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The study of cancer patients' distress

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Background. Distress of cancer patients is often left unnoticed and it induces various problems: it is harder for patients to adjust to the illness, the quality of life is poorer, it causes much distress for the team of oncologists. 1 year before in the VU Institute of Oncology the Distress Thermometer was started to be used for all patients in the hospital.

Purpose. To explore distress prevalence and features of cancer patients' in the hospital.

Participants and methods. There were 488 participants. The Distress Thermometer (DT) was used to evaluate distress of the participants. DT consists of a Likert type scale from 0 to 10 that assesses the strength of experienced distress, and a problem list that includes practical, family, emotional, spiritual and physical problem groups.

Results. The mean score of distress of all participants was 3.47 (SD = 2.47). 82% of participants pointed from 0 to 5 scores, 18% of participants indicated from 6 to 10 scores. There was a statistically significant correlation between the distress score and the number of problems ($r = 0.43$, $p < 0.01$). The mean number of problems was 1.95 (SD = 2.60). The most frequent problems were anxiety (31.6%), fears (20.5%), fatigue (16.8%), nervousness (15.2%), etc. The mean score of women distress (4.07) was significantly higher than that of men (2.68) ($p < 0.001$). The younger the participants, the higher the distress was ($r = -0.13$, $p < 0.01$). The patients of surgical treatment pointed higher distress ($M = 3.98$) than the patients of therapeutic treatment ($M = 2.51$) ($p < 0.01$).

Conclusions. 1/5 of patients experience high distress. Women experience higher distress and problems than men. Patients in surgical treatment experience higher distress and emotional problems than patients in therapeutic treatment. DT is a very optimal method to assess the distress of cancer patients but the results need to be cautiously evaluated.

Key words: distress, Distress Thermometer, cancer patients

INTRODUCTION

Distress of cancer patients is called “a multifactorial unpleasant emotional experience of a psychologi-

cal, social, and / or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment” (NCCN, 2005). The prevalence of distress among cancer patients is big: up to 50% of patients experience psychiatric illnesses such as adjustment disorders, delirium, depression (4), they experience strong emotions that are just a normal reaction to the crisis

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although it itself is still a distress. This distress can cause other problems such as harder adjustment to the illness and treatment, more visits to the doctors; it causes more stress to the team of oncologists (4); patients are less satisfied with treatment and the team of oncologists (13); patients with higher distress have poorer quality of life (9); some studies show that patients with higher distress have shorter life duration (11).

During the last decades the psychological well-being of cancer patients is often discussed. Often patients experience cancer as a traumatic event. For this reason there are a lot of methodological issues discussed about how to inform patients about their illness, how to notice some signs of psychological distress of patients. Still there are some evidence that often distress of cancer patients is left unnoticed by oncologists (1). As a consequence, some independent methods evaluating distress of people with cancer are being used.

One of the most widely used methods is the Distress Thermometer (DT) (NCCN, 2005). The task of the method is to select patients who experience heightened levels of distress and give psychological help that could lessen such a psychological state. Before one year the DT was started to be used in the Vilnius University Institute of Oncology. It is the first and still the only hospital in Lithuania where such an instrument is applied for all patients in the hospital. Therefore, in our study we analyze the prevalence and peculiarities of distress of cancer patients in the VU Institute of Oncology.

MATERIALS AND METHODS

Participants. There were 488 participants in our study. The minimum age was 18 and the maximum age was 85. Participants were collected by conven-

ient sample formation from different departments of the hospital. All of the departments were divided in two broader groups: surgical and therapeutic treatment. The main characteristics of the participants are presented in Table 1.

Distress. Distress was evaluated using the Distress Thermometer (DT) (NCCN, 2005). The method consists of a Likert type scale from 0 to 10 that assesses the strength of experienced distress, and a problem list that includes practical, family, emotional, spiritual and physical problem groups. Patients assess the strength of experienced distress and mark the problems they confronted during the last week. In reference to the National Comprehensive Cancer Network (2005) (5), the score 6 and above show heightened distress that needs further evaluation and psychological help.

