The need for psycho-oncological support for melanoma patients
Central role of patients' self-evaluation

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Abstract

Despite an increasing number of promising treatment options, only a limited number of studies concerning melanoma patients' psycho-oncological distress have been carried out. However, multiple screening tools are in use to assess the need for psycho-oncological support. This study aimed first to identify parameters in melanoma patients that are associated with a higher risk for being psycho-oncologically distressed and second to compare patients' self-evaluation concerning the need for psycho-oncological support with the results of established screening tools.

We performed a cross-sectional study including 254 melanoma patients from the Center for Dermatooncology at the University of Tuebingen. The study was performed between June 2010 and February 2013. Several screening instruments were included: the Distress Thermometer (DT), Hospital Anxiety and Depression Scale and the patients' subjective evaluation concerning psycho-oncological support. Binary logistic regression was performed to identify factors that indicate the need for psycho-oncological support.

Patients' subjective evaluation concerning the need for psycho-oncological support, female gender, and psychotherapeutic or psychiatric treatment at present or in the past had the highest impact on values above threshold in the DT. The odds ratio of patients' self-evaluation (9.89) was even higher than somatic factors like female gender (1.85), duration of illness (0.99), or increasing age (0.97). Patients' self-evaluation concerning the need for psycho-oncological support indicated a moderate correlation with the results of the screening tools included.

In addition to the results obtained by screening tools like the DT, we could demonstrate that patients' self-evaluation is an important instrument to identify patients who need psycho-oncological support.

Abbreviations: CMMR = central malignant melanoma registry, DT = distress thermometer, HADS = hospital anxiety and depression scale, HADS-A = hospital anxiety and depression scale-anxiety, HADS-D = hospital anxiety and depression scale-depression, PP = psychotherapeutic or psychiatric.

Keywords: distress-thermometer, HADS, hospital anxiety and depression scale, melanoma, psycho-oncology

1. Introduction

Melanoma is one of the most serious types of cancer and has an increasing incidence rate worldwide.[1,2] According to the current German S3 Guideline on melanoma, surveillance is recommended for 10 years, including psycho-oncological support.[3]

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Despite an increasing number of promising treatment options and more and more insight into the tumor biology, only a limited number of investigations have been conducted into psycho-oncological distress in melanoma patients.[4]

Some important predictors for psycho-oncological distress in melanoma patients are female gender, younger age, patients who are separated or living alone and initial diagnosis not longer than 3 years ago.[5–7] It is worth mentioning that psycho-oncological distress has an impact not only on patients' quality of life but also on patients' compliance concerning treatment and follow-up schedules.[8] Brief and reliable psycho-oncological screenings such as the "distress thermometer" (DT) are therefore of great importance.[9] Furthermore, it is known that physicians and their team sometimes have problems identifying patients who need psycho-oncological support,[10,11] and the importance of patients' self-evaluation was recently shown.[12] Approaches that consider patients' perspectives report 40% to 50% of cancer patients desire psychosocial support.[13]

As a consequence, our study's first objective was to identify parameters in melanoma patients that are associated with a higher risk for being distressed according to the DT, and the second objective was to compare patients' self-evaluations concerning the need for psycho-oncological support to the results of established screening tools.

1.1. Ethics statement

Ethical approval was obtained from the local ethics committee of the Medical Faculty at the University of Tuebingen (reference number 52/2010).

2. Methods

We performed a cross-sectional study, including melanoma patients from the Center for Dermatooncology at the University of Tuebingen.

Inclusion criteria were: German-speaking women and men with any kind of melanoma. Excluding criteria were: severe problems with the German language, severe physical symptoms (e.g., sedation, loss of strength, concentration deficits), or illiteracy. The study was performed between June 2010 and February 2013 and included 254 patients consecutively. The participants gave informed consent via an electronic device and completed the questionnaire on a tablet PC in the waiting area before they consulted the physician. The patients were accustomed to using a tablet PC; even older patients showed no problems using it.[14]

2.1. Demographics

The assessment for socio-demographic data included: marital status, children, current living situation, highest level of education, and occupational status. The assessment for mental history included questions about tranquilizers, antidepressants, or sleep-inducing drugs as well as psychotherapeutic or psychiatric (PP) treatments at present or in the past.

