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Oncology Outpatient and Provider Responses to a Computerized Symptom Assessment System

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Abstract

Purpose/Objectives—To assess patient and provider responses to a computerized symptom assessment system.

Design—Descriptive, longitudinal study with retrospective, longitudinal medical records review.

Setting—University-based National Cancer Institute–designated outpatient cancer center.

Sample—80 oncology outpatients receiving chemotherapy, 8 providers, and 30 medical records.

Methods—Patients completed the computerized assessment during three chemotherapy follow-up clinic appointments (times 1, 2, and 3). Patient usability was recorded via an observer checklist (ease

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of use) and the computer (completion time). Patient satisfaction and impact were assessed during telephone interviews two to three days after times 1 and 3 only. Provider usability and impact were assessed at the end of the study using a questionnaire and focus groups, whereas effect on provider documentation was assessed through chart audits.

Main Research Variables—Patient usability (ease of use, completion time), satisfaction, and impact; provider usability and impact.

Findings—Patients reported good usability, high satisfaction, and modest impact on discussions with their providers. Providers reported modest usability, modest impact on discussions with patients, and had varied reactions as to how the system affected practice. Documentation of symptoms was largely absent before and after implementation.

Conclusions—This system demonstrated good usability and satisfaction but had only a modest impact on symptom-related discussions and no impact on documentation.

Implications for Nursing—A computerized system can help address barriers to symptom assessment but may not improve documentation unless it can be integrated into existing medical records systems.

Careful symptom assessment is vital for providing quality cancer care (Institute of Medicine, 2003). However, systematic assessment is complex. Patients with cancer may experience multiple symptoms at any one time (Patrick et al., 2004) but tend not to spontaneously share information about those symptoms (Stone et al., 2000; Ward et al., 1993). Healthcare providers also may find addressing multiple symptoms during a single patient encounter difficult or time-consuming. In addition, provider documentation can be incomplete or may not reflect patients' symptoms (DeVon, Ryan, & Zerwic, 2004; Stromgren, Groenvold, Pedersen, et al., 2001; Stromgren, Groenvold, Sorensen, & Andersen, 2001). Computerized symptom assessment systems have been proposed as a means of overcoming these barriers. Previous reports suggest that touch screen systems with printed reports are feasible, can be completed in a reasonable timeframe, and may increase discussions of symptoms initiated by providers. This article describes patient and provider responses to a computerized symptom assessment system that was pilot-tested in a university-based National Cancer Institute–designated outpatient cancer center.

Literature Review

Lack of Symptom Assessment and Documentation

More than two decades of research indicate that patient- and provider-related barriers interfere with adequate symptom assessment. Patients may not inform providers of their symptoms. In one study, 52% of 538 patients with cancer had never informed their physician they were experiencing fatigue (Stone et al., 2000). As a result, only 14% had received any treatment for fatigue, and 33% reported that their fatigue was being poorly managed. In addition, providers may have difficulty identifying symptoms. In a mixed sample of 1,109 outpatients with cancer, oncologists and oncology nurses had limited ability to recognize moderate-to-severe depression (McDonald et al., 1999; Passik et al., 1998). Patients and providers may feel pressure to restrict discussion of symptoms because of limited time during a typical clinic visit (Rogers & Todd, 2000).

Provider documentation may not accurately reflect patients' symptom experiences. One study indicated that many symptoms and issues were reported more often by inpatients undergoing palliative care than were documented by physicians or nurses (Stromgren, Groenvold, Pedersen, et al., 2001; Stromgren, Groenvold, Sorensen, et al., 2001). Physician documentation agreed with patient reporting of pain only (Stromgren, Groenvold, Pedersen, et al.) and nursing

documentation agreed with patient reporting of pain and functioning only (Stromgren, Groenvold, Sorensen, et al.).

Use of Computers in Symptom Assessment

Computerized systems may help standardize symptom assessment, documentation, or management (Berry et al., 2004; Detmar & Aaronson, 1998; Mullen, Berry, & Zierler, 2004; Taenzer et al., 2000; Velikova et al., 1999; Wilkie et al., 2001, 2003; Wright et al., 2003). Previously described systems have been separate from existing electronic medical records systems, perhaps because of the inherent complexities involved in integrating two or more systems. Other commonalities across systems have included use of desktop or laptop touch screens (Berry et al.; Mullen et al.; Velikova et al.; Wilkie et al., 2001, 2003; Wright et al.) and printed reports for patients or healthcare providers (Berry et al.; Detmar & Aaronson; Mullen et al.; Taenzer et al., 2001; Wright et al.) and inclusion of questions from standardized questionnaires (Berry et al.; Detmar & Aaronson; Taenzer et al.; Velikova et al.; Wilkie et al., 2001, 2003; Wright et al.). At least one article suggested computerized and paper assessments were comparable (Velikova et al.). Compared to paper, computerized assessments require less or comparable time to complete, provide similar data, and result in reliable assessments. In one computerized study, three-hour test-retest reliability was equal to or greater than 0.75 for 15 of 17 subscales on a quality-of-life instrument; the remaining anxiety and depression subscales each showed 56% agreement (Velikova et al.).

