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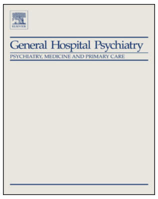

Use of the distress thermometer to evaluate symptoms, outcome and satisfaction in a specialist psycho-oncology service☆,☆☆

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ABSTRACT

Objective: The National Institute for Health and Care Excellence recommends the use of structured tools to improve holistic care for patients with cancer. The Distress Thermometer and Problem Checklist (DT) is commonly used for screening in physical health settings. However, it has not been integrated into the clinical pathway within specialist psycho-oncology services. We used the DT to examine the broad clinical effectiveness of psycho-oncology intervention and to ascertain factors from the DT linked to an improved outcome. We also evaluated patients' satisfaction with their care.

Method: We asked 111 adult outpatients referred to York Psycho-Oncology Service to complete the DT at their first appointment. Individuals offered a period of psycho-oncology care re-rated their emotional distress, problems and service satisfaction on the DT at discharge.

Results: Median distress scores decreased significantly (from 6 to 4, Wilcoxon's $z=-4.83$, $P<.001$) indicating a large clinical effect size (Cohen's $d=1.22$). Frequency of emotional problems (anxiety, depression and anger) fell significantly by 15–24% despite no significant change in patients' physical health or practical problems. Number of emotional problems was the best predictor of distress at discharge (beta=0.468, $P=.002$). Satisfaction was high and correlated with lower distress scores ($r=-0.42$, $P=.005$) and fewer emotional problems ($r=-0.31$, $P=.04$) at discharge but not with number of appointments attended. Qualitative thematic analysis showed patients particularly value supportive listening and advice on coping strategies from professionals independent of their physical care.

Conclusion: The DT is an acceptable and useful tool for enhancing the delivery of structured psycho-oncology care. It may also provide evidence to support the effectiveness of specialist psycho-oncology interventions.

1. Introduction

The diagnosis and treatment of cancer can lead to high levels of psychological distress and significantly impair quality of life [1]. In order to improve holistic and supportive care, the National Institute for Health and Care Excellence (NICE) recommends using screening tools that assess patients' emotional and physical health needs at regular points in the patient's treatment pathway [2]. The distress thermometer [Distress Thermometer and Problem Checklist (DT)] and its associated problem checklist is the most widely used rapid screening instrument within United Kingdom cancer services [3]. It has a similar sensitivity (77–100%) and specificity (49–67%) to other brief tools such as the Hospital Anxiety and Depression Scale and the Patient Health Questionnaire [4,5]. The DT has been validated against structured clinical interviews in the outpatient setting and is also acceptable to patients [3,4,6].

However, accumulating evidence suggests that simply screening patients is not enough [7,8]. Screening is only one part of a holistic clinical assessment. An effective service for psychological distress in patients affected by cancer has three main components: identification of patients in need, referral to appropriately trained professionals and evidence-based treatment of symptoms and problems [9]. Currently, the clinical efficacy of interventions offered by psycho-oncology teams remains uncertain [10,11]. A systematic review of outcome measures used following psychosocial treatments within cancer services concluded that none of the existing tools provide a suitable index that records levels of general distress as well as anxiety and depression [12].

The DT was originally developed as a screening tool to identify significant problem areas for cancer patients. In many hospitals, it has been used to prompt referrals to psycho-oncology specialists [13] rather than for systematic use by those specialists. Recent reviews of the clinical application of the DT have found evidence of its benefit in

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facilitating communication in consultations as part of a holistic therapeutic conversation [14,15]. These study authors concluded that future interventions should focus on the "real-world" integration of the DT within a structured distress management program. In addition, prospective research suggests that the DT can be used to monitor changes in psychological distress over time [16], yet it is not currently used as a tool to assess clinical outcome.

2. Aims of this study

Against this background, we used the DT — not as a screening tool in generic cancer services, but as an integrated tool within a specialist psycho-oncology service. We wanted to evaluate the service by using the DT at the beginning and end of a period of psycho-oncology care. We also took the opportunity to add a new measure of service satisfaction.

Our aims were to:

(1) Examine the effectiveness of psycho-oncology intervention from a patient–client perspective and
(2) Ascertain patient and service factors linked to an improved clinical outcome
(3) Evaluate patients' satisfaction with their psycho-oncology care.

In particular, we wanted to determine whether any therapeutic changes were related to the nature of an individual's presenting problems, the number of psycho-oncology appointments attended and their distress score at discharge.

