Effects of a Computerized System to Support Shared Decision Making in Symptom Management of Cancer Patients: Preliminary Results

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Abstract Objective: (1) To evaluate preliminary effects of a computerized support system on congruence between patients’ reported symptoms and preferences and those addressed in the patient consultation and (2) to investigate the system’s ease of use, time requirements, and patient satisfaction.

Design: Fifty-two patients were randomly assigned to intervention or control conditions.

Measurements: Cancer patients scheduled for an outpatient visit used the system on a tablet computer to report their symptoms and preferences prior to their consultation. This information was processed, printed, and provided to the patient and clinician in the subsequent consultation in the experimental group but not in the control group.

Results: While patients in both groups were equivalent at baseline in symptom characteristics, there was significantly greater congruence between patients’ reported symptoms and those addressed by their clinicians in the experimental group. The system scored high on ease of use. There were no significant group differences in patient satisfaction.

Conclusion: This study provided beginning evidence that eliciting patients’ symptoms and preferences and providing clinicians with this information prior to consultation can be an effective and feasible strategy to improve patient-centered care.


Evidence-based patient care and shared decision making (SDM) have, at least in theory, been adopted as models for good clinical practice.1,2 Over recent years, there has been a rapid development of models, methods, and support systems for eliciting patient preferences and SDM. Different types of applications have been used, such as decision boards and audio-guided workbooks,5 or computer-supported tools such as interactive video-discs3,4,6 or palm-top7 or Web-based applications.8–11 In the clinical, health services, and methodologic literature, terms such as evidence-informed patient choice and shared decision making are used to describe the process of involving patients, in appropriate ways, in making decisions about their health care with their providers that are informed by the best available evidence about available options and potential benefits and harms, and that consider patient preferences.5 Decision aids (DAs) designed to help patients in these decisions have shown positive effects on cognitive functioning and social support,12 shown more active and satisfying participation in decision making,13 shown better scores on general health perceptions and physical functioning,6 improved knowledge,14 and reduced decisional conflict.15

However, SDM tools have, so far, been mostly confined to support patients in decisions about single episodes of screening/treatment choices. Much less work has been devoted to the development of computer-supported systems that assist clinicians in eliciting and integrating patients’ illness experiences and preferences into symptom/illness management of serious or chronic conditions such as cancer. To manage patients’ symptoms effectively during long-term serious or chronic illness and treatment, clinicians need to understand patients’ symptoms, their severity, and their importance to the individual patient. Clinicians need to engage in an SDM process with their patients to address patients’ problems and symptoms appropriately. Computerized support systems can provide such assistance.

The purpose of this pilot study was to explore and evaluate a newly developed support system for preference-sensitive symptom management in cancer patients. We investigated initial effects of CHOICEs (Creating better Health Outcomes by Improving Communication about Patients’ Experiences) on congruence between patients’ reported symptoms and preferences and those addressed in their outpatient...
consultations. We also examined the system’s feasibility in terms of time requirements, ease of use, and patient satisfaction.

**Methods**

**CHOICEs**

CHOICEs includes (1) a comprehensive patient assessment tool for cancer-specific symptoms; functional problems; and preferences along physical, psychosocial, emotional, and spiritual dimensions; and (2) a SDM/ care planning component that highlights for clinicians which symptoms patients are experiencing, including their severity, degree of bother, and importance to patients. This information can be used together with the patient for appropriate treatment and care planning in patients’ consultations.

