COMMENTARY

Management of Distress in Patients with Cancer—Are We Doing the Right Thing?

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Abstract

Background Screening for distress and referral for the provision of psychosocial care is currently the preferred approach to the management of distress in patients with cancer. To date, this approach has shown a limited effect on the reduction of distress. Recent commentaries have argued that the implementation of distress screening should be improved. On the other hand, the underlying assumption that a referral for psychosocial care is required for distressed patients can be questioned. This has led to the development of an alternative approach, called emotional support and case finding.

Purpose In the context of finding innovative solutions to tomorrow's health challenges, we explore ways to optimize distress management in patients with cancer.

Methods and Results We discuss three different approaches: (i) optimization of screening and referral, (ii) provision of emotional support and case finding, and (iii) a hybrid approach with multiple assessments, using mobile technology.

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Conclusions We suggest continued research on the screening and referral approach, to broaden the evidencebase on improving emotional support and case finding, and to evaluate the utility of multiple assessments of distress with new interactive mobile tools. Lessons learned from these efforts can be applied to other disease areas, such as cardiovascular disease or diabetes.

Keywords: Distress · Cancer · Screening · Implementation · Support · Case finding

Introduction

The diagnosis and treatment of cancer can trigger an unpleasant emotional experience. This emotional experience has been described in terms of "distress" [1], or in terms of traditional psychiatric diagnostic categories, such as an anxiety or mood disorder [2]. The prevalence of an unpleasant emotional experience is high, in terms of distress (35%–52%; [3, 4]) and in terms of psychiatric disorders (31.8%; [2]). Distress may interfere with decision making in clinical encounters [5] and is associated with a poor outcome in physical, mental and social life domains [6]. Clearly, effective management of distress is highly desirable.

Screening for distress and referral for the provision of psychosocial care is currently the recommended approach to distress management. Clinical guidelines in the United States, Australia and Canada, among others, recommend implementing distress screening, using a validated measure of distress [1, 7-9]. The clinical team should provide support to patients with mild distress, and a referral to psychosocial care for patients with moderate or severe distress. So far, this approach has resulted in improvement on process measures (e.g., more discussion of distress); however, the effect on the reduction of distress is limited. A Cochrane review found very low-certainty evidence for the effect of screening on distress (16 studies). Of these studies, 14 found no effects, and two found beneficial effects of screening [10]. Two recent studies not yet included in the Cochrane Review also failed to demonstrate a beneficial effect [11, 12]. Commentaries reflecting on these findings have argued that the implementation of distress screening is suboptimal and should be improved, to obtain better outcomes [13]. Dissemination and implementation science may guide efforts to optimize the design, implementation, and evaluation of distress screening programs [14].

On the other hand, the underlying assumption that a referral is required for distressed patients can be questioned, as a considerable number of distressed patients have been found to decline a referral for psychological care. In a recent study, treatment was systematically offered to all distressed patients, but only 11.4% of the distressed patients accepted active distress treatment [11]. Other studies found similar results and reported that patients prefer emotional support instead [15–17]. Moreover, patients may view the offered distress management interventions as not relevant to addressing the cause of their distress [18]. These observations suggest that a fundamental reconceptualization of distress management is warranted. Recently, an alternative approach to distress management, called "emotional support and case finding," has been proposed (Dekker, Karchoud, Braamse, Buiting, Konings, van Linde, Schuurhuizen, Sprangers, Beekman Verheul. Clinical management of emotions in patients with cancer: Introducing the approach "emotional support and case finding"; submitted for publication).

In the context of finding innovative solutions to tomorrow's health challenges, we explore ways to optimize distress management in patients with cancer. We discuss three different approaches: (i) optimization of screening and referral, (ii) provision of emotional support and case finding, and (iii) and a hybrid approach with multiple assessments, using mobile technology.

