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DESCRIPTIVE STUDY

The Impact of Emotional Burden on Caregivers: A Descriptive Correlational Study in the Province of Piacenza

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Findings:

This study reinforces the established link between patient distress and caregiver burden in oncology. The use of validated tools such as the ZBI and DT to assess caregiver burden and patient distress establishes a reliable framework for assessing these factors in clinical practice.

Acknowledgements:

The authors would like to thank AMOP (Associazione Malato Oncologico Piacentina) and its volunteers for their continuous support to our team.

ABSTRACT

BACKGROUND: The Zarit Burden Interview (ZBI) is a validated tool for assessing caregiver burden, while the Distress Thermometer (DT) measures patient distress. Research highlights a correlation between patient and caregiver burden, influenced by treatment type, duration, and disease progression. Interventions targeting caregivers can indirectly benefit patients by addressing insights from these tools.

AIM: To evaluate caregiver burden and patient distress and analyze related factors.

METHODS: The ZBI (22 items, Likert scale, threshold ≥ 24) assessed caregiver burden, and the DT (threshold ≥ 4) measured patient distress.

RESULTS: Patients were older than caregivers, with both groups predominantly female and residing in Piacenza province. Emotional distress affected 58.38% of patients, with worry and fatigue being most common, while 23.78% of caregivers reported significant burden, primarily fears about the future. A positive correlation ($r=0.387$) was found between patient distress and caregiver burden.

CONCLUSIONS: These findings highlight the interconnectedness of patient distress and caregiver burden, emphasizing the need for targeted interventions to support caregivers, particularly younger women balancing multiple responsibilities, and to address the emotional and physical challenges faced by oncology patients undergoing intensive treatments

Implications for Practice: The significant correlation between patient distress and caregiver burden underscores the importance of integrating routine caregiver assessments into clinical oncology practice.

KEYWORDS: Caregiver burden; Cancer patients; Distress Thermometer; Emotional distress; Nurse; Oncology; Patient distress; Psychosocial support; Zarit Burden Interview; Work-life balance.

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DESCRIPTIVE STUDY

L'impatto del carico emotivo sui caregiver: uno studio descrittivo-correlazionale nella provincia di Piacenza.Letizia Franzini¹, Martina Maserati², Gabriele Cremona², Luigi Cavanna³, Francesca Costa², Chiara Citterio²¹ Casa di Cura San Giacomo, Ponte dell'Olio, Piacenza, Italia² Dipartimento di Oncologia, Azienda USL di Piacenza, Piacenza, Italia³ Casa di Cura Piacenza, Piacenza, ItaliaRiscontri:

Questo studio rafforza il legame consolidato tra il disagio del paziente e il carico emotivo del caregiver in oncologia. L'utilizzo di strumenti validati come lo ZBI e il DT per valutare il carico del caregiver e il disagio del paziente costituisce un quadro affidabile per l'analisi di questi fattori nella pratica clinica.

Ringraziamenti:

Gli autori desiderano ringraziare AMOP (Associazione Malato Oncologico Piacentina) e i suoi volontari per il loro continuo supporto al proprio team.

ABSTRACT

INTRODUZIONE: Lo Zarit Burden Interview (ZBI) è uno strumento validato per valutare il carico del caregiver, mentre il Distress Thermometer (DT) misura il disagio del paziente. La ricerca evidenzia una correlazione tra il disagio del paziente e il carico del caregiver, influenzata dal tipo di trattamento, dalla sua durata e dalla progressione della malattia. Interventi rivolti ai caregiver possono indirettamente beneficiare i pazienti affrontando le informazioni emerse da questi strumenti.

SCOPO: Valutare il carico del caregiver e il disagio del paziente e analizzare i fattori correlati.

MATERIALI E METODI: Lo ZBI (22 item, scala Likert, soglia ≥ 24) ha valutato il carico del caregiver, mentre il DT (soglia ≥ 4) ha misurato il disagio del paziente.

RISULTATI: I pazienti erano più anziani rispetto ai caregiver, con entrambi i gruppi prevalentemente di sesso femminile e residenti nella provincia di Piacenza. Il disagio emotivo ha interessato il 58,38% dei pazienti, con preoccupazione e affaticamento come sintomi più comuni, mentre il 23,78% dei caregiver ha riportato un carico significativo, principalmente legato a paure riguardo al futuro. È stata riscontrata una correlazione positiva ($r=0,387$) tra disagio del paziente e carico del caregiver.

