Supportive Care in Cancer (2019) 27:2799–2807
https://doi.org/10.1007/s00520-018-4579-1

ORIGINAL ARTICLE

Evaluation of the adherence of distress screening with the distress thermometer in cancer patients 4 years after implementation

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Received: 9 July 2018 / Accepted: 27 November 2018 / Published online: 11 December 2018

Abstract

Purpose Identifying and assessing psychosocial distress with an appropriate screening instrument is essential when caring for cancer patients. Since 2012, the distress thermometer (DT) has been used by nurses for all cancer inpatients at the Comprehensive Cancer Center Zurich. We wanted to identify nurses' adherence to the screening protocol, differences between screened and not screened patients and the relationship between screening rate and productivity.

Methods This retrospective descriptive study used screening and referral data as well as socioeconomic and disease-related data of inpatients at the Comprehensive Cancer Center Zurich. This was collected from the electronic patient documentation system. Additionally, data showing the productivity of all wards was used. All data were analyzed descriptive.

Results Since 2012, 40.6% (4541) of the 11,184 patients have been screened. The screening rate was initially significantly lower but settled at 40% after 2 years. There was a higher screening rate among Swiss, married, male, and emergency patients and patients with hematology diseases, brain tumors, or head and neck cancer ($p < 0.001$). Every fourth patient with a moderate to severe distress level requested referral to a psychosocial service. Significantly more screened patients were referred to the social service (44.7%) than to the psycho-oncology service (9.4%). Only 22.9% of all referrals were made on the day of screening or a day later. There were only two wards of 15 with a significant relationship between productivity and screening rate.

Conclusions Screening is useful in recognizing distress among patients, but screening practice needs to be reconsidered.

Keywords Distress screening · Psychosocial support · Distress thermometer

Background

Between 20 and 40% of all cancer patients suffer from emotional, psychosocial, social, or spiritual distress during therapy [1]. Feldstain et al. suggested that between 35 and 40% would benefit from simple psychosocial intervention, e.g., need of additional information, and up to 15% of all cancer patients would benefit from complex psychosocial care [2]. For this reason, the identification of patients with increased psychosocial distress with an appropriate screening instrument is essential in the care of cancer patients.

In 2011, we evaluated that only 4.5% of all cancer inpatients were referred to the psycho-oncological service. Based on this experience, we implemented the NCCN distress thermometer (DT) in all inpatient wards of the Comprehensive Cancer Centre Zurich (CCCZ) [3–5]. Since then, the DT has been used by nurses for all inpatients.

The efficacy and performance of distress screening is discussed controversially in the literature [6–9]. The screening helps patients identified as distressed to benefit from a psychosocial intervention. Yet, the question is whether patients are correctly classified as "cases" and how patients with positive distress screening are reliably offered treatment and how many of them accept this treatment.

Distress can lead to non-adherence to treatment, poorer quality of life and may negatively impact survival, as well as increase treatment burden to the oncology team and health system [6]. Trials that linked screening with mandatory referral or intervention showed improvement in patients' well-

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being [7]. The screening also supported health professionals to talk about psychosocial issues and about issues that might have otherwise been overlooked [2]. So, worldwide organizations, such as the American College of Surgeons' Commission on Cancer, require a routine psychosocial distress screening for accreditation.

Mitchell summarized four problems of distress screening: First, patients already diagnosed with anxiety or depression and receiving psychological treatment do not benefit from the screening [7]. Secondly, patients screened positive often do not accept the offered treatment [8]. Thirdly, patients who are not screened as distressed wish psycho-oncological referral and should therefore have access treatment possibilities, what, however, contradicts the meaning of screening. Fourthly, screening and referral can be a burden to staff and patient because it is time and resource consuming [7]. Zebrack et al. criticize "that screening standards do not prescribe a screening instrument nor dictate when or how often screening is to occur" [9]. Furthermore, the benefits of screening were mostly investigated under research conditions. Yet, in studies, the medical staff is often better trained than in day-to-day work and there are usually more staff and time resources available. In addition, patients and medical staff are focused and sensitized [10]. Therefore, it is interesting how screening is performed in the daily work routine and accepted by patient and health professional.

