

EMOTIONAL DISTRESS SCREENING IN CANADIAN CANCER CARE

A survey of utilization, tool choices and practice patterns

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Abstract

Rationale: While elevated levels of distress are pervasive in cancer patients, little is known about whether or not cancer care facilities across Canada systematically screen cancer patients for emotional distress, and how this screening is conducted. *Methods:* This article describes results of a study based on a questionnaire sent to all eligible cancer care institutions across Canada, either via email using Survey Monkey software or by regular mail. *Results:* Of a total of 146 institutions, 84 responded to the questionnaire. Among responding cancer care facilities, 27 (36.5%) routinely screen patients for emotional distress at the time of admission, and almost all of these add the information to the patients' charts. Reported barriers to implementing routine screening were time constraints, inconsistent usage, lack of resources for followup psychologic treatment, and lack of "buy-in" by some staff. The measures most frequently used were the ESAS, the PSSCAN and the Distress Thermometer. With regard to preferred length for a screening tool, most respondents favoured a questionnaire of 10-20 items. *Conclusions:* This survey showed that a large number of cancer care facilities in Canada have established screening for emotional distress, and that Canadians use standardized tools more often than do US or UK cancer centres. Areas in need of improvement were the quality of assessment tools and consistency of follow-through with patients whose scores exceed cut-off points. A need for further education about the benefits of best practices for screening was apparent.

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RATIONALE

Along with the other vital signs (i.e. temperature, respiration, heart rate, blood pressure and pain), emotional distress is now considered the 6th Vital Sign in healthcare.¹ The process of being proactive in identifying patients with high anxiety and/or depression is referred to as distress screening.

On March 6 and 7, 2008, about 60 cancer care clinicians, administrators and researchers met in Calgary to begin building a shared rationale and recommended practice pattern for psychosocial distress screening in cancer care. Meeting participants reached a high level of consensus on the need for distress screening and a desire to collaborate across Canada, while recognizing that we are only at the beginning of this process. Professionals working in psychosocial cancer care concur that patient distress is prevalent and requires intervention,² yet we currently lack both an agreed-upon catalogue of appropriate tools and a transparent knowledge base about who is doing what in Canada, and how well different approaches work.³ In the US, a nationwide survey of 1000 oncologists revealed that 65% reported they screen for distress but only 14.3% used a standardized instrument to do so.⁴ Further, only 32.3% reported being at least somewhat familiar with the National Comprehensive Care Network (NCCN) guidelines for screening. Similarly, a study from the UK⁵ showed that only 10% of 226 physicians and nurses surveyed use a validated screening tool.

As a critical step towards making distress screening routine in the care of people with cancer, we undertook a systematic scan of the cancer care environment in Canada in order to learn:

- how many cancer centres are already using routine distress screening
- which distress measurement tools are used most often
- when in the cancer care trajectory this assessment is conducted and how the information is used
- what difficulties practitioners have encountered with implementing and maintaining the system.

METHODS

Participants

Using the member database of the Canadian Association of Psychosocial Oncology (CAPO) as a starting point to collect addresses of hospitals and other centres treating cancer patients, we created a preliminary address list. When several names were available from the CAPO database for a centre, we asked up to 2 persons per institution to complete the survey. Next we expanded this list via a systematic Internet search, using the respective province, “hospital,” “cancer” and “cancer centre” as search terms.

We sent the survey to the person who appeared to have primary responsibility for psychosocial care if we could retrieve an appropriate name; otherwise we sent it to the institution. We asked whether the person to whom we sent the survey was the right one to give information on distress screening, and requested that the survey be forwarded to the most knowledgeable person for completion. Finally, the list of survey respondents was rounded out by adding the names and addresses of all attendees of the March 2008 conference in Calgary. The resulting address list included 100 institutions with an email address and an additional 46 institutions with only a mailing address. The email survey used Survey Monkey software (www.surveymonkey.com).

Prior to sending out the final survey we sought feedback about clarity and user friendliness from 6 individuals in 2 provinces. At this time we learned from colleagues in Quebec that their entire cancer care delivery system was in the middle of a massive restructuring and that no centralized mailing list was available. In addition, we were told that any attempt to extract information about practice patterns in Quebec would be misleading because it could not reveal how the future care system would handle the issue of distress screening.

Survey characteristics

The survey began with this question:

- Is screening for emotional distress routinely performed with a standardized screening tool?

