Computers that Show Recognition of Patients' Symptoms

Alemi F, Hesham H, Williams AR, Williams PD, Donley B, Kheirbek RE

Farrokh Alemi PhD, Chief of Performance Improvement, District of Columbia Veteran Administration Medical Center, Washington DC, USA
Hosai Hesham, MD, Otolaryngology Section Chief, District of Columbia Veteran Administration Medical Center, Washington DC, USA.
Arthur R. Williams, PhD, MA(Econ), MPA, Research Associate, CINDRR, US Department of Veterans Affairs, and Professor, HPM, COPH, University of South Florida, Tampa, Florida
Phoebe D. Williams, PhD, MN, MA, RN, FAAN, Professor, School of Nursing, Kansas University Medical Center, Kansas City, Kansas
Blaine Donley, Quaso LLC, Montross, Virginia,
Raya E. Kheirbek RE, MD, Deputy Chief of Staff, Washington, DC VA Medical Center

farrokh.alemi@va.gov; hosai.hesham@va.gov;
arthur.williams1@va.gov; pwilliam@kumc.edu;
blaine.donley@quaso.com; raya.kheirbek@va.gov

Abstract. The goal of automated symptom management has often been narrowly defined as collection and reporting of data. Yet, an automated system can do more. These systems can mimic human reassurance for patients that their symptoms have been recognized. Patient engagement has long been recognized as central in symptom management. An electronic system was built to collect the Treatment Related Symptom Checklist (TRSC) and to reassure patients. In this paper we discuss the design of the system and procedures taken to show recognition of patients' symptoms. The literature on clinician-patient interactions was reviewed selectively. Methods used by clinicians to promote patient engagement during medical history were identified. Similar methods were incorporated into the symptom management system in order to facilitate understanding by the patient. These included (a) conversational data collection as opposed to survey style or standardized questionnaires, (b) short response phrases indicating understanding of the reported symptom, (c) use of open ended questions to reduce asking long lists of symptoms, (d) leading questions that ask for confirmation of expected symptoms, (e) review of symptoms at designated stages, and (d) alerting patients when computer has informed the clinician about patient-reported symptoms. We are in the process of pilot testing the system among oncology patients in one hospital. Examination of existing informatics knowledge eases integration of well established paper-based tools into automated systems.

Keywords: Symptoms' recognition, Feedback loop, Symptom management, Man machine interaction, Therapy-Related Symptom Checklist, Cancer

1 Introduction

Computer monitoring of symptoms is increasingly common. Despite widespread use, few automated data collection systems go beyond data collection and show that they have recognized patient reported symptoms. These narrowly constructed data collection methods follow the "biomedical interview" type, known to reduce satisfaction of both providers and patients [1]. Better health outcomes are achieved when interviews (1) allow the patient to express his or her needs, (2) the doctor explores symptoms, and (3) the patient is informed [2,3]. In this paper, we discuss how computers can go beyond biomedical interviews.

There are few scenarios where patients prefer automated data collection systems over clinicians. For example, studies have established that patients are more comfortable when they report their symptoms to computers, especially in highly emotional settings such as in reporting drug abuse, suicide plans or sexual dysfunctions [4,5]. In most situations, the majority of patients prefer contact with other humans. Machines are no substitute for these contacts. At the same time it may be reasonable to expect that if a computer has to collect patient symptoms, then machines that show recognition and understanding are preferred to machines that do not.

Recognizing and acknowledging patients' symptoms is different from showing sympathy [6]. Recognition validates patients' emotions; sympathy is sharing of feelings. If a patient reports "I feel awful," a possible way of recognizing the symptom is to explore it further. The computer can ask: "Tell me more why you feel awful." A sympathetic response would share the feeling by saying: "Sorry to hear that." The former verifies how and why the patient feels awful while the later shares the feeling. A machine that shows sympathy is fundamentally flawed as patients know that machines do not feel. Machine sympathy may not seem credible. On the other hand, machines that show that they have understood the symptoms expressed by the patient fulfill the role that patients expect from these machines, i.e. to explore, record, and report what symptoms the patient faces.

This paper is focused on machines that are programed to exhibit recognition and it starts with several hypotheses regarding why machines should show their understanding to patients. We then describe implicit and explicit ways in which machines can show understanding. We review the literature on how computers and humans show recognition. This paper ends with the design of a pilot study for testing the value of computers showing recognition

2 Impact of "Caring" Computers

The helping relationship is a cornerstone of good medical care. When humans (friends, significant others and clinicians) care for the patient, there are profound effects on physiology, cognition and emotional states of the patient. One hypothesis is that computers that mimic helping relationships could have lesser but similar impacts on patients. Computers that are perceived as helping may make the patient feel supported and cared for. While machines do not and cannot replace human contact, they

could partially meet the need for support, especially among patients who are otherwise isolated [7,8,9].