Nurses' adherence to screening guidelines over several years may be an indicator for the successful implementation of screening in routine patient care and for the acceptance in a medical team [7, 9]. There are only few international studies investigating the implementation and daily usage of screening in the "real world" [11, 12]. Zebrack et al. demonstrated that 47–74% of outpatients were screened [9, 13]. In another study, a screening rate of 22–49% was reported per outpatient clinic [14]. There is only limited data available on how long-term screening is successfully performed in inpatient care in everyday life and on the difficulties that arise, especially since there are no clear screening standards. Therefore, it was our intention to examine the screening behavior and experiences of nurses over the past 5 years to show the usage and the benefits and problems of distress screening.

Objectives

Our first goal was to investigate nurses' adherence to the screening protocol and to consider how many and which inpatients of the CCCZ were screened and referred to psychosocial service. Secondly, we wanted to identify whether screened and non-screened patients differ in socio-demographic, disease-related characteristics, or in their desire for psychosocial support. Lastly, we wanted to explore whether screening rates were lower during months with higher workload.

Method

Design

This retrospective descriptive health service research study was part of a mixed method research program about the usage and efficacy of the distress thermometer. With this study, we evaluated the implementation of distress screening since 2012. Therefore, we reviewed the electronic health records (EHR) of the CCCZ over the last 5 years. The advantage of the retrospective design is that trial conditions did not influence the screening habits.

Study sample

The CCCZ includes all medical departments of the University Hospital Zurich involved in diagnostics, treatment, or care for cancer patients. Since 2012, a total of 14,000 patients were registered. We reviewed the EHR of every inpatient case that should have been screened with the DT according to the protocol between September 2012 and December 2016.

Data collection

Data were collected from the EHR-system and the CCCZ's database, which receives patient medical information from the clinical information system (KISIM; Cistec AG, Zurich, Switzerland). The data were extracted by clinical computer scientists according defined variables. A random sample of the extracted data set was verified checking the patients' records. Data were then merged into one data set. Diagnosis and nationality, which were summarized in bigger category, were blinded doubled checked by a second investigator. Data on workload and productivity were retrieved by the electronic nursing workload management system.

Measures

Following variables that were extracted from the EHR, their explanations are presented in Table 1.

Distress thermometer and screening protocol

The DT is a simple numeric rating scale consisting of a line with a 0-to-10 scale, indicating "No Distress" at 0 and "Extreme Distress" at 10 [1]. Patients are asked the question "How distressed have you been during the past week on a scale from 0 to 10?" According to the German validation of Mehnert et al., a cutoff of 5 or above is considered to be

Table 1 Definition and explanation of extracted variables

	Variables extracted from EHR	Data used for analyzes
Distress thermometer	The first completed DT of every patient	Yes/no
		Date of completion
Incomplete distress thermometer	Completion of the DT was not possible	Yes/no
		Described reason
Distress level	Mentioned distress level at the numeric rating scale	0–10
Agreement for referral	Agreement for referral to psycho-oncology noted in electronic version of DT	Yes/no
	Agreement to referral to social service referral noted in DT	
	Agreement to referral to spiritual care note in DT	
Psycho-oncological referral	First psycho-oncological visit noted	Date
Social service referral	First visit of the social worker noted	Date
Gender	Woman/men	Woman/men
Nationality	Nationality according declaration at admission	Summarized nationality according the statistic of the Swiss federal statistical office: Swiss, Italy, Germany, Austria, Portugal, France, Kosovo, Spain, Serbia, Turkey, Rest Europe, Amerika, Asia, and all other
Age	Date of birthday	Years
Marital status	Single, married, divorced, widowed according declaration at admission	Single, married, divorced, widowed
Cancer diagnosis	Cancer diagnosis according Swiss diagnosis-related group code	Summarized in main cancer site:
		Brain/CNS
		Lymphoma
		Leukemia
		Melanoma
		Colorectal
		All other gastrointestinal
		Gynecologic (breast, ovary, uterus)
		Prostate/testis
		Urinary system
		Head and neck
		Lung
		Bones and tissue
		All others
Hospitalization	Type of admission	Regular/emergency
	Date of admission	Date
	Duration of the hospitalization	Days
Palliative treatment	Special palliative treatment according Swiss diagnosis-related group code	Yes/no

