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A Denúncia de Uma Ausência: O Estranho Caso do Cuidado que Precisa Ser Humanizado

Fulvio Bergamo Trevizan

Sempre que ouvimos a expressão “cuidado humanizado”, somos atravessados por um paradoxo: afinal, não seria o cuidado, por essência, um ato humano? Se precisamos reafirmar que este cuidado é “humanizado”, é porque, de alguma forma, reconhecemos que também existe, e infelizmente é frequente, um cuidado que se distancia daquilo que o torna humano. Esse paradoxo expõe uma contradição que merece ser problematizada: ao naturalizarmos a expressão, corremos o risco de aceitar que parte do cuidado possa prescindir do humano, quando, na verdade, isso deveria ser inaceitável. A própria necessidade de reafirmar o óbvio revela o quanto nossas práticas estão tensionadas por modelos que priorizam a produtividade e a eficácia técnica em detrimento da integralidade da vida que cuidamos.

Esse distanciamento entre o cuidado e o humano pode ser sutil ou explícito. Ele se revela em práticas automatizadas, centradas apenas em protocolos, na fragmentação do paciente em diagnósticos e números, ou na pressa de um sistema que coloca a doença no centro e relega a pessoa ao segundo plano. Nessas situações, o cuidado deixa de ser encontro e se torna procedimento. Ao reduzir o sujeito a um prontuário ou a um leito numerado, perdemos de vista o que constitui o sentido da prática em saúde: a presença diante de outro ser humano em situação de vulnerabilidade. O protocolo é necessário, mas não pode se tornar absoluto. Ele deve ser guia, não destino. É nesse espaço entre o prescrito e o vivido que nasce o cuidado, e aqui eu falo: verdadeiramente humano.

Quando falamos em cuidado humanizado, portanto, não estamos inventando um novo conceito do qual devemos nos orgulhar. Estamos denunciando uma ausência. Estamos lembrando a nós mesmos, profissionais de saúde, que a técnica sem vínculo se torna fria, que a ciência sem escuta se torna insuficiente, e que a clínica sem olhar integral se torna desumana. Essa denúncia não é apenas retórica, ela aponta para as lacunas de um sistema que forma técnicos altamente especializados, mas muitas vezes frágeis em habilidades relacionais. Humanizar exige resgatar a dimensão ética da prática clínica, em que cada gesto, cada silêncio e cada palavra possuem peso no processo de adoecimento e de cuidado.

Humanizar não é, e nem deveria ser, um “adicional” ao cuidado. É devolvê-lo à sua essência, reconhecendo que, diante de nós, não há apenas um corpo doente, mas uma história, uma rede de afetos, uma biografia única. Humanizar é lembrar que comunicação, empatia e dignidade não são “recursos terapêuticos opcionais”, como se viessem em opções de combos, mas parte do próprio ato de cuidar. Significa, portanto, aceitar que o encontro clínico é também um encontro humano, e que a dimensão subjetiva não é adorno, mas central. Humanizar é afirmar que a escuta qualificada, a comunicação transparente e a empatia ativa são tão terapêuticas quanto a prescrição ou o procedimento técnico, porque dão ao paciente algo que nenhuma tecnologia pode substituir: o reconhecimento de sua dignidade.

Talvez o desafio seja este: transformar o “cuidado humanizado” em simplesmente Cuidado. Um cuidado que não precise de adjetivos porque já nasce do encontro humano, sustentado pela técnica, mas atravessado pelo respeito, pela escuta e pela compaixão. Isso implica mudar nossa linguagem, mas sobretudo nossas práticas. O dia em que não for mais necessário qualificar o cuidado como “humanizado” será o dia em que teremos resgatado sua natureza essencial. Até lá, permanece a responsabilidade de cultivar um modo de cuidar que seja inteiro, ético e compassivo, onde ciência e humanidade não se opõem, mas se integram em benefício da vida.

E aqui fica a provocação: até quando precisaremos reafirmar a necessidade do cuidado humanizado? Não seria o momento de resignificar nossa prática para que todo cuidado, sem exceção, seja essencialmente humano? Essa pergunta não busca apenas uma resposta imediata, mas a abertura de um compromisso coletivo. Reafirmar o humano no cuidado é tarefa diária, que exige reflexão crítica, coragem institucional e escolhas éticas em cada encontro clínico. Que essa provocação se transforme em movimento, capaz de inspirar uma geração de profissionais a fazer do cuidado não um protocolo vazio, mas um ato pleno de humanidade. Para finalizar, não falo de cuidado humanizado como moda ou slogan, mas como urgência: devolver ao cuidado aquilo que é inseparável dele: o humano.



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Invasive Cutaneous Melanoma: Survival and Prognostic Factors

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RESUMO

O melanoma cutâneo invasivo é uma neoplasia maligna de características heterogêneas, com potencial comportamento biológico agressivo. Com o objetivo de estimar a sobrevida global doença-específica em indivíduos acometidos por melanoma cutâneo invasivo e analisar sua relação com fatores de risco, foi realizado um estudo de coorte com 221 participantes tratados em um serviço de oncologia no período de 2000 a 2023. O seguimento mediano da coorte foi superior a 13 anos. A sobrevida global doença-específica foi estimada pelo método de Kaplan-Meier, e a análise da associação entre as variáveis prognósticas foi realizada por meio do modelo de riscos proporcionais de Cox. A idade mediana dos participantes foi de 54 anos. As taxas estimadas de sobrevida global doença-específica foram de 96,8% no primeiro ano, 94,9% aos 2 anos, 90,4% aos 5 anos e 87,0% aos 10 anos. A análise das variáveis clínicas indicou que os níveis de Clark IV e V, o índice de Breslow acima de 2,6 mm, a presença de ulceração, a ausência ou infiltração linfocitária leve, o número de mitoses acima de 5/mm² e os estágios III e IV (TNM) foram identificados como marcadores independentes de pior prognóstico. Conclui-se que a classificação de Clark, o índice de Breslow, a presença de ulceração na lesão primária, o grau de infiltração linfocitária, a taxa de mitoses e o estágio clínico são importantes fatores preditivos de risco em indivíduos com melanoma cutâneo invasivo.

Palavras-chave: Melanoma. Sobrevida. Epidemiologia.

no conflicts interest

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ABSTRACT

Cutaneous invasive melanoma is a malignant neoplasm characterized by heterogeneity and the potential for aggressive biological behavior. To estimate disease-specific survival in individuals diagnosed with cutaneous invasive melanoma and to analyze its association with risk factors, a cohort study was conducted involving 221 participants treated at an oncology center between 2000 and 2023. The median follow-up duration exceeded 13 years. Disease-specific survival was estimated using the Kaplan-Meier method, and associations with prognostic variables were analyzed using the Cox proportional hazards model. The median age of participants was 54 years. Estimated disease-specific survival rates were 96.8% at 1 year, 94.9% at 2 years, 90.4% at 5 years, and 87.0% at 10 years. The analysis identified several clinical variables as independent markers of poor prognosis: Clark levels IV and V, Breslow index greater than 2.6 mm, presence of ulceration, absent or mild lymphocytic infiltration, mitotic rate exceeding 5/mm², and TNM stages III and IV. In conclusion, Clark level, Breslow index, presence of ulceration in the primary lesion, degree of lymphocytic infiltration, mitotic rate, and clinical stage are important predictive risk factors in individuals with invasive cutaneous melanoma.

Keywords: Melanoma. Survival. Epidemiology.

INTRODUCTION

Cutaneous melanoma (CM) is the most aggressive form of invasive malignant neoplasm of the skin, despite being the least frequent type of skin cancer. It accounts for approximately 1% of skin cancer cases in the United States and 3% in Brazil⁽¹⁻³⁾. Originating from melanocytes, CM is characterized by a heterogeneous oncological behavior, typically associated with a favorable prognosis when diagnosed at early stages, but potentially highly aggressive if identified in advanced stages^(1,3).

In Brazil, an estimated 704,000 new cancer cases are expected annually during the 2023–2025 triennium, with the highest incidence observed in the South and Southeast regions, which together account for approximately 70% of cases⁽²⁾. Regarding melanoma specifically, 325,000 new cases were estimated in 2020, representing approximately 1.7% of all skin cancers. Of these, 175,000 were diagnosed in men (3.80 per 100,000) and 151,000 in women (3.00 per 100,000). The South region of Brazil

shows a higher prevalence of melanoma in both sexes compared to other regions of the country⁽²⁾. In the United States, 97,620 new cases of invasive melanoma and 89,070 cases of melanoma in situ were projected for 2023, with 7,990 deaths attributed to the disease⁽¹⁾. In Europe, the annual incidence of malignant melanoma ranges from 3 to 5 per 100,000 in Mediterranean countries to 12 to 35 per 100,000 in Nordic countries. In countries such as Australia and New Zealand, incidence rates may exceed 50 per 100,000. Globally, the incidence of melanoma has been increasing steadily over the past four decades, although mortality appears to be stabilizing—except among elderly men⁽⁴⁾. According to the International Agency for Research on Cancer, there were an estimated 324,635 new cases and 57,043 deaths due to melanoma worldwide in 2020⁽⁵⁾.

There is a scarcity of regional epidemiological studies in Brazil that specifically address melanoma survival rates and investigate prognostic factors associated with the disease⁽⁶⁾. In this context, the present cohort study was conducted in the northern region of Rio Grande do Sul with the objective of evaluating survival rates in cases of invasive cutaneous melanoma and examining their association with clinical and histopathological risk factors in the affected population.

METHOD

This retrospective cohort study was based on hospital records of individuals diagnosed with invasive cutaneous melanoma who received cancer treatment at the Clinical Oncology and Radiotherapy Center in Erechim, Rio Grande do Sul, between 2000 and 2023. Inclusion criteria comprised a confirmed diagnosis of invasive cutaneous melanoma by histopathological examination and having undergone oncological treatment at any time during the designated study period. Data on initial exposure (histopathological diagnosis), clinical characteristics, and outcomes (censoring or death) were collected through a systematic review of hospital medical records. The study was conducted in accordance with the ethical principles outlined in Resolution No. 466/12 of the National Health Council of the Ministry of Health (CNS/MS) and was approved by the Research Ethics Committee (CEP) of the Integrated Regional University (URI) of Erechim-RS, under approval number 6.136.573, dated June 22, 2023.

For the survival analysis, the following criteria were applied: the observation period commenced on the date of the histopathological diagnosis; the final day of 2023 was established as the cut-off date for cohort entry; and follow-up extended until March 30, 2024. Death due to melanoma or directly related to its treatment was considered the primary outcome for the analysis of overall survival. Deaths from other causes were treated as censored events, with censoring occurring on the date of death. Participants who remained alive at the end of the follow-up period were censored at the date of the last entry in their medical records. Those lost to follow-up contributed to the survival analysis until the last recorded date in their medical records.

The risk factors (explanatory variables) considered in the analysis included: age, sex, histological subtype, primary tumor location, Clark level, Breslow thickness, presence of ulceration, degree of lymphocytic infiltration, mitotic index, and clinical stage (TNM classification) of the primary tumor. These variables were stratified based on cut-off points established in the literature and were presented both descriptively and analytically. The survival function was estimated using the Kaplan-Meier method. Hazard ratios (HRs) and corresponding 95% confidence intervals (CIs) were calculated to assess the association between prognostic variables and the risk of death, using Cox proportional hazards models to determine statistical significance.

RESULTS

Table 1 presents the characteristics of the study cohort and the association between the selected variables and the occurrence of death as an outcome. The mean follow-up duration for the cohort of 221 participants was 13.3 years. Data for the variables of interest were complete, with the exception of lymphocytic infiltration in tumor tissue, which was available for 200 participants (90.5%), and the mitotic index (number of mitoses/mm²), which was documented for 191 participants (86.4%) within the cohort.

The median age of the cohort was 54 years, with a minimum age of 19 and a maximum of 89 years. A predominance of participants (45.7%) were aged between 40 and 59 years. Among the 221 individuals included in the study, 113 (51.1%) were female and 108 (48.9%) were male.

Regarding histological subtype, superficial spreading melanoma was the most prevalent,

observed in 134 participants (60.6%). The nodular subtype was identified in 63 participants (28.5%), while other histological variants were found in 24 participants (10.9%).

The primary anatomical site of the melanoma was the head and neck region in 46 participants (20.8%), the trunk in 98 participants (44.3%), and the limbs or other locations in 77 participants (34.9%).

Clark's histopathological levels were stratified as follows: levels I to III were observed in 133 participants (60.2%), level IV in 69 participants (31.2%), and level V in 19 participants (8.6%). In relation to Breslow thickness, 95 participants (43%) presented with a tumor thickness of <0.75 mm; 59 participants (26.7%) with a thickness between 0.75–1.50 mm; 20 participants (9%) between 1.51–2.25 mm; 16 participants (7.3%) between 2.26–3.00 mm; and 31 participants (14%) with a thickness >3.00 mm.

Ulceration of the primary tumor was assessed, with 149 participants (67.4%) presenting without ulceration and 72 participants (32.6%) exhibiting ulceration. Regarding lymphocytic infiltration, 104 participants (52%) demonstrated absent or mild infiltration, 74 participants (37%) had moderate infiltration, and 22 participants (11%) showed intense lymphocytic infiltration.

