Palliative and Supportive Care (2017), **15**, 205–213.
© Cambridge University Press, 2016 1478-9515/16
doi:10.1017/S1478951516000560

How much psychological distress is experienced at home by patients with palliative care needs in Germany? A cross-sectional study using the Distress Thermometer

STEFANIE KÜTTNER, M.D.,[1] JOHANNES WÜLLER, M.D.,[2] AND TANIA PASTRANA, M.D.[3]

[1]Department of Hematology and Internal Oncology, Hospital of Düren, Düren, Germany
[2]Home Care Städteregion Aachen, Aachen, Germany
[3]Department of Palliative Medicine, Medical Faculty, RWTH University Aachen, Aachen, Germany

(RECEIVED February 13, 2016; ACCEPTED June 15, 2016)

ABSTRACT

Objective: The aims of the present study were (1) to describe the prevalence of psychosocial distress in palliative care patients living at home and the related factors, and (2) to test implementation of the Distress Thermometer (DT) within a home-based palliative care service.

Method: Ours was a 15-month prospective study beginning in September of 2013 in western Germany with consecutive patients cared for by a home care palliative care service. The research was implemented during the first visit by the 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 Distress Thermometer (DT), a Problem List (PL), and a structured questionnaire for evaluation were applied and sociodemographic and medical data collected.

Results: A total of 103 patients (response rate = 70%; mean age = 67; female = 54%; married = 67%; oncological condition = 91%; Karnofsky Performance Status [KPS] score 0–40 = 34%, 50–70 = 60%, >80 = 6%) were included. The incidence of distress (DT score $\geq$4) was 89.3% (mean = 6.3 ± 2.5). No statistical association was found between level of distress and sociodemographic or medical factors. The five most reported problems were "fatigue" (90%), "getting around" (84%), "eating" (63%), "bathing/dressing" (60%), and "sleep" (57%). The number of problems reported correlated with level of distress ($\rho = 0.34$). The DT was comprehensible, and 80% considered its completion as unremarkable, while 14% found it "relieving."

Significance of results: A significant proportion of patients treated at home reported symptoms of distress. The most oft-mentioned problems were physical and emotional in nature. The findings of our study highlight the importance of creating new concepts and structures in order to address the psychosocial needs of patients in home care with palliative needs.

KEYWORDS: Psychological distress, Home, Distress Thermometer, Problem List, Germany

INTRODUCTION

Distress is defined as an unpleasant emotional state that may affect one's way of feeling, thinking, and acting (National Comprehensive Cancer Network, 2013). Patients with advanced disease often suffer from psychosocial distress (Block, 2001; Gotze et al., 2014; Gruneir et al., 2005; Mazzocato et al., 2000). Its prevalence varies depending on the measurement instrument used (Thekkumpurath et al., 2008). It has been associated with a decrease in patients' adherence to their treatment, with the ability

---

Address correspondence and reprint requests to Tania Pastrana, Department of Palliative Medicine, Faculty of Medicine, RWTH Aachen University, Pauwelsstr. 30, 52074 Aachen, Germany. E-mail: tpastrana@ukaachen.de.

to cope with the diagnosis, and with an increase in the symptom burden, and it has been determined to have a negative effect on overall quality of life (Jacobsen et al., 2005; Kelly et al., 2006; Kennard et al., 2004). Nevertheless, psychological distress tends to be underdiagnosed and undertreated in the palliative care setting (Thekkumpurath et al., 2008). Ultrashort screening methods such as the Distress Thermometer (DT) were developed to facilitate detection of distress by patients and clinicians (Mitchell, 2007).

Since many patients wish to spend their last days at home (Escobar Pinzon et al., 2011), the practice of home-based palliative care has grown significantly in recent years in Germany (Müller-Busch, 2008). This particularly applies to specialized outpatient palliative care, which is supported by the law (German Social Code, Book V, April 2007). A 2015 amendment supports expansion of general outpatient palliative care. Around 99% of the German population is insured; however, emotional and psychosocial care are not covered by health insurance nor included in home care service packages. Insurance covers full psychotherapeutic treatment only after a diagnosis of a syndrome has been made. This requires patients to go through a burdensome process to request a consult and long waiting periods for appointments. The German Association of Palliative Medicine recommended the DT among the instruments for palliative basic assessments, but its use is still limited. Studies on the psychosocial distress of patients in palliative care living at home in Germany are very limited, and research on assessment tools is certainly lacking.

The aims of our paper were (1) to describe the prevalence of psychosocial distress and related factors in palliative patients being treated at home, and (2) to test the implementation of the DT within a home-based palliative care service.

METHODS

Ours was a 15-month prospective study that began in September of 2013 in western Germany with consecutive patients cared for by a home care palliative care service. The survey was conducted during the first contact (at registration). 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.

