

Assessing the need for psychooncological support: screening instruments in combination with patients' subjective evaluation may define psychooncological pathways

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Abstract

Background: Cancer patients suffer from severe distress. About one third show mental comorbidities. Nevertheless, there is no common agreement on how to measure distress or identify patients in need for psychooncological services using screening questionnaires.

Patients and methods: A sample of $N = 206$ patients with confirmed breast cancer, being inpatient for surgical treatment, filled in distress assessment instruments: Distress Thermometer, Hospital Anxiety and Depression Scale, Patient Health Questionnaire 2, Hornheider Screening Instrument and parts of the EORTC-QLQ-C30. Additionally, they were asked for their subjective need for psychooncological counselling.

Results: The correlation between the assessment instruments is low to medium. The number of patients above the cut-off criteria varies quite a lot according to the instrument (10% to 66%). Therefore, the congruence between the instruments' indications is quite low. Patients with and without subjective need do not differ in personal data but in distress scores.

Conclusions: Recommended instruments for distress assessment in psychooncology measure different areas of distress. They do not sufficiently agree in indicating a patient's need for psychooncological treatment. Hence, one should neither compare results of studies using different assessment instruments nor implement a screening without reflecting the used instrument's characteristics compared to the others. The subjective need seems to provide additional information to the assessment. At present, the combination of an assessment instrument and patients' subjective need is seen as a best practice for identifying patients in need of psychooncological treatment.

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Background

Cancer causes severe distress and may lead to mental illnesses. About 6% to 17% of cancer patients develop a depression, and 10% to 12% develop an anxiety disorder. Roughly 11% to 15% of patients are diagnosed with adjustment disorder [1–3]. In total, a significant portion of about one third of oncological patients shows mental comorbidities [3] with breast cancer patients having the highest prevalence of 42%. Mental symptoms as well as patients' quality of life seem to be linked stronger to psychosocial factors than to the type or stage of tumour or treatment possibilities [4,5]. However, strong somatic symptoms, particularly pain and fatigue, as well as prior mental illness are risk factors in the development of mental symptoms [6–10]. Patients who are satisfied with the information they received concerning treatment options and their disease in general seem to have lower anxiety and depression as well as a better quality of life [11]. Major needs of breast cancer patients include

information and psychological needs, with fear of tumour progression as one of the most prevalent ones. These needs change with status of disease or treatment. Younger patients as well as advanced stage or recurrence have greater needs [12].

Though there seem to be more dimensions in defining a patient's distress or need of psychooncological treatment, there is most often an orientation towards psychosomatic or psychiatric comorbidity using specific questionnaires (e.g. depression screener). Depending on the study and its respective definition, the number of burdened patients varies. Studies that focus on global distress measures or screen for subclinical symptoms show a significantly higher number of patients in need of support, sometimes up to 50% [13–15]. Approaches that consider a patient's perspective report 40–50% of cancer patients who desire psychosocial support [5,16]. Patients' resources and their needs are seldom considered. This may explain the gap between elevated distress and the acceptance of help [17].

The appropriate identification of burdened patients is very important as mental symptoms may cause problems in cancer treatment, e.g. because of lack of compliance. Previous research revealed that clinicians as well as nurses do not reliably identify oncological patients with distress in routine inpatient treatment [18,19]. Therefore, international and national guidelines recommend more and more a psychooncological routine-screening [6,20]. A recent review as well as a study shows that a well implemented distress assessment is likely to improve psychooncological supply [21,22]. It also may influence the doctor–patient communication in a positive way [23]. As demonstrated in a former study, there is high acceptance of a computer based distress assessment in patients. Measures do not differ from a classical paper–pencil questionnaire [24].

There are recommendations as to which questionnaire may be used for screening purposes [25,26], but evidence-based recommendations are still missing. The fact that screening instruments cannot replace appropriate diagnostics is often overlooked. For example, a recent paper [2] clearly shows, that out of $n=4365$ cancer patients with a total HADS-score >15 , which elsewhere is often equated with the diagnosis of depression, only $n=2030$ had a Major Depression (examined using the depression section of SCID in a telephone interview). Furthermore, a definition of a psychooncological need of treatment does not exist (which seems to be different from sheer psychiatric comorbidity). Thus there is no gold standard on how to identify patients in need.