The mitotic rate of the primary tumor, measured in mitoses per mm², was also evaluated. Among the cohort, 102 participants (53.4%) had no detectable mitoses; 57 participants (29.8%) exhibited 1 to 4 mitoses/mm²; 14 participants (7.4%) had 5 to 7 mitoses/mm²; and 18 participants (9.4%) demonstrated more than 8 mitoses/mm².

Clinical staging at the time of diagnosis, based on the TNM classification, revealed that 132 participants (59.7%) were in Stage I; 44 participants (19.9%) in Stage II; 29 participants (13.1%) in Stage III; and 16 participants (7.3%) in Stage IV.

At the conclusion of the follow-up period, 194 participants (87.8%) were alive, while 27 participants (12.2%) had died due to invasive cutaneous melanoma. The median disease-specific survival rate was estimated at 96.8% at 1 year, 94.9% at 2 years, 90.4% at 5 years, and 87.0% at 10 years of follow-up (**Figure 1**).

DISCUSSION

The analysis of prognostic factors within the studied cohort revealed certain predictive associations. Age was not statistically significant in relation to prognosis across the intervals analyzed; however, there was a

Table 1: Association between selected factors and the occurrence of death in a cohort of 221 patients with melanoma, Erechim, RS.

Variables	n	%	death		HR (IC95%)	P
			events	%		
Age						
<40	42	19	1	2.4	1	
40 – 59	100	45.2	13	13.0	5.76 (0.75 – 44.07)	0.091
≥60	79	35.7	13	16.5	8.02 (1.04 – 61.34)	0.045
Gender						
Female	113	51.1	10	8.8	1	
Male	108	48.9	17	15.7	1.86 (0.85 – 4.07)	0.118
Histological Type						
Superficial extensive	134	60.6	13	9.7		
Nodular	63	28.5	14	22.2	2.25 (1.06 – 4.78)	0.035
Others	24	10.9	0	0.0	-	-
Location						
Head and neck	46	20.8	9	19.6	1	
Upper body	98	44.3	12	12.2	0.58 (0.24 – 1.38)	0.219
Members and other locations	77	34.9	6	7.8	0.36 (0.12 – 1.02)	0.055
Clark						
I, II e III	133	60.2	1	0.8	1	
IV	69	31.2	19	27.5	44.96 (6.01 – 336.26)	<0.001
V	19	8.6	7	36.8	54.60 (6.71 – 443.86)	<0.001
Breslow, mm						
<0.75	95	43	1	1.1	1	
0.75 – 1.50	59	26.7	3	5.1	4.73 (0.49 – 45.45)	0.179
1.51 – 2.25	20	9	2	10.0	9.68 (0.88 – 106.80)	0.064
2.26 – 3.00	16	7.3	6	37.5	48.28 (5.80 – 401.80)	<0.001
>3.00	31	14	15	48.4	62.24 (8.21 – 472.05)	<0.001
Ulceration						
Absent	149	67.4	5	3.4	1	
Present	72	32.6	22	30.6	10.23 (3.87 – 27.02)	<0.001
Lymphocyte infiltration						
Absent /Mild	104	52	3	2.9	1	
Moderate	74	37	9	12.2	4.57 (1.24 – 16.88)	0.023
Intense	22	11	5	22.7	9.21 (2.20 – 38.53)	0.002
Mitosis/mm²						
Absent	102	53.4	2	2.0	1	
1 a 4	57	29.8	5	8.8	4.64 (0.90 – 23.90)	0.067
5 a 7	14	7.4	3	21.4	14.03 (2.34 – 84.25)	0.004
≥8	18	9.4	7	38.9	23.89 (4.96 – 115.16)	<0.001
TNM Stage						
I	132	59.7	1	0.8	-	
II	44	19.9	3	6.8	9.50 (0.99 – 91.44)	0.051
III	29	13.1	8	27.6	47.14 (5.86 – 379.06)	<0.001
IV	16	7.3	15	93.8	405.67 (51.44 – 3199.16)	<0.001

TNM: classification of malignant tumors (T: tumor, N: lymph nodes, M: metastases)
 HR: hazard ratio, P: statistical significance obtained from a Cox regression model

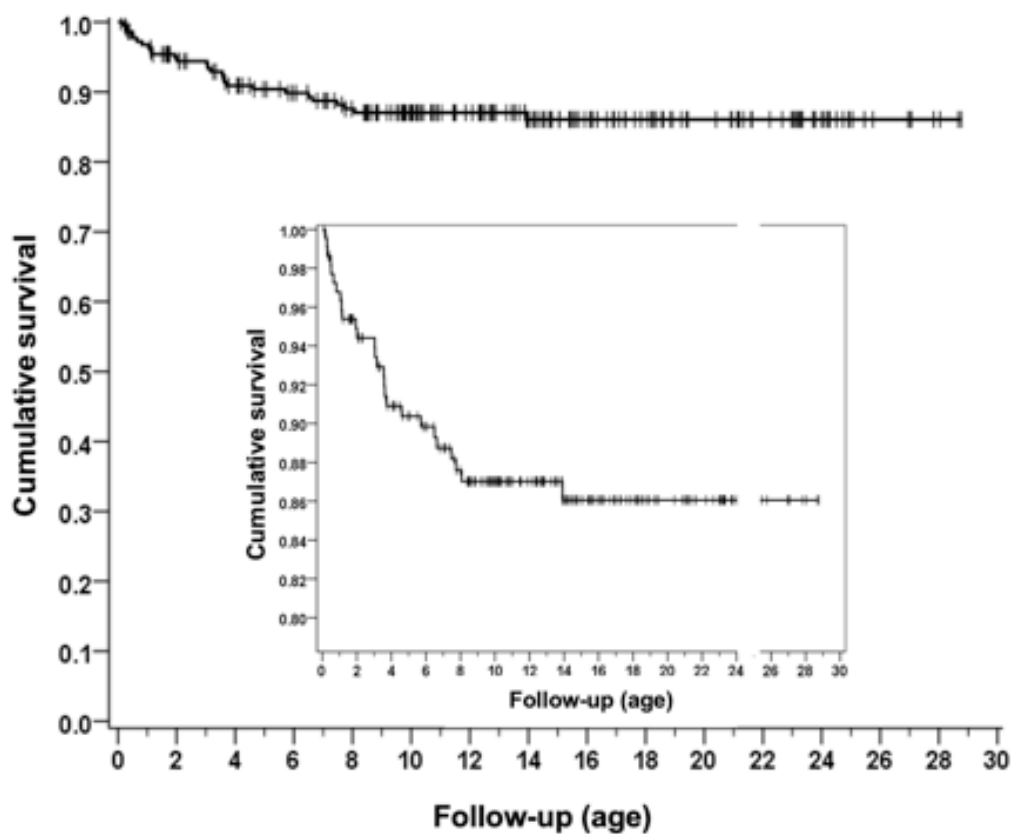


Figure 1. Disease-specific overall survival curve, cohort of patients with invasive melanoma, n = 221, Erechim.RS.

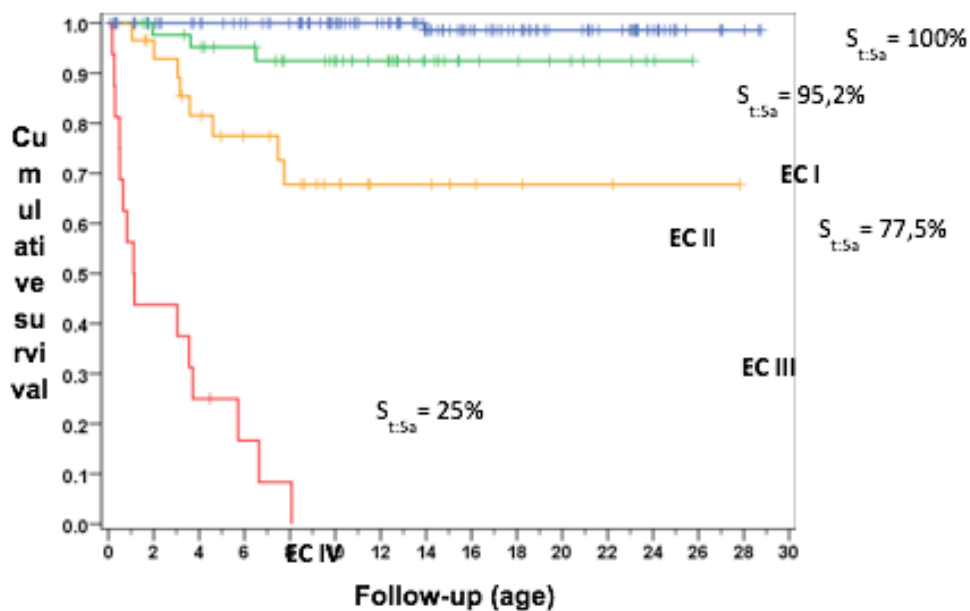


Figure 2. Disease-specific overall survival curves stratified according to TNM stage, cohort of patients with invasive melanoma, n=221, Erechim.RS.

trend toward increased mortality among participants aged 60 years or older (Hazard Ratio [HR] = 8.02; 95% Confidence Interval [CI]: 1.04–61.34; $p = 0.045$). In Europe, the incidence of melanoma peaks at approximately 65 years of age, although individuals of all ages may be affected⁽⁴⁾.

As for gender, no statistically significant association with prognosis was observed. Nevertheless, there were 17 deaths (15.7%) among male participants, suggesting a trend toward poorer outcomes in this group (HR = 1.86; 95% CI: 0.85–4.07; $p = 0.118$). A cohort study conducted in São Paulo in 2020 reported lower survival rates among male patients with invasive cutaneous melanoma⁽⁷⁾. Similarly, a study published in 2021 also identified a worse prognosis for invasive melanoma in men⁽⁸⁾. The histological subtypes of cutaneous melanoma were categorized into three groups for analysis. Among these, the nodular subtype was associated with a significantly poorer prognosis when compared to the superficial spreading subtype. Participants with nodular melanoma exhibited a higher risk of mortality (14 death events; Hazard Ratio [HR] = 2.25; 95% Confidence Interval [CI]: 1.06–4.78; $p = 0.035$). In contrast, a cohort study conducted in São Paulo did not identify a statistically significant difference in survival based on histological subtype⁽⁷⁾. A possible explanation for this discrepancy is that nodular melanomas tend to present with greater thickness, which may independently contribute to poorer outcomes⁽⁹⁾.

The distribution of the primary anatomical location of the tumor was also assessed. The trunk was the most frequently affected region (44.3%), followed by the lower limbs (34.9%) and the head and neck region (20.8%). However, no statistically significant association was found between tumor location and prognosis. A Japanese study published in 2018 reported that the sole of the foot was the most common site of melanoma in both sexes, with a higher prevalence of lower limb involvement in women⁽⁹⁾.

Clark's classification, which evaluates the level of tumor invasion, revealed that cases classified as Clark levels IV and V were significantly associated with worse prognosis when compared to levels I–III. Specifically, Clark level IV was associated with an HR of 44.96 (95% CI: 6.01–336.26; $p < 0.001$), and Clark level V with an HR of 54.60 (95% CI: 6.71–443.86; $p < 0.001$). In contrast, the 18-year retrospective study from São Paulo published in 2021, while reporting a predominance of Clark level IV, did not observe statistically significant prognostic differences across Clark levels⁽⁸⁾.

Breslow thickness is a well-established prognostic indicator for invasive melanoma⁽¹⁰⁾. In our cohort study, a clear trend was observed indicating that increased tumor thickness is associated with a poorer prognosis. Notably, tumors with a Breslow thickness greater than 2.26 mm were statistically associated with the worst outcomes when compared to those with a thickness less than 0.75 mm. Similarly, a cohort study conducted in São Paulo and published in 2020 reported that the risk of mortality was 5.37 times higher in cases with a Breslow thickness exceeding 4.0 mm compared to those with a thickness below 0.75 mm⁽⁷⁾.

Ulceration was identified in 32.6% of the cases in our cohort. Statistical analysis revealed that the presence of ulceration in the primary tumor increased the risk of death by a factor of 10.23 compared to non-ulcerated cases. A 2004 study, which contributed to the validation of ulceration as a prognostic factor in the American Joint Committee on Cancer (AJCC) staging system for melanoma, similarly demonstrated lower survival rates among patients with ulcerated tumors measuring between 2 and 4 mm in thickness. However, this association did not reach statistical significance in tumors with a thickness of less than 1 mm or greater than 4 mm, as assessed using the Cox proportional hazards model⁽¹¹⁾.

It is important to note that the data used to construct the cohort were obtained through the analysis of histopathological reports, which, at present, must adhere to the criteria established in the eighth edition of the American Joint Committee on Cancer (AJCC) melanoma staging and metastasis classification (TNM). These reports include critical parameters such as the maximum tumor thickness in millimeters (Breslow), reported to the nearest 0.1 mm (rounded from 0.05 mm), the presence of ulceration, and the status of surgical margins. Although mitotic rate and the presence of regression are not formally included in the eighth edition of the AJCC classification, their evaluation is recommended across all tumor thickness categories due to their significant prognostic relevance^(4,12).

