Mental Health Distress

Oncology nurses’ strategies and barriers in identifying distress in patients with cancer

Leeat Granek, PhD, Ora Nakash, PhD, Samuel Ariad, MD, Shahar Shapira, MA, and Merav Ben-David, MD

BACKGROUND: Oncology nurses have an important role in identifying mental health distress; however, the research to date indicates that oncology nurses often do not accurately detect this distress.

OBJECTIVES: The aim of this study is to explore oncology nurses’ perspectives on indicators of distress in patients, the strategies they use in identifying these signs of distress, and the barriers they face in recognizing these indicators.

METHODS: Twenty oncology nurses were interviewed. The study used the grounded theory method of data collection and analysis.

FINDINGS: Nurses relied on a number of emotional and behavioral indicators to assess distress. Nurses reported that indicators of mental health distress were often expressed by patients or their caregivers. Strategies to identify distress were limited, with nurses reporting that their only method was directly asking the patient. Barriers to identifying distress included patients concealing distress, nurses’ lack of training, and time constraints.

KEYWORDS
prevention and detection; distress management; depression; anxiety

DIGITAL OBJECT IDENTIFIER
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consisting of a line with a 0–10 scale, anchored at the 0 point with “no distress” and at the 10 point with “extreme distress.” Patients who score 4 and above are considered distressed enough to need intervention. The measure has been used extensively and successfully in research with patients with cancer (Donovan, Grassi, McGinty, & Jacobsen, 2014; O’Donnell, 2013).

Despite these recommendations and the availability of reliable tools to measure distress, the research indicates that healthcare providers (HCPs) frequently fail to recognize mental health disorders in patients with cancer (Holland & Alici, 2010; Miyajima et al., 2014; Werner, Stenner, & Schüiz, 2012). Most published data suggest that HCPs’ ability to accurately detect emotional distress in patients with cancer is poor (Fallowfield, Ratcliffe, Jenkins, & Saul, 2003; Werner et al., 2012). For example, in one study (Söllner et al., 2001), only 30% of patients with cancer who were severely distressed were identified by their oncologists as experiencing any mental health issues. Although the recognition of emotional distress can be hampered by the unwillingness of patients to disclose such concerns, HCPs are also frequently reluctant to probe these areas adequately (Granek, Nakash, Ben-David, Shapira, & Ariad, 2018a; Söllner et al., 2001).

As this review indicates, mental health distress in patients with cancer is common, and accurate identification of this distress is critical for improving the quality of life of patients and their families. Oncology nurses play an important role when it comes to identifying distress, because they have frequent and ongoing contact with patients and their families (Estes & Karten, 2014; Vitek, Rosenzweig, & Stollings, 2007). For example, Mussiello et al. (2017) pilot tested routine screening by a psychologist and a nurse in an outpatient oncology clinic. Using the Distress Thermometer, they found that nurses spent more time talking to patients about the screening results and were more likely to make referrals to the appropriate services than the psychologists (Mussiello et al., 2017).

Despite this central role in potentially identifying distress, the research to date indicates that much like other HCPs, oncology nurses overall often do not detect patients’ mental health distress accurately (Kaneo et al., 2013; Miyajima et al., 2014; Nakaguchi et al., 2013). For example, McDonald et al. (1999) looked at 40 clinic nurses in 25 community-based ambulatory oncology clinics and found that, of 1,109 patients with cancer, nurses were able to correctly identify clinical depression only 29% of the time when the depression was mild, and only 14% of the time when the depression was severe. McDonald et al. (1999) concluded that nurses tended to underestimate the level of depression in their patients, particularly for those who were suffering from severe depression. Similarly, in another study conducted in Japan (Nakaguchi et al., 2013), 17 oncology nurses were asked to rate the supportive care needs of 439 patients who also filled out a needs assessment. The concordance rates between patients’ and nurses’ assessments of supportive care needs was low, and the authors concluded that nurses’ recognition of patients’ psychological needs was poor (Nakaguchi et al., 2013).

“A timely and accurate diagnosis of mental health disorders is the basis for mental health treatment.”