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 the health worker), duration of illness (time from diagnosis until first contact), and outcome (either death or discharge). In addition, for patients who died, the total number of days in the study were recorded.

The Distress Thermometer (DT) 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 utilized in different settings and patient populations (Donovan et al., 2014; Ma et al., 2014), including the palliative care setting (Gessler et al., 2008; Thekkumpurath et al., 2009). The DT has an 11-point range with endpoints labeled from 0 (“no distress”) to 10 (“extreme distress”). Respondents were instructed to circle the number (0–10) that described best how distressed they were during the previous week. A score of 4 or higher is defined as “significant distress” and should indicate the need for professional support (National Comprehensive Cancer Network, 2013). In the Problem List (PL), patients identify the source of their distress during the previous week from a list of five categories (emotional, familial, practical, spiritual, and physical).

The Problem List includes 38 problems commonly experienced by cancer patients grouped into five categories (practical, family, problems, spiritual/religious, and physical problems) (National Comprehensive Cancer Network, 2013). Respondents were instructed to indicate whether (“yes” or “no”) any of the items listed were a problem during the previous week. The PL helps determine what type of professional support is most appropriate. We employed the NCCN Guidelines (v. 2013), which we modified by skipping the item “ability to conceive children” (accepted by the NCCN) and translated based on the validated German version (Mehnert et al., 2006).

A structured questionnaire was applied after the DT to assess (1) the comprehensibility of the instrument (1 = “very understandable,” 5 = “not understandable at all”), and (2) whether completing the DT/PL was experienced as a burden or relief. Further comments were recorded as free text.

Sample Size Calculation

Our sample size calculation determined that 62 patients were required to achieve a 95% confidence interval, assuming that both the sensitivity and specificity of the Distress Thermometer were equal to 0.80 (nQuery Advisor®, v. 7.0). A sensitivity and specificity of 80% was 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 SPSS software for Windows (v. 21). After a descriptive analysis, the demographic and clinical parameters of patients who completed the study were compared to those of patients who did not. The DT score was considered the primary outcome. The chi-squared (χ^2) test was employed to compare categorical data, and an independent t test or Kruskal–Wallis test was utilized for continuous data. Pearson's correlations (ρ) were conducted to explore the univariate effects on the DT. The level of significance was set at $p < 0.05$.

RESULTS

During the study period, a total of 286 new individuals were registered for home care services. Of these, 138 were excluded from our study. The completion rate was 69.6% ($n = 103$). More than half of the participants ($n = 53$, 51.5%) completed the DT/PL by themselves, while the rest requested assistance. Completion of the DT/PL took an average of 9 (±4.8) min for those who did it alone and 16 (±7.9) min for those who needed help.

Participants were mostly women (54.4%). The mean age was 67 years (range = 45–89). The majority of participants were married or living in a formal relationship (67.0%). Some 95% of participants lived at home and were mainly cared for by relatives (60.2%). The main diagnosis was cancer (91.3%), mostly located in the reproductive organs (28.7%), respiratory tract (25.5%), and digestive system (25.5%). Participants had an average of four different diagnoses. The mean KPS score was 50 (±15.7). For 60% of participants, this score was found to be between 50 and 70.

The time between receiving the underlying diagnosis and first contact with the home care team was 29 ± 45 months (range = 25 days to 25 years). More than three-quarters (87.3%) of patients died within 9 (±11.7) weeks, and 12.7% were discharged within 15.5 (±17.7) weeks after first contact (Table 1).

Nonparticipants

A total of 138 patients were excluded because they did not meet the inclusion criteria: 95 (69.8%) had physical limitations or were at the end of life; ~23% of excluded persons reported so much emotional distress that they were unable to participate; and 7.4% did not speak German. Excluded patients had a shorter survival rate than participants, were older, less cared for by relatives, and had lower KPS scores than participants. Half of them died within three weeks after first contact and had less of a chance to stabilize. All other variables yielded no statistically significant differences (Table 1).

A total of 45 patients (15.7%) refused to participate. We were unable to determine the reason for these refusals in 64.4% of these cases. All other variables yielded no statistically significant differences (Table 1).

DT Score

The lowest reported score was 0, the highest 10, with an average of 6.3 ($SD = \pm 2.5$). Almost 90% (89.3%) of participants had DT scores above the DT cutoff (≥4). A third of participants scored ≥8. Figure 1 depicts the frequency distribution of DT scores.

According to the scale proposed by Bidstrup et al. (2011), almost 50% of participants reported severe distress (DT = 7–10) and 36.9% moderate distress (DT = 5–6, which means moderate to severe functional impairment) (Table 2).