Screening for Distress and Referral for the Provision of Psychosocial Care

Barriers and facilitators

Since 2015, the American Society of Clinical Oncology and the Commission on Cancer (COC) require accredited cancer centers to integrate psychosocial distress screening as a quality care standard [9]. Despite this mandate, only 50%–65% of eligible cancer patients undergo distress screening [19]. This slow rate of implementation is likely due to institutional and workforce barriers such as inadequate administrative support, lack of an interdisciplinary team, too few mental health professionals, no established distress screening protocols, an undereducated staff, and minimal referral networks to manage sources of distress.

A case example at a single cancer center highlights facilitators and barriers at the provider and system levels [13]. Facilitators at the provider level included identification of a distress screening "champion" and improved communication. Specifically, for this cancer center in the USA, the distress screening "champion" was a clinical psychologist who organized screening efforts, elicited support from leadership, identified information technology and workflow needs and streamlined the procedures for referrals. Identification of one individual or a group of individuals who can lead distress screening efforts is an initial step in the implementation process [20]. In addition, implementation of distress screening was facilitated by clear and consistent sharing of information about individual patients' scores, referrals and follow up. At this single institution, this communication most commonly occurred among medical assistants, social workers and a clinical psychologist. The patient's physician was notified if the patient triggered a referral based on the distress screening score. Barriers at the system level included challenges with integration of screening into the electronic health record, shortage of staff for triage and referral of patients with high distress, and inefficient workflow processes (e.g., need for manual entry of the distress score into the electronic health record; lack of an automatic referral) and lack of resources for screening over time.

Optimizing screening and referral

Many patient-level interventions designed to ameliorate distress are effective [21]. Examples of patientlevel intervention approaches that produced significant reductions in distress within randomized controlled trials include cognitive-behavioral therapy [22], mindfulness [23], and supportive-expressive psychotherapy [24]. While effective, few patient-level interventions have been evaluated as part of routine cancer care delivery across multiple settings. Much of the prior research on psychosocial interventions was conducted to evaluate intervention efficacy rather than focus on pragmatic outcomes relevant for application beyond the controlled research environment [14]. Thus, efforts need to move beyond individually focused patient care, and instead include multidisciplinary, system-level approaches addressing institutional barriers and facilitators [14].

Frameworks used in dissemination and implementation science provide an excellent foundation for identifying how to design and evaluate strategies for the optimization of distress screening and referral programs [14, 25]. For example, RE-AIM as applied to distress screening involves measurement of the *reach* (proportion of patients with access to and uptake of distress screening), effectiveness (patients' and providers' experiences with distress screening, clinical effectiveness of the screening), adoption (process, timing, use of both screening and referral procedures), implementation (use of screening as intended; barriers and facilitators; and costs) and maintenance (effectiveness, use and adaptations made over time) [14]. The Consolidated Framework for Implementation Research involves attention to intervention characteristics (e.g., distress screening and referral approach), the outer setting (e.g., policies; patient needs and resources related to distress screening), the inner setting (e.g., resources for and culture/attitudes toward distress screening, readiness for distress screening), characteristics of individuals (knowledge, beliefs and selfefficacy related to screening implementation) and process of implementation (e.g., planning, engaging, executing, and reflecting/evaluating) [26].

Example of a pragmatic trial using dissemination and implementation approaches.

In a pragmatic trial with randomization at the medical center level, medical centers assigned to the intervention arm received education, monitoring, feedback and referral tracking. Intervention sites were encouraged to adapt workflow procedures to fit the needs of their specific site to facilitate implementation of screening. Sites assigned to the comparison condition (usual control) were only provided with a screening tool. Initial results suggest successful uptake of distress screening procedures among women with newly diagnosed breast cancer (80% screening rate) with promising referral rates (95%) for those who scored as distressed [27].

Screening for Psychosocial Distress Program

The Screening for Psychosocial Distress Program (SPDP) was developed to support nationwide implementation of distress screening in the USA [25]. The SPDP was designed as an educational program with participants attending one workshop each year (total of two face-to-face workshops) with telephone support provided over the 2 years of participation to solve implementation issues.

