



Psychosocial distress in oncology: using the distress thermometer for assessing risk classes

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Abstract

Purpose Cancer patients often suffer for psychological distress, which can compromise their quality of life. Our study aimed to recognize risk classes for the development of psychosocial distress.

Methods Three hundred seventy-two adult cancer patients were assessed by the Distress Thermometer (DT) and Problem List at the National Cancer Research Centre “Giovanni Paolo II” of Bari. We also compiled a socio-medical and clinical-medical record survey ad hoc for collecting socio-demographic information and clinical variables. To examine the interplay among the different variables and distinguish internally homogeneous subgroups of patients with diverse risks of distress, the RECURSIVE Partitioning and Amalgamation (RECPAM) technique was used.

Results Most of patients were female and the most frequent diagnosis was breast cancer, followed by gastro-intestinal cancer and hematological cancer. Distress was present in 43% of the sample, with a total of 156 patients with a DT > 5. The RECPAM analysis identified three distinct and homogeneous patient subgroups (RECPAM classes) with different risks of distress: diagnosis, marital status, and Eastern Cooperative Oncology Group Performance Status.

Conclusion The use of the distress thermometer allows clinicians to identify patients with certain characteristics that may increase the risk of developing psychosocial distress. This evaluation can allow timely psychological intervention and improve the patient’s therapeutic program.

Keywords Cancer · Distress · RECPAM · Risk class · Distress thermometer

Introduction

In the last decades, several studies have shown the effects of cancer on psychological health and the increased risk of high emotional distress in cancer patients [1–4]. Previous research has highlighted the presence of emotional distress up to 40% of cancer patients, as an outcome of the disease and related treatments [5].

The National Comprehensive Cancer Network (NCCN) [6] defines distress as a multifactorial unpleasant emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer,

its physical symptoms, and its treatment. Distress may also compromise the quality of life [7] and it has been recognized as the sixth vital sign to be frequently and regularly monitored in the cancer care course, so as to classify patients who need psychosocial intervention [8]. In addition, many of the symptoms presented by distressed patients fall into the syndromes of anxiety disorders and depression [2, 3, 9, 10]. Unfortunately, less than 33% of them are recognized and treated, despite the fact that this condition has a strong impact on the quality of life of patients and their families [9].

Regarding these premises, the NCCN has developed guidelines for psychosocial screening based on the demonstration that clinical judgment alone is not sufficient and is not valid as a specific screening tool [11]. Recommended tools include the Distress Thermometer (DT) and the Problem List (PL). In recent years, DT has been one of the most used tools for the screening of psychological distress in cancer patients [9, 11]. Some research indicates a cut-off ≥ 4 , others ≥ 5 for a clinically significant distress level [3, 9, 11, 12]. In past decades, a cut-off score of 5 was used to select all patients experiencing significant distress [13, 14]. A more recent version of the

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NCCN practice guidelines for the management of distress recommends that a DT score of 4 or higher indicates moderate-to-severe distress [15]. The DT has all requirements including reliability and validity for use in oncology clinical trials [9, 16, 17]. Moreover, from the validation study of the Italian version conducted by Grassi in 2013, it emerged that the cut-off score > 5 of the DT had optimal sensitivity and specificity relative to both Hospital Anxiety and Depression Scales (HADS) and Brief Symptoms Inventory-18 (BSI-18) cut-off scores for general caseness and higher psychological distress, respectively [9]. Furthermore, DT is a very simple but quick-paced tool that is more easily accepted by patients and is preferred in those contexts where there is little time to identify psychological problems. It is expected that regular use of DT may improve the identification of distress in patients with cancer in clinical follow-up [9]. A very important aspect is that it allows the physician to identify possible causes of stress (physical, family, spiritual, emotional, related to practical issues) [18]. Finally, in terms of utility, DT may be a valuable tool to promote and enhance dialog between doctor and patient [11, 19].