2.2. Assessment instruments
2.2.1. Distress thermometer (DT).
This measurement is a scale with distress values from 0 to 10. 0 means "no distress" and 10 means "extreme distress." Psycho-oncological distress may occur as anxious or depressive symptoms which do not necessarily fulfil the full criteria of mental illness. The patients indicate which value best describes their level of distress during the last week. Furthermore, the DT comprises a problem list including 34 items on practical, emotional, family, spiritual, and physical problems.[10,15,16] There are different approaches to determine above-threshold values obtained by the DT.[15,17] Like others, we used a cutoff ≥ 6 to define patients above-threshold,[18] as indecisive patients usually tend to take the mean.

2.2.2. Hospital anxiety and depression scale (HADS).
The hospital anxiety and depression scale (HADS) measures anxiety (HADS-A) and depression (HADS-D). This instrument is meant as a screening tool for depressive or anxiety disorders.

The questionnaire includes 14 items in alternating order; 7 questions about depression and 7 questions about anxiety. For each item there are 4 answer choices. The score for each subscale, thus for depression and anxiety, ranges from 0 to 21. Two cut-off points are recommended: ≥ 8 for possible depression or anxiety and ≥11 for probable depression or anxiety.[19]

2.2.3. Assessment for the need for psycho-oncological support.
The subjective evaluation for psycho-oncological support was assessed by the following question: "Self-assessment concerning your present personal situation: Do you currently need either support in coping with the disease or psycho-oncological counseling?"

2.2.4. Central malignant melanoma registry (CMMR).
Tumor-specific data were obtained from the central malignant melanoma registry (CMMR). Routinely, all melanoma patients at Tuebingen's dermatological department are registered in the CMMR. Informed consent to this documentation was obtained from all the patients. Captured data include general information like date of birth, sex, origin, and date of death, if applicable. In addition, the CMMR provides melanoma-specific variables such as localization, size, histological type, Breslow tumor thickness, and Clark level.

2.2.5. Statistical analyses.
Socio-demographic and clinical data were presented descriptively. To analyze differences between the 2 dichotomous groups of self-evaluation (subjective need for psycho-oncological support present or not), a Mann–Whitney U test for metric-scaled, non-normally distributed variables, a χ^2 test for categorical variables, and Fisher exact test for small sample sizes were performed. To identify parameters that are associated with distress in melanoma patients, a binary logistic regression analysis for categorical and continuous variables was run. Statistical analysis was performed using the statistical program for social sciences SPSS Version 23 (IBM, New York).

3. Results

Two hundred fifty-four patients were included consecutively in the study. The mean age was 56.3 years (Y) (19–90 Y, interquartile range 46–69 Y). 48.4% (N=123) of the patients were women and 77.2% (N=196) were married or in a partnership. About half of the patients (48.8%; N=124) were still employed. 13.0% (N=33) of the patients had a current psychotropic medication, 23.3% (N=59) had a current or a former psychotherapeutic or psychiatric treatment (Table 1).

3.1. Tumor-specific data

The superficial spreading melanoma was the most frequent melanoma type (43%; N=109). The average time since primary diagnosis of melanoma was 48 months (m) (0–413 m, interquartile range 16–62 m).

At initial diagnosis of melanoma, 179 patients (71%) were not metastasized and classified as tumor stage I or II. Seventy-five patients had developed metastases: 64 patients (25%) were stage III and 11 patients (4%) stage IV.

Most of the patients remained stage I/II, that is, they developed no metastases from initial diagnosis until the time of the survey (51%; N=129). However, 20% of the patients (N=50) had a course of disease with metastases and entered stage III or IV from initial stage I or II until the survey.

Fifteen of the 254 patients (6%) were under systemic therapy at the time point of the survey. Six of these 15 patients (40%) had an adjuvant treatment with interferon, 9 of them (60%) were under systemic treatment with BRAF inhibitors (N=5) or chemotherapy (N=4) for metastases.

Seven of the 254 patients (3%) had previously received systemic therapy but were not undergoing it at the time of the survey (Table 1).

