Piloting an Automated Distress Management Program in an Oncology Practice

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Background: New administrative requirements to provide assessment and treatment for distress in patients with cancer, as well as concern for positive patient outcomes, highlight oncology practitioners’ need for a high-quality distress management program.

Objectives: Researchers designed, developed, implemented, and evaluated a nurse-led quality-improvement project that pilot tested a distress management program in an outpatient medical oncology practice.

Methods: The program used a tablet computer for data collection, immediate analysis, and recommendation display to provide individually tailored psychosocial coping recommendations, referrals, or both to nurses and patients.

Findings: Pre- and postprogram evaluations suggest that the program is feasible, safe, and effective for detecting and reducing distress in patients with cancer. In addition, tailoring psychosocial coping strategies to the patient’s emotional situation may have been key to the program’s effectiveness.

Healthcare systems in the United States, including private oncology practices, have mandates and guidelines to ensure that all patients with cancer are assessed, and, if necessary, treated for psychosocial distress. There are three primary administrative drivers for these practice changes. In 2012, the American College of Surgeons (ACS, 2015) Commission on Cancer (COC) created a standard about screening for distress that became a requirement for facility accreditation in 2015. About 1,500 accredited ACS COC sites throughout the United States are at risk of losing accreditation if they do not adhere to this new requirement. These 1,500 accredited sites treat 70% of newly diagnosed patients. The American Society of Clinical Oncology (JASCO), 2015 developed the practice-centered Quality Oncology Practice Initiative (QOPI®). This initiative requires about the same distress management program as the ACS COC standard to achieve accreditation (ASCO, 2015). In addition, the Patient Protection and Affordable Care Act (ACA) has a potential direct financial impact on oncology offices through the use of a reimbursement value-based payment modifier, established on quality indicators from the Centers for Medicare and Medicaid Services (CMS, 2014). CMS uses the Physician Quality Reporting System (PQRS), which specifically includes assessment and treatment of distress (Zhang & Polite, 2014). Several studies, however, indicate that oncology practices are still inconsistently assessing and offering treatment for distress, if at all (Donovan & Jacobsen, 2013; Hammelef, Friese, Breslin, Ribb, & Schneider, 2014; Jacobsen & Wagner, 2012).

To provide the type of care mandated and guided by these requirements, new processes embedded in medical oncology offices need to be created. Every patient should be routinely assessed for distress and, if significant distress is reported, a plan of care needs to be determined, provided, and documented. Considering the economic constraints and likely increase in the number of patients treated for cancer because of the ACA,
an operationally feasible, safe, and effective automated distress management treatment program may help practitioners meet these requirements.

Berwick (1992) described eight principles of improvement that positively affect quality of health care. The first step is the intention to improve. For this project, a small, privately owned medical oncology practice, the Cancer and Leukemia Center in Sterling, Michigan, recognized an opportunity to enhance psychosocial care to patients with cancer and meet the new required mandates and guidelines through an author-proposed distress management program. The providers agreed to implement a user-friendly assessment process and, if distress was identified, respond in an effective and efficient way to provide appropriate treatment. The providers agreed to use the National Comprehensive Cancer Network (NCCN), 2015 Distress Thermometer (DT) and Problem List as the screening instrument. The NCCN DT and Problem List is an internationally and well-accepted brief screening tool for distress that has been used successfully in cancer populations (Donovan, Grassi, Heather, McGinty, & Jacobsen, 2014; Lazenby, 2014). The NCCN DT uses a visual analog scale (e.g., a thermometer) for patients to indicate their level of distress from 0 (no distress) to 10 (extreme distress). Participants are asked to indicate distress on a daily basis for the past week.

The problems are grouped under practical, family, emotion, spiritual, and physical. Based on the NCCN DT and Problem List, the author designed and developed a treatment program that matched the patient-identified concerns from the Problem List with specific evidence-based coping strategies and referral information. The healthcare providers in the practice agreed to the decision algorithm and treatment protocols embedded in the program. The algorithms aligned the participants’ identified problems from the Problem List with the coping suggestions, such as referral information and/or specific suggestions on how to manage the problem. For example, under the area of emotional concerns, a participant would be provided referral information to a designated social worker located within walking distance of the office.

The Wayne State University Institutional Review Board determined that their approval was not necessary for this quality-improvement project; however, the practice’s privacy policies were observed.

The intent of this quality-improvement project was to implement and evaluate a pilot distress management program for a small ambulatory oncology practice to determine its feasibility, as well as impact on patient and practice. The distress management program needed to meet at least five of the six ACS COC requirements (ACS, 2016; Pirl et al., 2014) described in Table 1. The sixth requirement includes documentation in the minutes of a hospital committee meeting and did not apply to this project. Given that the project was administratively compliant, the project’s objectives were to evaluate the effects of the distress management program on patients and the practice by using the psychometrically sound NCCN DT and Problem List as a pre- and postprogram quantitative instrument and to evaluate practice effects using qualitative postproject individual interviews with the providers.

