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Accuracy of the Distress Thermometer for home care patients with palliative care needs in Germany

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ABSTRACT

Objective: Our aim was to examine the accuracy of the German version of the Distress Thermometer (DT) compared with the Hospital Anxiety and Depression Scale (HADS) in patients with palliative care needs living at home.

Method: Ours was a 15-month cross-sectional study beginning in September of 2013 in Germany with consecutive patients cared for by a palliative home care service. The survey was implemented during the initial visit by a home care team. Patients were excluded if they were under 18 years of age, mentally or physically unable to complete the assessment questionnaires as judged by their healthcare worker, or unable to understand the German language. During the first encounter, the DT and HADS were applied, and sociodemographic and medical data were collected.

Results: A total of 89 persons completed both the HADS and DT questionnaires (response rate = 59.7%; mean age = 67 years; female = 55.1%; married = 65.2%; living home with relatives = 73.0%; oncological condition = 92.1%; Karnofsky Performance Scale [KPS] score: 0–40 = 30.3%, 50–70 = 57.3%, >80 = 6.7%). The mean DT score was 6.3 ($\pm$2.3), with 84.3% of participants scoring above the DT cutoff ($\geq$4). The mean $HADS_{total}$ score was 17.9 ($\pm$7.8), where 64% of participants had a total HADS score ($HADS_{total}$) $\geq$15, 51.7% reported anxiety ($HADS_{anxiety} \geq 8$), and 73% reported depression ($HADS_{depression} \geq 8$). Using the HADS as a gold standard, a DT cutoff score $\geq$5 was optimal for identifying severe distress in patients with palliative care needs, with a sensitivity of 93.0%, a specificity of 34.4%, a positive predictive value (PPV) of 73.3%, and likelihood ratios LR+ = 1.42 (<3) and −LR = 0.203 (<0.3).

Significance of results: The DT performed satisfactorily compared to the HADS in screening for distress in our study and can be employed as an instrument for identification of patients with distress. Consequent to the high prevalence of distress, we recommend its routine use for screening distressed persons at home with palliative care needs in order to offer adequate support.

KEYWORDS: Psychological distress, Distress Thermometer, HADS, Home care, Germany

INTRODUCTION

Patients with advanced disease often suffer from psychosocial distress (Block, 2001; Gotze et al., 2014; Gruneir et al., 2005; Mazzocato et al., 2000). The reported prevalence of distress varies between 20 and 30% depending on what measurement instrument is employed (Thekkumpurath et al., 2008). Psychological distress tends to be underdiagnosed and undertreated in palliative care settings (Thekkumpurath et al., 2008). Ultrashort screening tools like the Distress Thermometer (DT) were developed to facilitate its detection (Mitchell, 2007).

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Several studies have examined the validity of screening tools in patients with early-stage disease. However, research and clinical guidance are lacking for treatment of patients with advanced disease (Thekkumpurath et al., 2009). The German Association for Palliative Medicine has recommended the Distress Thermometer (DT) and the Hospital Anxiety and Depression Scale (HADS) for basic assessment and identification of psychosocial distress in the context of palliative care (Herschbach & Weis, 2008). However, validation of a German version of these instruments in a palliative home care setting has not been yet been accomplished. Validation in a palliative care setting is important, because the properties of an instrument as a screening tool depend partly on the population in which it is investigated (Rouse, 2007). In a former study (Küttner et al., 2016), we demonstrated that the DT has a high degree of sensitivity and acceptability in persons at the end of life.

The objective of the current paper was to examine the accuracy of the DT and identify an optimal cutoff score for its German version (Mehnert et al., 2006) compared to the HADS in home care patients with palliative care needs.

METHODS

A 15-month cross-sectional study was begun in September of 2013 in Aachen (Germany) with consecutive patients cared for by a palliative home care service. The survey was conducted during the first contact. Patients were excluded if they were under 18 years of age, mentally or physically unable to complete the assessment questionnaires as judged by their healthcare workers, or unable to understand the German language.

Measures

Sociodemographic and medical data were collected. The variables assessed were sex; age; marital status; living situation (alone, with family, or in an institution); care situation; diagnosis; functional status (Karnofsky Performance Status [KPS] score reported by health worker); duration of illness (time from diagnosis to first contact); outcome (death or discharge); and, for patients who died, the total number of days in the study was recorded.