moderate or severe distress and requires referral to psychosocial care with 84% sensitivity and 47% specificity against the Hospital Anxiety and Depression Scale [3]. In addition, the DT contains a checklist with 34 problems that highlight potentially distressing areas of difficulty for a patient.

At the CCCZ, nurses hand out the DT at admission of a cancer patient. They discuss the result with the patient during nursing assessment. Patients with moderate or severe distress levels are, with their permission, referred to psycho-oncology, social service, or spiritual care. Data of the completed DT and agreement with referral is transferred into the EHR. If a patient did not complete the DT, the reason is listed. Patients with moderate or severe distress levels are screened again after 7 days to evaluate the intervention.

In this study, we collected all electronic DT for each patient. We confirmed adherence to the protocol if there was one completed DT per patient in the EHR. Additionally, we collected date, distress level (0–10), and the desire for referral to social worker, psycho-oncologist, or spiritual care. If a patient had several screenings, we took the first completed DT from the EHR.

Psychosocial service

The date of a patient's first referral to a social worker or psycho-oncologist was collected.

Socio-demographic and disease-related characteristics

Gender, nationality, age, and marital status were retrieved from the electronic database as well as cancer diagnosis, type of admission (emergency or regular), date and duration (days) of the hospitalization, medical ward, and special palliative treatment (yes/no).

Workload

Higher workload can contribute to a lower screening rate. Nursing workload is defined as the total minutes a nurse needs for direct nursing care [15]. Nurses record the time spend to every specific nursing interventions in each patient on every day of the whole hospitalization. We used the total workload per month of each medical ward, which has more than 150 cancer patients per year. Then, we used the adjusted workload per month by dividing the total workload by the staff time.

Ethical consideration

Patients sign a general consent to research upon admission. EHR of patients who rejected this consent were not reviewed. This study was carried out in compliance with the project plan, the current version of the Helsinki Declaration, and Swiss law. The research project was approved by the Cantonal Commission for Ethics in Zurich in December 2016 (BASEC-NR. 2016-01372).

Data analysis

The data set was examined for deviations and outliers and was cleaned up. Data were analyzed with the R program for Statistical Computing (version 3.3.3) (R Core Team, 2017). Data were analyzed descriptively per frequencies. To compare the different groups, we used a one-way ANOVA and chi-quadrat-tests. Spearman's rho was used to analyze the regression between screening and workload. As a pre-post-test, Wilcoxon signed rank test was performed.

Results

In our database, 13,237 inpatients were labeled with a cancer diagnosis. Of those, 2053 inpatients were excluded because they did not permit research. At the end, we included 11,184 inpatients. Patient characteristics are reported in Table 1.

Nurses' screening performance

Four thousand five hundred forty-one inpatients had at least one completed DT in the EHR, resulting in a screening rate of 40.6%. The screening rate was significantly lower shortly after implementation of the DT but settled at 40% after 2 years (see Table 2).

Two thousand seven hundred forty-eight (65.8%) of all screened patients were male (RR = 1.6) (Table 3). Screened and non-screened patients were of similar ages (Table 4). More Swiss patients were screened than those of another nationality, even German or Austrian patients, who also speak German. Significantly, more emergency patients were screened (RR = 1.4) than those admitted regularly. More patients with specialized palliative treatment were screened