In the VU Institute of Oncology the DT is given by nurses to all patients that get into the hospital. Before application of the DT nurses were briefly trained and explained how to apply the method. In our hospital psychological help is given to everyone who points the score 7 and above.

Demographic characteristics and information about the illness were collected from the case histories.

All the data was collected in February and March of 2014, after 8 months of DT application in the hospital. The data was not collected every day, but when it was collected then from all the patients that get into the hospital on that particular day.

Statistical analysis. The statistical analysis was performed using SPSS 17. Using the Shapiro-Wilk normality test we found that distress data is not distributed normally ($p < 0.001$). So we used non-parametric tests. The descriptive statistics was calculated. The differences of the mean values of the

Table 1. Participant distribution by gender, mode of treatment and age

	N	Age	
		M	SD
Gender			
Male	210 (43%)	65	11.10
Female	278 (57%)	59	13.50
Mode of treatment			
Surgical	317 (65%)	62	13.62
Therapeutic	171 (35%)	62	11.11
All cases	488	62	12.79

variables were tested with the Mann-Whitney U test and for calculating correlations the Spearman's correlation coefficient was used.

RESULTS

The mean score of the Distress Thermometer of all the participants was 3.47 (SD = 2.47). The most frequent score was 3, 2, 5, 0, etc. The frequency of the scores is presented in Table 2.

Table 2. The frequency of Distress Thermometer (DT) scores

The score of Distress Thermometer (DT)	Frequency, %
0	12.1
1	9.6
2	16.6
3	19.7
4	11.5
5	12.5
6	4.3
7	4.5
8	5.3
9	2.3
10	1.6
All scores	100

There was a significant correlation between the score of distress and the number of problems ($r = 0.43$, $p < 0.01$) which means that the more problems the higher the distress. The mean number of the problems was 1.95 (SD = 2.60). The most frequent problems were the following: 1) anxiety (31.6% of participants); 2) fears (20.5%); 3) fatigue (16.8%); 4) nervousness (15.2%); 5) sleep (14.8%); 6) sadness (10.5%); 7) pain (8%). None of the par-

ticipants pointed having spiritual / religious problems.

Further we compared the distress by gender. The mean score of women distress (M = 4.07) was significantly higher than that of men (M = 2.68) ($p < 0.001$). In all problem groups women pointed more problems than men. Results of the gender difference of distress is presented in Table 3. Also we found that the younger the patients the higher the distress ($r = -0.13$, $p < 0.01$).

Furthermore, we compared distress in different age groups. With reference to psychological development of the person (8) we distributed the participants into three age groups: young age patients (18–34 years), middle age patients (35–59 years) and old age patients (60–85 years). However, there were only 17 young age cases, so we did not include them in this stage of the study and compared only two age groups. There were 168 patients of middle age and 303 patients of old age. Middle age patients' distress (M = 4.00, SD = 2.77) was significantly higher than that of old age (M = 3.13, SD = 2.23) ($p < 0.001$). Patients in the middle age group pointed significantly more problems in all their groups, except physical problems, than old age patients. Results are presented in Table 4.

The mean score of distress among the patients in surgical treatment (M = 3.98, SD = 2.56) was significantly higher than among the patients in therapeutic treatment (M = 2.51, SD = 1.97) ($p < 0.01$). There was no significant difference of the number of problems in these two groups. However, the patients in surgical treatment pointed significantly more emotional problems than the patients in therapeutic treatment and the patients in therapeutic treatment pointed significantly more physical problems compared to the patients in surgical treatment. These results are presented in Table 5.

Table 3. Mean score of distress and problems by gender

	Men (N = 210)	Women (N = 278)	Statistical significance
	M	M	p
DT score	2.68	4.07	$p < 0.001$
Number of problems	1.33	2.42	$p < 0.001$
Practical problems	0.07	0.17	$p < 0.01$
Family problems	0.02	0.08	$p < 0.001$
Emotional problems	0.50	1.08	$p < 0.001$
Physical problems	0.74	1.09	$p < 0.01$

Finally, we compared problems in two groups of different distress levels. In the VU Institute of Oncology the score 7 is the lowest score from which the psychologist visits the patient. For this reason, we decided to compare problems in the group of patients with distress from 0 to 6, which we call lower distress, and in the group of patients with distress from 7 to 10, which we call higher distress.