At the first workshop at the beginning of first year, participants learned how to establish a psychosocial

committee within their organization, select a distress screening instrument and develop a distress screening policy. Participants were taught content on building a multidisciplinary team comprised of physicians, nurses, social workers and other health care professionals who would be involved in the distress screening as part of patient care. Strategies for achieving stakeholder (e.g., physicians, nurses, social workers and other professionals working within the organization) agreement to the approach and continued participation were discussed. Five necessary steps in comprehensive distress screening were developed: (i) administer the distress screen, (ii) evaluate patients' reported distress, (iii) refer to health care providers if distress falls above a predefined threshold, (iv) follow-up with patients and providers for referred patients, and (v) audit medical records for screening documentation [28]. At the end of first year, the goals were to establish distress screening and educate staff about the process. During the second year, the workshop training focus was on establishing a referral network for those most distressed, preparing for future accreditation site visits where distress screening would be evaluated, integrating distress screening with the electronic medical record, and leveraging the outcomes found through screening to support continuation of the distress screening program.

The program was advertised to cancer centers and ambulatory and community practices as having no-cost to the participants or institution; however the organizations had to provide time to attend and partial travel expenses. As an additional requirement for participation, letters of support were obtained from each administrator of the 90 institutions documenting support for distress screening implementation at their organization. This support was considered important because one of the most common barriers to screening implementation is institutional support.

One unique feature of the program was to enroll two oncology professionals from different disciplines from each institution (N = 90 U.S. cancer care institutions from 37 states and D.C.) for a total of 180 professionals, to help each other with organizational change. The participants' disciplines were social work (n = 76, 42%), nursing (n =49, 27%), psychiatry/psychology (n = 43, 24%) or other. Effective team building [29] was discussed to encourage dyads to work together to overcome the multiple barriers to distress screening given the time and work involved. Among the 90 institutions that sent professionals, 42 (47%) were community practices, 26 (28.8) were National Cancer Institute-designated comprehensive cancer centers, and the rest were either ambulatory oncology practices, advocacy groups or federal medical facilities.

Following the SPDP, there were significant improvements in implementation of the five steps over the 2 years of the study (Lazenby, Ercolano, Badger, McCorkle. Implementation of Distress Screening in 90 Cancer Care Organizations (manuscript in preparation)). By the end of 2 years, over half the institutions were effectively implementing the five steps in distress screening, supporting the success of this approach. As oncology professionals engage cancer center administrators in improving the infrastructure and policies to support comprehensive distress screening, institutional barriers should decrease. This program gave the teams the tools needed to overcome many of the barriers. Continued research at the patient, provider and system levels will allow evaluation of compliance with the five steps of comprehensive distress screening and provide data on patient outcomes to show the importance of caring for the whole patient.

Innovative approaches to symptom assessment

Caring for the whole patient involves understanding the range of symptoms patients are experiencing, and ideally, providing timely and high-quality management of those symptoms. Recent research using systematic, web-based assessment of patient-reported symptoms, paired with automated alerts to the medical team when symptoms worsened, demonstrated both improved quality of life and increased survival among patients with metastatic cancer [30, 31]. Similar efforts are underway as part of the IMPACT consortium, which is evaluating electronic symptom assessment of patient-reported outcomes and testing different approaches to symptom management [32]. If successful, future research could explore whether distress can be identified, tracked and appropriately managed using comparable approaches.

Emotional Support and Case Finding

An alternative approach

"Emotional support and case finding" refers to an alternative approach to the management of psychological distress in patients with cancer. The role of the clinical team (physicians, nurses, and allied health staff) is pivotal in this approach. The team supports patients in dealing with the emotional impact of cancer. The team is responsive to the emotional needs of their patients, provides emotional support, and provides information on external sources of emotional support (e.g., patient discussion and support groups). However, providing emotional support is not sufficient for all patients; some patients do need professional mental health care. The team relies on case finding to identify patients in need of professional mental health care (Dekker, Karchoud, Braamse, Buiting, Konings, van Linde, Schuurhuizen, Sprangers, Beekman, Verheul. Clinical management of emotions in patients with cancer: Introducing the approach "emotional support and case finding"; submitted for publication).

