Implementing Oncology Distress Screening in a Large Academic Health System

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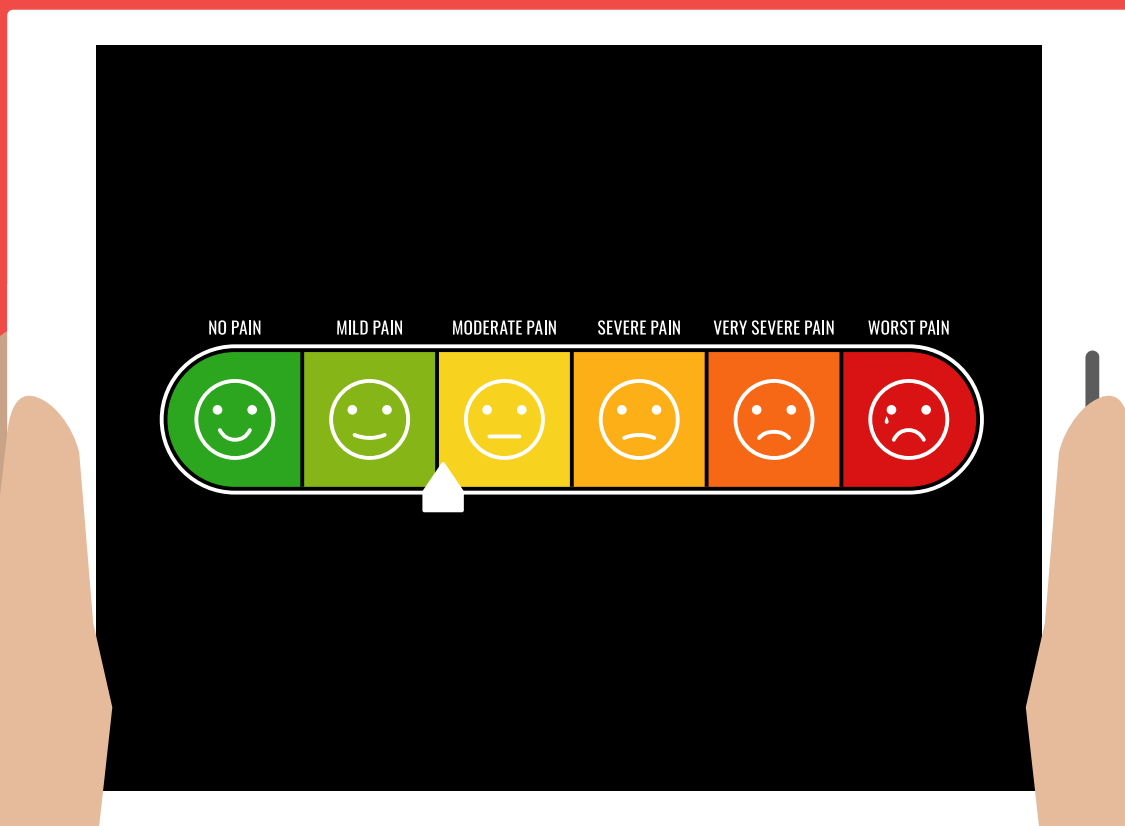
Distress is a common experience in people with cancer and is recognized by the psychosocial oncology field as an important experience to explore with patients. Patients with cancer in general have twice the risk of experiencing depression and anxiety than the general population.[1] Identified as the sixth vital sign,[2] distress screening is now a required component of cancer care thanks to initiatives and accreditation requirements from the National Comprehensive Cancer Network (NCCN), the National Academy of Medicine (formerly the Institute of Medicine), the American College of Surgeons Commission on Cancer (CoC), and the American Society of Clinical Oncology (ASCO). NCCN and the CoC continue to update guidelines for distress management[3,4]; however, these guidelines offer sweeping standards of care that are broadly developed and therefore, it is left up to the healthcare team to define the exact and appropriate method and tool to use, as well as intervals for screening based on clinic flow, staffing, and other resource- and patient-specific needs. Like other institutions seeking to meet both CoC requirements and the ASCO's Quality Oncology Practice Initiative Core Module measures, the University of Colorado Cancer Center looked to implement distress screening efficiently and in the most meaningful and useful way for patient care.[5]

In 2012 interested and pertinent parties at the University of Colorado Cancer Center created a distress screening working group that began to formally strategize and discuss distress screening in the oncology service line. The working group soon realized that discussions and decisions regarding distress screening needed to happen at the larger health system level, across the oncology service line, and throughout the largest health system in Colorado.