Studies overwhelmingly indicate patients’ responses to these systems are favorable. Inpatients and outpatients have reported that various systems are easy to use (Berry et al., 2004; Mullen et al., 2004; Wilkie et al., 2001, 2003; Wright et al., 2003), and patient satisfaction generally is high (Berry et al.; Taenzer et al., 2000; Wilkie et al., 2001, 2003). Patients either clearly prefer computerized over paper assessments (52%) or are indifferent (26%) (Velikova et al., 1999). In addition, patients indicate these systems improve communication with providers (Taenzer et al.). In one randomized study, 27 patients in a computerized assessment (with printout) group reported a significantly higher number of concerns being addressed during clinic visits than 26 patients in the usual care group (Taenzer et al.).

Only a few studies have evaluated provider responses to computerized systems. Although providers agree that these systems are useful, the perceived or actual impact has been mixed. When 12 oncology clinicians were surveyed, they agreed that a computerized system was helpful in identifying concerns and needs of patients, promoting communication, and guiding clinician-patient interactions (Mullen et al., 2004). Similarly, 13 physicians agreed that data from computer-generated printouts were a little to very useful during 63%–67% of 315 patient visits (Wright et al., 2003). However, they also indicated that the data provided added information in only 24% of visits and affected patient management in only 5% of visits (Wright et al., 2003). Conversely, studies have found that computerized systems increase the number of provider-initiated, symptom-related discussions (Detmar & Aaronson, 1998) and increase the number of patient concerns that are documented in medical records (Taenzer et al., 2000). Unfortunately, Taenzer et al. found documented treatment actions did not increase.

Key Points

- During chemotherapy follow-up clinic appointments, oncology outpatients reported good usability, high satisfaction, and mixed impact with a computerized assessment system, targeting multiple symptoms, symptom management strategies, and symptom outcomes.

- Oncologists and oncology nurses (i.e., providers) reported modest usability for the computerized symptom assessment system and suggested several changes to improve the system.
- Despite patient reports indicating symptoms were well addressed, lack of symptom documentation in medical records suggest that the computerized system did not affect provider documentation.

Model Guiding Conceptualization of the Computerized Symptom Assessment System

The University of California San Francisco School of Nursing Symptom Management Model (Dodd et al., 2001; Larson et al., 1994) guided the initial conceptualization of the computerized assessment system. The system discussed here was designed to include all three of the separate, yet interrelated components of the model: symptom experience, symptom management, and outcomes. For the system, symptom experience included patients' perceptions of the severity or frequency of symptoms. Symptom management included types of treatment strategies used and their effectiveness. One outcome, functional status, was included based on empirical research showing an association between the assessed symptoms and functional impairment (Escalante et al., 2001; Kim, McGuire, Tulman, & Barsevick, 2005; Savard & Morin, 2001; Serlin, Mendoza, Nakamura, Edwards, & Cleeland, 1995). To address the model's premise that symptoms can occur independently or within clusters, multiple symptoms were assessed. Programmed skip patterns allowed patients to skip all questions related to a symptom they were not experiencing. Patients experiencing one symptom completed questions only for that symptom. Patients experiencing two symptoms completed questions for both, and so forth. The presence or absence of each symptom was verified by patients rather than assumed a priori at each time point, which was consistent with the model's premise that symptom clusters can change over time.

Pain, fatigue, depression, anxiety, and sleep issues were included based on available literature. A 2002 National Institutes of Health State-of-the-Science conference on symptom management in cancer suggested that pain, fatigue, and depression should be studied in relation to anxiety and sleep issues (Patrick et al., 2004). Subsequently, several studies have reported a high degree of association among these symptoms in a variety of populations of patients with cancer, including those receiving chemotherapy (for review, see Barsevick, 2007).

Methods

Setting and Design

The present study was conducted at a National Cancer Institute–designated clinical cancer center in the midwestern United States, serving urban and rural populations. The study design incorporated two components (see Figure 1). Using a prospective, longitudinal design, system usability was assessed in the clinic and patients completed the computerized assessment during three chemotherapy follow-up appointments (times 1, 2, and 3). Patient satisfaction with the computerized system and perceived impact on discussions with providers were recorded during follow-up telephone calls two to three days after times 1 and 3 only. Provider usability and perceived impact were recorded once near the end of the study using questionnaires and focus group discussions. In addition, a retrospective, longitudinal design was used to assess whether the system affected provider documentation. A random sample of charts was selected from the population of patients seen in clinic prior to implementation of the computerized assessment. Documentation for those records was compared to documentation from a random sample of records of patients who participated in the computerized assessment.

