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Responding to the quality imperative to embed mental health care into ambulatory oncology

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In 2008, the IOM released a report entitled “*Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*” (Adler & Page, 2008). In this report, the IOM emphasized the need to address and embed psychosocial services in cancer care. The report called for: (a) facilitating communication between the patient and provider; (b) identifying psychosocial health needs; (c) designing and implementing a plan that links the patient with appropriate services (e.g., mental health counseling, etc.); and (d) updating and adjusting psychosocial care plans. This report brought attention to the fact that despite the growing number of people living with cancer, their psychosocial needs and practical concerns (e.g., financial burden, transportation to follow-up appointments, etc.) were not being adequately addressed. Diagnostic, decision-making and treatment planning experiences can be stressful and overwhelming for cancer patients and their families. Treatment is often associated with chronic and debilitating side effects, and cancer care for many patients can be complex, fragmented, toxic and expensive. Collectively, these challenges can cause psychological distress, a state that is characterized by “*unpleasant emotional, psychological, social, or spiritual experiences that can interfere with the ability to cope with cancer treatment*” (NCCN, 1999). Such distress states tend to be subjective in nature and occur on a continuum ranging from transient feelings of distress to persistent, severe and unresolved symptoms that can lead to diagnosable mental health disorders (Benedict & Penedo, 2013).

Prior to and following the IOM report, a body of literature documented the psychosocial needs of cancer patients given the stressful experiences associated with a diagnosis and treatment. About one in three cancer patients meets criteria for a diagnosable mental health condition. For example, Mehnert and colleagues (2014) found that based on symptoms reported over a 4-week period via clinical interviews, about 32% of cancer patients met criteria for DSM or ICD- defined mental health conditions. In a meta-analysis of 70 studies with over 10,000 cancer patients in ambulatory settings, rates of DSM or ICD defined major depression were 16.3%, while rates of DSM defined minor depression were about 19.2%. Results also showed that rates of adjustment disorder and anxiety were 10.3% and 19.4%, respectively, and that 38.2% of patients had any mood disorder (Mitchell, et al., 2011).

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While most studies documenting mental health disorders in cancer populations focus on prevalent, and not incident, conditions, several studies have shown that relative to individuals with no cancer, cancer patients report significantly greater rates of mental health disorders (e.g., Polsky, Doshi, Marcus et al., 2005). The challenges of navigating a cancer diagnosis and treatment extend beyond emotional concerns. Our work and others' has reported that fatigue, pain, anxiety, depression and nausea are among the most common and debilitating symptoms reported in oncology settings (Cella et al., 2008; Deshields et al., 2014). Depressive symptoms are a common component of psychosocial distress that can involve feelings of sadness, anhedonia, withdrawal and guilt. Depressive mood disorders that reflect persistent, debilitating and unresolved symptoms of depression have been associated with poorer survival in cancer patients (e.g., Kanani et al., 2016). Despite the challenges of cancer and its sequelae, and multiple calls for integrating psychosocial distress screening and services as standard of care, until recently few standards have been in place to guide implementation in oncology settings (Adler & Page, 2008). Given the extraordinary demands placed on clinical workflows which can impact physicians, nurses, social workers, palliative care teams and administrators, even fewer practical, realistic approaches have surfaced.

The article in this issue by Wagner and colleagues (*"Screening for depression in cancer patients receiving radiotherapy: Feasibility and Identification of effective tools in the NRG RTOG 0841 trial"*; 2016) presents results of a practical, valid approach to screening for depression in outpatient oncology settings. In this study conducted by the Radiation Therapy Oncology Group (RTOG), the authors evaluated whether a brief and valid 2-item depression screener effectively identified patients who were at need for further assessment for depression and the extent to which this brief instrument was as effective as lengthier assessments in identifying patients who met criteria for a depressive disorder. Below we reflect on the authors' findings and opportunities for systematic and efficient distress screening and intervention in clinical settings.

