Although distress is common among people with cancer, the current standard of care does not include consistent distress screening. To acquire or maintain accreditation, the American College of Surgeons Commission on Cancer will require cancer centers to have a distress screening program in place by 2015. When evaluating tools to screen for distress in patients with cancer, researchers should evaluate the literature to ascertain that tools have been tested for validity and reliability in the population of patients with cancer. Regardless of the distress screening tool chosen, studies support that screening patients for distress is beneficial to improving quality of life and outcomes by allowing for referral to appropriate interventions.

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Key words: cancer; distress; screening; anxiety; depression

Digital Object Identifier: 10.1188/14.CJON.E103-E106

A projected 1,660,290 new cancer cases will be diagnosed in the United States in 2014 (American Cancer Society, 2014). More than 14 million cancer survivors are alive in the United States, including those who are cancer free as well as people living with metastatic cancer. Many large-scale studies show that psychosocial distress associated with the diagnosis, treatment, and prognosis of the disease is prevalent in most patients diagnosed with cancer (Massie, 2004); however, distress in patients with cancer remains underdiagnosed and undertreated (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001). One article estimated that fewer than 10% of patients with cancer were screened and identified as having distress (Holland & Alici, 2010). Patients with cancer experience varying levels of distress throughout the disease trajectory associated with the diagnosis of cancer as well as the effects of the disease and treatments. Studies show that more than 45% of patients with cancer suffer significant psychological distress (Institute of Medicine [IOM], 2008), and 5% of people with cancer suffer from post-traumatic stress disorder per clinical criteria (Bellizzi & Blank, 2011).

Distress Screening

People with lung, brain, and pancreatic cancers are most likely to suffer distress; however, differences in psychological distress by cancer type are small (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). People with advanced cancer and poor prognosis may be at greater risk for distress (Holland & Alici, 2010). Patients with cancer who have a history of psychiatric disorders, substance abuse, and depression are also at an increased risk for suffering distress (National Comprehensive Cancer Network [NCCN], 2013). Long-term symptoms such as cognitive impairment, fatigue, pain, and anxiety can cause distress in people long after cancer treatments are completed (Zabora, BrintzenhofeSzoc, Curbow, et al., 2001).

Time constraints on healthcare professionals are the main issues cited as contributing to the infrequent use of distress screening questionnaires or tools in cancer care (Schofield, Carey, Bonevski, & Sanson-Fisher, 2006). In addition, knowledge deficit and lack of understanding of psychological distress evaluation may, to some extent, account for the infrequent use of distress screening (Vodermaier, Linden, & Siu, 2009). Other personal and professional obstacles in the use of psychological distress tools may include beliefs, values, and assumptions (Schofield et al., 2006). These barriers are often conveyed in the opinion that screening is pointless or is beyond what can be addressed or capably treated in a cancer care setting (IOM, 2008; Jacobsen & Ransom, 2007; Schofield et al. 2006).

Defining Distress in Cancer

The word distress describes objectionable emotional feelings. The NCCN panel of experts who authored the original 1997 guidelines for distress management chose the word distress...
because it suggested an acceptable emotional response to a crisis. They hypothesized that use of this word would avoid the stigma and negative connotations associated with terms such as psychiatric, emotional, anxiety, or depression (NCCN, 2013). Therefore, patients may be more willing to participate if asked to take part in a “distress” screening.

The NCCN (2013) described psychological distress in people with cancer as,

A multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, 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. (p. DIS-2)

Increased psychological distress can have a significant impact on overall well-being. Because it can impair decision making, cognitive function, and memory, distress can interfere with responsibilities in employment and everyday life. Distress can also hinder interpersonal relationships related to feelings of being out of control, anger, frustration, and preoccupation with thoughts and concerns of the disease (NCCN, 2013). All of these issues can lead to a decreased quality of life and may impede treatment adherence, which potentially can lead to a negative outcome in the cancer care setting. A growing body of literature supports the importance of effective screening, assessment, and management of psychological distress in patients with cancer to improve treatment adherence, which can improve outcomes in cancer care (Giese-Davis et al., 2011; Holland & Alici, 2010).

