

## Clinical management of emotions in patients with cancer: introducing the approach “emotional support and case finding”

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### Abstract

The current approach to the management of emotions in patients with cancer is “distress screening and referral for the provision of psychosocial care.” Although this approach may have certain beneficial effects, screening and referral programs have shown a limited effect on patient psychological well-being. We argue that this limited effect is due to a mismatch between patient needs and the provision of care, and that a fundamental reconceptualization of the clinical management of emotions in patients with cancer is needed. We describe the rationale and characteristics of “emotional support and case finding” as the approach to the management of emotions in patients with cancer. The two main principles of the approach are: (1) Emotional support: (a) The treating team, consisting of doctors, nurses, and allied health staff, is responsive to the emotional needs of patients with cancer and provides emotional support. (b) The treating team provides information on external sources of emotional support. (2) Case finding: The treating team identifies patients in need of mental health care by means of case finding, and provides a referral to mental health care as indicated. We present a novel perspective on how to organize the clinical management of emotions in patients with cancer. This is intended to contribute to a fruitful discussion and to inform an innovative research agenda on how to manage emotions in patients with cancer.

### Keywords

Emotions, Distress, Support, Screening, Case finding, Cancer

### DISTRESS SCREENING AND REFERRAL PROGRAMS

Distress refers to “a multifactorial unpleasant emotional experience of a psychological (i.e. cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, or its treatment” [1]. The term “distress” was introduced because it was considered to be more acceptable and less stigmatizing than psychiatric and psychological terminology [2]. Alternatively, traditional psychiatric diagnostic categories can be used to describe patients’ mental response to the diagnosis and treatment of cancer. The primary focus is usually

### Implications

**Practice:** The role of the treating team in the management of emotions in patients with cancer is pivotal. Mental health professionals mainly have an indirect role: they work through the treating team. Direct treatment occurs only in selected patients.

**Policy:** We recommend to revise existing guidelines, based on this approach.

**Research:** This approach informs an innovative research agenda on how to improve the clinical management of emotions in patients with cancer.

on anxiety and mood disorders; occasionally, other mental disorders are included as well [3]. Distress is very common among patients with cancer, irrespective of terminology, underlying theory, and associated assessment. In patients in the active anti-tumor phase of treatment, reported prevalence rates are 18% for anxiety or mood disorders [4], 30%–40% for any combination of anxiety, mood, or adjustment disorders [5], 32% for any mental disorder [3], and 35%–52% for general distress [6, 7]. The identification and treatment of distress are a clinical priority because distress is a risk factor for non-adherence to medical treatment [8] and for a poor outcome in the physical, mental, and social life domains [9].

Currently, “distress screening and referral for the provision of psychosocial care” is the dominant approach to the management of distress. This approach comprises the identification of distress by means of a distress-screening tool, provision of support by the treating team in case of mild distress, and referral to psychosocial care for patients with moderate or severe distress [1]. Guidelines issued in a broad range of countries recommend distress screening and referral to psychosocial care in patients with cancer [1, 10–13]. This approach may indeed have

certain beneficial effects (e.g., identification of distressed patients, or more doctor–patient communication about distress [14, 15]). However, screening and referral programs have shown a limited effect on patient psychological well-being [16–19]. A recent Cochrane review concluded that, although the certainty of the evidence is low and intervention and study characteristics were heterogeneous, the evidence does not support the effectiveness of screening of psychosocial well-being and care needs in patients with cancer [17]. Two recent studies not yet included in previous reviews reported similar results. In our recent randomized trial, we examined the outcome of a screening and referral program to identify and treat psychological distress in patients with metastasized colorectal cancer, comparing outcomes to usual care [16, 20]. We carefully created optimal conditions to ensure that the screening and referral program would be maximally effective. Nevertheless, the screening and referral program did not result in a reduction in psychological distress [16]. Another recent trial also failed to demonstrate a beneficial effect on global quality of life [21]. It should be noted that treatment of psychological distress per se is effective [22]; it is the current approach to identifying patients in need of treatment (i.e., distress screening and referral) which generally had a limited effect on psychological well-being.

A common response to these findings has been to advocate better implementation of screening and referral programs [23–30]. For example, use of an effective change management strategy, leadership, integration, customization, project management, and program evaluation has been recommended [23]. Other researchers have noted the heterogeneity in definitions and theoretical conceptualizations of distress, procedures for screening and referral, interventions, and outcomes [17, 30, 31]. This heterogeneity may have obscured beneficial effects of screening and referral programs. Beneficial effects could become discernible once the various features of the screening approaches are carefully disentangled. Although well intended, we believe that such efforts are unlikely to be effective. The main reason is that many patients with cancer are unwilling to accept a referral for psychosocial care and we believe that this is due to a mismatch between patient needs and the provision of care.

