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Systematic screening for distress in oncology practice using the Distress Barometer: the impact on referrals to psychosocial care

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Abstract

***Purpose*: This study evaluates how patterns of psychosocial referral of patients with elevated distress differ in a 'systematic screening for distress' condition versus a 'usual practice' condition in ambulatory oncology practice.**

***Methods*: The psychosocial referral process in a 2-week usual practice ($N = 278$) condition was compared with a 2-week 'using the Distress Barometer as a screening instrument' ($N = 304$) condition in an outpatient clinic with seven consulting oncologists.**

***Results*: Out of all distressed patients in the usual practice condition, only 5.5% of patients detected with distress were actually referred to psychosocial counselling, compared with 69.1% of patients detected with distress in the condition with systematic screening using the Distress Barometer. Only 3.7% of patients detected with distress in the usual practice condition finally accepted this referral, compared with 27.6% of patients detected with distress in the screening condition.**

***Conclusions*: Using the Distress Barometer as a self-report screening instrument prior to oncological consultation optimises detection of elevated distress in patients, and this results in a higher number of performed and accepted referrals, but cannot by itself guarantee actual psychosocial referral or acceptance of referral. There is not only a problem of poor detection of distress in cancer patients but also a need for better decision-making and communication between oncologists and patients about this issue.**

Introduction

High incidences (35–45%) of emotional distress have repeatedly been demonstrated in cancer patients in Western countries across their illness trajectory [1], with even higher levels of distress in advanced cancer patients [2]. Physician's awareness of the importance of elevated distress as a component of optimal cancer care has certainly increased [3]. Even more oncologists are realising that distress affects areas such as therapy adherence [4], satisfaction with care [5,6], length of hospitalisation [7], quality of life [8–11] and even possibly survival time [12–16].

The increased awareness of the importance of early assessment and evaluation of psychological morbidity has led to many initiatives worldwide such as the development of the Distress Management guidelines of the National Comprehensive Cancer Network, health policies for distress screening (in Canada and UK) and recommendations of professional societies on routine screening [17].

Despite the evidence that screening tools can improve detection of psychosocial distress [18–21], and can facilitate communication about psychosocial issues between professionals and patients [22–25], direct effect on quality of life in patients is still uncertain [26], and screening for distress often remains controversial [27]. A recent review article concerning 24 interventional studies concludes that screening for distress has certainly significant benefits on quality of care, but that success of screening is related to multi-domain screening including screening for unmet needs, acceptability of the screening programme, and acceptability and availability of psychosocial treatments and experts [27].

Some studies indicate that screening programmes contribute to higher rates of referral or better access to psycho-oncology service treatment [28,29], but this was not a consistent finding [30]. Low rates of referral acceptance have been observed [28–30]. Not all patients with clinically elevated distress seem to want a referral, and therefore, patients should be asked whether they want to receive additional care [31].

In 2006, an interdisciplinary project was initiated by the Psychosocial Supportive Team (PST) of the oncology department of the UZ Brussels hospital aiming at accurate detection of elevated distress in patients and supporting efficient referral to psychosocial support. In Belgium, prior to this project, no short screening instruments for psychological distress were used routinely, and there were no data on the acceptability and possible impacts of using

screening instruments. In a first study within this project, the Distress Barometer, which is a combination of the Distress Thermometer [32], a multi-domain rated complaints scale and a patient need for help scale, was developed as a rapid and valid screening instrument for distress [33]. In a subsequent multi-centre study, good acceptance of this tool by both physicians and patients was demonstrated [34]. The current study aims at evaluating the impact of systematic screening with the Distress Barometer on detection rates of patients with elevated distress and on rates of psychosocial referral comparing to usual practice. Moreover, the impact of screening for distress and screening for needs on acceptance of referrals are evaluated.

Method

Participants

Ambulatory patients 18 years and older of the Oncology Centre of the University Hospital (UZ Brussel), diagnosed with cancer, were eligible for the study if they were sufficiently fluent in the languages of the study (Dutch or French) and not affected by a cognitive disorder.

As the rate of referral to the supportive team was estimated at 5% during usual practice, and this was expected to increase to some 13% with systematic screening for distress (figures based on our previous study [32]), a two-sided test with a 5% significance level and 80% power would require samples of about 224 patients for both conditions. Because about 220 patients visit our ambulatory oncology hospital every week, it was estimated that a 2-week data collection period would suffice for each condition ('Usual Practice' versus 'Distress Barometer').

