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Development, implementation, and initial results of the UC San Diego Health Moores Cancer Center Wellbeing Screening Tool

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Abstract

Objective. All accredited cancer institutions are required to screen patients for psychosocial distress. This paper describes the development, implementation, and preliminary outcomes of the University of California San Diego Health Moores Cancer Center Wellbeing Screening Program.

Method. Essential steps learned in a formal National Cancer Institute–funded training workshop entitled "Implementing Comprehensive Biopsychosocial Screening" were followed to ensure successful program implementation. These steps included identification of stakeholders; formation of a working committee; establishment of a vision, process, and implementation timeline; creation of a screening tool; development of patient educational material; tool integration into an electronic medical record system; staff training and pilot testing of tool administration; and education about tool results and appropriate follow-up actions. Screening data were collected and analyzed retrospectively for preliminary results and rapid cycle improvement of the wellbeing screening process.

Results. Over an 8-month implementation and assessment period, the screening tool was administered 5,610 times of 7,664 expected administrations (73.2%.) to 2,394 unique patients. Visits in which the questionnaire was administered averaged 39.6 ± 14.8 minutes, compared with 40.3 ± 15.2 minutes for visits in which the questionnaire was not administered ($t = -1.76$, $df = 7{,}662$, $p = 0.079$).

Significance of results. This program provides a process and a tool for successful implementation of distress screening in cancer centers, in a meaningful way for patients and providers, while meeting accreditation standards. Further, meaningful data about patient distress and tool performance were able to be collected and utilized.

Introduction

Distress is an uncomfortable feeling that can influence a patient's thoughts and actions (National Comprehensive Cancer Network [NCCN], 2014). Patients with cancer are vulnerable to experiencing distress because of the nature of their diagnosis, treatments, and effect on their lives. Distress can be due to a number of psychosocial factors, such as emotional states, family dynamics, financial issues, and spiritual pain. It can encompass a range of emotions, including feelings of sorrow, abandonment, anxiety, and depression. Symptoms of distress may also point to more serious clinical diagnoses that warrant further assessment and intervention. Distress screening tools can identify sources of distress and help care teams determine needed resources and interventions, such as social support, community resources, religious and spiritual guidance, symptom management, psychological or psychiatric assessment/intervention, or support groups, which in turn has the potential to improve their quality of life (NCCN, 2014), and possibly, cancer related outcomes.

Several oncology care accreditation bodies and practice guidelines highlight psychosocial distress screening as an indicator of quality care. By the end of 2015, all Commission on Cancer (CoC) accredited institutions were required to phase in CoC 2012 *Standard 3.2: Psychosocial Distress Screening* (CoC, 2012). Additionally, by the end of 2014, Quality Oncology Practice Initiative (QOPI) Certified Practices were required to comply with QOPI Standard 11: Section D: "Assess and document psychosocial concerns and need for support, taking action when indicated" (American Society of Clinical Oncology, 2014). Further, the

NCCN guidelines (2014) state that "All patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated, especially with a change in disease status (i.e., remission, recurrence, progression, treatment-related complications)" (p. 4). Further highlighting the importance to cancer centers and quality care, "The public and healthcare payers are increasingly looking to specialty designations and certifications to determine the quality of cancer centers" (Johnson, 2013).

The University of California (UC) San Diego Health Moores Cancer Center (MCC), as of this writing, is an NCI-Designated Comprehensive Cancer Center participating in both CoC and QOPI accreditations and contributes to, and follows, NCCN guidelines. This outpatient center uses a transdisciplinary approach in the care of its patients, with disciplines such as medical, surgical, and radiation oncology; pathology; diagnostic radiology; nuclear medicine; nursing; social work; genetic counseling; nutrition counseling; psychological services; and psychiatric care.

This paper describes the process of developing and implementing the UC San Diego Health MCC Wellbeing Screening Program. Specific steps taken throughout the process will be highlighted, as will practical considerations in adopting and successfully implementing this, or similar distress screening programs. Preliminary outcomes are also presented. Although the tool that was developed has face validity, a formal evaluation of the tool is not presented.

Methods

Development of the program

Attendance of an NCI-funded workshop

Four program representatives (a psychiatrist, oncology nurse, psychologist, and social worker) were competitively selected to attend an NCI-funded intensive 2-day skills-based workshop entitled Implementing Comprehensive Biopsychosocial Screening. This expert-led workshop provided practical leadership and program development skills for creating screening programs that surpass standards for biopsychosocial screening in cancer care. A range of topics was covered, such as engaging stakeholders, creating organizational culture change, and overcoming common barriers. With what the representatives learned, the entire program team developed a 90-day project plan, which included identifying the institution's key stakeholders; identifying additional screening development and implementation committee members; defining roles and meeting frequency; identifying a screening tool; setting a timeline for implementation; identifying pilot clinics; educating pilot clinics on screening purpose, process, and benefits of screening; evaluating pilot outcomes; and engaging in rapid cycle improvement processes as the program was rolled out across all 14 care teams in the cancer center.

