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Diving deeper into distress screening implementation in oncology care

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Abstract

Background: Responding to calls for additional research that identifies effective distress screening (DS) processes, including referral practices subsequent to screening and receipt of recommended care, we engaged in qualitative research as part of a larger (mixed methods) study of distress screening. This qualitative inquiry of oncology professionals across different facilities in the United states examined routine DS implementation, facilitators and challenges staff encounter with DS processes, and staff members' perceived value of DS.

Participants and Methods: We conducted key informant interviews and focus groups with staff in 4 Commission on Cancer (CoC)-accredited oncology facilities (a total of 18 participants) to understand implementation of routine DS within oncology care. We used a rigorous data analysis design, including inductive and deductive approaches.

Results: Respondents believe DS enhances patient care and described ways to improve DS processes, including administering DS at multiple points throughout oncology care, using patient-administrated DS methods, and enhancing electronic health records infrastructure to better collect, record, and retrieve DS data. Respondents also identified the need for additional psychosocial staff at their facilities to provide timely psychosocial care.

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Disclosure statement
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Conclusions: Results reinforce the value of DS in cancer care, including the importance of follow-up to screening with psychosocial oncology providers. Understanding and resolving the barriers and facilitators to implementing DS are important to ensure appropriate psychosocial care for people with cancer. Insights from oncology staff may be used to enhance the quality of DS and subsequent psychosocial care, which is an essential component of oncology care.

Keywords

Cancer; cancer survivors; distress; distress management; distress screening; oncology; psychosocial; survivorship

Background and purpose

Distress is defined as an unpleasant psychological, social, emotional, and/or spiritual experience that interferes with the ability to effectively cope with a cancer diagnosis, symptoms, or treatment side-effects.[1] While approximately one-third of cancer survivors experience distress at some point during cancer treatment,[2-4] prevalence of distress varies by cancer type,[3,4] and poor prognois has been correlated with distress.[2,3,5,6] Lung and ovarian cancer survivors, in particular, have been shown to experience high levels of distress.[7-14]

Since 2015, the American College of Surgeons' Commission on Cancer (CoC) has required routine distress screening (DS) of cancer patients treated in their accredited facilities.[15] All cancer patients must be screened for distress a minimum of one time at a "pivotal" medical visit (e.g. during diagnosis, beginning and ending treatments, recurrence or progression) determined by the program, and preference should be given to visits at times of greatest risk for distress.[15] DS provides an opportunity to identify patients with concerns who may be unlikely to discuss these issues unless asked.[16,17] Early identification of distress and receipt of psychosocial support has been demonstrated to enhance quality of life for the survivor,[18,19] and addressing distress may improve cancer outcomes.[20] As well, oncology program adherence to a full DS protocol (which includes distress management) has the potential to decrease emergency room visits and patient hospitalizations.[21] Routine DS is merely a first step; addressing needs of patients experiencing distress is essential.[1,2,15,22,23]

Implementing DS in oncology settings requires thoughtful planning, the use of a scientifically valid tool[24,25], and contextual factors such as determining the timing of screening (i.e. the pivotal visit), training staff to incorporate DS into their routine practices, and having enough psychosocial staff to address the distress.[26-28] Studies of DS implementation have highlighted difficulties in screening for distress in certain populations[29,30] and that racial disparities in screening for and managing distress exist.[29,31-34]

A systematic review[27] highlighted the need for additional research to identify effective DS processes, including referral practices subsequent to screening and receipt of recommended care.[27,35] The current study sought to understand DS processes within oncology facilities to inform high-quality psychosocial care. We present results from a qualitative inquiry with oncology staff to explore experiences providing routine DS and follow-up, including their perceived value of DS, facilitators and challenges they encounter within DS processes, and suggestions for improvements.

Methods

Participants

A detailed description of study recruitment methods has been published previously.[36] Briefly, we recruited and enrolled 21 CoC-accredited healthcare facilities between August 2018 to May 2020 for a larger, mixed methods study of DS implementation and follow-up. For this qualitative study, we selected a subset of four facilities, stratified by geographic region, urbanicity, and facility type. Key informants were identified by points of contact from each of the four facilities sites, since they were individuals who served as senior administrators and were knowledgeable about the facility's DS protocols.