Distress Screening as a Standard of Care in Oncology Practice

The NCCN has been at the forefront of bringing attention to evaluating distress among patients in oncology settings and has proposed that *"Distress should be recognized, monitored, documented, and treated promptly at all stages of the disease"* (Holland et al., 2013). The American College of Surgeon's Commission on Cancer (CoC; 2016) has developed standards of care for oncology patients specific to identifying and addressing psychosocial needs. Standard 3.2 of the CoC states, *"The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care"*. The mandate does not provide a specific point in the cancer continuum for distress screening beyond the suggestion that it occurs at a "pivotal point" in the patients' care and that ongoing monitoring for distress should be in place. Diagnosis, treatment planning, and transition into follow-up care and surveillance, or end-of-life care are commonly considered pivotal points in the cancer continuum where patients face distinct challenges that may or may not lead to elevated distress. The CoC, along with other national bodies such as the NCCN and IOM call for routine distress screening. Collectively these standards include (a) screening patients for distress and

psychosocial health needs as a critical first step to providing high-quality care; (b) ongoing monitoring and documentation of distress at all stages of the disease; and (c) referral to the appropriate provision of supportive oncology care (e.g., psychologists, social workers, patient navigators, palliative care specialists, etc.; NCCN 2015; IOM 2008). As of 2016, to be accredited by the CoC, cancer centers must be at 100% compliance of standard 3.2. These are much-welcomed standards to psychosocial and supportive oncology clinicians who have first-hand experience in working with distressed oncology patients and their families and caregivers.

Implementation and Impact of Distress Screening in Patient Care

Regardless of the setting, there has been much discussion of how to effectively implement distress screening with brief and validated tools that are not resource intensive or disruptive to clinic workflows and patient care. In a survey conducted by the CoC regarding the readiness of cancer programs to implement distress screening, 58% reported they felt “completely confident” and 35% “somewhat confident” that they would be able to implement the distress screening standard by 2015. Therefore, 48% of these centers either lacked confidence or were somewhat confident about their ability to implement distress screening (ACoS/CoC, 2015). Given the comprehensive nature of the distress screening process and the variety of symptoms and challenges patients may experience, oncology settings also face the challenge of having available resources to refer and meet the psychosocial and physical needs of their patients. Widely used tools such as the NCCN Distress Thermometer (DT; 2013) assess distress via a visual analog where patients indicate how much distress they have been experiencing in the past week on a scale from 0 – 10 with 10 indicating extreme distress. The DT also evaluates problem areas that can be common sources of distress in cancer patients such as practical (e.g., financial, transportation), family (e.g., fertility, partner/spousal concerns), emotional (e.g., anxiety, depression), spiritual/religious and physical (e.g., pain, fatigue) problems. Another brief instrument such as The Patient Health Questionnaire-2 (PHQ-2) is a commonly used depression screener but does not address other emotional concerns such as anxiety, or physical or practical concerns. Nonetheless, work evaluating the efficacy, utility and clinical impact of screening programs remains limited.

In the first randomized clinical trial to evaluate distress screening outcomes, Carlson and colleagues (2010) randomized 1,134 patients with breast or lung cancer into one of three conditions: Minimal Screening—NCCN Distress Thermometer only; Full Screening—Distress Thermometer plus a Problem Checklist plus a Personalized Report; or Screening plus Triage for psychosocial care—Full Screening and phone referral to supportive oncology services. All screening was conducted online and showed that participants randomized to the triage condition showed significantly lower distress at a 3-month follow-up relative to minimal screening. Studies have also shown that systematic distress screening in oncology settings improves documentation of not only distress but also practical needs, and facilitates referrals to supportive oncology (Zebrack et al., 2015). Distress screening has also been associated with reducing patients’ unmet needs, particularly specific to patient education and communication with the medical team. Notably, as one would expect, these favorable outcomes are observed only if a triage plan is in place (Carlson et al., 2010; 2012). While

promising, much work is needed to establish optimal models of distress screening and documenting the impact of such programs not only on patient reported outcomes (PROs), but also on quality of care metrics and downstream cost savings to medical institutions.

Can Brief Be Clinically Valid?