If not, we only asked for the name of the institution, the institution’s province and the responder’s gender and profession. When screening was routinely offered, we asked for the measure that was used, and when routine screening had been established in the institution, we continued with more questions:

- At what time in the diagnostic and treatment process is the screening performed?
- Is emotional distress screening performed to document the trajectory of psychological distress?
- Is emotional distress screening used to measure effects of psychologic treatment?
- Are results of emotional distress screening entered into patients’ charts?
- What kinds of difficulties have been noted with implementation and maintenance of the system?
- How many items can a screening tool include and still be usable in routine care?

RESULTS

Questionnaires were sent to 146 institutions; a total of 84 answers (57.5%) from different institutions were received. Of these, 9 respondents (10.8%) said that they were not capable of answering the questions because they were not involved in psychosocial care. Of the 46 paper surveys mailed out, 25 (54.3%) were answered, and from 117 Survey Monkey requests 59 (50.4%) were returned, thus indicating that response rates did not vary as a function of survey delivery mode. In one case, we received 2 answers from the same institution, a large cancer centre, and as the answers were identical we only included one answer in the results.

Information on respondents

Of the 75 respondents included in the analysis, 70 provided information on their gender, profession and their province. Of these, 57 (81.4%) were female, 11 (15.7%) were physicians, 33 (47.1%) were nurses, 12 (17.1%) were psychologists and 12 (17.1%) social workers; another 2 respondents reported no professional designation. The majority of responses, 21 (28.0%), came from British Columbia, followed by 14 (19.8%) from Ontario, 14 (19.8%) from Alberta, 8 (11.3%) from Manitoba, 5 (7.0%) from Newfoundland, 3 (4.2%) from Nova Scotia, 2 (2.8%) from New Brunswick, Quebec and Saskatchewan, and 1 (1.4%) from Prince Edward Island. Of 70 responses that provided information about the type of institution they worked in, 42 (60.0%) were general hospitals and chemotherapy units, and 28 (40.0%) were university hospitals or specialized cancer centres.

Utilization of routine distress screening

Twenty-seven (36.5%) of the reporting institutions have established routine emotional distress screening using a standardized instrument. The proportions did not differ between email and paper responses. The Edmonton Symptom Assessment System (ESAS)⁶⁻⁸ was the most frequently used instrument, in 10 (38.5%) of the institutions surveyed, followed by the Psychological Screen for Cancer (PSSCAN)⁹ used by 4 (15.4%), and the Distress Thermometer (DT)¹⁰ used by 3 (11.5%). The General Health Questionnaire (GHQ)¹¹ was employed in 2 (7.7%) cancer institutions; and the Brief Symptom Inventory (BSI)¹² and Hospital Anxiety and Depression Scale (HADS)¹³ were used in 1 institution (3.8%) each. Apart from these, the Patient Oriented Record for Prostate Cancer Utility Scale (PORPUS),¹⁴ various symptom lists and other non-published scales were used. One institution uses an instrument that is a blend of the DT and the Anxiety and Depression Subscales of the PSSCAN, which we counted as the DT.

Among respondents who did use distress screening, the mean length of time since implementation was 4.1 years with a range of 1 to 14 years.

Time points of screening

The majority of respondents (n = 16) reported that distress screening is performed at the first contact with the hospital (61.5%). Another 5 (19.2%) screened once a medical treatment program had been initiated. Three (11.5%) reported that they conduct screening when a psychologic treatment

program is being considered or initiated and 2 (7.7%) once a positive medical diagnosis is established.

Fourteen respondents (53.8%) reported that distress screening was performed more than once to document the trajectory of psychologic distress. With the aim of measuring effects of psychologic treatment, 5 institutions (19.2%) used the screening tool more than once. Many respondents to this survey indicated that they used the same measure for initial screening to study the trajectory of well-being in cancer patients; others used their tool to measure the benefits of psychologic interventions as well. All but 1 respondent indicated that distress data were added to the patients' charts.

Preferred survey length

The great majority of responses, 92%, indicated that distress instruments with more than 5 but fewer than 20 items represent the best blend of brevity and informational detail; 46.2% endorsed a screening instrument with 5–10 items, 34.6% suggested a screening tool of no more than 20 items, 11.5% wanted a rather short screen of up to 5 items, and 7.7% thought that a questionnaire up to 100 items could still be used for screening.

Implementation challenges

Twenty-five survey responders provided information in narrative form about difficulties in implementing screening. Each of the authors reviewed the narratives and we compared our ratings for inter-rater agreement and settled discrepancies. We concurred that the responses addressed 5 underlying themes. Four of the 25 narratives reported problems with follow-through once a positive screening result was obtained; the major reason given for lacking follow-through was insufficient resources for counseling or psychotherapy. Nine respondents mentioned attitudinal reluctance or insufficient “buy-in” by healthcare staff to support distress screening. Another 9 described difficulties with applying the screening in a consistent manner, and 11 respondents mentioned time pressure on staff to complete and score the screening tool.