We (NM) conducted each key informant interview (KII) with a staff person who oversaw the administration and implementation of the DS program (e.g. Cancer Committee Chair, Oncology Director) in the participating facility. We then asked the key informant to help identify staff who had hands-on experience in the DS process (e.g. nurse, social worker or other mental health professional, nurse navigator, physician's assistant) for inclusion in the focus groups (FGs).

Data collection

For each of the four facilities, we first conducted an hour-long KII, after which we conducted a 1.5-h FG with 2–5 staff from the same facility. We used the qualitative data from the KII to inform tailored probes, as well as specific information from our previous DS publication,[34] to elicit more nuanced information from each FG. All KIIs and FGs were conducted over the phone by an expert interviewer (NM) and a note-taker (DN) between January 2019 and August 2020. Participants consented verbally prior to the start of the interview. KIIs and FGs were recorded, transcribed, and de-identified. The de-identified transcripts, recordings, and notes were stored on a secure server. In appreciation for their time, a small, token gift card was provided to participants. This study was reviewed by CDC's Human Research Protections Office and was approved for reliance on external Institutional Review Board (IRB) approval (Westat IRB approval #6282.07). Additional IRB approvals were obtained internally at each of the participating facilities. This study was also reviewed and approved by the Federal Government's Office of Management and Budget (OMB#0920-1270).

KII and FG questions explored the following domains: processes and protocols for DS; referrals to follow-up care; DS implementation challenges, facilitators, and suggestions for improvements; procedural issues with DS documentation and data reporting; and respondents' perceptions of the impact of DS on patients and staff. See Table 1 for sample questions from each domain.

Data analysis

We adhered to rigorous methods for qualitative analysis.[37] Four of the manuscript authors (EAR, JEB, SS, and KS), with combined expertise in social work, sociology/anthropology, qualitative research, communications, public health, and oncology facilities, read all KII and FG transcripts and developed preliminary codes (i.e. words or phrases that capture the meaning of transcript passages), using both inductive and deductive thematic analysis.[38,39] These authors then drafted a qualitative codebook, and met frequently to discuss recurring concepts and resolve differences.[38] We refined the codebook through consensus, adding inclusion and exclusion criteria and exemplar quotes. We then coded all transcripts (in MS Excel, Version 2208) using the final codebook. Each of the four authors on the analysis team was randomly assigned as a primary coder for several transcripts and secondary coder for additional transcripts, resulting in having at least two different coders for every transcript. The analysis team met weekly to discuss coded transcript data, identify themes, and resolve differences through consensus. We then organized codes into broader themes. Throughout the analysis, we maintained an audit trail to document all analytical decisions.

Findings

Professional staff interviewed in FGs had 2.5–20 years of experience working with cancer patients. Across KIIs and FGs, there were 18 unique respondents. See Tables 2 and 3 for more details about respondent and facility characteristics, respectively.

The following four themes relevant to DS arose from the data: (1) helpfulness to patients and staff, (2) process facilitators, (3) issues related to DS subsequent to the pivotal visit, and (4) suggested process and capacity improvements.

Helpfulness to patients and staff

We asked respondents for their perceptions about the impact of DS on patient care and on staff. Across facilities, staff described DS as being helpful to both patients and the care team. First, staff noted that routine DS normalizes psychosocial care (and any subsequent interventions needed for those who are distressed) as part of overall patient care. Since all patients get screened, patients do not feel singled out when approached to complete a DS, as this social worker describes:

> [It] gives the social worker a good reason to come in, because many people will be like, ‘Why do I need a social worker? Are you going to take my kids, or put me in a nursing home?’ So, they get to see that the social worker is a part of the team—an ally and not something to be distressed over.

Staff also stated that conducting DS is helpful to them because it can be hard to assess how a patient is coping by looking at them, as this nurse stated:

> It’s a quick tool to find out if the patient is having distress…sometimes you’re looking at that patient saying, ‘Oh they’re doing fine,’ and they’re actually falling apart. And it doesn’t matter [what their] socio-economic, support systems, etc. [are]. So, it is kind of a quick tool to get in there to find out the information and then intervene and help the patient.