CONCLUSIONI: Questi risultati evidenziano l'interconnessione tra disagio del paziente e carico del caregiver, sottolineando la necessità di interventi mirati a supportare i caregiver, in particolare le donne più giovani che devono bilanciare molteplici responsabilità ed affrontare le sfide emotive e fisiche dei pazienti oncologici sottoposti a trattamenti intensivi.

KEYWORDS: *Burden del caregiver; Pazienti oncologici; Distress Thermometer; Disagio emotivo; Infermiere; Oncologia; Disagio del paziente; Supporto psicosociale; Zarit Burden Interview; Equilibrio tra lavoro e vita privata.*

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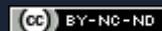
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BACKGROUND

The role of caregivers is crucial in the healthcare system especially for patients with chronic and severe diseases such as cancer. Caregivers provide emotional, physical, and practical support, often at the expense of their own psychological and physical well-being. Numerous studies have shown that caregiving can lead to distress, depression, anxiety, and other mental health issues among caregivers¹⁻². The well-being of caregivers is essential not only for their health but also for the quality of care they can provide to patients. Overburdened and stressed caregivers are less able to offer effective support, which can negatively impact the patient's health and recovery³. Therefore, identifying and alleviating caregiver burden is a priority in improving overall treatment outcomes. The literature highlights the utility of interventions that directly involves the caregiver and indirectly the patient⁴. During the Covid-19 pandemic, the need for connection and relationship between the patient and caregiver to improve mutual well-being became even more evident. In Piacenza, several studies were conducted, one of which emphasized the importance of home venous access for therapy to avoid patient transport. This approach reduced the burden on the caregiver who would otherwise struggle more and face a higher risk of infection. Furthermore, if the patient were hospitalized, they would not have the same opportunity to assist them⁵. It has been shown that caregivers have a higher risk of falling ill and taking more medications than those who do not care for their family members⁶. Various tools have been developed to assess caregiver burden and distress. The Zarit Burden Interview (ZBI) is one of the most widely used tools to measure perceived caregiver burden. The ZBI includes questions covering various aspects of caregiving, such as stress levels, time dedicated to care, and the impact on the caregiver's personal life⁷. Another useful tool for assessing emotional distress is

the Distress Thermometer (DT), which provides a quick and simple measure of distress level on a scale from 0 to 10. The DT is accompanied by a list of problems that may contribute to distress, allowing for a more comprehensive assessment of stress sources⁸. This study aims to explore the well-being of caregivers of cancer patients through a prospective quantitative evaluation using the ZBI and DT. The specific objectives are to measure the level of perceived burden among caregivers, assess the level of emotional distress among caregivers, and identify demographic and clinical factors associated with high levels of burden and distress. Through this research, we hope to provide a deeper understanding of caregivers' well-being and contribute to the development of support strategies that can improve the quality of life for caregivers and the patients they care for.



MATERIALS AND METHODS

This is a prospective descriptive correlational study. The inclusion criteria for the sample was caregivers and patients aged between 30 and 80 years, patients followed at the oncology day-hospital of Piacenza hospital who access for visits or therapy from June to October 2023, patients undergoing active therapy for neoplasms (i.e., having received therapy in the last 3 months), patients able to define only one caregiver who assists them, patients and caregivers who understand Italian well and capable of completing the evaluation scales administered to them. Instead the exclusion criteria was patients and caregivers under 30 or over 80 years old, caregivers and patients who are unable to understand and provide written informed consent.

To explore caregiver's burden we used the ZBI scale⁹ and its relationship with patient distress, measured through the DT¹⁰. The primary objective was to detect and evaluate the burden among caregivers of cancer patients using the ZBI scale. The secondary

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objectives were to assess the relationship between ZBI and DT results and evaluate the factors influencing caregiver and patient burden. The ZBI consists of 22 questions, each exploring a different aspect of perceived burden, and caregivers respond using a 5-point Likert scale ranging from "Never" to "Always." A threshold value of 24 points is typically considered an indicator of significant perceived burden, with a score of 24 or higher suggests that the caregiver is experiencing a level of burden that may require attention and support interventions⁷.