The computer interview itself has much in common with therapy. It is far more than data collection; it is an opportunity to tell patients that they are important. Their symptoms matter in the management of the disease. Patients' adherence to treatment and cooperation hinges on the sophistication of computer algorithms and their success in conveying information accurately. It is not surprising that in recent decades, there have been many attempts to create computers that can show feelings or affect patients' feelings [10]. Studies of computerized therapy demonstrate that patients may feel better after interacting with a computer [11]. These studies confirm that machines can be perceived as helping.

Machines that show understanding may improve the accuracy of patient interactions with the computer. Reporting what has been understood is a form of feedback. Increasing levels of feedback have been known to improve accuracy of data collection. Three levels of awareness are needed. First, patients need to be aware of their symptoms. Sometimes patients do not recall the symptom or do not have a word to describe the symptom accurately. Some patients describe their symptoms in unusual ways. For example, pain may be described with any of the following words: aching, alarming, burning, cramping, crushing, discomfort, dull, gnawing, heaviness, hurting, knife-like, numbness, ouch, piercing, pins and needles, pressure, radiating, ripping, sharp, shooting, squeezing, stabbing, tearing, tenderness, throbbing, tingling, unbearable, and many more. Sometimes, social morale makes the patient deny the existence of the symptom. Second, the patient needs to be aware that the computer has understood his/her symptoms. By helping the patient describe and sort out experiences, the computer helps in labeling a symptom and in sorting out how symptoms are related to each other and affect treatments. Such checks and balances improve the framing of symptoms and the frequency with which symptoms are reported. Research on symptom checklists shows that many symptoms are not reported to clinicians and a checklist or a computer that does so may affect patient management decisions [12]. In this process, patients may become aware that the computer is helping them articulate the symptoms. Finally, the patient needs to be aware that the computer's information has been transferred to clinicians. It seems reasonable to hypothesize that as a consequence of these increasing levels of awareness, the level of error and misunderstanding is reduced.

Finally machines that show understanding can improve patient self-empowerment by increasing frequency, timing, and efficiency of clinical engagement. If patients can see that they can direct a machine, they may feel more in control. One may hypothesize that in these situations the patient's feelings of helplessness and hopelessness may be reduced.

3 How to Show Understanding

When computers interview a patient about their symptoms, the interview provides an avenue to establish a helping relationship and show that patient symptoms have been

recognized by the computer. This section describes specific interviewing techniques the computer can use to show its understanding of patients' symptoms.

3.1 Random Change

Patients will differ on which of the following techniques works best for them and the computer must select and modify its approach based upon patient responses over time. The same patient may differ over time, particularly as treatment progresses. The patient may become angry, anxious, in denial, vague, tired and might want to embellish. The computer needs to recognize the situation and take corrective action. Not surprising, this may make each computer interview unique. The techniques that will be described should vary to fit patients' moods and expectations, a task that is not always possible to do. Sometimes, the techniques used by the computer should be changed randomly just to introduce variety, avoid repetition, and prevent a perception that the computer is insensitive to the patient's mood. Flexibility in how the computer asks questions suggests to the patient that the interview is tailored to their unique needs and reassures patients that despite computer use they are not being treated as merely an object.

3.2 Changing Format

Computers can ask about patient symptoms in different ways.

1. It can ask an open ended question such as "What are the symptoms you are experiencing since our last call?" Patients' responses are matched to keywords.
2. It can ask if the patient has a specific symptom, as in "Do you have fever?" To do so for many symptoms would lead to a long interview.
3. In order to avoid many questions, several symptoms may be combined into a group. The computer might ask about a group of symptoms such as: Did you have fever, vomiting or headache? The computer groups the symptoms together based on previous responses so that they share the same response. At least three methods exist for how symptoms could be clustered together. One could base the decision on probability of the remaining symptoms conditioned on symptoms reported at this point in the interview. It may be based on the history of the patient's reported symptoms. It may be based on population analysis of symptoms and the frequency with which symptoms co-occur.
4. It might change the words used in asking the same question. It might ask "Did you vomit," "Have you vomited," or "Did you throw up?" These get to the same underlying symptom but use different words.

By changing the format of asking questions a computer can better meet the needs of the patient. While change does not show understanding a failure to change despite patient's utterances will signal to the patient that the computer has not understood him/her. Changing question formats not only reduces monotony but also reassures patients that the interview reflects their needs.