Computerized Assessment System

The computerized assessment system was created by the study investigators and programmed by staff at People Designs, Inc. (Durham, NC), to run on touch screen tablet computers (Toshiba® Terca M4-5435, Toshiba Satellite R1-5-S822) and mobile printers (Canon® Pixma iP90, Cannon i80). Each computer had a 14.1" display. The program was designed to run as a stand-alone application on Microsoft® Windows® XP and required no other software. Once the participating patient arrived in the clinic, a research assistant opened the application, entered the patient's study identification number or name, and handed the tablet computer to the patient. Staff entered first, last, and preferred names at time 1 so that the computer could greet patients by name at all assessment time points (e.g., Welcome, Bob; Welcome back, Bob). Patients then used a stylus with the touch screen to answer 7 pain questions; 4 fatigue questions; 18 feelings questions to address depression, anxiety, and emotional distress; and 4 sleep questions. Questions were used with permission from standardized instruments, including the Brief Pain Inventory (Daut, Cleeland, & Flanery, 1983), the Brief Fatigue Inventory (Mendoza et al., 1999), the Hospital Anxiety and Depression Scale (Smith et al., 2002), the National Comprehensive Cancer Network (2006) distress scale, and the Pittsburgh Sleep Quality Index (Beck, Schwartz, Towsley, Dudley, & Barsevick, 2004). Demographic questions also were included at time 1 only.

Once the patient completed the assessment, a research assistant connected the computer to a dedicated color printer to generate two color-coded printouts. The assistant gave one printout to the patient, explained it as needed, and asked the patient to validate that the output accurately reflected how he or she was feeling. The assistant attached the second printout to the patient's chart for review by the provider. Providers were not required to use the printouts. Data from the assessments were available to the investigative team as .csv files saved to the hard drive of the tablet computer. These files were regularly copied to the university servers but could not be linked to electronic medical records at the time of the study.

The format of printouts was developed with input from providers. Printouts provided a graph of patient scores for each symptom over time. Each graph displayed a line indicating the cutoff score at which a problem should be addressed. For example, lines demarcating mild, moderate, and severe pain and 85% sleep efficiency were included.

Sample

Eligible patients were age 18 and older, were diagnosed with any stage solid tumor, were within 60 days of starting chemotherapy and still receiving chemotherapy treatment at time 1, had an anticipated life expectancy of six or more months, and were not diagnosed with cognitive impairment or blindness. Eligible providers were oncologists and oncology nurses who were directly caring for patients enrolled in the study.

Eligible medical records were from patients age 18 or older with any stage solid tumor who were receiving chemotherapy treatment and being seen for follow-up visits in the clinic and who had no diagnosed cognitive impairment. Records were matched by the clinic. Preimplementation records were from patients who had received chemotherapy during a three-month period prior to implementing the computer system. Postimplementation records were from patients enrolled in the study.

Procedures

The scientific review committee and the institutional review board at the cancer center approved all study procedures. For patient recruitment, a waiver of authorization to use protected health information for study recruitment was obtained. This allowed study staff to review patient medical records and discuss potential eligibility with clinic staff. Clinic staff

obtained patient permission for study staff to approach and introduce the study. Study staff then introduced the study, confirmed eligibility, and distributed study materials as appropriate. Patients provided written, informed consent at this initial introduction or were given the option to take materials home and consent at the subsequent clinic visit. Consented patients completed demographic questions and the computerized assessment on arrival for the next clinic visit. As an incentive, patient participants were given a \$20 gift card to a local retail store each time they completed the computerized assessment (\$60 total). When patients were in the clinic, study staff scheduled follow-up phone calls two to three days after time 1 and time 3 computer assessments to assess patient satisfaction and perceived impact.

Providers were recruited toward the end of the study, after almost all patients had been recruited. The principal investigator or project manager contacted providers by phone or e-mail and invited them to provide feedback by answering a questionnaire and taking part in a focus group discussion. Focus groups were scheduled at mutually convenient times and refreshments were offered. At the start of the meeting, providers signed an informed consent form and completed a satisfaction survey. They then were asked a series of open-ended questions. Focus groups were tape-recorded and transcribed verbatim, although a meeting with one physician was not. Thematic analysis of focus group data was performed by study personnel.

Medical records were selected randomly by study staff. First, a random sample of 15 patients was selected from among the population of patients seen in clinics prior to implementation of the computerized assessment system. None of those patients subsequently participated in the computerized portion of the study. Second, a random sample of 15 patients who had consented and participated in the computerized portion of the study was selected. Patients were matched on disease site and treating physician. Pairs of study personnel reviewed each medical record and evaluated the type and amount of symptom documentation present in two different electronic medical records systems—one used primarily by physicians and one used primarily by nurses. Complete agreement was achieved through discussion for all records.