> Oncology distress screening workflow has evolved over time and has varied based on clinic and/or location…different professions and/or staff might be part of the distress screening process dependent on each clinic's established workflow.

Step 1: Developing a Screening Tool

The distress screening working group first focused on picking the best tool for screening for distress. Though the NCCN distress thermometer and problem list is a commonly used measure, the team decided to alter the NCCN measure to better understand the distress rating score in relation to the problems that people with cancer are experiencing.[6] Subsequently, the working group created a modified measure with four domains of concern. This concerns-based distress screener has evolved over time.

The original instructions of the concerns-based distress screener form were twofold. First, patients were asked to check boxes next to any items that caused them distress. The 23 potential distress items were grouped into four areas of concern: emotional, health, social, and practical. The individual items that the patient can "check" as causes of distress were as follows:

1. *Emotional Concerns.* Worry/nervousness, sadness/depression, grief/loss, anger, body image, addiction, and other areas of concern (open-ended)
2. *Health Concerns.* Weight concerns, difficulty eating, loss of appetite, nausea, fatigue, difficulty sleeping, sexual health and intimacy, and other areas of concern (open-ended)
3. *Social Concerns.* Relating with spouse/partner, relating with children, relating with family, relating with friends, talking with healthcare team, and other areas of concern (open-ended)
4. *Practical Concerns.* Housing, bills/money issues, insurance, transportation, information/resources, and other areas of concern (open-ended).

Second, patients were asked to circle the number on each scale that shows how much distress they have had in the past week. For each area of concern (emotional, health, social, and practical), there was a 0-10 Likert scale ranging from *no distress* (0) to *extreme distress* (10). The statement above each Likert scale specifies the area of concern the patient should rank: "emotional concerns," "health concerns," "social concerns," and "practical concerns."

Several years into this process, a second iteration of the tool added two additional steps. First, patients were asked whether they wanted to complete the form: Step 1, "I would like to complete this form." A "yes" response moved them forward in responding, whereas a "no" response indicated they were provided with the screener but declined. Following the same original instructions as before (now Step 2 and 3), a fourth step was added to the distress screen. Patients were asked whether they wanted to be contacted by support services, "I would like to be contacted by support services staff," followed by the ability to respond "yes" or "no."

In 2017, after receiving feedback from patients and process improvement events, the distress screening working group made additional changes to the form. This included changing the name from the original "How are you doing?" to "Common Cancer Concerns." The goals of the name change were twofold: (1) to normalize the concerns that people have and (2) to try to minimize the number of non-cancer patients receiving or completing the distress screener. At this time the team also decided to remove the question for patients to decline or opt out of filling out the screener (patients could still opt out, but we were no longer prompting them to) and we removed the option of being contacted by support services. The word *spirituality* was added to the social concerns quadrant as an item that the patient can "check" as an area of concern, bringing the total number of potential distress items to 24.

Step 2: Developing a Distress Screening Policy
Following small-group committees' work throughout the health system, the initial Oncology Distress Screening Policy was formally put into place for the health system in 2015. The policy included many details on the specific workflow steps to be taken for screening patients. It included paging the oncology social worker for distress screen scores of eight or higher in any of the four quadrants and only if the patient indicated that he or she also wanted to be contacted by an oncology social worker. This policy noted that social workers would be contacted for distress screen scores of seven or below (created as an arbitrary cutoff) through an in-basket message in the electronic health record (EHR).

The policy was updated in 2018 after careful consideration and acknowledgement of the great variations in workflow at each of the six hospitals in the health system treating patients with cancer. It was determined that the original policy was too specific in the procedural details and that it would be better to have a general system-wide policy and then develop hospital-dependent procedures that offer greater detail into the specifics of the workflow for that location and/or clinic.