There were only 67 patients, which is 13.7% of all our sample, that pointed their distress level 7 and above. The rest participants pointed the score from 0 to 6. It was found that the patients of higher distress group pointed significantly more problems

in all their groups. Results are presented in Table 6. However, a significant positive correlation between the distress score and the number of problems was found only in the group of patients with lower distress ($r = 0.36$, $p < 0.001$), and such correlation was not found in the group of patients with higher distress.

DISCUSSION

In our study, we got the mean score of cancer patients' distress similar to results of other studies in other countries (2, 10). There are also some stud-

Table 4. Distress and problem groups in middle and old age group participants

	Middle age group participants (N = 168)		Old age group participants (N = 303)		Statistical significance
	M	SD	M	SD	p
DT score	4.00	2.77	3.13	2.23	$p < 0.001$
Number of problems	2.38	2.82	1.69	2.46	$p < 0.01$
Practical problems	0.24	0.53	0.04	0.20	$p < 0.001$
Family problems	0.10	0.30	0.02	0.14	$p < 0.01$
Emotional problems	1.09	1.34	0.68	1.16	$p < 0.01$
Physical problems	0.95	1.64	0.94	1.64	$p > 0.05$

Table 5. Distress of patients in surgical and therapeutic treatment

	Surgical treatment participants (N = 317)		Therapeutic treatment participants (N = 171)		Statistical significance
	M	SD	M	SD	p
DT score	3.98	2.56	2.51	1.97	$p < 0.01$
Number of problems	1.94	2.72	1.98	2.35	$p > 0.05$
Practical problems	0.14	0.39	0.11	0.38	$p > 0.05$
Family problems	0.07	0.25	0.04	0.18	$p > 0.05$
Emotional problems	0.94	1.30	0.63	1.10	$p < 0.01$
Physical problems	0.80	1.67	1.20	1.53	$p < 0.01$

Table 6. Problems of patients with higher and lower distress scores

	Higher distress participants group (N = 67)		Lower distress participants group (N = 421)		Statistical significance
	M	SD	M	SD	p
Number of problems	4.36	3.71	1.57	2.14	$p < 0.001$
Practical problems	0.34	0.64	0.09	0.31	$p < 0.01$
Family problems	0.19	0.40	0.03	0.18	$p < 0.01$
Emotional problems	2.04	1.65	0.64	1.03	$p < 0.001$
Physical problems	1.78	2.30	0.81	1.50	$p < 0.01$

ies showing a higher mean distress score and other studies showing that higher distress is more prevalent among cancer patients than we got in our study (3). One of the reasons could be that it is not clear how the Distress Thermometer is being presented and applied for patients in the VU Institute of Oncology that could easily distort the results.

We got that women experience higher level of distress and more problems than men. This also coincides with other studies of foreign countries (7, 12). This could not only be that men experience less distress than women but also could be associated with the ability and willingness to express it.

Cancer patients in surgical treatment experience much higher distress than patients in therapeutic treatment. Often patients get surgical treatment in the beginning of the illness, sometimes they still do not know about the illness. So in such cases the patient is still getting used to the illness and all the emotions are very alive and intense. This overlaps with our finding that patients in surgical treatment experience more emotional problems than patients in therapeutic treatment.

Finally, our study showed that patients who experience high level of distress also experience more problems. In the lower distress participants group we also got a significant positive correlation between the distress score and the number of problems, however, we did not get it in the higher distress participants' group. We could think that patients experiencing high distress cannot think rationally about their problems and cannot evaluate them – whether they have them or not. The psychic is occupied with emotions, such as anxiety and fears, and there might be not much space left for thinking.