In our own study [16], 60% of patients showed elevated distress during at least one of the screening time points. Nevertheless, only 15% chose watchful waiting and a mere 11% accepted active mental health care (consisting of guided self-help, face-to-face problem-solving therapy, or a referral to professional mental health care). This low uptake of mental health care resulted in the screening and referral arm of the trial showing no improvement of psychological distress compared to the usual care arm. Low uptake of psychosocial

care has been observed in several studies, in a range of countries and in several clinical settings [32]. In a UK-based study, only 36% of patients with elevated distress scores indicated a need for professional help with emotional problems [33]. An Australian study found that only 30% of distressed patients reported a need for help with distress [34]. In a USA-based study, screening was implemented to identify patients with distress: of the patients who screened positive for distress, only 14% had actually completed at least one appointment with the supportive care team after 14 days follow-up [35]. Finally, in a review of barriers to the delivery of psychosocial care in patients with cancer “no need for psychosocial services and support” was the most frequently reported barrier (reported by 39% of patients) [36]. Low uptake of psychosocial care, thus, seems to be a universal phenomenon. In view of this fact, we are skeptical that better implementation would result in effective programs for distress screening and referral. We would argue that a fundamental reconceptualization of the management of distress in patients with cancer seems to be warranted.

## EMOTIONS

Distress is defined as an “unpleasant emotional experience” [1]. Distress refers to emotions and negative emotions in particular. For reasons of clarity, in the remainder of the paper, we will use the term “emotions.” These include negative emotions such as fear, anxiety, depression, and hostility, but also positive emotions such as happiness, hope, and calmness.

Human emotions have developed through the course of evolution because they facilitate adaptation to important events [37]. Emotions alert, motivate and prepare us to deal with these events [38]. For example, fear causes cognitive, behavioral, and physiological changes which help to face a threatening event [37]. Sadness turns our attention inwards, promoting resignation and acceptance. The expression of sadness may elicit sympathy and support from other people [39]. Emotions are essentially *adaptive*—they help us to adapt to events in the environment, such as the diagnosis and treatment of cancer [32]. In contrast, emotions sometimes hamper adaptation, leading to significant distress and disability [40]. Emotions are *maladaptive* if they are disproportionately severe or persistent, and if they interfere with functioning. Examples include severe anxiety leading to the avoidance of cancer treatment, depression leading to unrealistic negative expectations and lack of motivation to continue treatment, or fear of death leading to unrealistic optimism regarding the outcome of further treatment.

Identification of patients with clinically relevant distress is usually based on the intensity of emotional

responses. The Distress Thermometer and other questionnaires use a cutoff score for the intensity of emotions; if patients score above the cutoff, they are considered to be distressed [1]. The underlying assumption is that a low intensity of emotions is to be preferred, that is, “less is better” [32]. The question arises whether this assumption is correct. Indeed, some patients scoring above the cutoff may experience maladaptive emotions. However, other patients scoring above the cutoff may actually experience adaptive emotions which facilitate coping with cancer. In general, a strong emotional experience in response to cancer is natural and potentially adaptive. Thus, equating an intense emotion with a maladaptive emotion is not a valid approach. Further research is needed to identify indicators that can differentiate between adaptive and maladaptive emotions in patients with cancer [41]. Psychological and psychiatric theories on emotions and mental disorders may guide the development of operational indicators that can distinguish between adaptive and maladaptive emotions, in addition to clinical criteria [40] and a patient’s personal evaluation of their own emotions. For example, the theory on emotion dynamics predicts that patients with maladaptive emotions are characterized by emotional symptoms that linger and perpetuate more across time, are more extreme, or are more unstable, compared to patients with adaptive emotions [42]. If confirmed in patients with cancer, an operational indicator could be developed to assess whether emotions are lingering, extreme, or unstable (instead of whether emotions are intense).

#### MATCHING THE PROVISION OF CARE TO PATIENTS’ NEEDS

We believe that the low uptake of mental health care is due to a mismatch between patient needs and the provision of care [32]. Patients experiencing *adaptive* emotions are expected to prefer to handle their emotions themselves [43–46]. They may welcome support from relatives, friends, peers, and primary care-givers (i.e., doctors and nurses). Patients with adaptive emotions can be expected to refuse a referral to mental health care; that is, care that primarily focuses on treating emotional problems. In contrast, professional mental health care such as psychotherapy or pharmacotherapy is indicated only in patients experiencing *maladaptive* emotions [47, 48]. We believe that matching the provision of care to the nature of emotions is in line with patients’ emotional needs: supportive interventions in case of adaptive emotions, and professional mental health care in case of maladaptive emotions [32].

