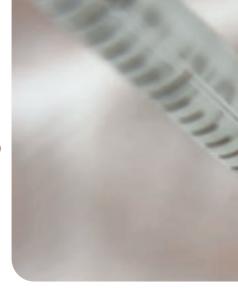
**Courses and directions** 

### THE MEASURE OF DISTRESS

# A practical thermometer for outpatient screening

Sandie Larouche, BScN, MScN and Linda Edgar, N, PhD



### Top-line summary

It is well known that the diagnosis of cancer and its treatments cause both physical and emotional suffering that hugely affect quality of life. Ways to efficiently evaluate levels and types of distress are needed to help mobilize those resources that will best serve the needs of people with cancer.

This article presents research conducted in 2 Montréal oncology outpatient clinics on the "Distress Thermometer," a tool specifically designed to screen patient distress. The researchers analyzed patient self-reports, compared assessments done by nurses with those of their patients, and evaluated the tool's suitability for use in an outpatient care setting via focus groups of oncology nurses. "Significant" distress was identified in 32% of patients; severity correlated with the number of specific concerns noted. The tool helped nurses and other caregivers identify important areas on which to focus care. Because it is brief, valid, practical and cost-effective, its implementation into routine usage appears feasible.

Reports of distress among cancer patients in outpatient settings place its prevalence at between 28% and 35%.<sup>1-4</sup> Further, as many as 30% of cancer patients also develop signs and symptoms of clinical depression.<sup>5-7</sup>

Although many patients do not meet the criteria for a diagnosis of major depression,1,7,8 they nevertheless are suffering.9 A 1999 survey carried out at the European Institute of Oncology in Milan found that 35% of cancer patients experienced significant distress but only 2% were referred for consultation.10 It been demonstrated that unresolved distress is linked to late-onset anxiety and depressive disorders11,12 and that consequent mood disorders associated with under-treated distress interfere with quality of life and treatment compliance.3,13 A recent study reported that depression and depressive symptoms identified in cancer patients within 5-17 months after diagnosis predicted increased mortality, highlighting the importance of regular screening of all patients.14

#### **UNDERTREATMENT OF DISTRESS**

Cancer care has shifted in recent years from an inpatient to an ambulatory outpatient setting, where oncology professionals are required to deliver quality care in a shorter period of time.<sup>15</sup> Nurses and physicians are increasingly called up to prioritize patient needs — especially in matters

related to chemotherapy administration — and they report spending less time managing psychosocial issues.<sup>5</sup> As a result of these constraints, patients are often reluctant to share feelings of distress with their team members.<sup>16</sup> Further, many nurses and physicians have conventionally been reluctant to delve into patients' emotional states for 2 main reasons: they believe that doing so would consume time and resources beyond their means, and they assume that a degree of distress is considered normal.

Some aspects of emotional distress such as anxiety are more easily identified than others. Anxiety and depression, however, may contribute only minimally to patient-reported distress.<sup>17</sup> A United Kingdom study in outpatient settings found that physicians failed to accurately assess the psychosocial status of 35% of patients, compared to the results obtained by a validated screening tool.18 The correlation between a patient's assessment of distress and that of the healthcare team (doctors and nurses) has been reported as low as from 0.21 to 0.5 (Pearson's correlation coefficient).17

#### THE DISTRESS THERMOMETER

Given limitations of time, one solution is to introduce a concise tool into regular practice that enables rapid screening of patients' distress and facilitates communication about the distress and its sources between patient and the oncology team. As the word "distress"

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translation method until the French version was judged by a bilingual panel of healthcare workers to accurately

reflect the English version and vice-versa.