The Distress Thermometer is a single-item self-report measure of distress (Roth et al., 1998). It was developed as an ultrashort screening tool for patients with a cancer diagnosis by the National Comprehensive Cancer Network (NCCN) (Holland et al., 2013; Roth et al., 1998) and has been validated and employed in different settings and patient populations (Donovan et al., 2014; Ma et al., 2014), including palliative care settings (Gessler et al., 2008; Thekkumpurath et al., 2009). It has an 11-point range, with endpoints from 0 ("no distress") to 10 ("extreme distress"). Respondents were instructed to circle the number (0–10) that best described how distressed they were during the previous week. According to the NCCN guidelines, a score of 4 or higher on the rating scale is defined as "significant distress" and indicates the need for professional support (Holland et al., 2013). On the associated problem list, patients identify the source of their distress during the previous week from five categories (emotional, familial, practical, spiritual, and physical).

The HADS is a 14-item self-rated scale with two 7-item subscales: depression and anxiety (Zigmond & Snaith, 1983). The cutoff scores used for the HADS are $HADS_{total} \geq 15$, $HADS_{anxiety} \geq 8$, and $HADS_{depression} \geq 8$ (Herrmann, 1997). The accuracy of the single-item DT has been compared with $HADS_{total}$ as the standard measurement. The HADS has been validated in patients with palliative care needs (Mitchell et al., 2010). Validation of the DT versus HADS has been conducted several times (Gessler et al., 2008; Roth et al., 1998; Thalén-Lindstrom et al., 2013). We employed the same approach in a palliative home care setting.

Sample Size Calculation

The sample size calculation showed that 62 patients were required to ensure that, to achieve 95% coverage probability, sensitivity and specificity equal to 80% with a tolerance of 10% were necessary (nQuery Advisor® 7.0). Sensitivity and specificity of 80% are considered to be indicative of a valid diagnostic measure.

Statistical Analysis

The data were anonymized and collected in a digital database. Statistical analysis was conducted using the Statistical Package for the Social Sciences for Windows (v. 21). A descriptive analysis of the demographic and clinical parameters of patients who completed the study was conducted. The linear relationship of DT score with $HADS_{total}$ score was investigated using Pearson's correlation coefficient (ρ). In addition, we analyzed the diagnostic quality of the DT using receiver-operating characteristic (ROC) curve analyses. The optimal cutoff score was determined according to the Youden criterion (maximized $Y = Se + Sp - 1$), also considering that a high sensitivity was important due to the increased risk of death associated with a high level of distress. The accuracy properties of sensitivity (Se), specificity (Sp), positive predictive value (PPV), negative predictive value (NPV), and positive and

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negative likelihood ratios (+LR and −LR) were calculated for each cutoff of the DT score versus $HADS_{total}$.

The ethics committee of the Medical Faculty of RWTH University Aachen approved our study.

RESULTS

During the study period, a total of 286 new individuals were registered for home care services. Of these, 138 were excluded from the study (Figure 1), and 103 of the remaining 148 eligible patients completed the questionnaires (DT and HADS). However, 14 HADS questionnaires were not evaluable, because some questions were disregarded, which left a total response rate of 59.7% ($n = 89$) (Figure 1). Those who did not complete the HADS questionnaire had higher DT values (t test, $p = 0.029$). No other statistically significant differences were found between participants and nonparticipants with regard to KPS score, age, sex, or polypathology. The following analysis includes these 89 subjects.

Most participants were women (55.1%, $n = 49$). The mean age of patients was 67 years (range = 45–89). The majority of participants were married or living in a formal relationship (65.2%, $n = 58$). Some 73% of participants lived at home and were mainly cared for by relatives (57.3%, $n = 51$). The main diagnosis was cancer (92.1%, $n = 82$), mostly located in the digestive system (29.3%, $n = 24$), reproductive organs (26.8%, $n = 22$), and respiratory tract (25.6%, $n = 21$). Metastases were registered in 60.7% ($n = 54$) of oncological diagnoses. Participants had an average of four different diagnoses. The mean KPS score was 50.8 ($\pm$15.9). For 57.3% ($n = 51$) of participants, this index was reported to be between 50 and 70, indicating severely impaired functional performance.

The average time between receiving the diagnosis and their first contact with the home care team was 29 $\pm$ 45 months (range = 25 days to 25 years). Some 86% of patients died within 10.2 ($\pm$12.3) weeks, and 13.6% ($n = 12$) were discharged (Table 1).

