Screening for Distress in Routine Oncological Care—A Survey in 520 Melanoma Patients

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Abstract

Introduction: Despite the increasing incidence of melanoma little is known about patients’ emotional distress associated with this disease. Supplemented by the problem list (PL), the distress thermometer (DT) is a recommended screening instrument to measure psychosocial distress in cancer patients. Our objective was to explore the acceptance and the feasibility of the DT and PL as a concise screening tool in an ambulatory setting for routine care and to elucidate determinants of distress in melanoma patients with regard to sociodemographic and clinical variables.

Methods: Consecutive melanoma outpatients were asked to complete the DT with the PL prior to their scheduled consultation. Demographic and clinical data were obtained from the patients’ charts. Clinical data included melanoma stage, time since diagnosis, previous treatment, current treatment, and other cancer disease.

Results: Out of 734 patients recruited into the study, 520 patients (71%) completed both the DT and the PL. Forty-seven percent met the ≥5 cut-off score for distress. Younger and employed patients reported higher distress than older and retired patients. A cut-off score of ≥5 was closely associated with self-reported emotional sources of distress, with practical problems, especially at work, family problems (dealing with the partner), and physical problems like pain, appearance, getting around, and nausea. Apart from higher distress under current systemic treatment, no associations were found between distress and clinical data.

Conclusion: The DT together with the PL seems to be an economically reasonable screening tool to measure psychosocial distress in melanoma patients. In particular, younger melanoma patients who are currently employed are prone to experience distress at some point after diagnosis, but there appears to be almost no association between clinical data and the extent of distress. To characterize the impact of distress on disease outcome and quality of life in melanoma patients, further research is needed.

Introduction

The National Comprehensive Cancer Network (NCCN) defines distress as a “multifactorial, unpleasant emotional experience of a psychological (cognitive, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment” [1,2]. Malignant melanoma is the sixth most frequent form of cancer in the USA, which has continuously increased reaching up to 22.2 per 100,000 population in 2008 [3] and usually appears during middle adulthood. Particularly common in fair-skinned populations [3], its occurrence and prognosis are strongly related to behavioral factors, especially sun exposure patterns and the use of indoor tanning booths. Despite a deepening understanding of melanoma tumor biology and promising advances in treatment, surprisingly little is known about the psychological impact melanoma has on patients’ lives. While the vast majority of cases are detected at an early stage and therefore treated effectively, recurrence remains a significant risk over many years. Thus, patients suffering from malignant melanoma have to grapple with an ongoing threat. Regular aftercare is therefore recommended for 10 years under the current German melanoma S3 guideline [4], including psycho-oncological treatment.

Yet, distress in malignant melanoma has remained understudied. Estimates of distress vary widely in patients with malignant melanoma. In a systematic review [5], the proportion of participants scoring in the clinical range for anxiety based on the Hospital Anxiety and Depression Scale (HADS) ranged from 18 to 44%, for depression symptoms the range was 6 to 28%. Risk factors for heightened distress were female sex, younger age, the absence of a spouse or partner, and lower levels of education. Surprisingly, stage of disease was unrelated, but physical deterioration and visibility of body site were associated with...
altered body image and fear of distress [6]. Further associations of distress were found with lack of social support, negative cognitive appraisal and an avoidant coping style [7].

There is evidence that psychological distress is associated with decreased adherence to treatment regimes, lower quality of life, reduced enrollment in follow-up programs, delay in seeking medical advice, increased recurrence rates and mortality, and increased medical costs [8–18]. Psychological distress, however, is often overlooked by physicians for many reasons. Patients are often reluctant to ask for help because they fear being stigmatized for having a psychological problem. They do not want to distract physicians from curing their cancer by mentioning psychosocial needs or fear being seen as overly demanding or difficult [13,19]. Symptoms associated with distress, anxiety, or depression like loss of appetite, fatigue or insomnia might be confounded by symptoms of malignancy or treatment side effects, and the medical staff are not always trained or skilled in perceiving and discussing emotional problems [20–22]. As the treatment of melanoma has increasingly been shifted to ambulatory care settings, physician consultations are shortened, thus limiting time to explore emotional well-being. Therefore, the development of screening strategies to improve the detection and management of psychological distress has become even more important.