The participants were adults diagnosed with solid or liquid cancers.
cancer diagnoses in varying stages ranging from newly diagnosed and undergoing treatment to survivors in post-treatment. All of the patients were seen at the medical oncology office for a regularly scheduled office visit, which included meeting with providers for follow-up and test results as well as meeting with the office nurse for chemotherapy treatment and nadir visits. The intervention was an automated tailored distress management program. The self-reported concerns identified through the NCCN DT and Problem List were automatically processed in real time through a rule-based expert system to provide referrals, evidence-based psychosocial cancer coping strategy recommendations, or both to the participants.

Methods
Setting
The medical and nursing staff in the privately owned medical oncology practice consists of three board-certified medical oncologists and two board-certified nurse practitioners. The practice is located in a medical office building connected to a teaching hospital with more than 400 beds.

The providers in this practice believed that they regularly assessed their patients for pain and fatigue levels and often charted intuitively perceived information on the patient’s level of emotional distress, but this process was inconsistent and un-systematic among providers. They also realized the providers’ assessment of distress and the patient’s self-reporting may be affected by low distress assessment concordance ratings between patients and physicians (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Werner, Stenner, & Schüz, 2012). The providers wanted to meet the mandatory standards and guidelines for psychosocial care, but, more importantly, they wanted to do what was best for their patients.

Planning the Intervention
To meet the requirements for a user-friendly, inexpensive, and minimally disruptive distress management program that included an assessment and real-time, individually tailored coping treatment and referral suggestions, a tablet computer-based application was developed by the first author and Emol Health in Royal Oak, Michigan. The NCCN DT and Problem List would be displayed on the touch screen of the tablet computer, participant responses would be recorded electronically into the program, then processed by an expert system, and the recommendations would be displayed. The expert system refers to an automated means of creating specified linkages to the individualized recommendations for the participant according to what they indicated as problem areas.

The core reasoning process of the application leveraged the first author's more than 30 years of experience as a psychiatric mental health advanced practice nurse helping adult patients with cancer and their families cope with disease and treatment sequelae. Evidence-based coping strategies (Decker & Weller-Ferris, 2009), aligned with the Oncology Nursing Society’s symptom management guidelines (Brown, 2015), and the Oncology Nursing Society (2015) Putting Evidence Into Practice interventions, formed the basis for the cancer coping strategy recommendations and would be considered level VII evidence according to the hierarchy of evidence (Melynk & Fineout-Overholt, 2015). Level VII is the “evidence from the opinion of authorities and/or reports of expert committees” (Melynk & Fineout-Overholt, 2015, p. 11). The rule-based expert system operationalizing this knowledge consisted of a database of “if/then” rules to mimic the reasoning of an expert. For this project, these rules take the form of “if [participant concern(s)], then [nursing strategy recommendation(s) triggered].” More specifically, if a participant self-reported distress on the DT and/or identified concerns from the Problem List, then the participant would receive evidence-based coping strategies, provider-approved referrals, or a combination that matched their concerns. For example, if a participant reported feelings of depression, the automated system may recommend an exercise program tailored to the individual’s health status (Jacobsen et al., 2013), as well as the suggestion to plan the desired activity ahead of time. If practical and family problems are checked, then the participant would receive referral to a specific cancer resource center with an identified social worker, as well as national cancer support information. If emotional problems are checked, then the participant would receive response-specific coping strategies and referral to a specific cancer resource center with an identified social worker. If spiritual or religious concerns are checked, then the participant would receive a referral to spiritual support. If physical problems are checked, then the participant would receive referral to a specific oncology nurse practitioner.

When a patient with cancer needs assistance with coping, using such a system to receive expert-level recommendations may help mitigate levels of distress. Diagnosed patients with any type of cancer at any stage would be eligible to participate in the project based on the evidence that a large percentage of patients with cancer, regardless of site and stage, experience significant distress (NCCN, 2015; Werner et al., 2012).

Methods of Evaluation
The program was evaluated in three areas: (a) the degree to which the distress management program met at least five of the

<table>
<thead>
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<th>TABLE 2. Sample Characteristics (N = 32)</th>
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<tr>
<td>Characteristic</td>
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<tr>
<td>----------------------------------------</td>
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<tr>
<td>Average age of women (years)</td>
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<td>Average age of men (years)</td>
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<td>Characteristic</td>
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<td>Gender</td>
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<td>Male</td>
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<tr>
<td>Cancer type</td>
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<td>Head and neck</td>
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<tr>
<td>Lung</td>
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<td>Genitourinary</td>
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<td>Glioblastoma</td>
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six ACS COC requirements, (b) the impact on participants, and (c) the impact on practice processes.