Respondents also described DS as being helpful at identifying potential issues early, which can help decrease a patient's anxiety. A social worker described DS as a starting point or roadmap for anticipating future needs:

> I was thinking roadmap. It just sort of gives me a little bit of vision or some direction on what…this patient [might] need, maybe [what] is going to come up for this patient. And that's something I try to do as a social worker in oncology: think ahead to, okay, what are they going to face next? And I think that DS helps me sort of, again, navigate, direct, assist that patient…I think then they feel like they really are in a cancer center supportive environment that's really looking out for them.

Additionally, staff described a positive outcome of DS at the facility-level as making patients' unmet needs (e.g. dietician consult, social work support/counseling needs) more apparent and helping inform the hiring of additional staff, as this nurse stated, "…I think using the distress scale has given us that pull, proving that [social workers] are needed. [Distress is] actually documented, and we have examples to show that we could use those [social work] services. That's been helpful." DS also provided opportunities for staff to identify specific resource needs (e.g. transportation), that could be improved at a systems level because these data were collected systematically during DS.

Process facilitators

While DS and follow-up is a required CoC standard, we found implementation processes varied across facilities. Each facility, and sometimes each oncology service line within the same facility, determined the pivotal visit to administer DS. Still, respondents identified some common facilitators to DS processes.

Designated staff to track eligibility—Staff across several facilities described that having a dedicated staff member, other than the social worker, who determines which patients are eligible for DS on a particular day takes the burden off the psychosocial staff, as this respondent explained:

> We've moved away from the social worker who identifies the eligible patients for DS and have moved that to more of a managerial operations person…[who identifies]…patients who need to be given the screening tool…If a patient is moderate to severe, then [the EHR] is tagged for the provider with the recommendation that they make the social work consult.

Patient-administered DS—Several respondents indicated that having patients fill out the DS tool independently offered advantages over having staff administer the questions face-to-face. Respondents explained that patient-administration of DS is efficient and can allow patients more privacy compared with having a staff member ask them the questions, as this respondent explained, "It doesn't take a lot of time, and it's just a great way to address the patient's needs. They can fill it out on their own and they can be a little more honest about things like that." Also, patient-administered DS tools can be completed while the patient is in the waiting room, which provides the opportunity for a nurse or social worker to discuss the DS responses during their appointment.

Technology streamlines DS processes—

Respondents noted that when patients use technology, such as a tablet, to complete their DS, it reduces the human error that can occur during manual entry into the medical record. For example, one respondent stated:

> I think the…paper process that we have…creates an opportunity for human error…[when someone transfers from paper to] electronic…So, the [DS] tablet that the patient [self-administers]…takes away one of the gaps. Papers have an opportunity to be laid on a counter, and [nobody] get[s] back to them. And [with technology], that doesn't happen.

Additionally, respondents explained that electronic DS (e.g., using a tablet) facilitates direct entry of information into the EHR and supports triaging patients who need follow-up with a psychosocial provider. EHR-generated staff alerts, based on moderate to severe distress scores calculated in real time, facilitate follow-up, as this respondent described, "The tablet's really a key thing because…[the DS score is] entered into [the EHR] automatically, and the provider and the social worker get feedback right away. Technology…can really help move processes along, lessen barriers."

Triage requires verbal staff communication—

Notably, respondents indicated that staff communication helped ensure that patients who scored high on the distress tool are contacted by the social worker that same day. Even in facilities where the technology facilitates the DS workflow, staff administering the DS tool also call the social worker directly when a patient has a high distress score, as this social worker described:

> …something that is working is the communication [from the medical assistants and nurses] administering DS… notifying the social worker of the distress that day…The best practice [alert in the EHR] is not going to do you any good if [the patient is] already gone.