Table 2 Personal and clinical characteristics

Variables	No. of patients	%
Patients, *N*	11,184	
Gender		
Male	6612	54.6
Female	5072	45.4
Age (mean SD)	62.47 ± 15.95	
Swiss nationality	8733	78.1
Marital status		
Single	1904	17
Married	6238	55.8
Divorced	1458	13
Widowed	1098	9.8
Cancer diagnoses		
Brain/CNS	672	6.0
Lymphoma	682	6.1
Leukemia	422	3.8
Melanoma	840	7.5
Colorectal	404	3.6
All other gastrointestinal	1044	9.3
Gynecologic (breast, ovary, uterus)	1416	12.6
Prostate/testis	747	6.7
Urinary system	547	4.9
Head and neck	1209	10.9
Lung	1092	9.7
Bones and tissue	281	2.5
All others	1828	16.3

Table 3 Adherence to screening protocol

Variables	DT	2012	2013	2014	2015	2016
Patients, *N*	11,184	1058	2408	2577	2410	2731
Screening						
Yes (%)	40.6	23.7	34.8	44.5	47.7	42.3
No (%)	59.4	76.3	65.2	55.5	52.3	57.7
Screening yes, *N*	4541	251	838	1147	1149	1156
Distress level						
< 5 (%)	51.5	44.1	49.6	51.9	54.0	51.7
≥ 5 (%)	48.5	55.9	50.4	48.1	46.0	48.3
Agreement with referral						
Psycho-oncology (%)	13.7	17.5	16.0	12.1	13.2	13.3
Social service (%)	13.7	16.3	15.4	13.4	12.1	13.8
Spiritual care (%)	7.1	8.8	8.0	6.8	6.5	6.9
Referral						
Psycho-oncology (%)	9.4	4.0	8.0	5.3	11.5	13.7
Social service (%)	44.7	47.4	46.5	43.5	45.2	43.6
Agreement to referral if distress level ≥ 5						
Psycho-oncology (%)	23.2	26.5	27.8	19.3	24.3	21.2
Social service (%)	20.2	16.7	24.5	18.5	19.4	20.3
Spiritual care (%)	10.5	10.6	12.0	9.2	10.7	10.3
Referral, if distress level ≥ 5						
Psycho-oncology (%)	13.7	6.1	11.5	6.1	17.6	21.3
Social worker (%)	52.7	48.5	55.5	51.8	53.6	51.5
Screening no., *N*	6643	807	1570	1430	1212	1575
Referral						
Psycho-oncology (%)	3.3	5.2	2.6	2.7	3.9	3.1
Social service (%)	28.3	33.8	28.2	30.0	28.5	23.9

(RR = 2.8). More patients with head and neck cancer, leukemia, or a brain tumor ($p < 0.001$) and less patients with melanoma and breast cancer were screened. In the last 2 years, breast cancer patients were screened by breast cancer nurses by using only the thermometer without the problem list and without documentation in the EHR.

In 10% (676) of all 7034 documented screenings, a reason for not screening was listed. The main reason was refusal by the patient because of futility ($N = 286$; 55.3%), highly distressed with cancer symptoms ($N = 51$, 9.9%), lack of time ($N = 22$), and fatigue ($N = 13$). Other reasons were foreign language ($N = 92$), cognitive impairment ($N = 49$), and terminal illness ($N = 4$). In addition to the refused DT, we discovered that completion of the DT was shifted to the days following admission, which is later than the screening protocol purports. Three thousand eight hundred thirty-three (54.5%) inpatients were screened on admission day, 1403 (19.9%) inpatients a day later, and 1796 (25.6%) inpatients later during the hospitalization.

According to the protocol, patients with a distress level ≥ 5 should be screened a second time. 48.2% (1005) of these inpatients were screened a second time. The mean stress level (mean = 6.89) dropped by the second screening (mean = 5.41). 19% of follow-up screenings were rejected.