Two distinct 2-week periods were chosen: a usual practice (UP) period in May 2010 and a 'distress screening with the Distress Barometer' (DB) period in June 2010. The month in-between these two conditions was intentionally installed to minimise a 'memory' or 'comparison', or even 'compensation' bias effect by the oncologists.

During these two periods, the same seven oncologists participated in the study, and data were obtained from 582 volunteering patients: 629 patients were invited to participate, of whom 29 were excluded and 18 refused for different reasons including weakness, illness and cultural reasons. The proportions of exclusions (.04 in DB versus .05 in UP; $z = -.37$; $p = .71$) and refusals (.02 in DB versus .04 in UP; $z = -1{,}1$; $p = .27$) did not differ significantly. This resulted in 278 participants in the UP condition, and 304 in the DB condition.

Measures and procedure

Demographic and medical data (age, gender, staging, type of treatment and medical history) were obtained from the patient database and medical records.

The DB [32] was administered after the consultation with the oncologist in the UP condition versus before the consultation in the DB condition. The DB comprises three parts[1]:

1. The *Distress Thermometer*, originally developed by Roth *et al*. [32] and translated to Dutch and French by Bauwens *et al*. [33], is a single-item instrument where patients rate their level of distress suffered during the previous week on a pictured thermometer. In the DB, the visual analogue scale was slightly adapted by using a background colour effect with anchors labelled 'no distress' (0 = green) through 'moderate distress' (5 = yellow) and 'extreme distress' (10 = red).
2. The *Coloured Complaint Scale*, which consists of 10 items that are rated on a coloured 5-point scale. Patients are required to rate how much each of a list of sources of distress has been troubling them lately: two physical sources, four emotional, one cognitive, one familial, one spiritual and one open item 'other' to accommodate any other potential source of distress. Patients rate the intensity of their complaints from 'not at all' (= pastel shade of green) to 'very much' (= dark red). This scale was designed to equip doctors with a convenient tool to assess the nature and intensity of complaints 'in a single glance'.
3. Additional *Wish-Needs Questions*: four additional questions let patients express their desire to communicate about their complaints and needs for further medical information and/or support: (1) 'I want to talk about these problems to someone' (Yes/No). (2) If 'Yes, indicate to whom (doctor, nurse, psychologist, social worker, other)'. (3) 'I need more medical information (Yes/No)' and (4) 'I need more support (Yes/No)'.

A previous study [33] showed that the DB has a relatively high sensitivity (0.79) and specificity (0.81), using the Hospital Anxiety and Depression Scale as standard.

In the UP condition, patients as well as oncologists were asked to fill out a multiple choice question: 'the content of the consultation was mainly (1) Good news, (2) Neutral news and (3) Bad news'. Also in the UP condition, oncologists had a form with four other questions: (1) their rating of patient's distress on a visual analogue scale (0–10), (2) if they considered referral necessary (yes or no), (3) if they actually gave an advice for referral (yes or no) and (4) if referral was accepted by patients (yes or no).

In the experimental condition, oncologists had a similar form with only the last three of these questions. In a collective 1-h session held shortly before the DB condition, oncologists were instructed in using the DB and were given a written explanation on how to interpret DB results.

In both conditions, oncologists were familiar with the existing supporting service.

The procedure for both conditions is shown in Figure 1.