Issues related to DS subsequent to pivotal visit

All four facilities included in the qualitative arm of the study implemented DS beyond the minimum CoC standard and discussed topics directly related to subsequent screening beyond the pivotal visit, such as during care transitions or disease progression. Several respondents noted subsequent DS screens to be critical in understanding patient psychosocial well-being throughout treatment, as this nurse said, "It's good to do [DS] at various intervals, so you can really capture a point in time where they're really having distress."

Lack of protocols—

Despite the frequently mentioned importance of subsequent DS, respondents described gaps in workflows for implementation of screening after the pivotal visit. This lack of a clear protocol left clinical staff deciding on an ad hoc basis when and how to administer subsequent screening, which reportedly occurred when they thought screening would be most beneficial (e.g., during a change in treatment, transition to post-treatment life). This respondent succinctly summarized: "Technically, you don't have to do [DS] for the second time. It's only if they're coming in for bad news or something like that. And sometimes it's not using the paper. It's just going by how the patient reacts."

Inconsistent documentation—Documentation of subsequent DS is often inconsistent, and follow-up completion is difficult to track. One respondent mentioned the haphazard nature of documentation saying, “Yeah, I know our policy says that it will be done once, and it will be done at the first visit. But there can be patients that if I pull up their chart, they may have three or four distress screens done…” Respondents also noted that sometimes when a subsequent DS is completed informally through discussion rather than using a DS screening tool, for example, it might not be documented at all, and clinic staff responsible for follow-up must rely on hearing about the need for further assessment through “word of mouth.” Without consistent documentation protocols, staff have difficulty running DS-related reports to know if and when patients are receiving subsequent screening. Another respondent discussed the missed opportunity to track patient distress levels over the course of treatment, saying, “So, [we] don’t have a good way to find out if they were tens when they first started coming, or an eight when they started and a ten when they finished then, or a zero. We don’t really have a good way to see if what we did impacted their scores.”

Lack of infrastructure to administer—Across multiple facilities, several respondents noted that staff had trouble finding an appropriate time and space for subsequent DS when no clear process was in place. Staff described their discomfort handing patients a form during an obvious time of distress, such as “bad news from a scan.” Also, finding a quiet, private space to ask patients about their psychosocial well-being was sometimes awkward, as exemplified by this quote:

> I think the initial one [DS at pivotal visit] is easy because it’s their first visit, they’re already doing paperwork, so you give it to them anyway. It’s always the follow-up ones that are the ones that you have the hardest time trying to find the time to do. We have a huge infusion room…so a lot of that conversation [which should be private] could happen out [where everybody could] hear. So that’s one huge barrier.

Despite these operational challenges, respondents repeatedly underscored the importance of implementing subsequent DS, especially at critical points in the care continuum, such as care transitions or disease progression.

Suggested process and capacity improvements

Respondents suggested several process and protocol improvements to enhance the quality of psychosocial care, including increasing staff capacity, better tracking of DS and follow-up in the EHR, and improving the use of DS-related data.

Increasing staff capacity—Respondents from all facilities stated that they needed additional on-site psychosocial staff to ensure they were delivering high-quality psychosocial care to those patients who were identified as experiencing distress. This administrator had a specific suggestion:

> In an ideal world that wasn’t limited by resource dollars and personnel, we would have a pool of social workers that if the patient preferred to see the social worker when they are [in the clinic] for their appointment—[which is] the [patients’]

> preference over being called [on the phone]—that we would have the personnel to supply that service.

Staff capacity also relates to ensuring staff are aware of the array of existing resources available to patients, so they have the capacity to refer patients to them. A nurse navigator stated, “I worked for the hospital before I [became a navigator]. I didn’t realize we had a lot of financial assistance. I didn’t realize [other hospital resources] existed…There’s a lot that our community has, even, that not everyone knows about.” Relatedly, some respondents commented that while most concrete needs can be met with hospital or community resources, there is a need for increased availability of and access to mental health resources in the community to support patients who experience distress.

Better integration of DS and follow-up in the EHR—Several respondents described challenges with EHR software that does not offer data collection functionality tailored for DS. Staff had to work with their existing EHRs and continually develop the tools, templates, and modules needed to document DS and follow-up. An administrator noted challenges because their EHR “did not have [DS] built into it already. And trying to create the tools and the things that we needed, get them into [the EHR], and get them working the way we need is a continual process.”