**Barriers to implementation** 

Although a brief, valid and reliable screening tool for distress is critically needed, introducing the DT into standard clinical oncology practice is a challenge. Screening scales are generally viewed as being time-consuming and as offering unclear benefits. The notion that patients can well recognize their own distress is relatively new, as is awareness that they frequently seek out appropriate means and resources to cope with it.<sup>20</sup>

Strategies are needed to encourage and support the medical and nursing staff to use the DT. Making a change in clinical practice involves a cultural and a philosophical shift. We tend to give lip service to the responsibility that patients have for their own health and wellbeing but still regard ourselves, as the caregivers, as being better able to furnish advice and direction. Success in introducing change is more likely if the innovation is simple, practical, non-intrusive, has readily observable benefits and outcomes, and fits within the norms and culture of the setting.<sup>21</sup>

### **DESIGN FOR IMPLEMENTATION**

This study's purpose was to examine the outcomes of introducing the DT into outpatient oncology settings and to answer specific questions:

- What are the distress levels and their causes in a sample of outpatients?
- Is there a relationship between distress levels, concerns, and age, gender and cancer type?
- How well do distress levels and concerns reported by patients correlate with assessments done by their nurses?
- What advantages and disadvantages result from using the DT in the clinical setting?

The 4-week study was conducted in the outpatient medical- and radiooncology clinics of 2 teaching hospitals in Montréal, Québec. Approved by internal review and ethics committees at both hospitals, it comprised:

 a convenience survey of patients to provide knowledge of levels of distress • a survey of nurse–patient dyads to examine congruence between their judgments of distress

**CONTINUING CARE** 

 focus groups of clinic nurses to explore the feasibility and utility of the DT

Our approach was partly based on the McGill conceptual model of nursing,<sup>22</sup> which advocates that patients share responsibility for their health with their healthcare teams by jointly identifying and focusing on the strengths of the patient and family. We conjectured that patients would themselves recognize their level and source(s) of distress and in many instances could take steps to prevent its escalation. Cognitive and behavioural therapy recognize that putting a label on a behaviour is one of the first steps in changing it.23 Patients would actively help the healthcare team to assess their distress and, subsequently, manage their own care appropriately, with the ultimate goal of coping well with their illness.

#### **Data collection**

English- and French-speaking patients with a confirmed malignancy were approached to participate by one of

### The 6th Vital Sign

The Council of the Canadian Strategy for Cancer Control endorsed the concept of screening for emotional distress as the "6th Vital Sign" in May, 2004 based on review of the position paper of the Rebalance Focus Action Group. Pain as the 5th Vital Sign was also endorsed. The council noted that lack of systematic assessment is the main reason that only a minority of patients who need psychosocial and supportive care services actually obtain them. For more information see www.cancer control.org (go to Publications, CSCC Bulletin Volume 7, June 2004 and supplement).

carries little stigma, and because most people consider that these feelings are normal consequences after being diagnosed, a multidisciplinary panel of the National Comprehensive Cancer Network developed a self-reporting visual analog scale called the "Distress Thermometer" (DT) in 1999. The panel defined distress as:

an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment, which extends along a continuum from common normal feelings of vulnerability, sadness, and fear, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis.

Visual analog scales are in common use to measure pain, fatigue and physical health, realms in which they have demonstrated good psychometrics and responsiveness to change.

The DT measures distress from 0 (none) to 10 (extreme). The midpoint of 5 indicates moderate distress, and has a high concordance rate with cutoff scores on the Hospital Anxiety and Distress Scale (HADS).<sup>17</sup> Validation of the DT has been acceptable so far, and more studies are expected to confirm this.<sup>1,17</sup> The tool is available online at www.nccn.org/professionals/ physician gls/PDF/distress.pdf.

Patients rate their distress level and then identify causes by checking from a list of 36 items divided into 6 subcategories of problems: physical, family, emotional, spiritual/religious, informational and practical. The tool takes approximately 3–4 minutes to complete. It was translated into French for our study using the back and forward

**TABLE 1. Distress scores** 

Distress intensity	n	%
Low (0-3)	102	45.5
Moderate (4—7)	98	43.8
High (8–10)	24	10.7

the clinic's volunteers or a research assistant, in either the waiting or treatment room. After learning about the study, agreeing to it and signing the consent form, patients were asked to complete the DT, which provided the main data on distress levels and specific concerns. Those who scored  $\geq 5$  were referred to one of the oncology clinic nurses for further assessment and intervention as appropriate.<sup>19</sup>

To obtain data on nurse–patient dyads, during 1 week of the study the research assistant asked patients who were to be followed by certain oncology nurses to complete the DT before the meeting. The nurses completed the DT directly after the meeting or interaction with that patient. At the end of the day, the nurses were given the patients' scores. Following this data collection phase, we carried out focus groups

with the nurses to evaluate the feasibility and usefulness of the Distress Thermometer as a screening tool.