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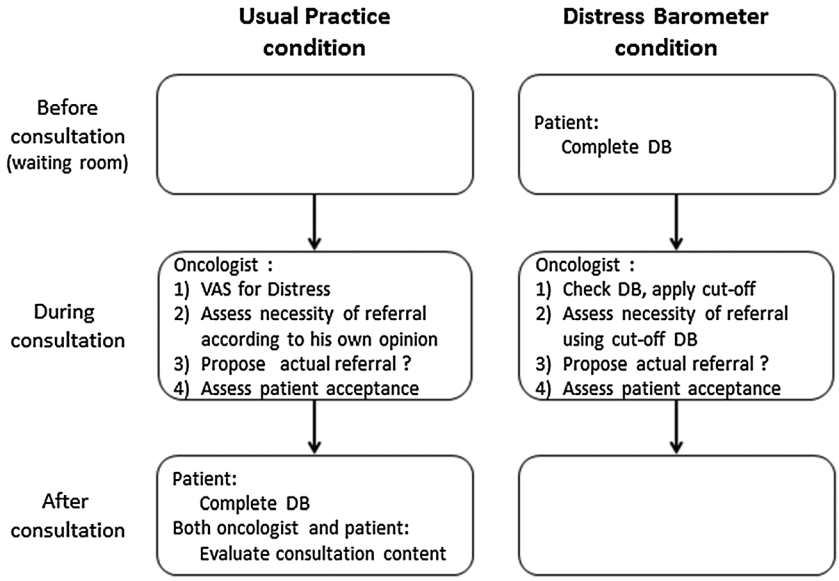

Figure 1. Impact of screening for distress on psychosocial referrals in oncology

The study protocol was approved by the Ethical Committee of University Hospital of Brussels. Because screening for distress is a recommended clinical practice in oncology and not likely to be harmful for patients, patients were not asked for written informed consent.

Data analysis

Analyses were performed using SPSS for Windows (version 19, IBM Corp., New York, USA). Standard descriptive statistics were used to characterise the demographic, clinical and distress variables in the sample. Independent samples *t*-tests, Chi-square analyses and McNemar's test for paired samples were used to explore the differences between the two conditions in demographic and clinical variables, the differences in rates of distress in the two conditions and the differences in referrals in the two conditions. Marginal homogeneity test was used to examine differences between the doctor and the patient in their appraisals of the same consultation.

Results

Patients

The demographic and clinical characteristics of the participants are presented in Table 1. No significant differences were found between the two conditions for age, gender, diagnosis, time since diagnosis, stage of disease at diagnosis, current stage of disease or treatment given in the past month.

Patient self-reported distress levels in both conditions

Even though distress levels were not measured at similar times (either *after* the consultation with the oncologist in the UP condition versus *before* the consultation in the DB condition), a previous pilot study [35] showed no significant differences in distress ratings obtained with the DB before versus after the consultation.

The global distress level, as measured with the Distress Thermometer, did not differ significantly between the UP condition (mean = 4.10, $SD = 2.86$) and the DB condition (mean = 4.35, $SD = 2.93$) ($t(572) = -1.06$, $p > 0.05$).

Distress screening by oncologists versus patients' self-reported distress

Detection rates of elevated distress by oncologists in the UP group versus self-reported elevated distress in the experimental condition are quite similar: 39.6% in the UP condition versus 41.6% in the DB condition. McNemar's test for paired samples showed no significant difference in the number of patients detected with distress by oncologists indicated after the consultation on the visual analogue scale (VAS) versus using the DB (patients) ($p > 0.05$).

In the UP condition, the average distress level on the VAS obtained from oncologists was 3.96 ($SD = 2.23$), whereas the average self-reported distress level on the Distress Thermometer was 4.10 ($SD = 2.86$). A paired samples *t*-test indicates that this difference is not significant ($t(277) = -0.898$, $p = 0.37$).

However, on average, the absolute difference in distress levels obtained from oncologists (VAS) and those obtained from patients (Distress Thermometer) equals 2.27 ($SD = 1.87$), which differs significantly from zero ($t(277) = 20.17$; $p = 0.001$). Oncologists' ratings showed a central tendency bias (more moderate ratings, closer to the middle of the scale) compared with patient's self-reported distress.

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Table 1. Demographic and clinical characteristics of study sample

