Reports from the Canadian Association of Psychosocial Oncology Symposium

Distress: screening and then what?

SCREENING FOR DISTRESS

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SUMMARY: Tools for the future


The North East Local Health Integration Network-13 (North East LHIN) is one of the largest of Ontario’s 14 LHINs, responsible for planning, integrating and funding healthcare services for more than 565,000 people across 400,000 square kilometers. The Northeast Cancer Centre and its 14 Community Oncology Clinic Network (COCN) sites in the Northeast LHIN systematically implemented symptom screening between 2007-2011 utilizing the Edmonton Symptom Assessment Symptom (ESAS)-revised, Patient Reported Functional Status and the Canadian Problem Checklist. This symposium focused on 1) the process for implementing an electronic assessment tool in rural and urban communities and sustaining symptom management efforts; 2) utilizing aggregate data to inform clinical decision making and program development; and 3) the unveiling of a new strategic direction to expand screening for distress within communities, new research initiatives and knowledge translation strategies to keep clinicians engaged.
**Commentary:** Two broad factors determine the inability to translate research into practice. The first is knowledge transfer, where the failure lies with the practitioner for not receiving and implementing lessons from research. The second is knowledge production, where the failure lies with researchers for producing the wrong kind of research. In this context, Screening for Distress (the 6th vital sign), is a rare success story, with progress from research to the implementation of national standards occurring in less than a decade. Cancer Care Ontario (CCO) developed an easy-to-use e-tool, the Interactive Symptom Assessment and Collection (ISAAC), that allows patients to systematically describe their symptoms, and enabled clinicians to track those symptoms over time and across care settings. Touch screen kiosks were deployed in the Regional Cancer Centres across Ontario as early as 2007, and since then several hundred thousand data points have been collected. Technology has also allowed that data to be consolidated monthly to generate reports for routine review, intrasite comparison, real-time trending on repeated measures, electronic medical report charting, etc.

The key concern raised at the symposium and in the literature is that implementing a screening program by itself is just a small first step toward improving patient care. Therefore, speakers at the CAPO symposium and others in the field have identified policies to enable whole patient care using Screening for Distress (SfD).

**Vision**
One core issue is sustainability, because the program is not operationally funded. Irrespective of how it is rolled out (electronic- or paper-based), SfD is not an intervention, but rather “a new way of working,” in the words of presenter Doris Howell from the Northeast Cancer Centre. The metrics used by administrators must therefore be modified so that cost effectiveness is assessed in relation to timely and proactive follow-through on the assessment with appropriate referrals and routine monitoring.

**Mission**
The language used around SfD has to be consistent across disciplines and service providers, and awareness must be increased around professional responsibility (who can do what) and the impact of different assessment approaches on what the patient says or does not say. Local needs vary within a province, and geography, language, ethnicity, etc. will have an impact on how the SfD program is accessed and used. Do we treat them all the same (equality of care) or do we take differences into account to enable equity in health outcomes? Analytics (see below) are key to the success of the mission.

**Objectives**
The implementation of SfD is just the first step in a much larger challenge of determining who should act upon the assessment. Does the centre have the resources to deal with concerns raised? There is a need to improve the cross-validity of patient responses, e.g. does a 3 out of 10 score on a particular item on the ESAS mean the same thing to different patients? If the mission is equity in health outcomes, then it is not enough to respond to a 65% prevalence rate of high fatigue merely by holding a fatigue class once a week. The population seeking that one resource will be skewed. Responses to a distress screen must be multipronged to increase uptake. Alternative options could include well-designed handouts or web resources, service provider-led videos, therapist-led group sessions, specialist referral, etc.

**Analytics**
It might be helpful to integrate patient demographics into analysis of assessments and enable comparison with other similar respondents. As well, rather than just focus on the respondents, the system needs to be cognizant of non-responders and why they are missing (system improvements in where/when the assessment is done, e.g. kiosk location). Patient-reported measures may serve as anchors to improve interpretation of access and utilization patterns of other resources in the system, such as palliative care, emergency departments, etc.

In addition to the two factors that determine the potential to translate research into practice, we propose a third factor: knowledge implementation. Implementation is a function of our capacity to adapt research into practice and our ability to accommodate differences. In research, gaps and missing data are limitations, however in the clinical setting, these represent lost opportunities. In the research...
exercise, the peaks and lows in symptom prevalence in conjunction with specific demographics make interesting findings. However, in the clinical setting, not only do we need to triage and deal with significant symptom burdens for each of those patients, we must also think programmatically to support patient clusters and deal with concerns they identify. Implementing a Screening for Distress program is just the end of the beginning. The road ahead requires a strong partnership between clinical leaders, administrators and patients to ensure that assessments produce more than statistics. The analytics have to evolve from being research tools to guiding the actions of clinicians, administrators and patients. Average scores and skew plots should be replaced by individual trends over time, as well as service access and utilization metrics. A logistic regression should not be seen as just an explanation of a phenomenon, but rather serve as a predictive tool to improve identification of, and services for, patients at risk.

References