This approach was designed to meet patient's preference for support. While approximately one-third to one-half of the patients with cancer experience clinically relevant distress [2-4], only about one-third of the distressed patients have been found to accept a referral for professional mental health care [15, 16]. The other twothirds prefer to deal with these emotions themselves and with support from relatives and friends [17], the clinical team [33], or other patients with cancer [34]. As patients often are not aware of local facilities, the team needs to provide information on peer support and other external sources of emotional support. Of note, the fact that one third to one half of the patients experience distress implies that the majority of patients do not experience distress [35]. Despite life-threatening disease and frequently intensive treatment, most patients are remarkably resilient. Still, even resilient patients may need support in dealing with the impact of the disease [33, 35].

Approximately one-third of the patients experiencing clinically relevant distress have been found to be in need of professional mental health care [15, 16]. Thus, experiencing emotions per se is not a sufficient reason to provide mental health care. Emotions like sadness or fear may be adaptive; that is, emotions help to deal with important events such as the diagnosis and treatment of cancer [36, 37]. Professional mental health care is indicated only when emotions are no longer adaptive. Emotions become maladaptive if they are disproportionally severe or persistent, and if they interfere with functioning.

Case finding seems to be indicated to identify patients in need of professional mental health care, rather than screening. Physicians and nurses have been reported to use several strategies to identify patients in need of professional mental health care [38, 39]. These strategies included inquiring directly, getting to know the patient, using one's intuition or judgement and checking the patient's medication and medical history. Optimization of these strategies for case finding may be a more promising approach for the management of psychological distress, rather than further attempts to implement distress screening and referral.

Preliminary evidence supporting this approach

Physicians and nurses have been reported to be rather insensitive to their patients' emotional experiences (e.g., [40]). If true, this observation would question the use of case finding. However, clinical assessment of emotions by physicians and nurses may be more accurate than previously concluded. In a recent study, it was hypothesized that well-trained and experienced physicians and nurses do recognize patients' emotions, but that they do not evaluate all emotions as necessitating professional mental health care [41]. Indeed, the results showed that clinical assessment of emotions by physicians and nurses was congruent with patients' expressed need for professional mental health

care [41]. This suggests that case finding by physicians

and nurses can be quite accurate. In a qualitative study, oncologists and nurses reflected on their decision to refer or not to refer a patient for professional mental health care. Respondents reported to monitor patients' psychological well-being, especially if patients exhibited specific risk factors (e.g., a history of emotional problems, or lack of social support). If they noted specific indicators of emotional problems (e.g., emotions having a negative impact on patient's daily life or treatment), they considered a referral for mental health care. Thus, oncologists and nurses appeared to use a strategy (built on monitoring, risk factors, and indicators of emotional problems) to evaluate the need for professional mental health care in their patients. Again, this suggests that case finding could be a feasible approach (Karchoud, de Kruif, Lamers, van Linde, Dodewaard, Braamse, Sprangers, Beekman, Dekker, Verheul. The need for professional mental health care in patients with cancer: a qualitative study among oncologists and nurses (in preparation)).

Research agenda

To broaden the evidence base for emotional support and case finding, we suggest an innovative research agenda. A prominent item on the research agenda concerns training of the clinical team in the assessment of emotions and the provision of emotional support. This approach requires that all members of the clinical team are trained in and feel comfortable to identify and address psychosocial needs of patients. This will require more extensive training and awareness by clinicians, as well as a shift in allocation of resources to make available psychosocial support by all team members. Furthermore, it is necessary to catalogue patients' potential risk factors for emotional problems (e.g., lack of social support and history of depression) to establish the conditions for case finding, thereby enhancing its accuracy. System efforts are needed to encourage patients to express their emotions, including distress to team members. Another item on the research agenda is the development of measurement instruments that are able to rapidly and reliably distinguish between patients who do or do not need professional mental health care. Finally, the result of this approach in terms of reduction of distress needs to be determined.