Measures

Sample description—Patients completed demographic questions, including two items about their prior experiences with computers adopted from previous research (Finkelstein, Cabrera, & Hripcsak, 2000). Patients indicated whether they regularly used a computer at home or work and, if so, how often using a seven-point scale. Type of cancer diagnosis was retrieved from medical records. Providers' gender and credentials (e.g., oncologist, oncology nurse) were recorded by study staff at the time providers consented. Medical records were de-identified. Only gender and clinic were recorded.

Patient responses—Usability (ease of use and completion time) was assessed each time the computerized assessment was used. Ease of use was assessed by an investigator-designed observer checklist. Study staff unobtrusively watched patients complete the computer assessment and documented the type and number of requests for help from the patient to the staff, family member, or others, as well as any issues with the computer, stylus, software, printouts, or other aspects of the system. Session completion time was recorded automatically by the computer in elapsed minutes and seconds. If patients did not complete the assessment for whatever reason, no time was recorded.

Patient satisfaction and perceived impact of the system were assessed during the follow-up phone calls using an investigator-designed questionnaire. The format of questions varied. For 17 items, patients indicated whether they agreed or disagreed with positive and negative statements about different aspects of the computer system (e.g., questions, computer, printout). For other items, patients indicated how much help they needed from 1 (none) to 3 (a lot) and

how helpful the printout was to them from 1 (not at all) to 3 (extremely), and rated satisfaction with the amount of time spent discussing symptoms from 1 (less than I would have liked) to 3 (just the right amount). Patients were asked whether they were having pain, feeling tired, feeling sad, feeling anxious, or were sleeping poorly in the week before they saw their doctor (no or yes). If they reported having a symptom, they were asked if they had talked about it with their physician (no or yes) and if the computer or printout helped them to talk about it (no, yes, or don't know).

Provider responses—Providers reported usability (ease of use) and impact at the end of the study using two methods. First, using an investigator-designed questionnaire, providers indicated whether they agreed or disagreed that the system disrupted clinic flow, added to the length of patient visits, or helped them to manage or discuss the various symptoms. For another item, providers indicated whether the system resulted in patients asking fewer, the same, or more than the usual number of questions about symptoms. Providers were asked whether the project stimulated discussion about symptoms with colleagues and to provide an overall rating of how well they believed patients responded to the system on a scale from 1 (very positively) to 4 (very negatively). Second, during focus groups, providers responded to questions designed to elicit positive and negative feedback about the system as well as suggestions for future consideration. Additional probing or clarifying questions were used as needed.

The impact of the system on provider documentation was assessed using an investigator-designed medical record review form. The form consisted of a table with rows for presence and type of documentation and columns for each symptom of pain, fatigue, depression, anxiety, and sleep issues. For each symptom, reviewers placed a check mark in the appropriate box to indicate whether documentation was present or absent. Reviewers marked whether documentation was absent (e.g., no mention of pain in the medical record), indicated the symptom was assessed but denied by the patient (e.g., patient denies pain), or indicated the symptom was assessed and confirmed by the patient (e.g., patient reports severe pain). For the latter, reviewers also recorded whether further documentation pertaining to assessment (e.g., intensity, frequency, distress, quality) or management (e.g., type or effectiveness of treatments, treatment plan) was present.

Results

Sample Description

Patients—By screening 156 consecutive patients, 115 eligible patients were identified, with 108 consenting and 80 completing all assessments. Attrition among consented patients was related to ineligibility ($n = 11$), no longer being seen in the clinics ($n = 6$), death ($n = 3$), withdrawal by study staff ($n = 3$), scheduling issues ($n = 2$), loss of interest ($n = 2$), or other ($n = 1$).

The 80 patients were mostly male (65%); non-Hispanic (91%), Caucasian (90%), or African American (5%); married or living with a partner (72%); and not currently working (66%). Median household income was \$40,000–\$80,000. Mean age was 57 years ($SD = 14$, range 23–83). Mean education was 14.6 years ($SD = 3.1$, range 2–20). The most common cancer diagnosis was sarcoma (35%). Other diagnosed cancer sites included gastrointestinal (31%), prostate (18%), other genitourinary (10%), and head and neck (6%). Most patients reported regularly using a computer at home or work (85%). Frequency of computer use was as follows: nearly every day (70%), at least once per week (13%), one to three times per month (7%), less than once a month (3%), or never used (7%).

Providers—Providers included four oncologists and four oncology nurses who completed the survey and focus group questions.

Medical records—Medical records used for the preimplementation data were from 11 male patients and 4 female patients who were seen in solid tumor clinics. Medical records used for the postimplementation data were from nine male patients and six female patients seen in solid tumor clinics.

Patient Responses

Usability—Table 1 shows percentages of patients needing help from research staff or family and friends at each time point and for what reason. Also included are the percentages of system issues that arose during each session. One of the most frequent issues was not knowing how to advance to the next screen because the system required patients to record their answer and then hit the “next” key. Patients thought the screen should advance automatically once they inputted their answers. In addition, the stylus was difficult to use and frequently malfunctioned. Patients also requested help to understand and answer computerized questions.