The NCCN (2013) stated that “distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings” (p. DIS-3). The American College of Surgeons (ACOS), 2012) Commission on Cancer echoed the critical value of psychological distress screening in its decision to require cancer centers to implement screening programs for psychosocial distress by 2015 to acquire or maintain accreditation. They stated that “all cancer programs will need to demonstrate that they screen patients diagnosed with cancer and identify the issues that can negatively impact treatment and outcome” (ACOS, 2012, p. 76). This is in recognition that reliable screening throughout the continuum of diagnosis, treatment, and survivorship allows clinicians to identify psychological distress early for effective and timely management. The Oncology Nursing Society (ONS), 2013, in a joint statement with the American Psychosocial Oncology Society and Association of Oncology Social Work, supported this stance when they stated that they endorsed the new standards on psychosocial distress screening and recognized that it will help address unmet needs (IOM, 2008).

Measuring Psychological Distress in Patients With Cancer

Typically conducted by professionals without mental health backgrounds, a distress screening is a quick self-report questionnaire to identify patients who may require additional referral for more extensive evaluation (Zabora, Smith-Wilson, Fetting, & Enterline, 1990). If deemed necessary, a mental health professional will conduct a more comprehensive psychosocial assessment interview. This follow-up should include more in-depth coping and adjustment questioning to evaluate how the patient is adapting to the demands of a cancer diagnosis and its treatment (National Cancer Institute [NCI], 2013).

Most screening tools involve the sequential steps of screening administration (oral, paper-based, or computer-generated questionnaire), scoring, evaluation based on previously determined criteria, and referral on to a mental health professional if the final scores of the screening fall outside the outlined standard measure. For positive outcomes, the final critical step should include follow-up and reevaluation by a mental health professional (IOM, 2008; NCCN, 2013).

Choosing a Distress Screening Tool

Instruments to measure psychological distress come in a variety of formats (e.g., visual scales, a list of straightforward questions about mood and feelings) and lengths (e.g., one item, 50 or more items). Although a plethora of screening tools exist for the screening of distress (Carlson et al., 2004), fewer questionnaires are validated in the assessment of psychological distress in patients with cancer. Some screening tools are more focused to a specific cancer type. Because of the assortment of tools available, a variety of opinions exist on which instrument is the most appropriate for use when screening for distress in general cancer care. ONS (2013) suggested that a screening tool should evaluate distress more generally without sole focus on one specific symptom or indicator because of the many facets of distress. The Psycho-Oncology Co-Operative Research Group (2014) cautioned against using a distress tool designed for a group other than the one for which it was tested and validated because results may not be reliable. Vodermaier et al. (2009) advised that, when choosing a distress screening tool, the clinician should assess the psychometric properties of the tool, particularly the instrument’s sensitivity and specificity. An ideal distress screening tool for patients with cancer should be brief, concise, uncomplicated, and simple to score (Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008). Emotional, social, and physical issues should be queried when evaluating a patient for distress (Akiyuki, Yamawaki, Akechi, Nakano, & Uchitomi, 2005).

Distress Screening Tools

Researchers have studied and established the potential for distress screening to enhance quality of life and cancer treatment outcomes by ensuring referral to appropriate interventions (Holland & Alici, 2010). The issue of choosing and implementing a distress assessment tool, however, is not quite as clear (Carlson & Bultz, 2005).

