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Validation of the Distress Thermometer in a Swedish population of oncology patients; accuracy of changes during six months

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A B S T R A C T

Purpose: To validate the Swedish version of the Distress Thermometer (DT) against the Hospital Anxiety and Depression Scale (HADS) for screening of distress and to explore how well DT measures changes of distress during six months in a population of heterogeneous oncology patients.
Methods: The DT was translated into Swedish according to the forward- and back-translation procedure. HADS total score ≥15 was used as gold standard. Consecutive patients were invited to participate at their first visit to the Oncology department. The HADS and the DT were completed at baseline and after 1, 3 and 6 months.
Results: 462 baseline and 321 six-month assessments were completed. The patients had a variety of cancer diagnoses ($n = 42$). Most patients (95%) received active treatment. The DT compared favourably with the HADS. The area under the curve was 0.86 (95% CI, 0.82–0.90). DT ≥ 4 showed a sensitivity of 87%, a specificity of 73%, a positive predictive value (PPV) of 52% and a negative predictive value (NPV) of 95% at baseline. The results from the 1, 3 and 6 months assessments were equivalent baseline results. The DT means changed in the same direction as HADS at all points of assessment. Patients with distress reported statistically significantly more problems in all categories on the associated 'Problem List' compared to non-distressed patients.
Conclusion: The Swedish version of the DT with a score ≥4 is valid for screening of distress in heterogeneous oncology patients. Its ability to measure changes in distress over time is comparable to HADS.

Introduction

Distress is defined as 'an unpleasant emotional experience of a psychological, social, and/or spiritual nature which extends on a continuum from normal feelings of vulnerability, sadness and fears to problems that become disabling, such as depression, anxiety, panic, social isolation, existential and spiritual crises' (Holland et al., 2011). In large heterogeneous groups of cancer patients the overall prevalence rate of distress is between 35 and 44% (Carlson et al., 2004; Zabora et al., 2001). Distress has been endorsed as the 6th vital sign in cancer care (after temperature, respiration, heart rate, blood pressure and pain) (Bultz and Carlson, 2006). Emotional stress, anxiety and depression are reported as top problems next after fatigue and pain in cancer patients (Carlson et al., 2004). However, oncologists and nurses lack appropriate methods to correctly identify cancer patients' psychological concerns (Fallowfield et al., 2001; Mitchell et al., 2010; Sollner et al., 2001). Routine screening for distress and the use of screening instruments are ways to enhance identification of patients with psychological problems and to facilitate communication between staff and patients about these issues (Carlson et al., 2012). The National Comprehensive Cancer Network (NCCN) has developed clinical practice guidelines for distress management and their standards of care for distress management states that 'All patients

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should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated especially with changes in disease status' (Holland et al., 2011).

The Hospital Anxiety and Depression Scale (HADS) is used for screening to detect patients with psychological distress (Sellick and Edwardson, 2007). The validity of HADS has been considered good to very good for screening of anxiety and depression in patients with cancer as well as other somatic diseases (Bjelland et al., 2002). The HADS is a short instrument with only 14 items, but it needs calculation of scores and assessment concerning cut-off levels for distress, anxiety and depression which can be time consuming. There is a need to develop screening instruments which are time-efficient and easier to use for patients and staff in daily clinical practice.

The Distress Thermometer (DT) is a single-item questionnaire (Roth et al., 1998). It performs favourably compared to other, more extensive measures used for screening of distress (Jacobsen et al., 2005; Ozalp et al., 2007; Roth et al., 1998). The sensitivity and specificity of the DT has been evaluated and the recommended cut-off scores for heterogeneous groups of cancer patients differ from ≥4 (Gunnarsdottir et al., 2011; Jacobsen et al., 2005; Ozalp et al., 2007; Shim et al., 2008) to ≥5 (Gessler et al., 2007; Tuinman et al., 2008). Sensitivity and specificity of the DT has also been evaluated for specific cancer diagnosis with the recommended cut-off score of ≥5 for prostate cancer patients (Roth et al., 1998) and patients candidate for bone marrow transplants (Trask et al., 2002) and ≥7 for patients recently diagnosed with breast cancer (Bidstrup et al., 2011a,b; Hegel et al., 2008). In the NCCN guidelines the DT is accompanied by a 'Problem List' which identifies sources of distress (Holland and Bultz, 2007). When evaluated statistically, the DT cut-off score was significantly related to most problems on the 'Problem List', especially emotional problems such as depression, fear, nervousness, sadness and worry (Jacobsen et al., 2005). Gessler et al. indicate limit evidence of the DT's capacity to monitor changes in psychological distress over time at four and eight weeks follow-up. The DT scores changed in the same direction as the scores of HADS, but had a low-to-moderate responsiveness. Additional research to assure evidence of the DT's capacity to monitor changes over time has been suggested (Gessler et al., 2007). There is also a lack of prospective longitudinal studies to evaluate the DT in clinical settings, as most previous studies have been cross-sectional (Gunnarsdottir et al., 2011; Jacobsen et al., 2005; Ozalp et al., 2007; Tuinman et al., 2008).