Recommendations for melanoma surveillance in German skin cancer centers include screening, evaluation, and treatment of distress of melanoma patients [23]. Distress has been studied by validated standardized screening tools, such as the HADS or the Brief Symptom Inventory [BSI] [24–27]. Despite their relative brevity, however, these multi-item measures still require more time than is available in busy outpatient skin cancer centers. To improve and implement psycho-oncological care in routine melanoma care programs, the development of brief screening tools to detect psychological distress and the identification of risk factors for distress are urgent needs. Recognizing the need for economical means to screen rapidly for distress in cancer patients, Roth and colleagues developed the single-itemed “Distress Thermometer” [DT] [28]. In order to identify the potential problems that can induce the distress reported, a problem list (PL) is often added covering the five domains of practical, family, emotional and physical problems, and spiritual/religious concerns.

This study was undertaken to explore the acceptance and feasibility of the DT and PL as a brief screening tool in an ambulatory setting for routine care, as determined by the rate of completed questionnaires. We wanted to elucidate the prevalence of distress and problem areas in melanoma patients. We expected that heightened distress is associated with a higher load of problems. Based on previous studies, we hypothesize distress to be increased in younger, female and single living patients with a more recent diagnosis and under current treatment.

### Methods

#### Participants

The study participants were consecutive melanoma patients attending the Skin Cancer Center of the University of Mainz Medical Center. The inclusion criteria were histologically proven diagnosis of melanoma, age of at least 18 years, the ability to read and understand the questionnaires, and the patient’s consent to participate. Using a cross-sectional design, patients were recruited at all stages of disease and treatment during aftercare. Demographic and clinical data were obtained by linking the patient’s questionnaire with information stored in the patient’s chart.

| Table 1. Patient Demography (n = 520). |
|---------------------------------------|
|                                | Total | N | % |
| **Sex**                          |       |   |   |
| Male                            | 277   | 53 |
| Female                         | 243   | 47 |
| **Employment status**           |       |   |   |
| Working                        | 223   | 43 |
| Retired                        | 171   | 33 |
| Other                          | 76    | 15 |
| Unknown                        | 50    | 10 |
| **Insurance status**            |       |   |   |
| Public                         | 431   | 83 |
| Private                        | 89    | 17 |
| **Status of relationship**      |       |   |   |
| Married                        | 363   | 70 |
| Widowed                        | 25    | 5 |
| Single (including divorced and separated) | 82 | 16 |
| Unknown                        | 50    | 10 |

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Figure 1. Participant flow, details of study recruitment.

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demographic variables considered were age, gender, employment state, health insurance, and marital state. Clinical data included melanoma stage, time since diagnosis, stage of treatment (pretreatment, current treatment), multiple melanomas, and other cancers.

| Table 2. Patient clinical variables (n = 520). |
|----------------------------------------------|
| Total | N  | %  |
| AJCC stage | | |
| In situ | 26 | 5 |
| I/II | 401 | 77 |
| III | 69 | 13 |
| IV | 24 | 5 |
| Time since diagnosis | | |
| 0–12 months | 143 | 28 |
| >12–24 months | 81 | 16 |
| >24–36 months | 50 | 10 |
| >36–48 months | 40 | 8 |
| >48–60 months | 44 | 8 |
| >60 months | 162 | 31 |
| SLNB | | |
| No | 361 | 69 |
| Yes | 159 | 31 |
| Lymph node dissection | | |
| No | 452 | 87 |
| Yes | 68 | 13 |
| Surgery for metastases (not skin, not lymph nodes) | | |
| No | 510 | 98 |
| Yes | 10 | 2 |
| Radiotherapy | | |
| No | 508 | 98 |
| Yes | 12 | 2 |
| Type of systemic therapy | | |
| None | 373 | 72 |
| Interferon | 132 | 25 |
| Other | 15 | 3 |
| Patient under systemic therapy | | |
| No | 468 | 90 |
| Yes | 52 | 10 |
| Multiple melanomas | | |
| No | 487 | 94 |
| Yes | 33 | 6 |
| Other nonmelanoma skin cancer | | |
| No | 487 | 94 |
| Yes | 33 | 6 |
| Other noncutaneous malignancy | | |
| No | 478 | 92 |
| Yes | 42 | 8 |

1Vaccination, Immunotherapy+Vaccination, Chemoimmunotherapy, Chemoimmunotherapy+Vaccination, Chemoimmunotherapy+Targeted Therapy, Interferon+Interleukin-2.

