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## Identifying design considerations for a shared decision aid for use at the point of outpatient clinical care: An ethnographic study at an inner city clinic

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### Abstract

**Background and Objective**—Computerized decision aids could facilitate shared decision-making at the point of outpatient clinical care. The objective of this study was to investigate whether a computerized shared decision aid would be feasible to implement in an inner-city clinic by evaluating the current practices in shared decision-making, clinicians' use of computers, patient and clinicians' attitudes and beliefs toward computerized decision aids, and the influence of time on shared decision-making.

**Methods**—Qualitative data analysis of observations and semi-structured interviews with patients and clinicians at an inner-city outpatient clinic.

**Findings**—The findings provided an exploratory look at the prevalence of shared decision-making and attitudes about health information technology and decision aids. A prominent barrier to clinicians engaging in shared decision-making was a lack of perceived patient understanding of medical information. Some patients preferred their clinicians make recommendations for them rather than engage in formal shared decision-making. Health information technology was an integral part of the clinic visit and welcomed by most clinicians and patients. Some patients expressed the desire to engage with health information technology such as viewing their medical information on the computer screen with their clinicians. All participants were receptive to the idea of a decision aid integrated within the clinic visit although some clinicians were concerned about the accuracy of prognostic estimates for complex medical problems.

**Implications**—We identified several important considerations for the design and implementation of a computerized decision aid including opportunities to: bridge clinician-patient communication about medical information while taking into account individual patients' decision-making preferences, complement expert clinician judgment with prognostic estimates, take advantage of patient waiting times, and make tasks involved during the clinic visit more efficient. These findings should be incorporated into the design and implementation of a computerized shared decision aid at an inner-city hospital.

### Keywords

Computerized decision aids; shared decision-making; health information technology; patient attitudes

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## INTRODUCTION

A growing body of evidence suggests that decision aids could facilitate shared decision making.<sup>1</sup> Shared decision-making is the process whereby patients and clinicians work together to arrive at decisions that are evidence-based and in line with patients' individual values and preferences<sup>2</sup> and is increasingly recognized as the preferred method of healthcare decision-making.<sup>3</sup> Although studies have shown that patients may prefer shared decision-making,<sup>4</sup> barriers to shared decision-making in practice include time constraints and difficulty communicating medical data and options to patients.<sup>5-9</sup>

Decision aids can help overcome several of these barriers to shared decision-making by providing information about outcomes associated with different health care options and translating this information into a language more easily understood by patients.<sup>10</sup> Studies have shown that in addition to increasing patient participation in the decision process, decision aids can increase patient knowledge of their treatment options, the risks associated with different options, and increase patient satisfaction with decision-making.<sup>11, 12</sup> Decision aids can be used by either patients or clinicians, or can be designed for shared decision-making by patients together with their clinicians. For such a shared decision aid to be feasible for use in outpatient clinical care, it must be integrated within the current clinic visit and workflow.

Computerized decision aids have been shown to be as effective as non-computerized decision aids,<sup>13, 14</sup> and could be more efficient to use at the point of care. Computers and health information technology are an increasingly important part of the outpatient clinic visit and are relied on by clinicians to complete tasks informing medical decision making including data retrieval and entry. Furthermore, "meaningful use" criteria as outlined by the Office of the National Coordinator for Health Information and Technology are linked to the reimbursement of healthcare institutions and are powerful incentives for the continued adoption of health information technologies throughout the United States. Computerized decision aids could be integrated into the clinic visit and facilitate shared decision-making,<sup>11</sup> while also meeting meaningful use criteria. However, a computerized decision aid may also present further barriers to shared decision-making, for example, if patients or care providers are not receptive to the use of a computer program to assist with decision-making. One study

of patients receiving primary care through the VA New York Harbor Healthcare System found that some patients perceived computers as distracting their clinicians from paying attention to them<sup>15</sup> and yet another study found that patients viewed doctors who consulted computerized decision support tools less favorably than doctors who made decisions independently or consulted an expert colleague.<sup>16</sup> Another potential barrier would be if clinicians felt computerized decision aids act as a barrier to their workflow and throughput, believing that computerized decision aids would increase the time needed for clinic visits.<sup>15</sup>