In the present cohort, lymphocytic infiltration and mitotic rate per mm² were also assessed. Data on lymphocytic infiltration were available for 90.4% of cases. Absence or minimal lymphocytic infiltration was associated with a poorer prognosis, with 22.7% of deaths occurring in this subgroup (HR = 9.21; 95% CI: 2.20–38.53; $P < 0.002$). A previous study evaluating the association between lymphocytic infiltration and sentinel lymph node metastasis, conducted between 2003 and 2015, found that moderate lymphocytic infiltration served as a

protective predictive factor against sentinel lymph node involvement in invasive melanomas ⁽¹³⁾.

Mitotic rate per mm², available in 86.4% of cases, also demonstrated a statistically significant association with poorer outcomes. The subgroups with mitotic rates of 5–7 mitoses/mm² and ≥8 mitoses/mm² exhibited the worst prognoses when compared to cases with no detectable mitotic activity. While the mitotic rate holds independent prognostic value in the evaluation of invasive melanoma, its predictive impact is generally considered to be less significant than that of primary tumor thickness and the presence of ulceration ⁽¹⁴⁾.

Over the past decade, more than a dozen new therapeutic agents have been approved for the treatment of unresectable melanoma, alongside several new approvals in the adjuvant setting and a growing body of research exploring neoadjuvant strategies. These advancements have contributed to a marked improvement in overall survival rates, with significant increases in long-term survival observed following the introduction of these novel therapies. However, the expansion of therapeutic options and the corresponding increase in survival have also resulted in longer consultation times and increased financial burdens for both patients and healthcare systems ⁽¹⁵⁾.

In this evolving therapeutic landscape, accurate staging using the AJCC classification system remains essential for guiding optimal treatment planning ^(4,12,16). In the present cohort, staging was performed according to the TNM system, and the following five-year survival estimates were observed, as illustrated by the Kaplan-Meier survival curves: Stage I,

100%; Stage II, 95.2%; Stage III, 77.5%; and Stage IV, 25% (**Figure 2**). Stages III and IV were associated with significantly worse prognoses when compared to Stage I, with eight deaths recorded in Stage III and fifteen deaths in Stage IV over the extended follow-up period.

It is important to highlight that, in this retrospective cohort, no patients were documented to have received adjuvant or neoadjuvant therapies.

CONCLUSIONS

In this study, we observed findings consistent with those reported in the literature. With a long-term follow-up of the cohort, the estimated overall disease-specific survival was 90.4% at five years and 87% at ten years, irrespective of individual prognostic variables. Among the variables analyzed, Clark's level, Breslow thickness, presence of ulceration in the primary lesion, degree of lymphocytic infiltration, mitotic rate, and clinical stage were identified as significant prognostic factors for patients with invasive cutaneous melanoma.

Regional cohort studies play a critical role in elucidating the epidemiological characteristics of specific populations and are essential for informing the planning and optimization of oncology care within local healthcare systems. In this context, the findings of the present study enhance our understanding of the natural history of cutaneous melanoma and support the development of more effective strategies for screening and early diagnosis. This, in turn, contributes to a more efficient and rational allocation of healthcare resources.

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Fear of recurrence therapy (fort) as a strategy for dealing with oncological treatment.

Terapia fort (terapia para medo de recorrência) como estratégia para lidar com o tratamento oncológico.

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ABSTRACT

This update article in the field of Psycho-Oncology aims to present FORT Therapy (Fear of Recurrence Therapy) as a psychological support strategy for patients after cancer treatment. When faced with cancer remission, patients seek to understand this new phase, and emotional, psychological, and existential issues often surface. Fear of Cancer Recurrence is a frequent concern in cancer patient care, which can significantly impact mental health and the patient's ability to cope with life after cancer. Professional development in psycho-oncological care is essential to address the diverse needs of patients and families of patients diagnosed with cancer throughout treatment. FORT Therapy is gaining notoriety in cancer survivor care due to its applicability, focus, and effectiveness in reducing symptoms associated with Fear of Cancer Recurrence.

Keywords: Psycho-Oncology, Fear, Recurrence, Cancer.

RESUMO

O presente artigo de atualização na área da Psico-Oncologia tem objetivo de apresentar a Terapia FORT (Fear of Recurrence Therapy) como estratégia de assistência psicológica ao paciente oncológico pós tratamento de câncer. O paciente, ao se deparar com a remissão do câncer, busca compreender esse novo momento, e, muitas vezes, questões de cunho emocional, psicológico e existencial vem à tona. O Medo da Recorrência do Câncer é uma demanda frequente no cuidado ao paciente oncológico, que pode causar prejuízos significativos na saúde mental e na forma como o paciente enfrenta a vida pós câncer. A atualização profissional na assistência psico-oncológica é fundamental para acompanhar as diversas demandas que os pacientes e familiares de pacientes diagnosticados com câncer lidam ao longo do tratamento. A Terapia FORT ganha notoriedade na assistência ao sobrevivente de câncer devido a sua aplicabilidade, foco e resposta na redução dos sintomas associados ao Medo de Recorrência de Câncer.

Palavras-chave: Psico-Oncologia, Medo, Recorrência, Câncer.

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INTRODUCTION

Fear of Cancer Recurrence (FCR) is a common concern among cancer survivors, characterized by the persistent fear that cancer may return or progress.¹⁻² Research shows that FCR affects between 50% and 70% of post-treatment patients and can be intense and long-lasting, even years after treatment completion.³⁻⁴ Severe FCR causes emotional distress and may lead to avoidant behaviors, frequent medical consultations for reassurance, and even negative impacts on personal relationships and work performance.^{5,6,7}

The psychological aspects of FCR highlight two significant issues: the nature of fear and the cycle of negative thought. The first can range from mild concerns to levels of anxiety that significantly interfere with quality of life. Fear is often exacerbated by physical symptoms, such as fatigue or pain, which may be misinterpreted as signs of recurrence.² Regarding the cycle of negative thoughts, patients with FCR may experience dysfunctional and catastrophic thought patterns, increasing stress and anxiety. This spiral of thoughts is one of the main areas of focus in FORT, which aims to identify cognitive errors and reframe dysfunctional thought associated with internal and external triggers.³

FCR strongly impacts interpersonal relationships, creating tensions with family and friends due to stress and the need for constant support. Survivors may feel misunderstood by others, leading to negative feelings and maladaptive behaviors such as isolation.⁴ Family dynamics can also be altered, especially if survivors feel they must hide their concerns to avoid burdening loved ones, which may result in less open communication and feelings of loneliness and helplessness.

FORT was developed specifically to address these concerns through a cognitive-existential intervention designed to help breast and gynecological cancer survivors manage persistent FCR.¹⁻² Current studies demonstrate that FORT is effective in reducing FCR and improving psychological well-being across different cancer types. Participants typically report decreased cancer-related anxiety and greater ability to cope with stress and uncertainty.³⁻⁴

FEAR OF RECURRENCE THERAPY (FORT)

FORT is a structured psychological intervention that combines cognitive-behavioral therapy techniques with existential strategies to address issues such as death-related anxiety, uncertainty, and

redefinition of priorities and purposes after cancer. Participants learn to identify FCR triggers, develop coping skills, restructure negative thoughts, and increase tolerance to uncertainty. The program includes two-hour weekly sessions over six weeks, delivered individually or in groups.^{1-2,3}

KEY COMPONENTS OF FORT1-2-3

Cognitive-Existential Approach: FORT combines cognitive techniques to identify and modify dysfunctional cancer-related thoughts with existential strategies to help individuals find meaning and purpose despite future uncertainty.

Structured Sessions: FORT consists of several structured sessions during which participants explore their cancer-related anxieties, learn to manage emotional triggers, and develop more effective coping strategies. Participants are reminded that they must attend all sessions to achieve their goals. If they need to miss a session, they must start a new cycle.

Relaxation/Mindfulness Techniques: In addition to cognitive approaches, FORT often incorporates relaxation techniques, such as breathing exercises and meditation, to help reduce physical and mental stress.

Therapeutic Journaling: Patients are encouraged to keep diaries to record thoughts and feelings, which can help identify negative thoughts patterns and anxiety triggers, even outside of the therapeutic setting.

Acceptance and Commitment Therapy (ACT): Techniques of ACT can be used to help patients accept difficult thoughts and feelings rather than fight them, focusing on action toward life goals.

STRUCTURE AND IMPLEMENTATION OF FORT

Interdisciplinarity: FORT is often implemented by an interdisciplinary team led by a psychologist and composed of oncologists and oncology nurses, offering a holistic approach to treatment.¹⁻²

Group or Individual Sessions: FORT can be offered in group, where participants share experiences and learn from each other, or as individual therapy, focused on the patient's subjective needs.²⁻³

Ongoing Support: After formal sessions are completed, patients can benefit from periodic support groups to help reinforce the skills learned.⁴ This is a crucial step for maintaining positive results over time.

Therapeutic Components: Sessions include techniques for identifying dysfunctional automatic thoughts, psychoeducation regarding triggers for fear of cancer recurrence and cognitive errors, cognitive restructuring, which helps patients challenge and modify irrational thoughts, and mindfulness exercises, which promote focus on the present and reduce rumination about the future.³⁻⁵⁻⁶

Personalization: Therapy is tailored to each patient's individual needs, taking into account their cognitive model and how they cope with the illness and the consequences of treatments. If therapy is carried out in a group, it needs to be structured according to factors such as cancer type, stage, treatment received, and available social support.

The use of therapies like FORT is crucial because MRC can lead to severe symptoms of anxiety and depression, impacting treatment adherence and overall recovery. By proactively addressing these fears, FORT helps survivors navigate their post-treatment lives more positively.¹⁻⁵

FORT represents a significant advancement in psychotherapy for cancer survivors, offering a targeted approach to addressing one of the most challenging aspects of emotional and psychological recovery from cancer.¹⁻³ While the immediate effects of FORT are well documented, studies seek to better understand the long-term sustainability of these results. Continued practice of learned coping skills can help maintain the benefits.¹⁻²⁻⁴ Participants are encouraged, after completing the six-session program, to continue practicing identifying dysfunctional thoughts, identifying internal and external triggers, and putting cognitive reframing into practice with the aim of reducing anxiety symptoms and improving their quality of life.

Due to promising results in international research and articles, there is a growing movement to integrate FORT into standard cancer care practices, making it accessible to more patients as part of a comprehensive recovery plan.¹⁻⁸ In Brazil, FORT

is still largely unknown and under-researched. It is important to train Brazilian psycho-oncology professionals in the application of specific techniques to the different stages of cancer.

ADAPTATION FOR FAMILY CAREGIVERS: FC-FORT

Recognizing that family caregivers also face high levels of FCR, FORT was adapted for this population, resulting in FC-FORT (Family Caregiver – Fear of Recurrence Therapy). This version can be offered virtually, with seven weekly sessions. Pilot studies indicated high participant satisfaction and good group cohesion, although adjustments are needed to improve feasibility and effectiveness before large-scale studies.⁴⁻⁷

Many possibilities for the development of FORT are being studied and researched to better address the fear of cancer recurrence. We understand the importance of further research in this area involving different types of cancer and adapting to the cultural differences of countries.

CONCLUSION

As cancer survival rates increase globally, the demand for interventions like FORT also grows, highlighting the importance of integrating psychological care into overall cancer treatment plans.⁴⁻⁶ FORT not only alleviates the fear of recurrence, but also promotes a more holistic approach to post-cancer health, helping survivors live fuller and more satisfying.¹⁻⁵

FORT represents a significant step forward in the field of Psycho-oncology, offering a structured and effective solution to a widely recognized problem among cancer survivors. Continued research and innovation in this area promises to further improve the quality of life for those who have faced cancer.⁵⁻⁶ It is necessary to reinforce the importance of adapting to and recognizing population differences and the constant changes in cancer treatments and their consequences.

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ARTIGO ORIGINAL | ORIGINAL ARTICLE

Natural ionizing radiation and breast cancer in Guarapari, state of Espírito Santo, Brazil

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ABSTRACT

Aim: To evaluate exposure to natural ionizing radiation from monazite sand and breast cancer mortality in Guarapari, state of Espírito Santo, Brazil.

Methodology: This retrospective study compared breast cancer mortality per 100,000 inhabitants in the municipalities of Guarapari (ES), Ilhéus (BA), Campos de Goytacazes (RJ), and Rio Grande (RG), coastal cities with similar socio-economic profiles and population pyramids. Data from the Brazilian Institute of Geography and Statistics (IBGE) and DATASUS (Ministry of Health) collected between 2002 and 2008 were used. Radiometric surveys were conducted by the Applied Physics Group of UFES for Guarapari, while the other locations followed CNEN recommendations. Statistical analysis considered $p \geq 0.05$.

Results: Accumulated natural radiation levels in Guarapari result in doses ranging from 3.65 mSv/year to 10.95 mSv/year, while in other locations, it is 1 mSv/year. The average breast cancer mortality rate between 2002 and 2008 was: Rio Grande = 26.7; Campos = 17.1; Ilhéus = 8.8; and Guarapari = 8.4. This indicates lower incidence of the disease in Guarapari, a fact that contradicts the theory of cancer induction even with low ionizing radiation levels; therefore, it is possible that there is a stimulating effect on the human biological process, resulting in a protective response. **Conclusion:** In this approach, the induction of malignant tumors was not confirmed; but the opposite appears to occur: *hormesis of breast cancer in Guarapari*, the most common tumor among Brazilian women.