DT Score and Sociodemographic and Medical Variables

Participants who were discharged due to stabilization of their medical status had lower distress scores than those who died later (t test). No significant correlation was found between distress level and age, survival time, KPS score, or multiple morbidities (Pearson's correlation). There were no statistical differences, neither between gender, primary care giver (family vs. professional or oncological care) (t test), nor marital status or living situation (Kruskal–Wallis test).

The relationship between a DT cutoff score of 4 to sociodemographic and medical variables was analyzed (Table 3). Analysis of primary sites of cancer diagnosis was limited to the three most frequent. No statistically significant relationship between a high DT score and sociodemographic or clinical variables was found. However, participants who were discharged due to stabilization of their symptoms had DT scores below 4. Participants with better KPS scores were more likely to complete the instrument without help and had lower DT scores (both statistically significant t tests).

Problem List

Overall, the physical concerns category was the most frequently selected, with 100% of patients selecting at least 1 of the 22 items. The second was the emotional concerns category, with 83.5% of patients selecting at least 1 of 6 items. Spirituality and family

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

Characteristics	Participants, $n = 103$ (%)	Excluded, $n = 138$ (%)	Non-participants, $n = 45$ (%)
Age (years), mean (±*SD*)	67.1 (±10.67)	69.8 (±13.73)	72.6 (±10.85)§
Sex			
Female	56 (54.4)	71 (51.4)	24 (53.3)
Male	47 (45.6)	67 (48.6)	21 (46.7)
Marital status			
Married/partnership	69 (67.0)	82 (59.4)	30 (66.7)
Widowed	17 (16.5)	34 (24.6)	10 (22.2)
Divorced	8 (7.8)	6 (4.3)	3 (6.7)
Single	6 (5.8)	11 (8.0)	2 (4.4)
No data	3 (2.9)	5 (3.6)	–
Living situation			
At home with relatives (partner or family)	77 (74.8)	98 (71.0)	27 (60.0)
At home alone	20 (19.8)	21 (15.2)	9 (20.0)
Institution (hospice or nursing home)	4 (3.9)	12 (8.7)	7 (15.6)
No data	2 (1.9)	7 (5.1)	2 (4.4)
Everyday care mainly by			
Relatives	62 (60.2)	59 (42.8)*	15 (33.3)*
Professional	19 (18.4)	55 (39.9)	21 (46.7)
No data	22 (21.4)	24 (17.4)	9 (20.0)
Diagnosis			
Oncological	94 (91.3)	123 (89.1)	40 (88.9)
With metastasis	64 (68.1)	85 (68.5)	24 (60.0)
Polypathology, mean (±*SD*)	4.2 (±2.54)	4.0 (±2.23)	4.8 (±2.21)
Primary site			
Reproductive system	27 (28.7)	29 (23.6)	11 (27.4)
Respiratory tract	24 (25.5)	33 (26.8)	10 (25.0)
Digestive system	24 (25.5)	42 (34.1)	10 (25.0)
Head and neck	6 (6.4)	4 (3.3)	2 (5.0)
Lymphoid, hematopoietic	5 (5.3)	3 (2.4)	2 (5.0)
Without specification of site	5 (5.3)	2 (1.6)	2 (5.0)
Mesothelium and soft tissue	2 (2.1)	2 (1.6)	–
Central nervous system	1 (1.1)	7 (5.7)	2 (5.0)
Melanoma	–	1 (0.8)	1 (2.5)
Karnofsky Performance Status, mean (±*SD*)	50 (±15.71)	30.9 (±16.7)§	52.0 (±9.2)
0–40	32 (33.7)	73 (75.3)	1 (10.0)
50–70	57 (60.0)	23 (23.7)	9 (90.0)
80–100	6 (6.3)	1 (1.0)	–
Months since diagnosis, mean (±*SD*)	28.7 (±44.97)	23.6 (±30.7)	17.1 (±21.7)
Outcome			
Death in weeks, mean (±*SD*)	89 (87.3)	128 (94.1)	34 (79.1)
	9.2 (±11.66)	5.2 (±7.1)§	9.4 (±9.0)
Discharge in weeks, mean (±*SD*)	13 (12.7)	8 (5.9)	9 (20.9)
	17.5 (±17.77)	8.4 (±6.7)	5.4(±5.1)

*Statistically significant ($p < 0.05$) χ^2 test.
§Statistically significant ($p < 0.05$) Kruskal–Wallis test.

problems were the least selected, with 5.8 and 29.1%, respectively. All patients selected at least one problem within one or more of the five categories, with an average of 11 (±4) mentioned problems and a maximum of 25 problems checked (median = 11). "Fatigue" was the most frequently mentioned problem, which concerned 90.3% of patients, followed by such everyday problems as "getting around" (83.5%), "eating" (63.1%), "bathing/dressing" (60.2%), and "sleep" (57.3%). Among the most frequently mentioned terms associated with physical problems were "pain" (60.2%) and "breathing" (55.3%). "Sadness" (61.3%), "worries" (53.4%), "fears" (50.2%), "loss of interest in usual activities" (46.6%), and "nervousness" (45.6%) were the most frequently mentioned emotional concerns (Table 4).