Demographics, specific concerns and distress level were first analyzed by calculating means and standard deviations (SDs). Student's t-test was used to establish whether the mean of 2 parameters differed significantly. Univariate regression analysis assessed the relationship between the level of distress and each of the parameters. Statistical significance was set at 0.05 for all analyses.

### STUDY RESULTS Patient self-reports

We report the results of 224 completed questionnaires, a response rate of 23%. A total of 957 patients attended the oncology clinics during the data collection phase in the spring of 2002. The low response rate was primarily due to the amount of time needed to fulfill the informed consent process, which left insufficient time to also complete the DT before the patient was seen by the clinic team. Further, there were not always enough volunteers available during peak periods to approach every patient. Some potential subjects were not in the waiting rooms long enough to receive or complete the questionnaire. Fewer than 10 patients (< 5%) actually refused, however.

The mean age of the patient sample was 57.2 years (SD  $\pm$  12.9); 70% (n = 157) were female and 30% (n = 67) were male. A total of 155 (69%) subjects spoke English; 69 (31%) spoke French. They represented a diverse range of cancer diagnoses including breast cancer (n = 86), lymphoma (n = 25), gynecologic (n = 17), lung (n = 16) and colon (n = 16) cancers. The mean time since diagnosis until completion of the Distress Thermometer was 30.8 months (range 1-362 months). (Complete demographic information is available from the authors.)

**Table 1** shows the overall distribution of distress scores. The mean level of distress for the sample was  $4.0 \, (\text{SD} \pm 3.0)$ . Seventy-one patients (31.7%) scored above 5.0 on the scale. The most distressed diagnostic groups were those with gynecologic and colon cancers, reporting average distress scores of  $5.0 \, (\text{SD} \pm 2.0)$  and  $5.0 \, (\text{SD} \pm 2.4)$ , respectively, followed by lung  $(4.0, \text{SD} \pm 3.0)$ , breast  $(4.0, \text{SD} \pm 2.8)$  and gastrointestinal  $(4.0, \text{SD} \pm 2.7) \, (\text{Table 2})$ . Respondents identified an average of  $5.0 \, (\text{SD} \pm 4.2)$  concerns; worry was the most frequent followed by fatigue

TABLE 2. Level of distress and concerns distribution by diagnosis

Cancer type	Level of distress	Total no. concerns	Physical problems	Family problems	Emotional problems	Information problems	Practical problems	Spiritual problems
	mean ± SD	n	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Breast	4 ± 2.8	384	214 (55.7%)	16 (4.2%)	101 (26.3%)	26 (6.8%)	20 (5.2%)	7 (1.8%)
Gynaecologic	5 ± 2.1	130	87 (66.9%)	6 (4.6%)	27 (20.8%)	3 (2.3%)	6 (4.6%)	1 (0.8%)
Colon	5 ± 2.5	70	46 (65.8%)	2 (2.9%)	14 (20.0%)	2 (2.9%)	2 (2.9%)	4 (5.7%)
Lung	$4 \pm 3.0$	98	54 (55.1%)	1 (1%)	24 (24.5%)	4 (4.1%)	12 (12.2%)	3 (3.1%)
Head and neck	4 ± 2.9	31	20 (64.5%)	1 (3.2%)	8 (25.8%)	1 (3.2%)	1 (3.2%)	0 (0%)
Gastrointestinal	$4 \pm 2.7$	46	30 (65.2%)	1 (2.2%)	10 (21.8%)	1 (2.2%)	2 (4.3%)	2 (4.3%)
Brain and CNS	$4 \pm 3.1$	14	10 (71.%)	1 (7.4%)	3 (21.4%)	0 (0%)	0 (0%)	0 (0%)
Genitourinary	4 ± 2.6	32	17 (53.1%)	1 (3.1%)	8 (25.0%)	5 (15.6%)	1 (3.1%)	0 (0%)
Hematalogic	$3 \pm 2.8$	204	119 (58.3%)	9 (4.4%)	46 (22.5%)	7 (3.4%)	16 (7.8%)	7 (3.4%)
Melanoma	$3 \pm 3.4$	62	28 (45.2%)	5 (8.1%)	17 (27.4%)	3 (4.8%)	5 (8.1%)	4 (6.5%)
Others	6 ± 3.7	22	13 (59.1%)	1 (4.5%)	4 (18.2%)	2 (9.1%)	0 (0%)	2 (9.1%)
Totals		1093	638	44	262	54	65	30