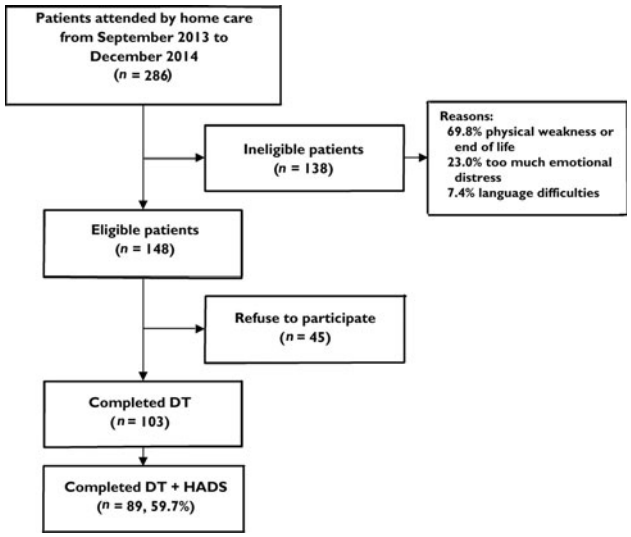

Fig. 1. Flow diagram of participant recruitment.

Table 1. *Sociodemographic and medical characteristics of the sample*

Characteristics	Participants, $N = 89$ (%)
Age, years, mean ($\pm SD$)	67 $\pm$ 10.6
Sex	
Female	49 (55.1)
Male	40 (44.9)
Marital status	
Married/partnership	58 (65.2)
Widowed	16 (18.0)
Divorced	7 (7.9)
Single	5 (5.6)
No data	3 (3.4)
Living situation	
At home with relatives (partner or family)	65 (73.0)
At home alone	19 (21.3)
Institution (hospice or nursing home)	3 (3.4)
No data	2 (2.2)
Everyday care mainly by	
Relatives	51 (57.3)
Professionals	17 (19.1)
No data	21 (23.6)
Diagnosis	
Oncological	82 (92.1)
With metastases	54 (60.7)
Polypathology, mean ($\pm SD$)	4.1 ($\pm$2.22)
Primary site	
Digestive system	24 (29.3)
Reproductive system	22 (26.8)
Respiratory tract	21 (25.6)
Without specification of site	5 (6.1)
Lymphoid, hematopoietic	4 (4.9)
Head & neck	4 (4.9)
Mesothelium and soft tissue	1 (1.2)
Central nervous system	1 (1.2)
Karnofsky Performance Scale score, mean $\pm SD$	50.8 $\pm$ 15.9
0–40	27 (30.3)
50–70	51 (57.3)
80–100	6 (6.7)
No data	5 (5.6)
Months since diagnosis, mean ($\pm SD$)	27.5 ($\pm$44.3)
Outcome	
Death	76 (86.4)
In weeks, mean $\pm$ SD	10.2 $\pm$ 12.3
Discharge	12 (13.6)

SD = standard deviation.

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Prevalence of Psychological Distress

The mean DT score was 6.3 ($\pm$2.3), with a range of 0 to 10. Using the DT, 89% ($n = 79$) of participants scored above the DT cutoff score ($\geq$4). The mean $HADS_{total}$ score was 17.9 ($\pm$7.8), with a range of 1 to 35. Using the HADS, 64% ($n = 57$) of participants reported distress ($HADS_{total} \geq 15$).

Patients with a DT score $\geq$4, indicating significant distress according to NCCN guidelines, had a significantly higher probability of dying within 1 to 10 weeks after completing the DT questionnaire (χ^2, $p < 0.0001$).

No statistically significant association was found between $HADS_{total}$ or DT scores and sociodemographic or medical variables.

Comparison of DT and HADS

The Pearson's correlation between the DT and $HADS_{total}$ scores was moderately positive ($\rho = 0.522$, $p < 0.0001$). Figure 2 depicts a scatterplot that displays DT-versus-$HADS_{total}$ scores.

Overall, DT rating was significantly higher for patients who scored above the recommended $HADS_{total}$ cutoff of 15 points (t test, $p = 0.002$) than for patients who scored below the cutoff ($HADS_{total} < 15$). The area under the ROC curve (Figure 3) yielded an area under the curve (AUC) of 70% (confidence interval = 0.58–0.82). In other words, the probability is that a randomly selected person defined as a case by $HADS_{total}$ will score higher on the DT than a randomly selected person defined as a "non-case" (Table 2).

With a DT cutoff score $\geq$4, sensitivity was 94.7% and specificity 21.9%, with a PPV of 70% and an NPV of 68.4%, and with 88.8% of participants identified as being distressed. Of those screened positive by the DT, 87.5% were false positives, and, of those screened negatively by the DT, 1.8% were false negatives. The Youden optimal cutoff score on the DT within our study population was identified to be 5, which yielded a similar sensitivity as a DT score of 4 (Se = 93.0%) and a 12%-increased specificity of 34.4%.