In their study, Mitchell et al. [5] highlighted that while 45% of the patients being diagnosed are in a state of psychological distress, according to DT, nurses have difficulty in identifying a distress situation with the sole use of their routine clinical judgment, committing both error sensitivities (false negatives) and fairly specific positives (false positives). These results were confirmed by Werner et al. [20] in a study of over 2600 outpatients with high occurrence of distress but a low level of detection by physicians. Among the causes of underestimation of distress in cancer patients, there is medical attention focused on physical symptoms and the belief of patients that a depressed mood or anxiety are an appropriate cancer response as well as their fear of being stigmatized by the emotional difficulty of being carriers. This situation has important consequences for the quality of life, leading to a low degree of adherence to the treatments, therefore pain and, in extreme cases, suicide [18].

Another interesting topic in the literature is the distribution of psychosocial distress between men and women and in the different types of cancer.

With regard to gender differences, various studies showed that women are more likely to experience distress than men [9, 11]. In particular, Jacobsen et al. [16] showed that with respect to the demographic variables, the score of the DT correlated positively only with the gender, confirming the previous studies to which women are more likely to report levels of psychosocial distress above the limit. According to Grassi et al. [9], this trend was associated with previous psychological disorders and the occurrence of stressful life events other than cancer. Concerning the cancer site, the literature reports greater distress in people with lung cancer, brain cancer, and Hodgkin's disease with relevant results also for breast and

head and neck cancer [10]. From the analysis of Zabora et al. [1] however, it emerged that despite the score of distress in lung cancer patients significantly exceeding the scores of patients with a different cancer site, they were not much higher than those of patients with brain, liver, pancreatic, and head and neck cancer.

On the basis of this theoretical framework, we evaluated the incidence of distress in a sample of hospitalized tumor patients and analyzed the possible correlation between the Distress Thermometer values and the Problem List. But above all, we aimed to identify risk classes for the development of psychosocial distress. In fact, we believe that early detection of the classes of patients at higher risk for emotional distress can help the clinician in therapeutic management, thereby improving the quality of life of patients and reducing medical costs [21].

Methods

Participants

We enrolled adult cancer patients at the National Cancer Research Centre “Giovanni Paolo II” of Bari between May and September 2016 at different stages of active treatment (waiting for diagnosis, hospitalization, surgery treatment, chemotherapy, etc.). Patients were assessed by the Distress Thermometer and Problem List. Participation was voluntary and inclusion criteria were as follows: minimum age 18; being able to understand the Italian language; being admitted to one of the Operative Units of the Institute for cancer treatment; having given consent to participate in the study. The research project was approved by the ethical committee of the institute involved.

Measures

Psychologists administered questionnaires and a copy of compiled DT was inserted inside the nursing folder of the patient, so that it could be directly consulted by the treatment team. Patients scoring 5 or above in the visual analogue scale were regarded as requiring psychological intervention.

The Distress Thermometer is a self-report, pencil and paper measure consisting of a line with a 0–10 scale anchored at the zero point with “No distress” and at scale point 10 with “Extreme distress.” The patient is asked to indicate on a scale from 0 to 10 the level of distress experienced in the last week, so he/she can mark it on the scale. DT was originally developed in 1998 [14] and was validated for screening of cancer patient distress by Mitchell and colleagues in 2011 [5]. In Italy, the first validation took place in 2013, by Grassi and colleagues [9] who confirmed its validity as a screening instrument, as well as its sensitivity and specificity for the investigation of psychosocial distress in cancer patients.

The problem list is an inventory of 36 issues that the patient can discern during the course of care and aims to identify the specific etiology of distress. These issues are divided into five different areas: practical problems, relational problems, emotional problems, spiritual problems, physical problems. The patient answers dichotomically choosing “yes”/“no” to indicate the type of problem experienced in the previous week.

The Eastern Cooperative Oncology Group Performance Status (ECOG PS) [22] is a simple tool that is used by physicians in everyday practice to assess the functional status of patients, with a range from 0 (fully active) to 5 (dead).