The least-mentioned problems were "spiritual/religious" (5.8%), "work/school" (4.9%), "dealing with children" (4.9%), "fever" (4.9%), and "drugs" (1.9%). Other physical problems were added: "dry mouth,"

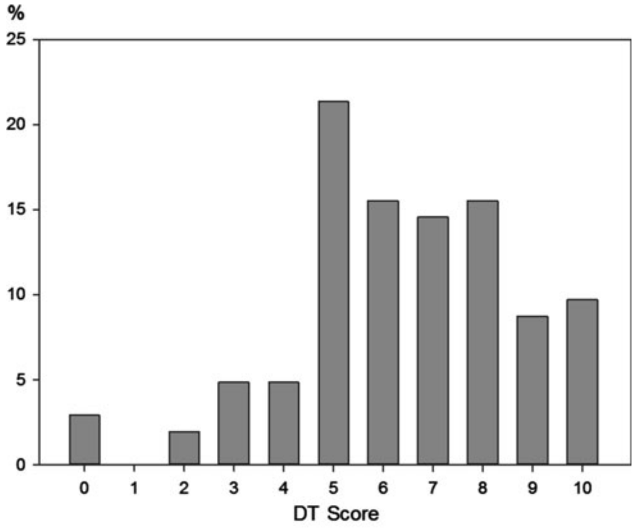

Fig. 1. Frequency distribution of DT scores ($n = 103$).

“sensitive skin,” “convulsions,” and “medication dependency,” as well as such mental problems as “loneliness,” “isolation,” and “inner restlessness.”

We found a statistically significant difference between the groups scoring above and below the DT cutoff with regard to the symptoms “fatigue,” “sadness,” “breathing,” “worries,” “fears,” “loss of interest in usual activities,” and “nervousness.” All these issues were mentioned more frequently by patients scoring above the DT cutoff (range = 90–100%). The least significant difference between the two groups was found for the issue of sexual problems (Table 4).

The DT score was positively correlated with total number of problems ($\rho = 0.344$, $p < 0.000$), as well as with the number of emotional ($\rho = 0.435$, $p \leq 0.000$) and physical ($\rho = 0.343$, $p \leq 0.000$) problems mentioned. The number of physical and emotional problems yielded a significantly strong correlation ($\rho = 0.495$, $p \leq 0.000$).

Patients with a DT score ≥ 4 checked off significantly more of these problems (t test): “child care” ($p = 0.018$), “depression” ($p = 0.028$), “fears” ($p = 0.001$), “nervousness” ($p = 0.001$), “sadness” ($p = 0.004$), “worries” ($p = 0.008$), “loss of interests in usual activities” ($p = 0.003$), “breathing” ($p = 0.019$), “constipation” ($p = 0.034$), “fatigue” ($p < 0.000$), “pain” ($p = 0.034$), and “sleep” ($p = 0.018$).

Table 2. *Grades of psychosocial distress according to Bidstrup et al. (2011)*

Grade	DT score	n (%)	Functional impairment
Minimal	0–2	5 (4.9)	None
Mild	3–4	10 (9.7)	Slight
Moderate	5–6	38 (36.9)	Moderate
Severe	7–10	50 (48.5)	Moderate to severe

Comparing participants cared for by professional health carers and those cared for by family members, the latter were statistically significantly more likely to report a higher number of problems (t test). This was also the case with regard to such emotional problems as “fears,” “nervousness,” “sadness,” “worries,” and “loss of interest in usual activities,” as well as with regard to such physical problems as “bathing/dressing,” “breathing,” “changes in urination,” “constipation,” “diarrhea,” “eating,” “fatigue,” “feeling swollen,” “getting around,” “indigestion,” “memory/concentration,” “mouth sores,” “nausea,” “nose dry or congested,” “pain,” “skin dry/itchy,” “sleep,” and “tingling in hands/feet” (χ^2 test).

Men reported statistically more sexual problems than women (χ^2 test). Patients with head and neck cancer reported more problems with eating and mouth sores (χ^2 test). No differences were found with regard to the other sociodemographic and medical variables.

Evaluation

The comprehensibility of the DT/PL was rated on average at 1.8 (±0.964) (1 = “very understandable” and 5 = “not understandable at all”), and 49% of participants considered it to be “very understandable.” In general, completion of the DT/PL was perceived as “unremarkable” by 80% of participants, and 14% found it “relieving,” while for the remaining 6% it was emotionally distressing, because it prompted them to more clearly realize the seriousness of their situation.