As far as we know there is no study that compares different screening approaches to measuring distress in oncological patients as it is suggested, recommended or used in clinical routine. This includes the usage of questionnaires for a psychooncological assessment that have actually been developed for another field. What do we really measure with which instrument? This study is meant to compare patients in need of psychooncological treatment identified through different approaches with consideration of patients' subjective need. With reference to current psychooncological research questions [27] we aim to obtain initial evidence for the usage of recommended instruments as well as indications on how to assess patients' own perspective on their needs in asking for their subjective need.

Methods and patients

We included all consecutive patients with confirmed breast cancer, who were an inpatient for surgical treatment. All of them were asked to complete questionnaires one day prior to surgery. They were supposed to fill in personal questions (civil status, living conditions, children, educational background and current occupational data) and current psychotropic medication, current or former psychotherapy or psychiatric treatment, as well as date of first diagnosis of the tumour. Five questionnaires have been used for the

assessment: The 'Distress Thermometer', 'Hospital Anxiety and Depression Scale' and 'Hornheider Screening Instrument' are recommended for distress screening in cancer patients in the national guideline [6]. While the national guideline recommends the 'Patient Health Questionnaire-9' we used the short form 'PHQ-2', which is discussed in the NCCN guideline [20] as ultra short measure. A fifth approach has been described by Meraner et al. [28].

The 11-level visual analogue scale of the 'Distress Thermometer' (DT) was shown to identify quite sensitive possible cases of patients with depressive and/or anxious symptoms [20,29–31]. As cut-off score a value ≥ 5 is recommended. The problem list of the DT was used to specify needs of the patient. It asks for practical problems, family problems, emotional problems, spiritual/religious concerns and physical problems. The 'Hospital Anxiety and Depression Scale' (HADS) [32,33] measures anxiety and depression with 7 items on each subscale. It has proven to have good psychometric properties [34] and is widely used in medical research to describe a patient's mental health. For each of the two subscales, a total score ≥ 11 is seen as evidence for anxiety or depression, whereas 8 to 10 are considered sub clinical symptoms. The 'Patient Health Questionnaire 2' (PHQ2) [35–37] is a 2-item depression screening instrument and asks for feelings of sadness or unhappiness as well as loss of interest or pleasure in normal activities. Cut-off score for evidence of depressive symptoms is ≥ 3 . The 'Hornheider Screening Instrument' (HSI) is a 7-item screening instrument which has good psychometric quality [38] and asks for physical condition, mental condition, level of information about illness and treatment, psychosocial distress apart from present illness, distress of relatives, the availability of people to talk to about concerns and anxiety and the ability to relax during the day. We used both methods to calculate a score: A total raw score ≥ 4 as well as a calculated score $>.30$ using the discriminant function [25]. Following a study of Meraner et al. [28], we used the subscales 'role functioning' and 'emotional functioning' of the Quality-of-Life-Questionnaire EORTC-QLQ-C30 [39]. They describe a sophisticated equation using both subscales as well as the information on prior psychotherapeutic or psychiatric treatment to calculate a score which indicates need of psychooncological treatment if $>.46$. Finally, we asked the patients whether they have a subjective need: 'Self-assessment concerning your present personal situation: Do you currently need support in coping with the disease or psychooncological counselling?'

All statistical calculations were done with SPSS© V21. We used a significance-level of $p < .05$ two-sided. To test for differences, we used a t-test or chi quadrat test and Fisher's exact test. For correlations we calculated a Pearson correlation. Values between $r = .100$ and $.299$ are seen as small, $r = .300$ and $.499$ as medium and $r > .499$ as large strength. To test the accordance of the screening

instruments, we used Cohen's Kappa. $K = .500$ to $.699$ is seen as moderate, $K = .700$ to $.799$ as good and $K > .799$ as very good agreement.

The local ethics committee approved the study protocol

Results

Sample

In total $N = 245$ eligible patients were asked to participate in the study. $n = 206$ (84%) gave informed consent and were included; $n = 39$ (16%) patients declined to participate. Non-participants did not differ from participants in age, marital status, living conditions, state of disease, children, period from diagnosis to surgical treatment, current usage of psychotropic medication, current psychotherapy or psychiatric treatment, score in HSI and subjective need. Participants had a higher educational background and longer employment than non-participants, and reported emotional problems more often.

The mean age of participants was 54 years (SD 11.0). Women suffering their first tumour episode were the dominant group with 87% in total. Nearly 80% were married or in a partnership. Sixteen percent lived alone. A quarter of the patients had a higher educational background. About 20% took psychotropic medication; a quarter has been in psychotherapeutic or psychiatric treatment before or was in treatment at the time of questioning. About 25% uttered a subjective need for psychooncological treatment; according to HSI screening 33% showed scores above cut-off.