The single-item NCCN Distress Thermometer (DT) allows patients to rate on a scale from 0–10 how distressed they are, and also identify sources of distress. The DT is brief and very easy to administer but its psychometric properties suggest that it is not always sufficient to effectively identify patients experiencing elevated depression and/or anxiety. Butt and colleagues (2008) showed that even increasing the DT cutoff from a 4 to a 5, the sensitivity and specificity of the DT relative to the HADS was less than optimal. The sensitivity, or true positive rate for anxiety and depression were .85 and .63, respectively. Similarly, specificity for anxiety and depression or the true negative rates were relatively poor, especially for depression (.78 for anxiety and .69 for depression). In contrast other instruments appear to be more precise measures, particularly for identifying depression. In Wagner's and colleagues (2016) study of patients enrolled in RTOG 0841 who were about to undergo radiotherapy, participants completed four clinic-based depression screening questionnaires: The Patient Health Questionnaire-9 Item (PHQ-9); two depression items from the PHQ-9 (PHQ-2); The Hopkins Symptom Checklist (HSCL-25) and the single-item National Comprehensive Cancer Network (NCCN) Distress Thermometer. About 16% of patients screened positive to depression in any of the four instruments. Although these rates appear somewhat low for oncology samples, they are consistent with prior work by Walker et al. (2013). Patients who screened positive for depression were then contacted by phone by a clinical psychologist and administered the Structured Clinical Interview for DSM-IV Disorders (SCID) Mood Disorder modules—a state of the art clinical diagnostic instrument for depression and other mental health disorders. The SCID administration found that 20.2% of patients meeting PHQ-2 thresholds met criteria for a mood or adjustment disorder. Results also showed that the PHQ-2 performed as well as the PHQ-9 and better than the DT supporting the utility of a brief, 2-item questionnaire. The PHQ-2 screener was a better screening measure than the commonly used National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT; 2013) insofar it accurately identified patients who were at risk for a depressive disorder. However, it should be noted that the NCCN DT, unlike the PHQ-2, was not specifically designed to screen for depression. Nonetheless, that a brief and valid 2-item depression screening instrument can be efficiently and effectively administered in an outpatient oncology setting is timely and of significance as cancer centers work to develop and implement distress screening protocols that include assessment of depressive symptoms to meet accreditation standards.

There are several important implications of Wagner's et al. (2016) work. *First*, oncology patients can be effectively engaged to undergo distress screening in clinic-based settings with brief screening tools. *Second*, validation analyses showed that a brief, 2-item measure, accurately identified patients experiencing clinical depression who are likely at greater risk for compromises in multiple facets for quality of life. Further, a 2-item measure performs better than a 1-item screen, and equivalent to a 9-item questionnaire. *Third*, this study suggests that CoC distress screening standards can be successfully met by utilizing brief

distress screening tools with minimal disruption to clinic workflows and patient care. Despite these implications, and the validity and efficiency of the screening tools, much work remains to be conducted to evaluate whether psychosocial interventions that are guided by these screening results can meaningfully impact PROs. Furthermore, it should be noted that there were several limitations in this work including a primarily female, non-Hispanic white, breast cancer sample that limits the generalizability of the findings. Despite these limitations, Wagner et al. (2016) provides good evidence that a brief 2-item screener for depression can successfully identify patients at risk of a depressive disorder. Nonetheless, given the complex and multidimensional nature of distress experiences and symptom burden (e.g., fatigue, pain) in oncology patients, one must ask how can we effectively measure other clinically meaningful PROs?

Brief, Precise and Valid Assessment of Multiple PROs

The Patient Reported Outcomes Measurement Information System® (PROMIS®; 2010) was created and supported by the NIH Common Fund to evaluate patients' self-reported health across various health conditions. PROMIS provides a brief, standardized and precise approach to measure various health domains. Several of these domains such as the mental health domains of Anxiety and Depression, as well as the physical health domains of Pain Intensity, Fatigue and Physical Function are particularly salient for oncology settings and evaluating distress and have shown excellent psychometric properties and feasible administration in cancer populations (PROMIS Measure Development & Research, 2016). By combining measurement science and computer technology, PROMIS has developed computer adaptive tests (CATs) that can efficiently assess symptom domains with as few as four items per symptom (Choi et al., 2010). PROMIS CATs provide T scores that represent a standardized score based on a mean of 50 and a standard deviation of 10 which is based on responses to the same questions in the US general population. By standardizing PROMIS scores across various symptom domains, investigators are able to establish a common metric that allows comparison to a reference population of interest. In a study by Cella and colleagues (2014), 22 multidisciplinary experts who had worked in oncology settings for three or more years and had expertise in treating anxiety, depression, pain, fatigue and physical function, participated in an all day workshop to evaluate the validity of PROMIS item banks based on their clinical expert judgment. PROMIS item bank data was collected on 840 oncology patients and converted to T scores. When PROMIS T scores were paired against clinician severity ratings for the participants, severity rankings made by the clinician consensus perfectly matched their associated PROMIS T scores. This suggested that PROMIS T score thresholds effectively differentiated levels of symptom severity for pain interference, fatigue, anxiety, and depression and thus supported the validity of the PROMIS symptom measures in deriving clinically relevant symptom severity levels. Therefore, using item response theory (IRT), PROMIS CATs provide a brief (about 4 items per domain to reach acceptable standard measurement error) and valid clinic- and computer-based approach at evaluating multiple dimensions of distress. Successful PROMIS CAT-based distress screening models via patient portals and in-clinic encounters are now in place across various oncology clinics and via electronic health records (EHR) patient portals.