Distress Thermometer

The NCCN Distress Thermometer has been one of the most studied and investigated tools to evaluate distress. For an updated
version of the Distress Thermometer, access the NCCN website (http://bit.ly/1i3JedY). A cancer-specific tool, the Distress Thermometer is similar to the rating scale used for pain. On a scale of 0–10, with 0 representing no distress and 10 being severe distress, the patient circles a number to indicate his or her level of distress. A patient marking a score of 4 or higher should trigger further evaluation by a medical professional and a referral made to the appropriate supportive service based on the identified problem. For a screening tool to be most functional, information on the level of distress experienced must be quantified and the specific issues associated with the distress identified. The Distress Thermometer not only evaluates the level of distress experienced by the patient, but also includes a checklist for the patient to identify specific issues that contribute to his or her distress. A 39-item list of issues identifies possible stressors in five different categories including practical (e.g., child care, insurance, financial) family (e.g., dealing with children/partner, ability to have children), emotional (e.g., depression, fears, sadness, worry), spiritual/religious, and physical (e.g., constipation, diarrhea, fatigue, nausea, pain) (NCCN, 2013). Although varying opinions exist on the accuracy of the Distress Thermometer, it appears to be a useful instrument for routine screening and ruling out elevated distress in patients with cancer (NCI, 2013; Tuinman et al., 2008).

Hospital Anxiety and Depression Scale

Another example of a short distress screening instrument validated in people with cancer is the Hospital Anxiety and Depression Scale (HADS). This scale takes two to five minutes to complete and consists of 14 items; seven items screen for depression and seven screen for anxiety. Patients answer each item based on how he or she felt during the past week on a four-point scale from 0–3. Scores range from 0–21 for anxiety and 0–21 for depression. A score of 0–7 in each category constitutes a normal range, a score of 8–10 suggests a possible issue, and a score of 11 or higher indicates a probable issue (Snaith, 2003). Various studies have deemed the HADS accurate in assessing anxiety and depression in primary care patients and the general population (Bjelland, Dahl, Haug, & Neckelmann, 2002).

Visual Analog Scale

The Visual Analog Scale (VAS) is a brief and simple distress screening instrument validated in patients with cancer. The VAS usually consists of a line with descriptors at both ends (i.e., from good to bad), and the line usually has no other markings, words, or numbers. Patients are asked to place a mark along that line to express their subjective feelings, and the distance of the mark from one end of the line is measured as the score. The lack of restricting patients to categories or numbers is an advantage of VAS with regard to accuracy. Although brief and simple, experts have described VAS as highly sensitive, reliable, and responsive to change with time and treatment (Hauser & Walsh, 2008), and state that VAS is at least as accurate as a questionnaire when evaluating distress levels (Lesage, Berjot, & Deschamps, 2012).

Brief Symptom Inventory 18

The Brief Symptom Inventory 18 (BSI-18) is another example of a short distress screening tool. It is a self-report scale designed to evaluate psychosocial distress. The BSI-18 contains 18 items in three subscales of somatization, depression, and anxiety. Each of the 18 items is rated on a five-point scale from 0 (not at all) to 4 (always). Examples of the 18 items appearing on the tool include (a) faintness or dizziness, (b) feeling no interest in things, (c) pains in heart or chest, (d) feeling hopeless about the future, (e) nausea or upset stomach, and (f) feeling fearful. This tool takes about four minutes to administer and was found to be reliable and valid in a large mixed sample of people with cancer (Vodermaier et al., 2009; Zabora, BrintzenhofeSzoc, Jacobsen, et al., 2001).

Conclusions

Vodermaier et al. (2009) provided an evaluation of the psychometric properties of many distress tools that are used to screen for psychosocial distress in patients with cancer. In the article, the authors employed extensive evaluation criteria (e.g., number of validation studies completed on each screening tool, total number of participants in the validation studies, reliability, sensitivity, specificity).

The decision to initiate screening in patients with cancer is important. Clinicians should evaluate tools to screen for distress in patients with cancer and, before making a final decision, they should research the literature to ascertain that the tool is tested for validity and reliability in the population of patients with cancer. Regardless of the distress screening tool chosen, the literature strongly supports screening to refer patients for interventions to assist in eliminating or lessening issues that cause distress.

References


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