A Hybrid Approach

A hybrid approach would consist of providing emotional support and identification of patients in need of further professional psychosocial support by the clinical team (case finding), as described above. However, even with training, case finding by the clinical team could be improved by providing additional information about patients' distress and other psychosocial needs over time, during the course of treatment. This can be achieved through an ecological momentary assessment approach, operationalized through a smartphone application. Repeated assessments of psychosocial needs provide a better accounting of the patients' psychosocial state and needs to the clinical team, compared with single assessments during a clinic visit. Assessments of psychosocial needs could be embedded within broader symptom assessments. Data collected in this fashion can be summarized and integrated into the electronic medical record, as noted above [32]. If certain thresholds of symptom or mood reports are crossed, the patient is encouraged to contact the provider and the care team is notified. Such a system was piloted in a small feasibility study with 36 cancer patients [42]. We found that over a 2 months period, 75% of patients completed all 16 assessments. (i.e., twice a week). Patients reported that the application was easy to use and provided useful tips and strategies to cope with common physical and emotional symptoms. This underscores the usefulness of symptom and psychosocial needs assessments outside the medical appointment.

Discussion

In this discussion paper, we explored how to optimize distress management in patients with cancer. The screening approach has been extensively tested, leading to the identification of facilitators and barriers to distress screening implementation. For successful implementation, a multilevel approach that targets the patient, provider and system level is indicated [13, 14]. The Screening for Psychosocial Distress Program (SPDP) is such a multilevel approach [25]. This approach indeed resulted in substantial improvements in the implementation of screening. Still, further work is needed to fully implement screening. Innovative solutions such as establishing screening champions in organizations, using electronic methods to screen that are easily accessible prior to the patient's visits, and integrating screening into the medical record are needed. Such solutions need to be evaluated further to assess adherence to the screening protocol. Importantly, the effectiveness of this method for

treating patient distress needs to be evaluated: does this approach indeed result in a reduction distress?

The approach of emotional support and case finding is new and there is still only modest evidence to support this approach. However, this approach allows clinicians to connect with their patient on an individual level and to take individual psychosocial reactions into account. Furthermore, this approach seems to be in line with patients' preferences [17, 33], as well as with the theoretical distinction between adaptive and maladaptive emotions [41]. This approach informs a research agenda on issues which so far have received little attention (see above).

The hybrid approach combines emotional support and case finding with repeated assessments of patients' psychosocial needs. Repeated assessments could be conducted through web- or application-based electronic approaches and may support the team's effort to monitor patients' psychosocial state and needs to provide timely management. The added value of such assessments is another item on the research agenda.

In conclusion, we suggest continued research on the screening and referral approach, as well as broadening the evidence base to include research on emotional support and case finding, and to evaluate the added value of repeated assessments of patients' distress and psychosocial needs. These suggestions on the management of distress in patients with cancer could be expanded to include other somatic diseases: the discussion on the optimal management of distress in cardiovascular disease [43] or diabetes [44] is very similar to the discussion in cancer.

Acknowledgements Terry A. Badger acknowledges contributions from E. Ercolano, M. Lazenby, and R. McCorkle. We also acknowledge work in this area by the Cancer Special Interest Group at the Society of Behavioral Medicine.

Funding This work was supported by the following awards: 11839 from the Dutch Cancer Society (Joost Dekker); P30CA051008 from the Georgetown Lombardi Survivorship Research Initiative (Kristi D. Graves); R25 CA177553-06 from the National Cancer Institute of the National Institutes of Health (PI: R. McCorkle; Terry A. Badger); U010H011690 from the Centers for Disease Control and Prevention of the Department of Health and Human Services (Michael A. Diefenbach); R01CA224918 from the National Cancer Institute of the National Institutes of Health (Michael A. Diefenbach); and a Research Scholar Award by the American Cancer Society (RSG-15-021-01-CPPB; Michael A. Diefenbach).

Compliance with Ethical Standards

Authors' Statement of Conflict of Interest and Adherence to Ethical Standards Joost Dekker, Kristi D. Graves, Terry A. Badger and Michael A. Diefenbach declare that they have no conflict of interest.

Authors' Contributions The authors contributed equally to this discussion paper.

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