Procedure
Patients were approached in the waiting areas at the center prior to a scheduled outpatient visit. After an explanation by trained nurses, participants were asked to complete the DT and PL.

Measures
Distress Thermometer and Problem List. The DT is a single-timed self-reported, pencil and paper measure consisting of a line with a 0–10 scale anchored at the 0 point indicating “no distress” and a scale point 10 indicating “extreme distress”. Patients are instructed to circle the number that best describes the level of distress during the past week. The DT is simple to score and easy to interpret, and since developed in 1998 it has been used and validated in numerous clinical studies and has been recommended as a screening module for distress by the NCCN Panel. In a mixed German sample of cancer patients undergoing rehabilitation, a cut-off score of 5 yielded the best discrimination for high levels of anxiety or depression (based on the HADS) with a sensitivity of 97% and a specificity of 41% [29]. Thus, the internationally recommended cut-off score of 5 was used in this study.

The PL was developed by the Distress Management Guidelines Panel of the NCCN. It consists of 35 problems commonly experienced by cancer patients in five categories (practical problems, family problems, emotional problems, spiritual-religious concerns, and physical problems). Patients indicate whether or not (“yes-no”) they have experienced any of those problems in the past 7 days.

Statistical Analysis
The acceptance and feasibility of the DT and PL as an extremely concise screening tool in an ambulatory setting for routine care of melanoma was determined by the proportion of completed questionnaires. Descriptive statistics were used to characterize the sample with regard to demographic and clinical variables. Following the recommendations of Mehnert et al. [29], we considered a patient as highly distressed when DT ≥5.

To determine the association of DT with demographics and clinical characteristics, we fitted cumulative logit models assuming

Figure 2. Frequency distribution of DT score among all patients completing the DT and the PL (n = 520).

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### Table 3. Association of demographic and clinical variables with high distress (n = 520).

| DT score ≥5 | No | % | Yes | % | Odds Ratio | 95% confidence interval |
|-------------|----|----|-----|----|------------|-------------------------|
| **Sex**     |    |    |     |    |            |                         |
| Male        | 153| 55 | 124 | 45 | 1.0        |                         |
| Female      | 124| 51 | 119 | 49 | 1.34       | [0.99; 1.81]            |
| **Employment status** |    |    |     |    |            |                         |
| Working     | 100| 45 | 123 | 55 | 1.0        |                         |
| Retired     | 104| 61 | 67  | 39 | 0.51       | [0.36; 0.72]            |
| Other       | 45 | 59 | 31  | 41 | 0.64       | [0.41; 1.01]            |
| Unknown     | 28 | 56 | 22  | 44 | 0.9        | [0.52; 1.53]            |
| **Insurance status** |    |    |     |    |            |                         |
| Public      | 225| 52 | 206 | 48 | 1.0        |                         |
| Private     | 52 | 58 | 37  | 42 | 0.79       | [0.53; 1.17]            |
| **Status of relationship** |    |    |     |    |            |                         |
| Married     | 192| 53 | 171 | 47 | 1.0        |                         |
| Widowed     | 14 | 56 | 11  | 44 | 0.75       | [0.37; 1.54]            |
| Single      | 43 | 52 | 39  | 48 | 1.25       | [0.82; 1.89]            |
| Unknown     | 28 | 56 | 22  | 44 | 0.86       | [0.51; 1.44]            |
| **AJCC stage** |    |    |     |    |            |                         |
| In situ     | 13 | 50 | 13  | 50 | 1.07       | [0.53; 2.13]            |
| I/II        | 219| 55 | 182 | 45 | 1.0        |                         |
| III         | 35 | 51 | 34  | 49 | 1.21       | [0.78; 1.89]            |
| IV          | 10 | 42 | 14  | 58 | 1.41       | [0.69; 2.89]            |
| **SLNB**    |    |    |     |    |            |                         |
| No          | 190| 53 | 171 | 47 | 1.0        |                         |
| Yes         | 87 | 55 | 72  | 45 | 0.99       | [0.72; 1.37]            |
| **Lymph node dissection** |    |    |     |    |            |                         |
| No          | 241| 53 | 211 | 47 | 1.0        |                         |
| Yes         | 36 | 53 | 32  | 47 | 1.14       | [0.73; 1.78]            |
| **Surgery for metastases (not skin, not lymph nodes)** |    |    |     |    |            |                         |
| No          | 272| 53 | 238 | 47 | 1.0        |                         |
| Yes         | 5  | 50 | 5   | 50 | 1.03       | [0.35; 3.08]            |
| **Radiotherapy** |    |    |     |    |            |                         |
| No          | 271| 53 | 237 | 47 | 1.0        |                         |
| Yes         | 6  | 50 | 6   | 50 | 1.53       | [0.56; 4.15]            |
| **Type of systemic therapy** |    |    |     |    |            |                         |
| None        | 196| 53 | 177 | 47 | 1.0        |                         |
| Interferon  | 72 | 55 | 60  | 45 | 1.1        | [0.78; 1.55]            |
| Other1      | 9  | 60 | 6   | 40 | 0.95       | [0.38; 2.33]            |
| **Patient under systemic therapy** |    |    |     |    |            |                         |
| No          | 254| 54 | 214 | 46 | 1.0        |                         |
| Yes         | 23 | 44 | 29  | 56 | 1.91       | [1.18; 3.16]            |
| **Multiple melanomas** |    |    |     |    |            |                         |
| No          | 257| 53 | 230 | 47 | 1.0        |                         |
| Yes         | 20 | 61 | 13  | 39 | 0.61       | [0.33; 1.14]            |
| **Other nonmelanoma skin cancer** |    |    |     |    |            |                         |
| No          | 259| 53 | 228 | 47 | 1.0        |                         |
| Yes         | 18 | 55 | 15  | 45 | 0.77       | [0.41; 1.42]            |
| **Other noncutaneous malignancy** |    |    |     |    |            |                         |
proportional odds for each variable. This type of model takes into account the ordinal scale of the DT and assumes that odds ratios for each predictor are constant over all possible dichotomizations [50]. It is a generalization of logistic regression to an ordinal outcome.

