dimension, spirituality was a widely mobilized resource by patients, in line with the literature that describes religious coping as a relevant strategy for coping with advanced cancer[7,38,42]. Recent studies corroborate its association with better quality of life and greater resilience towards the disease[8,9,43].

Regarding Importance (I), spirituality works predominantly as emotional and existential support, helping in the elaboration of suffering and maintenance of the meaning of life. This role is broadly described in the literature, which acknowledges it as a strategy for managing angst and uncertainty in the oncological context[13,42,43]. It was also observed that its influence on therapeutic decisions occurs indirectly, strengthening trust and adherence to care, without necessarily conflicting with medical conduct[44].

In the Community (C) dimension, it is highlighted that spiritual experience is not always tied to religious institutions, being often sustained by family networks and individual practices. This finding is in line with studies that differentiate organizational religiousness from intrinsic spirituality[10], reinforcing that spiritual support can happen outside formal structures. However, the literature suggests that demands for spiritual address by healthcare services are often not met[14], underscoring a relevant assistance gap.

Regarding Address (A), the heterogeneity of patients' preferences reinforces the need for person-centered care, respecting individuality and the different expectations regarding the integration of spirituality into clinical practice[16]. The coexistence of demands for neutrality and active reception suggests there is no unique way of addressing spirituality, requiring professionals to have specific competences to assess and conduct this theme[45-49]. In this sense, literature highlights spiritual training as an essential element for the quality of care[50].

The lack of systematic integration of spirituality into care can be understood in light of the gap between guidelines and clinical practice. Despite national recommendations acknowledging this dimension as a component of palliative care[24,26], its incorporation is still limited, directly impacting integral care planning. The inclusion of spiritual assessment in a structured way can favor interventions more aligned with the needs and values of patients, contributing to the integrity of care[20].

Finally, we highlight that the reduced interest of some patients in discussing spirituality with the team does not reflect a depreciation of the theme, but possibly a preference for boundaries in the approach or insecurity regarding how professionals are prepared to deal with it[16,49]. This finding reinforces the importance of sensitive, individualized, and clinical competence-based approaches.

Among the limitations, we highlight the reduced sample size and the convenience sample, which restrict the generalization of the findings, despite enabling transferability to similar contexts. Moreover, we acknowledge the potential bias inherent to qualitative research, mitigated by the previous training of the team, added to the methodological complexity of the spirituality study, given its subjective and multidimensional nature[9].

CONCLUSION

The main finding from this study was the heterogeneity of patients' expectations regarding how spirituality is addressed in clinical practice within SUS, indicating the nonexistence of a unique model and reinforcing the need for individualized, patient-centered assessment.

Spirituality was seen as a relevant resource for coping and finding meaning in the illness, regardless of formal religiosity. However, the variability of preferences highlights that its integration into care requires clinical sensitivity and adaptation to individual needs in the different care contexts of the public network.

We highlight the need to train teams to ethically and systematically incorporate this dimension into care plans, contributing to integral care and bridging the gap between guidelines and practice in SUS. Further studies may explore the impact of structured interventions in spiritual care in this context.

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CONTRIBUTIONS

Nestor Sousa Junior, Talita Farias Amorim, and Vanessa Mayara Souza Silva Martins contributed to the study design, planning, data acquisition, analysis and interpretation, wording, and critical review. Maiza Claudia Vilela Hipólito and Diego Salvador Muniz da Silva contributed to wording and critical review. All the authors approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

The research data must be requested from the corresponding author, as that is subject to ethical restrictions and approval by the Research Ethics Committee, aiming to ensure confidentiality, secrecy, and full protection of the participants' identities.

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