	Entire sample ($n = 582$)	Usual practice condition ($n = 278$)	Experimental condition ($n = 304$)
Age (±SD)	58.92 (±13.03)	59.08 (±12.97)	58 (±13.12)
Average months since diagnosis (±SD)	45.97 (±58.04)	43.83 (±54.96)	48.03 (±60.71)
Gender *N* (%)			
Male	187 (32.1)	85 (30.6)	102 (33.6)
Female	395 (67.9)	193 (69.4)	202 (66.4)
Cancer diagnosis *N* (%)			
Breast	255 (43.9)	124 (44.6)	131 (43.2)
Lung	58 (10.0)	22 (7.9)	36 (11.9)
Colon	50 (8.6)	26 (9.4)	24 (7.9)
Prostate	20 (3.4)	8 (2.9)	12 (4.0)
Gynaecological	45 (7.7)	23 (8.3)	22 (7.3)
Skin	55 (9.5)	27 (9.7)	28 (9.2)
Brain	43 (7.4)	18 (6.5)	25 (8.2)
Other	55 (9.5)	30 (10.8)	25 (8.2)
Stage disease at diagnosis *N* (%)			
Local disease	192 (33.0)	84 (30.2)	108 (35.6)
Locoregional disease	224 (38.6)	115 (41.4)	109 (36)
Advanced disease	165 (28.4)	79 (28.4)	86 (14.8)
Current stage disease *N* (%)			
Diagnosis	12 (2.1)	2 (0.7)	10 (3.3)
Active treatment curative intent	132 (22.7)	69 (24.8)	63 (20.8)
Active treatment palliative intent	308 (53.0)	150 (54,0)	158 (52.1)
Cured	57 (9.8)	22 (7.9)	35 (11.6)
Remission (partial/complete)	19 (3.3)	9 (3.2)	10 (3.3)
Palliative Care	2 (0.3)	1 (0.4)	1 (0.3)
Wait and see	29 (5.0)	17 (6.1)	12 (4)
Recent recurrence	22 (3.8)	8 (2.9)	14 (4.6)
Current treatment *N* (%)			
No treatment	141 (24.3)	60 (21.6)	81 (26.7)
Surgery	18 (3.1)	11 (4.0)	7 (2.3)
Radiation	10 (1.7)	6 (2.2)	4 (1.3)
Chemotherapy	252 (43.3)	131 (47.1)	121 (39.9)
Medication	110 (18.9)	46 (16.5)	64 (21.1)
Radiation + Chemotherapy	12 (2.1)	6 (2.2)	6 (2.0)
Chemotherapy + Medication	34 (5.8)	16 (5.8)	18 (5.9)
Radiation + Medication	4 (0.7)	2 (0.7)	2 (0.7)

Independent *t*-tests and χ^2 analysis showed no significant differences between the groups of the two conditions.

Differences between patients and oncologists in their appraisals of the consultation

Patients reported a more positive content of the consultation significantly more often than oncologists; a marginal homogeneity test for paired samples showed that this difference between the doctor's and the patient's appraisal of the consultation content is significant ($p < 0.001$).

Differences in referrals in the two conditions

The course of the screening and referral process in the two conditions is presented in Table 2. In the UP condition, oncologists used their own VAS assessment of distress to decide on an eventual referral, whereas in the DB condition, the cut-off point for the DB (Distress Thermometer ≥ 4 and elevated Coloured Complaint Scale) was used by the oncologists for this purpose [33].

Although a significant absolute difference was found between the patient's and the oncologist's assessment of distress (as found in the UP condition), which can probably be attributed to a central tendency response style in the oncologists, on average similar global rates of distress were found in the two conditions: 39.6% in the UP condition versus 41.6% in the DB condition.

At the time when oncologists were to decide if referral for psychosocial care was needed or not, however, an important difference was noted between the two conditions. In the UP condition, oncologists thought referral was necessary for only 13.8% of patients with elevated distress (according to their own VAS ratings), whereas in the experimental condition, they considered it necessary for all patients with distress according to the DB. Consequently, in UP condition, referral was thought necessary for 5.4% of all patients, whereas in the DB condition, psychosocial referral was considered necessary for 41.6% of all patients.

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Table 2. Comparison of numbers of patients with distress at consecutive stages in the decision process to referral

	Usual practice condition $N = 278$ patients	Distress Barometer condition $N = 296$ patients
Count of patients with elevated distress according to oncologists >4 on 0–10 VAS	$N = 109$ (39.6% of all patients)	(not recorded)
Count of patients with distress according to the Distress Barometer	$N = 98$ (35.3% of all patients), no feedback to oncologists	$N = 123$ (41.6% of all patients)
Referral (for psychosocial care) considered necessary	$N = 15$ (5.4% of all patients; 13.8% of patients detected with distress)	$N = 123$ (41.6% of all patients; 100% of patients detected with distress)
Actual referral by oncologists	$N = 6$ (2.1% of all patients; 5.5% of patients detected with distress)	$N = 85$ (28.7% of all patients; 69.1% of patients detected with distress)
Referral finally accepted by patients	$N = 4$ (1.4% of all patients; 3.7% of patients detected with distress)	$N = 34$ (11.5% of all patients; 27.6% of patients detected with distress)

Even when oncologists considered psychosocial referral necessary, an actual referral did not always take place. In the UP condition 6 out of the 15 patients for whom referral was considered necessary by the oncologists were actually referred to psychosocial care. In the screening with DB condition, 85 out of the 123 patients with elevated distress were referred.