Subjective need

Patients with and without subjective need did not differ in all personal data and status of disease but in usage of psychotropic medication, psychotherapeutic/psychiatric treatment (see Table 1), all distress scores and topics of the DT-problem list (see Table 2). Correlations with assessment instruments reach tight fitting medium strength.

Table 1. Personal data, status of disease and psychotherapeutic or psychiatric treatment; ^T = t-test, ^C = chiquadrate-test

Total: $n = 206$ patients with breast cancer ($n = 17$ subjective need not indicated)	No subj. need $n = 135$	Subj. need $n = 54$	Significance level
Age	53 years (SD 11.3)	52 years (SD 8.2)	$p = .379$ ^T
Marital status			
With partner (married/not married)	$n = 104$ (55%)	$n = 43$ (23%)	$p = .699$ ^C
Separated/divorced/widowed/ No partnership	$n = 31$ (16%)	$n = 11$ (6%)	
Living condition			
Alone	$n = 21$ (11%)	$n = 9$ (5%)	$p = .899$ ^C
With partner and/or children (Others)	$n = 111$ (59%) $n = 3$ (2%)	$n = 45$ (24%) $n = 0$	
Children			
Yes	$n = 107$ (57%)	$n = 46$ (24%)	$p = .395$ ^C
No (Not indicated)	$n = 27$ (14%) $n = 1$ (1%)	$n = 8$ (4%) $n = 0$	
Highest level of education			
Secondary (modem) school A-level/university education (Others) (Not indicated)	$n = 89$ (47%) $n = 33$ (17%) $n = 11$ (6%) $n = 2$ (1%)	$n = 32$ (17%) $n = 16$ (8%) $n = 4$ (2%) $n = 2$ (1%)	$p = .415$ ^C
Occupational status			
Employed Not employed (Not indicated)	$n = 86$ (46%) $n = 49$ (26%) $n = 0$	$n = 36$ (19%) $n = 17$ (9%) $n = 1$ (1%)	$p = .585$ ^C
Time period diagnosis—screening	Median 1 month (SD 29.0)	Median 1 month (SD 29.1)	$p = .897$ ^T
Status of disease			
First episode Relapse/secondary tumour/ currently not assessable	$n = 117$ (62%) $n = 18$ (10%)	$n = 46$ (24%) $n = 8$ (4%)	$p = .789$ ^C
Current psychotropic medication?			
No Yes	$n = 114$ (60%) $n = 21$ (11%)	$n = 33$ (17%) $n = 21$ (11%)	$p < .001$ ^C
Current or former psychotherapeutic/psychiatric treatment?			
No Yes (Not indicated) Time since end of psychotherapy	$n = 111$ (59%) $n = 24$ (13%) $n = 0$ Median 74 months (SD 56.9)	$n = 29$ (15%) $n = 24$ (13%) $n = 1$ (1%) Median 28 months (SD 61.0)	$p < .001$

Table 2. Distress as measured per questionnaire; ^T = t-test, ^C = chiquadrate-test, ^F = Fisher's exact test

Total: n = 206 patients with breast cancer (n = 17 subjective need not indicated)	No subj. need n = 135	Subj. need n = 54	Significance level
<i>Honheider Screening Instrument (HSI)</i>			
Mean (discriminant function)	-.316 (SD 1.2)	.799 (SD 1.8)	p < .001 ^T
Indication according to HSI			
Yes	n = 37 (20%)	n = 29 (15%)	p < .001 ^C
No	n = 92 (49%)	n = 20 (11%)	
(Missing data in HSI)	n = 6 (3%)	n = 5 (3%)	
<i>HADS</i>			
Mean depression	4.2 (SD 3.5)	7.4 (SD 5.4)	p < .001 ^T
Mean anxiety	6.8 (SD 3.9)	10.4 (SD 4.7)	p < .001 ^T
<i>EORTC-QLQ-C30</i>			
Mean (equation by Meraner et al.)	.45 (SD.3)	.67 (SD.3)	p < .001 ^T
<i>PHQ-2</i>			
Mean	1.4 (SD 1.3)	2.4 (SD 1.7)	p < .001 ^T
<i>Distress Thermometer</i>			
Mean	5.2 (SD 2.6)	7.2 (SD 2.4)	p < .001 ^T
<i>Problem list (Distress Thermometer)</i>			
Practical problems			
Yes (1 or more)	n = 13 (7%)	n = 11 (6%)	p = .045 ^C
No (0)	n = 122 (65%)	n = 43 (23%)	
Family-related problems			
Yes (1 or more)	n = 18 (10%)	n = 16 (8%)	p = .008 ^C
No (0)	n = 117 (62%)	n = 38 (20%)	
Spiritual/religious problems			
Yes (1 or more)	n = 5 (3%)	n = 8 (4%)	p = .011 ^F
No (0)	n = 130 (69%)	n = 46 (24%)	
Emotional problems			
Yes (1 or more)	n = 82 (43%)	n = 50 (26%)	p < .001 ^C
No (0)	n = 53 (28%)	n = 4 (2%)	
Physical problems			
Yes (1 or more)	n = 90 (48%)	n = 46 (24%)	p = .010 ^C
No (0)	n = 45 (24%)	n = 8 (4%)	