Step 3: Developing a Distress Screening Workflow
Oncology distress screening workflow has evolved over time and has varied based on clinic and/or location. It quickly became clear to the distress screening working group that different professions and/or staff might be part of the distress screening process dependent on each clinic's established workflow. To meet the minimum of all of the standards, the working group determined that the most efficient way would be to capture patients at the new patient visit (NPV). Utilizing this visit was deemed appropriate because it is a seminal appointment and easily identified in the EHR.

Ideally, the distress screening working group would like to give the distress screen at the second visit based on two factors: (1) the high anxiety experienced by patients during the initial meeting with the physician, which usually decreases after this initial meeting, and (2) the high number of second opinion patients seen at the University of Colorado Cancer Center who do not return for care. The distress screening working group agreed that it would also like distress screening to happen at other seminal visits (e.g., start of chemotherapy, end of chemotherapy, start of radiation, end of radiation) but struggled with how to allow the front desk to easily identify the correct patients to screen with those criteria. In the end, due to the size of the healthcare system and patient volumes, as well as Epic hard stops, the team ultimately determined that the best course for initial distress screening was to utilize the NPV.

Utilizing the appointment coding of "NPV" has some drawbacks. First, some non-cancer patients are seen at our clinics. Therefore, we know that some non-cancer patients are given our distress screener, even after we changed the name to "Common Cancer Concerns." Unfortunately, although this happened rarely, it has caused several episodes of confusion for non-cancer patients suddenly shocked by getting a questionnaire about cancer. We are working to remedy the system so that we no longer screen non-cancer patients. Second, many of our patients have more than one NPV visit in our cancer center. For instance, they will meet with a medical oncologist, a surgical oncologist, and a radiation oncologist. Currently at each NPV patients are given the distress screen questionnaire. Though this is not a bad thing in and of itself, there is currently no way to limit the time between

when patients are given the distress screen, so if they see the medical oncologist and surgical oncologist in the same week they are given the distress screener twice in a short time period.

Eventually, the working group determined that it was important to create a written process that outlines the procedural steps required for the distress screening. Accordingly, in 2017 the University of Colorado Hospital (Metro Denver) created an Oncology Distress Screening Process. This written process breaks down the steps that must happen at each point in the distress screening process for success, including who is responsible for each step and when, if needed, the social worker becomes involved.

Step 4: Modifying the EHR

Our institution uses Epic as our electronic health record. The initial distress screening Epic build request included creating a SMART FORM in which to enter the information the patient completed. Subsequent additional Epic builds have created automatic in-basket messages to the distress screening in-basket work queue based on the cutoff scores determined by the distress screening team. Over time the SMART FORM has been modified. It initially included the questions "I would like to complete this form" and "I would like to be contacted by support services staff," and eventually those questions were removed with the tool modifications in 2017 and the SMART FORM was updated to add the "spirituality" concern. Additional EHR modifications also include not allowing more than one number to be entered in the SMART FORM per quadrant.

The distress screening build in Epic includes recording the distress screen in a SMART FORM in the rooming portion of the EHR. Oncology social workers document a note in the patient's EHR after consulting the patient and "complete" the alerted in-basket message (and Epic action), signaling a closing of the loop.

Step 5: Staffing and Scripting

Based on staffing when the distress screening working group formed, it was determined that oncology social workers would provide the intervention for positive distress screens. Although oncology social workers were represented on the distress screening working group, buy-in about workflow, documentation, and the overall importance of distress screening has not been consistent with every oncology social worker. No additional resources were provided to start distress screening—it was assumed to be an important, integral, and required part of what we do for our patients.

Front-line clinic staff, including front desk check-in staff, medical assistants, and nurses, were naturally considered important people to engage and utilize in the distress screening process. Initial conversations started with clinic managers and leaders to get their buy-in and support for the process. They provided feedback on what specific steps would work best, limitations of various staff job descriptions, and EHR access and setup by job. Given the large and complex nature of our cancer center, it was determined that the best course for engaging and educating the staff who would be involved in distress screening was to use the

clinic oncology social workers to engage their clinic staff. Accordingly, oncology social workers met with staff members as teams to discuss and train in distress screening, as well as the process and procedure they were to follow, including helping people understand the reasons behind distress screening. Over time a group of oncology social workers created a presentation that has subsequently been modified and presented in its various iterations. Regular and ongoing quarterly emails are also sent to help educate and engage the staff about distress screening.