Working committee

A transdisciplinary subcommittee of the MCC's quality committee was formed and met weekly to oversee program development and implementation. The committee consisted of two coleaders serving as liaisons to cancer center administration; and representatives from psychiatry, psychology, social work, nursing, patient experience representative, quality, information science, and nurse education.

Institutional stakeholders

The following stakeholders were identified and engaged: the deputy director of clinical affairs, the chief administrative officer, an associate administrator, the director of psychology and psychiatry, the director of nursing, a quality analyst, two clinical systems analysts, the patient advisory council, the patient experience officer, front desk staff, medical assistants, oncologists, nurses, patients and families, nurse and patient educators, and psychosocial team members. Two key stakeholders that endorsed the program were the cancer center executive leadership team and the quality committee in support of accreditations important to the cancer center.

Establishing a vision, process, and timeline

Beginning in the Spring of 2014, the committee's initial meetings established a vision, process, and timeline for developing and implementing a screening program throughout the MCC by the end of 2014. The vision was to develop a program that would not only meet accreditation requirements, but also would potentially improve outcomes for patients and their families. It was also designed to meet the needs of the oncology clinics, oncologists, and patients, considering patient flow and clinic time.

Next, the committee worked on selecting an existing screening tool versus developing a novel one tailored to the institution, its resources, and its cancer population. The committee felt that integration of the tool into the existing systemwide electronic medical record system was paramount to successful implementation of the program. Just as important was the development of an efficient intervention protocol for screening outcomes. Other important issues included determining (1) how frequently to distribute the screening tool; (2) how to best train staff of various disciplines on their specific roles in the distribution, administration, assessment of results, intervention (including triage and referral), and follow-up of tool outcomes; (3) how to develop and provide patient education materials; and (4) how to document and capture screening data for quality control and rapid cycle improvement.

A timeline to pilot-test the screening program with one or two clinics was developed, with a stepwise rollout to clinics after incorporating feedback and outcomes from any previous clinic pilots. Additionally, the committee included a plan to make itself available in real-time during implementation, providing ongoing communication with clinics during pilot implementation to review screening workflow, troubleshoot if needed, and receive input/feedback regarding all aspects of the implementation process.

Development of UC San Diego Health MCC Wellbeing Screening Tool

The committee reviewed various existing distress screening tools in the literature, including those presented at the Implementing Comprehensive Biopsychosocial Screening workshop. Existing screening outcome data were carefully reviewed, including the most commonly endorsed domains of distress in cancer patients (Clark, 2013), and other reported data in the literature (Carlson, Waller, & Mitchell, 2011; Giese-Davis, 2012; Muriel et al., 2015; Wagner, Spiegel, & Pearman 2013). No single tool met the committee's expectations. As such, 13 items frequently endorsed by patients with cancer that also captured the breadth of biopsychosocial and spiritual wellbeing were chosen. The goal was to create a tool that would encompass several domains of wellbeing (not solely anxiety and depression), that was of an appropriate length (<15 items), that was responsive to the needs of the patients and clinic staff, that offered different phrases and keywords pointing to the same areas of wellbeing (to accommodate differing patient perceptions), and that met accreditation standards. We also chose to emphasize the tool as addressing “wellbeing” as opposed to distress to frame it in a positive manner for patients and providers.

The tool was reviewed by 10 patients and family members (combined) and 10 staff members randomly selected to provide feedback. Reviewers were asked to give feedback on the tool’s intended purpose, literacy/readability, length, and relevance. This information helped further revise the tool for initial pilot testing. The tool underwent 14 revisions during the pilot phase, which improved and clarified language to questions and instructions, enhanced formatting, added a Likert scale of 0 to 3, and led to the development of a certified Spanish translation. These revisions led to the final English/Spanish (bilingual) version (presented in the Appendix).

Development of patient education materials

Written education materials were compiled from publicly available reputable resources (e.g., NCI, American Cancer Society, Cancer Support Community, Cancer Care) for distribution to patients for each item on the screening tool. Written permission was obtained from each organization to use these materials. Any materials that did not already exist in Spanish were translated by a university-employed certified translator. Materials were uploaded into the electronic medical record to be easily accessed by staff and incorporated into a patient’s “After-Visit Summary”, that is routinely given to a patient at the end of each visit.