The DT is a questionnaire designed to be a quick and effective measure of emotional distress and patient concerns. It consists of a list of issues (physical, practical, emotional, spiritual) that may contribute to distress, allowing for a more detailed assessment of stress sources. A score ≥ 4 suggests that the participant is experiencing a level of distress that may require clinical attention and support interventions⁸. The researcher provided the information sheet related to the study during the visit or therapy at the Day Hospital asking the caregiver and patient for their availability to participate to the study or to be able to contact them to see each other and attend the next Day Hospital appointment. After providing comprehensive information and signing the informed consent, the patient was asked to complete the DT, and the caregiver to answer the questions on the ZBI questionnaire (22 items). Additionally a socio-demographic data sheet was also collected for both caregiver and patient, along with specific data related to the neoplastic disease and treatment for the patient only.

Patient data sheet collected data included age, sex, neoplasm, date of diagnosis; type of treatment; frequency, duration and therapeutic line; other treatments such as radiotherapy or palliative care; place of residence, work, family status, relevant comorbidities, and DT.

Caregiver's data sheet collected data included age, sex,

place of residence, work, family status, relevant comorbidities, ZBI scale. The study began after receiving favorable opinions from CE AVEN and the Piacenza Health Authority on 22/06/2022 (Protocol No. 2022/0182851) and concluded on 30/10/2023. The data of each pair, caregiver and patient, were recorded in a specific database and pseudo-anonymized.

Statistical Analysis

Comparing with the number of patients who accessed the medical oncology day hospital at Piacenza hospital for visits or therapy from June 2022 to October 2023 with that of previous years and including only those aged 30 to 80 years, receiving active therapy, a number of 230 patients was estimated. Considering a margin of 20% of patients not meeting the inclusion criteria (who do not speak Italian, unable to understand and complete the evaluation scales, with multiple caregivers) and those who refuse to participate in the study, it is expected that 184 patients and their respective caregivers would be included in the study.

Descriptive statistics were used to analyze the data. Quantitative variables were described by median and interquartile range (IQR), after assessing normality. Categorical variables were described by relative and absolute frequencies. Variable distribution was evaluated using chi-square or Fisher's test for categorical variables and t-test or Mann-Whitney test for quantitative variables, depending on the normality of the distribution. Correlation between variables was assessed using Spearman's correlation coefficient. A univariate and multivariate logistic regression model was applied to estimate the effect of the variables assessed on the burden score obtained with the scales. All analyses were conducted using the RStudio statistical program. The significance level will be set at $p < 0.05$.

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RESULTS

Data analysis revealed that the median age of patients was higher than that of caregivers; both patients and caregivers were predominantly female (61.62% of 185 patients and 64.86% of 185 caregivers), and most lived in the province of Piacenza rather than in the city (63.78% of 185 patients, 58.92% of 185 caregivers). While most caregivers were employed, the majority of patients were not (45.41% vs. 56.52%). Both patients and caregivers were mostly married or cohabiting and had children (Table 1).

Table 1. Demographic, Oncological, and Treatment Data for Patients and Demographic Data for Caregivers.

Variables	Patients (n=185)	Caregivers (n=185)
Median age in years [IQR](range)	62[54-68] (26-80)	56[47-64.5](20- 80)
GENDER N(%)		
F	114(61.62)	120(64.86)
M	71(38.38)	65(35.14)
RESIDENCE N(%)		
Piacenza	67(36.22)	60(32.43)
province	118(63.78)	109(58.92)
anknown	0(0)	16(8.65)
WORKERS N(%)		
Yes	84(45.41)	104(56.52)
no	101(54.59)	66(35.87)
anknown	0(0)	16(7.61)
MARRIED N(%)		
Yes	150(81.08)	127(69.40)
no	35(18.92)	42(22.95)
anknown	0(0)	14(7.65)
CHILDREN N(%)		
Yes	148(80)	123(66.85)
no	37(20)	47(25.54)
anknown	0	14(7.61)
COPATHOLOGIES N(%)		
Yes	79(42.70)	27(14.67)
no	106(57.30)	143(77.72)
anknown	0(0)	14(7.61)

NEOPLASM SITE N(%)

colorectal	27(14.59)
esophagus-stomach	17(9.19)
genitourinary	18(9.73)
gynecological	22(11.89)
breast	51(27.57)
pancreas	17(9.19)
lung	23(12.43)
other	10(5.41)

