Guiding Lay Navigation in Geriatric Patients With Cancer Using a Distress Assessment Tool

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Abstract

Background: There is growing interest in psychosocial care and evaluating distress in patients with cancer. As of 2015, the Commission on Cancer requires cancer centers to screen patients for distress, but the optimal approach to implementation remains unclear. **Methods:** We assessed the feasibility and impact of using distress assessments to frame lay navigator interactions with geriatric patients with cancer who were enrolled in navigation between January 1, 2014, and December 31, 2014. **Results:** Of the 5,121 patients enrolled in our lay patient navigation program, 4,520 (88%) completed at least one assessment using a standardized distress tool (DT). Navigators used the tool to structure both formal and informal distress assessments. Of all patients, 24% reported distress scores of 4 or greater and 5.5% reported distress scores of 8 or greater. The most common sources of distress at initial assessment were pain, balance/mobility difficulties, and fatigue. Minority patients reported similar sources of distress as the overall program population, with increased relative distress related to logistical issues, such as transportation and financial/insurance questions. Patients were more likely to ask for help with questions about insurance/financial needs (79%), transportation (76%), and knowledge deficits about diet/nutrition (76%) and diagnosis (66%) when these items contributed to distress. **Conclusions:** Lay navigators were able to routinely screen for patient distress at a high degree of penetration using a structured distress assessment.

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Background

Since the inception of the Distress Thermometer in 1998,[1] the tool has been refined and used in multiple cancer populations to identify patients with distress and to characterize causes of distress.[2–9] NCCN recommends use of the Distress Thermometer or similar tools as a method for consistent measurement of distress for patients with cancer.[10] In 2015, the Commission on Cancer (CoC) began a phased-in program to screen for distress as part of its certification requirements. Despite the CoC initiative, implementation of distress screening has been challenging, with only

half of NCCN Member Institutions screening all outpatients in 2012.[11]

Barriers to implementation of distress screening in routine clinical practice include time limitations of staff, knowledge deficits, and lack of reimbursement for time devoted to screening.[12] Moreover, the optimal approach to screening is unclear. Some institutions use patient interviews, some use patient self-report with paper or electronic questionnaires, and some use a combination of these methods.[11] When interviews are used to assess distress, oncology nurses[13] and nurse navigators[14] are often tasked with administering distress evaluations as part of their workflow, but an advanced clinical skill level may not be essential for distress screening.

In previous studies, 31% to 62% of patients reported high distress levels.[3–5,9,15] Increased distress is associated with reduced quality of life, increased mortality, and higher health care expenditures.[14,16,17] In geriatric patients, 14% to 40% report depression and more than 40% report significant distress.[15,18] In urban geriatric patients, poor physical function was a predictor of distress.[15] Few data exist on screening of geriatric patients in rural, community settings. In addition, the sources of distress for this patient population have not been characterized.

Patient navigators may be able to both screen for and mitigate sources of distress for patients with cancer. Navigators help patients navigate the health system and overcome barriers to receiving high-quality health care.[19] The CoC now requires provision of navigation services for accreditation.[20] There are a growing number of lay navigation programs using non-nurse community members (specialized community health workers) to provide these services to patients, particularly in underserved communities.[21] Navigator programs have shown benefits in reducing disparities in access to care for prevention, early detection, and early treatment of cancer,[22–26] and improving patient experience.[13,27,28]

However, despite mounting evidence of the benefits of navigation and the emergence of navigator training programs with recommended competencies,[29–31] the process of navigation is yet to be standardized, and tools to guide daily operations are lacking.[29] We proposed that lay patient navigators could use a distress tool (DT) to guide interactions with geriatric patients (aged ≥65 years) with cancer. We conducted an exploratory, descriptive implementation study of the integration of the DT into routine practice within a lay navigation program to guide patient interactions and respond to patient needs.