There is no previous study on how the DT performs in a Swedish context. We aimed to validate the Swedish version of the DT against the HADS for screening of distress and to explore its ability to monitor distress, its ability to discriminate between medical and demographic subgroups, its clinical suitability for repeated use and how well it measures changes over time compared to HADS in a population of heterogeneous oncology patients over a period of six months. A further aim was to compare distressed patients with non-distressed patients regarding problems on the 'Problem List'.

Materials and methods

Design and settings

Between September 2005 and June 2006, patients were invited to participate in the study at their first visit or within one month after their first visit at the Department of Oncology, Uppsala University Hospital. Patients were invited consecutively, regardless of diagnosis, stage or time since diagnosis. The patients were informed about the study and invited to participate by a research nurse (RN) at the hospital (in person) or by telephone. After the informed consent form was signed, the questionnaires were distributed to the patients by the RN or sent by post to the patients with an addressed prepaid envelope for the return. Exclusion criteria were inability to speak and understand Swedish, cognitive inability or constant need of hospital care (Karnofsky <40). The study was approved by the Regional Ethical Review Board, Uppsala University.

Out of 644 approached patients, 547 (85%) patients gave their written informed consent. Four hundred and sixty-two of them (84%) completed the baseline assessment (Fig. 1). The patients completed the questionnaires again after 1, 3 and 6 months. The 6 month assessment was completed by 339 (73%) of the patients who answered baseline assessment.

Data collection

Data regarding sex, age, marital and occupational status, residential area, diagnosis, stage, oncological treatment and disease status at 6 months were collected from the medical records.

The Distress Thermometer

The patient reports distress on a thermometer, similar to the 11-point Likert scale, with scores from 0 (no distress) to 10 (high distress) (Roth et al., 1998). The NCCN 'Problem List' consists of 35 problems commonly experienced by cancer patients, grouped into

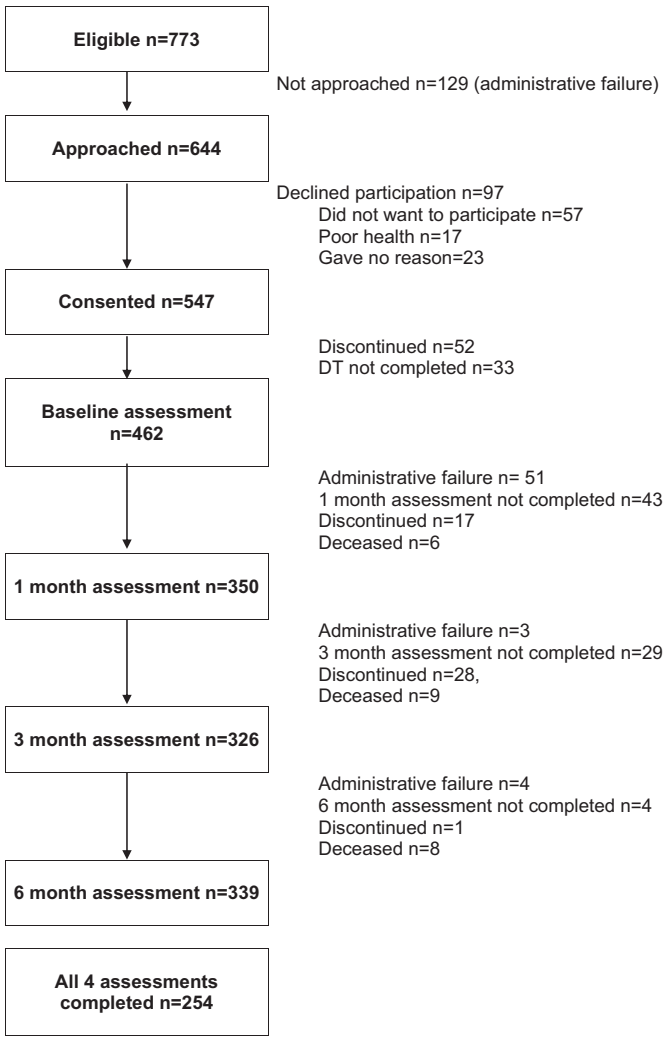

Fig. 1. Flow chart.