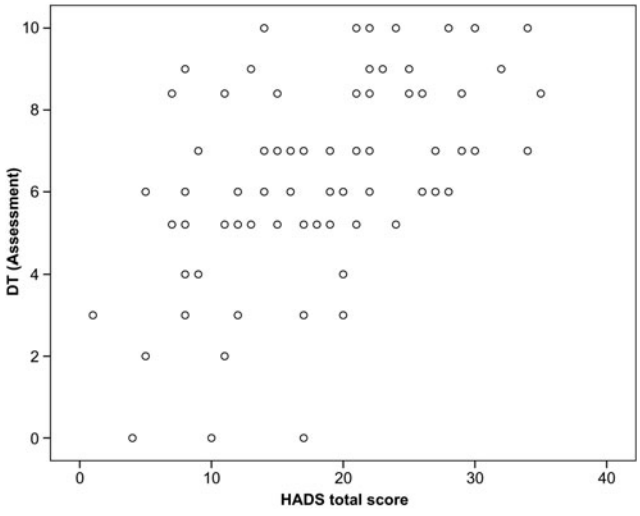

Fig. 2. Scatterplot displaying DT score versus $HADS_{total}$ score.

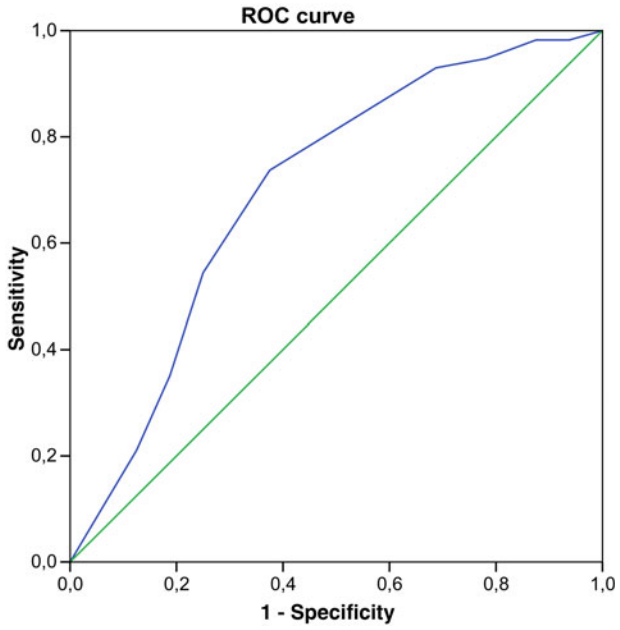

Fig. 3. Receiver operating characteristics curve of DT score versus $HADS_{total}$ score.

Comparison of DT and HADS subscales

On the HADS subscales, 51.7% of participants reported anxiety ($HADS_{anxiety} \geq 8$), and 73% reported depression ($HADS_{depression} \geq 8$). The mean $HADS_{depression}$ score was 10.10 ($\pm$4.7), while the mean $HADS_{anxiety}$ score was 7.8 ($\pm$4.7). The value of Pearson's correlation coefficient between DT scores and $HADS_{anxiety}$ or $HADS_{depression}$ was moderately positive, being higher for $HADS_{anxiety}$ ($\rho = 4.06$, $p < 0.0001$) than for $HADS_{depression}$ ($\rho = 3.62$, $p < 0.0001$).

Patients with $HADS_{depression}$ scores $\geq$8 achieved significantly higher DT scores than those who scored below 8 (similar for $HADS_{anxiety}$ scores $\geq$8; t test, $p <$ 0.0001 for both). However, no statistically significant difference was found for the sociodemographic and medical variables.

Contingency analysis between being distressed ($DT \geq 4$) and testing positive for anxiety ($HADS_{anxiety} \geq 8$) or depression ($HADS_{depression} \geq 8$) was not statistically significantly coherent (χ^2). Contingency analysis between being distressed ($DT \geq 5$) and testing positive for anxiety ($HADS_{anxiety} \geq 8$) was statistically

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Table 2. *Accuracy measure for DT scores according to $HADS_{total}$*

