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SHORT REPORT

Screening for distress in patients with cancer: methodologic considerations

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ABSTRACT

Distress has been declared the 6th vital sign in Canadian cancer care. Accordingly, health care professionals in Canada are expected to screen for distress in patients with cancer, for which a toolkit has been developed. Identifying patients who may be in need of further resources has the potential to improve quality of care because those patients are more likely to have their existing distress identified and to be referred for appropriate follow-up services. The present article briefly reviews the background literature and the validation of the measures in the toolkit, and highlights future directions for methodologic validation of the toolkit for use according to the protocol.

KEY WORDS

Screening for distress, validation, ESAS, Distress Thermometer, Canadian problem checklist

1. INTRODUCTION

Distress has been identified as the 6th vital sign in cancer care, and cancer programs across Canada are required to implement appropriate screening programs (reviewed in Bultz *et al.*[1] and Thomas and Bultz[2]). In 2008, experts and policymakers in the field of cancer gathered to revise current practices and to develop a new Canadian national strategy. Guidelines were put forth[1], with recommendations about when and how to screen for distress.

Distress is "a multi-factorial unpleasant emotional experience which extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fear to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis"[3]. Emotional reactions, including distress, are normal when facing cancer. Distress becomes clinically significant only when it interferes with the patient's general functioning, with their anticancer treatment, or with their progress in cancer care[4]. The clinical significance of distress can be influenced by many factors, such as disease characteristics (that is, the type of cancer), individual factors (the patient's personality), and other factors (for example, social supports)[4]. Treatment can be effective[5] if patients in need are identified.

2. SCREENING FOR DISTRESS

Screening is a quick examination of the domains of interest to identify patients who might require or benefit from additional services. Referral, comprehensive assessment, or intervention by a more specialized health care professional can then be arranged if necessary[1,6,7]. It has been found that, when distress screening is implemented, staff members are enthusiastic about screening and appreciate the associated training[7]. Staff members report that screening fits well within their medical role and noted that it allows for conversations about issues that might have otherwise been overlooked[8]. Staff involved in screening implementation have been dedicated and collaborative[9], and the available psychosocial resources have not been overwhelmed by positive screening cases[10]. Nonetheless, additional research investigating the practicalities of adopting such programs in clinical practice is still needed[11]. Carlson *et al.*[9] found that, despite enthusiasm, 38% of clinicians believe that screening is impractical for routine use, and 43% of nurses and radiographers rated a screening program as "not useful." And yet others argue that screening has several benefits: it allows for follow-up and coordination of appropriate services, and it increases outreach to patients[1,7,9,12,13]. Accordingly, debate is ongoing in the literature.

Screening for and treating distress has been shown to save the health care system 20% of costs for patients receiving medical care, although it was noted that improved screening is necessary[8]. It is estimated that only 10%–15% of patients would benefit from

complex psychosocial care, that 35%–40% could benefit from a basic psychosocial intervention, and that 30% could benefit from slightly more resources, such as education. Screening would help to identify those patients.

In summary, some argue that screening for distress can positively influence the well-being of patients, especially when barriers—for example, receipt of appropriate aftercare, lack of training or resources, low acceptability—are overcome. Others have argued that screening is resource-intensive and that evidence is lacking that screening programs actually improve patient outcomes over routine care[14]. Screening for distress should therefore be implemented only if the benefits exceed the costs, at both the patient and the system levels. Despite the current debate, screening for distress is mandated in Canada, and an evaluation of the existing program is therefore important to highlight potential shortcomings and possible refinements, which is the current goal.

2.1 Methodologic Considerations

According to the Canadian guidelines[1], the toolkit contains at least two tools to use when screening for distress (although many more are available). The Edmonton Symptom Assessment System (ESAS) and the Canadian Problem Checklist (CPC) are the minimum measures recommended, although additional measures can be used[9]. For example, the Distress Thermometer (DT) is often completed by patients because it usually accompanies the CPC.

The ESAS (see Bultz *et al.*[1]) is a self-report measure of distress originally developed for patients in palliative care[15]. Patients indicate the severity of each symptom on a scale ranging from 1 (no experience of the symptom) to 10 (worst experience of the symptom). The English version of the ESAS has been validated for use within a palliative population. Only sparse research has examined the ESAS outside of the palliative care population. For example, in a 15-year retrospective review of validation articles, Nekolaichuk *et al.*[16] found that only two of the eleven studies in cancer patients were not from palliative populations, one of which sampled "mostly elderly male patients with advanced cancer"[11]. Additionally, studies that have been credited for including nonpalliative populations are often cited erroneously. For example, Chang *et al.*[11] and Wanatabe *et al.*[17] are both credited for examining nonpalliative populations when their samples were, in fact, almost exclusively from palliative or advanced-stage populations. Validation outside of those populations is therefore pending.