Research on oncology nurses’ self-perception corroborates these findings. In some survey studies, oncology nurses expressed concern about their abilities to detect distress in patients with cancer (Kaneo et al., 2013; Pehlivan & Küçük, 2016). In a study by Kaneo et al. (2013) of 88 oncology nurses who filled out a questionnaire, more than half reported that they were very concerned about their abilities to assess anxiety and depression of patients with cancer. In another study of 157 nurses who were evaluated for their ability to detect distress, more than 20% of the sample reported that they felt they did not have the knowledge to perform psychosocial evaluations on patients (Pehlivan & Küçük, 2016).

Oncology nurses’ barriers in identifying mental health distress in patients with cancer include a lack of time and resources (Dilworth, Higgins, Parker, Kelly, & Turner, 2014; Güner, Hıdırurmac, Kocaman Yıldırım, & İnci, 2018; Turner et al., 2018), lack of knowledge (Güner et al., 2018), and lack of privacy to talk to patients about their potential distress (Turner et al., 2018).

Given that patients with cancer often suffer from mental health distress that is not identified and not treated by their HCPs, and given the evidence that this treatment gap may be caused by oncology nurses’ inability to accurately detect mental health distress, this study aimed to explore how oncology nurses address this problem. In this study, oncology nurses were asked directly about what they look for and how they identify mental health distress in patients with cancer, with an additional focus on strategies for and barriers to identifying distress from their own perspectives.

Methods
Design and Participants
This study came out of a larger research project examining how oncology HCPs identify suicidality in patients with cancer (Granek et al., 2017, 2018a, 2018b). The study used the grounded theory method of data collection and analysis (Charmaz, 2006; Glaser & Strauss, 1967). Grounded theory emphasizes a method of inquiry and the products of that inquiry. It can be used to explore people’s experiences and can aim toward theory development. Although a theoretical model was developed in previous articles from this project (Granek et al., 2017), the research question asked in this
study did not lend itself well to developing a theoretical model. Nonetheless, the study employed all the hallmarks of grounded theory, including no preconceived codes or categories and the use of theoretical sampling, memos, line-by-line coding, and constant comparison in data analysis. Recruitment involved 20 nurses who were interviewed about their perceptions on indicators of mental health distress in patients with cancer. Nurses were asked about what strategies they use in identifying this distress and the barriers they face in recognizing distress. All nurses who participated in the study worked exclusively with patients with cancer in oncology units (see Table 1).

The principal investigator is a psychologist with a background in mental health in the oncology context. To maximize perspectives on the study topic and reduce bias toward mental health services, an interprofessional research team was composed; it included a health psychologist, clinical psychologist, radiation oncologist, medical oncologist, and research assistant with a social sciences background. Discussions resulted in a diversity of professional and disciplinary views about the emerging dataset. When discussing indications of mental health distress in patients, the psychologists were able to describe definitions of clinical depression and anxiety, and the medical and radiation oncologists were able to shed light on the importance of physical symptoms as indications of distress.

**Procedure**

Research ethics board approvals were obtained at the start of the study. Potential participants were emailed information about the study by the co-investigators and asked to respond if they wished to hear more about the research. Twenty nurses responded. Participants signed a consent form before beginning the interview. A semistructured interview guide was used. All interviews were audio recorded and later transcribed, with all information that could identify participants removed from the transcripts. Questions focused on how nurses identify mental health distress in patients, including probes about symptoms they look out for, things that stand out to them that require special attention, and concrete examples of patients in whom distress was identified. Questions also focused on challenges and struggles in identifying distress in patients.

**Data Analysis**

Data collection and analysis took place at the same time, and analysis proceeded with line-by-line coding of the transcripts. Analysis was inductive. Categories and codes emerged from participants’ stories, rather than from codes or categories that were preconceived. Throughout the analysis, constant comparison was used to explore the relationships within and across codes and categories. The study team met frequently to discuss emerging findings and to ensure consistency in the emerging coding scheme throughout the process of data collection and analysis.

Data collection was stopped when data saturation was reached. NVivo, version 10.0, was used to store and organize the data.