Improved use of DS-related data—Respondents across facilities stated it was difficult, if not impossible, for them to use DS-related data to track patients’ psychosocial outcomes, due to documentation limitations. One respondent expressed, “If you could come up with a way to track them as far as [distress scores or things] that would be covered in the distress, somewhere [in the medical record] to determine if their distress has decreased with the supports that they have gotten.” Tracking patients’ distress levels, or other psychosocial issues, over time was a problem even for facilities where the DS process is built into their EHR, as this respondent explained:

> “We do have the screening tool built in, and the referral process is built into the computer system. While all of the downstream actions of the other team members are also documented, and any physician or any team member can see their notes right in the system, sometimes being able to look at it or view it as a continuous process [within the EHR] is what’s challenging.”

Data use problems also exist at the aggregate level. When staff at one facility was required to query aggregate DS data to report to their institutional cancer committees, they were not able to easily run reports; instead, they used “manual processes to try to keep track of all of that” because they were “having difficulty getting that kind of data” from the system. Staff at other facilities similarly mentioned using “spreadsheets” to keep track of DS and follow-up, despite having an EHR where DS-related data was documented.

Discussion

Our findings support a recently published framework[40] for planning the delivery of psychosocial oncology services that are responsive to DS that identified three principles for best practices: (1) psychosocial oncology should be considered a key component of oncology care; (2) resources, aims and scope of program determine the psychosocial services offered by a facility; and (3) cancer care facilities should deliver high-quality psychosocial care across all components of care.

Psychosocial oncology considered key component of oncology care.

Our results underscore that ensuring a facility has sufficient psychosocial staff (e.g. social workers, other mental health clinicians, patient navigators) to meet survivors' needs following a distress screen is essential. With enough psychosocial staff, patients who are experiencing high levels of distress can be seen by an oncology social worker, or other psychosocial provider, while they are receiving treatment, rather than receiving a phone call after they've left the facility.

Resources, aims and scope of the DS program determines the psychosocial services offered.

Several respondents described having personnel dedicated to overseeing the DS process to ensure that patients do not fall through the cracks. While this may work for a larger facility with sufficient resources and patient volume to warrant this staff member, smaller facilities may need to have different processes in place. Other aspects of DS, such as the timing of the pivotal visit or which cancer service lines administer DS may also correspond with the resources available at a given facility.

Respondents in this study stated there were no differences across patients with different types of cancer in DS processes. This differs from our previous results which found that across the 21 facilities in the larger study, DS rates for lung and ovarian cancer patients ranged from 6%-91%, indicating some facilities lacked DS protocols for lung and/or ovarian cancer service lines.[34] This discrepancy could be because respondents in the qualitative study may have been unaware of the protocols across all cancer service lines in their institution.

High-quality psychosocial care delivered across all components of care.

Our study highlights several critical issues related to this principle. First, our study uncovered a need to improve documentation of follow-up to DS. Data related to receipt of psychosocial assessment for patients experiencing distress and referral for further services, where appropriate, were difficult to find in the medical record in a linear fashion, making it hard to measure intervention efficacy. Similarly, all respondents described gaps in technology, protocols, and processes for administering DS after the pivotal visit and tracking DS scores and psychosocial outcomes over time. Without standard processes for DS at multiple points along a patient's care trajectory, these processes were haphazard and made it difficult to assess whether patients were getting services and resources to manage their distress. These gaps also make it difficult to assess whether DS and related psychosocial care are administered across all cancer care components. Also related to this third principle is improved DS-related reporting capacity from the EHR. Our study found gaps in data consistency, which could lead to missed opportunities for using data for population management, performance assessment, and increasing the number of psychosocial staff. Improved documentation of DS could lead to developing resources at the population level (aggregation of all individual patient DS) and to understanding DS-related disparities associated with patient demographics and/or cancer diagnosis[34] for achieving health equity.