Median time since diagnosis
in month [IQR](range)
8[3-26](0-369)

THERAPY TYPE N(%)

chemotherapy	102(55.14)
immunotherapy	15(8.11)
biological therapy	24(12.97)
hormone	10(5.41)
chemo-biological therapy	18(9.73)
chemo-immunotherapy	16(8.65)
Administration n(%)	
intravenous	157(84.86)
oral	18(9.73)
intramuscular/ subcutaneous	10(5.41)

THERAPY FREQUENCY N(%)

weekly	10(5.41)
biweekly	49(26.49)
monthly	126(68.11)

Therapeutic Line

neo/adjuvant	54(29.19)
I	91(49.19)
over the I	40(21.62)

42.70% of 185 patients had comorbidities, whereas only 14.67% of 185 caregivers did. The sample predominantly consisted of patients with breast cancer (27.57%), colorectal cancer (14.59%), and lung cancer (12.43%). The median time from diagnosis to questionnaire completion was 8 months (range 0-369 months). Most patients were receiving chemotherapy (55.14%), primarily intravenously (84.86%), with monthly frequency (68.11%), and mainly first-line (49.19%).

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In the DT (Table 2 and 3), more than half of the 185 patients reported an emotional distress value ≥ 4 (58.38%).

Table 2. Distress Thermometer (DT) Results for Patients.

Question	n(%)
DT-distress level	
<4	77(41.62)
≥ 4	108(58.38)
DT's questions	
Child care problems	13(7.03)
Food	51(27.57)
Housing	48(25.95)
Insurance, financial	15(8.11)
Transportation	26(14.05)
Work/school	20(10.81)
Therapy decisions	27(14.59)
Dealing with children	12(6.49)
Dealing with partner	16(8.65)
Ability to have children	6(3.24)
Family health issues	31(16.76)
Depression	40(21.74)
Fears	96(47.57)
Nervousness	102(55.14)
Sadness	102(55.14)
Worry	140(75.68)
Loss of interest in usual activities	51(27.57)
Spiritual/religious concerns	4(2.16)
Appearance	55(29.73)
Bathing/dressing	28(15.14)
Breathing	32(17.30)
Changes in urination	27(14.67)
Constipation	33(17.84)
Diarrhoea	48(25.95)
Eating	56(30.27)
Fatigue	137(74.05)
Feeling swollen	65(35.14)
Fevers	14(7.57)
Getting around	40(21.62)
Indigestion	14(7.57)
Memory/concentration	53(28.65)
Mouth sores	26(14.05)
Nausea	58(32.35)

Nose dry/congested	45(24.32)
Pain	64(34.59)
Sexual	24(12.97)
Skin dry itchy	67(36.22)
Sleep	82(44.32)
Substance use	6(3.24)
Tingling in hands/feet	71(38.38)
Other	10(5.41)

Among the questions in the DT, the main issues reported by patients are: worry (75.68%), fatigue and tiredness (74.05%), nervousness (55.14%), sadness (55.14%), fears (47.57%). Conversely, few patients reported concerns about fertility (3.24%), problems related to their faith or spiritual aspects (2.16%), and substance use (3.24%).

Table 3. Comparison of Variable Distribution Between DT<4 and DT ≥ 4 Groups

Variables	Patients DT<4 (n=77)	Patients DT ≥ 4 (n=108)	P-value
Median Age in years [IQR] (range)	62[56-68](26-80)	62[54-69](37-80)	<.001
Gender n(%)			
F	46(59.7)	68(63)	0.771
M	31(40.3)	40(37)	
Residence n(%)			
Piacenza	28(36.4)	39(36.1)	1
province	49(63.6)	69(63.9)	
Workers n(%)			
yes	32(41.6)	52(48.1)	0.461
no	45(58.4)	56(51.9)	
Married n(%)			
yes	63(81.8)	87(80.6)	0.98
no	14(18.2)	21(19.4)	
Children n(%)			
si	60(77.9)	88(81.5)	0.682
no	17(22.1)	20(18.5)	
Copatologies n(%)			
yes	37(48.1)	42(38.9)	0.275
no	40(51.9)	66(61.1)	