3. Method

3.1. Setting

York Hospital serves a population of 280,000 and sees around 2900 patients who are newly diagnosed with cancer each year. The Psycho-Oncology (Cancer Psychology) Service is based within its Cancer Care Centre. A team of three clinical psychologists and one liaison psychiatrist from the Department of Psychological Medicine staff it on a sessional basis. The service is well established, having been in existence since 2003. It has good relationships with referrers from local cancer and palliative care services and with local general practitioners. Audit data from 2011 show that 8% of those diagnosed with cancer are referred and seen for specialist psycho-oncology care. The mean waiting time to be seen is 16 days, with 85% of referrals seen as outpatients.

3.2. Psycho-oncology service

The psycho-oncology team provides a comprehensive assessment and a holistic range of interventions. Liaison with doctors and nurses who deliver the physical care, supporting and advising relatives and signposting to other appropriate services, comprise an important part of the work. The three clinical psychologists each offer a similar range of formulation-based therapeutic models in their contact with patients — primarily cognitive–behavioral therapy (including "third wave" approaches, mindfulness and compassion mind techniques) and other short-term focussed interventions. The psychiatrist offers diagnostic, risk and capacity assessment, including prescribing of medication for more severe depressive and anxiety disorders when appropriate.

3.3. Distress thermometer tool

The DT was devised in the USA [13] and developed in the United Kingdom [15]. It is one of the tools recommended by a number of United Kingdom Cancer Research Networks. The DT is a simple self-report measure that quickly assesses a patient's distress and current problems. First, patients circle the number that best describes how much distress they have felt in the past week on a visual analogue scale ("thermometer"). This ranges from zero (no distress) to ten (extreme distress). Second, patients are given a checklist of 33 problems (practical, family, emotional, spiritual/religious, physical and other). They are asked to tick any problems that have been a cause of distress in the past week.

We used two color-coded versions of this tool to evaluate patient distress "before" (green DT1) and "after" (pink DT2) psycho-oncology input. The DT2 included the feedback question "How satisfied have you been with the care you have received from the psycho-oncology service?" Patients circled a number from zero ("not at all satisfied") to ten ("extremely satisfied") on a linear scale. We also asked "What have you found most useful?" and "What could be improved?"

3.4. Patient population

We included all patients who attended for one or more clinic appointments with a psycho-oncology professional more than an 18-month period in 2010–2011. Patients were age 18 years or older and receiving care from local cancer services. We excluded inpatients, relatives and those who declined to complete the DT forms or were unable to do so for any reason. However, patients could ask for help in completing the DT from a friend or relative.

Psycho-oncology professionals, assisted by reception staff, asked all newly referred patients to complete the DT1 questionnaire. This was done in the waiting area before being seen for their first psycho-oncology clinic appointment. The DT1 was then reviewed and discussed with patients within the first session. Responses were used to inform the holistic assessment and plan interventions. A copy of the DT1 was kept in the patient records. All individuals who were offered followed up (on the basis of clinical need) and later attended one or more additional psycho-oncology appointments were asked to complete a DT2 upon final discharge. Patients could choose to complete the DT2 in the clinic area and hand in at reception, or take it home to post back later. They were given a stamped envelope addressed to the psycho-oncology administrator (not the clinician who had seen them) for this purpose. We did not send reminders to return the DT2 or give DT2 forms to patients discharged after a single assessment because they had just completed the DT1 at the same appointment.

Completed DT forms were matched to clinical records for referring speciality, patient gender, age and total number of psycho-oncology appointments attended. Data on histological type and staging of cancer were not available. We also requested feedback from psycho-oncology clinicians regarding use and acceptability of DT1 and DT2.

3.5. Data analysis

Data were anonymized and analyzed using the Statistical Package for Social Sciences for Windows, version 16.0. Dichotomous variables were examined using the chi-squared test. Nonparametric tests were applied to ordinal and continuous variables: Wilcoxon's signed rank test for paired data on patient problems and Mann–Whitney *U* and Spearman's correlation coefficient for independent samples. We used multivariate regression modeling [analysis of variance (ANOVA)] to examine predictors of distress thermometer score at discharge. Free text responses to service satisfaction questions were categorized by qualitative thematic analysis.

3.6. Ethical approval

This was a service evaluation of recommended clinical care, supported by NICE [2] and Regional Cancer Network Guidance [17]. Local research guidance was that formal ethical approval was not required.

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Table 1
Distress thermometer score and number of patient problems: Spearman correlations at start and end of care

Type of problem	DT1 score (*n*=106)	DT2 score (*n*=50)
	r (*P*)	*r* (*P*)
All problems	0.36 (<.001)***	0.60 (<.001)***
Practical	-0.01 (.93)	0.35 (.01)**
Family	0.25 (.01)**	0.10 (.54)
Spiritual/religious	0.06 (.52)	0.04 (.80)
Physical	0.27 (.005)**	0.43 (.002)**
Emotional	0.42 (<.01)**	0.64 (<.001)***

* *P*<.05.
** *P*<.01.
*** *P*<.001.