In this study we sought to better understand whether a computerized decision aid, designed to facilitate shared decision-making, would be acceptable and feasible to implement in an inner-city clinic by evaluating the current practices and perceptions of shared decision-making, clinicians' use of computers, patient and clinicians' attitudes and beliefs toward computerized decision aids, and the influence of time on shared decision-making. This study adopted a qualitative research methodology that focused on understanding the environment, technology and people that comprise the system to inform the design of the proposed technology of a computerized decision aid. Historically, design approaches in health systems have under-utilized approaches from other disciplines that seek to understand the environment to inform design (such as user centered design or workflow evaluation). In these settings, people and their workflows, are forced to adapt to systems that may not include their needs. This approach to design, can lead to unintended consequences, low adoption of otherwise useful technologies, and sometimes safety problems. We aimed to establish an understanding of the environment, the user, and their skills / abilities / available resources to inform the design before development and implementation. The ethnographic approach described in this study was designed to understand key elements of the sociotechnical system people, work tasks, and technology to begin to inform the design of a computerized decision support tools.

## METHODS

We completed a one-week observational study in an outpatient pulmonary clinic at the Bellevue Hospital in New York City, from June 18 to 22, 2012. Eleven clinicians and 18 patients were consented to participate in the study. All participants consented to be observed during their clinic visit and to complete a semi-structured interview after the clinic visit. One patient declined to complete the interview after being observed due to time constraints. All study protocols were approved by the authors' university Institutional Review Boards. Participants received \$10 for completing the study.

The sample was diverse in terms of gender, race, and ethnicity as outlined in Table 1. Study protocols included: 1) observations of patient-clinician clinic visit, 2) semi-structured interviews of patients and clinicians independently, and 3) observations of the overall clinic visit. Participants (both patients and providers) were assured that their interview data would remain confidential and anonymous. Observations of the patient-clinician clinic visits and the overall clinic visit were conducted by researchers with expertise in human factors and ergonomics engineering. Observers had extensive experience on ethnographic approaches to examining human interaction with computers, technologies, and health care systems. Semi-structured interviews were designed to elicit attitudes and practices of decision-making with

particular attention to the role of computers; interviews lasted approximately 20 to 35 minutes. Interviewers were trained to ask additional probing questions based on clinicians and clients' answers. Some of the questions included: How do you and/or your doctor make decisions about your treatment? Can you tell me about how you use the computer during the clinic visit with your patients? Does your doctor use the computer to share information with you? How do you feel about the use of decision aids in the clinical setting?

Data consisted of over 23 hours of live observations, 28 interview transcripts, 18 field notes, and 28 demographic questionnaires. Qualitative data were iteratively sorted, coded, and compared until saturation was reached using a constant comparative method.<sup>17, 18</sup> The analysis centered on key issues related to decision-making (i.e. communication, trust, and use of technologies) with particular emphasis on the role of computers in this process. Initially, the entire research team reviewed the data (audio, observations, interviews, and notes) in debriefing meetings concurrent with data collection. During this process, open codes were captured using post-it notes. Open codes were then used to create a preliminary scheme of codes. Two of the investigators independently coded all the transcripts ( $n = 28$ ) and compared results in order to reach a consensus about the appropriateness of assigning a particular code to a given passage or quote. Consensus was reached on the nature of the themes emerging from the data. During this process memos were written to bring meaning to the data and document the analytic decisions. Codes were compared and contrasted to create progressively more complex and comprehensive categories. NVivo 10 software was used to help separate and sort coded material based on each category. Several strategies for rigor were employed including peer-debriefing within the analytical process and data collection: independent and co-coding of transcripts, refinement of categories, and the use of memo-writing to aid in the development of ideas and to establish a decisional audit trail.<sup>19</sup>

## RESULTS

Four main themes related to decision-making between patients and clinicians emerged from the interviews and observations. These themes reflect on potential opportunities for the design and implementation of a computerized decision aid for shared decision-making, and included: the process of decision-making between patients and clinicians, clinicians' uses of computers, attitudes toward computerized decision aids, and time as an influential factor in decision-making.

### Process of decision-making between patients and clinicians

Patients were asked about the way in which they make decisions with their clinicians. Most patients identified some elements of shared decision-making. However, in most cases clinicians made the final decisions. As one patient explained,

“She asks me questions and based on what I respond, she discusses what she feels is better and she gives me the option on going forward, let's try this, let's try that.”

Most patients expressed satisfaction with the clinic visit when their doctors gave them time to express concerns and feelings, and when their doctors showed interest in their health conditions. This form of rapport emerged as an influential factor in the process of decision-making. For example, one participant stated,

“I like that she gives you time to express what you are feeling. We have been able to talk about different issues that I may be experiencing and she gives me suggestions about what I could do, what treatment I should receive.”