3.2. Psycho-oncological distress, depression, and anxiety

Thirty-four percent of the patients (N=86) were screened positive by the DT, indicating the need for psycho-oncological support. Concerning the related problem list, 72% (N=188) of

Table 1

Sample description.

	Subjective evaluation negative n=229 (90.2%)	Subjective evaluation positive n=25 (9.8%)	Overall n=254 (100%)	Significance level
Sex				P=.039 *
Male	n=123 (53.7%)	n=8 (32.0%)	n=131 (51.6%)	
Female	n=106 (46.3%)	n=17 (68.0%)	n=123 (48.4%)	
Age	57.03 y (SD 15.43)	49.80 y (SD 11.27)	56.32 y (SD 15.21)	P=.010 ‡
Marital status				P=.297 †
With partner (married/not married)	n=176 (76.9%)	n=20 (80.0%)	n=196 (77.2%)	
Single	n=22 (9.6%)	n=1 (4.0%)	n=23 (9.1%)	
Others	n=31 (13.5%)	n=4 (16.0%)	n=35 (14.2%)	
Children				p=.844 *
Yes	n=178 (77.7%)	n=19 (76.0%)	n=197 (77.6%)	
No	n=51 (22.3%)	n=6 (24.0%)	n=57 (22.4%)	
Life and living situation				P=.059 †
Alone	n=41 (17.9%)	n=6 (24.0%)	n=47 (18.5%)	
With partner, child (ren) or parents	n=184 (80.3%)	n=18 (72.0%)	n=202 (79.5%)	
(Others)	n=4 (1.8%)	n=1 (4.0%)	n=5 (2.0%)	
Educational level				P=.188 †
A-level/university education	n=83 (36.2%)	n=10 (40.0%)	n=93 (36.6%)	
Secondary school	n=131 (57.2%)	n=15 (60.0%)	n=146 (57.5%)	
(Others)	n=15 (6.6%)	n=0	n=15 (5.9%)	
Working state				P=.739 *
Working	n=111 (48.5%)	n=13 (52.0%)	n=124 (48.8%)	
Not working	n=118 (51.5%)	n=12 (48.0%)	n=130 (51.2%)	
Time since diagnosis	49.12 m (SD 50.76)	37.56 m (SD 45.72)	47.98 m (SD 50.32)	P=.032 ‡
	(min 0, max 413)	(min 2, max 160)	(min 0, max 413)	
Current psychotropic medication?				P<.001 *
No	n=206 (90.0%)	n=15 (60.0%)	n=221 (87.0%)	
Yes	n=23 (10.0%)	n=10 (40.0%)	n=33 (13.0%)	
Distress-thermometer				P<.001 ‡
DT ≥ 6	n=65 (28.4%)	n=21 (84.0%)	n=86 (33.9%)	
Total score mean	3.98	7.23	4.30	
Range	0–10	4–10	0–10	
SD	2.50	1.50	2.64	
Missing	n=2 (0.9%)	n=1 (4.0%)	n=3 (1,2%)	
HADS-A				P<.001 ‡
≥ 11 probable anxiety	n=18 (7.9%)	n=12 (48.0%)	n=30 (11.8%)	
≥ 8 possible anxiety	n=31 (13.5%)	n=9 (36.0%)	n=40 (15.7%)	
Total score mean	4.94	10.30	5.53	
Range	0–15	1–19	0–19	
SD	3.55	4.26	4.01	
Missing	n=12 (5.2%)	n=2 (8.0%)	n=14 (5.5%)	
HADS-D				P<.001 ‡
≥ 11 probable depression	n=15 (6.6%)	n=6 (24.0%)	n=21 (8.3%)	
≥ 8 possible depression	n=19 (8.3%)	n=6 (24.0%)	n=25 (9.8%)	
Total score	Mean 3.91	Mean 8.48	Mean 4.36	
	Min. 0	Min. 1	Min. 0	
	Max. 16	Max. 18	Max. 18	
	SD 3.55	SD 4.50	SD 3.91	
Missing	n=13 (5.7%)	n=2 (8.0%)	n=15 (5.9%)	
Current or former psychotherapeutic/ psychiatric treatment?				P<.001 *
No	n=186 (81.2%)	n=9 (36.0%)	n=195 (76.8%)	
Yes	n=43 (18.8%)	n=16 (64.0%)	n=59 (23.2%)	
AJCC stage				P=.005 *
I/II	n=167 (72.9%)	n=12 (48.0%)	n=179 (70.5%)	
III	n=55 (24.0%)	n=9 (36.0%)	n=64 (25.2%)	
IV	n=7 (3.1%)	n=4 (16.0%)	n=11 (4.3%)	
Time period since diagnosis				P=.001 *
0–2 y	n=77 (33.6%)	n=17 (68.0%)	n=94 (37.0%)	
>2–5 y	n=88 (38.4%)	n=2 (8.0%)	n=90 (35.4%)	
>5 y	n=64 (27.9%)	n=6 (24.0%)	n=70 (27.6%)	
Tumor type				P=.226 †