The association of the DT with PL items was described by fitting proportional odds cumulative logit models for each item, adjusting for demographic variables found to be associated with the DT. To assess the joint influence of PL items on the DT, a proportional odds cumulative logit model was fitted and variables were selected using backward selection. We considered models starting a) with all PL items, b) with the numbers of problems of specific types, and c) the overall number of problems; again we adjusted for demographic variables found to be associated with the DT. The analyses were performed using GraphPad Prism 5.0 and SAS 9.3.

Results

Patient characteristics

Out of a total of 891 patients with melanoma visiting the skin cancer center during the study accrual period, 734 (82%) patients agreed to participate in the survey. Of these, 629 (86%) patients scored the DT and 729 (99%) patients filled in the PL. Both screening measures were filled in by 624 patients (85%). One or more (on average 3.18) items of the PL were omitted by 147 (20%) of the 729 patients who had filled in the PL. Both the DT and the PL were complete for 520 of 734 recruited patients (71%) (Figure 1). The statistical analysis has been restricted to those 520 patients who completed both the DT and all items of the PL.

The patient characteristics are summarized in Table 1 and Table 2. The average age of the patients included in the analysis was 58.5 (range 18–89, SD 14.0) years. Two hundred forty-three (47%) patients scored the DT score ≥5, whereas 243 (47%) scored ≥5 on the DT.

Association between distress score, categorical and continuous variables

The mean DT score was 3.9 (SD: 3.0), and the median score was 4, with a range from 0 to 10. Figure 2 summarizes the distribution of the DT scores. Two hundred seventy-seven (53%) patients reported a distress score of <5, whereas 243 (47%) scored ≥5 on the DT.

The association between patient characteristics and distress levels is shown in Table 3. Distress scores show a decreasing trend with age (OR = 0.97 per year, 95% CI [0.96; 0.98]). We found the DT to be associated with employment status, with retired patients having lower DT scores than working patients (OR = 0.51, 95% CI [0.36; 0.72]). Patients under systemic therapy had higher DT scores than patients not currently treated (OR = 1.91, 95% CI [1.16; 3.16]).

In order to assess the joint influence of demographics and clinical characteristics, we fitted a multivariate cumulative logit model and found that it was sufficient to include age; adding employment status or therapy status did not improve the model. Other sociodemographic variables such as sex, health insurance, or marital status did not affect distress levels. The detailed results are included in Table 3.

Interestingly, no further association with the distress score was found. In particular, no association exists between disease stage and distress level. Other melanoma-associated parameters such as type of treatment, presence of multiple melanomas, or another cancer diagnosis did not influence distress score, either. Shorter time since diagnosis was not associated with higher distress scores (OR = 1.0 per year, 95% CI [0.96; 1.03]).