Program processes were compared to ACS COC requirements to determine degree of adherence. The first author collected patient preintervention survey data at the practice during a five-day period in 2014. Patients who were identified by a provider (doctor or nurse practitioner) or an office nurse as distressed were asked to participate in the project. Providers and an office nurse identified patients who may be distressed by using visual cues and a myriad of other possible indicators, such as treatment status or test results. Those agreeable were approached by the first author, given further explanation about the project, and provided with a brief tutorial on using the tablet computer to complete the NCCN DT and Problem List. The computer automatically processed the results, and the appropriate number of hard copies of the DT results and recommendations were printed. One hard copy summary report was placed in the participant’s healthcare chart for the provider or nurse. The report used an alert-type format that indicated in red the exact self-reported DT score and identified problems to quickly indicate the overall distress level and the identified concerns from the Problem List. If a participant reported physical problems, a copy was given to the appropriate nurse practitioner, who placed it in the participant’s chart with a note documenting the action taken. Within minutes after the patient completed the survey, the author provided a paper copy of the summary and recommendations to the participants and reviewed the information with them. The participants were also provided a plan for the follow-up survey.

The postintervention NCCN DT and Problem List surveys were conducted via telephone no earlier than two weeks and no later than seven weeks after the baseline screening to allow the participants’ time to implement coping strategies, referral actions, or both. In addition, many of the participants had return visits to the providers within two to six weeks, so this time period allowed for ease of administration of the post-test. For the postintervention survey, four items were added to determine whether the participant used the coping recommendations and referral information provided. The first three items were questions:

- If provided, did you use the coping suggestions?
- If provided, did you follow up with your suggested referrals?
- If provided, did you follow-up by contacting the office nurse practitioner?

Finally, all participants received an open-ended request that stated, “Please share your thoughts about the distress management program.”

Descriptive statistics were used to characterize the population sample demographics and cancer types. Repeated-measures paired t tests were used to measure pre- and postintervention test results. McNemar’s chi-square test was used to detect changes in Problem List distress symptoms. Qualitative data from participants were systematically analyzed by looking for themes within the open-ended responses.

To determine the perceptions of the program on practice processes, two providers and one office nurse met individually with the first author within two days of the completion of the initial survey of all participants. The author queried the providers and nurses about the ease of implementation, effects of the DT, and assessment of probable effectiveness and efficiency of the intervention. These qualitative data were analyzed for recurring themes and summarized.

### Participant Characteristics

Thirty-two participants constituted the patient sample (see Table 2). Thirty-one of 32 participants completed the post-test survey. One participant died one week following the initial survey. Two providers and one office nurse also participated in follow-up interviews.
Results

Changes in mean scores on the DT, where 0 equals no distress and 10 equals highest distress, were used to measure the overall intervention effect on patients. A paired t-test determined significance. On the 10-point DT scale (n = 31), the preintervention mean was 4.3 (SD = 3) and the postintervention mean was 3.0 (SD = 2.8), and the difference was significant (p = 0.0166). The possible effects of the intervention by problem area and symptom are shown in Table 3. Statistics show that an overall downward trend exists in most problem areas, but numbers were small. The problem area most affected by the intervention was emotional problems. All participants reporting emotional problems on the NCCN DT and Problem List received referrals and coping recommendations (see Table 4). The highest-referred emotional problem in patients who were pre- and post-tested was “sadness and worry.” The emotional problem “worry” rated highest in follow-up testing.

To determine the perceived impact of the program on practice processes, individual interviews with providers were conducted. A medical oncologist and an oncology nurse practitioner participated. The interviews were instructed and sought to extract information on the impact of the program. The interviews were completed within two days of the final participant completing the pretest. Provider-reported response themes included (a) ease of use, (b) the importance of receiving distress information at the time of the office visit, (c) appreciation for the ability to choose treatment and referral options, and (d) surprise over the extent of physical concerns despite receiving chemotherapy education and ongoing symptom management.

Discussion

Significant positive changes in distress scores were measured in patients’ distress ratings from the pre- to post-test period. The quantitative data suggest that general participant effect, as measured by decreases in DT scores, was significant (p = 0.0166). Pre- and postprogram changes in the number of symptoms reported on the Problem List overwhelmingly trended positive, with an average of 36 symptoms reported pretest and 25 symptoms reported post-test. Changes were statistically significant for some symptoms. The scores of participants with emotional problems changed the most, suggesting that they seemed to derive the most benefit from the interventions. Additional analysis showed that, for participants with emotional concerns on the Problem List who implemented referral actions alone, benefits were not derived. Participants who implemented coping strategies alone benefited (p = 0.0455) for “worry” and “loss of interest in usual activities,” and participants who did both benefited more. This suggests a harmonious effect between referral actions and coping strategies. Implementing the coping strategies recommended by the expert system appeared to be a necessary factor in lowering levels of distress for these participants.