4. Results

4.1. Clinical population

DT1 questionnaires were fully completed by 106/111 (95%) new patients. The five new patients who did not complete a DT1 were offered further appointments and all completed a DT2 at discharge. Of the 72 patients in total who attended two or more appointments, 50 completed the DT2 questionnaire, giving a follow-up response rate of 69%. The mean age was 53 years (S.D., 12.3; range, 18–77), and 91 (82%) were women. The most common referral source was oncology (21 patients, 19%), followed by breast cancer (18, 16%), general surgery (14, 13%), general practice (8, 7%) and palliative care (7, 6%). A further 43 referrals (39%) came from six other departments, most often via a clinical nurse specialist. The three clinical psychologists saw a total of 89 referrals (80%) and the psychiatrist 22 (20%) patients. Patients attended a mean of 3.4 (S.D., 3.93; range, 1–30) psycho-oncology appointments, with 39 (35%) attending one, 22 (20%) attending two, 15 (14%) attending three and 35 (31%) attending four or more.

4.2. Distress thermometer scores

There was a significant reduction in reported distress following a period of psycho-oncology care. The mean DT1 score for 106 patients was 5.7 [median, 6; interquartile range (IQR), 4–7], decreasing to a mean DT2 score of 3.8 (median, 4; IQR, 2–6), Wilcoxon signed ranks test z=-4.83, P<.001. We calculated the clinical effect size [18] for the reduction in DT scores for those 50 patients for whom there was paired data. Their mean DT1 score was 6.83 (S.D., 2.46) and mean DT2 score was 3.8 (S.D., 2.22). Correcting for dependence between means (r=0.46) using standard formula [19], Cohen's d was 1.22. This indicates a large clinical effect size.

4.3. Problem checklist

Distress scores correlated significantly with numbers of problems in different categories (Table 1). However, for both DT1 and DT2, the strongest correlation of distress was with emotional problems. Reduction in distress (DT1 minus DT2 score) was also significantly associated with the initial number of emotional problems (r=0.34, P=.03).

Table 2 shows the number of patients who listed one or more problems in each category. Table 3 presents the data as the median number of problems per patient. Data are shown before and after psycho-oncology intervention, with types of emotional problem described in detail.

The majority (97%) highlighted multiple difficulties. Emotional problems were the most common (93%), whereas only 4% had spiritual or religious problems. Multiple problems were present before and after psycho-oncology input (median of 7 versus 5 per patient). However, analysis of paired data showed a significant reduction in the number of emotional problems reported by each patient following psycho-oncology care. The number of patients affected by each type of emotional problem also decreased by between 15% and 24%. For example, the proportion with worry fell from 70% to 46%, depression from 33% to 16% and anger from 36% to 18%. There was no comparable significant reduction in the proportion of patients affected by other categories of problem (physical, practical or family).

Table 2
Problems identified by distress thermometer: number of patients affected at start versus end of care

Type of problem	Patients affected at start (*n*=106)	Patients affected at end (*n*=50)	chi-Square (*P* value)
	No. (%)	No. (%)	
All problems	102 (97)	47 (94)	0.39 (.53)
Practical	40 (45)	18 (36)	0.04 (.83)
Family	39 (37)	18 (36)	0.01 (.92)
Spiritual/religious	4 (4)	3 (6)	0.39 (.53)
Physical	91 (87)	39 (78)	1.51 (.22)
Emotional (all types)	98 (93)	38 (76)	8.23 (.004)**
Worry	74 (70)	23 (46)	8.19 (.004)**
Sadness	47 (45)	14 (28)	3.81 (.05)*
Depression	35 (33)	8 (16)	4.93 (.02)*
Nervousness/anxiety	64 (61)	20 (40)	5.68 (.02)*
Anger	38 (36)	9 (18)	5.14 (.02)*
Loss of enjoyment	35 (33)	9 (18)	3.79 (.05)*
Concerns about the way I look	37 (35)	13 (26)	1.24 (.27)

* *P*<.05.
** *P*<.01.

4.4. Gender

Significantly more women than men were concerned about their appearance at the point of referral (35/86, 41% versus 2/19, 11%, P=.01, Fisher's exact test). This gender difference was not statistically significant following psycho-oncology input (30/42, 29% women versus 1/8, 13% men, P=.66). There were no significant associations between gender and types of problem or distress scores.