Keywords: breast cancer, natural ionizing radiation, hormesis

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INTRODUCTION

Ionizing radiation is considered one of the factors that promotes cancer induction⁽¹⁾. This is a debatable and controversial topic because there are no defined limits to this occurrence, with radiodiagnosis, for example, being widely used in the diagnosis of malignant tumors. It should be highlighted that radiotherapy is an important therapeutic agent in their control.

This approach demonstrates the experience with chronic ionizing radiation caused by monazite sands of Guarapari, state of Espírito Santo, and the occurrence of breast cancer.

METHODOLOGY

This is a retrospective study with data collected between 2002 and 2008 from DATASUS, an agency of the Ministry of Health, and IBGE (Brazilian Institute of Geography and Statistics). The municipalities analyzed were Guarapari (ES), Campos de Goytacazes (RJ), Rio Grande (RS), and Ilhéus (BA), coastal locations with similar socioeconomic profiles and equivalent population pyramids.

The variable used was the breast cancer mortality rate in Guarapari compared to that in the other locations evaluated, recorded in the municipal health records annually prepared by DATASUS.

The natural ionizing radiation levels were established by the Applied Physics Group of the Federal University of Espírito Santo for Guarapari, considering values found in indoor and outdoor environments originating from 222Th present in monazite sands,

a radioactive element that decays to stable 209Pb. Further details of this measurement are shown in a previous study⁽²⁾. The levels in the other locations followed recommendations of the National Nuclear Energy Commission (CNEN) for areas located at sea level, with comparable atmospheric pressure and relative humidity⁽³⁾.

A one-way fixed-effects Analysis of Variance model was used to compare the average cancer mortality rates in the four Brazilian municipalities. The Dunnett’s multiple comparison test was used to determine whether the average mortality rate in Guarapari differed significantly from the other locations. To ensure that the distribution of residuals from the ANOVA model was Gaussian and homoscedastic, a Box and Cox1 logarithmic transformation was applied to data. Since the sample was small, with only 28 observations, the test power was calculated, and the value of 99.97% was found. $P \leq 0.05$ was considered significant⁽⁴⁾.

RESULTS

Irradiation doses for the population of Guarapari ranged from 3.65 mSv/year to 10.95 mSv/year, considering a daily exposure of 1 hour during 365 days. The irradiation considered for the populations of Campos, Rio Grande, and Ilhéus was 1 mSv/year.

Table I shows the populations of the four locations measured by the 2010 IBGE census, with Guarapari having the lowest. Regarding neonatal mortality, Guarapari was also lower. Ilhéus showed the lowest Human Development Index, with the others being equivalent.

TABLE I - Information on the compared municipalities - 2010 census

	Ilhéus (BA)	Guarapari (ES)	Campos (RJ)	Rio Grande (RS)
Population	162,334	105,286	463,731	197,228
HDI	0.690	0.731	0.716	0.744
Neonatal Mortality rate	17.97	10.72	13.74	11.44

Table II shows breast cancer mortality rates, with lower values for Guarapari. The mean mortality rates differ significantly between at least two locations ($p < 0.0001$). According to the Dunnett's test results, which compared Guarapari with the other municipalities, it was found that: the mean breast cancer mortality rate is significantly lower in Guarapari than in Campos ($p = 0.0025$) and significantly lower than the mean rate in Rio Grande ($p < 0.0001$). On the other hand, the average breast cancer mortality rates in the municipalities of Guarapari and Ilhéus do not differ significantly ($p = 0.9358$), although the former tends to be lower.

TABLE II - Breast cancer mortality rate

	MORTALITY PER 100,000 INHABITANTS							
	2002	2003	2004	2005	2006	2007	2008	Mean
Ilhéus (BA)	5.4	5.4	18.0	5.4	6.3	10.7	10.8	8.8
Campos (RJ)	15.0	17.7	18.0	17.3	16.7	19.1	16.1	17.1
Rio Grande (RS)	13.3	26.4	27.2	28.8	23.6	31.2	36.7	26.7
Guarapari (ES)	4.2	4.1	14.1	3.8	5.5	12.5	15.3	8.4

DISCUSSION

The occurrence of harmful health effects at low doses or dose rates caused by ionizing radiation, such as those found in nature or even occupational radiation, has been emphasized in theory, as initially pointed out⁽¹⁾. These aspects are concerning, but epidemiological information may be of significant importance because they can provide more conclusive results in humans, both somatic and germinal aspects. International organizations already recognize that there is a dose threshold for the occurrence of damage⁽⁵⁾. The information available shows that cancer is not this type of damage^(2,5,6).

Ionizing radiation causes interactions with cytoplasmic elements, the most abundant of which is water, resulting in the formation of oxidative radicals, which react with the production of antioxidants to preserve homeostasis. This mechanism occurs in approximately 60% of cellular aggression, while the interaction in the nucleus, at DNA level, causes single strand breaks, double strand breaks, and cross-

links in the helix bands, which can result in chromatid and chromosomal aberrations, accounting for approximately 40% of this effect. DNA alteration repair mechanisms are highly elaborate in cellular metabolism, especially in humans, and are activated and maintained at low dose rates. Furthermore, cell apoptosis (death) and intervention by the body's autoimmune response can occur⁽⁷⁻¹⁰⁾. This explains why populations occupationally exposed or exposed to natural radiation levels have lower cancer rates than the general population, due to biological adaptation, also known as hormesis⁽¹¹⁾.

The analysis of breast cancer mortality data conducted here shows lower rates in Guarapari compared to other coastal locations in the country (Campos, Rio Grande, and Ilhéus). These findings are consistent with other morbidity studies carried out by Orlando et al., who found lower incidence of the disease in Guarapari compared to other locations in the state of Espírito Santo⁽¹²⁾, and this epidemiological information is consistent.

CONCLUSION

The lower incidence of breast cancer in Guarapari may be linked to existing natural ionizing radiation levels, due to biological adaptation. It is possible to consider this as a **hormesis** of this radiation.

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Declaration - For all purposes, we declare that there is no conflict of interest in the presentation presented here.

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The Experience of Having a Child with Cancer Relapse: A qualitative study

*A Experiência de Ter uma Criança com Recaída de Câncer:
Um estudo qualitativo*

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ABSTRACT

Background: Upon completion of cancer treatment, the predominant fear among parents is the potential recurrence of the tumor. Consequently, the relapse of pediatric cancer can trigger feelings of depression, anxiety, and stress among parents. **Purpose:** This study aimed to comprehend the common experiences among parents of children who have undergone a cancer relapse. **Method:** The final sample comprised 15 mothers and fathers of children and adolescents undergoing treatment for cancer relapse. Unstructured interviews were recorded on video and analyzed qualitatively using Content Analysis and Qualitative Comparative Analysis. **Results:** The results revealed that uncontrollability and the absence of active coping strategies, particularly the lack of distraction techniques and information-seeking, were pivotal factors associated with parental emotional problems. Additional contributing factors included the lack of social support, absence of religiosity/spirituality or acceptance, and the presence of repression strategies. **Conclusion:** The findings emphasize the importance of developing early interventions for parents of children with cancer recurrence to mitigate vulnerabilities in this population.

Key-words: recurrence, cancer in children, parents, oncological treatment, relapse.

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A Experiência de Ter uma Criança com Recaída de Câncer: Um estudo qualitativo

RESUMO

Justificativa: Depois do tratamento de câncer ser finalizado, um medo predominante nos pais é a possibilidade do tumor retornar. Assim, a recaída do câncer pediátrico pode acarretar sentimentos de depressão, ansiedade e estresse nos pais. **Objetivo:** Este estudo objetivou compreender as experiências comuns aos pais de crianças que passaram por uma recaída de câncer. **Método:** A amostra final consistiu em 15 mães e pais de crianças e adolescentes que estavam em tratamento ativo para recidiva de câncer. Entrevistas não-estruturadas foram gravadas em vídeo e analisadas qualitativamente através de Análise de Conteúdo e Análise Qualitativa Comparativa. **Resultados:** Os resultados mostraram que a incontrollabilidade e a falta de estratégias de enfrentamento ativas, particularmente a falta de técnicas de distração e busca de informação, foram fatores centrais associados com problemas emocionais parentais. Outros fatores contribuintes adicionais foram a falta de rede de apoio, a ausência de religiosidade/espiritualidade ou aceitação, e a presença de estratégias de repressão. **Conclusões:** Os dados enfatizam a importância do desenvolvimento de estratégias de intervenção precoces para pais de crianças com recidiva de câncer, a fim de mitigar as vulnerabilidades psicológicas desta população.

Palavras-chave: recidiva, câncer em crianças, pais, tratamento oncológico, recaída.

INTRODUCTION

The diagnosis of cancer in a child is an immensely challenging and stressful experience for parents. Globally, it is estimated that approximately 400,000 families find themselves in this situation each year¹. Throughout the treatment process, parents commonly undergo a decline in their quality of life, navigating a spectrum of emotions that include anxiety, fear, and hope². Nevertheless, as the oncological treatment concludes, a prevalent concern among most parents is the potential recurrence of the tumor³.

Hence, when parents receive the distressing news of their child's cancer relapse, they feel frustration and distress, confronted by a more tangible prospect of death^{4,5}. Despite the occurrence of pediatric cancer recurrence not being uncommon, the psychosocial impact on caregivers remains under-

explored in scientific literature, with minimal evaluations of this specific population⁶. Qualitative studies that delve deeply into this experience are also notably scarce.

The existing literature in this field highlights substantial adjustment challenges for parents, including elevated rates of depression, anxiety, stress, and family or marital conflicts following the relapse diagnosis^{7,8}. These outcomes are associated with the uncertainty and uncontrollability of the prognosis, as caregivers navigate between hope for a cure and the fear of potential loss⁴.

The heightened levels of uncontrollability lead to a phenomenon known as the "conspiracy of silence," where parents limit the information shared with their children to shield them from distress. However, this approach often results in increased feelings of uncertainty, reduced trust in healthcare professionals, and, consequently, lower adherence to treatment^{9,10}. When children perceive that their parents are withholding information, it can impact their relationship, potentially escalating to heightened parental overprotection and hypervigilance¹¹.

In this scenario, certain parental coping strategies have the potential to eliminate or alleviate aversive stimuli, as well as suppress or diminish the negative feelings arising from the cancer experience. Thus, coping strategies can be categorized into active strategies, aimed at eliminating aversive stimuli (taking actions to alleviate or remove the stressor, such as seeking information or social support) or passive strategies (escaping or avoiding the stressful stimulus, employing denial or isolation). Effective coping strategies in this context are more likely to be active, as they are associated with increased control over the situation and improved psychological adjustment¹².

Nevertheless, when parents confront the uncontrollability associated with pediatric cancer recurrence, they tend to employ strategies linked to acceptance. Given the impossibility of physically escaping the situation, acknowledging that some level of suffering is unavoidable helps parents adjusting to the new treatment¹³.

On the other hand, prior research indicates emotional growth and increased family cohesion resulting from the experience of pediatric cancer recurrence^{5,14}. As treatment for relapse is generally long, parents can accumulate experience and knowledge about the disease, aiding in reducing uncertainty and fostering emotional resilience¹⁰.

Therefore, given the inconsistencies in the literature and the scarcity of studies on parental feelings in the pediatric recurrence scenario, there

is a need to enhance comprehension of the unique and common experiences among parents of children who have suffered one or more cancer relapses. Thus, the present study used a qualitative method to describe these experiences in depth. This research also aimed at understanding the relation between coping strategies and stressors experienced at the time of relapse with parents' psychological adjustment.

METHOD

Participants

Forty-eight parents of children who had experienced at least one cancer relapse and were currently undergoing active treatment were invited to participate in this research. These participants were recruited from two Brazilian public pediatric oncology hospitals. Parents were approached by the main researcher after analyzing the children's medical records to ensure they met the inclusion criteria.

The inclusion criteria for participants were as follows: (a) being the primary caregiver of the child; (b) the child undergoing active treatment for a cancer relapse, which could include a recurrence of the primary tumor, a second neoplasia (at least 12 months after completing the first tumor's treatment), or a progression of the first tumor (metastasis); (c) the child not being terminally ill; and (d) the child falling within the age range of 6 to 14 years old (due to the age limit of psychological tests applied to children in another part of this research).

Among the 48 individuals approached, 16 parents declined to participate in the research. The primary reason for non-participation was a lack of interest or time, accounting for 63% of cases (10 subjects). Conversely, 17 parents initially agreed to participate, but two were subsequently untraceable. Consequently, the final sample for this study comprised 15 mothers and fathers of children and adolescents actively undergoing treatment for cancer recurrence. Participants were contacted, on average, five months after their child's last diagnosis.

Instrument

An unstructured interview format was employed, beginning with an initial question: "I would appreciate hearing about your experience of having a child with cancer recurrence. Please share whatever you feel comfortable discussing". This approach was selected to facilitate open expression of individuals' experiences without interference or predetermined themes.

PROCEDURE

Data collection

Parents who consented to participate in the study were individually invited to enter an unoccupied hospital room. In this setting, the researcher introduced the study, addressed any questions, and obtained the participant's signature on the Informed Consent Form. Following a brief rapport, the interview was recorded on video, lasting from 45 minutes to 1 hour and 30 minutes. Only one caregiver (mother/father) per child took part in this study.