No significant associations were found between actual referrals and demographic or clinical variables (all χ^2 tests showed p-values above 0.05), not for the total group nor in the different conditions.

Acceptance of referrals by patients

When considering the efficacy of actual referrals, it was found that only four referrals of patients (that is 3.7% of all patients detected with distress) were actually validated by the patients in the UP condition, against 34 (27.6% of all patients detected with distress) in the DB condition (Table 2).

For the two conditions, acceptance of referral was not related to any demographic or clinical variables (all χ^2 tests: $p > 0.05$).

Wish for help and referral acceptance in the experimental condition

In the third part of the DB (Wish-Needs Questions), 31% of patients in the DB condition endorsed their wish to talk to someone about their problems, 27% of the patients indicated they wanted more medical information and 8% marked they needed more support. Among non-distressed patients, 20% expressed a wish to talk to someone, 18% wanted more medical information and 3% wanted more support. For patients with elevated distress, these percentages increased to 47%, 38% and 14%, respectively (Figure 2).

The desire to talk to someone about problems was significantly related with positive acceptance of referral (χ^2 (1) = 38.18; $p = 0.001$), which contrasts with the need for more medical information, which was not related to acceptance of referral ($\chi^2(1) = 0.97$; $p = 0.323$). The need

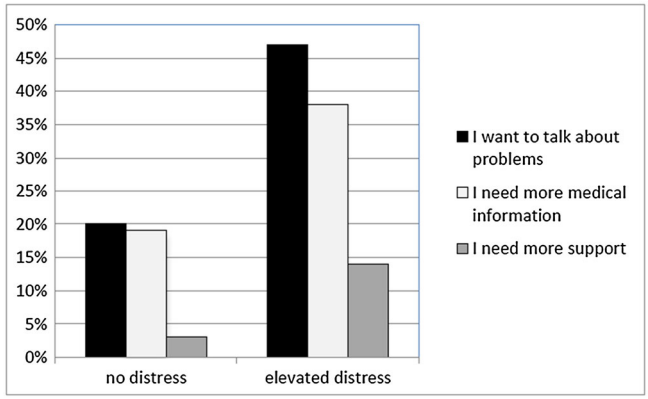

Figure 2. Wish-Needs Questions

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for more support was also significantly related to referral acceptance (χ^2 (1) = 6.24; p = 0.026).

Four patients (11%) with elevated distress, but who expressed no wish to talk about it, nevertheless accepted a referral. Of the patients with elevated distress but no reported need for more support, 19 patients (35%) accepted a referral.

Discussion

This study clearly indicates that self-reporting of distress, using the DB, leads to both increased numbers of referrals to psychosocial professionals and more actual acceptances of these referrals. However, analysis of the referral process demonstrates that using the DB does not, by itself, guarantee distressed patients' access to additional support. Rather, it seems that using the DB may facilitate the communication about referrals among oncologists and their patients, and to a lesser extent helps patients to overcome hesitations about an actual referral.

Detection of distress

At first sight, the overall percentages of detected elevated distress are quite similar in both conditions, but further analysis reveals a different picture. The central tendency response style as observed in the oncologists in the UP condition corresponds to reports on such bias in previous studies [36,37], where oncologists tended to report an intermediate rate of distress, possibly resulting from their uncertainty in assessing patient distress. Oncologists possibly recognise some notion of distress in their patients but find it difficult to appraise its severity and need for additional care.