Integration of the screening tool into the electronic medical record

A nurse informaticist and member of the electronic medical record (EMR) team was an active member of our committee and present throughout the duration of our screening program development to build and operationalize the screening tool into the existing EMR system. The screening tool was developed on both a paper intake form and for electronic entry in discrete, searchable, fields in the EMR. An algorithm was designed to trigger a reminder for check-in staff to provide the screening tool in paper form at check-in at appropriate intervals according to accreditation standards. Additionally, searchable patient instruction text templates for educational materials corresponding to each tool item were created within the EMR to import easily into the after-visit summary. The educational information was also available online to patients through a secure web portal via the EMR, links to which also appeared in the after-visit summary.

Staff training on screening tool administration, assessment of results, and referral process

The proposed screening processes were presented and approved by managers/supervisors and/or representatives of each care discipline. Pilot clinics were identified, and a clinical nurse from the committee provided in-service and in-clinic training to all pilot clinic nurses regarding their roles and the processes involved in administering the screening tool, documenting the results, communicating with the care team, and documenting any actions taken. Screening was purposely designed as a nursing-led program with nursing staff responsible for reviewing completed screening tools with patients, facilitating conversations with other providers, helping to determine interventions or referrals, discussing recommendations, and providing written information and referrals as agreed or requested by patients. Similarly, check-in staff, medical assistants, and providers were educated and trained on the purpose of the screening, steps on how to incorporate it into the routine clinic flow, and how to assess and use information from the completed screening tool. Special training material was developed for all providers and staff about their specific responsibilities for successful screening tool implementation and use. This material included a brief background on the accreditation standards, proposed processes to meet these standards, required changes to clinic workflow, and any additional responsibilities specific to each discipline. As a final step, these processes were written and supplemented by visual images (screenshots) of the EMR to facilitate learning. Multiple group trainings were offered, in addition to as-needed individual sessions. Committee members were present in clinics during the pilots to offer live in-person guidance, positive reinforcement, and real-time troubleshooting to all involved during the pilot phase.

Workflow

The MCC check-in staff was provided with a list of providers/clinics participating in the Wellbeing Screening pilot. Based on this list, the staff would print and attach the Wellbeing Screening Tool to other intake paperwork and hand it to eligible patients. Patients had the option of choosing who would fill it out (family vs. self), documenting who filled it out, and from whose perspective the answers were given. They were also given the opportunity to decline outright or decline as issues were screened and/or being addressed. Clinic medical assistants would enter the results from the paper form into a matching electronic form in the EMR and hand the paper form to the nurses for review and discussion with the patients. Nurses would determine the need for further interventions and /or referrals, discuss with the nurse practitioner/ physician, and document relevant information in their nursing notes.

Outcomes

Approval from the University of California San Diego institutional review board was obtained to retrospectively examine screening data and performance collected during the pilot phase. Data collected included number of visits eligible for tool administration, number of administrations, implementation rate, number of unique patients that received the tool, and the proportion of patients reporting no, low, moderate, and high levels of distress on each item. Further, as an estimate of the time impact on providers, clinic flow, and patients resulting from administration of the wellbeing tool, time (in minutes) from collection of vital signs to printing of the after-visit summary was collected. The tool was not formally evaluated as part of this process.

Results

Between July 7, 2014, and February 28, 2015, the total number of visits in which patients were eligible to receive the tool was 7,664; the screening tool was administered 5,610 times to 2,394 unique patients, for a total implementation rate of 73.2%. Total rates of implementation by a care team are presented in Table 1. Table 2 provides the proportion of patients reporting no, low, moderate, and high levels (0–3 on the tool, respectively) of distress for each item on first administration. In addition, for all cvisits in which the tool should have been administered

Table 1. Implementation rates by disease team

Disease team	No. of unique patients	Eligible visits	Wellbeing tool administered	% Implementation
Breast	817	1,765	1,699	96.3
Bone marrow transplant	183	1,593	1,332	83.6
Gynecologic	480	748	581	77.7
Gastrointestinal	247	1,114	708	63.6
Hematology	267	894	555	62.1
Neurology	81	427	225	52.7
Lung	79	463	240	51.8
Genitourinary	227	627	265	42.3
Head and neck	13	33	5	15.2
Total	2,394	7,664	5,610	73.2

Data were collected between July 7, 2014, and February 28, 2015.