Distress score and Problem list

Table 4 provides an overview of the problems that were mentioned most frequently in the problem list, stratified by distress score (high versus low). The strength of association is measured by the odds ratio, adjusted for age.

Most patients mentioned at least one physical problem (n = 353; 68%), and at least one emotional problem was reported by 269 (52%) patients. Practical problems were indicated by 86 (17%) patients, and other problems by 51 (10%) patients. Spiritual problems were rarely mentioned (n = 8; 1.5%).

Patients reporting more problems were more likely to score highly on the DT. This applied to emotional problems in general (OR = 4.51, 95% CI [5.25; 6.25]) and to each emotional problem in particular (nervousness (OR = 3.85, 95% CI [2.75; 5.40]), worries (OR = 4.19, 95% CI [2.92; 6.00]), fear (OR = 4.33, 95% CI [2.97; 6.33]), sadness (OR = 4.14, 95% CI [2.82; 6.09]), depression (OR = 4.76, 95% CI [2.96; 7.66]), and loss of interest in daily activities (OR = 3.95, 95% CI [2.16; 7.22]). This was also true for family problems in general (OR = 4.55, 95% CI [2.96; 6.94]) and for each family problem in particular (Table 4). The most pronounced association of a family problem with the DT was observed in “dealing with partner” (OR = 5.81, 95% CI [3.36; 10.06]). In practical problems, work/school problems and problems with child care were associated strongly with high distress scores. Problems with housing also showed a strong association with the DT, but were observed only in 23 patients (4.2%).
Table 4. Association of problems indicated with high/low distress (n = 520).

| Problem present | Distress (high vs. low)¹ |
|-----------------|--------------------------|
|                 | DT score < 5 | DT score ≥ 5 | DT score < 5 | DT score ≥ 5 | Odds Ratio | 95% confidence interval |
| At least one problem | 86 20 19 91 46 223 54 | 6.09 | [4.03; 9.21] |
| Practical problems | 236 62 147 38 41 96 70 | 3.08 | [2.14; 4.42] |
| Child care | 273 55 224 45 17 19 83 | 2.60 | [1.24; 5.46] |
| Housing | 271 55 226 45 6 26 17 74 | 3.58 | [1.71; 7.49] |
| Insurance/financial | 264 55 217 45 13 33 26 67 | 2.54 | [1.43; 4.53] |
| Mobility/transportation | 264 55 219 45 13 35 24 65 | 1.73 | [0.96; 3.10] |
| Work/school | 252 58 181 42 25 29 62 71 | 3.25 | [2.12; 4.98] |
| Family problems | 259 60 175 40 21 68 79 | 4.53 | [2.96; 6.94] |
| Dealing with children | 269 55 223 45 8 29 20 71 | 2.15 | [1.10; 4.19] |
| Dealing with partner | 268 57 205 43 9 19 81 | 5.81 | [3.36; 10.06] |
| Dealing with parents | 269 56 215 44 8 22 28 78 | 2.63 | [1.44; 4.80] |
| Emotional problems | 180 72 71 28 97 36 172 64 | 4.51 | [3.25; 6.25] |
| Depression | 263 58 193 42 14 22 50 78 | 4.76 | [2.96; 7.66] |
| Fear | 246 62 153 38 31 26 90 74 | 4.33 | [2.97; 6.33] |
| Nervousness | 226 64 128 36 51 31 115 69 | 3.85 | [2.74; 4.50] |
| Sadness | 248 61 159 39 29 26 84 74 | 4.14 | [2.82; 6.09] |
| Worries | 235 65 129 35 42 27 114 73 | 4.19 | [2.92; 6.00] |
| Loss of interest in daily activities | 266 55 218 45 11 31 25 69 | 3.95 | [2.16; 7.22] |
| Physical problems | 119 71 48 29 158 45 195 55 | 3.25 | [2.32; 4.55] |
| Appearance | 271 56 213 44 6 17 30 83 | 3.12 | [1.70; 5.71] |
| Bathing/dressing | 269 54 228 46 8 35 15 65 | 2.06 | [0.99; 4.30] |
| Breathing | 261 56 204 44 16 29 39 71 | 2.94 | [1.79; 4.82] |
| Changes in urination | 255 54 217 46 22 46 26 54 | 1.64 | [0.97; 2.77] |
| Constipation | 266 54 224 46 11 37 19 63 | 2.05 | [1.07; 3.92] |
| Diarrhea | 265 54 224 46 12 39 19 61 | 2.04 | [1.08; 3.86] |
| Eating | 253 54 219 46 24 50 24 50 | 1.96 | [1.17; 3.33] |
| Fatigue | 212 61 135 39 65 38 108 62 | 2.29 | [1.65; 3.18] |
| Feeling swollen | 248 55 205 45 29 43 38 57 | 1.90 | [1.21; 2.99] |
| Fears | 273 53 240 47 4 57 3 43 | 0.70 | [0.19; 2.61] |
| Getting around | 260 56 207 44 17 32 36 68 | 3.47 | [2.09; 5.76] |
| Indigestion | 264 55 218 45 13 34 25 66 | 1.88 | [1.05; 3.35] |
| Mouth sores | 262 54 223 46 15 43 20 57 | 2.28 | [1.25; 4.17] |
| Nausea | 269 55 219 45 8 25 24 75 | 3.16 | [1.67; 5.95] |
| Nose dry/congested | 245 56 196 44 32 41 47 59 | 1.75 | [1.15; 2.66] |
| Pain | 247 60 164 40 30 28 79 72 | 3.31 | [2.26; 4.85] |
| Sexual | 255 55 209 45 22 39 34 61 | 1.85 | [1.14; 3.01] |
| Sleep | 221 59 153 41 56 38 90 62 | 2.02 | [1.43; 2.83] |
| Tingling in hands/feet | 234 57 180 43 43 41 63 59 | 1.70 | [1.17; 2.47] |
| Spiritual problems | 274 54 238 46 3 38 5 63 | 4.52 | [1.32; 15.47] |
| Other problems | 259 55 210 45 18 35 33 65 | 2.34 | [1.41; 3.90] |