Referral problems

Oncologists, when they indicated distress in their patients in the UP condition, seem to find it difficult to assess the necessity of psychosocial referral. Distress may be disregarded as 'understandable' and not 'avoidable'. It remains difficult for doctors to decide if and to whom patients suffering from distress should be referred. In the experimental condition, it seems that using the screening instrument with indication of the nature and intensity of complaints and the wish/needs of the patient may not only help oncologists to decide the necessity of a referral, and also helps them to effectively carry out the referral. Possibly using a screening instrument facilitates the communication with the patient about a potential referral. In the UP condition, reasons that a referral judged as necessary did not result in an actual referral were not systematically questioned, but often, doctors added spontaneously reasons as 'too early' and 'maybe next time'. This observation suggests that the use of a screening tool may accelerate the referral process, which could confirm the study of Ito [30] who concluded that a screening programme seemed useful for introducing psychiatric treatment at an earlier stage.

Acceptance of referral and need for help

In line with previous research [38,39], this study indicates that although elevated distress and the wish to talk with someone about problems were positively related, 53% of distressed patients reported no need to talk and 20% of the non-distressed patients reported a need to talk. However, a significant number of distressed patients without reported needs accepted a referral. Both findings confirm that patient's needs for psychological support cannot be satisfied solely by screening for distress, nor can such screening guarantee willingness to accept referral. This study confirms Baker-Glenn [38] who claimed that additional screening for needs may highlight those who are willing to accept referral for additional support, but it also demonstrates that such screening cannot replace negotiation and consultation about referral.

Limitations of the study

This study has some limitations. First, no full structured interview was carried out to assess symptoms, so it was not examined in this study whether each patient was a true positive case or not. However, a previous study on the DB showed its relatively high sensitivity (0.79) and specificity (0.81) [33] and because oncologists in the UP condition showed a central tendency response style with as consequence a low specificity, we do not expect a larger proportion of false positive and false negative patients to be included in the experimental group than in the UP group. A further limitation is our ignorance about patients referred and supported by the PST in terms of outcome, which is the ultimate criterion to evaluate the usefulness of screening. Third, participants were typically many months from diagnosis at the time of the study, which may have influenced patterns of referrals, but in this study, no statistical evidence was found for this. Fourth, although the sample of cancer patients was large in this study and the feasibility and acceptability of the DB was shown in a previous study, a period of 2 weeks may be too short to evaluate the impact of a screening instrument on the referral process. However, the positive impact of the routine use of a screening tool on the referral process has by now been demonstrated in other studies with longer screening periods. One study [30], with a 6-month screening programme showed no higher proportion of patients with major depressive disorder or adjustment disorder being referred to Psychiatric Services, but the screening seemed useful for introducing psychiatric treatment at an earlier stage. Another study [29] with a 1-year screening programme indicated a higher and more accurate referral of patients. A further limitation was that reasons that a

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necessary referral was not converted into an actual referral by oncologists and reasons that patients did not accept referral were not systematically inquired. Because the PST of the hospital in both conditions (as usual) tried to offer immediate (within days) help, reasons for no actual psychosocial referral cannot be associated with, for example, long waiting lists. Regarding acceptance of an actual referral, this study cannot exclude that some patients may have accepted a referral later on or elsewhere. Finally, although the current study had clear advantages (relatively large sample of cancer patients with various diagnoses, various stages of disease, various lengths of disease, comparable UP group, very high completion rate, first study to quantify both distress rate, referral necessity, actual referral, acceptance and needs of patients), this study was performed in a single hospital cancer centre, and our findings should therefore probably not be interpreted independently from the hospital culture and the individual attitudes of the collaborating oncologists. Further research is therefore needed to confirm our findings.

Conclusion

Accepted referrals occurred nearly 10 times more often in this study when using the DB than in the UP condition, which confirms the idea that implementing a screening instrument does not only contribute to better detection of distress but also facilitates the recognition of necessity of psychosocial help and the communication with patients about a possible referral. It supports the selection of patients who need referral and helps oncologists to refer without losing time.

However, even with the systematic use of the DB, more than two-thirds of patients detected with distress actually did not consult a psychosocial caregiver after the consultation. The results of this study underline the important recommendations of Carlson, Waller and Mitchell concerning screening for distress programmes [26]. Screening with an instrument certainly is recommended, but it does not replace the need for supplementary training of health professionals in communication skills and a clear guidance on referral management.

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Note

1. The Distress Barometer is freely available at http://homepages.vub.ac.be/~ptheuns/DistressBarometer/DistressBarometerEN.pdf.

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