Table 2 compares ease of use (requests for help and system issues) and completion time over the three assessment points. Requests for help from research staff significantly decreased over the three time points. Requests from family and friends decreased from time 1 to 2 and then remained stable at time 3. Number of system issues significantly decreased over time. Session completion time also significantly decreased, indicating patients became faster at using the system over time.

Satisfaction and impact—Table 3 shows the percentages of patients agreeing with various survey items at time 1 and time 3. At both time points, more than 80% of patients reported that the computer included understandable and appropriate questions, was likeable and easy to use, the printouts were likeable and accurate, the project was worthwhile, and they would recommend the system for all patients with cancer. On average, about half of the patients agreed that the computer or printout made it easier to talk with their doctor or that the doctor used the printouts. Fewer patients reported that they spent more time discussing symptoms. A small percentage reported feeling more rushed to complete the assessment at time 1, but this decreased significantly by time 3. Satisfaction on other items did not change over time.

Satisfaction on the three additional items with varied response options (not shown in Table 3) also was high. Patients reported needing significantly less help over time ($p = 0.04$). At time 1, 60% of patients needed no help, 37% some help, and 3% a lot of help. At time 3, 69% needed no help and 31% some help. In addition, most patients agreed the printout was helpful to them. At times 1 and 3, patients rated the printout as somewhat helpful (60%, 70%) or extremely helpful (20%, 25%), respectively. Fewer patients felt the printout was not helpful (15%, 5%) or were unsure (5%, 0%). When asked about time spent talking about symptoms with their provider, almost all patients reported feeling they had spent just the right amount of time (92% at time 1, 95% at time 3).

Impact—Data shown in Table 4 indicate that most patients who had a given symptom discussed it with their provider ($\geq 64\%$ of patients at both time points). Although fewer than half of those patients felt the computer or printout helped them discuss the symptom with their provider at time 1, slightly more than half felt it helped at time 3. This change was not significant. At times 1 and 3, fatigue was the most prevalent symptom and discussion of fatigue was facilitated by use of the computer and printout. By time 3, the computer and printout helped patients talk about depression and anxiety the most.

Provider Responses

Usability—Most providers felt the system did not add to the length of clinic visits (62.5%), did not disrupt clinic flow (62.5%), resulted in the same number of questions about symptoms

from patients (100%), and was positively received by patients (100%). Usability data from the focus groups are presented in Figure 2. When questioned, providers described positive and negative aspects of the system and suggested improvements to consider in the future.

Impact—Percentages of providers who believed the computerized system enhanced symptom management were pain 37.5%, fatigue 50%, depression 62.5%, anxiety 75%, and sleep issues 50%. Percentages of providers who felt the computerized system enhanced discussions with patients were pain 50%, fatigue 62.5%, depression 87.5%, anxiety 75%, and sleep issues 62.5%. In the focus groups, providers had varied reactions as to how the system affected provider-patient interaction, documentation of symptoms, and treatment.

Medical records review showed very little documentation of symptoms by oncologists or oncology nurses in the outpatient clinic records. Most had no documentation for certain symptoms (i.e., no reference to or information about that symptom). For oncologists, prior to implementation of the computerized system, most charts had no documentation related to depression (53%), anxiety (73%), or sleep issues (67%). Similarly, after implementation, most charts had no documentation by oncologists for depression (73%), anxiety (73%), or sleep issues (80%). For nurses, prior to implementation of the system, 93%–100% of charts had no documentation related to fatigue, anxiety, depression, or sleep issues. After implementation, 50% of charts contained some nursing documentation related to fatigue, although 100% still contained no nursing documentation of anxiety, depression, or sleep issues.

Discussion

Computerized systems have been proposed as a means of overcoming barriers to systematic symptom assessment in patients with cancer. Previous studies suggested that patients' responses to such systems are favorable. This article describes patient and provider responses to a computerized symptom assessment system that was pilot-tested in a cancer center.

Patients encountered some minor difficulties but rapidly learned to use the computerized assessment system over time and reported being highly satisfied with several aspects of the system. Although about one-fourth of patients requested help or encountered a problem with the system at time 1, with each subsequent assessment, patients requested less help, encountered fewer system issues, and more rapidly completed the questions. On average, patients required 25% less time to complete the assessment by time 3 than they needed at time 1. Although other investigators have evaluated time required to complete various computerized assessment systems (Berry et al., 2004; Detmar & Aaronson, 1998; Velikova et al., 1999; Wilkie et al., 2001, 2003), no reports were found comparing this over time. Because the vast majority of patients agreed they were satisfied with the system and would recommend it for other patients, continued use is likely to be well received by other patients. However, issues with usability of the stylus need to be addressed in future iterations of the system. Recommendations include automatically advancing to the next screen after the patient records an answer, increasing the size of the area on the screen that is receptive to the stylus, or eliminating the need for a stylus by changing to a fingertip-touch pad screen.