and nervousness (**Table 3**, page 38). Pain was listed as a concern contributing to distress by 19% of the respondents. No relationship was found between distress and gender (P > 0.05), time since diagnosis (P > 0.05) or age (P > 0.05). In contrast, the correlation between level of distress and the numbers of concerns patients reported was significant (R = 0.66, P < 0.01).

#### Nurse vs patient reports

We obtained data on 20 nurse–patient dyads, involving 6 nurses and 20 patients. The nurses agreed 34% of the time with the patients' distress ratings. There was a tendency to underestimate rather than overestimate the distress: patients checked 162 concerns while nurses checked 70. The greatest agreement occurred in the area of physical concerns, particularly fatigue, followed by the specific emotional concern of worry.

### Nurses' evaluation of the process

Two focus groups were held with 8 nurses in total. We asked whether they found the tool useful and solicited feedback to identify its strengths and weaknesses. An overriding observation was "Patients tend to report more concerns in writing than they do verbally to nurses." An important benefit noted was "It will prevent patients who are less talkative or not well known by the healthcare team from falling through the cracks of the system." Key points arising from the focus group discussions are highlighted in the box.

A major consideration was how to ensure that DTs were distributed to participants and returned to the nurses in time for their meeting with the patient. Should volunteers administer the DT? Could it be handed out by the clinic receptionist or secretary? Should patients bring their completed form to the meeting with the nurse? If the patient did not see his or her nurse that day, who would review it? Would the patients then be instructed to give it to the physician? The nurses agreed that oncology-trained volunteers or clinic receptionists were suitable and well able to encourage patients to fill out the DT. Clinically, we have

### Focus group summary

Two groups of oncology nurses gave the following key feed-back points on the pros and cons of the Distress Thermometer.

- After reviewing the checked concerns, some nurses asked their patients
  why they had not verbalized their feelings in the past. The most common
  response: patients simply did not want to disturb the nurses because they
  appeared to be too busy.
- Patients often "perform" in front of their healthcare providers and thus under-report distress. As one nurse stated, "Many patients are not even capable of verbalizing their feelings, never mind be aware of them. And when they are, not many choose to verbally put their feelings out there on the table." Another comment was that "patients who completed the questionnaires tended to be more honest than when directly asked about how they are doing."
- There was agreement that nurses, "are frequently so busy that we have no time to explore the needs of our patients the Distress Thermometer allows us to directly focus on the concerns the patients noted."
- The nurses reported being more accurate in identifying the distress levels
  and concerns of patients with whom they spent more time, and that discrepant
  assessments occurred when patients came for very brief visits, received short
  treatments or arrived during peak clinic times.
- Nurses were surprised about some of the concerns listed and found it helpful
  to explore the missed items with patients. The nurses agreed that DT was
  "needed" in their practice, and felt able to discuss patients' concerns with them.
- Most shared a favourable view of the distress questionnaire's structure: "rapid, short, and easy to complete, all a good match for these patients attending these clinics who are very ill and don't have enough energy to fill out lengthy questionnaires."
- Nurses expressed little apprehension about identifying concerns requiring resources not available to them.

found that administering it about every 3 months to a given patient is a reasonable time frame.

