



Perceived need for psychosocial support depending on emotional distress and mental comorbidity in men and women with cancer



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ABSTRACT

Objective: Although elevated levels of distress are supposed to constitute a need for psychosocial support, the relation between elevated distress and need for support does not appear to be straightforward. We aimed to determine cancer patients' perceived need for psychosocial support, and examine the relation of need to both self-reported emotional distress and the interview-based diagnosis of a mental disorder.

Methods: In a multicenter, cross-sectional study in Germany, 4020 cancer patients (mean age 58 years, 51% women) were evaluated. We obtained self-reports of need for psychosocial support. We measured distress with the National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) and depressive symptoms with the Patient Health Questionnaire (PHQ-9). In a subsample, we evaluated the presence of a mental disorder using the Composite International Diagnostic Interview (CIDI).

Results: 32.1% (95%-CI 30.6 to 33.6) of patients perceived a need for psychosocial support. Younger age, female sex, and higher education were associated with more needs, being married and living with a partner with fewer needs, respectively. While up to 51.2% of patients with elevated distress levels reported a need for psychosocial support, up to 26.1% of those without elevated distress levels perceived such a need. Results were similar across distress assessment methods.

Conclusion: Our findings emphasize that the occurrence of mental distress is one important but not an exclusive factor among different motives to report the need for psychosocial support. We should thus consider multifaceted perspectives, facilitators and barriers when planning and implementing patient-centered psychosocial care services.

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Introduction

Up to one third of cancer patients are considered having a need for psychosocial support [1–8]. In this context, need may have different

meanings, according to the various perspectives involved, such as patients' desire (felt need) and their demand for service (expressed need), on the one hand, as well as professionals' judgments (normative need) on the other [9,10]. Currently, the evaluation of cancer patients' needs for psychosocial support relies heavily on screening for emotional distress [10]. While distress screening may be considered as an important step towards fulfilling patients' unmet needs for professional psychosocial support, it is guided by normative needs rather than by felt or expressed needs. However, although elevated levels of emotional distress may increase patients' expressed supportive care needs, this link

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seems not particularly close [2,11]. While at most up to one half of those classified as highly distressed seek professional help [4,10–14], a substantial proportion of patients scoring below distress thresholds also express having needs for professional psychosocial support [4,10].

Therefore, other factors may significantly contribute to patients' perceived psychosocial support needs. Several studies have examined additional factors beyond emotional distress that might be predictive of supportive needs. Results were inconsistent, however. Predictors found included younger age [2,4,5,15], but also higher age [1], female sex [2,15], but also male sex [1,5], living alone [4,5], being diagnosed with breast cancer [15], but also not being diagnosed with breast cancer [5], and not being diagnosed with prostate cancer [4]. Together, conclusive evidence regarding this issue is lacking.

Our study, which was based on a large, representative sample of cancer patients, therefore had three objectives. We aimed to (1) determine cancer patients' perceived need for psychosocial support, (2) identify demographic and medical variables associated with perceived need, and (3) examine the relation of need to both self-reported emotional distress and the interview-based diagnosis of a mental disorder.

Method

The methods of the study are described in detail elsewhere [16]. In this multicenter, epidemiological cross-sectional study, we enrolled cancer patients from acute care hospitals, outpatient facilities, and cancer rehabilitation clinics in five study centers in Germany (Freiburg, Hamburg, Heidelberg, Leipzig, and Würzburg).

Study participants

Patient inclusion criteria comprised the evidence of a malignant tumor and age between 18 through 75 years. Patients across all tumor entities and disease stages were included stratified by nationwide incidence of cancer diagnoses. Patient exclusion criteria comprised the presence of severe physical, cognitive and/or verbal impairments that would interfere with a patient's ability to give informed consent. All patients who fulfilled the inclusion criteria were contacted by trained research assistants and consecutively recruited at the participating institutions. All participants were screened for depressive symptoms with the Patient Health Questionnaire depression module (PHQ-9) [17] and then asked to provide additional self-report data. In addition, slightly more than 50% of our sample completed a structured clinical interview, the results of which are presented elsewhere [18]. The study complied with the Declaration of Helsinki and was approved by the Ethics Committees of all participating centers [16]. All participants provided written informed consent.