Methods

Setting: Patient Care Connect Program

The Patient Care Connect Program (PCCP) is a lay navigation program that serves patients with cancer older than 65 years with primary fee-for-service Medicare insurance within the University of Alabama at Birmingham (UAB) Health System Cancer Community Network. This network includes 12 sites across Alabama, Georgia, Florida, Mississippi, and Tennessee (Figure 1). The PCCP, including navigator salaries, was supported by a Center for Medicare & Medicaid Innovation (CMMI) grant from 2012 to 2015 and was first implemented at UAB in March 2013. Extensive training was provided to site medical directors (oncology physicians), nurses, and other members of oncology care teams to orient them to navigation processes and goals, including routine distress assessment and reporting. Program leadership visited each site quarterly to reinforce relationships and program processes. Navigators at all sites were assisting patients within the program by October 2013.

We report data collected on patients enrolled over a 1-year period from January 1, 2014, through December 31, 2014. The evaluation of the PCCP process and effectiveness was approved by the Institutional Review Board of UAB and affiliate sites.

Navigators

PCCP navigators are lay individuals (non–clinically trained) from the community hired at each institution as part of the PCCP. They may have previous experience in health care, such as working as a chaplain, receptionist, or medical assistant, but this is not a requirement. Each of the 12 sites across the network has responsibility for recruiting their navigators, who ideally are trusted members of the community they serve. The navigators receive 80 hours of didactic training covering basic concepts of navigation, communication, advanced care planning, palliative care, and cancer followed by an additional 80 hours of site orientation, communication practicum, and shadowing in clinical settings. Within this program, approximately 40 lay

Site[a]	Location	Number of Affiliated Medical Oncologists	Rural vs Urban Status	Practice Structure
Memorial Hospital (1)	Chattanooga, TN	15	Urban	Private practice
Northside Hospital Cancer Institute (2)	Atlanta, GA	58	Urban	Hospital-owned
Gulf Coast Regional Medical Center (3)	Panama City, FL	4	Urban	Private practice
Fort Walton Beach Medical Center (4)	Fort Walton Beach, FL	4	Urban	Hospital-owned
Singing River Health System (5)	Pascagoula, MS	5	Urban	Hospital-owned
Southeast Alabama Medical Center (6)	Dothan, AL	6	Urban	Private practice
Russell Medical Center (7)	Alexander City, AL	2	Rural	Hospital-owned
Northeast Alabama Regional Medical Center (8)	Anniston, AL	5	Urban	Private practice
Marshall Medical Center (9)	Albertville, AL	2	Rural	Hospital-owned
USA Mitchell Cancer Institute (10)	Mobile, AL	6	Urban	AMC
Medical Center, Navicent Health (11)	Macon, GA	14	Urban	Private practice
UAB Comprehensive Cancer Center (12)	Birmingham, AL	28	Urban	AMC
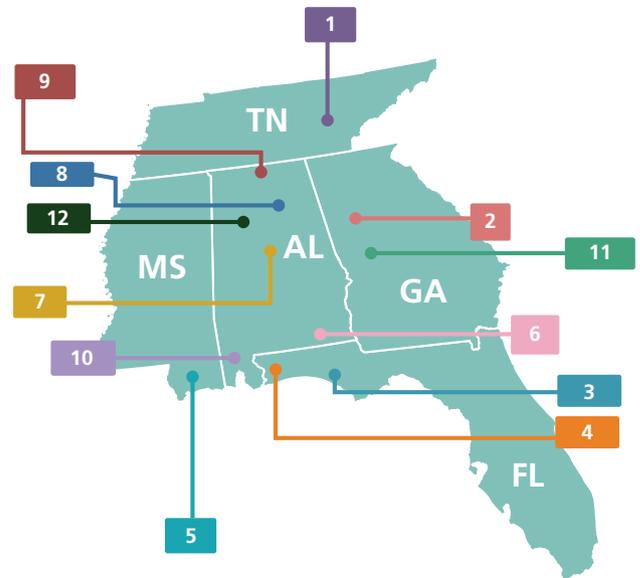
Figure 1. The University of Alabama (UAB) Health System Cancer Community Network.
Abbreviation: AMC, academic medical center.
[a]Numbers behind the site correspond to location on the map.

navigators at 12 cancer centers provide support to patients with cancer across the continuum of disease from the time of diagnosis through survivorship and/or the end of life. A nurse site manager at each location supervises the navigators. Each navigator is able to provide support to as many as 135 patients at a given time.