4.5. Age

Older patients had more practical problems at the point of referral (r=0.31, P=.001) but fewer family problems (r=−0.28, P=.04).

Table 3
Problems identified by distress thermometer: median number per patient at start versus end of care

Type of problem	No. of problems at start (*n*=106)	No. of problems at end (*n*=50)	Wilcoxon *z* (*P* value)
	Median (IQR)	Median (IQR)	
All problems	7 (5–10)	5 (3–8.5)	−3.73 (<.001)***
Practical	0 (0–1)	0 (0–1)	− 0.816 (.42)
Family	0 (0–1)	0 (0–1)	−2.03 (.042)*
Spiritual/religious	0 (0–0)	0 (0–0)	− 0.577 (.56)
Physical	3 (2–5)	2 (1–4.25)	−1.84 (.065)
Emotional (all types)	3 (2–4)	1.5 (0.75–3.25)	−4.4 (<.001)***
Worry	1 (0–1)	0 (0–1)	2.67 (.008)**
Sadness	0 (0–1)	0 (0–1)	-1.94 (.05)*
Depression	0 (0–1)	0 (0–0)	−2.31 (.02)*
Nervousness/anxiety	1 (0–1)	0 (0–1)	−2.98 (.003)**
Anger	0 (0–1)	0 (0–0)	−2.31 (.02)*
Loss of enjoyment	0 (0–1)	0 (0–0)	−1.16 (.25)
Concerns about the way I look	0 (0–1)	0 (0–1)	−3.12 (.02)*

* *P*<.05.
** *P*<.01.
*** *P*<.001.

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Table 4
Predictors of distress thermometer score at discharge

Predictive covariate[a]	Regression coefficient (beta)	*P* value
DT score at start	0.265	.052
No. of appointments attended	-0.064	.647
No. of emotional problems at discharge	0.468	.002**
No. of physical problems at discharge	0.298	.024[a]
Satisfaction with care	−0.101	.435

[a] Multivariate regression analysis (ANOVA) of predictors of final distress thermometer score.

There were no significant correlations between age and other categories of problem or distress scores.

4.6. Number of appointments

Patients who attended more appointments had a greater number of emotional problems at the start ($r=0.22$, $P=.03$) and end ($r=0.50$, $P=.001$) of care. Attendance also correlated with distress scores ($r=0.26$, $P=.007$ for DT1; $r=0.30$, $P=.03$ for DT2). However, the size of reduction in distress (DT1 minus DT2 score) showed no significant correlation with number of appointments ($r=0.002$, $P=.99$). Age and gender were not significantly associated with attendance.

4.7. Origin of referral

There was no significant difference in patient characteristics, distress scores or problems with regard to the clinical specialty of the referring department.

4.8. Regression analysis

The strongest predictor of final DT2 score using multivariate regression analysis (Table 4) was the number of emotional problems at discharge ($P=.002$) followed by the number of physical problems at discharge ($P=.024$).

4.9. Clinician feedback

All four psycho-oncology professionals reported that introducing the DT into routine practice was acceptable and useful. It was found to add structure and additional information to their initial assessment and provide a useful baseline for reviewing progress at a later date.

4.10. Service satisfaction

Of 43/50 (86%) patients who replied, 28 (65%) rated their global satisfaction with psycho-oncology care as 10/10 and the remaining 15 (35%) rated satisfaction between 6 and 9/10 (median satisfaction score, 10; IQR, 9–10). Satisfaction scores showed a significant inverse correlation with DT2 ratings (Spearman's $r=-0.424$, $P=.005$) and number of emotional problems reported at discharge ($r=-0.314$, $P=.04$). We found no significant correlation between patients' satisfaction scores and their age, gender, origin of referral, number of appointments attended, DT1 score, change in DT score (DT1 minus DT2) or number of problems in other categories at discharge.

Patients made 57 free text comments about the most helpful aspects of their psycho-oncology care (Table 5). The most common themes were being able to talk openly ("X was so easy to speak to…"), feeling supported ("X understood how I feel…") and advice on specific coping strategies. Eight patients made suggestions for service improvement, including more group work, greater links with employment organizations and improved funding to cut waiting times. Twelve patients commented positively that they felt nothing could be improved ("My partner and I were very happy") because they were entirely satisfied with their care ("This is an excellent service for both emotional and practical support").

5. Discussion

5.1. Summary of main findings

The results of this study suggest that the distress thermometer can be a useful tool to enhance the delivery of structured psycho-oncology care. It may also be helpful when evaluating the clinical outcome following specialist input.