In general, the team observed that the patients were not encouraged by the clinicians to actively participate in the process of decision-making. Although most clinicians asked questions about patients’ understanding of their disease process and their perceptions, minimal efforts were made to foster participation when making the final decisions. For example, when asked whether his doctor gave him any options about his treatment, one participant stated: “Umm not really, I mean I can’t recall right now any options he gave me”.

Most of the time, clinicians made decisions based on what they believed was in the patients’ best interest. One clinician expressed this view by stating,

“There are patients who very clearly tell you what would you do, or what would you do if it is your grandmother, father, whoever. I’m comfortable saying this is what I would do. So, that is certainly one way in which things play out, that is if people don’t seem to understand then I’ll just give them my opinion. Um, there’s a whole sort of set of patients that don’t seem to understand, but won’t go with what you are suggesting and that’s actually because they don’t have the capacity to make decisions, it’s almost easier than when they do have capacity, but they just don’t agree with you. That’s always very frustrating...”

This example also demonstrates clinician frustration in cases where patients disagreed with them. In addition, several doctors expressed using third parties (i.e. family members) as a strategy for negotiation. In another case, a clinician expressed the need to occasionally make paternalistic decisions, as stated: “if there is lack of understanding, sometimes you have to invoke medical incompetency and make decisions yourself.”

### Clinicians’ use of computers

Clinicians used computers to look at patients’ medical histories, past clinical notes, previous emergency room visits, and hospitalizations. Clinicians also used computers to document medical information, order prescriptions and referrals, and to access professional medical education programs such as UpToDate® and Micromedex®. In addition, clinicians used computers to show patients laboratory results, pulmonary function tests, imaging results, graphs, pictures of anatomy and medical devices, and medications. Clinicians also used computers to retrieve information from websites, such as graphics that might assist them in explaining information to patients. For example, a patient stated,

“I told him that I take liquid iron. He told me, I never heard this. He checked the computer, he showed it to me, and he told me is this it. I say yes, he told me that if I want, that’s good. That, that’s good.”

One clinician explained how he used the computer to interact with patients,

“Uh, I put the screen on and turn the screen to the patient and I just start saying; these are your lungs, this is the right side of your lung, this is what should be looking normal, this is an abnormality that we are trying to figure out what it is.”

When asked about whether they believed clinicians should be using computers more during the clinic visit, only one clinician considered the impact on patients, stating,

“If you’re using it to advance patients’ understanding of what’s happening, then I think that’s all right.”

Some clinicians used computers, but did not actively share information in the computer with the patients. The following statement from a patient describes this scenario,

“She does not show me. It’s just that I’m sitting there and able to view it. It’s not like she highlights the screen.”

Additionally, we observed patients reaching over the desk to see the computer screen, indicating a desire to view the information in the computer. In some cases in which clinicians did not share the information they were viewing on the computer, or did so poorly, patients expressed dissatisfaction,

“I would like to see in the computer what is written in my test. When they do the tests, I would like them to go over it with me in the computer and show me the tests and what this means, and what this means about my tests.”

Patients expressed satisfaction when doctors did share the information they were viewing on the computer with them. For example,

“The way in which he used it [the computer] was very good because he was getting information and sharing the information with me and he was showing me what would happen in the future if he had not taken very good care of...”

Most patients expressed positive attitudes toward the use of computerized technologies in their clinical visits. As one participant stated,

“I think the computer gives the doctors more chances to give the best information, you know. Maybe it’s faster, it’s easier to check.”

While a couple of patient participants expressed they were “not into computers,” these participants also said that if their doctors would like to use computerized technology, they would agree with their doctor’s decision.

### **Attitudes toward computerized decision aids**

Clinicians were asked about their opinion of computerized decision aids. Generally, clinicians expressed having little to no experience with computerized decision aid programs. Most clinicians perceived computerized decision aid programs as an asset in clinical practice. As this clinician stated,

“I think it is helpful. It gives you information about how to appropriately treat the problems. I have used UpToDate®, it’s easy to use and it gives you up to date information in terms of treatment and contraindications.”

However, several concerns were raised about the utilization of decision aid programs. A common concern was that a program could mislead the diagnosis. Other clinicians expressed doubts about the utilization of these programs for complex differential diagnoses. One clinician stated,

“I think that for medication doses they [computerized decision aids] are really helpful...for more complex problems, it is not as useful. You have to do a little more research than just, if you have this, then, this is what you should do.”