Our results also highlight that respondents found DS useful to both oncology staff and patients. Oncology staff consistently reported that DS made it easier for them to discuss psychosocial concerns with patients. This is consistent with a Canadian study in which health care providers reported greater confidence with addressing and managing distress in their patients as a result of a provincial-wide project to standardize DS implementation.[41] Our findings also correspond with study results that found women with gynecologic cancer perceived DS as integral to their cancer care.[42] DS reassured the women that their psychosocial wellbeing was being considered, helped the women discuss psychosocial concerns with their treatment team, and connected them with needed services or emotional support.[42] Our findings also underscore the importance of connecting patients who are distressed with psychosocial services to ensure these patients receive quality psychosocial care.[28,43]

Limitations/strengths

A limitation of any qualitative work is that the results are not generalizable;[44,45] however, the aim of qualitative work is to provide a deeper understanding of the context and issues, not generalizable results. Our qualitative inquiry was limited to four facilities, due to the time and resources needed for facility recruitment. Despite this limitation, similar issues and somewhat consistent information was reported from the 18 respondents, representing various provider types and facilities. Finally, our results do not include patients' views on DS or their experiences working with psychosocial providers, since direct patient feedback was beyond the scope of this study. To mitigate limitations, we used the rigorous methods described previously, and several public health experts who were not directly involved in the study served as external auditors.[46]

Conclusions/implications for psychosocial providers

Results reinforce the value of DS in cancer care, including the importance of follow-up to screening with psychosocial oncology providers. Understanding and resolving the barriers and facilitators to implementing DS are important to ensure appropriate psychosocial care for people with cancer. Future clinical practice and research could evaluate tools that can be embedded into EHRs to track and document DS and management of distress, including results of psychosocial assessments and uptake of psychosocial services offered to cancer patients.

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Table 1.

Interview question domains and sample questions.

Domain	Sample questions and probes
Processes and protocols for DS	What are some organizational policies and practices at your healthcare facility relating to DS?
	Please describe the process for administering DS to patients at [HEALTHCARE FACILITY NAME].
	Probe: What is the “pivotal medical visit” during which the DS is typically administered?
Referrals and follow-up care	What are the different types of services available at [HEALTHCARE FACILITY NAME] for distressed patients?
	Probe: How are patients generally linked to these types of services (within and outside the facility)? Is there any follow-up of the patients to see if they accessed the services?
DS Implementation challenges, facilitators, and suggestions for improvement	What are some factors at [HEALTHCARE FACILITY NAME] that help or make it difficult to screen patients?
	Probe: Do you have any recommendations for improving screening, referral and follow-up care for distressed patients?
Procedural issues with DS documentation and data reporting	How is DS assessment, referral and/or follow-up documented?
	Probe: Are there regular reporting procedures for DS and their results (i.e. for your unit/healthcare facility)?
Perception of the impact of DS on patients and staff	Overall, how are the DS procedures working for the patients?
	Probe: Are there positive impacts of DS on patients at [HEALTHCARE FACILITY NAME]?
	Probe: Are there positive impacts of DS on patients at [HEALTHCARE FACILITY NAME]?
	Overall, are DS procures working for staff?
	Probe: Are there positive impacts of DS on providers at [HEALTHCARE FACILITY NAME]?
	Probe: Are there positive impacts of DS on providers at [HEALTHCARE FACILITY NAME]?

Table 2.

Key informant interview and focus groups respondent characteristics.

Respondent type (*n* = 18)	**Number of key informant interviewees**	**Number of focus group participants**
Oncology Director	1	
Director of Research	1	
Cancer Support Services Manager	1	
Nurse Manager	1	2
Nurse Navigator		1
Nurse[*]		6
Social Worker		4
Survivorship/Research Coordinator		1
Total	4	14

[*] Nurse category includes these titles/roles respondents identified themselves as: nurse, RN, oncology nurse, nurse practitioner.

Table 3.

Facility characteristics.

Facility types (CoC survey application record) (*n* = 4)	**Number of rural facilities**	**Number of urban facilities**
Comprehensive Community Cancer Program		1
Integrated Network Cancer Program		1
Community Cancer Program	2	
Total	2	2