Patients reported a clinically and statistically significant reduction in their psychological distress following a period of psycho-oncology intervention. DT scores were significantly associated with physical, emotional and practical types of problems. However, the reduction in numbers of problems after intervention was mainly explained by patients having fewer emotional problems (such as anxiety, depression and anger), rather than other categories of problem that may be less amenable to psychological approaches.

Our findings suggest that cancer patients with higher levels of distress are being appropriately referred. The median DT1 score of six is above the suggested threshold of four out of ten for referral to psycho-oncology from screened generic cancer services [4] and significantly higher than that observed in a local renal outpatient

Table 5
Patient satisfaction with psycho-oncology service: qualitative thematic analysis

Most helpful aspect of care	No. of responses ($n=57$)	Examples (anonymized quotes)
Being able to talk openly	16	Feeling free to talk/being able to open up Discussing cancer and using the "C" word Just talking — but in a controlled environment Discussing my problems in an objective way
Feeling supported/listened to/understood	14	Support with my illness Reassurance I won't be left alone Regular appointments with a sympathetic listener Being listened to without feeling judged
Advice on coping strategies	10	Clear ideas about how to improve my quality of life Practical/CBT suggestions on coping Methods learned to deal with stress/anxiety/OCD Thinking differently about all aspects of my life
Professional is independent	8	Someone neutral to discuss my thoughts with Being able to talk about my fears with a person not involved in my physical care
Other	9	Talking to psychiatrist to review medication Getting test results Clarifying concerns about cancer treatment & surgery Help in understanding myself better

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population (3.2, $n = 183$) within the same hospital [20]. Distress scores and emotional difficulties were significantly associated with the number of psycho-oncology appointments attended. This may be due to clinicians offering longer contact to patients according to need, patients requesting more contact or both.

Satisfaction with care was linked to lower distress scores at discharge and to having fewer emotional problems, but interestingly not to the number of appointments provided. This may indicate that it is the quality rather than the quantity of care that is most valued by patients. Qualitative analysis of feedback received following psycho-oncology input suggests that patients particularly value generic therapeutic skills (such as supportive listening) provided by a professional who is independent from their physical care. Systematic reviews of cancer care outcomes confirm that professional empathy is associated with higher patient satisfaction and lower distress [21]. This is separate from the development of coping skills and empowerment through medical knowledge.

5.2. Strengths and limitations

The strengths of this study include successful embedding of the distress thermometer within a nationally recommended clinical care pathway and the high response rate achieved across a diverse population of cancer patients. The DT tool was used in an innovative way to re-evaluate distress and problems over time and it included both quantitative and qualitative measures of satisfaction as a linked outcome.

The study has several important limitations. We did not compare the DT with established outcome measures, and this was a prospective service evaluation, not a controlled study of psycho-oncology intervention versus standard care. We do not know whether the improvements that occurred can be directly attributed to the care provided or to any particular psychotherapeutic approach. There is a potential for selection bias among respondents, as the outcome of those discharged after one appointment, and those who did not complete the DT2, remains uncertain. Use of the DT itself may also have contributed to a sense of being cared for. However, there is indirect evidence to suggest that the passage of time alone is unlikely to explain the significant reductions in psychological distress. First, most (94%) patients reported multiple continued problems at psycho-oncology discharge, including physical, practical and family-related difficulties. Second, a recent randomized controlled trial [22] comparing the effect of screening cancer patients using the DT with usual care found no difference in psychological distress between the two groups at 12 months follow-up. Significantly, in that study, less than 3% had received any form of specialist intervention from a clinical psychologist or psychiatrist.

The results may not be generalizable to inpatient settings, primary care or to patients aged 18 years or younger. In addition, the sample size may be insufficiently powered to detect real differences in outcome between some patient characteristics. The high level of patient satisfaction may also have produced a "ceiling" effect masking differences between patients. This is consistent with research examining patient satisfaction in other areas of health care [23,24]. Finally, we cannot assume that high levels of satisfaction with cancer care have a wider impact upon patients' lives, although one meta-analysis of controlled trials of psychosocial interventions [25] found significant improvements (effect size, 0.31) in patients' general quality of life.

5.3. Implications for future practice

The United Kingdom Cancer Care Strategy emphasizes the need for regular holistic assessment of individuals with cancer [26]. Further work is required to determine the validity and test–retest reliability of this tool as an outcome measure [3,10]. However, this study suggests that specialist psycho-oncology services could usefully integrate the distress thermometer into their assessment and discharge care pathway. The routine addition of a service satisfaction component may further enhance "real world" communication that remains important to professionals and patients alike.

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