Cutoff (equal or greater)	*n* (%) ≥cutoff	Sensitivity	Specificity	PPV	NPV	+LR	−LR
0	89 (100)	100%	0%	64.0%	–	1	–
1	86 (96.6)	98.2%	6.3%	66.7%	65.1%	1.05	0.29
2	86 (96.6)	98.2%	6.3%	66.7%	65.1%	1.05	0.29
3	84 (94.4)	98.2%	12.5%	80.0%	66.7%	1.12	0.14
4	79 (88.8)	94.7%	21.9%	70.0%	68.4%	1.21	0.24
5	74 (83.1)	93.0%	34.4%	73.3%	71.6%	1.42	0.20
6	54 (60.7)	73.7%	62.5%	57.1%	77.8%	1.97	0.42
7	39 (43.8)	54.4%	75.0%	48.0%	79.5%	2.18	0.61
8	26 (29.2)	35.1%	81.3%	41.3%	76.9%	1.88	0.80
9	16 (18.0)	21.1%	87.5%	38.4%	75.0%	1.69	0.90
10	6 (6.7)	7%	93.8%	36.1%	66.7%	1.13	0.99

PPV = positive predictive value; NPV = negative predictive value; −LR = negative likelihood ratio; +LR = positive likelihood ratio.

significantly coherent (χ^2, $p = 0.003$). Depression ($HADS_{depression} \geq 8$) was not associated with being distressed (DT ≥ 4).

Establishment of a DT Cutoff Score

A sensitivity and specificity analysis suggested that a $HADS_{total} \geq 5$ cutoff score was Youden optimal and achieved a sensitivity of 93.0% and specificity of 34.4%, as well as a PPV of 73.3% and NPV of 71.6%. In contrast to the ≥4 cutoff, the specificity and predictive values were increased, while sensitivity was maintained. Although cutoff scores of 4 and 5 suffer from low specificity, resulting in good negative and bad positive likelihood ratios (−LR = 0.24 resp. $0.20 < 0.3$; +LR = 1.21 resp. $1.42 < 3$), a further increase in cutoff score dropped sensitivity by 20%, in exchange for a 30% increase in specificity. Since we were interested in a sensitive cutoff score, the Youden optimal score was identified as the best choice for the population at hand.

DISCUSSION

The emphasis of our study was placed on examining the accuracy of the DT in identifying distress in persons with palliative care needs in Germany, with the help of the HADS, in order to validate the DT as a palliative screening tool for Germany and to identify an optimal cutoff score for the DT.

High psychosocial distress in palliative patients has been described in the literature (Neuwohner et al., 2011; Thekkumpurath et al., 2008). Some 84% ($n = 75$) of all palliative care patients who participated in our study showed clinically significant psychosocial distress as measured by the DT according to the DT ≥ 5 cutoff criterion, and 64% ($n = 57$) according to the $HADS_{total}$ score. Distress scores were higher using the DT than the HADS (including the subcomponents). The AUC was 0.7, which indicated a fair accuracy of the DT in our population.

The ideal cutoff for the DT in palliative care patients is a matter of controversy (Mitchell, 2007). The importance of validating the DT for special populations has already been established, and an adjustment is required (Gunnarsdottir et al., 2012). In a systematic review, Ma et al. (2014) recommended a cutoff of 6 in end-of-life situations. We suggest a cutoff of ≥5 for screening and identifying distressed patients in palliative care in Germany based on achieving a sensitivity of 93% along with a reasonable specificity of ∼34%. In another palliative patient population in the United Kingdom, Thekkumpurath et al. (2009) achieved similar results (cutoff ≥5). This cutoff showed a PPV of 73.3% and an NPV of 71.6%. These findings indicate that nearly 75% of patients scoring above the cutoff on a screening questionnaire will have diagnosable psychological distress. A lower cutoff score would have greater sensitivity but very low specificity, leading to a high rate of false positives.

The only variable associated with high levels of distress by DT and $HADS_{depression}$ scores was the occurrence of death within the following weeks. No further sociodemographic or medical variables showed a statistically significant influence on levels of distress. Neither sociodemographic nor medical variables had an impact on levels of distress. Previous studies have reported a positive association between a high distress level on the DT with female gender, younger age, and lower functional status (Waller et al., 2011). In our setting, distress can be considered a general phenomenon in patients experiencing a palliative situation at home, suggesting that the palliative situation outweighs other possible sociodemographic factors.

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CONCLUSIONS

The DT performed satisfactorily compared to the HADS for screening distress in our patient population. A significant proportion of home care patients reported the symptoms of distress.

Due to the high prevalence of distress, we recommend its routine use for screening distressed persons at home with palliative care needs so that adequate support can be provided.

This is particularly important considering that even high-level distress often goes unnoticed by doctors and nursing staff (Sollner et al., 2001). The findings of our study support the use of the DT for screening persons with palliative care needs and suggest that its use can help create new concepts and structures with which to address the psychosocial needs of home care patients and achieve relief from suffering. The DT should be an integral part of the procedures utilized to detect patients' distress, and it is thus an important tool for effectively targeting adequate support to those in need.

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