Table 1

(continued).

	Subjective evaluation negative n=229 (90.2%)	Subjective evaluation positive n=25 (9.8%)	Overall n=254 (100%)	Significance level
SSM	n=102 (44.5%)	n=7 (28.0%)	n=109 (42.9%)	
NM	n=34 (14.9%)	n=7 (28.0%)	n=41 (16.1%)	
LMM	n=9 (3.9%)	n=0 (0.0%)	n=9 (3.5%)	
ALM	n=17 (7.4%)	n=0 (0.0%)	n=17 (6.7%)	
Mucous membrane	n=6 (2.6%)	n=1 (4.0%)	n=7 (2.8%)	
MM on naevus	n=1 (0.4%)	n=0 (0.0%)	n=1 (0.4%)	
Not specified, others	n=44 (19.2%)	n=4 (16.0%)	n=48 (18.9%)	
Missing	n=16 (7.0%)	n=6 (24.0%)	n=22 (8.7%)	
Progression				$P=.012$ [*]
Course of disease without metastases (stage I/II)	n=123 (53.7%)	n=6 (24.0%)	n=129 (50.8%)	
Course with metastases (stage I/II to III/IV)	n=44 (19.2%)	n=6 (24.0%)	n=50 (19.7%)	
Initial diagnosis with metastases (stage III/IV)	n=62 (27.1%)	n=13 (52.0%)	n=75 (29.5%)	
Systemic therapy				$P=.356$ [*]
Under systemic therapy	n=12 (5.2%)	n=3 (12.0%)	n=15 (5.9%)	
No systemic therapy	n=211 (92.1%)	n=21 (84.0%)	n=232 (91.3%)	
Former systemic therapy, not currently	n=6 (2.6%)	n=1 (4.0%)	n=7 (2.8%)	

AJCC = american joint committee on cancer.

[*] χ^2 test.

[†] Fisher exact test.

[‡] Mann–Whitney U test.

the patients indicated physical problems and 49% (N=125) emotional problems. Twenty-two percent (N=57) of all the patients indicated practical and 12% (N=31) family problems. Religious problems were extremely rare (5%, N=12).

Concerning HADS, 8% (N=21) of the patients were above-threshold (cutoff ≥ 11) in the HADS-D ("depression") and another 10% (N=25) showed borderline results with values ≥ 8. HADS-A ("anxiety") revealed 12% (N=30) of the patients above-threshold (cutoff ≥ 11) and 16% (N=40) presented with borderline findings (value ≥ 8).

Ten percent (N=25) of all the patients stated a subjective need for psycho-oncological support. Twenty-one of them (84%) were also above-threshold in the DT. Among all patients with DT values ≥ 6 (N=86), 24% (N=21) indicated subjectively the need for psycho-oncological support.

Concerning the Hospital Anxiety and Depression Scale-A, 12 patients were above-threshold in the HADS-A, and they also indicated the subjective need for psycho-oncological support. Sixty percent (N=18) of the patients above-threshold in HADS-A did not indicate the subjective need for psycho-oncological support.

In view of the Hospital Anxiety and Depression Scale-D, 6 patients were above-threshold and also indicated the subjective need for psycho-oncological support. Seventy-one percent (N=15) of all the patients above-threshold in HADS-D did not state the subjective need for psycho-oncological support (Table 1).