DISCUSSION

Response rate

Our survey had a slightly higher response rate (51% vs 46%) than the only known US survey.³ While these response rates are fairly good for nation-wide, anonymous surveys, they remain unsatisfyingly low overall and raise questions about whether the observations made can be generalized. Given that centres not doing distress screening were less likely to respond, the survey probably overestimates the proportion of institutions using standardized screening tools to identify distressed cancer patients.

Response rates varied widely by province, with the best rates in Manitoba and British Columbia. These provinces, incidentally, have fairly transparent and centralized service delivery systems. In Quebec, the current reorganization of the care delivery system represents an excellent opportunity to build routine screening into that province's practices.

Which tools and when?

This survey revealed that 36.5% of responding institutions conducted distress screening with a standardized instrument, thus indicating notably higher usage of standardized tools in Canada than the 14% reported in the US.⁴ We posit that it is good news for Canadians that our care centres appear to be more than twice as likely as US centres to use standardized tools for screening. Most institutions with established routine distress screening favoured a cancer-specific questionnaire over general distress measures. The most widely used tool was the ESAS, which has 10 questionnaire items and has been validated only in palliative care patients;^{6–8} ESAS use is predominant in Ontario, resulting from a Ministry of Health initiative to standardize distress screening practices in this province for all cancer and palliative care populations.

The PSSCAN,⁹ with 21 items, was the second most frequently used instrument and has been validated for a more mixed cancer population; acquisition of further normative data and criterion validation via comparison with the general population and other medical populations has also been completed.¹⁵ The single-item, cancer-specific DT has advantages in routine care because of its brevity. Validation research offers some support for its utility but these validation studies use weak methodologies and have revealed that the DT has only moderately high sensitivity and specificity.¹⁶

A meta-analysis¹⁷ has shown that ultra-short screening tools with up to 4 items tend to have only modest specificity and therefore should not be used for emotional distress screening on their own; also, they are not sensitive enough for taking repeated measurements. Interestingly, our survey revealed that the majority of respondents did not report perceiving a need for ultra-short screening tools.

Our findings confirm that screening for emotional distress has become routine in some institutions and is sustainable. Among 16 (61.5%) responding institutions the respective screening tool is presented at the first contact with the hospital or clinic, and all institutions except 1 enter the results of the distress screening into the patients' charts. In many institutions emotional distress screening was implemented several years ago, but some have conducted screening for up to 14 years.

Overcoming barriers

Respondents described several barriers to translation of the concept of distress screening into practice. They cited inconsistency of usage, time pressure and fear of lacking resources for subsequent counseling or referral as the most important barriers.


Regarding time pressure and resources, the literature reports wide variation in prevalence of anxiety and depression in cancer patients, ranging from an absence of symptoms to reported presence of symptoms in up to 90% of patients.^{18–20} Reasons for these massive discrepancies include different cancer types and stages, gender of the samples (women report more symptoms), time of data collection in the illness trajectory, and whether a clinical diagnosis or simply presence of symptoms was used as the criterion. Typically, depression is more prevalent than anxiety,

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especially after patients have coped with the initial diagnostic shock.¹⁸ Later in the disease trajectory, cancer patients do not differ from the general population except for heightened depressive symptoms.¹⁸ Thus, provided that referral is only made if a patient actually meets criteria for clinical diagnosis of a disorder, there appears to be little danger of patient counseling services being overrun if routine screening is implemented.

Further, difficulties with buy-in were mentioned by more than a third of respondents. The notion of buy-in refers to vague and dismissive comments like “yet more paperwork” or doubts expressed about potential benefits. We posit that further education about the value of screening may help address problems related to buy-in. Such education will need to mesh with and respond to the very specific beliefs and attitudes held by service providers, and the information provided needs to help them see how screening can either simplify or improve the quality of their work. A simple top-down approach for such educational efforts is unlikely to work.

CONCLUSION

A minority of Canadian cancer care institutions provide routine psychological distress screening with standardized tools, with a trend for higher frequency of screening in the larger clinics and those with their own in-house psychosocial support staff. No respondent indicated having initiated a screening program and then later abandoning it. Pervasive concerns are inconsistent application and follow-through, lack of staff resources for the screening and scoring, and the actual treatment of cancer patients' distress. 

Disclosure

The authors declare no conflict of interest pertaining to this study report.

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