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Screening for Distress in Cancer Patients: Performed by Whom?

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Abstract

Objective: The study was designed to evaluate the implementation of a screening procedure for distress and supportive care needs to patients who were attending the Clinical Oncology Department, Ain Shams University hospitals. The main aim was to gather descriptive information concerning distress levels and the number and type of difficulties encountered.

Methods: The Distress Thermometer (DT) and a problem checklist (translated to Arabic) were administered to 248 recently diagnosed patients who were attending the department.

Results: The study was conducted between November 2012 and June 2013, we completed DT sheets from 248 patients. The mean age was 53.8 years and the median value 56 years [range 27-80]. The male to female percentage was similar. The subjects presented three tumor locations: lung, genitourinary and mediastinal. The majority of the patients in our study (154 patients; 62.1%) had to be considered as exhibiting significant distress since they had a DTS equal to 4 or more. The problem list evaluation made it possible to identify the number of problems reported by each patient. In total, 74.2% of the patients reported practical problems, 93.5% physical problems, 29% family problems and 70.9% emotional problems. Religious problems were not reported by any of the patients. Difficulties and limitations were also described.

Conclusions: This first clinical experiment conducted in an Egyptian cancer center has provided evidence that a considerable degree of distress is present in patients warranting its routine implementation throughout the disease trajectory and appropriate training of the non-specialist professionals involved.

Keywords: Screening; Oncology; Cancer; Distress; Distress thermometer

Background

Transient mood disturbances occur frequently among cancer patients during the disease trajectory, and depression often persists in these patients [1]. Consequently, psychosocial counseling has become an integral part of cancer care, and several meta-analyses support its efficacy [2-4]. To maximize the use of limited treatment resources and provide equitable access to mental health services, emotionally distressed cancer patients need to be reliably identified. Traditionally, referrals for mental health services are either self-initiated or based on physician judgment. However, the concordance rates between patients' self-report and physicians' clinical impressions are low, thus identifying a need for standardized validated tools for measuring emotional distress [5,6]. A distinct advantage of systematic screening of cancer patients for emotional distress is that it is likely to promote equal access to psychological services, whereas a system that is based only on physician- or patient-initiated referrals might fail to identify and/ or overlook a substantial proportion of emotionally distressed patients who are in need of supportive treatment. Furthermore, systematic screening allows mental health staff to forecast their workload [7]. However, only a minority of cancer centers in the United States [8], the United Kingdom [9], and Canada [10] have implemented emotional distress screening of patients with standardized tools. Time constraints of health professionals and

insufficient knowledge about the appropriate screening tool may partially account for the infrequent use of high-quality screening instruments in cancer care settings. The widely acknowledged shortage of professional staff for treatment follow-through suggests a need for screening tools with high sensitivity and high specificity that ensure that all patients in need of psychological support are identified. We posit that the choice of a screening tool ought to consider the psychometric properties of the instrument, with special emphasis on its sensitivity and specificity, the treatment environment, and the patient's disease stage.

In 2010, the Union International for Cancer Control endorsed the new quality standard, stating "global authorities declare distress the sixth vital sign in cancer care, and the International Society of Pediatric Oncology endorsed the new psychosocial standard. Together, these international care organizations provide a platform from which to improve psychosocial care globally for children and adults with cancer and their families [10].

Aim

The study consisted of a clinical experiment designed to evaluate the implementation of a screening procedure for distress and supportive care needs and was organized and made available to recently diagnosed patients who were attending the Clinical Oncology Depatment, Ain Shams University hospitals. The main aim was to gather descriptive information concerning distress levels and the

number and type of difficulties encountered. The secondary aim was to study the feasibility of this approach being adopted by the relevant professionals.

Patients and Methods

All outpatients over 18 years of age with a pathological cancer proof were eligible to participate as long as they were not suffering from an organic brain disease. They were asked for a verbal or written initial consent followed by the completion of the DT aided by one of the authors.

Assessment tools

The following tools were used:

Anarabic translation was derived from the distress thermometer 'DT' [10].

The NCCN Simplified Problem List, whose aim was to identify the causes of the expressed distress?

Results

Population

The study was conducted between November 2012 and June 2013, we completed DT sheets from 248 patients who presented to the Lung and Genitourinary clinic on certain days at the Clinical Oncology Department, Ain Shams University. Our population represented approximately 20% of the patients intended to be treated at the department per annum. The mean age was 53.8 years and the median value 56 years 27-80. The male to female percentage was similar (51.6% males and 48.4% females). Seventy one percent (176 cases) were rated 1 according to the ECOG performance status. The subjects presented three tumor locations: 160 had lung cancer (64.5%), 80 genitourinary (32.3%) and 8mediastinal (3.2%) cancer. The lung cases were distributed as 88 patients with non small cell lung cancer (35.5 %), 24 with small cell lung cancer (9.7%) and 48 with mesothelioma (19.4%). Genitourinary cases were distributed as 32 (12.9%) bladder, 24 (9.7%) prostate, 16 renal cell carcinoma (6.5%) and 8 (3.2%) adrenocortical carcinomas. The 8 mediastinal cases were thymic carcinomas. The tumor was loco regional in 67.7%of cases (168patients) and metastatic in 32.3% of cases (80 patients).