¹The odds ratios and corresponding 95% confidence intervals in this table are obtained by fitting a proportional odds cumulative logit model for each problem list item, adjusting for age. The odds ratios given here describe the odds for high distress in the presence of a problem relative to the odds in the absence of the problem.
In general, physical problems were also associated with high DT scores (OR = 3.25, 95%CI [2.32; 4.55]); the most pronounced associations were observed in problems with pain (OR = 3.31, 95% CI [2.26; 4.85]), appearance (OR = 3.12, 95% CI [1.70; 5.71]), getting around (OR = 3.47, 95% CI [2.09; 5.76]) and nausea (OR = 3.16, 95% CI [1.67; 5.95]). Spiritual problems showed more than a random association with high DT scores (OR = 4.52, 95% CI [1.32; 15.47]); however, they were rare in our patients. Fears, changes in urination and problems with bathing/dressing did not show any association with DT scores.

As expected, distress scores were associated with the number of problems indicated by patients (OR = 1.24 per problem, 95%CI [1.19; 1.29]); i.e. patients with multiple problems had higher distress scores (Figure 3).

We modeled the joint influence of problems on the DT using a cumulative logit model, adjusting for age and applying backward selection. The first considered model started with all problem list items. Work/education related problems, problems dealing with partner, fear, nervousness, worries, breathing problems and pain remained in the selected model. When this model was fitted, we found 72% concordant pairs. The model selected when starting with the numbers of specific problems, i.e. practical, emotional, physical, spiritual, and family problems, contained the number of practical problems (OR = 1.35 per problem, 95% CI [1.10; 1.67]), number of emotional problems (OR = 1.66 per problem; 95% CI [1.48; 1.87]), and number of physical problems (OR = 1.95 per problem, 95% CI [1.37; 2.78]); here we found 71.7% concordant pairs. When only considering the overall number of problems, we found similarly good classification properties: 70.4% concordant pairs.

Discussion

In general melanoma patients seem to be highly motivated to participate in psycho-oncological screening programs as 82% of the patients agreed to participate in this survey. Of the patients willing to participate, 71% filled in both screening measures, the DT and the PL, completely. Compared to the literature, which reports DT participation rates of about 80% to 90% [31,32], our data are consistent. In the studies where DT with PL were combined, there are no clear data regarding the completeness of the PL, as often imputations were made for missing data [32]. To our knowledge we have presented this kind of data for the first time in detail within a patient collective of 734 participating patients. We found a high motivation to participate in general as well as to fill in both the DT and the PL screening measures. However, there were some problems in filling in the complete survey with missing data in 29% of participating patients (average 3.18 missing items per patient). We have no information on why those patients skipped some items as we could not find any pattern of missing single items. Potential reasons could be that patients found some items not applicable for themselves or not important enough to mention.