Data analysis

The interviews were transcribed in full, and their content was analyzed following the approach proposed by Bardin¹⁵, with two researchers working independently. Initially, the interviews were read in their entirety, and then their content was categorized into the following thematic recording units: 1) parents' feelings regarding the cancer relapse, 2) distinctions between recurrence and the initial oncological treatment, 3) primary stressors encountered by parents, 4) psychosocial impact of treatment on participants' lives, 5) coping strategies employed by parents, and 6) the relationship between parents and patients.

Categorization was performed within these themes, based on the absence or presence of each category in each participant's speech. This was achieved through a descriptive analysis of the percentage of individuals. The creation of these categories was informed by the existing literature in the field¹⁰.

Subsequently, a qualitative comparative analysis was conducted (QCA)¹⁶ to derive a model elucidating contributors to parental positive or negative outcomes. Coping strategies were categorized as active or passive, according to Gelkopf et al.¹⁷.

Active strategies encompassed seeking support from the healthcare team, ventilating emotions, searching social support, seeking information, and utilizing distraction. Passive strategies were associated with relying on religion/spirituality, using denial, isolating oneself, and accepting uncontrollability. Hence, for the comparative qualitative analysis, the variables "coping strategies" (categorized as active or passive) and "main stressors" were regarded as predictors of "negative feelings in the relapse situation" (with these feelings considered as indicators of psychological maladjustment). Negative feelings encompassed fear of loss, denial and/or shock, depressive feelings, and stress, all grouped into a

unified category labeled “negative feelings”. Additionally, the interaction between predictors was examined.

The fuzzy sets of data were transformed into clear dichotomous sets of 0 or 1 (indicating absence or presence) by calibrating the categories based on their frequency (categories with a frequency equal to or greater than 50% were categorized as present, while those with a frequency less than 49% were categorized as absent for each participant). This calibration was applied to both the predictors and the dependent variable, considering that many participants’ reports fell into conflicting categories (e.g., using both passive and active strategies; in such cases, the participant’s main strategy was determined by the most frequent one—equal to or above 50%). Additionally, a minimum gross consistency of 0.8 was set as a parameter. In the logical minimization procedure of the first analysis, the category “active coping strategies” was excluded as it was redundant in the formula, being encompassed within the variable “coping strategies”.

A second analysis was conducted using the same qualitative comparative analysis method, with the aim of enhancing comprehension regarding the contributory role of coping strategies and stressors in parental psychological adjustment. In this analysis, all coping strategies (without categorizing them as active or passive) and all stressors (without grouping) were examined, along with their interactions. The procedures for this analysis mirrored those of the previous one. During the logical minimization stage, the variables “lack of information” and “routine” were excluded due to their very low frequencies. Additionally, the intersection of the coping strategy “seeking support” with the stressor “lack of social support” was eliminated as it was redundant.

The intermediate solution was adopted in both QCA analyses, as it simplifies the assumptions about the main causal conditions. This solution was then compared with the parsimonious solution to delineate the “core” and “contributory” causal conditions influencing the psychological adjustment of parents with children undergoing cancer recurrence. All analyses were conducted using FsQCA software version 4.0.

Ethical Considerations

This research was approved by the Brazilian ethics committees of Hospital de Amor and Centro Infantil de Investigações Hematológicas Dr. Domingos A. Boldrini under the number 01576312.5.00.5376 in *Plataforma Brasil*.

RESULTS

The participants were predominantly women (86.7%), serving in the role of mothers (86.7%), with an average age of 35.36 years old (SD=5.78). The majority were married or in a stable relationship (80%) and identified as religious (85.7%). Most participants had completed high school (38.5%), and the average family income was 2.14 minimum wages (SD=1.79).

Concerning the children, 53.3% were male, with a mean age of 10.27 years-old (SD=2.34). The majority received a diagnosis of acute lymphocytic leukemia (46.7%), experienced a single relapse (66.7%), were undergoing treatment for an average of 36 months (SD=28.01), and were in the relapse situation for an average of 6.2 months (SD=8.48).

Speech analysis

1. Feelings regarding their children’s cancer relapse

The predominant emotions experienced by the participants (60%) during the relapse had depressive characteristics. P14 and P15 described feelings of apathy, loss of appetite, and persistent crying, while P9 expressed emotions of impotence and defeat. P6 and P8 reported sensations of chest tightness and ongoing anguish. P11, P13, P14, and P15 acknowledged experiencing constant irritability and aggression, while P5 conveyed feelings of intense anger and sadness. P1 encapsulated his situation, stating: “It’s as if I’m in a well that has no rope, no way out, you know? There’s nothing. (...) My wife feels the same way”.

Eight participants (53.3%) reported apprehension about losing their child, given the heightened aggressiveness of the disease. For instance, P14 described the relapse diagnosis as “So terrible... terrible! It seemed that it was a death sentence”.

Denial and shock were also acknowledged by three parents (20.0%), while symptoms of stress, including insomnia and irritability, were reported by five parents (33.4%). Conversely, four participants (26.7%) expressed a sense of increased predictability in the relapse situation. Another four (26.7%) conveyed experiencing emotional growth during the relapse treatment, characterized by emotional fortitude and a more positive perspective on life.

2. Relapse versus first diagnosis

Three participants (20%) expressed that the first diagnosis had been more challenging (as it was something new and difficult to accept). Another six (40%) conveyed that the relapse was more distressing

than the initial diagnosis, since there was a more tangible threat of death: "Now that I know everything we've been through, I had to tell her (child) everything that happened... But now I'm more scared than I was before (...) Scared of the worst-case scenario becoming a reality" (P3).

3. Major stressors experienced by the participants

The most frequently mentioned stressor (46.7%) was the lack of social support, often attributed to relocating to another city for the child's treatment. Participants associated the lack of social support with a heightened level of stress, as exemplified by P2: "Since all of this happened, I've been the sole caregiver staying with him (child) at the hospital, you know? I don't have anyone to switch shifts with me. So, I'm the one who must stay strong (...) If the doctor tells me something, I'm the one who must confront this situation". Additionally, three participants (20%) mentioned having social support at the beginning of the first treatment, but over time, this network diminished as people gradually distanced themselves.

Three parents (20%) highlighted uncontrollability as a potential stressor, considering the treatment's potential negative physiological reactions and complications. Additionally, financial losses arising from job loss or treatment costs were identified as stressors by another three participants (20%), while the hospital routine was mentioned by two participants (13.4%).

4. Treatment's psychosocial impact

Eight participants (53.3%) conveyed that their lives were put on hold during the treatment for the relapse, discontinuing their work, studies, and/or physical exercise routines. P14 shared the impact, stating: "I wish I could be working, but I resigned from my job last month. I truly love my job. After he (child) completed the first treatment, I began studying pedagogy. But then he experienced a relapse, and I had to discontinue my studies".

Moreover, cancer treatment resulted in job loss and/or financial setbacks, causing apprehension for 40% of the participants, as exemplified by P13: "Previously, we were employed, but now we have financial obligations that we cannot meet or fulfill... It's very stressful".

The parent-sibling relationship experienced negative repercussions from the oncological treatment for three participants (20%), primarily due to the imposed physical and emotional distance. Marital life was also affected by cancer treatment for two

participants (13.4%). In contrast, another two participants (13.4%) expressed that the treatment for cancer recurrence strengthened family cohesion, emerging as a crucial source of social support.

5. Coping strategies

Distraction was the most frequently reported strategy (60%). This often involved engaging in activities such as crafting or going out, as mentioned by P9: "I gaze out of the window, watch TV, or iron clothes, you know? My relief valve is the internet".

Spirituality/religiosity was also mentioned by the majority of the participants (53.3%), as illustrated by P15: "It's faith. It is the faith that strengthens me. Both me and him (child)". This spirituality was often associated with an acceptance of the uncontrollability of the relapse. A significant proportion (40%) explicitly mentioned this acceptance considering the uncertain prognosis: "We cry, we let it out. It passes. That's how it goes. You have to accept it, don't you? I've come to accept the treatment once again..." (P10).

Seven participants (45.7%) stated that receiving social support, especially from other parents whose children were also undergoing treatment, was their coping strategy, such as P8: "We got to know a lot of people here (in the hospital). People we didn't even know, they're not our relatives, they're not related to us, yet offered us more support than our own family". Furthermore, support from family, the healthcare team, friends, teachers, and the religious community was also acknowledged.

One participant (6.7%) who had access to social support found it beneficial for venting their feelings. Additionally, four parents (26.7%) mentioned relying on support from the healthcare team as a coping strategy during their children's treatment. Seeking information, either through internet research or by consulting healthcare professionals, was cited by two parents (13.3%).

On the other hand, five participants (33.3%) adopted isolation, denial, or repression as coping strategies. The reasons for choosing isolation were associated with concerns about people's judgment and a lack of trust in others.

6. Relationship parents-patient

Five participants (33.3%) characterized the relationship between parents and the patient as remarkably close and marked by intense attachment. In all these instances, mothers served as primary caregivers and conveyed that they engaged in all activities together with their children, as the latter were unable to be

without them. Within this constant caregiving dynamic, hypervigilance (13.3%, two individuals) and overprotection (6.7%, one individual) were justified by the prevailing fear of loss.

Similarly, in an effort to shield their child from additional suffering, four participants (26.7%) revealed that they chose not to disclose details about their illness, treatment, or the gravity of the situation. Meanwhile, two mothers (13.4%) reported that the patients may still discern the situation and derive secondary benefits. On a different note, two participants (13.4%) highlighted their ability to maintain routines and discipline even during cancer recurrence treatment, in order to provide security and well-being to their children.

Three parents (20%) acknowledged being the primary coping models for their children, and consciously refrained from displaying emotions in front of their children as a means of supporting them through the treatment's challenges. Additionally, three mothers (20%) expressed that the patients served as a vital source of emotional support for them.

Qualitative comparative analysis

The first comparative qualitative analysis aimed to examine the connection between coping strategies (both passive and active) and psychological adjustment problems among parents of children facing cancer relapse. Additionally, the association between the number of stressors and parents' psychopathological symptoms was explored. The results of this analysis indicate that the predominant use of passive coping strategies (such as relying on religion/spirituality, employing denial, isolation, or acceptance) is more closely linked to parental "negative feelings". This association is evident both in the absence of active coping strategies (such as seeking support from the healthcare team, expressing emotions, seeking social support, searching for information, and engaging in distraction) and when passive strategies are combined with an increased number of stressors (as observed in the first analysis from **Table 1**).

The second analysis described in **Table 1** provides a comprehensive examination of specific coping strategies and types of stressors associated with poorer parental adjustment (more negative feelings) in the context of a relapse situation. Path 1 stands out as a robust analysis, highlighting that the core factors contributing to a heightened presence of negative symptoms include the combination of uncontrollability, the lack of distraction strategies, and the absence of information-seeking behavior.

Path 2 further elucidates that, beyond these core conditions, other factors also contribute to parental adjustment challenges. These additional factors encompass the use of repression, or the absence of coping strategies related to accepting uncontrollability, seeking social support, and/or employing religiosity/spirituality.

DISCUSSION

The results of this study suggest that the experience of having a child with cancer relapse is highly stressful for parents. Depressive symptoms and fear of loss were prevalent among most participants, consistent with previous research^{7,6}. Indeed, some participants reported that the relapse situation caused a more significant emotional impact, as it represents a more tangible possibility of the child's death. Consequently, the second (or third) childhood oncological treatment imposes a substantial emotional burden on parents. Moreover, the first cancer experience may contribute to heightened parental psychological vulnerability when faced with a new diagnosis¹⁸.

In the context of a relapse situation, the analysis has revealed that the core contributive factors to parental negative feelings are associated with a higher number of stressors, particularly those related to uncontrollability, and their interaction with the lack of active coping strategies (such as information seeking and distraction). These results align with observations from previous research^{17,12}.

Given the heightened uncontrollability and uncertainty surrounding the prognosis during a relapse, which significantly impacts parents' quality of life, their relationship with their children, and their marital dynamics, the cultivation of active coping skills becomes paramount^{4,8}. These coping strategies play a crucial role in facilitating decision-making, regulating emotions, and fostering a greater sense of control, ultimately reducing parental stress in this highly demanding situation^{12,13}.

The results of this study also reveal that coping with uncontrollable circumstances and its consequential impact on parents' mental health can be facilitated through secondary strategies such as acceptance, social support, and religious/spiritual coping mechanisms. The acceptance that suffering is inevitable to some extent appears to enhance the psychological adjustment of participants facing highly uncontrollable situations¹³. Conversely, spirituality often offers comfort, hope, and aids in acceptance and coping, enabling parents to maintain their emotional connection with the child¹⁹.

Table 1

Configurational paths about psychological adjustment problems (negative feelings) in parents of children with cancer relapse.