The CHOICEs application builds on experiences from previous studies and beginning cumulative evidence of the effectiveness and feasibility of such systems to improve patient-centered care. Two previous studies on a palm-top–based support system for preference-sensitive care of rehabilitation patients have shown significant effects on congruence between patients’ problems and patient care and on patient outcomes of functional status and preference achievement. Similar to this earlier system, CHOICEs for preference-sensitive symptom management of cancer patients was developed based on a thorough and critical review of the evidence-based literature to identify problems, specific symptoms, and functional limitations commonly encountered by cancer patients. This search and literature review included the health care bibliographic databases as well as the World Wide Web (WWW) for clinical guidelines, educational material, workbooks, measurement tools, and other relevant material. It resulted in a preliminary list of symptoms and functional problems for potential inclusion in the CHOICEs assessment. An expert focus group with specialists in cancer care (physicians, nurses, social workers) critically reviewed the clinical evidence abstracted from the literature and the WWW for relevance, comprehensibility, and completeness/level of detail and supplemented it with expert opinion. Particular attention was paid to describing symptoms and problems in simple, understandable, non-medical lay language. The focus group also critically reviewed the design and interface during the development of the CHOICEs application. A preliminary version then was presented to 15 cancer patients (9 women, 6 men; 5 inpatients and 10 outpatients; mean age, 60; range, 40 to 74 years) who were asked to complete and evaluate the assessment for preference-sensitive symptom management of cancer patients is necessary to discuss such symptoms at every patient–clinician encounter.

The next assessment screen (Fig. 4, available as an online data supplement at www.jamia.org) asks patients about the degree of severity and bother of their selected symptoms. In addition, patients are asked whether they wish to discuss their symptoms with their care provider at this time. This option is included because patients may have symptoms that last over time but are under control. Patients may not feel it is necessary to discuss such symptoms at every patient–clinician encounter.

Finally, patients are asked to rate the importance of their problems as priorities for treatment/care on analog scales from 0 to 10 (patient preferences; Fig. 5, available as an online data supplement at www.jamia.org). This allows clinicians to pay particular attention to those problems that are most important to patients.

After the patient is done, an assessment summary (Fig. 6, available as an online data supplement at www.jamia.org) asks patients about the perceived overall health and health-related quality of life (HRQoL) on analog scales (range 0 to 10; Fig. 1).

**Procedures**

Prior to this pilot study approval from the institutional review board for protection of human subjects was obtained. Patients were enrolled consecutively into experimental and control groups over a period of two months. Inclusion criteria were more than 21 years of age; able to read, write, and speak English; no cognitive impairment; able to provide informed consent; not too fatigued; and participation approved by patients’ physicians. New patients coming for their first consultation were excluded because these visits differ from regular visits.

The day before patients were scheduled for their outpatient visit, a list of names was provided by the clinic’s secretary to the interview assistant (IA), and patients were screened for eligibility. Upon arrival at the clinic, patients were
approached by the IA prior to the consultation. The IA explained the study and asked for informed consent. She then explained the use of the touch-screen computer to consenting patients in a quiet area adjacent to the waiting room. After completion of a few demographic questions, all patients completed the CHOICEs assessment on the computer, either alone or with the help of the IA. Thereafter, they completed the “Ease of Use” questionnaire. In the experimental group, assessment summaries were printed and given to the patient and clinician in the subsequent consultation. In the control group, data collection proceeded in the same manner, but assessment summaries were neither printed nor given to the patient or clinician at any time.

Immediately after the consultation, patients in both groups came back to the interview area to complete the “Consultation Checklist” (see below) on which they marked those symptoms and health problems they had discussed with their clinician during the consultation and the “Patient Satisfaction with Decision Making” questionnaire. In the experimental group, assessment summaries were printed and given to the patient and clinician in the subsequent consultation. In the control group, data collection proceeded in the same manner, but assessment summaries were neither printed nor given to the patient or clinician at any time.

Prior to data collection, clinicians who were expected to see study patients in the outpatient cancer clinic were informed about the study, asked for permission to enroll their patients, and informed that they might receive assessment summaries that they could use together with their patients. A template of an assessment summary was presented to them and its content explained. All approached clinicians agreed to participate in this study.

Design Considerations
A major design consideration was the possibility of carryover effects between groups. For example, a clinician who was seeing experimental group patients and had assessment summaries available may have started to request similar information from control group patients and, therefore, change his or her usual consultation style. To avoid potential carryover effects, randomization was, therefore, done on the level of clinicians, not patients. At study initiation, clinicians were assigned randomly to intervention and control groups. Patients’ assignments to experimental and control conditions were then “matched” with the assignment of their clinicians.