Increases in symptoms during the treatment period were likely related to the cancer trajectory and/or side effects from the treatment regimen and not the distress management intervention. Therefore, the intervention appeared to have no harmful or negative effects. No participants reported negative effects of the program. Analysis of the qualitative data suggests the program was feasible and acceptable to providers and participants.

Strengths

The distress management program implemented a stand-alone, user-friendly tablet computer application that collected data, processed the data through an expert system, and displayed recommendations and reports to the user. The digitization of core aspects of the intervention enables inexpensive, upward scalability. For example, the data collection could be implemented on any Internet-connected device. Among other benefits, this would allow the patient to complete the NCCN DT and Problem List prior to arriving for his or her regularly scheduled appointments or at any time throughout treatment.

Participants in this project had many different types of cancer diagnoses and varied by treatment stage. Some participants were in active treatment, and others were not currently being treated. This program was piloted in a small practice in the midwestern United States but could easily be scaled up to a larger healthcare system in any location.

Although not examined in detail as part of this project, the cost of program implementation would likely be far exceeded

<p>| TABLE 4. Emotional Distress Symptoms in Patients Who Received Referral and Coping Suggestions at Pre- and Post-Test (N = 32) |
|--------------------------------------------------|--------------------------------------------------|--------------------------------------------------|</p>
<table>
<thead>
<tr>
<th>Emotional Problem</th>
<th>Referral Follow-Up (n = 2)</th>
<th>Coping Follow-Up (n = 9)</th>
<th>Follow-Up With Both (n = 17)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pretest</td>
<td>Post-Test</td>
<td>p</td>
</tr>
<tr>
<td>Depression</td>
<td>1</td>
<td>2</td>
<td>0.3173</td>
</tr>
<tr>
<td>Fears</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Loss of interest in usual activities</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Nervousness</td>
<td>1</td>
<td>2</td>
<td>0.3173</td>
</tr>
<tr>
<td>Sadness</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Worry</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Note. McNemar’s chi-square test was used to test the changes in distress symptoms.
Implications for Practice

- Meet the challenges of distress management through an automated program.
- Tailor psychosocial interventions to patients’ emotional situations.
- Provide patients with immediate referral and coping strategies to manage their distress.

by the benefits of retaining accreditation and income from the Centers for Medicare and Medicaid (2014) value-based payment modifier. This aligns with previous studies that indicate minimum delivery cost and financial offsetting benefits when providing psychosocial support with or without the use of automated screening and treatment methodology (Carlson & Bultz, 2003; Northouse et al., 2014; Thomas, Nandamohan, Nair, Robinson, & Pandey, 2009). This suggests that the program may be efficient from the practice standpoint in addition to being effective for patients. The patients and providers thought that the system was user-friendly and improved the overall care provided at the office. The patients appreciated being able to move through the program at their own pace, as well as receiving quick feedback for coping suggestions, referral therapists, and social workers that were located on site.

Limitations

Although the digitization may enhance implementation and usability, the small sample size at a single practice inhibits generalizability to other practices and patients. In addition, the analysis may not allow a true effect to be detected with enough power because of the small sample size. The DT scores were significantly reduced between the pre- and post-test, but additional studies are needed to fully understand the application of these findings in other clinical sites. When participants were seen in the clinic, they may have had worries that were reduced over time as a result of normal adjustment to new health problems or other factors, so time may have been a confounding variable. The pretest was taken by the participant on the tablet computer, and the post-test was conducted via telephone interview by the author or the practice’s nurse practitioner because of time constraints. This threatens validity through procedural inconsistency and a possible Hawthorne effect. Although successful in evaluating possible outcomes and processes, this pilot program was not designed to determine cause-and-effect conclusions. Randomized, controlled trials are needed to enable more definitive statements regarding the effects of coping strategies and referrals on DT scores and Problem List outcomes. Because no significant outcome or process barriers were found in this pilot program, conducting randomized, controlled trials is the next logical step.

Conclusion

Oncology nurses and practices across the country are affected by new requirements to provide distress assessment and treatment to people with cancer. The intent of this pilot project was to design, implement, and evaluate a tablet-based, distress assessment and management program in a small ambulatory oncology practice. A systematic, automated, tailored distress management program that meets administrative requirements and is feasible, safe, and effective may serve to increase the probability of oncology practices successfully decreasing distress in their patients.

References