Despite good usability and satisfaction, patients had mixed reactions as to whether the system helped them discuss issues with their providers. Findings were similar whether patients were asked about discussions in general or discussions of specific symptoms. At time 1, less than half to a third of patients reported that one-time use of the system had improved their ability to talk with their provider. After using the system three times (time 3), about half of the sample felt it had positively improved discussions with their provider. With training, the program appeared to help patients discuss depression and anxiety the most. Although these changes were not statistically significant, they may be clinically meaningful. Others have attested to a

positive impact on patient perceptions of communication about symptoms or on the number of symptoms addressed during clinic visits (Taenzer et al., 2000).

The limited sample of providers similarly indicated good usability and mixed impact. The system was not perceived as disrupting clinic flow or adding to the number of patient questions needing to be addressed. In terms of impact, providers reported that the system raised their awareness and management of psychological symptoms (depression and anxiety) but had little impact on pain, possibly because pain was more common and already being well addressed. Providers also reported that patients seemed “primed” or more ready to discuss symptoms after using the system and that the system helped them to focus on issues and stay on time with appointments. Issues identified by providers included difficulty interpreting the printout and the lack of sufficient detail. Provider suggestions for improvement that will be important to incorporate into future system versions included adding other symptoms that are not routinely addressed, assessing the significance of the symptom to the patient and whether intervention is needed or desired, adding more data points to the printout to allow visualization of trends over time, and giving the printout to the physician and nurse. Focus group data suggested additional ways to measure impact (e.g., quality or depth of discussion related to the “priming” effect, length of clinic visit) that could be incorporated into future studies.

The lack of symptom documentation in the medical record was surprising given patient responses. Patient data indicated that the majority of patients talked to their doctors about specific symptoms at times 1 and 3 and that they were satisfied with the amount of time spent discussing symptoms. Thus, documentation at the cancer center may not reflect all symptoms addressed during a clinic visit, a problem previously reported by others (Stromgren, Groenvold, Pedersen, et al., 2001; Stromgren, Groenvold, Sorensen, et al., 2001). This, in part, may be a result from the widespread use of paper symptom assessment forms that are not formally approved by the institution and, therefore, are not maintained in the file and do not become a permanent part of the medical record. An alternative explanation may be that oncology nurses in the cancer center spend significant time assessing and managing symptoms via phone consultations with patients between clinic visits. Assessment and interventions delivered during these telephone consults may not be fully documented in the medical records.

As other studies have shown, the utility and impact of this computer-assisted symptom assessment system may be limited, in part, because it was not an integral piece of the medical record. Providers in the present study stated that a uniform system focused on symptom management that integrated input from patients and all care providers (physicians, nurses, nutritionists, psychologists) was needed to provide quality cancer care. This system should be an integral part of electronic medical records wherein all relevant symptoms can be assessed routinely and the effectiveness of symptom management strategies evaluated.

Nursing Implications

Research

Considerations for future research include minimizing system issues as discussed previously. Second, consideration should be given to a brief training program to enable patients and providers to use the printout to their best advantage. Third, usability and satisfaction do not appear to be good indicators of impact and, thus, impact should be measured as a separate variable. Fourth, whether symptoms are adequately documented in medical records in institutions that use informal paper assessment forms should be evaluated.

National efforts are under way to establish systems to standardize the routine collection of patient-reported outcomes, including symptoms. The National Institutes of Health (2007) recently funded a roadmap initiative titled “Patient-Reported Outcomes Measurement

Information System” (PROMIS). This initiative “aims to revolutionize the way patient-reported outcome tools are selected and employed in clinical research and practice evaluation.” Outcomes researchers from National Institutes of Health and seven collaborating institutions are working to establish a national resource for accurate and efficient measurement of patient-reported symptoms and other health outcomes in clinical practice. PROMIS aims to develop ways to measure patient-reported symptoms, such as pain and fatigue, and aspects of health-related quality of life across a wide variety of chronic diseases and conditions, including cancer.

The Oncology Nursing Society (2007) also has begun developing a core dataset to address nursing-sensitive patient outcomes as one strategy to promote and support multisite research in oncology. Because symptom assessment and management are the responsibility of oncology nurses in many settings, these will likely be significant components of the nursing-sensitive patient outcomes dataset. Plans are under way to finalize the priority outcomes and measures and to begin testing the data collection system in 2008.

Researchers need to stay informed about systems that are under development to improve symptom management for patients with cancer in a way that is cost effective. The challenge in the future, however, may not be a shortage of computerized systems but the lack of integration of these systems, which would allow patients and all of their healthcare providers to communicate effectively with one another about symptoms.