Measurement of Variables and Instruments

Health Problems, Symptoms, and Preferences
To assess patients’ symptoms, functional problems, and preferences, CHOICEs was used as described above.

Congruence
Congruence data between patients’ reported symptoms and preferences and those addressed by clinicians were obtained by matching data entered into the CHOICEs system prior to physician consultations with data subsequently reported on the Consultation Checklist, a paper-based version of CHOICEs, comprising all 112 symptoms and problems included in the electronic instrument. Patients marked those symptoms that were discussed with their clinicians during the outpatient consultation. The greater the number of patients’ reported problems and symptoms that were addressed with their clinician in the patient consultation, the higher the congruence. To take into account patient preferences, patients’ problems also were weighted by the importance ratings patients had assigned to them.

Time Requirements
The time it took patients to complete assessments with CHOICEs is part of the system’s functionality and was automatically recorded by the system.

Ease of Use
CHOICEs’ ease of use was measured using the “Ease of Use” scale developed by Davis. This six-item Likert-type scale measures users’ perceptions of the ease of use of an information system. Answer categories range from “strongly disagree” to “strongly agree.” Two items pertaining particularly to CHOICEs were added.

Patient Satisfaction
Patient satisfaction was measured with the 12-item “Patient Satisfaction with Decision Making” questionnaire that has been used in studies to measure patient satisfaction with participation in treatment decisions. Patients respond to questions on Likert scales from “strongly disagree” (1) to “strongly agree” (5); or from “excellent” (1) to “poor” (5). Three additional questions were added pertaining to the CHOICEs application.

Results

Sample Characteristics
Seventy-three patients were approached and asked for participation. Fourteen patients did not wish to participate because they were already enrolled in other studies at the same time. Of the 59 patients who consented, three patients withdrew because they had received such bad news during the consultation that they did not wish to complete the questionnaires afterward, two said they did not feel well, and two patients did not like computers. The final sample used for analyses consisted of 52 patients who were undergoing treatment for various cancer diagnoses and who were scheduled for an outpatient consultation at Dartmouth Hitchcock Medical Center, Lebanon, New Hampshire: 27 patients in the experimental group and 25 in the control group. Mean age was 56.3 years (SD, 11.3; range, 23 to 77). Fifty-nine percent were women. Mean number of years of education was 12.8 years (SD, 2.38; range, 4 to 20).

The clinician sample consisted of 14 physicians who worked in teams with nurse practitioners. Nine were assigned to the experimental and five to the control condition. Clinicians were seeing a mean of 3.5 study patients (SD, 2.8; range, 1 to 9).

Patients’ Symptom Characteristics, Perceived Health, and HRQoL
Patients’ mean scores for their perceived overall health were 6.17 (SD, 2.51; range, 0 to 10) and for perceived HRQoL 6.59 (SD, 2.44; range, 0 to 10). Patients selected a mean of 15.10 (SD, 13.96; range, 1 to 50) symptoms. There were no significant differences in numbers of reported symptoms in the intervention and control groups. Of the 16 problem categories in CHOICEs, energy problems with associated symptoms were the most frequently selected category (63.5% of the sample), followed by “pain” (53.8%), “worries/concerns” (50.0%), and “sleep/rest” and “mood and feelings” (both 46.2% of the sample). Of the 112 possible symptoms available for selection in the CHOICEs assessment, almost all symptoms were selected by at least one patient. There were
large variations in patients' reports of frequency, severity, degree of bother of symptoms, and importance.

**Group Differences in Congruence**

This study evaluated initial effects of CHOICEs on congruence between patients’ reported symptoms and preferences and those addressed in the patient consultation. Table 1 displays means (Ms), standard deviations (SDs), and group differences in congruence between experimental and control groups. In the variable called *importance-weighted congruence*, patients’ symptoms are weighted by the importance ratings patients had assigned to them.

Table 1 shows that when clinicians had information about patients’ symptoms and their importance available in the experimental group, significantly more of these symptoms were addressed in the patient consultation. Given a mean of approximately 15 symptoms, on average, approximately 51% were addressed in experimental group, whereas only about 19% were addressed in the control group. These group differences persisted when patients’ symptoms were weighted by patients’ importance ratings.