All in all, the Distress Thermometer is a very valuable method to use in the VU Institute of Oncology to optimally assess cancer patients' distress. However, this is not a sufficient method to evaluate psychological or any other state of the patient. One can point a high score but no problems because of his flooding emotional state and the other can point a relatively low score but be preoccupied and therefore psychologically intense because of his many problems.

CONCLUSIONS

1. 1/5 of the participants evaluated experienced distress for 6 and more scores. The mean distress

score of patients in the VU Institute of Oncology was 3.47. The higher the score the more problems were marked.

2. Women experienced higher degree of distress. The younger the patients the higher the distress score and the more problems.

3. The mean distress score of patients in surgical treatment was higher than in therapeutic treatment. The participants in surgical treatment marked more emotional problems than in therapeutic treatment and the participants in therapeutic treatment marked more physical problems than in surgical treatment.

4. Higher distress participants' group experience more problems. Also, in the lower distress participants' group the higher the distress score the more problems.

Limitations

There are some limitations of the study. First, we do not know how DT is being applied in the hospital as it is applied by a lot of nurses. Second, we do not know who is eventually filling the DT and what we measure – whether it is a patient, whether relatives, who are willing to give help for the patient, but then they evaluate some kind of their distress. Third, the concept of distress is still not very clear. Patients can understand it differently. It overlaps with the concept of stress but it is not the same as, for example, sadness is also a part of distress. Finally, it is very important to take into account the type of the illness which we could not make in our study.

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ONKOLOGINIŲ PACIENTŲ PATIRIAMO DISTRESO TYRIMAS

Santrauka

Įvadas. Onkologinių pacientų distresas dažnai lieka nepastebėtas ir tai gali sukelti įvairių sunkumų: pacientai sunkiau prisitaiko prie ligos, prastėja jų gyvenimo kokybė, tokia pacientų būklė sukelia didesnę distresą ir onkologų komandai. Prieš vienerius metus Vilniaus universiteto Onkologijos institute visiems besigydantiems pacientams buvo pradėtas naudoti Distreso termometras.

Tikslas. Ištirti onkologinių pacientų distreso paplitimą ir jo ypatumus.

Tiriamieji ir metodika. Iš viso dalyvavo 488 tiriamieji. Pacientų distresui įvertinti naudotas Distreso termometras (DT). DT sudaro Likerto tipo skalė nuo 0 iki 10, kuria vertinamas patiriamas distreso stiprumas, ir praktinių, šeimos, emocinių, dvasinių ir fizinių problemų grupių sąrašas.

Rezultatai. Visų tiriamųjų distreso balo vidurkis buvo 3,47 (SD = 2,47). 82 % tiriamųjų nurodė distreso balą nuo 0 iki 5, likę 18 % tiriamųjų nurodė balą nuo 6 iki 10. Rasta statistiškai reikšminga koreliacija tarp distreso balo ir problemų skaičiaus ($r = 0,43$; $p < 0,01$). Vidutinis problemų skaičius – 1,95 (SD = 2,60). Dažniausiai buvo patiriamas nerimas (31,6 %), baimė (20,5 %), nuovargis (16,8 %), nervingumas (15,2 %) ir kt. Moterų vidutinis distreso balas (4,07) buvo reikšmingai didesnis nei vyrų (2,68) ($p < 0,001$). Kuo jaunesni pacientai, tuo stipresnis distresas ($r = -0,13$; $p < 0,01$). Chirurgiškai gydyti tiriamieji patyrė stipresnę distresą ($M = 3,98$) nei tiriamieji, kuriems buvo taikytas terapinis gydymas ($M = 2,51$) ($p < 0,01$).

Išvados. 1/5 pacientų patyrė stiprų distresą. Moterų distresas buvo stipresnis ir jos turėjo daugiau problemų nei vyrai. Chirurgiškai gydyti tiriamieji patyrė stipresnę distresą ir turėjo daugiau emocinių problemų nei terapinio gydymo pacientai. DT yra efektyvus metodas nustatant pacientų distresą, tačiau rezultatus reikėtų vertinti atidžiai.

Raktažodžiai: distresas, Distreso termometras, onkologiniai pacientai