#### EMOTIONAL SUPPORT AND CASE FINDING

These considerations regarding emotions, and matching of care to the *nature of emotions* (adaptive vs. maladaptive emotions) rather than the *intensity of*

#### Box 1. Approach to the clinical management of cancer-related emotions: Emotional support and case finding.

1. Emotional support
  - (a) The treating team consisting of doctors, nurses, and allied health staff is responsive to the emotional needs of patients with cancer and provides emotional support.
  - (b) The treating team provides information on external sources of emotional support.
2. Case finding
 

The treating team identifies patients in need of mental health care by means of case finding, and provides a referral to mental health care as indicated.

*emotions*, have led us to propose a new approach to the management of emotions in patients with cancer. We call this approach “emotional support and case finding” (see Box 1).

#### Emotional support

Cancer is a life-threatening disease, its treatment is demanding and burdensome, it is associated with powerful emotions, and approximately one-third of patients fulfill the criteria of a mental disorder [3] or experience distress [6]. Nevertheless, the majority of patients with cancer display resilience: they adapt and are able to cope with cancer. In this respect, cancer resembles other potentially traumatic events: in the face of such events, humans are remarkably resilient and most people maintain an ability to function effectively [49].

However, the fact that patients are resilient does not mean that they have no need for support. In contrast, patients may need emotional support from relatives, friends, and peers [50–53], as well as the treating team consisting of doctors, nurses, and allied health staff. A recent study reported that patients perceived the treating team as an important source of emotional support [54], and patients felt that the treating team understood the burden of disease, so that they felt no need to explain the impact of disease [54]. Patients valued care that was provided with empathy and in accordance with their wishes [54]. In our own trial, we observed that enhanced discussion of psychosocial concerns by nurses and oncologists improved patient well-being [16].

Oncologists recognize the provision of emotional support as an important clinical task. It is one of the reasons why oncologists are passionate about oncology care [55]. Oncologists consider an emotional response to be a normal and natural reaction to receiving a cancer diagnosis or being treated for cancer [56], and report that they respond to their patient’s emotions by establishing a supportive relationship, normalizing the patient’s experience,

calming the patient, and maintaining continuity of care [57]. Similarly, nurses consider delivery of emotional care and support to patients and their families a major component of their work [58].

Emotional support can also be provided by other means, including online self-management support [59], patient discussion and support groups (peers), and expert volunteers [60]. As patients are frequently unaware of these resources [36], information on these external resources should be made more readily available.

These considerations lead us to propose the first principle of the new approach, referred to as “emotional support”: (a) *The treating team consisting of doctors, nurses, and allied health staff is responsive to the emotional needs of patients with cancer and provides emotional support.* (b) *The treating team provides information on external sources of emotional support.*

#### Case finding

Some patients with cancer will experience maladaptive emotions, leading to the need for mental health care. As argued above, screening is unlikely to be an effective approach toward the identification of patients in need of mental health care. We propose that, in place of screening, case finding can be used to identify patients in need of mental health care [61]. Case finding is to be distinguished from screening, both conceptually and operationally. *Screening* is defined as “the application of a diagnostic test or clinical assessment in order to optimally rule-out those without the disorder with minimal false negatives (missed cases). Screening is often performed in a large population as the first of several diagnostic tests. (...) *Case finding* <is> the application of a diagnostic test or clinical assessment in order to optimally identify those with the disorder with minimal false positives (...). Case finding is often performed in a selected population at high risk for the condition” (p. 150) [62, 63]. In the present context, case finding is the purposive identification of patients with emotional problems for which a referral for mental health care is indicated. Risk factors for emotional problems in patients with cancer are well established. For example, younger age, lack of social support, and a relatively burdensome disease or treatment trajectory are well-known risk factors for distress [64, 65]. These risk factors warrant a clinical examination for case finding. We propose “case finding” as the second principle of the new approach: *The treating team identifies patients in need of mental health care by means of case finding, and provides a referral to mental health care as indicated.*

#### CONSIDERATIONS REGARDING THE APPROACH

Above, we have presented a dichotomous view of emotions: adaptive versus maladaptive. This is a simplification, as no absolute distinction between

adaptive and maladaptive emotions exists. However, in clinical practice one needs to make a binary decision: to refer or not to refer the patient for the provision of mental health care. For that reason, we distinguish between adaptive emotions (no referral needed) and maladaptive emotions (referral needed).