**Time Requirements**

Completion of CHOICEs assessments took patients a median of 9 minutes (SD, 10.35; range, 0.5 to 49 minutes). However, this time is somewhat inflated because it also includes time to talk with the IA during the interview, which a number of patients did. Twenty-five percent of the sample used 5 minutes or less.

**Ease of Use**

Eighty percent of the patients completed assessments on touch pad computers without any assistance. Main reasons for why the remaining 20% had some assistance were that they either felt too weak, had disabilities, or simply out of convenience when assistance was available. However, reasons for assistance were not systematically recorded, which is recommended for future studies. That patients perceived few problems using CHOICEs was shown by a positive Ease of Use score (Table 2). A Cronbach’s alpha of 0.98 shows excellent reliability of the instrument in this study. Two questions in the instrument addressing whether patients perceived CHOICEs as a useful tool (question 6), and whether assessment questions were easy to answer (question 8) received particularly high ratings. Several patients supported their answers with personal comments about the usefulness of CHOICEs for eliciting their symptoms and preferences, and for SDM and care planning. Answers to two questions added to the questionnaire, asking patients about previous computer experience and what they thought about being asked about their symptoms in preparation to seeing their clinician, indicated that, on average, patients thought this was a good or very good idea. Not surprisingly, ease of use was correlated with previous computer experience \( r = 0.42; p < 0.01 \).

**Patient Satisfaction**

There were no significant group differences in patient satisfaction measured with the “Patient Satisfaction with Decision Making” questionnaire\(^4,20\) \( t = 0.75; p = 0.45 \). Patient satisfaction scores were positively skewed in both groups. Cronbach’s alpha as measure of reliability was 0.86 in this study.

**Additional Results**

In addition to analyzing study questions, we also were interested to learn whether the number of symptoms reported by patients would have an influence on the number of those addressed in the patient consultation. Given the short consultation time that is usually assigned to each patient, we reasoned that there may be a limit to how many symptoms a clinician can attend to during one consultation and that this may have an effect on congruence. We, therefore, analyzed group differences controlled for an increasing range of symptoms. Table 3 displays analysis of covariance (ANCOVA) results for congruence.

To better illustrate the pattern that emerged, we plotted the F-statistics for group differences in congruence for the same range of reported symptoms in a graph (Fig. 7, available as an online data supplement at www.jamia.org). The graph shows an almost bell-shaped pattern. When patients reported a relatively small number of symptoms, there were no significant group differences in congruence. With increasing numbers of symptoms, there were increasing differences. Beyond 25 symptoms, congruence gradually decreased again. The range, 0 to 50 that represents the entire sample shows the overall effect of CHOICEs on congruence when controlled for number of symptoms and supports the results displayed on Table 1.

**Discussion**

In spite of a small sample size, this pilot study found significant initial effects of CHOICEs on greater congruence between patients’ reported symptoms and preferences and those addressed in their patient consultations. Using the application to elicit patients’ symptoms and preferences and to provide clinicians with this information seems to be an effective and feasible strategy to improve patient-tailored symptom management for cancer patients. This study’s findings are supported by previous studies on effects of similar support systems for preference-sensitive symptom management in rehabilitation patients.\(^7,16\) However, previous studies were done primarily with nurses as clinicians. The fact that similar effects also appeared when physicians used CHOICEs as part of their clinical practice is encouraging. It suggests that the application may have the potential to improve interdisciplinary clinical practice toward more patient-centered care. The ease with which patients were able

*Table 1* ■ Group Differences in Congruence between Patient-reported Symptoms and Those Addressed in the Patient Consultation

<table>
<thead>
<tr>
<th></th>
<th>Control Group ((n = 25))</th>
<th></th>
<th>Experimental Group ((n = 27))</th>
<th></th>
<th>(t)</th>
<th>(df)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Congruence</strong></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.84</td>
<td>2.98</td>
<td>7.63</td>
<td>7.37</td>
<td>3.11**</td>
<td>50 (1)</td>
</tr>
<tr>
<td>Importance-weighted congruence</td>
<td>12.8</td>
<td>15.7</td>
<td>33.0</td>
<td>33.7</td>
<td>2.84**</td>
<td>50 (1)</td>
</tr>
</tbody>
</table>

\(^*\text{p} < 0.01\)
to complete computerized assessments also attests to the applicability of the system.