DISCUSSION

High psychosocial distress in palliative care patients has been described in the literature (Neuwohner & Lindena, 2011; Thekkumpurath et al., 2008). Approximately 90% of all palliative patients who participated in our study showed clinically significant psychosocial distress as measured by the Distress Thermometer according to the cutoff criteria. This prevalence rate is higher than that described in previous studies. Thekkumpurath et al. (2009) reported that more than a third of palliative care patients experienced psychological distress. Weingaertner et al. (2014) used the DT (cutoff 4.5–4.6) for patients with advanced chronic obstructive pulmonary disease or lung cancer and presented a prevalence of 72–74% of patients with a significantly high level of distress. This result suggests the need for complex and intensive care for the psychosocial problems of palliative care patients being treated at home.

Table 3. *Relation of a Distress Thermometer cutoff score of 4 to sociodemographic and medical variables*

Variable	DT score <4 *n* (%)	DT score ≥ 4 *n* (%)	*p* Value
Age (years), mean (±*SD*)	67.4 (±10.15)	67.11 (±10.72)	n.s.§
Sex			n.s.*
Female	5 (8.9)	51 (91.2)	
Male	6 (12.8)	41 (87.2)	
Marital status			n.s.*
Married/partnership	8 (11.6)	61 (88.4)	
Widowed/divorced/single	3 (9.7)	28 (90.3.)	
Living situation			n.s.*
At home with relatives	9 (11.7)	68 (88.3)	
At home alone or institution	2 (8.3)	22 (91.7)	
Everyday care mainly by			n.s.*
Relatives	8 (12.9)	54 (87.1)	
Professional	0 (0)	19 (100)	
Diagnosis			
Not oncological	1 (11.1)	8 (88.9)	n.s.*
Oncological	10 (10.6.3)	84 (89.4)	n.s.*
With metastasis	8 (12.5)	56 (87.5)	
Without metastasis	2 (6.7)	28 (93.3)	
Polypathology, mean (±*SD*)	3.7 (±1.19)	4.3 (±2.34)	n.s.§
Primary site			
Reproductive system	2 (7.48)	25 (92.6)	n.s.*
Yes	8 (11.9)	59 (88.1)	n.s.*
No	3 (12.5)	21 (87.5)	n.s.*
Respiratory tract	7 (10.0)	63 (90.0)	
Yes	3 (12.5)	21 (85.5)	
No	7 (10.0)	63 (90.0)	
Digestive System			
Yes			
No			
Karnofsky Performance Status, mean (*SD*)	45 (±14.33)	50.6 (±15.84)	n.s.§
0–40	6 (18.8)	26 (81.3)	n.s.*
50–70	4 (7.0)	53 (93.0)	
80–100	0 (0)	6 (100)	
Months since diagnosis, mean (±*SD*)	10.33 (±10.51)	31.21 (±47.22)	n.s.§
Outcome			0.001*
Death in weeks, mean (±*SD*)	6.3 (±3.67)	9.43 (±12.02)	n.s.§
	6 (6.7)	83 (93.3)	
Discharge, mean (±*SD*)	9.2 (±7.15)	22.6 (±20.81)	n.s.§
	5 (38.5)	8 (61.5)	

$^{*}\chi^2$ test.
$^{\S}t$ test.

A correction of the cutoff in this setting may be pertinent. The ideal cutoff for the Distress Thermometer for palliative care patients is a matter of some controversy (Mitchell, 2007). The NCCN has recommended that a cutoff score of 4 was too low for the palliative care field and instead suggested a cutoff of 5 or 6 (Ma et al., 2014; Thekkumpurath et al., 2009). The importance of validation of the DT for special populations has already been established, and an adjustment is required (Gunnarsdottir et al., 2012).

Interestingly, no statistical associations between level of distress reported and sociodemographic or medical variables could be found. Previous studies have reported a positive association between high distress levels on the DT with female gender, younger age, and lower functional status (Jacobsen et al., 2005; Waller et al., 2011). In our setting, distress can be considered a general phenomenon of patients experiencing a palliative situation at home, suggesting that the palliative situation outweighs other possible sociodemographic factors (Gotze et al., 2014).

