Distress—the 6th vital sign

D. Howell RN PhD[*] *and K. Olsen RN PhD*[†]

Distress is a common concern across the cancer trajectory, beginning at diagnosis and extending to the post-treatment phase of cancer and long term [1]. All patients experience distress in response to a cancer diagnosis and treatment effects [2]. About one third of the cancer population will experience significant levels of distress requiring targeted psychosocial intervention [3,4]. Heightened distress is associated with worse patient outcomes in terms of worse health-related quality of life, lesser treatment adherence, lower satisfaction with care, and possibly lower survival [5–7].

Despite the prevalence of distress, an understanding of its multifactorial nature, its occurrence along a continuum, and the potential for early intervention by the clinical team is lacking. In general, distress may be caused by physical, psychological, emotional, or social problems as consequences of illness. The National Comprehensive Cancer Network (NCCN) defines distress [1] as

> a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional) social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

They also recommend the use of the term "distress" rather than "anxiety and depression" because of the stigma associated with those latter terms.

Several studies have shown that distress is under-recognized in cancer programs [8]. Fallowfield *et al.* [9] reported that the oncologist accurately identified only 29% of patients with serious psychological distress. Thus, it is not surprising that the Canadian Partnership Against Cancer [10] and the NCCN [1] recommend that cancer patients be routinely screened for distress, at a minimum during times of vulnerability across the cancer trajectory, such as at the time of initial diagnosis, before treatment, during and after treatment, and at transition to end-of-life or palliative care. Consequently, distress is now endorsed as the "6th vital sign" both nationally and internationally. Accreditation Canada also includes assessment, evaluation, and monitoring of emotional distress in clients as an accreditation standard [11]. Appropriate screening for distress helps to ensure early identification of people in need of additional support, with targeted intervention by the clinical team and referral to psychosocial services for those at higher risk for negative health outcomes.

Various substantive reviews have considered the issue of screening for distress in cancer [1,8,12,13]. Taken together, those works broadly group distress screening tools into 3 categories: screening for emotional distress, screening for symptoms, and screening for sources of distress, such as related problems and concerns. Several approaches are available to assess distress, including standardized symptom assessment tools with valid cut-off scores, such as the Memorial Symptom Assessment System [14], and numerical rating scales for distress, such as the distress thermometer [1].

Numerous factors contribute to distress, including the physical burden of disease (symptoms), declining functional status that interferes with daily living, and the emotional and social changes wrought by a cancer diagnosis. Indeed, as recommended by the U.S. Institute of Medicine [8], instruments that screen for distress should be used to detect a comprehensive range of problems or concerns that can contribute to distress. The selected tools should also be reliable, valid, and brief for clinical use, and they should be able to discriminate those with distress based on a reliable cut-off score to optimize case finding. As a result, the Canadian Partnership Against Cancer recommends that distress screening should include a complete physical and psychological symptom intensity approach using the Edmonton Symptom

Copyright © 2011 Multimed Inc. Following publication in *Current Oncology*, the full text of each article is available immediately and archived in PubMed Central (PMC).

Assessment System [15] and the Canadian Problem Checklist [10]. The Canadian Problem Checklist is a short list of problems in 6 areas (practical, emotional, spiritual, social/family, information, and physical) that have been reported in the peer-reviewed literature to be correlates of distress [16,17].

As with any screening approach, the screening alone is not enough. Distress screening should be followed by a more comprehensive and focused assessment to guide the selection of appropriate and relevant interventions, or the need for referral to psychosocial resources, or both [8,18]. Further assessment may lead to better outcomes through several possible mechanisms [1]:

- The direct implementation of new care processes (that is, psychosocial interventions or team-based care planning) [2]
- The provision of more information to guide appropriate referral to psychosocial services [3]
- An enhancement of the patient's experience of the care received (for example, communication with the provider or satisfaction with care) [18]

It is expected that clinicians will act on the findings of their assessment to optimize the potential for positive outcomes. A growing body of literature in this area references both drug and non-drug interventions for the management of distress. Evidence-based guidelines for managing distress and its common symptoms have been developed by the Canadian Partnership Against Cancer in collaboration with the Canadian Association of Psychosocial Oncology through a synthesis of evidence in the field using rigorous methods for adapting evidence and the consensus of experts [10]. A review of evidence-based approaches for the management of distress is also available from the NCCN Web site (http://www.nccn.com) and the Canadian Partnership Against Cancer (http://www.partnershipagainstcancer.ca). These Pan-Canadian guidelines can also be accessed at the Canadian Association of Psychosocial Oncology Web site (http://www.capo.ca).