> Physician buy-in has been a constant struggle in this process. With the historical and current tool, physicians are not involved in the specific distress screening process or steps.

Though specific scripting around distress screening was not originally available for staff, over time it became clear that our staff needed (and requested) such scripting. For the staff who give the distress screener to the patient at check-in, this scripting includes describing the purpose of the distress screening tool and instructions on how to complete the tool. Scripting also exists for the person reviewing the tool in the room with the patient, so that the patient is aware of the next steps, depending on his or her score.

Physician buy-in has been a constant struggle in this process. With the historical and current tool, physicians are not involved in the specific distress screening process or steps. Many physicians are aware when one of their patients has a high distress score due to the presence of the oncology social worker after receiving a page. Best practice would involve the physician in this process, but the specifics of how and when to do that are still a question. One idea from a physician was to have the distress scores automatically put into the patient's note. To allow this to happen, the designated health professional reviewing the distress screener with the patient and entering it into the EHR would need to enter it in real time. We have struggled to have the distress score entered at point of service and, many times, unfortunately, found stacks of unentered distress screens at the end of the day.

Step 6: Assigning Leadership

One struggle of implementing distress screening has been lack of leadership for the project. The initial distress screening working group was comprised of a diverse group of staff with various stakes or interests in the project with no leadership assigned or determined. Though both were involved in the distress screening team in 2016 (implementation and process), the two authors of this article received leadership positions that allowed them to take charge of oncology distress screening. Through active lead-

ership we have accomplished more and moved our distress screening program forward. Changes to the screener, policy, and procedures have been under our leadership. We have helped standardize the implementation of the distress screening tool, its policy, and procedures across the healthcare system. We have worked to screen every new patient for distress to meet CoC guidelines. We have created scoring and documentation processes and an appropriate referral system for those who have a positive screen. By utilizing the EHR, we have also created the ability to track and collect data to measure outcomes.

Barriers

Though the University of Colorado Cancer Center has had many successes in distress screening, implementation has not been without obstacles. Obvious difficulties include implementing a standard process in a large healthcare system, connecting and building within the EHR, and championing and connecting to staff through patient care. Below is a list of the barriers faced during distress screening implementation.

Process and Procedure Barriers
- No designated clinical leadership.
- Lack of consistency of policies and/or procedures across the healthcare system.
- Determining responsibility for inputting the distress scores.
- Timing of screening; that is, screening when it is meaningful and practical given how information is stored and/or viewable in the EHR by certain staff.
- Timing of distress screening tool (currently given at NPVs, which we believe may skew scores because of high health distress before talking with providers and oncology social workers, noting that patients' distress is decreased within minutes and/or hours after meeting with a physician).
- Lack of consistency in the assessment and documentation conducted by oncology social workers.
- Accurate data collection of new patients with cancer versus non-cancer patients.
- Variable communication across the healthcare system regarding distress screening changes.
- Issues with Epic and overall data collection.

Resource Barriers
- Limited staff to cover oncology distress screening needs.
- Continued use of paper screens.
- Use of tablets and/or iPads would be the preferred way to have patients fill out screens, but we do not have integration between patient-facing versions of those and our EHR.

Staff-Related Barriers
- Limited buy-in of clinical staff due to frustration of this additional task.
- Limited and varied knowledge and skills of front desk staff to explain the use of the distress screen to patients.
- Non-compliance with regards to response times of social work staff for contacting patients.

Patient-Related Barriers
- Declining to be screened. This was higher when we specifically asked the patients in the first question of the screen whether they wanted to complete the form.
- Not understanding the purpose of the form when they receive it in a packet. This could happen because the form was not explained to them or they did not hear the instructions (possibly due to focusing on other things during the NPV).
- Lack of understanding of what the screener was and our process.
- Disconnect between completing the form and receiving contact from an oncology social worker if they had a high score.