Socio-demographic information (age, marital status, presence/absence of children, schooling, profession) and clinical variables (time from diagnosis, tumor location, treatments performed, use of psychopharmaceuticals, comorbidity) were collected through ad hoc record survey.

Statistical methods

The baseline characteristics of the study population were compared according to their distress value using the Pearson χ^2 test for categorical variables and the Mann–Whitney U test for continuous and ordinal variables. The two groups of interest were determined using the median distress score as a cut-off level ($\leq 5, > 5$). Results were expressed in terms of mean \pm standard deviation (sd) and frequencies (%), depending on the nature of variables. The covariate considered were as follows: age, sex (female, male), marital status (single, married, separated, widower); education (illiterate, primary, middle, high, university); diagnosis (waiting for diagnosis, breast, gastric-intestinal, genitourinary, lymphoma, leukemia, myeloma, other); treatment (yes/no); comorbidity (yes/no); ECOG (1,2,3,4). To assess the relations among the diverse variables and recognize internally homogeneous subgroups of patients with different risks of distress, the RECURSIVE Partitioning and Amalgamation (RECPAM) method was used [23, 24]. This method conjugates the return of the main effect of standard regression with the tree-growing techniques. RECPAM grows a tree from a dataset, which is represented by the root node, by recursively splitting. The selected variable at each node (and its best split) is the one with the highest power to discriminate between the two levels ($\leq 5, > 5$) in the result of interest (DS) while adjusting for all the other variables explored. In this study, the minimal number of events and the minimal node size (stopping rules) were set to 15 and 30, respectively. The final leaves, referred to as RECPAM classes, are obtained by a pruning and amalgamation sequence of the initial large tree. The set of variables tested in the RECPAM logistic analysis were the same as tested in the baseline comparison. Patient characteristics according to RECPAM classes were then compared using Kruskal–Wallis test for continuous variables and the Mantel–Haenszel χ^2 test for linear trend for categorical variables. At

last, we ran a multivariate logistic analysis with every other characteristics not entering the tree and the RECPAM classes forced in the model. All the analyses were performed using SAS Language (Release 9.4. Cary, NC, USA). For the RECPAM analyses, we used an SAS macro routine.

Results

A total of 372 patients participated in the study. The mean age was 59.65 (± 13.11) years, and 244 patients (65.59%) were female. Most of them were married (75%) and had high education (34.41%), while the most frequent diagnosis was breast cancer (38.44%) followed by gastro-intestinal cancer (18.01%) and hematological cancer (12.63%). Almost 90% of patients had undergone antineoplastic treatment and ECOG corresponded to 0 in 88% of cases (Table 1).

Distress was present in 43% of the sample, with a total of 156 patients with a DT > 5 .

Patients with higher scores at PL were those with higher distress ($p < 0.05$ for all correlations).

At univariate analysis, only the diagnosis ($p = 0.04$) resulted as being significantly associated with DS (Table 1).

The RECPAM analysis identified three distinct and homogeneous patient subgroups (RECPAM classes) with different risks of distress (Fig. 1). The variable that most of all differentiated the risk of DS was the diagnosis. Going deeper into the logistic tree, the risk was further differentiated on the basis of two other variables: marital status and the ECOG. At the end of the tree-growing algorithm, three RECPAM classes were obtained: the risk progressively decreased from class 1 to class 3 considered as the reference class. In particular, patients with a diagnosis of breast, lung, genitourinary cancer or with lymphoma/leukemia/myeloma and who were married or widowers had the highest risk of DS > 5 (OR = 3.44; 95% CI = 1.85–6.40). Patients with the same diagnosis as the previous ones but who were single or separated exhibited a twofolds higher risk compared with the reference class (OR = 2.02; 95% CI = 1.01–4.05). To the same class of risk belonged patients waiting for a diagnosis or with a diagnosis of gastro-intestinal cancer or other and with an ecog > 0 . The RECPAM classes were also compared in terms of all the clinical characteristics that did not contribute to discriminating between tree subgroups (Fig. 1). Only sex was found to have a significant association with the classes of risk: the first two RECPAM classes had a higher percentage of females compared to the last one ($p < 0.0001$).