Patients

All patients older than 65 years with primary fee-for-service Medicare insurance and a cancer diagnosis are included, with the exception of incarcerated patients and those living in a skilled nursing facility. During the first encounter with patients, navigators record characteristics including cancer stage, cancer type, diagnosis date, age, sex, race/ethnicity, presence of selected high-risk comorbidities (eg, congestive heart failure, chronic obstructive pulmonary disease, interstitial lung disease, renal disease, diabetes, stroke).

Distress Assessment

The DT was adapted from the Distress Thermometer used by NCCN.[10] The tool includes both a thermometer image, which is used to quantify the distress level from 0 (no distress) to 10 (extreme

distress), and a problem list to help delineate the source of distress within the past week.[10,12] A distress score of 4 is considered the cutoff for clinically meaningful elevations in the level of anxiety and distress.[32] Distress levels of 8 or greater were considered high, warranting same-day notification of the clinical team. This cutoff was chosen based on investigator experience in order to capture patients with acute needs, particularly symptoms, who required prompt referral to the clinical team. To provide a more comprehensive view of patient's distress, we expanded the problem list to include additional barriers, which were identified through a review of literature on geriatric syndromes,[33–35] consensus of investigators and geriatric consultant experts, and early navigator encounters with patients.[5,14,36] This revised DT identifies problems in the following domains: practical, family, emotional, spiritual, financial, and physical (see eFigure 1, available with this article at JNCCN.org). This tool was built into a standardized, publically available navigation software, Medical Concierge (Open Software Solutions LLC, Davenport, IA), which was used by all sites.

Navigation Process

Navigators are trained to use a systematic algorithm with distress assessment at the center to guide contact with patients. Contacts occur both in person and via telephone. At their first patient encounter, navigators assess patients and record an overall level of distress and any problems that contribute to distress as part of a formal distress screen. When navigators identify a patient-reported source of distress, they ask the patient whether they desire assistance with that item. Distress levels, causes of distress, requests for assistance, and resources used to respond to distress are recorded after each contact in a shared HIPAA-compliant electronic database.

Navigators intervene when the overall distress score is 4 or high or the patient requests assistance. Distress scores of 4 or more triage patients to more frequent contact (at least monthly). For those with moderate or high distress (>8), the navigator responds to any issues they can address and escalates the issue to the clinical team via the nurse manager. Interventions include supporting self-management, troubleshooting barriers to care with patients, connecting patients with community resources, and engaging health care providers. Navigators follow up with the patient again within 1 month and complete either a formal DT or an informal DT. A formal DT includes review of all domains, whereas an informal DT is a focused review without evaluation of all items on the DT. These informal DTs are most often completed as a second or later DT in response to a previously identified patient need. Although formal DTs are recommended for the first contact, navigators may use an informal DT to report concerns identified when they are not able to complete the full formal DT for any reason. A previously reported distress item is recorded as "addressed" when the patient reports that they no longer need help with it during a follow-up DT. For patients with low distress levels and no active concerns, the follow-up schedule prompts navigator contact at least every 3 months. Patients are considered high-risk and are triaged to more frequent contact schedules if they report high distress, have active concerns, are diagnosed with high-risk cancers, are on high-risk medication, or have high-risk comorbidities (see supplemental eAppendix 2). Navigators are instructed to perform a formal DT at initial contact and at least every 6 months for navigated patients.

Fidelity to distress assessment, data collection, and use of care maps to address sources of distress was supported through real-time review of data, monthly calls with site managers and medical directors to reinforce processes, and weekly teleconferences with navigators to reinforce consistency and address challenges encountered.

