Addressing Distress in Patients With Head and Neck Cancers: A Mental Health Quality Improvement Project

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Abstract

This study sought to improve mental health care for patients with head and neck cancers (HNCs) through the implementation of an evidence-based process for identifying and managing psychological distress. This process in an HNC medical oncology clinic was assessed and redesigned using quality improvement (QI) methods from November 2010 through April 2012. The redesign, starting in January 2011, involved a 2-component QI intervention: the validated NCCN Distress Thermometer and an evidence-based treatment decision algorithm. Screening processes were improved through Plan-Do-Study-Act (PDSA) cycles. Before January 2011, distress identification was based on a provider's clinical assessment. Cause-effect diagramming suggested that lack of a formalized process for distress assessment contributed to missed diagnoses. Providers were also unfamiliar with mental health resources. After implementing process changes, biweekly distress screening rates rose from 0% to 38% between January and July 2011. Furthermore, with additional PDSA cycles, these rates increased to 74% between October 2011 and April 2012. Similar to proposed benchmarks, 84% (n=47) of newly diagnosed patients (n=56) were screened. Improvement in screening was attributed to process changes and involvement of senior leadership. QI principles can be applied to the cancer setting in order to create systems of care which more reliably identify and address the needs of patients with psychological distress. (*J Natl Comp Canc Netw* 2014;12:1005–1013)

Symptoms of psychological distress, such as depression and anxiety, are common with any cancer but are particularly prevalent with head and neck cancers (HNCs), affecting as many as 35% of patients.^{1,2} Several factors likely contribute to risk, including posttreatment disfigurement and history of substance abuse.^{3–7} At-risk patients, however, are often not identified by providers.^{8–12} Left untreated, distress can contribute to poorer quality of life (QOL) and reduced survival.^{13–20}

The importance of identifying those at risk is reflected in the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Distress Management, which recommend that cancer centers incorporate distress screening into routine care (available at NCCN.org).¹ For example, NCCN recommends using the validated Distress Thermometer (NCCN-DT), a visual analogue scale that allows patients to rate their perceived level of distress in the last 7 days on a scale of 0 (“no distress”) to 10 (“extreme distress”). Patients clarify the source of distress using a 39-item problem list with 5 categories: practical, family, emotional, spiritual/religious, and physical. A score of 4 or greater suggests heightened distress and is a cue for providers to further assess identified patients and their need for treatment.¹

Although distress screening is an integral part of patient-centered cancer care and is included in ASCO's Quality Oncology Practice Initiative (QOPI) measures,^{1,21–24} few US cancer centers have adopted formalized screening programs for distress.²⁵ In response, a quality improvement (QI) project was developed to improve care through identifying and addressing distress in HNC medical oncology patients. Specifically, a microsystem-based theory was used to apply the available evidence on distress screening to the local setting.²⁶ This work has the potential to inform the planning and implementation of distress screening programs in cancer centers nationally.

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Local Problem

Norris Cotton Cancer Center (NCCC) is one of 41 NCI-designated Comprehensive Cancer Centers, serving patients living throughout Northern New England. Patients with HNCs are treated in the multidisciplinary HNC program and those requiring chemotherapy are followed up in the HNC medical oncology clinic. The clinic is staffed by a medical oncologist, a nurse practitioner, a dietitian, a licensed nursing assistant (LNA), a social worker, and other ancillary staff. In 2010, the clinic cared for 548 patients with a mean age of 62.7 years (SD, 12.5) and 59% (n=324) were men.

No institutional policy for distress screening exists, and before January 2011, the HNC medical oncology clinic lacked a formalized process, relying instead on the clinical assessment of providers to identify and manage distress. To better understand this care process, a retrospective chart review was conducted of 56 patients seen from March 2009 through January 2010. This review found that rates of identified distress, including depression, were lower than anticipated from the literature (18% in this review vs 50% reported in the literature⁵), suggesting possible missed diagnoses. Two suicides were also noted in the last 10 years in the HNC medical oncology clinic in patients not previously identified as distressed. Patients and providers voiced concerns about lack of familiarity with available mental health resources.

Intended Improvements/Aims

In response to these findings, provision of quality, patient-centered, evidence-based mental health care for all patients in HNC medical oncology clinic became the global aim. The specific goal was to ensure that 100% of patients were screened for distress and, if indicated, received evidence-based treatment.

Methods

Organizing for Improvement

In the fall of 2010, a QI team within the HNC medical oncology clinic brought together a group of individuals with a shared interest in improving the psychosocial care of patients. The team consisted of a team leader who was a resident in Leadership Preventive Medicine (LPM) and psychiatry, a medical oncologist, an oncology nurse practitioner, and an LNA.²⁷

The QI team received active coaching in QI principles from the team leader, who was supported by an LPM coach and participated in LPM multidisciplinary work rounds with other residents and faculty. The QI team had weekly meetings or communicated via email. Data were collected weekly and analyzed, and then distributed to HNC providers for review and discussion.