Table 2. Distress levels by item

	Level of distress			
Item	None N (%)	Low N (%)	Moderate N (%)	High N (%)
Sleep/energy/fatigue	613 (35.3)	415 (23.9)	480 (27.6)	230 (13.2)
Anxiety/nervousness/on edge	855 (11.7)	433 (24.5)	336 (19.0)	144 (8.1)
Depression/sadness/feeling down	1,026 (58.2)	407 (23.1)	235 (13.3)	95 (5.4)
Worry or uncertainty about the future	846 (47.5)	432 (24.3)	308 (17.3)	194 (10.9)
Physical symptoms or side effects	962 (54.3)	352 (19.9)	312 (17.6)	147 (8.3)
Memory/concentration/thinking	1,005 (57.0)	406 (23.0)	273 (15.5)	78 (4.4)
Intimacy/infertility	1,351 (79.9)	184 (10.9)	98 (5.8)	57 (3.4)
Prognosis/course of illness	951 (58.8)	320 (19.1)	264 (15.8)	139 (8.3)
Finances/housing/transportation	1,190 (68.9)	242 (14.0)	171 (9.9)	124 (7.2)
Concern about friends/family/partner	992 (56.9)	326 (18.7)	266 (15.3)	159 (9.1)
Being a burden to others	1,173 (68.5)	243 (3.3)	177 (10.3)	119 (7.0)
Worry/ability to cope with stress/emotional issues	1,032 (60.1)	343 (20.0)	226 (13.2)	115 (6.7)
Spiritual/religious issues	1,454 (85.6)	143 (8.4)	62 (3.6)	40 (2.4)

Row sums vary because of missing responses.

($n = 7{,}664$), the time (in minutes) from collection of vital signs to printing of the after-visit summary when the tool was administered was 39.6 ± 14.8 ($n = 5{,}610$) versus 40.3 ± 15.2 minutes when it was not administered ($n = 2{,}054$); ($t = -1.76$, df $= 7{,}662$, $p = 0.079$).

Conclusions

This paper is among the first to describe the implementation of a wellbeing (distress) screening program in an NCI-designated comprehensive cancer center. The results suggest that the program is implementable, feasible, and achieves the primary goal of screening all patients receiving cancer therapies at appropriate intervals in accord with standards set forth by accreditation bodies and national guidelines. Further, it has been useful in identifying areas of patient/family distress and improving patient-provider interactions with little effect on clinic flow. Anecdotal data from both staff and patients suggest they feel this tool has benefited clinical care. Further study is needed to determine effect on clinical care delivery, quality, and both cancer and psychosocial outcomes.

Overall, during the first 3 months of implementation, the tool was successfully administered to >73% of all eligible cancer outpatients in the pilot clinics. Further, the inclusion of the wellbeing screen had minimal effect on clinic flow, whereby visit lengths with and without were not significantly different, and lasted approximately 40 minutes, on average. It is possible that the screening tool may have streamlined the provider's assessments, thereby facilitating the patient–provider discussion to address and intervene for any distress and more quickly ascertain specific areas in which the patient required attention, making up for any additional time added by the screening process.

Although implementation was successful overall, implementation success rates varied across disease teams. This could be due to differential clinic flows, provider comfort and facility with the process, varying amounts of baseline distress across cancer types, differing check-in processes in different locations, timing within the pilot implementation, or other yet-unknown factors. At one point, before the automated screening trigger was implemented, it was determined via rapid-cycle improvement monitoring that it was difficult for the check-in staff to keep track of which clinics, and which of that clinic's patients, were part of the pilot testing, which also led to differing implementation rates.

Although every clinic and care system can be unique and the screening process outlined may not fit all cancer care settings, the process by which the tool was developed, implemented, and reviewed could provide a model for all systems attempting to implement wellbeing screening. With rapid-cycle improvement, this process should be able to be honed for any clinical setting.

Future directions include implementation of an electronic entry system (remote and in clinic) for the tool connected to the EMR; continued recording and reporting the rapid-cycle improvement of all aspects of the process; and evaluating effect on clinical outcomes, service utilization, and patient/provider satisfaction. Formal evaluation of the tools' operating characteristics is needed as well. Further, a deeper dive into the differing implementation rates is warranted. Last, to ensure long-term program sustainability, it will be important to identify key management staff to conduct orientations of the program for new employees with updated materials and information, as well as give continuous outcome feedback to the quality committee, key leadership, and care teams.

Overall, this program appears to be implementable in a rapid fashion, with a good success rate, while achieving quality and accreditation guidelines. The tool was found to be a great "start a conversation" tool between patient and provider because it illustrated the wide array of support possible for patients, while reminding the oncology teams of the wide range of support patients may need.

In conclusion, this program provides a process and a tool for successful implementation of distress screening in cancer centers, in a meaningful way for patients and providers, while meeting accreditation standards.

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Supplementary Material. To view supplementary materials for this article, please visit https://doi.org/10.1017/S1478951518000810.

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