Data Collection and Analysis

To describe the use of the DT, data were extracted from the electronic database on all patients actively enrolled in the program from January 1, 2014, through December 31, 2014. One additional month of data collection was included to ensure that patients enrolled late in 2014 had at least 1 month in the program, during which we would expect a DT to be completed. The statistical analysis is descriptive; we provide frequency count and percentage for category variables, mean and standard deviation, and median with range for continuous variables.

Outcomes

For this implementation study, we explored the feasibility and penetration of distress screening, sources of distress, and the delivery of navigation services in geriatric patients with cancer.

- Feasibility: reported as the proportion of the total population that was screened for distress.
- Distress characterization: we describe the distress level and sources of distress.
- Delivery of navigation services: we describe requests for assistance generated through distress assessment and proportion of requests that were addressed by the navigator.
- Navigator reporting: we describe methods of navigator reporting to practices and health systems.

Results

Patient Demographics

A total of 5,121 new patients were enrolled in PCCP from January 1, 2014, through December 31, 2014. The average length of time in the program was 5.16 months. Patient characteristics are shown in Table 1. The average age of participants was 75 years (range, 65–100 years). Among the participants, 14% were minorities and 35% had at least one other high-risk comorbidity in addition to their cancer diagnosis.

Feasibility of Using Distress Screening as a Navigation Tool

Of the 5,121 patients identified to be eligible for PCCP, 4,520 (88%) completed at least one DT. More than half of the DTs were completed though telephone contact. Common reasons for missing DTs included patient death before contact (2%), inability to reach the patient after 3 attempts (3.3%), refused services (1.1%), and change in eligibility status between identification and first contact (2.3%).

Of the 4,520 initial DTs completed for patients, 84.4% were formal and 15.6% were informal DTs. Of those with an initial informal DT, 38.6% of patients later completed a formal evaluation. Of all initial DTs, 20.9% of patients had a DT with distress items but no overall distress score. Repeat DTs were available on 2,630 patients (58.2% of total). Of the second distress screenings, 62.4% were formal and 37.6% were informal. The maximum number of distress screenings collected on one patient was 33 over an 11-month period and the average number per patient was 2.3 (median 2).

Distress Levels in Geriatric Patients With Cancer

The mean distress score was 2.32 for the 3,572 patients with a recorded distress level (range, 0–10); 24.0% of patients reported distress scores of 4 or greater and 5.5% reported distress scores of 8 or greater.

Sources of Distress

The most common sources of distress at initial assessment were pain (408 of 5,254 cases reporting a cause of distress), balance/mobility difficulties (404 cases), and fatigue (399 cases; Figure 2A). This breakdown was similar for formal and informal DTs. Patients with distress scores of 8 or greater were more likely to report psychological symptoms, such as anxiety, feeling depressed, or worry (Figure 2B). Minority patients reported similar sources of distress as the overall program population, with increased relative distress related to logistical issues, such as transportation and financial/insurance questions (Figure 2C).

Delivery of Navigation Services for Distress

Although symptoms (pain and fatigue) were the most common sources of distress identified, only 46.3% of individuals reporting pain also requested assistance for pain. Patients were most likely to ask for help with questions about insurance/financial needs

(79.1%), transportation (75.5%), and knowledge deficits about diet/nutrition (75.9%) and diagnosis (67.1%) when these items were sources of distress (Figure 2A).

When patients requested assistance with a source of distress, 94.7% were subsequently reported as addressed to the patient's satisfaction (Figure 2). The interventions used to address patient's distress varied based on the type of distress. Common interventions used to address distress include coaching for self-management, referral to provider, referral to nurse site manager, connection to community resources, and provision of information from the NCI, American Cancer Society, and other trusted resources (see supplemental eAppendix 3). As an example, for transportation, the navigators often assisted the patient to identify a ride from a family member or friend. When this was not possible, they connected patients with community resources to obtain gas cards and access to "Angel Bus" or other charity transportation companies.