The mean distress score in our melanoma patients was found to be 3.9, with 47% of patients reporting distress intensity between 5 and 10 on the DT. The mean score and percentages fell in the middle range reported in previous studies with ambulatory care cancer patients (mean of DT score of previous studies: 2.47–4.7) [31,33–35].

In our sample, elevated distress scores were not associated with most disease-specific melanoma aspects such as previous treatment, localization of the tumor, tumor stage, or time since diagnosis. Only current treatment was associated with an increased distress, which is supported by the literature; a considerable number of our patients received adjuvant interferon alpha treatment, a treatment known to affect several aspects of quality of life [36,37]. Apart from younger age and employment state, there was no association of distress with demographic data, including gender, health insurance, or marital state. This finding could indicate that melanoma patients are not strongly distressed due to their disease. Indeed, compared to other cancer entities, long-time melanoma survivors as well as prostate cancer patients seem to perform better [27]. To assess the impact of melanoma-specific distress, studies including distress data from the general population should be initiated.

Melanoma patients differ from other cancer patients in several aspects. On average, melanoma patients are younger than other cancer patients. This implies that diagnosis usually occurs at a time when most patients are still active at work, have to care for their children or pay off their mortgage. Being confronted with a possibly life-threatening disease in a period of life characterized by career and family duties may cause existential concerns, particularly in younger patients [1,38].

Most melanoma patients are diagnosed at an early stage of the disease without the need for further adjuvant treatment after initial surgery. The absence of any signs of disease together with a lack of physical impairment may distract the patient from the cancer diagnosis and may enable the patient to cope well with his or her disease. Indeed, most patients with melanoma seem to cope well; however even patients with early-stage disease have to deal with the possibility of recurrence or systemic spread, which is highest in the first 3 years but can also occur more than 10 years after diagnosis. This underlying fear could explain the distress of our patients regardless of disease stage, suggesting that the possibility of disease recurrence/metastasis is the major stress factor.
Accordingly, the most prevalent problems of our patients who had distress scores indicating psychosocial referral were of emotional nature. Consistent with published data [39], in addition to other emotional problems worries and fear were strongly associated with high distress. In a recent survey of 1490 cancer patients, Mengshoel et al. [31] found that 97% of patients appreciated speaking with their doctor about their distress, and 56% felt better than usual after this consultation. As distress in our patients was not only associated with emotional problems but also with practical, family, and physical problems like dealing with their partner, problems at work, nausea, or pain, the role of the primary physician to meet and treat unmet needs should not be underestimated. The DT with the PL can help identify distress sources and stimulate doctor-patient communication. The primary physician than can act as a gate keeper, who refers the patient to the specific professional he or she needs: for physical problems to physicians or nurses, for emotional problem to psycho-oncologists, and for practical problems to social workers.

There are certain limitations in our study that should be considered. First, it has a cross-sectional design. A longitudinal study could probably better address patients’ needs during their disease process and identify patients in need for professional psychosocial support. Second, DT and PL have only been studied in cancer patients but not in the general population, and third, we did not investigate the influence of comorbidities, especially chronic diseases other than cancer and mental illnesses. Therefore the impact of melanoma disease on distress still has to be defined in further studies considering these issues.

Conclusions

The present findings have important implications for future research and clinical practice. First, the results suggest that the DT and PL may be used to identify distressed melanoma patients. It seems to be an economically reasonable initial measure and helps to better identify patients who would actually profit from further psychosocial intervention. Even though melanoma patients regardless of stage seem to cope well with their disease, younger patients who are currently employed and patients under current systemic treatment should be followed more cautiously. As distress can be influenced not only by disease-specific items but also by problems of daily living, comorbidities, a patient’s history, or socioeconomic issues, a patients’ concerns depicted by the DT and PL should stimulate doctor-patient communication and help to guide the patient to psychosocial professionals according to the patient’s needs.

Author Contributions

Conceived and designed the experiments: CL, AW, MEB. Performed the experiments: CL, VS. Analyzed the data: CL, VS, NS, IS, SR, AW, MEB. Contributed reagents/materials/analysis tools: CL, NS, IS, SR. Wrote the paper: CL, VS, NS, IS, SR, AW, MEB.

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