Discussion

In our sample, 43% of patients showed distress, a figure similar to that obtained by Bellè et al. [25]: the authors found 41.6% of psychological distress in a sample of 102 onco-

Table 1 Patients' characteristics according to their DT level

Patients' characteristics	Frequency (%) or mean (\pm sd)			<i>p</i>
	Overall	≤ 5 216	> 5 156	
Age (years)	59.65 (\pm 13.11)	60.79 (\pm 12.82)	58.08 (\pm 13.38)	0.07
Sex				
M	128 (34.41)	83 (38.43)	45 (28.85)	0.05
F	244 (65.59)	133 (61.57)	111 (71.15)	
Marital status				
Single	41 (11.05)	27 (12.50)	14 (9.03)	0.56
Married	278 (74.93)	156 (72.22)	122 (78.71)	
Separated/divorced	19 (5.12)	12 (5.56)	7 (4.52)	
Widowed	33 (8.89)	21 (9.72)	12 (7.74)	
Education				
Illiterate	20 (5.38)	7 (3.24)	13 (8.33)	0.06
Primary	71 (19.09)	50 (23.15)	21 (13.46)	
Middle	100 (26.88)	56 (25.93)	44 (28.21)	
High	128 (34.41)	73 (33.80)	55 (35.26)	
University	53 (14.25)	30 (13.89)	23 (14.74)	
Diagnosis				
Waiting for diagnosis	23 (6.18)	17 (7.87)	6 (3.85)	0.04
Breast	143 (38.44)	74 (34.26)	69 (44.23)	
Gastro-intestinal	67 (18.01)	46 (21.30)	21 (13.46)	
Lung	29 (7.8)	15 (6.94)	14 (8.97)	
Genitourinary	35 (9.41)	18 (8.33)	17 (10.90)	
Lymphoma-leukemia-myeloma	47 (12.63)	25 (11.57)	22 (14.10)	
Other	28 (7.53)	21 (9.72)	7 (4.49)	
Treatment				
No	39 (10.48)	22 (10.19)	17 (10.90)	0.82
Yes	333 (89.52)	194 (89.81)	139 (89.10)	
Comorbidity				
No	211 (56.72)	119 (55.09)	92 (58.97)	0.46
Yes	161 (43.28)	97 (44.91)	64 (41.03)	
ECOG				
0	219 (58.87)	135 (62.50)	84 (53.85)	0.29
1	105 (28.23)	59 (27.31)	46 (29.49)	
2	25 (6.72)	10 (4.63)	15 (9.62)	
3	19 (5.11)	10 (4.63)	9 (5.77)	
4	4 (1.08)	2 (0.93)	2 (1.28)	
Time to diagnosis (years)	1.95 (\pm 4.40)	2.08 (\pm 4.89)	1.78 (\pm 3.64)	0.48

hematologic inpatients assessed by Distress Thermometer and Problem List.

Our findings, by the other hand, are quite different from those of previous research (Meggiolaro et al. [26]; Menhert et al. [27]; Grassi et al. [9]). For example, the multicentric Italian study by Grassi highlighted the presence of psychological distress in 57% of patients in a sample of 1108 cancer patients. The previous studies by Meggiolaro and Menhert

showed a higher prevalence compared to our sample (respectively 60% and 52%). Meggiolaro's study found the prevalence of emotional distress of 60% (26.1% mild, 18.8% moderate, and 14.9% severe distress) in a sample of 302 cancer patients from one Middle European (Austria) and two Southern European (Italy, Spain) countries. These differences may depend on the width of the sample, but also on cultural factors.