**Findings**

**Identification of Mental Health Distress**

When oncology nurses were asked to speak about identifying mental health distress in patients with cancer, they reported on three major themes: (a) emotional indicators, with the subthemes

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<th>TABLE 1. SAMPLE CHARACTERISTICS (N = 20)</th>
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*Participants could choose more than one response.
of major depressive symptoms, anger and irritation, anxiety, and avoidance and depersonalization; (b) behavioral indicators, including crying, the patient’s physical appearance, and the patient’s social isolation; and (c) verbal indicators, including expressions of concern from the patients and their families (see Figure 1).
Emotional Indicators of Mental Health Distress
Nurses reported that the first symptoms they noticed that indicated mental health distress in patients were indicators of major depressive disorder. These symptoms could include anhedonia, apathy and withdrawal, general sadness, hopelessness and helplessness, flat affect, and despondency. Nurses also considered expressions of irritability and anger as potential signs of mental health distress. This could be expressed by patients by being generally irritable, or it could be anger and aggression directed toward the nurses or doctors treating the patients.

Fear and anxiety also were reported as signs of mental health distress. This anxiety could be around the diagnosis, the prognosis, treatments, the unknown, and death and dying. Signs of this anxiety in patients included experiencing rumination and intrusive thoughts, being uncooperative, being restless, and having difficulties sleeping. Nurses reported that when patients appeared to have an incongruent response to the treatment, or when they wanted to avoid all conversation about their condition, it could indicate mental health distress in the form of avoidance and depersonalization.

Behavioral Indicators of Mental Health Distress
Nurses reported that an obvious sign of mental health distress in patients was when they cried while receiving treatments or while talking about their condition. The way a patient looked also could indicate mental health distress. Examples included when a patient looked disheveled or appeared to be neglecting activities of daily living, such as personal hygiene and diet (e.g., not showering, eating less, appearing to be unkempt). Nurses noted that patients who isolated themselves out of choice or who appeared to be lonely without any social support could also indicate mental health distress.

Verbal Indicators of Mental Health Distress
Nurses reported that patients often verbalize their mental health distress explicitly. These indicators included statements like the following:

- “I’m sick and tired of this.”
- “I want to die.”
- “I don’t want to live in pain.”
- “I don’t have meaning in life.”
- “I don’t want to suffer.”
- “It’s too hard to cope.”
- “I’m in distress.”

In addition to a patient’s verbal indicators of distress, nurses reported that family members or caregivers often talked to the nurse about the patient’s mental state. This included reporting on the patient’s depression, asking that the patient be given antidepressants, or asking the nurse to intervene to help the patient with distress.

Strategies for Identifying Mental Health Distress
When nurses were asked about their strategies for identifying mental health distress in patients, they reported only on one theme that involved inquiring directly with patients. Supporting quotations are presented in Figure 2.

Nurses reported that they asked patients directly about how they were doing in multiple domains of their life. This included asking patients about their work; how they were feeling acutely and how they feel on a day-to-day basis; and how they were doing generally, physically and emotionally. In addition, nurses reported that they inquired about how they were before the disease and how they were doing currently in each of these domains to assess the level of their distress.

Barriers to Identifying Mental Health Distress
When asked to report on barriers to identifying mental health distress in patients, nurses spoke about three main themes that included patients concealing the distress, nurses’ lack of training to identify distress, and time constraints. Supporting quotations are presented in Figure 3.

One barrier in the detection of mental health distress is when patients themselves concealed their feelings from the healthcare staff. Nurses reported that this distress often was mentioned by caregivers of these patients but rarely seen by the healthcare staff. Oncology nurses reported that they had no formal training in the identification of mental health distress. In their view, this was a significant barrier to helping patients. The only nurses who did receive training on identification of mental health distress were those who had training in supportive or end-of-life care.
“Truth is, I was never in any setting that indicators for mental health distress was a lack of time to sit and listen to the patient. Sometimes you don’t have the time to physically sit with the patient. Sometimes there’s a small window of opportunity when we find –

LACK OF TRAINING
- “I refer patients to social workers because they have more knowledge. To tell you the truth—I don’t have the right tools.”
- “I haven’t received any training of a psychologist or a social worker, but my experience has taught me a lot on how to manage mental health distress in patients.”
- “Truth is, I was never in any setting that indicators for mental health distress in patients was discussed.”