Path	Configuration	Raw cover	Individual cover	Consistency
First analysis				
1	~Activecoping*passivecoping	0.43	0.14	1
2	Passivecoping*stressors	0.43	0.14	1
		Solution cover: 0.57		
		Solution consistency: 1		
Second analysis				
1	~distraction*~informationseek*~uncontrollability	0.67	0.67	1
2	~distraction*~religion*~acceptance*~socialsupportdeek*~informationseek	0.08	0.08	1
3	~distraction*repression*~informationseek*uncontrollability*finantialloss	0.08	0.08	1
		Total solution cover total of the 3 models: 0.83		
		Total solution consistency of the 3 models: 1		

Note: Active coping= seeking support from the healthcare team, ventilating emotions, activating social support, seeking information and utilizing distraction. Passive coping=relying on religion/ spirituality, negating, self-isolating and accepting uncontrollability. ~ = absence; * = interaction.

Furthermore, actively seeking social support can significantly alleviate adjustment problems for parents, especially those in low socioeconomic families and those geographically distant from their places of origin^{20,21}. The distance resulting from the treatment's routine creates a new support network, wherein parents who are distanced from their families find mutual support, functioning as both an expansion of the support network and a coping model²².

In contrast, participants facing the challenges of relapse often resorted to repression strategies, which significantly contributed to greater emotional difficulties, consistent with earlier findings^{7,23}. Repression was also associated with the lack of searching for social support, as parents relying on repression mentioned a preference for isolation and not sharing treatment-related worries.

Nevertheless, it is important to note that the sample in this study was composed mostly of low-income families, which already have several risk factors for parental and child psychological adjustment²⁴. In this context, financial losses—another contributive condition—caused by layoffs, job resignations, or an increase in medical and non-medical expenses, can have a greater impact and increase the burden on low-income families²⁵. Moreover, low-income families tend to have a poorer perception of social support than families from other socioeconomic strata²⁶.

Thus, we can assume that a deficient family income and the absence of social support, combined with late diagnosis and lower treatment adherence, commonly observed in low-income families, may contribute to a poorer prognosis²⁰. In fact, this scenario can intensify the negative feelings experienced by parents of children facing cancer relapse.

On the other hand, similar to the observed variations in the literature regarding the psychological adjustment of parents of children with cancer, the present study also reflects a diverse range of responses⁶. While many participants exhibited depressive symptoms, a minority demonstrated resilience and emotional growth, aligning with findings from other research studies^{5,14}. The initial diagnosis was considered a valuable learning opportunity for anticipating and navigating potential challenges during relapse, ultimately providing a sense of control¹⁰. However, despite the insights gained, the experience of relapse was emotionally more challenging than the initial diagnosis, leading to difficulties in adjustment and adaptation.

Overall, the present study underscores the significance of active coping skills in mitigating

negative emotions, such as fear of loss, stress, and depressive symptoms, among parents of children in cancer relapse. While the effectiveness of activating the support network is supported by robust scientific evidence, the role of distraction for this population remains underexplored in the literature. Although distraction techniques are employed with adult cancer patients²⁷, discussions surrounding distraction strategies for children's caregivers primarily focus on the pediatric patient, with parents mainly serving as mediators²⁸. Therefore, future research could benefit from a more comprehensive assessment of the impact of distraction strategies on the psychological adjustment of parents of children with cancer.

Finally, this study has some limitations. Firstly, the small sample size makes it challenging to comprehend the common experiences of parents of children with cancer relapse, although the qualitative methodology allows for an in-depth exploration. One study bias may be associated with the use of unstructured interviews. While they enabled parents to express themselves more freely, they may have omitted other relevant factors in this context that were not mentioned by the participants.

CONCLUSION

This study revealed that the uncontrollability is a central stressor in childhood cancer relapse, leading to negative feelings among parents. The findings underscore the significance of active coping strategies, particularly those related to distraction and information seeking, in mitigating these negative emotions. Additionally, secondary contributive factors for parental adjustment problems included the absence of social support, a lack of religiosity/spirituality and/or acceptance, as well as the use of repression strategies. Recognizing these conditions is crucial, as it can guide healthcare teams in designing specific interventions for these families, addressing the most relevant and urgent aspects for this population.

In this sense, parents could benefit from early interventions that teach them active coping skills, starting at the relapse diagnosis. This approach aims to expand their repertoire of dealing with stressors and facilitate not only their own adjustment but also their child's. It is, therefore, suggested the promotion of distraction strategies through various spaces and opportunities. Additionally, increasing the quantity and quality of information provided to parents is recommended. This

approach aligns with the goal of achieving more humanized assistance and fostering greater communication between parents and the healthcare team, in line with the guidelines of the Brazilian National Cancer Institute – Inca²⁹.

Given the challenges inherent to pediatric cancer recurrence, it is crucial to provide psychological and spiritual support to parents and activate the support network. This aims to minimize their vulnerability to the uncontrollability of the situation and prevent the emergence of possible psychopathologies. Therefore, a transdisciplinary approach in caring for parents of pediatric cancer patients is essential, along with the integration of prevention, promotion, and treatment actions, as outlined by the Brazilian Health Ministry³⁰.

Moreover, this study underscores the importance of incorporating qualitative assessments for caregivers alongside quantitative evaluations.

Since parents of children with cancer relapse are dealing with an abnormal situation, traditional standardized instruments may not adequately capture their specific challenges, potentially pathologizing parental adaptation to this condition²³. Therefore, a qualitative assessment becomes essential to capture the unique experiences of this population.

In light of these findings, it is suggested that parents of children undergoing cancer relapse, particularly those with psychosocial vulnerabilities, may constitute a group at psychological risk requiring immediate and early interventions. Specifically within the Brazilian context, there is a need for the development of accessible and low-cost interventions. This is essential to align available resources with the needs and demands of families whose children are undergoing treatment for cancer recurrence.

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RELATO DE CASO | CASE REPORT

Sarcomatoid carcinoma of the pancreas: A rare case report and literature review

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ABSTRACT

Sarcomatoid carcinoma is a rare malignant neoplasm of the pancreas. It presents a spindle cell component and may or may not show an epithelioid component. It can also be found in other regions of the gastrointestinal tract, as well as in the breast, urinary tract, thyroid, and respiratory tract. In this study, we describe the case of a 77-year-old female patient with sarcomatoid carcinoma in the tail of the pancreas, confirmed by histology and immunohistochemical examination.

Keywords: Sarcomatoid carcinoma, malignant pancreatic neoplasm, spindle cells, undifferentiated pancreatic carcinoma.

INTRODUCTION

Sarcomatoid carcinoma of the pancreas is a rare and aggressive malignant neoplasm. It presents a spindle cell component, with or without an epithelial component, and lacks specific mesenchymal differentiation. In this study, we describe the case of a 77-year-old female patient with sarcomatoid carcinoma of the pancreatic tail, confirmed by histology and immunohistochemistry.

CASE REPORT

A 77-year-old female patient presented with anorexia, fatigue, and discomfort in the epigastrium and left hypochondrium for six months. On physical examination, she appeared mildly pale and had slight tenderness on deep palpation in the epigastrium and left hypochondrium. No palpable mass or visceromegaly was found. She had an ECOG performance status of zero. Her past medical history included systemic arterial hypertension, diabetes mellitus, and coronary artery disease with a previous angioplasty. She denied smoking and alcohol use. There was no family history of cancer in first-degree relatives.

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Laboratory tests revealed anemia (hemoglobin: 9.6 g/dL; hematocrit: 30.8%) and normal tumor markers (CEA, CA19-9, and CA125). An abdominal MRI showed an oval, partially defined solid expansive mass in the retroperitoneal region behind the pancreatic tail, adjacent to splenic vessels and extending into the splenic hilum, measuring 7.5 x 7.2 x 7.1 cm. (Figure 1)The lesion showed isosignal on T2-weighted sequences, marked diffusion restriction, and mild heterogeneous contrast enhancement. No secondary abdominal implants or thoracic metastases were found.

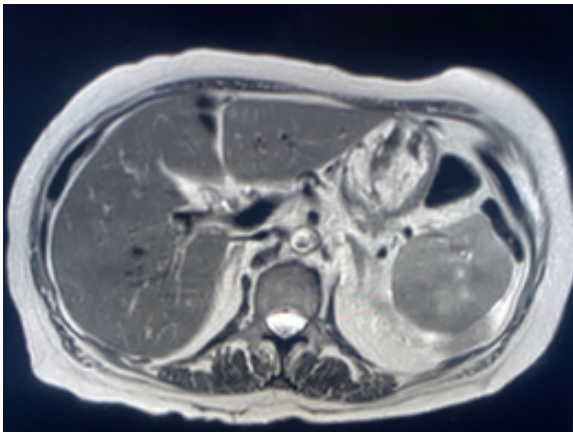


Figure 1: Solid expansive mass in the tail of pancreas(green arrow)

After preoperative cardiologic evaluation, the patient underwent robotic distal pancreatectomy with splenectomy in September 2022. With robotic assistance, estimated blood loss was about 100 mL, operative time was 4 hours, and the patient had early mobilization and minimal postoperative pain. Figure 2 below depicts the surgical specimen.



Figure 2: Surgical Specimen

Histological (Figures 3 and 4) and immunohistochemical analysis (Figures 5 and 6) confirmed the diagnosis of sarcomatoid carcinoma of the pancreas, with no lymph node involvement and direct extension of the tumor into the spleen.

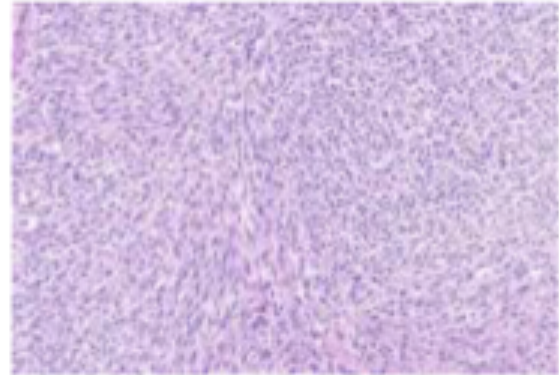


Figure 3: Spindle cell component

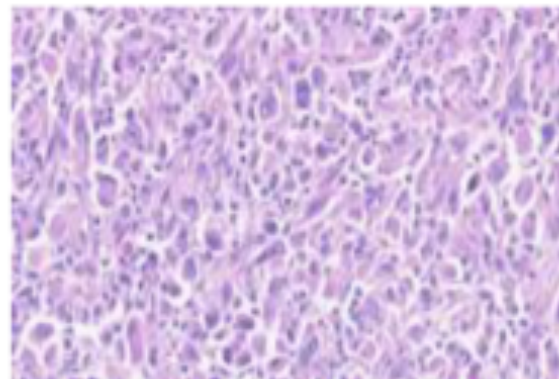


Figure 4: Epithelioid compone

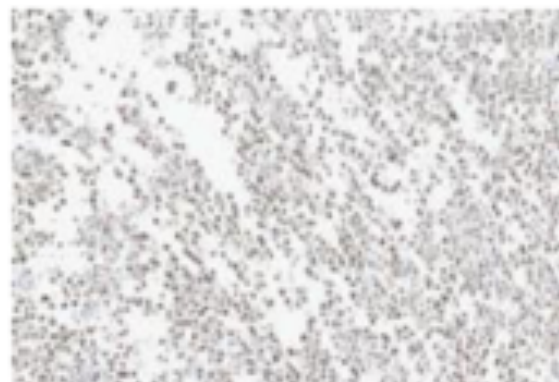


Figure 5: Cytoplasmic expression of cytoqueratin AE1/AE3 in neoplastic cells.

Antigen	Antibody(clone)	Result
AE1/AE3	AE1/AE3/PCK26	Positive,variable expression in 40% of neoplastic cells
CD117(KIT)	EP10	Negative
CD34	QBEnd10	Negative
CD99	O13	Negative
DESMIN	DE-R-11	Negative
Ki67	30-9	Positive in 40% of nucleus
MELAN A	A103	Negative
S100	Policlonal	Negative

Figure 6. Immunohistochemical analysis

On postoperative day 3, the patient developed a grade A pancreatic fistula, according to the International Study Group of Pancreatic Fistula (ISGPF). She was discharged on postoperative day 7 with a surgical drain, which was later removed at the outpatient clinic.

The patient received adjuvant chemotherapy with gemcitabine 1000 mg/m² intravenously on days 1 and 8 every 21 days for six cycles, from October 2022 to February 2023. At 30 months postoperatively, she remains alive with no evidence of disease recurrence.

DISCUSSION

Sarcomatoid carcinoma is a rare and poorly differentiated malignancy more commonly found in the breast, lung, and kidney. It is extremely rare in the pancreas, accounting for only 0.1% to 5.7% of all malignant pancreatic tumors. This neoplasm is composed of spindle-shaped cells that typically express keratin, indicating an epithelial origin. Some cases show mesenchymal features, with vimentin and desmin expression and loss of E-cadherin expression. It is believed that epithelial-mesenchymal transition of an epithelial tumor leads to its formation.

It has a higher incidence in males (2.5:1) and is more commonly located in the pancreatic head. Zhao et al. reported that the mean tumor size was 5.1 cm and that most lesions appeared round or ovoid and were poorly defined. Vascular invasion on imaging was noted in 5 of 10 cases.

Histologically, pancreatic sarcomatoid carcinoma predominantly consists of spindle-shaped mesenchymal-like tumor cells originating from the pancreatic ducts and acini, without glandular differentiation. The tumor has a distinct biphasic pattern of carcinoma and sarcoma.