CHOICEs extends previous SDM tools in two significant ways: (1) it is designed to support clinicians in eliciting and including patients’ reported symptoms and preferences in patient care and (2) it extends SDM tools from supporting patients in singular treatment/screening decisions into the realm of symptom management. The importance of extending SDM tools into symptom management of serious or chronic illness was supported by the fact that almost all of the 112 symptoms available in CHOICEs were selected by at least one patient in this study. Large variations in patients’ reports of frequency, severity, and degree of bother of these symptoms indicate that clinicians cannot automatically anticipate what symptoms and problems patients are experiencing or what patient care is in their best interest. Therefore, clinicians can benefit from the assistance that support systems such as CHOICEs can provide. This study contributes to a larger research program devoted to improving SDM for symptom management and patient–provider partnerships in health care, and the development, implementation, and evaluation of information systems to support it.

An interesting finding in this study was the influence of the number of patients’ reported symptoms on congruence between these symptoms and those addressed in the patient consultation. This suggests that there may be an “ideal” symptom range for which the CHOICEs intervention was most effective and supports the system’s feature that allows patients to rate the importance of their symptoms as priorities for treatment and care. This can be particularly valuable for patients with many symptoms as it will make it more likely that at least their most important symptoms will be addressed.

It may seem, however, somewhat surprising that CHOICEs had little effect on congruence when patients reported few symptoms. Reasons are not clear. Patients with few symptoms may be more likely to remember and discuss those symptoms with their care provider regardless of the assistance from any system. Both groups completed assessments with CHOICEs immediately prior to the consultation. Control group patients may have easily been able to recall and discuss their symptoms if these were few. The absence of group differences for patients with few systems may, therefore, be due to contamination by a recall effect. A future clinical trial on the effect of CHOICEs should include an additional control group receiving “usual” care to separate the effect of the assessment itself from the effect of providing clinicians with the resulting information.

Given the positive results of the intervention on congruence between patients’ problems and preferences and those addressed in the patient consultation in this study, the lack of an effect on patient satisfaction may also seem surprising. However, studies measuring the effect of SDM tools on patient satisfaction often have failed to produce positive results.21,22 The “satisfaction with decision making” instrument used in this study was originally developed to measure patient satisfaction with treatment decisions and may have lacked sensitivity when used for measuring patient satisfaction with SDM in symptom management as in this study. Also, highly positively skewed patient satisfaction scores in both groups obtained in this study may have contributed to the failure to detect group differences. In addition, other factors reported in the literature as affecting patient satisfaction also may have confounded patient satisfaction here, such as patients’ expectations, illness status, treatment outcome, health providers’ behaviors, and their interpersonal relationships with patients.23,24 Many of the patients in this study were very ill and had diagnoses with uncertain outcomes.

An interesting observation that deviates from most findings in the SDM literature is the effect on patient care of the CHOICEs intervention. Studies examining the adoption of SDM tools to support patients in treatment or screening decisions have reported clinicians’ reluctance to use such

Table 2  ▪ Ease of Use

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Control Group</th>
<th>Experimental Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Learning to operate the computer to fill out the questionnaires is easy for me.</td>
<td>0.64</td>
<td>1.57</td>
</tr>
<tr>
<td>2. I find it easy to get the computer to do what I want it to do.</td>
<td>0.45</td>
<td>1.58</td>
</tr>
<tr>
<td>3. It was clear and understandable how to operate the computer.</td>
<td>0.69</td>
<td>1.50</td>
</tr>
<tr>
<td>4. I find the computer to be flexible to interact with.</td>
<td>0.50</td>
<td>1.51</td>
</tr>
<tr>
<td>5. It would be easy for me to become skillful at using the computer.</td>
<td>0.44</td>
<td>1.50</td>
</tr>
<tr>
<td>6. Questions were easy to answer.</td>
<td>1.18</td>
<td>1.11</td>
</tr>
<tr>
<td>7. Overall, I find the computer easy to use.</td>
<td>0.55</td>
<td>1.51</td>
</tr>
<tr>
<td>8. I find this to be a useful tool.</td>
<td>1.89</td>
<td>1.54</td>
</tr>
<tr>
<td>Total score (possible range, −16 to +16)</td>
<td>5.06</td>
<td>11.03</td>
</tr>
</tbody>
</table>

n = 41 (possible range, −2 to +2).