TIME BARRIERS
- “Sometimes there’s a small window of opportunity when we find ourselves one-on-one [with a patient]. Because usually we’re like mice: coming, going, hanging [IVs], running to the next patient. So when there’s time, a conversation can be developed. But since I came here it’s been more ‘putting out fires’ than initiated conversations with patients.”
- “Sometimes you don’t have the time to physically sit with the patient. At the same time you got some other patients who want to get their treatment and go home. Identification of mental health distress requires one-on-one care, sitting together for an hour, and not for the 15 minutes we have. I don’t think I have the conditions at work to identify.”
- “Less of our time is dedicated to really sitting with the patients, hearing them, or talking with them. The work is very intensive. It does happen from time to time, but usually we don’t have time. We are so busy with all the things ‘around’ the patient and not with the patient, so we see less of the patient.”

Therefore, identification of distress was based on experience rather than formal training.

Finally, nurses reported that a major barrier to identifying mental health distress was a lack of time to sit and listen to patients. Nurses also reported being so overburdened with practical care responsibilities that they rarely had time to get to know patients and talk to them about their emotional well-being.

Discussion
This study explored oncology nurses’ identification of mental health distress in patients. Previous studies have surveyed nurses about their abilities to identify distress or examined the concordance rate between patients’ assessment of their psychosocial needs and nurses’ abilities to accurately identify these needs (Kaneko et al., 2013; McDonald et al., 1999; Nakaguchi et al., 2013). To the authors’ knowledge, this is one of the few studies to explore in-depth what nurses look for when identifying distress and what challenges they face in this task. The authors found that nurses relied on a number of indicators to assess emotional distress. These included emotional indicators, such as symptoms of major depressive disorder, anger and irritation, anxiety or fear, and avoidance or depersonalization. Behavioral indicators included crying, physical appearance, and social isolation. Finally, nurses reported that indicators of mental health distress often came directly from patients or their caregivers. Strategies for identifying mental health distress were limited, with nurses directly asking patients as their only approach. Finally, barriers to identification of distress included patients concealing distress, nurses’ lack of training, and time constraints.

These findings help illustrate nurses’ abilities to correctly name indicators of distress. For example, symptoms of major depressive disorder (e.g., poor appetite, apathy, sleepiness, seeming depressed) are appropriate cues to follow up on in patients with cancer. Other indicators reported, such as crying, physical appearance, anger, and social isolation, are more ambiguous and may or may not indicate emotional distress in patients. Nonetheless, the naming of these indicators suggests that oncology nurses are highly attuned to patients’ affective and physical state and rely on a number of cues to help them assess whether a patient is in distress. Conducting direct observations using explicit diagnostic questions provides more reliable diagnostic information and reduces bias (Nakash & Alegria, 2013).

However, more concerning findings from this study pertain to the limited strategies in identifying distress and the barriers listed in attending to this task. Asking patients directly is one effective way to assess distress, but it is limited in scope, particularly when administered in an inconsistent and unstructured manner. Some patients may be reluctant to answer these personal questions, and asking patients in an ad hoc way about their distress may not generate an accurate assessment of their emotional state. Other research, primarily among patients receiving psychiatric care, suggests that using ad hoc strategies for assessment can result in missing information and misdiagnosis (Nakash & Nagar, 2018).

Barriers to identification of distress, including lack of training and the perception that patients are concealing their distress, also can be addressed. A few studies have evaluated the efficacy of communication skills training for oncology nurses to improve detection of mental health distress in patients (Brown et al., 2009; Fukui, Ogawa, Ohtsuka, & Fukui, 2009). For example, one
randomized controlled trial found that nurses who received communication skills training were better able to detect distress in newly diagnosed patients with cancer compared to those who did not receive the training (Fukui et al., 2009).

Limitations
For this study, selection bias may pose a risk to generalizability, because it is possible that nurses who agreed to participate in the study were those who felt more comfortable with and skilled in managing issues related to emotional distress among patients. It is plausible that the challenge of making correct diagnostic decisions and recognizing emotional distress may be even more prominent among the oncology nursing community at large. Further research could include surveying the patients themselves to see whether a treatment gap exists between patients' needs and nurses' ability to identify them. In addition, the data presented in this study can be supplemented by recording clinical encounters and analyzing what transpires in these interactions and where nurses may miss opportunities to identify patients' distress.