Pancreatic carcinosarcoma (CSP) also arises in the pancreas and has similar biphasic features. The terms "carcinosarcoma" and "sarcomatoid carcinoma" are often used interchangeably in the literature, though their definitions vary. According to the 5th edition of the WHO classification of exocrine pancreatic tumors (2019), sarcomatoid carcinoma (SCP) and CSP are both classified as undifferentiated carcinoma of the pancreas (UCP).

UCP, a subtype of pancreatic ductal adenocarcinoma (PDAC), is a group of rare tumors accounting for about 5% of pancreatic cancers. Unlike conventional PDAC, which shows abundant desmoplastic stroma with few neoplastic glands, UCP

is hypercellular with minimal stroma and sparse desmoplasia. SCP consists of spindle cells and may contain heterologous elements such as bone and cartilage. Microscopic features are essential to distinguish SCP from CSP.

Surgical resection with negative margins is the only potentially curative treatment. Since there is no specific chemotherapy protocol for sarcomatoid carcinoma, treatment follows the same guidelines as ductal adenocarcinoma.

Currently, in patients with good performance status, adjuvant chemotherapy with mFOL-FIRINOX (oxaliplatin 85 mg/m², leucovorin 400 mg/m², irinotecan 180 mg/m² on day 1, followed by 5-FU 2400 mg/m² continuous infusion over 46 hours every 14 days for 12 cycles) is recommended based on the PREOPANC-1 and NORPACT-1 trials.

For patients not suitable for mFOLFIRINOX, adjuvant chemotherapy with gemcitabine 1000 mg/m² on days 1, 8, and 15, combined with capecitabine 1660 mg/m²/day from days 1 to 21 every 4 weeks for 24 weeks (as per the ESPAC-4 trial), may be used. Due to the patient's age and possible toxicity, we opted for gemcitabine monotherapy on days 1 and 8 only.

Another option is gemcitabine combined with nab-paclitaxel (125 mg/m² on days 1, 8, and 15), every 4 weeks, as studied in the APACT phase III trial. In cases with positive margins, postoperative radiotherapy may be considered following chemotherapy. Options include: - 4,500 cGy + 540 cGy boost with 5-FU 500 mg/m²/day for 3 consecutive days at the beginning and end of RT; - 4,500 cGy + 540 cGy boost with 5-FU 375 mg/m²/day for 5 consecutive days during weeks 1 and 5; - IMRT combined with capecitabine 1600 mg/m²/day (Monday to Friday), as per ESPAC-1. Prognosis for sarcomatoid carcinoma of the pancreas is worse than ductal adenocarcinoma, with median survival less than one year.

CONCLUSION

This paper describes a rare case of sarcomatoid carcinoma of the pancreas treated surgically through a robotic approach, followed by adjuvant chemotherapy. Despite the poor prognosis associated with this neoplasm, the patient remains alive and disease-free 30 months after surgery.

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What is the Weight of Compassion? Facing Professional Fatigue in Palliative Care – An Integrative Review

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ABSTRACT

Introduction: Palliative care plays a critical role in supporting patients with life-threatening and advanced-stage illnesses. Within this context, healthcare professionals and caregivers face unique emotional and psychological challenges, often experiencing a phenomenon known as Compassion Fatigue. **Objectives:** This study aims to investigate and describe the emotional experiences of healthcare professionals and caregivers working in palliative care, emphasizing how compassion fatigue affects their quality of life. Additionally, it seeks to identify coping strategies used to manage the constant exposure to death and loss. **Materials and Methods:** An integrative review was conducted through a bibliographic search on the topic of compassion fatigue. After applying inclusion and exclusion criteria, selected articles were read in full and analyzed. The search was performed using the Virtual Health Library (VHL). The research followed steps including the development of a guiding question, source selection, data extraction, analysis, synthesis, and final interpretation. **Results:** Findings revealed the significant impact of compassion fatigue on the quality of life of healthcare professionals and caregivers, as well as the coping strategies employed to reduce stress. The reviewed articles led to the identification of key categories: ⁽¹⁾ Emotional Responses of Healthcare Professionals, ⁽²⁾ Self-care and resilience, ⁽³⁾ Pandemic Impacts and Preventive Strategies, ⁽⁴⁾ Professional–Patient–Family Relationship, ⁽⁵⁾ Psychosocial and Emotional Aspects, ⁽⁶⁾ Professional Education and Training, and ⁽⁷⁾ Family caregivers. **Conclusion:** Compassion fatigue is common among palliative care professionals and caregivers, driven by emotional overload, lack of support, and training gaps. Its effects compromise well-being and care quality. The literature highlights the need for preventive strategies like self-care, resilience training, and institutional support.

Keywords: Palliative care; Healthcare professionals; Caregivers; Compassion fatigue; Emotions; Patient-professional relationship; Stress.

INTRODUCTION

Palliative care is a multidisciplinary and holistic approach that seeks to alleviate suffering and improve the quality of life for individuals with life-threatening illnesses and their families. It addresses physical, psychological, social, and spiritual distress.¹ According to the World Health Organization², palliative care aims to prevent and relieve suffering through early identification, comprehensive assessment, and management of pain and other multifaceted problems.

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The modern palliative care movement originated in the 1960s in the United Kingdom, led by physician, nurse, and social worker Cicely Saunders. In the 1970s, psychiatrist Elisabeth Kübler-Ross helped spread the model to the United States.³ In Brazil, palliative care was introduced in the 1980s, and its expansion accelerated from 2000 onwards. By 2022, 234 services were registered, with 52.6% being publicly funded through the Unified Health System (SUS).¹ Despite the increase, palliative care services remain insufficient and unequally distributed across Brazilian regions.

Only in 2024 was the National Policy on Palliative Care (PNCP) officially approved in Brazil, promoting an integrated approach across all levels of healthcare and emphasizing the need for professional training and cultural change.⁴ A significant barrier to access is the limited number of trained professionals—Brazil currently meets only 10% of the necessary workforce demand.⁵ Furthermore, cultural misconceptions often equate palliative care solely with end-of-life care.⁶

Timely integration of palliative care is essential. Early referral improves quality of life and mitigates suffering throughout the disease trajectory—not just at its terminal phase.⁷ Contrary to public perception, receiving palliative care from the time of diagnosis can provide patients with sustained symptom control, psychosocial support, and a sense of dignity.⁸

However, delivering palliative care can significantly impact the mental health of healthcare professionals. Constant exposure to pain, suffering, and death may lead to Compassion Fatigue,⁹ a condition characterized by emotional exhaustion, reduced empathy, and psychological distress.¹⁰ Common symptoms include sadness, anxiety, helplessness, and emotional detachment.¹¹ Additionally, the overemphasis on technical training often overlooks the need for inner development and emotional resilience, contributing to professional dehumanization.¹²

This study aims to investigate the impact and coping strategies associated with Compassion Fatigue among healthcare professionals and caregivers working in palliative care. Specifically, it seeks to assess its prevalence, identify risk factors, examine symptom manifestations, evaluate the impact on patient care quality, and explore effective prevention and intervention strategies.

METHODS

Study design

We conducted an integrative literature review to synthesize and analyze scientific evidence on Compassion Fatigue among healthcare professionals and caregivers, specifically within palliative care settings.

Procedures and data collection

We conducted a literature search on May 17, 2024, using the Virtual Health Library (BVSaLud), accessing the following databases: MEDLINE, LILACS, BDNF (Nursing), and INDEX PSICOLOGIA. The search aimed to identify full-text articles published between 2019 and 2024 that addressed Compassion Fatigue among healthcare professionals and caregivers in palliative care settings. Articles were eligible for inclusion if they met these criteria; we excluded studies that lacked full-text access, as well as monographs or articles that did not align with the defined focus. The study was guided by the research question: How does Compassion Fatigue affect the health of healthcare professionals and caregivers working in palliative care? Two independent researchers carried out the search using the following descriptors. The initial search retrieved 172 articles; after applying the inclusion and exclusion criteria,¹³ articles were selected for final analysis (figure 1).

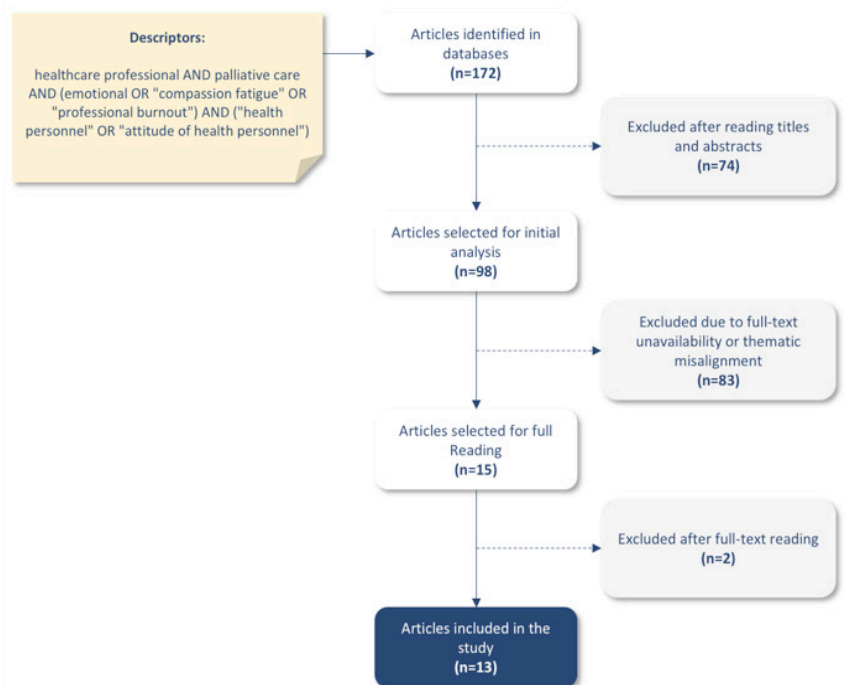


Figure 1. Systematic flowchart illustrating the search strategy, article identification, eligibility assessment, selection process, and final inclusion.

RESULTS

Following the application of the search strategy—which included defining keywords and selecting relevant databases—we implemented the predefined inclusion and exclusion criteria to ensure the relevance and quality of the selected studies. As a re-

sult of this process, we selected a final sample of 13 articles deemed most suitable for analysis. **Table 1** presents a synthesis of the main findings and contributions of each study, providing a comprehensive overview of the current state of research on palliative care and the experiences of healthcare professionals in this field.

Table 1. Summary of the analyzed articles, categorized by authors, journals, study objectives, and main outcomes.

Authors / Year / Country	Journal	Study Aims	Key Outcomes
Beserra et al., (2024); ¹³ Brazil	Cadernos de Saúde Pública	Analyze difficult situations and emotions arising in healthcare provision.	Palliative care settings evoked a wide range of painful emotions—such as sadness, anguish, helplessness, fear, loneliness, despair, and disgust—yet also fostered experiences of gratitude and compassion.
Davis et al., (2023); ¹⁴ United States	Journal of Transcultural Nursing	Explore insights into training, self-care, work environment, and relationship-building impacting the well-being of palliative care professionals.	In this sample, spirituality emerged as a core element of palliative care practice, as reflected in the participants' narratives.
Garcia et al., (2022); ¹⁵ Brazil	Journal of Pain and Symptom Management	Investigate mindful self-care, self-compassion, and resilience among palliative care providers during the COVID-19 pandemic.	Findings suggest that interventions promoting mindful self-care and self-compassion can enhance the resilience and well-being of palliative care providers.
Gallana et al., (2022); ¹⁶ Spain	Journal of Pain and Symptom Management	Examine how self-compassion mediates the relationship between self-care, awareness, and quality of life among healthcare professionals.	Self-care, understood as both health promotion and preservation of personal integrity, is essential for managing occupational stress among healthcare professionals—making it an imperative rather than a choice.
Hill et al., (2021); ¹⁷ United Kingdom	Current Opinion Support Palliative Care	Assess optimal integration of supportive care into treatment for affected individuals.	During the COVID-19 pandemic, early referrals to palliative care increased workload and contributed to healthcare staff burnout. Preventive strategies must be tested and implemented to support frontline providers.
Rodrigues et al., (2021); ¹⁸ Brazil	REME	Map scientific evidence on compassion fatigue among nursing professionals in palliative care settings.	There is a pressing need to improve work processes to address the impact of compassion fatigue on nurses' professional and personal lives. Enhancing caregiver autonomy and strengthening the caregiver-patient-family triad are crucial. <u>Managerial support is key to promoting occupational health initiatives.</u>
Leal et al., (2021); ¹⁹ Brazil - Colombia	Revista Ocupación Humana	Reflect on meanings and challenges experienced by two occupational therapists working in palliative care.	Palliative care requires professional self-recognition as emotional beings who need to be heard and supported—underscoring the importance of safe, open spaces for emotional dialogue and support.
Gallana et al., (2020); ²⁰ Spain	Health Qual Life Outcomes	Present a brief version of the Professional Quality of Life Scale (ProQOL), measuring burnout, compassion fatigue, and compassion satisfaction.	Self-compassion enhances interpersonal skills and correlates with key quality-of-life determinants such as empathy. Proper self-care practices are essential to sustaining professional well-being. The study concluded that the Short ProQOL scale is a robust tool for assessing healthcare providers' quality of life.