The Committee for the Protection of Human Subjects concluded that this project met criteria for quality activity without a research component and was exempt from additional review.

Planning and Implementation

Using a clinical microsystems approach, the team evaluated and worked to improve care in the HNC medical oncology clinic between November 2010 and April 2012 through a series of Plan-Do-Study-Act (PDSA) cycles.²⁸ QI techniques, such as brainstorming, cause-effect analysis, and statistical process control charts, were used to connect the available evidence on distress screening to the local setting.^{26,28} Patient input was obtained through interviewing 28 patients and conducting a focus group of 7 patients and their caregivers. Cause-effect diagramming suggested that the lack of a formalized process for distress assessment contributed to potential missed diagnoses.

Based on these initial findings, a standardized process for distress screening and management was designed and implemented into routine care. In keeping with NCCN recommendations, the NCCN-DT was used to assess for heightened psychological distress.¹ A recommended cutoff score of 4 or greater was used to identify heightened distress, and emotional problems were defined as anxiety or depressive disorders.¹ Process changes were initially limited to one clinic day during the week, and paper copies were used to allow flexibility in testing how routine screening can be best integrated into workflow.

Figure 1 outlines the process for distress screening and management, and administered the tool to all patients brought to the examination room, and informed patients that the purpose of the tool was to help providers better address patient needs. The provider reviewed these results during the examination and relied on an evidence-based clinical decision tree, created with input from the team, to guide management.^{1,29,30} Findings were documented in clinic notes and on a data collection form. Paper copies were scanned into the patient's electronic medical record (EMR).

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Figure 1 Process flow map for distress screening with the NCCN Distress Thermometer (NCCN-DT) in Head and Neck Cancer Medical Oncology, January 2011 through April 2012. Process revisions are outlined in dark blue. Abbreviation: LNA, licensed nursing assistant.

Outcome Measures

The main outcome was improvement in the bi-weekly proportion of patients screened for distress. Secondary outcomes included proportion of patients identified with heightened distress, source of distress, and a plan for treatment of distress. In addition, patient and provider satisfaction with process changes were assessed.

Analysis

To determine whether distress screening improved over time, a proportion-chart (p-chart) was used. The p-chart is a statistical process control (SPC) chart used in QI in which the proportions of patients with a given outcome are plotted over time. The SPC chart contains upper and lower control limits, which are set at 3-sigma, offering the best tradeoff

between risks for type 1 and II errors. SPC charts are commonly used in QI work and differentiate between 2 types of variation: common and special cause. Processes are in statistical control when rates over time fall within the upper and lower control limits. A statistically significant change occurs when there is a special cause variation in which 1 or more points go beyond the control limits or when a process shift occurs in which 8 or more successive values fall on the same side of the overall rate.³¹ When a significant change occurred, the overall rate and limits were recalculated.

These results, in addition to qualitative feedback from patients and providers, guided future PDSA cycles. Specifically, special-cause signals were investigated to understand their contribution to the process (whether

positive or negative). Once the process was in statistical control, additional small tests of changes were pursued.

Associations between categorical variables were determined using chi-square statistic.

Results

Between January 2011 and April 2012, a total of 510 patient visits occurred in the HNC medical oncology clinic. Of these, 324 (64%) patients were successfully screened at least once for distress with the NCCN-DT. A successful screen included (1) the patient was handed a hard copy of the NCCN-DT by the LNA at the beginning of the visit, (2) the provider personally reviewed the physical copy of the completed tool during the course of the visit, and (3) the tool was collected at the end of the visit and scanned into the patient's EMR by the clinic secretary. Figure 2 shows an annotated p-chart of biweekly screening rates and describes the impact that specific PDSA cycles had on screening rates.

PDSA Cycle #1

Clinic notes were revised to provide visual prompts for providers to incorporate distress screening into their routine care. To address concerns that providers had insufficient knowledge, comfort skills,

or resources for managing distress, the team developed an antidepressant guideline (based on current evidence) and a list of available mental health resources.

Although providers found these resources helpful, the interventions alone had little impact on screening rates. The average screening rate for the first 4 months (January–April 2011) was 29%. The clinic also transitioned to a new EMR in April 2011. As a result, the focus shifted as the clinic adapted to workflow changes necessitated by the change, including learning a more complex documentation and ordering system.