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Neoplasm Site n(%)

colorectal	8(10.4)	19(17.6)	
esophagus-stomach	6(7.8)	11(10.2)	
genitourinary	7(9.1)	11(10.2)	
gynecological	7(9.1)	15(13.9)	0.284
breast	25(32.5)	26(24.1)	
pancreas	5(6.5)	12(11.1)	
lung	14(18.2)	9(8.3)	
other	5(6.5)	5(4.6)	

Median time since diagnosis in [IQR](range)	month	8[3-19](0-209)	7.5[2-30.25](0-369)	<.001
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Therapy type n(%)

chemotherapy	35(45.5)	67(62.0)	
immunotherapy	10(13.0)	5(4.6)	
biological therapy	16(20.8)	8(7.4)	
hormone	1(1.3)	9(8.3)	0.004
chemo-biological therapy	9(11.7)	9(8.3)	
chemo-immunotherapy	6(7.8)	10(9.3)	

Administration n(%)

intravenous	65(84.4)	92(85.2)	
oral	9(11.7)	9(8.3)	0.64
intramuscular/subcutaneous	3(3.9)	7(6.5)	

Therapy frequency n(%)

weekly	3(3.9)	7(6.5)	
biweekly	16(20.8)	33(30.6)	0.203
monthly	58(75.3)	68(63.0)	

Therapeutic Line

neo/adjuvant	21(27.3)	33(30.6)	
I	39(50.6)	52(48.1)	0.889
over the I	17(22.1)	23(21.3)	

From the ZBI analysis (Table 4 and 5), 23.78% of 185 caregivers scored ≥ 24 on the ZBI test. The question most frequently answered with “often” or “always” is Number 7 “Are you afraid of what the future holds for your relative?” (29.89% and 28.80%). No caregiver answered “often” or “always” to questions Number 4 “Do you feel embarrassed by your relative’s behavior?”, Number 6 “Do you feel your

relative currently negatively impacts your relationship with other family members and friends?”, and Number 18 “Would you like to entrust the care of your relative to someone else?”. Finally, to question Number 22 “Overall, how burdened do you feel by caring for your relative?”, most (46.74%) answered “not at all,” although some answered “quite a bit” (17.39%) and “very much” (8%).

Table 3. Zarit Burden Interview (ZBI) Results for Caregivers

Question	Score n(%)
ZBI-1 Do you think your family member is asking you for more help than he need?	
Never	101(54.59)
Rarely	47(25.41)
Some times	30(16.22)
Often	4(2.16)
Almost always	3(1.62)
ZBI-2 Do you feel like you don't have enough time for yourself because of the time involved in caring for your family member?	
Never	92(49.73)
Rarely	42(22.70)
Some times	36(19.46)
Often	7(3.78)
Almost always	8(4.32)
ZBI-3 Do you feel stressed caring for your family member and trying to meet other responsibilities?	
Never	66(35.68)
Rarely	40(21.62)
Some times	53(28.65)
Often	18(9.73)
Almost always	8(4.32)
ZBI-4 Do you feel embarrassed by your family member's behavior?	
Never	158(85.41)
Rarely	14(7.57)
Some times	12(6.49)
Often	1(0.54)
Almost always	0(0)

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JOURNAL HOMEPAGE: [HTTPS://RIVISTE.UNIMI.IT/INDEX.PHP/DISSERTATIONNURSING](https://riviste.unimi.it/index.php/dissertationnursing)**ZBI-5 Do you feel angry when you are with your family member?**

Never	140(75.68)
Rarely	27(14.59)
Some times	17(9.19)
Often	0(0)
Almost always	1(0.54)

ZBI-6 Do you feel that your family member is currently negatively influencing your relationships with other family members and friends?

Never	152(82.16)
Rarely	19(10.27)
Some times	14(7.57)
Often	0(0)
Almost always	0(0)

ZBI-7 Are you afraid of what the future holds for your family member?

Never	16(8.7)
Rarely	19(10.33)
Some times	55(29.89)
Often	53(28.8)
Almost always	41(22.28)

ZBI-8 Do you feel that your family member is dependent on you?

Never	51(27.72)
Rarely	51(27.72)
Some times	50(27.17)
Often	21(11.41)
Almost always	11(5.98)

ZBI-9 Do you feel tired when following your family member?

Never	96(51.89)
Rarely	46(24.86)
Some times	34(18.38)
Often	7(3.78)
Almost always	2(1.08)

ZBI-10 Do you think your health has been affected by caring for your family member?