Discussion

Lay navigators were able to routinely screen for patient distress at a high degree of penetration using a structured distress assessment. In this implementation, screening by navigators was highly successful with 9 of 10 patients within the program having a DT recorded. Among patients who did not have a completed DT, this was most commonly due to inability to contact the patient, patient refusal, and death. Although nurse-based screening during clinic appointment might capture additional patients, such an approach uses skilled nursing time, perhaps inappropriately, and does not easily allow for screening for distress between visits. Navigators effectively called patients between visits to identify problems experienced outside of the isolated clinic visits. The levels of distress observed in this population and the concerns identified are consistent with studies conducted with more formal methodologies, suggesting that lay navigators were able to accurately assess and record sources of distress using a distress tool.[37,38]

The DT expands on a typical symptom-based evaluation by providing a structure to identify concerns in multiple domains, including informational, logistical, financial, social, emotional,

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Table 1. Patient Characteristics (N=5,121)		
	%	**N**
Age, y		
65–74	52.7%	2,701
75–84	36.4%	1,863
≥85	10.9%	557
Sex		
Male	45.6%	2,335
Female	53.8%	2,755
Missing	0.6%	31
Race		
White	85.1%	4,358
Black	12.5%	638
Other	1.3%	66
Don't know/not sure	0.8%	40
Missing	0.4%	19
Comorbidities		
0	19.2%	982
1	13.2%	678
2	18.1%	925
≥3	49.5%	2,536
High-risk comorbidities[a]		
0	64.6%	3,309
1	27.7%	1,416
2	6.4%	329
3	1.3%	67

[a]Include congestive heart failure, chronic obstructive pulmonary disease, interstitial lung disease, renal disease, diabetes, and stroke.

and spiritual aspects of care. This multidimensional evaluation provides a patient-centered framework for the navigator/patient interaction. In this implementation, patient engagement in the process was further encouraged in that they were asked to prioritize issues for navigator assistance. The navigators were also directed to respond to moderate or greater distress levels (score ≥4)[32] by increasing the frequency of contact to monthly or more frequently. This targeting methodology maximizes the intensity of the intervention to patients with higher demonstrated need.

The navigators reported that patients' needs were met in 95% of cases in which the patient requested assistance. Given the nature of these data, we are unable to ascertain whether the problem was actually resolved or patients were reporting that they no longer felt a need for assistance with the distress item.

Patients often did not want assistance with all items that contributed to distress. The most frequently reported sources of distress in this sample were physical symptoms, such as pain and mobility issues, yet patients were less likely to request assistance with these items. Anecdotally, navigators reported that patients often attributed symptoms to chronic physical issues that were managed on current medications or that were being addressed by their physician. "New" and "chronic" sources of symptom burden were not distinguished in this study. It is possible that patients may be more likely to request assistance from the navigator on nonclinical issues, such as transportation, and rely more on the clinical team for clinical concerns. Although lay navigators in this program escalated clinical needs to the clinical teams as directed by care plans, patients may have effectively "self-edited" their requests for assistance to those items they felt were within the navigators' influence. This merits further exploration as we seek to examine how distress assessment can assist in identifying patient needs and framing care.

Rather than using free text notes, the lay navigators used the Medical Concierge Navigator software tool to record their interactions. Navigators could provide reports on individual patients to other members of the health care team. This approach allowed for transmission of information to the oncology physicians and nurses in a consistent format and allowed for robust standardized data collection across the population. Through screening with a comprehensive distress assessment, the navigators were able to assist with many sources of distress that may not have come to the attention of the physician. Within this model, the navigators were able to address the nonclinical issues and notify other members of the care team about clinical concerns, so that the oncologists and nurses could focus on clinical management during clinic visits. Such a model has the potential to enhance both the quality and efficiency of oncology care, and therefore further examination of this impact is merited.