PDSA Cycle #2

After implementing the new EMR, the team regrouped and brainstormed additional strategies. It became apparent that a culture shift was needed within the clinic to have distress screening become the “norm” rather than the “exception.” To this end, in May 2011 a patient-centered poster was developed to educate patients about distress and encourage them to take a more active role in their care. Posters were hung in visible areas throughout the clinic. The team obtained patient-friendly pamphlets on distress from the American Cancer Society and placed these in examination rooms.³²

Despite these efforts, a significant decrease in screening rates to 18% initially occurred in June

Figure 2 Proportion chart showing biweekly rates of screening with the NCCN Distress Thermometer (NCCN-DT) and associated Plan-Do-Study-Act iterations in head and neck cancer medical oncology, January 2011 through April 2012. Unplanned events are highlighted in green. Abbreviations: EMR, electronic medical record; QI, quality improvement.

2011. Discussions among team members suggested that several factors likely contributed. Although the LNA was now accustomed to administering the tool, she occasionally would be replaced by a floating LNA who was unfamiliar with the project and thus less familiar with (or invested in) the work. Providers and the LNA also found it difficult to adhere to the process when clinic volume was unusually high or patients had complex issues.

The team also observed that the process was not reliable or sustainable without close monitoring. Screening was highly dependent on the provider remembering to print out copies of the NCCN-DT every clinic day and hand them to the LNA. To address this process limitation, the LNA began storing paper copies in a workspace folder. Providers also made efforts to inform floating LNAs about the improvement initiative at the start of the clinic day. Finally, in response to provider feedback that the existing treatment decision algorithm was not user-friendly, it was revised and posted in the provider workroom (Figure 3).

As a result of these combined process revisions, screening rates significantly improved, with overall screening increasing to 64% between July and September 2011.

PDSA Cycle #3

The team brainstormed additional strategies to improve screening. These included revising provider note templates to ease the burden of documentation. A significant improvement in screening occurred between early October 2011 and April 2012, with overall rates increasing to 74%. These improvements were attributed partly to a shift in the clinic's culture, with screening becoming more integrated into care processes and providers gaining a deeper appreciation, through successful patient encounters, of the role that screening could play in improving patient care. This also empowered the LNA to participate and engage providers in discussions about the scores of various patients.

Creating a Sustainable System

Several ongoing barriers to screening were observed, including a heavy reliance on the LNA for the process to run smoothly. Providers also had difficulty remembering to document scores, especially in the context of a busy clinic. Furthermore, in Spring 2012, the cancer center revised its workflow patterns

for patients undergoing active chemotherapy. As a result, some patients went directly to the infusion suite and bypassed the clinic altogether. Thus, providers had to remember to bring paper copies of the tool to the infusion suite or inform the nurse. Finally, the rooming process became more streamlined and patients had less time to complete the tool before providers entered the examination room.

To address these issues, the team collaborated with the cancer center's QI Director and formed a workgroup in March 2012 to consider strategies for creating a more sustainable process. The workgroup included clinic providers, the cancer center's QI Director and Support Services Director, reception, nursing, IT, social work, and volunteer services. The group identified that incorporating screening into the EMR was a critical step for project sustainability, because most of the clinic's workflow was now built around the EMR. The team explored several options, including using volunteers to assist with electronic completion of the NCCN-DTs at clinic check-in or delegating this responsibility to LNAs. Results would then be uploaded into the patient's chart and available to the provider during the examination. A pilot trial is planned as a next step.

Initial success of the project led to interest among other clinics in piloting similar distress screening protocols, representing an important step toward integrating a universal cancer center screening program.

Secondary Measures

Between January 2011 and April 2012, the clinic cared for 138 unique patients. Of these, 71.0% (n=98) were screened at least once with the NCCN-DT and 33.0% (n=46) were screened several times. In addition, 83.9% (n=47) of the 56 new patients were screened, consistent with previously described benchmarks for best performing cancer centers.²³

Table 1 outlines additional findings from the QI work. All patients identified with heightened distress were offered treatment, ranging from prescriptions for antidepressants to mental health referrals.

Patient and Provider Responses

Ten clinic patients were randomly selected for an interview to assess their satisfaction with process changes. These patients found that the NCCN-DT was easy and straightforward to complete. Several reported that they had been identified with heightened distress during their illness and received treat-

Figure 3 Treatment algorithm for managing heightened psychological distress.

Abbreviations: ADLs, activities of daily living; NCCC CARES, Norris Cotton Cancer Center Cancer and Related Events Survivorship Clinic.

^aAdapted from Holland et al,¹ ONS PEP Guidelines,²⁹ and Cancer Care Ontario Symptom management tools.³⁰

^bAn antidepressant handout was created by the team to guide treatment decisions and is available from the authors by request.