Never	106(57.92)
Rarely	35(19.13)
Some times	32(17.49)
Often	7(3.83)
Almost always	3(1.64)

ZBI-11 Do you think you don't have the intimacy and privacy you would like because of your family member?

Never	146(78.92)
Rarely	25(13.51)
Some times	12(6.49)
Often	1(0.54)
Almost always	1(0.54)

ZBI-12 Do you think your social life has been affected by caring for your family member?

Never	109(58.92)
Rarely	39(21.08)
Some times	26(14.05)
Often	6(3.24)
Almost always	5(2.7)

ZBI-13 Do you feel uncomfortable inviting friends over because of your family member?

Never	167(90.27)
Rarely	11(5.95)
Some times	3(1.62)
Often	3(1.62)
Almost always	1(0.54)

ZBI-14 Do you think your family member expects you to take care of them as if they were the only person you depend on?

Never	105(57.07)
Rarely	33(17.93)
Some times	26(14.13)
Often	11(5.98)
Almost always	9(4.89)

ZBI-15 Do you feel like you don't have enough money to care for your family member in addition to your personal expenses?

Never	123(66.85)
Rarely	30(16.30)
Some times	19(10.33)
Often	5(2.72)
Almost always	7(3.80)

ZBI-16 Do you think you won't be able to take care of your family member for much longer?

Never	145(78.8)
Rarely	23(12.5)
Some times	11(5.98)
Often	3(1.63)
Almost always	2(1.09)

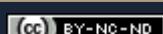
ZBI-17 Do you think you no longer have control of your life since your family member got sick?

Never	126 (68.48)
Rarely	33(17.93)

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Some times	19(10.33)
Often	2(1.09)
Almost always	4(2.17)

ZBI-18 Would you like to entrust the care of your family member to someone else?

Never	169(91.85)
Rarely	9(4.89)
Some times	6(3.26)
Often	0(0)
Almost always	0(0)

ZBI-19 Do you feel unsure about what to do for your family member?

Never	55(29.89)
Rarely	53(28.8)
Some times	64(34.78)
Often	10(5.43)
Almost always	2(1.09)

ZBI-20 Do you feel you should do more for your family member?

Never	54(29.35)
Rarely	41(22.28)
Some times	60(32.61)
Often	16(8.7)
Almost always	13(7.07)

ZBI-21 Do you think you could do better in caring for your family member?

Never	52(28.42)
Rarely	53(28.96)
Some times	60(32.79)
Often	11(6.01)
Almost always	7(3.83)

ZBI-22 Finally, how much do you feel overloaded by taking care of your family member?

Nothing	86(46.74)
A little	51(27.72)
Enough	32(17.39)
Very	13(7.07)
A lot	2(1.09)
Sum	
<24	141(76.22)
≥24	44(23.78)

Evaluating the Spearman correlation coefficient between the DT score and the ZBI total score ($r=0.387$) for the entire sample and after dividing it into quartiles (0.243 r1; 0.123 r2; 0.270 r3; 0.218 r4), a statistically significant correlation was found with the score obtained in the DT and ZBI, this correlation held true when analyzing the caregiver-patient pairs as a whole.

DISCUSSION

These results are consistent with the existing literature regarding the demographics of caregivers and oncology patients. Previous studies have highlighted that caregivers are often younger than the patients. A study published in *Cancer Nursing* found that most caregivers are family members aged between 45 and 64, while the patients they care for are often older¹¹. The majority of caregivers and patients in the oncology field are women. A study from the *Journal of Clinical Oncology* reported that about 75% of oncology caregivers are women, often wives or daughters of the patients. This trend is supported by additional studies showing that women are more frequently involved in caregiving due to social expectations and traditional gender roles that see them more predisposed to taking care of sick family members¹².

The predominance of breast cancer patients is expected, given the high incidence of this neoplasm¹³. The higher percentage of employed caregivers compared to patients suggests an additional layer of stress for caregivers, who must balance work responsibilities with caregiving demands. The high prevalence of comorbidities among patients requires an approach to managing their treatment that consider their various medical conditions. For caregivers, the dual burden of working and caring for a patient can lead to greater distress and perceived burden, as evidenced by the ZBI and DT scores.