Implications for Practice and Research
A cost-effective solution to address time limitations is conducting a short systematic screening for emotional distress (Adler & Page, 2007; Institute of Medicine, 2008). Diagnostic determinations of mental health distress in the oncology context are frequently made in environments that are low on resources and high on demands. Therefore, the use of any diagnostic system must address missing information. One potential approach to increasing diagnostic efficiency is using question probes to make an accurate psychiatric diagnosis. Probes to identify major depressive disorder can include questions assessing mood (low or depressed) and interest or pleasure (diminished or reduced). A study conducted among patients in outpatient mental health clinics showed that using these probes can significantly improve the accuracy of diagnostic decisions (Nakash, Nagar, & Kanat-Maymon, 2015). Future research can examine whether these probes or other screening questions can improve diagnostic decisions in oncology care.

A different approach to facilitating a time-efficient assessment of emotional distress can include using reliable and valid screening measures for prevalent mental health disorders, such as anxiety and depression. Implementing such an approach will require a systematic screening of all patients to avoid bias in evaluation. Patients who meet the cutoff points can be followed up with by a thorough assessment by an oncology nurse or a social worker. Systematic screening for emotional distress fosters a holistic and comprehensive approach to care for patients with cancer (Adler & Page, 2007; Institute of Medicine, 2008). One commonly used measure for emotional distress screening is the Distress Thermometer (Holland & Bultz, 2007). This is a one-item self-report measure that is simple to administer and has been recommended for clinical use in oncology care (Donovan et al., 2014; O'Donnell, 2013), including by oncology nurses (Vitek et al., 2007). To date, there is limited empirical research that has examined outcomes of systematic screening for mental health disorders among patients with cancer (Carlson, Waller, & Mitchell, 2012).

This study's findings emphasize the need to allocate appropriate resources (primarily dedicated effort time) to help nurses identify and address the mental health concerns of patients. In addition, to provide integrative care, nurses can receive basic training to systematically identify mental health distress and, perhaps more importantly, to provide initial response to alleviate the emotional suffering of patients. Such training can provide a foundation about mental health concerns, as well as tools to address these concerns. Nurses have a critical role as gatekeepers in recognizing emotional distress and providing initial response and, when needed, appropriate referral to specialized care.

Stepped Care
To facilitate a stepped care model, nurses can receive training to provide low-intensity psychological interventions (Bennet-Levy, Richards, & Farrand, 2010), which generally are based on cognitive behavioral therapy and delivered via written materials or information technology with limited professional guidance. Implementing low-intensity interventions in the general population (e.g., school counseling) can reduce anxiety and depressive symptoms. In addition, studies among primary care physicians showed that they can be trained to deliver initial care of common mental disorders, particularly for uncomplicated cases (Andrews, Cuijpers, Craske, McEvoy, & Titov, 2010; Araya et al., 2003; Cuijpers, Donker, van Straten, Li, & Andersson, 2010; Osborn, Demoncada, & Feuerstein, 2006; Tatrow & Montgomery, 2006). Therefore, stepped care can significantly improve the accessibility and availability of services and provide a model for holistic care for comorbid mental health disorders for patients with chronic illnesses. The American Society of Clinical Oncology has recommended that different care options be offered, depending on symptom presentation and general clinical information. Across these different options, the role of HCPs is critical in mitigating the severe consequences of comorbid mental health disorders (Andersen et al., 2014). Being able to provide integrated care will not only improve patient care but also will improve oncology nurses' knowledge and competency in identifying emotional distress.

**IMPLICATIONS FOR PRACTICE**
- Assess for mental health distress indicators in patients with cancer; these include physical, emotional, and behavioral symptoms.
- Use standardized screening tools (e.g., the Distress Thermometer) to identify mental health distress.
- Institute a stepped model of care that includes training nurses in providing low-intensity psychological interventions.
Mental Health Distress

Conclusion

Identifying emotional distress among patients with cancer is only the first step to providing holistic psychosocial care and diminishing the mental health treatment gap. Attention can be given to implementing training models that help nurses improve their communication skills in general and their recognition of potentially treatable anxiety and depression. Referral to specialized mental health care should be offered to patients for whom an increased risk is identified. This stepped care can ensure the delivery of evidence-based treatment (psychotherapy and psychopharmacology) to patients who need treatment for their emotional distress.

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