Referral to specific service

13.7% of screened patients agreed to a referral for social service and the same percent for psycho-oncology, yet significantly more screened patients were referred during the treatment to the social service (44.7%) than to the psycho-oncology service (9.4%) (Table 2). While the referral rate to the social service has remained almost at a constant of around 45%, the referral rate to a psycho-oncologist has continuously increased and adjusted by 13.7%. In the first 2 years after implementation, there were not enough resources to refer distressed patients to a specialist. In the last 2 years, there have been enough resources. Referral of non-screened patients was, at 3.3%, lower than of screened patients and decreased slightly over the years. Only every fourth inpatient with a high distress level agreed to a referral to a specific service, 23.3% to psycho-oncology and 20.2% to social service and 13.7 were referred to psycho-oncology and 52.7 to the social service. Male patients agreed to psycho-oncological referral less often

Table 4 Difference between screened or non- screened patient

Variables	Screened Patient	Not screened patient	*p* value	RR
Patients, *N*	4175	6643		
Gender %			< 0.001	
Male	65.8	47.1		1.6
Female	34.2	52.9		
Age (mean)	62.42	62.29	0.595	
Marital status (%)			< 0.001	
Divorced	14.8	12.8		
Single	16.2	19.0		
Married	61.0	56.6		
Widowed	8.1	11.6		
Admission type (%):			< 0.001	
Elective	76.2	85.7		0.71
Emergency	21.5	13.4		1.4
Palliative care (%)	3.8	1.4	< 0.001	2.8
Swiss nationality (%)	82.9	77.5	< 0.001	1.22
Cancer diagnosis (%)			< 0.001	
Brain	9.4	3.1		1.78
Lymphoma	5.8	2.9		1.48
Leukemia	7.7	1.1		2.10
Breast	1.3	10.3		0.16
Colorectal	4.0	3.2		
Liver	3.2	4.6		0.78
Prostate	7.6	4.7		1.34

(RR = 0.37) than female patients. The mean age of patients who agreed was significantly lower (mean = 59.27) than of those who refused (mean = 62.94). Single patients agreed 1.3 times more to referrals than married patients. Emergency patients requested 2.29 times more psycho-oncological care than patients with regular admission. Patients with specialized palliative treatment requested 4.6 times more referrals. Leukemia, lymphoma, and brain tumor patients wanted psycho-oncological treatment more often ($p < 0{,}001$). However, prostate, liver, and head and neck cancer patients wanted a referral significantly less often.

However, 20% of the psycho-oncologic referrals were delivered prior to screening. 22.9% of the referrals were delivered on the day of the screening or 1 day later. The remaining 55.8% of referrals were made later during treatment.

Screening rate by wards and workload

Each year, 15 wards treated more than 150 cancer patients. The screening rate was in average between 4 and 62% of each ward that means screening rate varied between 0 and 100% per month per ward (Fig. 1). Wards with mainly cancer patients in general had a higher screening rate. The workload fluctuated between 504 and 4806 h per month per ward. The adjusted workload ranged between 0.61 and 1.44 (very busy). The relationship between adjusted workload and screening rates was slightly negative (Spearman's rho = − 0.177; $p < 0.001$) across all selected wards. Investigating this relationship per individual ward, there were only two wards with a significant relationship.

Discussion

This study aimed to investigate the distress screening behavior of our nurses in the last 5 years in the "real world." Fewer than half (40.6%) of patients treated in the CCCZ were screened. Our screening rate is in the range of other studies with rates between 22 and 74% [9, 13, 14]. With a 40% screening rate, there is the possibility that many distressed cancer patients were not identified, not referred, and consequently did not benefit from psychosocial intervention. There may be some reasons for this low screening rate, including the screening tool, the screeners' training, and attitudes, but also patient-related characteristics. We chose the DT because it is a very short instrument, which is easy to understand and not too burdensome for patients, with a nevertheless good sensitivity. One of the most important advantages is that it avoids the psychiatric terms "anxiety" and "depression" and therefore helps against stigmatization, which is still an important topic