Clinicians also identified some benefits for patients when using computerized decision aids, as one stated,

“For the patients I think it’s good so they can ask questions, we are very bad at prognosis too, I think that these programs if they are more accurate, which I’m not sure it would be more accurate, that would be helpful for patients too.”

Some patients expressed lack of interest in participating in computerized decision aid programs, although none of the patients had previous experience using such programs. However, when given a definition of decision aids in general, most patients agreed that having their clinicians use a computerized program that would improve their clinical care. Furthermore, patients who perceived that their doctors did not use the computer in the clinic visit as much, or used it poorly, complained. For example, one patient said: “She rarely uses the computer, yeah, she is a bit antiquated, I would like her to get more information, like to get more information to educate herself more.”

### **Time as an influential factor in decision-making**

Time emerged as an influential factor in the process of decision-making among both clinicians and patients. Although complete wait times from when patients arrived at the clinic to when they were seen by their clinician were not recorded, at least four patients were observed to be waiting over one hour, which was common for this clinic during the time it was observed. Some patients complained about having to wait too long before the clinic visit. In those cases, the long wait seemed to set the tone of the interaction between clinicians and patients in the clinic visit. Some patients reflected about the time constraints of their clinicians and suggested potential opportunities to improve time efficiency, as one patient stated,

“I don’t think the doctors have time, but maybe if they, maybe they could look over everything first before they have the patient come in and then they could talk with the patient.”

Another patient, when asked about the way his clinician used the computer in the clinic visit, stated,

“Really, I would love to ask more questions, but even if I decided to do that, you know the thing is the time, that is the problem. Also, other patients are waiting... I will take their time too.”

Clinicians reflected on how the interaction with their patients and process of decision-making in the clinic visit was limited by time constraints. Specifically, they pointed to work system constraints, such as administrative concerns and technology usability concerns. As this clinician stated,

“I feel like I probably waste a good amount of time in each visit, giving patients a paper to go to the front desk. ...And also just ordering certain tests, if we are not

familiar with them, the system is really cumbersome so you have to search...to find the test that you have to order and the same thing with medications. I think if the system were a little easier...in terms of searching for things, it would be more efficient.”

In addition, the same clinician expressed how computers limit the available time for the clinic visits,

“We have to spend a fairly significant time of the assessment just clicking buttons to try to get them to be checked out, so that takes a lot of time, I don’t find the system very easy, I almost feel like it would be easier to do it another way.”

These time-related system constraints were reinforced when clinicians had to use translation services with patients that speak languages other than English. (Note: Interpreters were available by phone and five of the 18 clinic visits we observed in our study involved the use of a Spanish interpreter.) For example, a clinician stated,

“I think [the translation service] significantly slows me down. But I don’t think there’s any way around that because it’s just as if you’re having the entire conversation twice.”

We observed that in the cases in which the clinicians were limited in time, either because they were running late or were using the translation service, a less participatory and more paternalistic approach to decision-making was used with the patients during the clinic visit.

## DISCUSSION

In this study the team sought to understand whether a computerized decision aid, specifically designed to facilitate shared decision-making, would be feasible to introduce in an inner-city clinic. The results indicate several opportunities for the design and implementation of a computerized decision aid in this clinic setting.

### **Opportunity for decision aid to bridge clinician-patient communication and to facilitate shared decision-making while considering patients’ decision-making preferences**

The team observed that clinicians often started with two key elements of shared decision-making, obtaining information from patients about their underlying disease and providing basic information about diagnosis, but then did not provide alternative treatment options and did not elicit patient preferences and often switched to a more paternalistic decision-making pattern. The qualitative data suggests two main barriers to shared decision-making: clinicians’ beliefs that patients would not understand the medical information due to language and educational status, and lack of time. These findings parallel barriers identified in other clinical studies.<sup>5-10</sup> In addition, medical communication difficulties were augmented by language and cultural barriers in this inner-city patient population. Importantly, although patients appreciated being asked about their opinions on diagnostic procedures and treatments, some patients preferred their clinicians make treatment recommendations for them. A decision aid could bridge the communication gap about treatment options and possible outcomes and could facilitate clinicians continuing the process of shared decision-making rather than switching to a more paternalistic decision-making pattern. However, the



decision aid should be flexible to allow clinicians to make recommendations to the extent desired by each individual patient and should help identify the decision-making preference of each patient. In addition, this study demonstrates the importance of decision aid design that considers cultural barriers such as language. For example, given the prevalent use of telephonic translators, decision aid screens should be accessible to translators to facilitate translation. Decision aid designers could also supply print-outs in a range of prevalent languages to augment the computerized decision aid.