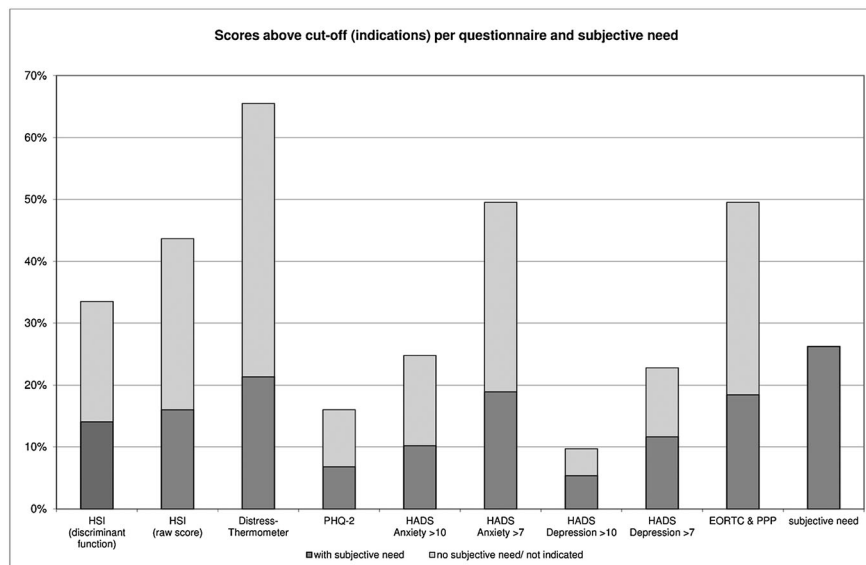


Figure 1. Scores above cut-off (indications) per questionnaire and subjective need

Table 3. Scores above cut-off (indications) by comparison: congruence of indications in percent (arrows point to the instrument indicating more patients); measure of agreement of indications: K = Cohen's Kappa (all reported scores are significant at $p < .05$); r = Pearson correlation of scores (all are significant at $p < .001$)

	HSI (raw score)	DT	PHQ-2	HADS-Anxiety	HADS-Depression	EORTC & PPP	subjective need
HSI (discriminant function)	↑83% K = .663 r = .932	↑53% K = .145 r = .295	←73% K = .367 r = .573	←71% K = .344 r = .574	←72% K = .298 r = .600	↑66% K = .337 r = .514	←68% K = .275 r = .344
HSI (raw score)		↑59% K = .181 r = .328	←61% K = .212 r = .525	←64% K = .281 r = .567	←62% K = .220 r = .582	↑63% K = .262 r = .514	←61% K = .205 r = .326
DT			←44% K = .111 r = .310	←50% K = .159 r = .469	←44% K n.sig. r = .275	←60% K = .174 r = .359	←49% K = .139 r = .340
PHQ-2				↑80% K = .415 r = .657	←88% K = .501 r = .703	↑60% K = .221 r = .609	↑69% K = .155 r = .277
HADS-Anxiety					←83% K = .455 r = .747	↑66% K = .340 r = .443	↑69% K = .213 r = .364
HADS-Depression					←58% K = .190 r = .747	↑72% K = .443 r = .641	←62% K = .260 r = .364
EORTC and PPP						↑57% K = .185 r = .637	↑73% K = .187 r = .333
						↑64% K = .312 r = .637	↑74% K = .325 r = .333
							←61% K = .243 r = .319

Indications by comparison

There is a wide range in number of indications for psychooncological counselling depending on which questionnaire is used with min 10% (HADS-Depression >10) and max 66% (Distress Thermometer) indications. In mean, 34% of all patients are seen as in need (see Figure 1).