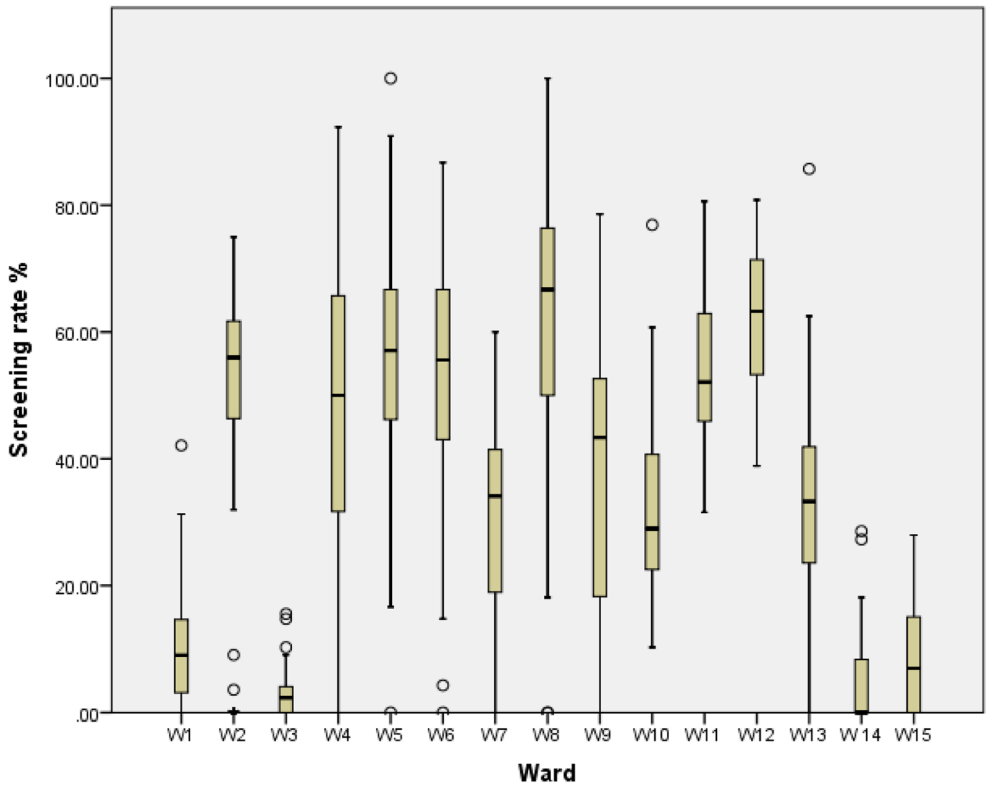

Fig. 1 Screening rate per ward

in cancer patients [1]. In our research and clinical practice, we use the German word "Belastung" which is the translation of "distress" and which is a simple an easy understandable concept for patients. However, every tenth patient was not able or refused to complete the DT. Refusal may be still related to stigmatization. Some patients assert their refusal, not recognizing a benefit of the screening. On the other hand, in our study, inpatients were not able to fill out the DT because of cognitive, linguistic, and physical problems. Inpatients frequently suffer from multimorbidity and have mostly a poor performance status. A recent review of outpatient screening reported a recruitment rate of between 76 and 92% [10]. Perhaps, the screening rate is higher in outpatients, because they have a better performance status and therefore a greater capability to fill out the DT. Inpatients seemed also to be overwhelmed on the busy admission day and preferred to complete it later. Then it happens easily that the screening gets forgotten overall. These problems have to be investigated in further studies. At all, even the screening with short instruments and not stigmatizing psychiatric wording seems to be problematic in the screening praxis. Additionally, the DT tool has some limitations. First, the specificity is low and therefore there may be many false positive cases, which may be related to higher distress for patients and even higher costs. Second, because the DT is a single item tool nor internal consistency can be calculated. Another limitation is that the distress concept "is poorly operationalized, and it corresponds only approximately to known psychiatric disorders [7]."