Practice

Computerized systems have several implications for oncology nursing practice. Clinic nurses should be aware that high patient satisfaction ratings may not equate with high comfort in communicating symptoms with providers. To improve communication, nurses may need to encourage discussion of symptoms or provide education on communication strategies. Nursing managers should be aware that an additional resource nurse or other staff person may be needed to help with trouble-shooting when similar systems are newly implemented. Patients appeared to need the most assistance the first time they used the system and then became faster and more proficient users. Thus, the need for such a resource person is likely to decrease over time. In addition, data showing underdocumentation of symptoms should remind clinic nurses and nurse managers of the importance of adequate documentation of symptoms.

Conclusions

A computerized symptom assessment system designed for patients with solid tumors at a university-based outpatient clinical cancer center demonstrated good usability and satisfaction from patients and providers, modest impact on discussions about symptoms and symptom management, and no significant effect on provider documentation of symptoms. Integrating similar systems with existing electronic medical records is strongly encouraged.

Acknowledgments

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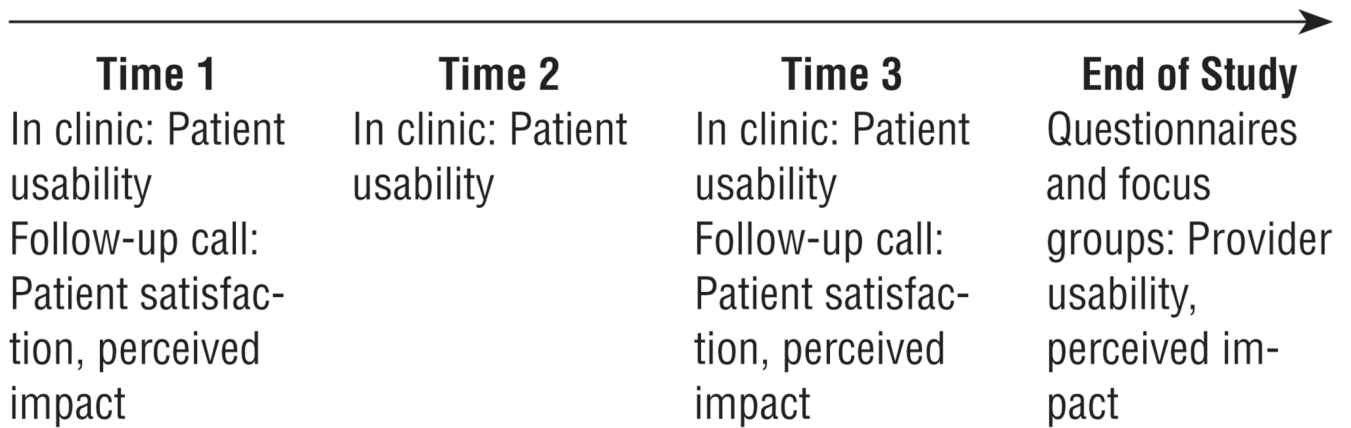
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Prospective, Longitudinal Component



Retrospective, Longitudinal Component

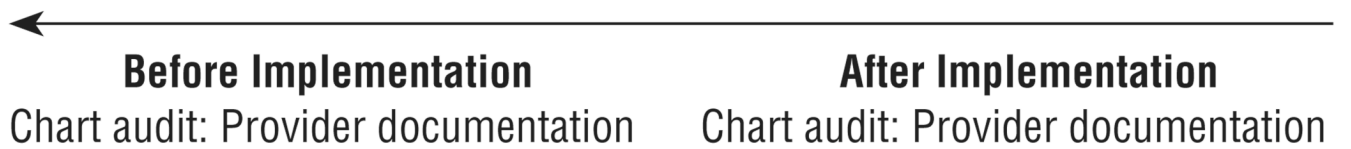


Figure 1.
Study Design and Assessment Schedule

Focus Group Questions Responses

Usability

What was your general impression of how this computerized assessment worked in your clinic? What worked well? What problems did you encounter? What would you like to see done differently?

Pros

- Computer-savvy patients (i.e., able to use the system)
- Having assistant helped patient
- No disruption in clinic flow
- Patients felt watched over and that their physician was more aware of symptoms.
- Helped soothe nerves of patients waiting to see physician

Cons

- Printout problems (i.e., no patient name, needed to learn how to interpret, unable to quickly interpret, and difficult to see changes because of symptom management strategies)
- Replicated other assessments already being done
- System could not provide detailed information, so it did not substitute for history or physical.
- No agreement on best time to do assessments (e.g., clinic visit, home monitoring)
- No agreement on whether system identified patients who tend not to verbally report symptoms

Suggested Changes

- Add other symptoms not routinely assessed.
- Add whether patient wants or needs intervention.
- Add more data points to see trends over time; add descriptors and serial data such as better, worse, or the same since last visit.
- Give printout to nurse and physician.
- Plan to schedule patient earlier to allow time to complete.