EHR Barriers
- The desire to have an electronic screen, yet not having the technology available to connect a patient-facing questionnaire with our EHR. Subsequently we are left with paper screens that can be lost, forgotten, or have their numbers incorrectly copied into the EHR.
- Epic lags in generating in-basket messages or in-basket messages are unavailable due to upgrades and updates.
- Functionality is confusing and not supported by Epic team, and a disconnect exists between the Epic and clinical teams, with lack of oversight.
- Multiple distress screening scores under one category of concern. Epic allowed two scores to be entered when only one should have been allowed. Subsequently it was impossible to determine the correct score for certain quadrants when this happened. This has since been rectified.

Data Collection and Analysis Barriers
- Difficulty in identifying and separating non-oncology vs. oncology patients.
- Need to develop a method to track actual social work referrals resulting from the distress screening.
- Identifying and implementing best practice for pivotal visits.
- Relating psychosocial intervention to improved or declining scores is a subjective, manual process. Plus, we currently only consistently screen patients one time, so many patients do not have a second distress screening time to compare for improving or declining scores. Manual data analytics are time-consuming, complex, and difficult to quantify.

Resolution of Barriers

Of the barriers listed above, we have been able to successfully overcome some, whereas others remain. Below we share some of our strategies for eliminating these barriers.

Resolution of Process and Procedure Barriers
- Follow Quality Oncology Practice Initiative and CoC guidelines.
- Establish clinical leadership.
- Develop policy and workflow.
- Design and implement staff training.
- Host regular and ongoing staff training.

- Have system-wide regular meetings to identify barriers and fine-tune processes.

Resolution of Resource Barriers
- Data reports through Epic demonstrated the need for additional oncology social work staff.
- Electronic distress screening with patient-facing tablets needs to demonstrate efficiency and requires capital funds to initially acquire tablets and ongoing budgetary funds for maintenance.
- Correlating psychosocial intervention to improved or declining scores will require additional meetings with Epic team and clinical leadership.

Resolution of Staff-Related Barriers
- Implemented a mandatory staff training and education that included scripting, visualization exercise, history of distress screening, workflow, and open discussion that identified barriers.
- Clinical leadership put in place to oversee staff response times, implementation, process, and policy.
- Ongoing communication with staff about distress screening policy and process and open request for questions, concerns, and discussions about barriers.

Resolution of Patient-Related Barriers
- Removed "Declined" from the tool.
- Scripting for staff to explain the purpose of the tool and how to complete the tool when handing it to patients.
- Ongoing examination of how to change *when* the distress screen is given to patients.

Resolution of EHR Barriers
- Developed essential close working relationship with Epic analysts throughout the healthcare system.
- Successfully created scoring system, Epic interface, and in-basket messages to manage screen scores.
- Created resource reports and referrals.
- Conducted ongoing meetings with Epic team to discuss and resolve barriers.

Resolution of Data Collection Barriers
- Staff training and education is necessary to identify non-cancer patients vs. patients with cancer. Identifying patients with a diagnosis of cancer vs. no cancer diagnosis at the front desk (which is when our patients are given the distress screening tool) is not possible given the limited personal patient information available to the check-in staff. This is an ongoing area to try to improve identification of only appropriate patients to receive the distress screen.
- Identification and implementation of pivotal visits is a continued discussion.
- Correlating psychosocial intervention with outcomes continues to be a topic of discussion with no current resolutions.

Next Steps

Though the University of Colorado Hospital has come a long way in developing and evolving the distress screening process, we know that there is more evaluation and refinement necessary for improvement over time. Our distress screening tool satisfies the requirements of being brief and normalizing these concerns for our patients and is easy to administer, score, and interpret. Our tool lacks empirical data for a specific cutoff value and specific validity and reliability, so we are currently working on validating the tool. We also need to build an electronic administration and referral system interface through Epic that can function with our EHR to decrease patient and staff burden and errors or oversights. Ongoing assessment of fidelity of the process and script is an important and ongoing part of distress screening; if the staff are not invested and properly trained, the program cannot succeed. ◲

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