#### **OBSERVATIONS**

Our results regarding the prevalence of distress and its causes were similar to those found in other studies, whether or not the DT was used. 1-4-24 Combining emotional, family information, practical and spiritual problems into 1 category yielded 455 (42%) non-physical problems, compared to a total of 638 (58%) physical problems. Thus, while physical problems predominated, emotional-

type concerns were an important contributor to distress. Some important observations for clinical practice include:

- Our finding that fatigue, loss of energy and worry are the most frequent concerns has important implications for oncology healthcare providers, as many approaches are available to alleviate these symptoms.<sup>25-27</sup>
- The total number of concerns checked by a patient strongly predicted his or her level of distress while age, gender and time since diagnosis did not.

**TABLE 3. Concerns reported overall (n = 1093)** 

Concern	Patients	reporting*	Concern	Patients reporting <sup>†</sup>	
	n	%		n	%
Physical problems			Emotional problems		
fatigue	105	46.8	worry	112	50.0
skin dry/itchy	54	24.0	nervous	61	27.1
sleep	49	21.8	sadness	53	23.6
constipation/diarrhea	44	19.6	depression	36	16.0
pain	43	19.1			
hair loss	42	18.7	Spiritual problems		
getting around	37	16.4	related to God	24	10.7
eating	34	15.1	loss of faith	6	2.7
nose dry/congestion	31	13.8			
nausea	30	13.3	Information problems		
tingling of hands/feet	29	12.9	information/too much/too little	22	9.8
feeling swollen	28	12.4	information confusing	17	7.6
change in urination	24	10.7	information incomplete	15	6.7
breathing	23	10.2			
indigestion	19	8.4	Practical problems		
sexual problems	18	8.0	work/school	30	13.3
bathing/dressing	12	5.3	transport	14	6.2
mouth sores	11	4.9	childcare	8	3.6
fever	5	2.2	housing	7	3.1
			insurances	6	2.7
Family problems					
dealing with partner	25	11.2	Other problems <sup>†</sup>	10	4.4
dealing with child	19	8.4			

<sup>\*</sup> Number and % of patients that checked this concern as the cause of their distress.

- Focusing on the results of the DT may be a good starting point for discussion with patients and may minimize the natural tendency of healthcare staff to categorize patients by age, gender or cancer stage.
- Helping patients cope with one problem at a time may reduce distress.
- Completing the Distress Thermometer seemed to help restore a sense of personal control for the patients and encouraged them to feel that they are active partners in their care.

#### **EVALUATION AND NEXT STEPS**

The DT is an acceptable self-report measure for patients and nurses —

less than 5% of patients refused to complete it, and some of those refusals may have been due to the burdensome informed consent procedure. The oncology nurses' assessment of the distress tool was highly positive — it reflected their need for acceptable ways to detect and help those patients in distress in a care setting with severe time constraints. The nurses in our study felt confident that they had the resources needed to assist patients in resolving their concerns. The tool met all the criteria of a successful innovation. It has been adopted into routine use by one of the clinics, and plans are underway to implement it in the other.

Future work could focus on how patients are empowered by identifying

the specific causes for their distress, and whether they indeed benefit by such knowledge and subsequent interventions by themselves and their healthcare providers. Patients could be instructed on the meaning of the scores and given a resource list of options to consider. Different settings may adapt use of this tool to fit their particular structures. The referral, treatment and documentation patterns of distress in each clinic will vary according to available resources and supports.

Distress can be experienced at any point in the cancer trajectory, but time constraints and other barriers make it difficult for patients to disclose concerns to the healthcare team. Early

<sup>†</sup> Included waiting, financial concern, future planning, uncertainty, frustration, loneliness, infection and diminution of concentration.

detection is crucial to managing care, improving quality of life and preventing subsequent development of mood disorders. Implementing this brief screening method helps to quickly and accurately detect and treat patients at risk, promoting a comprehensive, individualized, biopsychosocial approach to cancer care.

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