Impact

Did you think it was beneficial to have this computerized assessment in your clinic? How did it affect how you interacted with your patients? How did it affect how the patients interacted with you? How did it affect your documentation of symptoms? How did it affect your treatment of symptoms?

Pros

- Made providers more aware of symptoms, particularly those not routinely assessed, such as depression and anxiety
- System “primes” the patient for provider assessments (i.e., the patient already was thinking about symptoms).
- System helped to focus on problems and stay on time with appointments.
- Confirmed importance of symptoms patients might be experiencing
- One provider developed a paper data collection sheet as a result of the project.

Cons

- Providers already using other systems (e.g., paper assessment forms) and were more comfortable using these than a computer.

Figure 2.
Provider Responses: Usability and Impact of the Computerized Symptom Assessment System
From Focus Groups

Table 1
Patient Responses: Ease in Using Computerized Symptom Assessment System During Clinic Visit

Issue of Concern	Time 1 (%)	Time 2 (%)	Time 3 (%)
Patient requested help from research staff to			
Understand a question.	14	6	9
Figure out the best answer.	16	9	9
Advance to the next screen.	23	21	9
Go back to the previous screen.	3	-	-
Pause or stop.	1	-	-
Use the stylus.	23	9	3
Read the screen.	1	1	-
Interpret printouts.	4	1	-
Record an answer.	6	4	4
Understand the skip pattern.	4	4	4
Patient requested help from family or friend to			
Understand a question.	5	1	3
Figure out the best answer.	9	4	3
Advance to the next screen.	4	3	-
Go back to the previous screen.	-	-	-
Pause or stop.	-	-	-
Use the stylus.	4	1	-
Read the screen.	-	1	-
Interpret printouts.	3	1	1
Record an answer.	-	-	-
Understand the skip pattern.	-	-	-
System problems			
No power	-	-	-
Crashed or froze	1	-	1
Accidentally turned off	4	-	1
Spin piece problems	-	-	-
Stylus not working	23	10	11
Software malfunctioning	1	-	-
Patient printout not produced	-	-	-
Provider printout not produced	-	-	-
Unable to locate chart for printout	1	-	-
Printout delivery problem	9	3	8
Other	-	-	-

N = 80

Table 2
Patient Responses: Ease of Use and Time to Complete Computerized Symptom Assessment System in Clinic

Variable	Time 1		Time 2		Time 3	
	X	SD	X	SD	X	SD
Number of requests for help from research staff	0.94	1.11 ^a	0.55	0.87 ^b	0.33	0.78 ^c
Number of requests for help from family and friends	0.24	0.68 ^a	0.11	0.60 ^b	0.06	0.33 ^b
Number of system problems per patient	0.39	0.63 ^a	0.13	0.33 ^b	0.21	0.44 ^c
Time to complete (in minutes and seconds)	10:33	5:03 ^a	7:50	3:27 ^b	7:43	5:41 ^c

a, b, c Differing superscripts within a row denote significant differences at $p < 0.01$.

N = 80

Table 3

Patient Responses: Satisfaction With and Perceived Impact of the Computerized Symptom Assessment System per Follow-Up Telephone Call Data

Item	Time 1 % Agree	Time 3 % Agree
Satisfaction		
Most questions easy to understand	100	100
Liked using computer	94	96
Computer easy to use	95	99
Project has been worthwhile to me.	90	98
Liked the way printout looked	86	91
Computer asked about symptoms that were important to me.	85	91
Would recommend system for all patients with cancer	81	89
Printout accurate	80	93
Printout easy to understand	69	86
Felt more rushed on computer than would have if paper ^a	10	-
Too many questions	10	10
Screen difficult to read (glare, poor lighting)	4	1
Questions made me worry about cancer.	1	3
Perceived impact		
Printout made it easier to talk with doctor.	49	53
Computer made it easier to talk with doctor.	46	61
Doctor used printout during visit.	41	54
Spent more time talking about symptoms with doctor	30	44

^aPercentage of patients agreeing with this item significantly decreased over time ($p = 0.002$).

N = 80

Table 4
 Patient Responses: Perceived Impact on Discussion of Symptoms With Provider After Completing Computerized Assessment at Times 1 and 3 Follow-Up Telephone Calls

Symptom	Time 1			Time 3		
	Had Symptom (n)	Talked to Doctor About It (% of n)	Computer or Printout Helped to Talk About It (% of n)	Had Symptom (n)	Talked to Doctor About It (% of n)	Computer or Printout Helped to Talk About It (% of n)
Pain	31	91	35	31	94	55
Fatigue	55	89	42	61	90	55
Depression	14	79	36	15	73	64
Anxiety	28	64	39	30	73	59
Sleep problems	29	72	43	28	82	57
Functional problems	30	73	36	29	83	54

N = 80

Note. No significant changes were noted over time in proportion of patients reporting computer or printout helped to talk about each symptom based on Wilcoxon-matched pairs tests ($p > 0.50$).