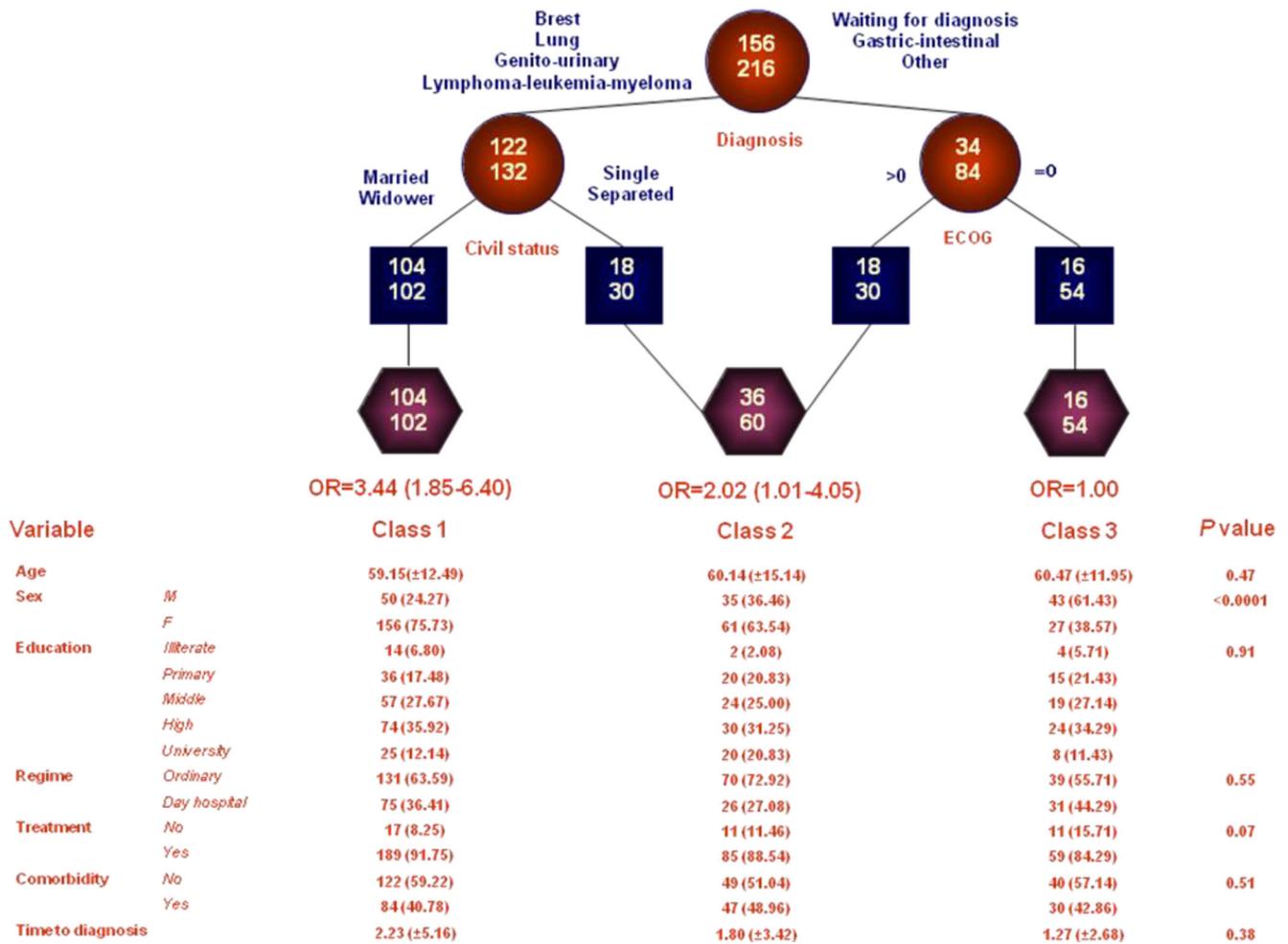


Fig. 1 Classification RECPAM TREE

Anyway, the fact that nearly half of our sample was compromised by distress is evidence of the need to constantly monitor the symptoms of emotional distress, considered as the sixth vital sign.

In line with the study by Grassi [9], in our sample patients with most issues at PL were those with the highest distress.