Distress level and problems reported

The majority of the patients in our population (154 patients; 62.1%) had to be considered as exhibiting significant distress since they had a DTS equal to 4 or more of these, 54.5% (84 cases) were men and 68% (105 cases) were at a locoregional stage (Table 1 and 2).

The problem list evaluation made it possible to identify the number of problems reported by each patient: one practical problem for 38.7% of patients and two or more for 35.5%; a family problem in 16.1% of the population and two or more 12.9%; one emotional problem for

16.1% of the patients and two such problems for 54.8% and one physical problem for 12.9% of the patients, two for 3.2% and three or more for 77.4%. Finally, religious problems were not reported by any of the patients. In total, 74.2% of our population reported practical problems, 93.5% physical problems, 29% family problems, 70.9% emotional problems and, finally, 12.9% reported one or more problems of a different type (Table 3).

Age	
56 [27-80]	Median [range]
Gender, N (%)	
120(48.4)	Female
128 (51.6)	Male
Performance status (ECOG)	
32 (12.9)	0
176 (71)	1
32 (12.9)	2
8 (3.2)	3
Cancer diagnosis, N (%)	
160 (64.5)	Lung
80 (32.3)	Genitourinary
8 (3.2)	Mediastinal
Stage, N (%)	
168 (67.7)	Locoregional
80 (32.3)	Metastatic

Table 1: Characteristics of the population (N=248)

PDS score	
6 (0-10)	Median [range]
154 (62.1)	PDS score>3 N (%)
By gender, N (%)	
70 (45.5)	Female
84 (54.5)	Male
By stage, N (%)	
105 (68)	Locoregional
49 (32)	Metastatic

Table 2: Distress level

Patients with DT+= 4N=154	All patients N=248	
Patients reporting+= 1 problem(s), N (%)		
126(81.8)	184 (74.2)	Practical
154(100)	232(93.5)	Physical
42(27.3)	72(29)	Family
126(81.8)	176(70.9)	Psychological
		Others

Table 3: Problems reported

Discussion

This screening procedure enabled us to measure the prevalence of distress among patients who had recently been diagnosed as having cancer and were starting their treatment. It is also the first study attempting to measure distress in Egyptian cancer patients (after thoroughly searching the internet for the use of screening tools for this purpose to see if any arabic translation had been acquired). We were not able to compare data from the previous distress screening process with the one described in this paper. This data was registered in the medical chart only recently and as a part of this study solely. Implementation of this screening process gave us the opportunity to attempt the recording of this information in the medical file. Thus this enabled the performance of descriptive analyses of the procedure. Therefore, it is not possible at this initial launching of this screening procedure to conclude whether there has been an improvement in the referral process, and this point is clearly a limitation of our qualitative study.

The concept of distress as the sixth vital sign (such as blood pressure, temperature, heart frequency, breath, and pain) and the need to use the DT as a screening method in cancer patients has been repeatedly pointed out [11]. Good communication between practitioners and patients is essential. It should be supported by evidence-based written information tailored to the patient's needs. Treatment and care, and the information patients are given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English [12]. Standard application of simple 1-item tools (e.g. the NCCN-DT), short questions [13] or short psychometric questionnaires (e.g. the 14-item HADS) may facilitate clinicians in assessing anxiety and depression among cancer patients and in increasing the likelihood of referral of those with clinical conditions needing treatment. With respect to this, it has been extensively shown that oncologists tend to underestimate psychosocial morbidity in general, especially depression in their patients [14] and that the referral rate to mental health services is quite low (1-7%) [15].

In a study of 135 cancer patients, the DT was used with the specific aim of rapidly screening patients and facilitating psychiatric treatment for major depression and adjustment disorders [16]. However, ultra-short methods should be considered only as a first-stage screen to rule out cases of depression and cannot be used alone to make a diagnosis or pretending to receive information that can be gathered through more structured interviews [17,18].

The DT, a single item visual analog scale, which can be easily completed and interpreted, performs equally well as the GHQ-12 or BSI-18, both of which are lengthier and require some expertise to interpret [19]. This is especially relevant in a population that is very ill and close to death. There is evidence that this may be true across languages and cultures [20]. This was a crucial point to consider when we embarked on this study. This screening procedure enabled us to measure the prevalence of distress among patients who had recently been diagnosed as having cancer and were commencing their treatment. Similar male to female distribution was noted (51.6% males and 48.4% females) and presented a cancer at aloco-regional stage in 67.7% of cases (168 patients) and metastatic in 32.3% of cases (80 patients), including 64.5% with a lung malignancy.