Integration of PROs Screening into EHRs and Clinical Workflows— Technology Matters

As systematic distress screening and provision of identified psychosocial needs become the standard of care in oncology settings, there have been strong efforts to integrate screening tools into EHRs to facilitate administration and triaging of patients who report elevated distress. Several cancer centers across the US have incorporated eHealth and EHR based distress screening solutions for their oncology patients that are based within patient portals and/or EHR platforms with real-time assessment, scoring and triaging. One successful example of EHR integration is the Lurie Screening Initiative of the Robert H. Lurie Comprehensive Cancer Center of Northwestern University (Wagner et al., 2015; Pearman et al., 2015). The Lurie Screening Initiative addresses and surpasses the requirements of the CoC standard for psychosocial screening and referral to psychosocial care. Our Cancer Survivorship Institute, and the Cancer Control and Survivorship Research and Supportive Oncology programs have joined efforts to develop and implement PRO symptom assessments using PROMIS CAT measures. The Lurie Screening Initiative allows patients to complete brief online assessments of their fatigue, pain, physical function, depression, anxiety, as well as psychosocial and practical needs (e.g., transportation, informational needs, insurance, childcare, etc.). Patients can also request information about their diagnosis and treatment, or nutritional information from a dietician. Patients complete the screening via Northwestern Medicine's® *MyChart*, the EHR patient communication portal, or at our clinics. *MyChart* assessments occur 72 hours prior to a visit with their medical team but occur only once over a 30-day period to minimize patient burden. Patient results immediately populate their electronic health records and any severe symptoms trigger notifications to providers via the EHR inbox who can then make necessary referrals to supportive oncology (e.g., for elevated anxiety, practical concerns) or other members of the medical care team (e.g., nursing for elevated pain or fatigue), and care decisions in real time. All alerts are addressed within a 72-hour period, even if the patient misses their appointment. All PROMIS T scores and items per domain assessed, as well as needs identified, are recorded in the EHR. Clinically elevated PROMIS scores on pain, fatigue or physical function are flagged and sent to the treating oncologist and nursing pool, while elevated scores on depression and anxiety are sent to social work providers for triaging. All scores, along with alerts and endorsed practical concerns are available to the treatment teams via the EHR portal. This seamless integration of a screening platform that is integrated into a patient portal with real time population and messaging in our EHR streamlines the screening process. In addition to promoting high-quality cancer care, the Lurie Screening Initiative allows investigators to study how regular symptom assessments and systematic follow-up impact patient care and health outcomes. Our group is currently evaluating how systematic and comprehensive distress screening that also includes attention to PROs such as pain and fatigue, and referrals to various relevant services such as supportive oncology, palliative care, psychiatry, etc. prospectively impact health related quality of life, healthcare system utilization (e.g., downstream referrals & revenue, unnecessary ER visits, readmissions), system costs, and survival as part of our cancer care delivery research initiatives. Recent work in this area by other investigators (Basch et al., 2016) is promising and has shown that weekly tablet-based monitoring of PROs among patients undergoing chemotherapy, relative

to clinician-based monitoring only, was associated with significantly greater improvements in health related quality of life, lower ER visits or hospitalizations, better treatment adherence and greater survival.

In summary, with new CoC standards for accreditation in place, the calls by the IOM to fully integrate psychosocial care into oncology practice are brought closer to being implemented. These new standards of care have raised greater awareness of available instruments, their validity and clinical utility, and implementation processes that are in place. This work by Wagner and colleagues (2016) lends support to the utility of a brief, clinic-based questionnaire in identifying patients at risk for depression. Given the multiple challenges faced across the cancer care continuum, we recommend that multidimensional approaches that extend beyond assessment of depression and anxiety, and consider physical symptoms and practical concerns, be considered as part of systematic psychosocial screening in oncology practice. Computer-based and EHR-integrated PROMIS CATs offer a brief, efficient and precise approach to validly capture patient experiences and improve patient care.

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