Overall, an emerging body of literature suggests that screening for distress is acceptable to patients and clinicians, and that such screening does not appear to place a significant burden on patients. More importantly, distress screening has many potential clinical benefits: facilitating communication, guiding selection of appropriate psychosocial and supportive care interventions, stimulating quality improvement in clinical care, and ensuring early referral for those in need of more intensive psychological interventions.

Consensus has been reached that a programmatic approach to initiating and sustaining screening for distress, with equal attention to best practices to ensure the high quality of the response to distress, is critical to improving the patient and family experience of cancer care.

CONFLICT OF INTEREST DISCLOSURES

The authors have no conflicts of interest to disclose. DH has a leadership role in developing distress management guidelines as a member of the Distress Management team of the Canadian Partnership Against Cancer and a board member for the Cancer Journey Advisory Group; however, these activities are not viewed as a conflict of interest given their volunteer nature.

REFERENCES

1. National Comprehensive Cancer Network (NCCN). *NCCN Clinical Practice Guidelines in Oncology: Distress Management.* Version 1.2011. Fort Washington, PA: NCCN; 2010. [Available online at: http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf (free registration required); cited August 30, 2011]
2. Fitch MI. Supportive care framework: theoretical underpinnings. In: Fitch MI, Porter HB, Page BD, eds. *Supportive Care Framework: A Foundation for Person-Centered Care.* Pembroke, ON: Pappin Communications; 2008.
3. Carlson LE, Bultz BD. Cancer distress screening: needs, methods and models. *J Psychosom Res* 2003;55:403–9.
4. Bultz BD, Carlson LE. Emotional distress: the sixth vital sign in cancer care. *J Clin Oncol* 2005;23:6440–1.
5. Kennard BD, Stewart SM, Olvera R, *et al.* Nonadherence in adolescent oncology patients: preliminary data on psychological risk factors and relationships to outcome. *J Clin Psychol Med Settings* 2004;11:30–9.
6. Von Essen L, Larsson G, Oberg K, Sjödén PO. "Satisfaction with care": associations with health-related quality of life and psychosocial function among Swedish patients with endocrine gastrointestinal tumors. *Eur J Cancer Care (Engl)* 2002;11:91–9.
7. Steel JL, Geller DA, Gamblin TC, Olek MC, Carr BI. Depression, immunity, and survival in patients with hepatobiliary carcinoma. *J Clin Oncol* 2007;25:2397–405.
8. Adler NE, Page AEK, eds. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs.* Washington, DC: The National Academies Press; 2008.
9. Fallowfield L, Ratcliffe D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. *Br J Cancer* 2001;84:1011–15.
10. Canadian Partnership Against Cancer (CPAC), Cancer Action Journey Group. *Guide to Implementing Screening for Distress, the 6th Vital Sign: Moving Towards Person-Centered Care.* Part A. Background, recommendations and implementation. Toronto, ON: CPAC; 2009.
11. Accreditation Canada. *Qmentum Program 2009 Standards: Cancer Care and Oncology Services.* Ver. 2. Ottawa, ON: Accreditation Canada; 2008.
12. Mitchell AJ. Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. *J Clin Oncol* 2007;25:4670–81.
13. Mitchell. Are one or two simple questions sufficient to detect depression in cancer and palliative care? A Bayesian meta-analysis. *Br J Cancer* 2008;98:1934–43.

Copyright © 2011 Multimed Inc. Following publication in *Current Oncology*, the full text of each article is available immediately and archived in PubMed Central (PMC).

14. Portenoy RK, Thaler HT, Kornblith AB, *et al.* The Memorial Symptom Assessment Scale: an instrument for evaluation of the symptom prevalence, characteristics, and distress. *Eur J Cancer* 1994;30A:1326–36.
15. Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991;7:6–9.
16. Fitch MI. Supportive care for cancer patients. *Hosp Q* 2000;3:39–46.
17. Sanson–Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer* 2000;88:226–37.
18. Howell D, Currie S, Mayo S, *et al. A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient.* Toronto, ON: The Canadian Association of Psychosocial Oncology; 2009.

Correspondence to: Doris Howell, 610 University Avenue, Room 15-617, Toronto, Ontario M5G 2M9.
E-mail: doris.howell@uhn.on.ca

* University Health Network, Princess Margaret Hospital, and Lawrence Bloomberg Faculty of Nursing, University of Toronto, Toronto, ON.
† Faculty of Nursing, University of Alberta, Edmonton, AB.

Copyright © 2011 Multimed Inc. Following publication in *Current Oncology*, the full text of each article is available immediately and archived in PubMed Central (PMC).