Sixty two percent had to be considered as exhibiting significant distress, with similar gender distribution but most of them surprisingly were in the locoregional stage (68%). This is higher than a similar French screening study performed (43%) [21]. It is also higher than the mean level of prevalence observed in cancer patients questioned at different times during their healthcare trajectories (http://www.ipos-society.org/ professionals/meetings-ed/ed-online-lectures.htm), a fact which may be due to the particularly high level of anxiety associated with the recent diagnosis and the period of great uncertainty and cognitive confusion during which the responses were recorded, i.e. while the patients were finding out about the healthcare trajectory.

Perhaps such a finding can be interpreted as a different perception of disease due to the cultural environment. One study found Swedish men scored better than Egyptian men on the FACT-BL and HADS, although the latter improved with time after surgery. These results show that patient-assessed outcomes differ in patients from different sociocultural backgrounds. This should be recognized when analyzing results from comparative studies. Also, the use of culture-fair instruments is important when assessing patients with different sociocultural backgrounds [22]. The main problem reported in our study was physical (93.5%), the second was practical (74.2%) followed by psychological (70.9%). Patients with higher levels of distress had increased percentages of these problems: 100, 81.8 and 81.8% respectively. The problems mentioned by the patients questioned in a French study were primarily physical (70%) and psychological (66%) in nature. Among the patients exhibiting a significant level of distress, these percentages increased to 76 and 80%, respectively. Practical problems were less than in our study; 60% [21].

Again this cross-cultural comparison is difficult but the high percentage of practical problems reflects a need for greater social support for our population of patients. None of our patient reported any religious concerns, a peculiar finding; however we could not find any studies reporting this point per se. This particular fact only serves to emphasize the distinct nature of our society and perhaps is another point of interest which must be put into great consideration when using tools in people of different cultural and social backgrounds. Perhaps the view of cancer as God's will, and the belief that acceptance is the desirable reaction [23] may make Arab patients reluctant to report negative feelings. Yet these patients too may experience high level of distress, which impairs quality of life; culture-specific means of

accurate diagnosis and treatment are needed. This raises questions about the applicability of the use of the DT and other short screening instruments to identify patients in distress in specific ethnic groups. This concern is applicable to many ethnic groups from Eastern countries and South American countries who reside in Western countries. DT validation studies in these countries have not addressed the discriminative ability of the DT for these groups [24]. Two studies that included arab subjects reported significant distress rates. More than half of the participants,52% [24,25] and 70% rated their distress as four or higher.

Unidimensional scales attract immediate attention from clinicians because of their simplicity and ease of use. One example is the Distress Thermometer, which is becoming increasingly used in cancer settings. Many of these questionnaires rely on a degree of self-evaluation and familiarity with the construct that it measures. These may pose problems in non-Western populations less familiar with such constructs [20].

Female patients, young patients and those with advanced disease, functional impairment or a specific type of cancer such as lung cancer were reported to be predisposed to psychological distress [26]. The latter point can aid in the explanation of the high level of distress found as we have a majority of 64.5% of cases in this category. We could not find any similar studies in our region to explain this higher than expected figure however it signals the alarm for immediate measures to be taken. In the face of the growing need for managing distress among cancer patients, many hospitals have established routine programs for screening and treating this condition. A recent Korean study reported that the prevalence of psychological distress as defined by the DT was 56.5% and that this condition was associated with poor performance status. However, limitations such as a small sample size and a low response rate made it difficult to generalize the results of this study among Korean cancer patients [27]. Also another Chinese study found the DT has acceptable overall accuracy and reliability as a screening tool for testing distress severity and specific problems. They concluded it was worth being used in the oncology clinic, the rapid screening and interview could help caregivers to identify psychological and psychiatric problems of cancer patients and provide useful information for further treatment [28].

The current sample size should have been larger in order to validate the results. As the participants in this study were newly diagnosed cancer patients, they may not be representative of the general cancer population. We analyzed data from only one institution and from one of the clinics. In addition, the proportion of patients with other malignancies most notable of which is breast cancer, a substantial percentage of the cancer load in Egypt, were not included. It may also be a burden to the members of a psychiatric service to try to provide psychiatric assessment for all cancer patients screened as positive based on the thresholds suggested in this study (i.e.,62% of study participants in our study).Most patients who met distress criteria had not sought professional psychosocial support nor did they intend to in the future. Many patients who report high levels of distress are not taking advantage of available supportive resources (in the practical needs arena in particular). Barriers to such use, and factors predicting distress and use of psychosocial care, require further exploration. Social support networks need to be advertised more and strengthened.

Nonetheless it is time to take steps, if not leaps, even if as minor as we have attempted to do here. Personnel working with cancer subjects need to be trained/ oriented to the psychological screening process and firm links made to available psychiatric, social and supportive services.

A multicenter, longitudinal study with a larger sample size should be conducted to confirm these results and to overcome the limitations of our study. It is time to treat the Egyptian cancer patient as a whole person.

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