Correlations of scores of all questionnaires as well as subjective need are highly significant ($p < .001$). There is a minimal relation between Distress Thermometer and HADS-Depression ($r = .275$). For this comparison, Cohen's Kappa measuring the agreement of indications is not significant. The correlation is at a maximum between HADS-Anxiety and HADS-Depression ($r = .747$), second HADS-Depression and PHQ-2 ($r = .703$). Only for them Cohen's Kappa is above moderate level ($K > .500$). The congruence of indications between Distress Thermometer and HADS-Depression is minimal (36%) and maximal between PHQ-2 and HADS-Depression (88%). There is a remarkably low congruence (49%), correlation ($r = .340$) and Cohen's Kappa ($K = .139$) between Distress Thermometer and subjective need (see Table 3).

Discussion

As to our knowledge this is the first study that compares different screening approaches to measure distress in breast cancer patients as it is suggested, recommended or often used in clinical routine. The study focuses on patients' subjective needs. We were able to show differences in the identification of patients between global and specific screening approaches and provide initial evidence on the importance of combining distress screening with asking for patients' subjective need.

In mean, the questionnaires show that about a third of all patients have elevated distress scores. These patients are seen as being in need of psychooncological treatment. This finding aligns with results of other studies [3,40]. The examined instruments, however, show quite different numbers of patients (range 10%–66%) with scores above cut-off. Despite a highly significant correlation of all five instruments among themselves (mainly in medium to large strength), the congruence of indications for need of support is low to moderate. Moreover, Cohen's Kappa as measure of the agreement of indications only reaches a moderate level twice (one time when comparing two specific depression screener PHQ-2 and HADS, the other time within the two subscales of the HADS). Others are below. These findings clearly show that recommended and often used questionnaires in psychooncology [25,26] measure different areas of distress (especially global ones like Distress Thermometer compared with specific questionnaires like Patient Health Questionnaire 2). They do not sufficiently agree in indicating patients in need for psychooncological treatment. Because of this big difference in identified

patients, these questionnaires – though validated – should not be used unreflectively as screening instrument. Up to now, this has not yet been discussed in psychooncological literature and recommendations or guidelines.

The subjective need seems to be independent from personal data. Patients with subjective need report significantly more problems and a higher distress. This shows its partial link to experienced distress—like it has been found for supportive care needs [41]. As correlations with screening measures are highly significant but in only small to medium strength, they provide additional information about requiring psychooncological treatment. The question used to inquire about this subjective need is believed to encourage patients to ponder their need with available resources. A weak correlation between subjective need and Distress Thermometer as well as a very low congruence and low Cohen's Kappa supports this hypothesis. Up to now studies are missing on how to assess a subjective need in a valid and reliable way [42]. This single question could be one possibility even though it requires a patient's knowledge about psychooncological services—its validity has to be scrutinized further in a subsequent study.

Experiences in clinical psychooncological routine show that the subjective need reliably separates the group of patients with distress into (subjective need=yes) patients who want to make use of psychooncological counselling and (no) those experiencing distress but who only wish to receive information about psychooncological treatment possibilities at the time of screening. There is a group of patients without elevated distress measures but with a high need to talk (indicated with yes in subjective need). In our experience, psychooncological professionals rate about half of latter patients as in need for counselling. Most often these patients do have concrete topics they want to talk about. These topics can already be asked for in a screening, e.g. using the problem list of the distress thermometer. This provides the opportunity for well-directed inclusion of social workers and pastoral care in psychooncological pathways.

Limitations of this study

As this study included patients with breast cancer, the applicability for patients with other tumour entities has to be scrutinized. Because of consecutive inclusion and a low non-participation rate of only 16% which showed some minor differences in personal data compared with participants we claim to have a representative sample of breast cancer patients.

Conclusion

There is an urgent need to clearly define what is to be understood as a psychooncological need. Only then will it be possible to decide on a gold standard assessment. At present, common instruments show a mixed pattern with

little concordance in indicating a need for treatment. Global (e.g. Distress Thermometer) and specific (e.g. PHQ-2) assessment instruments are often used for a psycho-oncological screening without reflecting their original field. Studies show that psychooncological assessment should cover depressive and anxious symptoms, current and former mental morbidity, somatic symptoms (especially pain and fatigue), the burden of significant others, psychosocial distress, and resources [2,3,6,28]. In order to define a criteria for distress, respectively, a need for psychooncological treatment, the evaluation of patients' subjective need as balance of distress and resources are to be implemented. This subjective need is linked to distress

measures in only small to medium strength and therefore additional important information to complete assessment instruments.

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