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ment that they described as beneficial. More than half of patients also expressed that integrating psychosocial care into the clinic was very important. As one patient stated, “if you’re stressed and going into a situation, my feeling [is that] you won’t be able to focus on what needs to happen.”

Providers similarly described that the availability of distress screening data and a treatment guideline enabled them to provide more comprehensive, patient-centered care. They found it reassuring to have access to data that helped confirm clinical suspicions for heightened distress. Providers also acknowledged that some challenges exist, including incorporating distress screening in the context of a very busy clinic, or encountering patients with complex circumstances. Providers expressed that it was very important to build screening into the EMR to relieve the burden of documentation, and to help track patient needs over time.

Discussion

As a result of this QI initiative, the process for addressing the mental health needs of patients with

HNCs improved. Through a series of PDSA cycles, 84% of new patients were screened with the NCCN-DT, and this screening rate met previously described benchmarks for best performing cancer centers.²³ Distress screening also became an integral component of clinic work flow. In fact, although initially only 29% of patient visits were formally assessed for distress every 2 weeks, the average rose to 74% by the end of this phase of the QI work. Furthermore, providers and patients reported that the process improvement produced meaningful changes, in that providers appreciated having a tool to identify high-risk patients and an evidence-based guideline to help inform clinical care. Patients valued the opportunity to discuss this aspect of their health and to know that the treatment plan addressed their mental and physical health needs.

Keys to Success

An analysis of the factors that may contribute to diagnoses of distress being missed in the HNC medical oncology clinic highlighted several important barriers, including providers’ lack of familiarity with treatment guidelines and limited access to mental health resources. To address these concerns, the screening

Table 1 Results of Distress Screening in Head and Neck Cancer Medical Oncology, January 2011–April 2012

	Frequency (n)	Suggested Benchmark ^a	Significance
Total seen	(138)		
Ever screened	71.0% (98)		
New patients screened ^b	83.9% (47)	84%	
Identified with heightened distress			
Distress score ≥4	47.0% (46)		<i>P</i> < .001 ^c
Source of heightened distress			
Emotional	28.0% (13)		
Physical	28.0% (13)		
Emotional and physical	35.0% (16)		
Other ^d	9.0% (4)		
Treatment of heightened distress			
Antidepressant	41.3% (19)		
Mental health referral	17.4% (8)		
Supportive care ^e	34.8% (16)		
Declined treatment	4.3% (2)		

^aBenchmark proposed by Jacobsen et al.²³

^bOf 56 new patients evaluated, 47 were screened for distress.

^cCompared with preintervention results, which suggested that only 18% of clinic patients (10/56) had heightened distress based on provider’s clinical judgment.

^dOther sources of heightened distress included family and practical problems.

^eSupportive care included interventions such as referral to support groups.

program was designed to support providers in managing psychological distress within the scope of their clinical practice. Patients with more complex needs were referred to mental health services. Providers responded favorably to these clinical decision aids.

Another integral component to the success of this QI project included the involvement of a team of individuals with a shared vision of improving the psychosocial care of patients. Providers were willing to engage in the improvement process to ensure that each patient received the best care possible at the right time. Screening rates improved significantly over time as the team worked systematically to understand barriers to care and to address them. In particular, modifying workflow patterns and engaging patients through visual aids such as posters helped foster a culture that welcomed routine distress screening. In fact, patients began to anticipate filling out an NCCN-DT as part of their clinic visit.

The decision to seek out and engage cancer center leadership was a critical component to creating momentum to sustain the screening program. The cancer center leadership recognized the important role this QI project played in furthering their mission and was invested in providing the necessary resources to make the project sustainable.

To the best of our knowledge, few studies have examined the role of QI initiatives in the context of cancer-related distress.^{33–35} Existing studies, however, reflect similar findings. For example, Cancer Care Ontario's QI initiative implemented the Edmonton Symptom Assessment System into multiple cancer centers and found that clinicians valued objective measurements of patient's physical and emotional status.³⁴ These authors reported that key elements for success included involvement of senior leadership, tracking of data over time, and providing guides and algorithms to involved clinicians.³⁴

Limitations

Factors that may make these findings less generalizable include the fact that results are representative of small sample sizes and a unique context and setting. The improvement effort was led by a team leader who had significant protected time and was supported by a dedicated coach and improvement specialist. This level of support may be difficult to replicate in other institutions.

Conclusions

QI methods can be used to design systems that more reliably identify and manage cancer-related distress. Specifically, cancer centers should consider the following steps in the design of a screening program: (1) characterize and address the unique needs of their patients and providers, (2) incorporate screening into established workflow patterns and EMR, (3) track outcomes of interest over time and share results with key stakeholders, and (4) involve senior leadership in improvement efforts.

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