3.3. Comparison of the groups with and without subjective need for psycho-oncological support

Patients with (10%, N=25) and without (90%, N=229) a subjective need for psycho-oncological support did not differ in any personal data except sex and age. They differed in use of psychotropic medication, psychotherapeutic/psychiatric treatment, distress scores, american joint committee on cancer tumor stage, and time period since diagnosis. Patients with a subjective need for psycho-oncological support showed significantly higher scores in all mental health dimensions assessed (Table 1).

There is a moderate correlation between the Distress Thermometer and subjective need ($r=.399$), between the HADS-Depression total score and subjective need ($r=.362$) and between the HADS-Anxiety total score and subjective need ($r=.433$).

3.4. Parameters for psycho-oncological need according to DT

A binary logistic regression was performed to assess the impact of patients' subjective evaluation among other, objective factors on the likelihood that melanoma patients develop distress. Since the DT is a widely used instrument to assess the need for psycho-oncological support, we defined the DT result as the response variable (DT ≥ 6, distress, DT < 6, no distress).

The model contained 8 variables: positive subjective evaluation, patients with PP treatment, female gender, course of disease with metastases (Progress I/II to III/IV), and initial diagnosis with metastases. Further metric variables were age and duration of illness in months (Table 2). The full model containing all parameters was statistically significant, $\chi^2(N=251)=67.31$, $P<.001$, indicating that the model was able to distinguish between distressed patients and nondistressed patients. The model explained between 23.5% (Cox and Snell R-squared) and 32.5% (Nagelkerkes R-squared) of the variance and correctly classified 75.3% of cases. As shown in Table 2, 5 variables made a unique statistically significant contribution to the model (positive subjective evaluation, PP-treatment, female gender, duration of illness in months, and age). The strongest predictor of psycho-oncological need according to DT was the variable "positive subjective evaluation" with an odds ratio of 9.888. This means that patients indicating a need for psycho-oncological support were over 9 times more likely to achieve values above-threshold in the DT, controlling for all other factors in the model. Further significant parameters for values above-threshold in the DT, indicating the need for psycho-oncological support were: PP-treatment, female gender, shorter duration of illness in months, and younger age. Increasing age was found to reduce the risk for distress, as well as an increasing duration of illness.

Table 2

Odds ratio for the need for psycho-oncological support according to the distress score (DT).

Variables	Odds ratio	Standard error	P value	95% CI Lower bound	Upper bound
Positive subjective evaluation	9.888	0.679	.001	2.613	37.427
PP treatment	3.102	0.335	.001	1.607	5.987
Female gender	1.855	0.341	.049	1.002	3.434
Longer duration of illness in months	0.989	0.005	.022	0.980	0.998
Increasing age	0.972	0.011	.008	0.952	0.993
Course of disease with metastases (progress I/II to III/V)	1.600	0.436	.282	0.680	3.762
Initial diagnosis with metastases	1.257	0.359	.532	0.622	2.541

DT = distress thermometer, PP treatment = psychological, psychotherapeutic, or psychiatric treatment (current or former).

Patients with a course of disease with metastases and patients with initial metastases showed a nonsignificant tendency toward a higher risk of developing distress according to the DT.

4. Discussion

Patients' self-evaluation concerning the need for psycho-oncological support, female gender, and PP treatment at present or in the past had the highest impact on values above-threshold in the DT. A longer period of time since primary diagnosis of melanoma and an increasing age of the patients were significantly associated with a lower risk for being distressed according to DT.

Patients who indicated a subjective need for psycho-oncological support had significantly higher scores in the screening tools used in our study. Thus, some patients indicating the subjective need of psycho-oncological support were not above threshold in the screenings. To explain this, it is important to consider the different approaches of the screening tools. DT aims to capture the patients' distress in the last week on a scale from 0 to 10 and is a nonspecific screening tool whereas patients' self-evaluation already focuses on the need for psycho-oncological support. This question goes beyond a scale and might consider factors of the patients' situation that are not captured by classical screening tools.