When evaluated in aggregate, health systems can use DT reports to identify gaps in care within the community and match philanthropic efforts with patient needs. For example, transportation
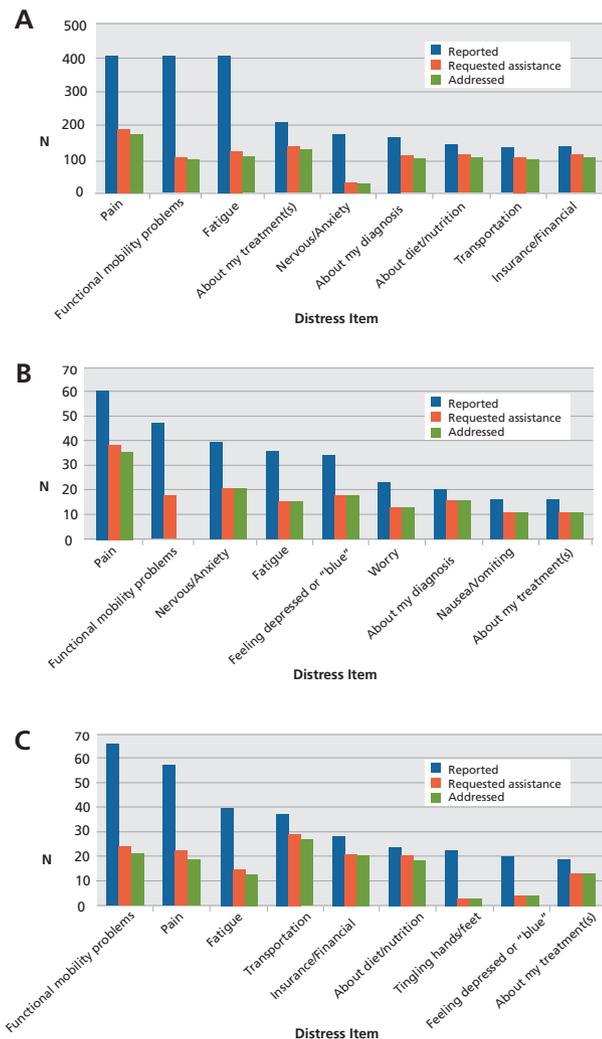
Figure 2. Distress items, requests for assistance, and resolution of patient concerns in (A) all patients, (B) patients with a distress score ≥8, and (C) minority patients.

of lay navigators into patients' health care teams may be challenging for some institutions. For distress screening to have an impact on symptom burden, identified distress items must be rapidly communicated to the health care team to address patient's symptoms. In this implementation, the communication protocol was developed before initiation of screening.

Conclusions

Distress screening can be integrated into navigation programs to enhance uptake of distress screening. The described use of the DT supports systematic screening of navigated patients. This approach has the additional advantage of providing standardization of care, standardization of data collection, and a structure for lay (non–medically trained) navigators to extend the workforce available to support patients during their cancer journey. Monitoring of data from the distress assessments allows a unique opportunity to understand the causes of distress and unmet needs of patients. Technology to allow the monitoring of data in real time can facilitate the development of initiatives to improve patient experience. This approach also allows for programmatic monitoring of navigator contact with patients, assessments, and interventions. Finally, the use of distress assessments during navigation allows programs to demonstrate their impact by recording their ability to respond to causes of distress. Further work is needed to determine the impact of distress screening on patient outcomes within multilevel, multimodal programs such as the navigation program we describe.

was a barrier to care for many patients within our health system. At one site, these data were used to demonstrate need to the hospital, which responded by developing a transportation fund for patients in their community to address this gap.

One limitation of this study is that lay navigators do not have research expertise, which may have impacted data collection. Specific training in data integrity and quality assurance processes was provided to lay navigators, and facilitated consistent implementation and use of the DT. This limitation presents an addressable challenge, and is balanced by the richness and validity of the data collected as part of routine practice within a lay navigation program. We also acknowledge that the integration

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