The distress thermometer is a quick screening tool used to measure psychological symptoms in patients with cancer

A tool to measure levels of psychological distress

In this article...

- Why patients with cancer need psychological support
- How the distress thermometer was used to measure symptoms
- Pilot results and ongoing work

Keywords: Cancer/Psychological symptoms/Distress thermometer

- This article has been double-blind peer reviewed

As a result, the distress thermometer was piloted in this department and we found it to be a useful tool for two purposes:

- Screening and identifying patients who need our service;
- Addressing the above key recommendations.

What is distress?
Distress is a feeling of unease stemming from concerns or worries. People undergoing cancer treatment and their carers may experience distress, depression and anxiety. These can manifest in many ways, such as:

- Panic attacks, irritability and poor sleeping;
- Feelings of apprehension and worry;
- Being in denial about the cancer diagnosis and poor concentration.

Subsequently, distress can influence quality of life and participation in medical treatment. Although not everyone wants to openly discuss their feelings and emotional distress, research shows that early advice, support, education and intervention with small worries can avoid the demand for intensive intervention and clinically significant psychological problems at a later stage.

Why a distress thermometer?
Quick screening tools involving fewer than five questions have been recommended as a simple method of detecting distress, anxiety or depression in several different types of cancer settings.

The National Comprehensive Cancer Network (1998) in the US developed the distress thermometer, which has been widely used for people with cancer. Results of the research and evaluation show that:

- People who score four or below are considered to have “expected distress symptoms” and need simple intervention, while those who score above four are considered to have more serious distress symptoms.

Patients and carers have different needs at different phases of the illness and our service needs to be responsive to this. Although it is important that all patients have equal access to the Macmillan radiographer service, owing to resources and time constraints it is impossible, and not always necessary, to see and support everyone undergoing radiotherapy.

Results from a recent audit indicated only 50% of people having radiotherapy treatment had contact with our service and 35% were unaware that it was available. We felt that a tool would be useful for screening all patients and, where appropriate, accompanying family members and carers attending the department. This would help to identify those with information and support needs and ensure all patients referred for radiotherapy are offered access to our service and followed up with extra information and support if needed.

The National Institute for Health and Clinical Excellence (2004) recommended that people with cancer should have their physical, psychological, social, spiritual and financial needs assessed, and that this should be undertaken at key points in their cancer experience:

- Around the time of diagnosis;
- When treatment begins;
- When the primary treatment plan finishes;
- If the disease recurs;
- At the point when it is recognised the cancer cannot be cured;
- At the point when dying is diagnosed;
- At any other time that patients request.

Professionals should carry out these assessments in partnership with patients and carers.

Psychological distress is common among people affected by cancer and is an understandable response to a traumatic and threatening experience. People draw on their inner resources to help them cope and many seek emotional support from family and friends. However, some are likely to benefit from additional professional intervention because of the level and nature of their distress.

In practice, psychological symptoms are often not identified and people with cancer lack sufficient access to psychological support services.

The Macmillan information and support radiographers at the Ipswich Hospital Trust provide accurate, evidence-based information and support (psychosocial, psychosexual and emotional) to anyone affected by radiotherapy treatment. Relevant information and support is given sensitively and at an appropriate time for patients and carers, and is available at any stage of the clinical care pathway.

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Pilot of the distress thermometers
Thirty patients were given the tool to complete at their first appointment in the radiotherapy department. The distress thermometer was returned to the Macmillan information and support radiographers for assessment, who then met with patients scoring four or more on the thermometer, and those who highlighted several concerns on the list. During this consultation practitioners looked at the list with patients to identify key areas of concern. They asked further questions to determine how patients could be best supported to minimise their distress.

This involved simple intervention for expected distress symptoms. Symptoms and interventions could include those outlined in Box 1.

The distress thermometer was completed again during treatment and also used to plan care and follow-up needs after treatment.

Results of the pilot
The distress thermometer was easy and quick to fill in. It gave patients time to consider their problems, talk about anxiety levels, explore issues openly and allowed time for reflection.

Both patients and the Macmillan radiographers noticed that their interactions were more focused, with a more efficient use of consultation time.

Patients already known to the service had fewer issues and scored lower than those who had not met the Macmillan radiographers before attending the radiotherapy department. Levels of distress decreased when the distress thermometer was repeated later in treatment.

The thermometer was useful in screening patients and identified those who needed help and access to the service. In the free-text area many gave useful feedback about the tool.

We have developed guidelines for radiographers to use the tool and they have adopted it in the radiotherapy department for all patients. However, if patients prefer not to complete the distress thermometer then staff respect this and make a note on their treatment sheet.

Patients having more than 15 treatments are given another form to complete to plan care after this.

The distress thermometer can also be given to carers to help them with their concerns and emotional issues; we have found that carers’ levels of distress are often much higher than patients’. Current research recognises this and it is an area that requires more recognition within information and support roles.

Oncology site-specific clinical nurse specialists at the trust have now adopted the distress thermometer as the recommended assessment tool and we are in the process of rolling it out following government guidelines (Department of Health, 2007).

Conclusion
This work has become part of the in-house “moving on” programme to help people living with cancer, and part of the National Cancer Survivorship Initiative.

We are hoping to provide better signposting and a more effective service for our patients, as well as training radiographers to help patients needing simpler interventions.

References

BOX 1. PSYCHOLOGICAL SYMPTOMS AND INTERVENTIONS

Symptoms
● Problem solving
● Treatment concerns
● Concerns about the illness
● Sadness about the loss of good health
● Anger and the loss of control
● Poor sleep, concentration and appetite

Interventions
● Listening and practical advice such as applying for Macmillan grants
● Explaining and managing side-effects, fear, worry and concerns about the future
● More complex intervention and referral to other agencies such as support groups, social work, complementary therapy and counselling

FIG 1. THE DISTRESS THERMOMETER
Source: Macmillan Cancer Support

5 key points
1 Psychological distress is common among people affected by cancer
2 Psychological symptoms are often not identified and people with cancer lack access to support services
3 Patients should have their physical, psychological, social, spiritual and financial needs assessed at key points in their cancer experience
4 The distress thermometer is quick and easy to fill and patients find ticking boxes about intimate matters easier than discussing them
5 The thermometer is useful in screening patients and identifying those who need help and access to the service

and require more specialist interventions;

People like the thermometer and it is easy to use. It generally takes about 20 seconds to complete and patients and carers reported that it helped them focus on their true concerns.

Our adaption of the distress thermometer is an A5-sized sheet with a definition of distress, a thermometer (Fig 1), a list of causes of distress and areas of concern, and an explanation of the role of the Macmillan information and support radiographers. Patients and carers are also invited to write down anything they want to tell us that is not included on the form. Our contact details are given with the form along with instructions for returning it.

Patients are asked to consider their levels of distress over the last week and score themselves between 0 (no distress) and 10 (extreme distress).