The number of problems mentioned correlated directly with level of distress, with an average of 11 ± 7 of the 25 listed problems per patient (see Table 5). Most of the reported problems fell within the physical and emotional categories. These results confirm

Table 4. *Most frequently mentioned problems both for the total population and for participants scoring below and above the DT cutoff score**

Problem	$N = 103$ n (%)	<4 n (%)	≥ 4 n (%)	p Value
Fatigue	93 (90.3)	5 (5.4)	88 (94.6)	<0.000
Getting around	86 (83.5)	8 (9.3)	78 (90.7)	n.s.
Eating	65 (63.1)	5 (7.7)	60 (92.3)	n.s.
Sadness	*63 (61.3)*	*3 (4.8)*	*60 (95.2)*	*0.015*
Bathing/dressing	62 (60.2)	4 (6.5)	58 (93.5)	n.s.
Pain	62 (60.2)	5 (8.1)	57 (91.9)	n.s.
Sleep	59 (57.3)	4 (6.8)	55 (93.2)	n.s
Breathing	57 (55.3)	3 (5.3)	54 (94.7)	0.048
Worry	*55 (53.4)*	*2 (3.6)*	*53 (96.4)*	*0.013*
Indigestion	54 (52.4)	4 (7.4)	50 (92.6)	n.s.
Fears	*52 (50.5)*	*2 (3.8)*	*50 (96.2)*	*0.023*
Loss of interests in usual activities	*48 (46.6)*	*1 (2.1)*	*47 (97.9)*	*0.008*
Nervousness	*47 (45.6)*	*0 (0)*	*47 (100)*	*0.001*

Problems not displayed had a frequency $<45\%$ and were not significantly different between scores above and below the cutoff with a χ^2 test.
*Psychological problems are in italics.

previous studies in palliative care settings using different measurement methods (Neuwohner & Lindena, 2011). “Fatigue” is already considered one of the most common and distressing symptoms mentioned by patients in palliative care (Bradley et al., 2005; Jansky et al., 2012; Teunissen et al., 2007). In the home environment, patients have to complete a greater number of everyday activities, which makes them realize even more how restricted they are. It is probably for this reason that activities like “getting around,” “eating,” and “bathing/dressing” become so relevant (Oechsle et al., 2014; Ruijs et al., 2013) when adaptation is not achieved. Experiencing such functional limitations as immobility, physical weakness, and helplessness while trying to provide personal care and getting dressed, even during the final weeks of life, has a great impact on patient well-being. It may generate an awareness of the progress of the disease through realization of decreased performance compared to former skills and independence. In addition, increasing difficulties in coping with everyday life leads to dependence on others and thus loss of autonomy. These points have been reported by patients in palliative situations to be very stressful (Ruijs et al., 2013). Providing assistance to palliative patients so that they can complete everyday tasks may be as important as medical and nursing care (Weingaertner et al., 2014).

Table 5. *Correlations between DT score and number of problems according to categories*

Category	Mean (±*SD*)	ρ^*	p Value
Practical problems	0.6 (0.925)	0.128	n.s.
Family problems	0.4 (0.673)	0.139	n.s.
Emotional problems	2.8 (1.920)	0.435	<0.000
Spiritual problems	0.05 (0.235)	0.092	n.s.
Physical problems	9.5 (3.52)	0.342	<0.000
Total	10.6 (4.20)	0.344	<0.000

*ρ = Pearson’s correlation coefficient.

Emotional problems cause severe burdens for palliative patients (Neuwohner & Lindena, 2011; Oechsle et al., 2014; Ruijs et al., 2013). Psychologically related distress plays a larger role in community-dwelling palliative patients than in other areas/settings (Neuwohner & Lindena, 2011). Therefore, the rate of depression (Austin et al., 2011) and anxiety (Jansky et al., 2012) are higher in patients cared for at home than in hospitalized palliative patients. It has also been observed that psychological stress in palliative patients remains undetected to a large extent and that there are fewer control mechanisms available than for physical symptoms (Kelly et al., 2006), especially in outpatient palliative care (Ventura et al., 2014). Financial difficulties were not an issue, probably because nearly all German citizens have health insurance (VanHoose et al., 2015).

Analyzing single symptoms, patients cared for by relatives reported physical and emotional problems more often. This suggests the need for professional healthcare personnel to provide supportive care at home. Perhaps better education and training of relatives involved in care duties at home could reduce the level of distress in patients. It has been shown that relatively short psychoeducational interventions can enable family caregivers to feel more prepared and competent in the role of supporting a dying relative (Hudson et al., 2013).

Our study also described patients’ ability to complete the Distress Thermometer on their own. It was observed that most inpatients (64%) who were transferred to home care services were not able to respond and use the instrument. This high percentage may be due to the fact that upon their first contact with home care services patients were at the end of their lives or already in poor somatic, cognitive, and psychological condition (Watanabe et al., 2011). Participants and excluded patients had similar sociodemographic and medical characteristics, which suggests the possibility of finding similar results in both groups (Weingaertner et al., 2014). Only a few of the participants perceived completing the DT as relieving or distressing. They considered it understandable, which endorsed the results of other studies (Hughes et al., 2011). The suitability of self-assessment methods—even ultrashort ones—for palliative care patients is considered highly questionable. Nevertheless, our study highlights that those who are able to complete written instruments like the Distress Thermometer can benefit by expressing psychosocial needs and problems.