To our knowledge, this is the first study identifying a risk class for distress in a split of hospitalized cancer patients, using the RECPAM method.

The first aim of our study was to recognize risk factors for distress in a sample of cancer patients and our results showed that patients with a diagnosis of breast, lung, genitourinary or hematological cancer and who were married or widowers had the highest risk for Distress > 5.

Concerning the diagnosis, Menhert and colleagues [27] found higher distress in breast cancer patients, confirming our results, and even the study by Grassi [9] showed that the DT score was related to the diagnosis of breast cancer [27].

Menhert et al. [3] found lower distress in lung cancer patients, while in our sample having lung cancer is one of

the variables present in the risk class for distress. Previous research on lung cancer patients demonstrated that their level of distress usually exceeds that of other patients with cancer due to negative physical and psychosocial factors. Zabora and colleagues [1] found in a great sample of cancer patients, that those affected by lung cancer reported the highest prevalence of distress compared with patients with other cancer sites, at a rate of 43.4%. The authors identified patients with lung cancer as a “truly high-risk” group for distress.

Moreover, in our class of risk, the diagnosis of hematological cancer is also present and this data is supported by the results of an Italian study by Bellè [25] that found distress in 41.6% of a sample of onco-hematologic patients.

Among other study variables, only sex showed a positive association with the risk class: in fact, there were more women than men, in the first two classes of risk. This result is in line with many scientific findings regarding greater vulnerability to psychological distress in women compared to men [1, 9, 26–29]. For example, Menhert’s [27] study showed significantly higher levels of psychosocial distress in women in a

sample of 3724 cancer patients. These results are in agreement with those of other studies, such as the Italian multicenter one conducted by Grassi [9] in a cancer population of 1108 patients. The European study of Meggiolaro [26] also confirmed higher levels of distress in female cancer patients in a sample of 302 patients.

The causes of these gender differences in psychosocial distress levels are not yet known; however, it could be hypothesized that they are due to the use of emotional coping style by women [30, 31]. Or even to a difference between man and woman to denounce psychological distress; or again, it could be linked to biological, social, and demographic differences.

Another variable that appeared in the risk class is related to marital status: married or widowed patients were at greater risk for developing psychosocial distress. A possible explanation for this is that married patients are emotionally charged with the possible suffering that their illness sparks in their spouse. In fact, it is well recognized that cancer is not just an individual disease, but involves the entire family. In addition, in clinical practice, we often observe a sense of guilt linked to this concern: “how will my spouse react? How can I protect him/her from my suffering?”. Moreover, married patients also have responsibilities and practical or economic tasks towards their family and spouse, who are intrinsically in the civil status, and which they often cannot fulfill due to their illness. In this regard, for example, Iacorossi et al. [32] found higher scores at DT in married women, especially in the practical areas.

Widowed patients, on the contrary, may more often suffer from feelings of loneliness, which are added to the suffering associated with cancer diagnosis and therapies increasing their distress. In addition, patients often have to deal with family and/or social responsibilities by themselves, and which were previously shared with their spouse. Berhili and colleagues [33] found in a sample of Moroccan breast cancer patients that not having social support from the family was associated with DT.

Having identified a risk class for the development of distress, it seems very important to provide physicians with a more accurate observation lens of their patients. If the use of DT was performed on a daily basis and extended to all patients, the care team would have a more effective, quick, and efficient tool to identify those most in need of evaluation and/or also psychological intervention.

This kind of assessment would allow a more rapid and adequate intervention by the psychologist and also the more timely start of psychological support or psychotherapy.

The limitations of the present study are first of all the lack of a control group; secondly, the cross-sectional nature of the research design and therefore the lack of a longitudinal observation of the course of the psychosocial distress in the disease trajectory.

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Compliance with ethical standards

Conflict of interest Authors declare to have not a financial relationship with the organization that sponsored the research. Authors state to have full control of all primary data and they agree to allow the journal to review their data if requested.

Statement of human rights All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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