### **Opportunity for decision aid to complement expert judgment**

The team observed that computer programs were an integral and accepted part of the clinic visit. Clinicians relied on these programs to access patients' medical histories, clinical care trajectories including outcomes of hospitalizations, and to look up diagnostic data. Clinicians expressed interest in a computerized decision aid being integrated in their clinic visit. Although some clinicians expressed concerns about the accuracy of prognostic estimates calculated by computerized software including a decision aid, they simultaneously recognized their own limitations in prognostication. Several patients viewed their clinicians who used computers as being more informed and saw computer programs as a necessary component of their medical care. This is in contrast to other clinical studies about patients' attitudes about clinicians using computer programs for medical information.<sup>15, 16</sup> In particular, patients appreciated that clinicians could access their medical histories more efficiently. Several patients expressed interest in viewing the clinical data their clinicians were viewing together with their clinicians – in fact one patient was observed stretching across the desk to view the computer screen. These findings lend support for a computerized decision aid to be used by clinicians together with patients. However, if a decision aid includes calculated prognostic estimates in addition to validation studies, the results of this study suggest that estimates need to be compared to clinicians' independent prognostication to improve acceptability among clinicians. Design requirements should include features to help clinicians and patients develop appropriate trust in the decision aid,<sup>20</sup> where their expert judgment complements the aid recommendations.

### **Opportunity for decision aid to utilize patient waiting times and to make clinic visit tasks more efficient**

Time constraints were a prominent barrier to shared decision-making particularly in situations requiring language translation. Interestingly, some patients expressed reluctance to ask additional questions due to their awareness of the doctor's limited time. Clinicians identified difficulty navigating the electronic health records for medication and diagnostic testing orders as being an important time barrier. Outside of the clinic visit patients were observed to be waiting for extended periods of time before seeing their clinicians. Opportunities for integration of a computerized decision aid into the current clinic visit might include a function that facilitates medical record documentation and order entry. For example, the decision aid could automatically enter notes on the decision-making discussion into the clinic visit note and automatically order follow-up visits or medications. In addition, the decision aid could take advantage of patients' extended wait times before seeing their clinicians. One example would be to provide basic medical information with translation of key terms that may be discussed in the clinic visit. In addition, patients could use the

decision aid to learn about the process of shared decision-making, self-assessment and their rights and responsibilities for their medical care.

### Limitations

Several limitations of our study should be addressed in future research. These limitations include understanding the impact of culture<sup>21</sup> or other relevant factors that may shape patients' decision-making preferences. Further insight into these factors would enhance the design and implementation of a computerized decision aid that is sensitive to patient diversity. Future studies could also integrate quantitative data collection to support these qualitative findings; for example, by adjusting the participant recruitment strategy so full wait times can be recorded. Along these lines, more research is needed to assess patients' willingness to utilize the wait times as suggested.

In summary, our study has identified several potential opportunities for the design and implementation of a computerized decision aid in this inner-city clinic and for other outpatient clinical environments. These findings can inform the design and implementation of computerized decision aids for shared medical decision-making and inform the design of health information technologies for a wide range of clinical contexts.

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**Table 1**

## Participant characteristics

	Patients (n=18)	Clinicians (n=11)
Gender		
Female	9 (50%)	6 (55%)
Male	8 (44%)	5 (45%)
Unknown	1 (6%)	0 (0%)
Race/Ethnicity*		
Hispanic	6 (33%)	
White	6 (33%)	
Other	3 (17%)	
African American	2 (11%)	
Unknown	1 (6%)	
Mean age, years	57	37
Education		
Highest education completed		
High school or less	13 (72%)	--
Some college	1 (6%)	--
College degree	3 (17%)	--
MD	--	9 (82%)
RN	--	1 (9%)
Other	--	1 (9%)
Unknown	1 (6%)	--
Years of training after medical or nursing school	N/A	
0-2		0 (0%)
2-4		0 (0%)
4-6		6 (55%)
6-8		3 (27%)
8 +		2 (18%)

\* Data on race/ethnicity were not collected for clinicians.