Monteiro et al., (2020); ²¹ Brazil	Psicologia: Ciência e Profissão	Understand perceptions, emotions, and challenges faced by healthcare professionals when caring for dying patients.	Preventive measures must consider both individual and collective challenges, emotional experiences, professional satisfaction levels, and the need for personal empowerment. A nuanced understanding of how professionals perceive illness and death is critical for effective intervention.
Silva et al., (2019); ²² Brazil	Revista Ciência, Cuidado e Saúde	Analyze scientific literature on daily caregiving experiences of health professionals and informal caregivers in home-based palliative care.	Family caregivers of home-based palliative care patients often experience predominantly negative emotions. Comprehensive support that addresses their biopsychosocial and spiritual needs is essential.
Ribeiro et al., (2019); ²³ Brazil	Revista Ciência, Cuidado e Saúde	Identify sociodemographic characteristics, lifestyle, work habits, and caregiving activities of informal caregivers.	Most caregivers in the study were women, around 50 years old, living with the palliative patient, providing care for over a year without formal employment, training, or external support—often for 5 to 10 hours daily.
Carter et al., (2019); ²⁴ Canada	CJEM	Evaluate patient/family satisfaction and paramedics' confidence and comfort in care delivery.	A new training program enhanced paramedics' comfort and confidence in delivering palliative and end-of-life care. It resulted in high patient/family satisfaction, with families particularly noting the paramedics' compassion and professionalism.
Gallana et al., (2019); ²⁵ Spain	Journal of Pain and Symptom Management	Develop and validate a short version of the Death Coping Self-Efficacy Scale.	Competence in dealing with death is critical for palliative care professionals, who face daily exposure to end-of-life situations.

After analyzing and synthesizing the 13 selected articles, we identified and categorized the main recurring themes into seven distinct categories. These categories reflect the various dimensions addressed across the studies and enable a deeper understanding of the dynamics surrounding the work of healthcare professionals, particularly within the context of palliative care. Each of these categories is explored in detail below (Table 2).

Table 2. Categories, impacts, and mitigation strategies of compassion fatigue in palliative care health professionals: findings from an integrative review.

Category	How does it affect?	How can it be mitigated?
Cat. 1 Emotional Responses of Healthcare Professionals	Emotionally intense situations with terminal patients evoke sadness, distress, helplessness, guilt, and sometimes aversion	Effective emotional regulation and communication skills to build emotionally intelligent teams.
Cat. 2 Self-Care and Resilience	Significant increase in burnout, compassion fatigue, and emotional exhaustion in palliative care.	Team communication through group discussions, self-care techniques promoting emotional well-being, focus, empathy, and social connection.
Cat. 3 Pandemic Impacts and Preventive Strategies	High levels of anxiety, fear, stress, and compassion fatigue due to workload, emotional demands, and contamination fears.	Psychological support and structured self-care programs to reduce fatigue effects.
Cat. 4 Professional–Patient–Family Relationship	“Conspiracy of silence” hinders communication and fosters emotional isolation.	Transparent communication to build trust and validate emotional experiences.
Cat. 5 Psychosocial and Emotional Aspects	Emotional exhaustion, sleep disturbances, and reduced empathy affect clinical decisions, communication, and job satisfaction.	Psychological support programs, rest periods, and self-compassion practices.
Cat. 6 Professional Education and Training	Lack of preparation harms communication and leads to emotional exhaustion.	Palliative care education covering self-compassion, communication, and emotional management.
Cat. 7 Family Caregivers	Mental fatigue, concentration difficulties, emotional numbness, and anticipatory grief due to overload, lack of guidance, and care complexity.	Strengthening social and health support networks, including training and emotional support.

Note: Cat.: Category/

See, in **Table 3**, the relationship between the identified categories and the analyzed articles.

Table 3. Occurrence of thematic categories across the analyzed articles.

	Emotional Responses of Healthcare Professionals	Self-Care and Resilience	Pandemic Impacts and Preventive Strategies	Professional-Patient-Family Relationship	Psychosocial and Emotional Aspects	Professional Education and Training	Family Caregivers
Beserra et al. (2024) ¹³	◆	◆	-	◆	◆	-	-
Davis et al. (2023) ¹⁴	◆	◆	-	-	◆	-	-
Garcia et al. (2022) ¹⁵	-	◆	◆	-	◆	-	-
Galiana et al. (2022) ¹⁶	◆	◆	-	-	◆	-	-
Hill et al. (2021) ¹⁷	-	-	◆	-	-	-	-
Rodrigues et al. (2021) ¹⁸	◆	-	-	◆	◆	◆	-
Leal et al. (2021) ¹⁹	◆	◆	-	-	-	-	-
Galiana et al. (2020) ²⁰	-	◆	◆	-	-	-	-
Monteiro et al. (2020) ²¹	◆	◆	-	-	-	-	-
Silva et al. (2019) ²²	-	-	-	-	-	◆	◆
Ribeiro et al. (2019) ²³	-	-	-	-	-	◆	◆
Carter et al. (2019) ²⁴	-	-	-	◆	-	◆	-
Galiana et al. (2019) ²⁵	-	◆	-	-	-	◆	-

DISCUSSION

The reduced number of articles (N=13) highlights the need for more scientific research specifically addressing issues such as compassion fatigue and professional burnout among healthcare professionals working in palliative care. This scarcity of studies focusing directly on the emotional and attitudinal variables of this group reinforces the importance of further exploration into their psychological well-being.

Findings suggest that working in palliative care is not purely negative. Rather, it involves an emotional dialectic, in which the suffering of patients and the fatigue of professionals coexist with the potential for deep empathy and the appreciation of human care. This underscores the importance of continuous emotional support and coping strategies tailored to these professionals. Nunes and Milano²⁶ emphasize the role of psychologists in palliative care teams, not only to facilitate the expression of emotions, anxieties, and fears but also to promote a healthy work environment and prevent mental health issues.

In alignment, Galiana et al.¹⁶ and Rodrigues et al.¹⁸ stress the significance of self-care and self-compassion as essential tools to preserve mental health. The practice of self-care, along with an awareness of quality of life, functions as a mediating variable between occupational stressors and emotional well-being. However, implementing these practices effectively remains a challenge, particularly in high-demand work environments. Hill et al.¹⁷ illustrate this through the significant increase in burnout during the COVID-19 pandemic, emphasizing the urgency of developing more robust preventive strategies.

Other studies highlight the role of spirituality and professional training in promoting both the well-being of professionals and the quality of care. Davis et al.¹⁴ and Carter et al.²⁴ report that spirituality is considered essential in palliative care practice in the United States. Meanwhile, Canadian findings suggest that specialized training programs enhance professional satisfaction and confidence, benefiting both professionals and patients.

These results indicate the value of a holistic approach to palliative care, encompassing physical, emotional, and spiritual well-being. Arrieira et al.²⁷ found that spirituality offers comfort to both patients and families, facilitates more dignified end-of-life experiences, and helps professionals understand patient values. Similarly, Leal et al.¹⁹ emphasize the importance of professionals recognizing themselves as emotional beings who require support, especially in emotionally taxing environments. Rodrigues et al.¹⁸ reinforce this by highlighting compassion fatigue among nurses and the necessity of prioritizing occupational health. Here, collaboration between managers and care teams is key for implementing effective health promotion policies.

Finally, studies by Silva et al.²² and Ribeiro et al.²³ broaden the discussion by including family and informal caregivers. These caregivers—often women, with no formal training—face emotional overload and limited support. Delalibera et al.²⁸ found that 78.3% of family caregivers were women, and 65% were the patient's children. This reinforces the idea that palliative care must address the bio-psycho-social-spiritual dimensions not only of patients but also of those who care for them. Thus, support and training programs for caregivers are essential to reduce emotional suffering and ensure quality care.

Emotional Responses of Healthcare Professionals

Healthcare professionals in palliative care frequently confront emotionally intense situations, including managing terminal illness and death. These experiences can evoke sadness, distress, helplessness, guilt, and even disgust.^{13,14,18} Compassion fatigue arises when professionals internalize patient suffering, leading to emotional overload and an increased risk of burnout. Chronic exposure to death may gradually erode emotional resilience, making it crucial to acknowledge and manage these emotions.^{29,30}

Frustration and emotional exhaustion often result from the perception of limits in alleviating patient suffering.^{21,31} Beserra and Brito¹³ reports simultaneous experiences of anxiety, guilt, and sadness. Amaral et al.³² notes that emotional distress among resident physicians may stem from a biomedical education that emphasizes fighting death instead of accepting it. Additionally, team conflicts contribute to emotional strain.³³ In this context, emotional regulation and communication skills are critical to fostering emotionally intelligent teams and sustaining quality care.³⁴

Self-Care and Resilience

Self-care and resilience are central to preventing compassion fatigue and emotional exhaustion in palliative care.^{15,16} Resilience—the ability to recover from adversity—supports professionals in maintaining emotional stability and care quality.³⁵ Practices promoting self-compassion and emotional balance protect mental health and reinforce boundaries between work and personal life.³⁶

Several studies advocate institutional efforts to promote self-care. Resilient professionals demonstrate improved emotional regulation and performance.^{20,21,37} One study highlighted the use of circular dance as a self-care intervention, which enhanced emotional well-being, empathy, and social connection. Additionally, psychological support services are effective in building resilience.^{38,39}

Pandemic Impacts and Preventive Strategies

The COVID-19 pandemic exacerbated stress and compassion fatigue among palliative care workers due to increased workloads, emotional demands, and fear of infection.^{17,20} In this context, psychological support and structured self-care programs became indispensable for mitigating emotional distress.⁴⁰

Francelino et al.⁴¹ documented elevated levels of anxiety and fear among professionals managing rapid patient decline, family visitation bans, and patient isolation. Castro et al.⁴² reported staff shortages and extended shifts, while teleconsultation was adopted to ensure care continuity and reduce infection risks.⁴³ These adaptations were key to maintaining communication and symptom management during the crisis.

Professional–Patient–Family Relationship

The complex dynamics between professionals, patients, and families are central to palliative care. While these relationships can be deeply meaningful, they may also contribute to emotional fatigue when faced with suffering and death.^{13,18,24} A multidisciplinary approach can help distribute emotional demands and strengthen mutual support within care teams.

A particularly challenging issue is the “conspiracy of silence,” a tacit agreement to avoid discussing death. This behavior, often intended to protect patients and families, may hinder open communication and increase emotional isolation.^{44,45} Transparent, compassionate communication strengthens trust and validates emotional experiences—key components of high-quality palliative care.

Psychosocial and Emotional Aspects

Compassion fatigue manifests through emotional exhaustion, sleep disturbances, reduced empathy, and compromised clinical judgment.¹³⁻¹⁵ These symptoms impair both care quality and professional well-being. Thus, institutional strategies—such as workload management, mental health services, and fostering a supportive culture—are crucial.⁴⁶

Without such interventions, professionals risk losing their capacity to care effectively. Programs that promote rest, self-compassion, and emotional resilience are vital for sustaining long-term mental health.²⁰

Professional Education and Training

Training in palliative care must encompass technical, emotional, and humanistic components.⁴⁷ Education that includes emotional intelligence, self-compassion, and communication skills helps prevent burnout and improve job satisfaction.^{18,22} Well-prepared professionals are more adept at identifying emotional fatigue and implementing coping mechanisms.⁴⁸

Teamwork skills are also fundamental. When professionals are unprepared for collaborative work, tensions may arise. Educational strategies such as clinical simulations, communication workshops, and conflict resolution training enhance team cohesion and foster healthier work environments.⁴⁹

Family Caregivers

Though not part of formal healthcare teams, family caregivers experience similar emotional burdens, especially when caring for terminally ill loved ones.^{24,25} These individuals, often without adequate training or support, are highly vulnerable to compassion fatigue.

Structured inclusion of family caregivers in the care process—through training programs and

emotional support services—can improve both caregiver well-being and patient outcomes. Delalibera et al.²⁸ highlight that caregivers are predominantly women, often children of patients, and typically lack professional guidance. Providing multidimensional support, encompassing physical, psychological, social, and spiritual aspects, is essential for ensuring the sustainability of home-based palliative care.

This study presents limitations that affect the interpretation of results. The integrative review design, limited by specific descriptors and inclusion criteria, resulted in a small sample (13 studies), restricting the scope of findings. The scarcity of robust literature on compassion fatigue and its long-term emotional impact on palliative care professionals underscores the need for further research. Cultural and regional contexts may also limit generalizability. Future studies should expand sample diversity, explore cross-cultural settings, and deepen analysis of coping strategies to support more effective interventions.

CONCLUSION

This study, through an integrative literature review, examined the impact of palliative care work on the development of compassion fatigue among healthcare professionals and family caregivers. The findings indicate that compassion fatigue is prevalent and intensified by high emotional demands, insufficient support, and inadequate training. Symptoms include physical exhaustion, emotional distress, and cognitive impairments, which negatively affect care quality and professional well-being. The study suggests the importance of structured interventions such as self-care practices, emotional resilience training, continuous supervision, and institutional support networks. These strategies may be essential to help prevent compassion fatigue, sustain empathy, and contribute to the quality of care. The findings also point to the relevance of further research and policy development that prioritize the mental health of professionals and caregivers involved in palliative care.

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