The effect of home-based palliative care on distress will be analyzed in a future research paper.

Measures Taken

Given the high prevalence of distress identified among these patients, the home care team took steps to address their emotional needs and suffering. However, as noted in the introduction, home care teams are not able to provide professional psychological care, and, unless there is a previous diagnosis, there is no professional help available unless paid for privately by the patient.

CONCLUSIONS

A significant proportion of seriously ill patients dwelling at home reported high levels of distress. Most of their problems were emotional and/or physical. This is particularly significant considering that even high-level distress often goes unnoticed by doctors and nursing staff (Sollner et al., 2001). The findings of our study highlight the importance of creating new concepts and structures in order to address the psychosocial needs of home-dwelling patients. The Distress Thermometer should be employed as an integral part of the procedures involved in a "global diagnostic evaluation" to detect patient distress.

ACKNOWLEDGEMENTS

The authors are very thankful to Petra Schaubeck, Bernd Wehbrink, Brigitte Brings, Karin Hack, Karin Schnurbusch, Karin Thielemann, Lothar Rißmayer, Marlies Frohn, and Ute Armbruster for their invaluable support; to Andrea Peterman-Mayer for her critical input; to Ann Foldenauer for her statistical support; and to Kerstin Paus for her review of the language in the manuscript.

REFERENCES

Austin, P., Wiley, S., McEvoy, P.M., et al. (2011). Depression and anxiety in palliative care inpatients compared with those receiving palliative care at home. *Palliative & Supportive Care*, *9*(4), 393–400.

Bidstrup, P.E., Johansen, C. & Mitchell, A.J. (2011). Screening for cancer-related distress: Summary of evidence from tools to programmes. *Acta Oncologica*, *50*(2), 194–204.

Block, S.D. (2001). Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: The art of the possible. *The Journal of the American Medical Association*, *285*(22), 2898–2905.

Bradley, N., Davis, L. & Chow, E. (2005). Symptom distress in patients attending an outpatient palliative radiotherapy clinic. *Journal of Pain and Symptom Management*, *30*(2), 123–131.

Donovan, K.A., Grassi, L., McGinty, H.L., et al. (2014). Validation of the distress thermometer worldwide: State of the science. *Psycho-Oncology*, *23*(3), 241–250.

Escobar Pinzon, L.C., Claus, M., Zepf, K.I., et al. (2011). Preference for place of death in Germany. *Journal of Palliative Medicine*, *14*(10), 1097–1103.

Gessler, S., Low, J., Daniells, E., et al. (2008). Screening for distress in cancer patients: Is the Distress Thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. *Psycho-Oncology*, *17*(6), 538–547.

Gotze, H., Brahler, E., Gansera, L., et al. (2014). Psychological distress and quality of life of palliative cancer patients and their caring relatives during home care. *Supportive Care in Cancer*, *22*(10), 2775–2782.

Gruneir, A., Smith, T.F., Hirdes, J., et al. (2005). Depression in patients with advanced illness: An examination of Ontario complex continuing care using the Minimum Data Set 2.0. *Palliative & Supportive Care*, *3*(2), 99–105.

Gunnarsdottir, S., Thorvaldsdottir, G.H., Fridriksdottir, N., et al. (2012). The psychometric properties of the Icelandic version of the Distress Thermometer and Problem List. *Psycho-Oncology*, *21*(7), 730–736.

Holland, J.C., Anderson, B., Breitbart, W.S., et al. (2013). *NCCN clinical practice guidelines in oncology: Distress management*, version 2.2013. Available from http://oralcancerfoundation.org/treatment/pdf/distress.pdf.

Hudson, P., Trauer, T., Kelly, B., et al. (2013). Reducing the psychological distress of family caregivers of home-based palliative care patients: Short-term effects from a randomised controlled trial. *Psycho-Oncology*, *22*(9), 1987–1993.

Hughes, K.L., Sargeant, H. & Hawkes, A.L. (2011). Acceptability of the Distress Thermometer and Problem List to community-based telephone cancer helpline operators, and to cancer patients and carers. *BMC Cancer*, *11*, 46.

Jacobsen, P.B., Donovan, K.A., Trask, P.C., et al. (2005). Screening for psychological distress in ambulatory cancer patients. *Cancer*, *103*(7), 1494–1502.

Jansky, M., Lindena, G. & Nauck, F. (2012). Befinden von Palliativpatienten im Verlauf einer spezialisierten ambulanten oder stationaren Versorgung [in German]. *Schmerz*, *26*(1), 46–53.

Kelly, B., McClement, S. & Chochinov, H.M. (2006). Measurement of psychological distress in palliative care. *Palliative Medicine*, *20*(8), 779–789.