Measures

Psychosocial care needs

To assess patients' perceived supportive care needs, we used single items that had proven suitable in earlier studies [19,20]. To determine the need for psychosocial support, we asked participants, "Do you have a need for psychosocial support?" Response options were "yes" or "no". In addition, we asked participants to rate the strength of their wish for talking to someone, "Do you currently have the wish to talk to someone about the psychological distress because of your disease?" with response options "not at all", "somewhat", "quite a bit", "strongly", and "very strongly".

Acceptance of support

To determine the acceptance of psychosocial support offers, we asked, "Would you accept an offer of psychosocial support?" with a yes/no response format. Further, we asked whether patients would follow a recommendation provided by their physician to utilizing psychotherapeutic help if necessary, "Consider your physician would diagnose

psychological distress as e.g. an anxiety disorder or a depression. Would you follow your physician's recommendation to utilizing psychotherapeutic help?" with response options "yes", "perhaps", and "no". In addition, we aimed to determine patients' confidence of conveying their supportive needs to their doctor by asking the following question, "If you had the wish to talk to someone about the psychological distress because of your disease, would you be able to convey your wish to your attending physician?" with response options "yes", "no", and "can't tell". We also asked patients "What is your general attitude to psychosocial support?" using an 11-point numerical rating scale ranging from "0 = negative", to "10 = positive". Finally, we asked for reasons for not having utilized psychosocial support, "If you have not utilized psychosocial support because of your cancer, what were the reasons for this?" The response options were "I do not need any support"; "I do not know who to turn to"; "I did not know that such offers exist"; and "other".

Opportunity to talk to someone

Using a 5-point response format ranging from "not at all" to "very strongly", we asked patients about having the opportunity of talking to someone, "Do you currently have the opportunity to talk to someone about the psychological distress because of your disease?" Lastly, we requested patients to evaluate their opportunities of talking about their distress to different persons, including family, friends, general practitioner (GP), and clinical oncologist. We asked patients "How well would you be able to talk to the below-mentioned persons about the psychological distress because of your disease?", with response options "not at all", "somewhat", "moderately", "well", and "very well", to be rated for each of the individual persons as indicated above.

Emotional distress

We used both the National Comprehensive Cancer Network (NCCN) Distress Thermometer [21] and the Patient Health Questionnaire (PHQ) depression module [22] to assess emotional distress. Both instruments have recently been recommended as screening tools in cancer patients [23,24].

The widely used NCCN Distress Thermometer measures patients' distress on an 11-point numerical scale with scale endpoints described as "no distress" and "extreme distress", respectively, thus using non-stigmatizing wording. This very short tool is well accepted, feasible, and highly sensitive when evaluated against established criteria [25]. For its German version, a cut-off score of 5 has been recommended [21].

We measured depressive symptoms using the PHQ-9 [22]. It evaluates the presence of the nine symptoms of a depressive episode according to the Diagnostic and Statistical Manual of Mental Disorders, 4th Revision (DSM-IV). The PHQ-9 has good reliability and validity and compared favorably to other screening instruments when evaluated with diagnostic criteria provided by the DSM-IV as reference standard [22]. Higher values indicate more severe symptoms. A cut-off value of 9 or higher has been recommended to screen for any depressive disorder [22].

Mental disorder

For assessing the presence of a mental disorder according to DSM-IV, we used the standardized, computer-assisted, highly reliable and valid Composite International Diagnostic Interview (CIDI) [26–28], supplemented with questions regarding adjustment disorders according to DSM-IV criteria (CIDI-O) [29]. It covered the following disorders: mental disorders resulting from general medical condition, substance use disorders, mood disorders, anxiety disorders, somatoform disorders, eating disorders, and adjustment disorders. The CIDI-O was conducted in patients scoring 9 or higher on the PHQ-9 and a random sample of 50% of those scoring below this cut-off [16,18].

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