The significant positive correlation between the DT and ZBI scores highlights the interconnectedness

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between the emotional distress of oncology patients and the perceived burden of their caregivers. The strong correlation ($r=0.988$) suggests that the two assessment tools measure related aspects of the caregiving experience in oncology. The DT, designed to assess the level of psychological distress in patients, reflects the emotional stress that inevitably impacts caregivers as well. The ZBI, on the other hand, measures the overall perceived burden of caregivers, including emotional, physical, and social aspects. The strong correlation between the two tests suggests that an increase in psychological distress in patients is closely linked to an increase in the perceived burden on caregivers.

The results of this study provide a detailed insight into the differences between patients and caregivers based on levels of distress (DT) and burden (ZBI). In particular, variables such as age, time since diagnosis, type of therapy, and gender exhibited significant differences between the studied groups. The observed age difference may indicate that younger patients perceive greater distress, perhaps due to a greater perception of life and daily activity disruption caused by the illness and treatment¹⁴.

Moreover, the time since diagnosis was longer in patients with $DT \geq 4$. This may suggest that a longer period since diagnosis could be associated with an accumulation of distress, as patients face the ongoing challenges of illness and treatment over a prolonged period¹⁵. Specifically, one patient with 369 months (since 1991) from their diagnosis skews the median time to diagnosis in the data analysis, but it is also known in the literature that breast cancer, due to its high incidence in the population, is more likely to become chronic and increase survival; otherwise, the median time to diagnosis would be around 2007.

The type of therapy is another crucial factor. In the $DT \geq 4$ group, a significantly higher percentage of patients receive chemotherapy (62%) compared to the $DT < 4$ group (45.5%). This is understandable since chemotherapy is often associated with significant

physical and psychological side effects that can increase the patient's level of distress. Similarly, a higher percentage of patients in the $DT \geq 4$ group receive hormone therapy, suggesting that different types of treatment may have varying impacts on the perceived level of distress¹⁶.

The age difference in caregivers could indicate that younger caregivers may perceive a greater burden, perhaps due to higher work commitments or additional family responsibilities that make caregiving more onerous¹⁷. Another significant difference is gender: caregivers with $ZBI \geq 24$ are primarily women (77.3%). This finding is consistent with existing literature that highlights how women are often more involved in caregiving activities and may perceive a greater burden due to social expectations and multiple responsibilities. Caregivers with $ZBI \geq 24$ tend to care for older patients; older patients may require more intensive and continuous care, increasing the caregiver's burden. Additionally, it is interesting to note that caregivers with $ZBI \geq 24$ are primarily associated with patients without comorbidities (54.5%). This might reflect the fact that patients without comorbidities may have greater survival rates and therefore require a longer period of care, thereby increasing the perceived burden on caregivers. Finally, all caregivers with $ZBI \geq 24$ care for patients receiving treatment lines equal to or greater than the first. This suggests that more advanced and potentially more complex treatments can increase the caregiver's burden, likely due to the need for more assistance and the greater stress associated with managing more intensive treatments.

The clinical implications of our findings are significant. Identifying caregivers at risk of high burden and distress can allow for timely interventions aimed at reducing their burden and improving their well-being. Implementing psychological support and training programs could provide effective strategies and adequate resources. Despite its strengths, our study has some limitations. Firstly, the sample was

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limited to caregivers of patients undergoing active therapies, and specific groups of oncological diseases were created, which could limit the generalizability of the results. Additionally, we did not consider potentially confounding variables such as social support and existing strategies. The wide range of time from diagnosis to questionnaire completion could introduce significant variability in the experiences of patients and caregivers. Future research should include a larger and more diverse sample and consider additional variables. Furthermore, the effectiveness of specific interventions aimed at reducing caregiver burden and improving their well-being should be explored in future studies.

The context of Piacenza did not include the support of structures such as the Community Houses when the study started, indeed there was born with the implementation of DM 77/2022.

Therefore, the data were collected only in the Day Hospital/DSA of Piacenza. It would be useful in the future to enhance the research with the territorial reorganization that has been implemented from 2022-2023 and is still evolving, in order to re-evaluate the results, also considering the distance of residence of the patient and caregivers.

CONCLUSIONS

This study has highlighted important demographic and clinical aspects of oncology patients and their caregivers. The correlation between caregiving burden and patient's distress underscores the need for targeted interventions that can alleviate the emotional burden and improve the quality of life for both patients and caregivers. Identifying and supporting caregivers at risk is essential to ensure optimal care for oncology patients.

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