Kennard, B., Stewart, S., Olvera, R., et al. (2004). Nonadherence in adolescent oncology patients: Preliminary data on psychological risk factors and relationships to outcome. *Journal of Clinical Psychology in Medical Settings*, *11*(1), 31–39.

Ma, X., Zhang, J., Zhong, W., et al. (2014). The diagnostic role of a short screening tool. The Distress Thermometer: A meta-analysis. *Supportive Care in Cancer*, *22*(7), 1741–1755.

Mazzocato, C., Stiefel, F., de Jonge, P., et al. (2000). Comprehensive assessment of patients in palliative care: A descriptive study utilizing the INTERMED. *Journal of Pain and Symptom Management*, *19*(2), 83–90.

Mehnert, A., Müller, D., Lehmann, C., et al. (2006). Die deutsche Version des NCCN Distress-Thermometers [in German]. *Zeitschrift für Psychiatrie, Psychologie und Psychotherapie*, *54*(3), 213–223. Available from http://econtent.hogrefe.com/doi/abs/10.1024/1661-4747.54.3.213.

Mitchell, A.J. (2007). Pooled results from 38 analyses of the accuracy of Distress Thermometer and other ultra-short methods of detecting cancer-related mood disorders. *Journal of Clinical Oncology*, *25*(29), 4670–4681.

Müller-Busch, H.C. (2008). Palliativmedizin in Deutschland: Menschenwürdige Medizin am Lebensende—ein Stiefkind der Medizin? [in German]. *G + G Beilage Wissenschaft*, *8*(4), 7–14.

National Comprehensive Cancer Network (2013). *NCCN clinical practice guidelines in oncology: Distress management*, version 2.2013. Available from http://oralcancerfoundation.org/treatment/pdf/distress.pdf.

Neuwohner, K. & Lindena, G. (2011). Assessment of distress with physical and psychological symptoms of patients in German palliative care services. *Onkologie*, *34*(3), 94–98.

Oechsle, K., Wais, M.C., Vehling, S., et al. (2014). Relationship between symptom burden, distress, and sense of dignity in terminally ill cancer patients. *Journal of Pain and Symptom Management*, *48*(3), 313–321. Epub ahead of print Apr 21.

Roth, A.J., Kornblith, A.B., Batel-Copel, L., et al. (1998). Rapid screening for psychological distress in men with prostate carcinoma: A pilot study. *Cancer*, *82*(10), 1904–1908.

Ruijs, C.D., Kerkhof, A.J., van der Wal, G., et al. (2013). Symptoms, unbearability and the nature of suffering in terminal cancer patients dying at home: A prospective primary care study. *BMC Family Practice*, *14*, 201.

Sollner, W., DeVries, A., Steixner, E., et al. (2001). How successful are oncologists in identifying patient distress, perceived social support, and need for psychosocial counselling? *British Journal of Cancer*, *84*(2), 179–185.

Teunissen, S.C., Wesker, W., Kruitwagen, C., et al. (2007). Symptom prevalence in patients with incurable cancer: A systematic review. *Journal of Pain and Symptom Management*, *34*(1), 94–104.

Thekkumpurath, P., Venkateswaran, C., Kumar, M., et al. (2008). Screening for psychological distress in palliative care: A systematic review. *Journal of Pain and Symptom Management*, *36*(5), 520–528.

Thekkumpurath, P., Venkateswaran, C., Kumar, M., et al. (2009). Screening for psychological distress in palliative care: Performance of touch screen questionnaires compared with semistructured psychiatric interview. *Journal of Pain and Symptom Management*, *38*(4), 597–605.

VanHoose, L., Black, L.L., Doty, K., et al. (2015). An analysis of the distress thermometer problem list and distress in patients with cancer. *Supportive Care in Cancer*, *23*(5), 1225–1232. Epub ahead of print Oct 16, 2014.

Ventura, A.D., Burney, S., Brooker, J., et al. (2014). Home-based palliative care: A systematic literature review of the self-reported unmet needs of patients and carers. *Palliative Medicine*, *28*(5), 391–402.

Waller, A., Williams, A., Groff, S.L., et al. (2011). Screening for distress, the sixth vital sign: Examining self-referral in people with cancer over a one-year period. *Psycho-Oncology*, *22*(2), 388–395. Epub ahead of print Dec 2.

Watanabe, S.M., Nekolaichuk, C., Beaumont, C., et al. (2011). A multicenter study comparing two numerical versions of the Edmonton Symptom Assessment System in palliative care patients. *Journal of Pain and Symptom Management*, *41*(2), 456–468.

Weingaertner, V., Scheve, C., Gerdes, V., et al. (2014). Breathlessness, functional status, distress, and palliative care needs over time in patients with advanced chronic obstructive pulmonary disease or lung cancer: A cohort study. *Journal of Pain and Symptom Management*, *48*(4), 569–581.