For this reason, patients' self-evaluation contributes valuable additional information and should therefore be used in addition to screening tools to identify patients who need psycho-oncological support.[12,20] The physician and his team should therefore also ask the patients for their own opinion regarding psycho-oncological support as already recommended by current guidelines.[20]

It is obvious that the DT values, evaluating by definition the patients' last week in total, also assess stressful situations outside the patients' illness: problems in the family or the financial situation. This might be a reason for the difference between 86 patients with DT values above-threshold but only 25 patients indicating subjectively the need for psycho-oncological support. Another reason for this disequilibrium could be the presence of cognitive dysfunctions, for example due to depression. It is known that depressive patients might have a "negative filter" and tend to ignore positive aspects such as the possibility of psycho-oncological support.[21] In this sample, almost 1 in every 5 patients showed a value in HADS-D above threshold. It should therefore be considered that cognitive dysfunction could hinder the interpretation of results obtained by a subjective evaluation.

Another reason for not indicating subjectively the need for psycho-oncological support could be the fact that patients might not address their private problems to psycho-oncologists even though psycho-oncologists might be able to help the patients with these problems. In this context it could be helpful to announce the different types of support that can be provided by psycho-oncologists. Furthermore, it might be important to define the term "psycho-oncological support" to avoid the fear of stigmatization.[22] For that reason, we prefer the term psycho-oncological "support" instead of a psycho-oncological "treatment."

Like others, we were able to show that psychiatric comorbidities (PP treatment) and female gender elevated the risk of being distressed, whereas longer duration of illness and increasing age reduced it. These findings are in line with other data.[5,23–25] Meraner et al[24] indicated PP treatment at present or earlier time is a good predictor of the need for professional support. In addition, female gender is a known risk factor for the development of psycho-oncological distress,[25] whereas patients with a longer time span since primary diagnosis tended toward a lower risk for psycho-oncological distress.[23] One can assume that a longer duration of illness since diagnosis implies the patients having had more time to deal with the disease and to manage an extremely distressing life event.[26] On the other hand, this result underlines the importance of psycho-oncological support at an early time in disease, that is, at the time of first diagnosis.[20]

In agreement with other studies, mainly younger patients suffered from psycho-oncological distress.[27–29] With increasing age, psycho-oncological distress abates. In this context, it has to be considered that melanoma patients are younger than other cancer patients and after their convalescence, most of the patients start to work again.[30–33] It is obvious that younger patients have to deal with more distinct problems in their lives than older, often retired patients.[23] The associated problem list of the DT can help to identify immediately such problems.

We suggest considering patients' self-evaluations in combination and not instead of established screening instruments like the DT and HADS. Patients indicating the subjective need for psycho-oncological support showed significantly higher scores in the DT and HADS. Nevertheless, not all of the patients with a subjective need for psycho-oncological support were also above-threshold in the DT or HADS and vice versa. As psycho-oncological support can improve patients' compliance and therefore most probably the medical outcome,[34,35] it should be offered to all distressed patients as soon as possible.

4.1. Strengths and limitations

The present survey has some limitations. First, we determined the data in a cross sectional design. The influencing parameters we found have to be regarded as explorative. For generating predictors, a prospective study design should be conducted. Second, the patients' distress was assessed in the waiting area before they consulted the physician. This could have had a

distressing effect on the patients resulting in a possible bias when answering the questionnaires. Third, our study includes only a very small number of metastatic melanoma patients. That is why conclusions concerning metastasized patients should be drawn with caution. Our results should be verified with a larger collective of metastasized melanoma patients.

There are also strengths of the survey as we were able to include a relatively high number of patients and use tumor-specific data from the CMMR.

5. Conclusion

In addition to the results obtained by screening tools like the DT or HADS, patients' self-evaluation is an important way to identify patients with the need for psycho-oncological support. Patients indicating the subjective need for psycho-oncological support showed significantly higher scores in the DT and HADS. Nevertheless, not all of the patients with the subjective need for psycho-oncological support were also above-threshold in the DT or HADS and vice versa. According to the results of our study, we introduced psycho-oncological screening, including the DT and also patients' self-evaluations in the routine care for our melanoma patients.

Acknowledgment

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