Table 3  ▪ Group Differences in Congruence for Different Symptom Ranges Controlled for the Number of Reported Symptoms

<table>
<thead>
<tr>
<th>Number of Reported Symptoms</th>
<th>Control Group</th>
<th>Experimental Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>0–10</td>
<td>27</td>
<td>2.25</td>
</tr>
<tr>
<td>0–15</td>
<td>33</td>
<td>2.25</td>
</tr>
<tr>
<td>0–20</td>
<td>38</td>
<td>2.18</td>
</tr>
<tr>
<td>0–25</td>
<td>41</td>
<td>2.17</td>
</tr>
<tr>
<td>0–30</td>
<td>43</td>
<td>2.17</td>
</tr>
<tr>
<td>0–40</td>
<td>49</td>
<td>2.63</td>
</tr>
<tr>
<td>0–50 (total)</td>
<td>52</td>
<td>2.84</td>
</tr>
</tbody>
</table>

*p < 0.01; *p < 0.05.
tools, primarily due to their concerns that this may add additional tasks for which they do not have time. Attention to the workload, time requirements, feasibility, and acceptability are important factors to consider when introducing new SDM tools in clinical practice. CHOICEs may be easier to implement than other types of SDM tools that have been designed primarily to support patients. Its purpose was, from the onset, to support clinicians, and, therefore, particular attention was paid to integrating the CHOICEs application into the workflow of clinical practice. When patients were seen by clinicians in this study, assessments of their symptoms and problems that usually are part of the consultation were already completed beforehand. Thus, clinicians had this information ready when they saw the patient, which may have been perceived as helpful. Future studies should, however, include an investigation of not only patients’ but also clinicians’ opinions about the systems’ usefulness and feasibility in clinical practice. It would also be important to explore the mechanisms by which the CHOICEs intervention affected the patient consultation, e.g., how the elicitation and availability of information about patients’ symptoms and preferences may change the interaction between patient and provider or change the focus of the conversation or communication that takes place. The use of support systems such as CHOICEs requires considerably more research.

Limitations
This pilot study should be regarded as primarily exploratory, and results need to be interpreted with caution. The major limitation is sample size, which was not based on power calculations and was too small to allow validity and reliability testing of CHOICEs and its subscales. Unlike other instruments, in CHOICEs, each patient completes a different subset of items, dependent on his or her initial selection of problem categories. While almost all symptoms were chosen by at least one patient, some subscales and symptoms were selected by so few patients that this did not permit reliability analysis. Based on this preliminary study, funding has been obtained for a larger randomized clinical trial (RCT) that is sufficiently powered to detect significant effects on patient care and outcomes and that will permit factor analysis on the CHOICEs instrument. Data collection currently is in progress for this RCT, which also includes additional measures that will allow us to evaluate CHOICEs convergent and discriminant validity.

Another potential confounder in this study is that the number of participating clinicians per group was too small to cancel out individual consultation styles. The ideal would have been a nested design that would allow for controlling clinician variables. Such a design often is difficult to implement due to limited numbers of available clinicians. It usually requires a multisite clinical trial that increases the possibility of other confounding variables and the cost of the research.

Conclusion
The primary purpose of this study was to gain first-hand experience in administering the computer application, testing its feasibility in interdisciplinary practice, and measuring its effect on patient care. The results provide beginning evidence about the usefulness and feasibility of use of a new support system in a clinical setting. CHOICEs seems to be an application that can help clinicians with better symptom management consistent with patients’ problems, symptoms, and preferences.

References