The ESAS anxiety and depression items were evaluated in a systematic review and found to be "fair"[18]. They were generalizable and had a moderate criterion measure and moderate validity. Internal consistency was not applicable because only two items were being measured, and test–retest reliability was not considered because mood is a function of disease trajectory and is inconsistent in patients with cancer. Several studies have applied the ESAS in French populations, but translations seem to be in-house rather than validated versions (for example, Pautex *et al.*[19]). Further independent validation of the ESAS items is necessary if this measure is to be used for screening distress.

The CPC (see Bultz *et al.*[1]) is a list of 21 items grouped by domain (emotional, physical, and so on). Patients indicate any item that has been a source of difficulty. The CPC was created for the toolkit as a complement to the ESAS; it assesses the most commonly reported problems with the minimum number of questions[20]. It is often accompanied by the DT so that the patient's responses likely indicate some of the causes of their distress. Possibly because this measure was only recently developed, validation studies are not available. Additionally, validation might be limited given the yes-or-no output of a checklist (yielding lower reliability estimates, for example).

Although the DT is not part of the toolkit, it is reviewed here because it is often included. It is a single-item self-report measure of global distress. Patients use a visual analog thermometer to indicate their level of distress, from 1 (no distress) to 10 (extreme distress), during the preceding week. Clinically significant levels of distress reported in the literature correspond, on average, to scores of 4 or 5 (for example, see Gessler *et al.*[21]), but actual cut-off scores ranged up to 7[22]. The psychometric properties of the DT for use with cancer patients have largely been investigated[21,23] and have been established across cultures[22,24]. Although there are discrepancies between the studies, consensus about the predictive validity appears to have been reached: the negative predictive validity (range: 93.4%–95%) is greatly superior to the positive predictive validity (range: 34.2%–39%). Thus, it is better to rule out distress than to accurately identify it. Because of overall moderate sensitivity (0.76–0.80) and specificity (0.6–0.82), the DT is considered an acceptable screening tool for distress among cancer patients.

Research on the psychometric properties of the process of distress screening has been limited. It is recommended that patients be screened for distress at least when entering the health care system and when transitioning between critical time points (that is, diagnosis, treatment, survivorship, palliative care, end-of-life care)[1,7]. Several screenings are recommended, because distress can vary by disease phase and type[9]. Little is known about the performance of the toolkit across the disease trajectory because most studies provided only single screenings, usually at diagnosis. The effects of repeated screening—that is, test–retest validity and incremental validity of repeated screenings compared with a single screening—have to be examined.

In sum, validation of the DT, but not the ESAS or the CPC, is well established in an English Canadian population at various points in the cancer trajectory. Validation of all three tools is lacking with respect to use in French Canadian populations. That validation is an important area for future research, given that French is an official language in Canada, that 22% of Canadians completing the 2011 census reported speaking French as their mother tongue, and that French Canadians reside in every province and territory[25]. As demonstrated by Dolbeault *et al.*[26], validation of measures in one population might not be acceptable across cultural groups, making validation a salient consideration. These methodologic issues could be important to consider for future refinement of this ongoing national screening program.

3. SUMMARY AND CONCLUSIONS

Screening for distress has the potential to reduce the difficulties that patients face during the cancer experience by identifying those who could benefit from additional resources. Once identified, patients can receive additional information, referrals, or appropriate follow-up to help them cope. Screening programs have been mandated in cancer programs across Canada and a minimal toolkit has been developed. The toolkit includes the ESAS, a measure that is well validated for English-speaking patients, mostly those in palliative care. The CPC was created for the toolkit, but its validation is pending, possibly because of its novelty. Neither measure is validated for French Canadian populations, and additional psychometric properties will have to be evaluated for their proposed repetitive use in screening programs. With ongoing psychometric validation and with the further development of screening programs according to outcomes data, screening for distress could potentially reduce a portion of the unnecessary burden both for patients and for the health care system.

4. ACKNOWLEDGMENTS

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5. CONFLICT OF INTEREST DISCLOSURES

The authors declare that they have no financial conflicts of interest.

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