Previous studies have demonstrated a disconnect between clinician-rated and patient-reported emotions [66–68]. However, doctors and nurses may be more sensitive to patients’ need for mental health care than previously reported. In a recent study, we assumed that doctors and nurses intuitively distinguish between adaptive emotions that do not require mental health care and maladaptive emotions that do require mental health care. This led us to hypothesize that the sensitivity of assessment of emotions by doctors and nurses would be higher when tested against patients’ need for mental health care as a reference standard, compared to patients’ emotional distress as a reference standard. This hypothesis was indeed confirmed [69]. This finding suggests that the clinical assessment of emotions in patients with cancer may be more accurate than previously reported.

Nevertheless, the accuracy of case finding may need to be optimized. Training of the members of the team may improve the accuracy of the identification of emotional problems. Oncologists and nurses have been observed to use various strategies to identify patients in need of mental health care. These include inquiring directly, getting to know the patient, using intuition and subjective judgment, and checking the patient’s medical history [56, 70]. Both doctors and nurses have indicated a need for further training in the identification of emotional problems [56, 70]. Training may thus improve the accuracy of case finding. Topics could include criteria for emotions to be considered maladaptive (e.g., interference with doctor–patient communication or functioning in daily life), risk factors for emotional problems, communication strategies to evaluate emotions, and cultural variations in the presentation of emotional problems.

The approach presented here is a proposal on how to organize care for emotions in patients with cancer. In this approach, the role of the treating team in the management of emotions in patients with cancer is pivotal. An important task for psychologists and other mental health professionals is to provide training to the treating team in applying this approach: training in providing emotional support, in differentiating adaptive from maladaptive emotions, in identifying patients in need of mental health care, and in motivating selected patients to accept a referral for mental health care. In some cases, mental health professionals provide treatment to patients with maladaptive emotions. However, psychologists and other mental health professionals

mainly have an indirect role: they work through the treating team; direct treatment occurs only in selected patients (for a similar approach towards exercise therapy see [71]).

“Emotional support and case finding” constitutes a novel perspective on how to organize the clinical management of emotions in patients with cancer. As such, neither support nor case finding is new. The novelty of this approach lies in clearly articulating this approach and providing a rationale for this approach. This represents a significant improvement on current clinical practice: instead of poorly defined and intuitive usual care, we now present an explicit approach to the management of emotions in patients with cancer and we provide the rationale for this approach. This provides a backbone to current clinical practice, the approach can be used to upgrade clinical practice, and it informs an innovative research agenda (see below).

Furthermore, the fact that our approach is rather close to current clinical practice may facilitate implementation. Oncologists and nurses recognize the provision of emotional support as an important clinical task and they have been observed to use various strategies to identify patients in need of mental health care, as mentioned above. This is an important stepping-stone for successful implementation.

Finally, our approach could contribute to the prevention of poor clinical outcomes. The provision of emotional support by the treating team is intended to enable patients to better adapt and cope with cancer. This may prevent emotions from becoming maladaptive, requiring professional mental health care. In addition, improved management of emotions may prevent non-adherence to medical treatment and the associated poorer treatment outcomes [8].

## FUTURE RESEARCH

The approach “emotional support and case finding” informs an innovative research agenda to further improve clinical practice. We suggest the following research agenda.

- To explore the training needs of the treating team, and to develop effective and feasible training methods. Training may concern the assessment of emotions and the provision of emotional support.
- To identify risk factors for emotional problems and to target case finding to those patients exhibiting risk factors (e.g., lack of social support, an earlier episode of depression).
- To develop measurement instruments that can distinguish between adaptive and maladaptive emotions. These instruments should support and improve decision making that currently is based on clinical evaluation and patient’s subjective need only.
- To optimize interventions to support patients with adaptive emotions as well as interventions to treat

emotional problems in patients with maladaptive emotions. Such interventions are available, but may need further optimization.

- To explore other factors that may influence the successful implementation of the new approach. For example, although oncologists and nurses recognize the provision of emotional support as an important clinical task, in a busy clinic time to perform these tasks is limited. How the treating team might perform the proposed tasks within the constraints of daily clinical practice needs to be investigated. In studying factors that may influence the successful implementation of the new approach, international variation in the organization of supportive cancer care needs to be taken into account as well.
- And finally, to evaluate the extent to which clinical practice based on the new approach leads to enhanced health outcomes.

In conclusion, the approach “emotional support and case finding” provides a novel perspective on how to organize the clinical management of emotions in patients with cancer. This approach can be used to upgrade clinical practice, and it informs an innovative research agenda on how to further improve clinical practice.

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