Nurses show also barriers for routine screenings. Training and existing infrastructure like referral possibilities can influence screening [10, 16]. In the latter 2 years almost, every patient who agreed to a referral was seen by a specialist. Nurse training and infrastructure is similar for all CCCZ wards. Since some wards have a significantly higher screening rate, it is questionable whether these factors have a big influence. Secondly, some studies have mentioned high workload in daily work as a barrier [9, 13, 14]. We found no correlation between productivity and screening rate over the last 5 years. Thirdly, screening habits probably depend on the attitude of the wards and nurses [17]. Wards with higher screening rates may recognize more benefits or may, through regular screening, consider it a commonplace. Mitchel et al. showed in their study that 35.9% of health professionals rated screening as not useful, but 41.9% changed their clinical opinion after screening, with more than 50% noticing some benefit in communication [16]. Stigmatization may also impact the behavior of the "screener." Nurses seem to screen more patients if they consider them to be more distressed, such as patients with palliative care. Even more emergency patients were screened, although their care is less projectable and busier. Even more patients with more distressing cancer diagnoses like leukemia, brain tumors, or head and neck cancer were screened. Perhaps in these cases, nurses are prompted to screen more or use screening to verify their clinical assessment. Nurses' attitude about screening but also the influence of ward style and leadership must therefore be investigated in a subsequent study as well as patients' attitude.

Our results also show that some psycho-oncological referrals were not dependent on the screening, with 20% of patients being referred before screening. Visibly distressed persons were referred without screening, and 55.8% days later, when they either developed severe distress or felt a need for psychological support. It seems difficult to fix the appropriate time and frequency for screening. Screening patients only once during treatment could mean that patients who develop severe distress during the treatment are missed. Screening patients every 7 days can lead to higher patients' refusal. The percentage of patients refusing screening doubles in repeated screenings, further increasing with every repetition. Although a study of patients with radiation treatment recommended screening every 7 days, our results cast doubt on the feasibility of this [18]. There is a lack of clear data specifying a reasonable screening frequency.

In sum, the implementation of routine distress screening in the CCCZ has achieved a higher referral rate (9.4%), to the psycho-oncology service than before implementation (4.5%). According to our screening protocol, every severe distressed patient had to agree before referral, but only 20% of the inpatients did. This is comparable to the referral rate of other studies [6, 7, 18, 19]. According to a recent study of Tondorf et al., there are three main topics for non-agreement. Patients felt supported enough by family and friends, reported mental and physical well-being, or did not consider psychological support to be helpful. In this study, they also identified a "vulnerable group of ambivalent patients by high distress levels and low uptake behavior" [8]. The authors suggest that these patients would benefit from a different approach ("if-then") to overcome their ambivalence. The way nurses ask or talk about psycho-oncology referral influences the agreement. The agreement also depends on patients' attitudes and socialization. For example, female and younger patients were referred more often in our sample. It seems easier to convey the benefits of social service to patients, 50% of patients had at least one appointment. It may be also the problem of the poor operationalization of distress, that patients and nurses are not clear which special service should be involved to reduce the distress. At admission, a patient suffers of a problem like pain causing high distress level, the distress level may decline with the treatment. The screening does not distinguish the reason causing distress and it is not clear if all patients should be referred to psycho-oncology, independently of the distress causing problem. Other studies show higher referral rates when psycho-oncologists visit distressed patients mandatorily that, of course, opens significant ethical questions [7]. However, the implementation of screening to enhances the awareness of the psycho-oncology service and the psychosocial problems of cancer patients.

Limitations

This study is a health service research study with a retrospective design. Due to this, no correlations can be explained causally. We depend on data from the EHR. Ongoing care by an external psycho-oncologist or transfer to an external service was not recorded in the EHR and was not considered in the data analysis. Nevertheless, it shows how screening is applied in everyday life. Finally, this study was conducted in a single center and conclusion about breast cancer patients cannot be made. The results, therefore, cannot be generalized without problems, since habits and structural factors have an influence on the screening behavior.

Conclusion

The recognition and referral of distressed patients by nurses is an important part of the supportive care of oncological patients. Screening enhances the awareness of psychosocial issues but its use in everyday life is associated with some difficulties. Further practical studies should investigate patient and nurses' experiences to complete our results. In addition, it should be considered which alternatives can be offered to patients, who are unable to complete the screening.

Compliance with ethical standards

This study was carried out in compliance with the project plan, the current version of the Helsinki Declaration, and Swiss law. The research project was approved by the Cantonal Commission for Ethics in Zurich in December 2016 (BASEC-NR. 2016-01372).

Conflict of interest The authors declare that they have no conflict of interest.

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