3.3 Levels of Error Response

Computers sometimes do not understand patients' responses, specially open ended responses. In response to the question "what symptoms have you experienced since the last call?" the patient may say words that are not registered correctly, or are symptoms that the computer had not anticipated. In such instances, the patient can feel misunderstood and if this persists the patient can become frustrated. There are several techniques to reduce misunderstanding and to prevent frustrations. The machine is perceived as flexible by having different ways to solve the problem. A computer must distinguish the causes of error and respond differently. An error may occur if the patient has given an unanticipated response, has not said anything, or if there is too much background noise. If nothing has been clearly stated, the computer gives a new example of what is expected and asks the patient if he/she wants to have more time. If there is too much noise in the background, the computer acknowledges the noise and asks if the patient can press keys on the keypad to continue. If the patient says a word that is not among the keywords used by the computer, then the computer needs to acknowledge the problem and ask for another way of saying the same thing. If the word is still not understood, the computer can record the symptom and have a human being review the recording or transfer the call to an operator for help. Either way, each error message must be uniquely different so that the patient does not feel trapped and forced to abandon the interview. These steps call for error processing routines that can discern the cause of the error.

3.4 Transitional Statements

Before proceeding with each new section, the computer makes a clear transitional statement. For example, "I have reviewed the symptoms you had in our last call. Let me check now if there are any new symptoms." These statements prepare the patient for what is coming next, show progress, and acknowledges what has occurred so far. Transitional statements are common in conversations and are an necessary step for changing patient's expectations [13].

3.5 Explicit Verification

A computer that is collecting data on patient's symptoms can explicitly show understanding by checking with the patient that the recorded symptom is a correct one. It can repeat the same words used by the patient or preferably use alternative words that have the same meaning. Explicit verification of symptoms is very mechanical and rewording is often used to break the monotony. For example, when a patient reports "I threw up last night" the computer may validate this feeling by saying "Last night you vomited." In our pilot study, we ask the patient an open ended question: "Tell us how you felt since our last call?" The response to this open-ended question is verified by standardized words used by the machine. If the patient says: "I felt tired." The computer matches the word "tired" and classifies it as "fatigue" and might say: "You are reporting fatigue." Finally, computers can provide a summary of symptoms collected

from the patient. A statement such as "So far, you have reported that you have fatigue and vomiting," is also an example of explicit verification.

3.6 Signs of Deliberation

The length of the pause gives the impression that the computer is thinking through the patient's statement. The computer might say: "I see." Or, it might say: "I am going to come back to this later." These and other similar statements suggest that an important statement has been made by the patient.

3.7 Connecting to History

In this approach, the patient's symptom is validated by connecting it to the history of the patient. The computer might say: "This is a new symptom." Or it might say: "You also mentioned fever last time. It seems you continue to suffer from it." A history shows to the patient that not only the computer has understood the current symptom but it also has captured and understood past reports.

3.8 Asking for More Details

Asking for more details shows the patient that they are being heard. When the patient says "I threw up" the computer might respond: "How severe was it?" "Was it after dinner?" or "Was it a projectile?" In our pilot, we routinely asked about the severity of a symptom after each symptom. In addition, computers can ask about chronology, bodily location, quality, quantity, setting, any aggravating or alleviating factors, and associated manifestations. The details may or may not matter but asking about them indicates that the original report of the symptom was understood.

3.9 Suggesting Coping Methods

One way to acknowledge the presence of a symptom is to suggest methods that can be used to cope with the symptom. For example, if the patient reports vomiting, then the computer can ask "I see that you were prescribed pills for vomiting. These are the small blue pills. Are you taking these pills?" These additional statements reassure the patient that their reported symptom has been understood. If symptoms are considered very severe, or if symptoms are a threat to successful treatment outcomes, the patient can be put in touch with a clinician. Clinicians can also instruct the computer to more frequently and explicitly monitor a particular symptom that they are concerned about.

3.10 Active Listening

Computers can listen tirelessly to the patient but when the patient pauses it is important to use active prompts to encourage additional comments. After the patient has reported one symptom, the computer can prompt for more detail by re-wording the

patient's reported symptom into a question. It may ask "You felt short of breath?" A pause after such a question would solicit more details. Whether these details are integral to the check list of symptoms is immaterial. The fact that the patient provides the details confirms to the patient that the computer has understood his/her earlier report of the symptom. Active listening might also take the form of short phrases such as "Tell me about another symptom?" or "Tell me more" for short.

3.11 Getting to Yes

An important way to reassure patients that they have been understood is to anticipate their responses by asking leading questions. Clinicians often do this. Early in clinic visits clinicians ask general questions but later during the same visit good clinicians ask questions that anticipate patients' responses [14,15]. Leading questions signal that the clinician has arrived at conclusions. A computer can do the same. It can change questions into declarative statements and follow it with a brief verification. For example, if the computer, based on the patient's history, anticipates that the patient has fever, it may change from "Do you have fever?" to "You still have fever, right?" The response to these leading questions is organized to be "Yes." It signals to patients that the computer is aware of their condition.

3.12 Reporting on Human Connection

An easy way for computers to tell the patient that they are being understood is to report that their data has been communicated to their clinician. Even if the data are not yet examined by a clinician, the computer needs to inform the patient. A statement such as "The symptoms you reported in the last call were sent to the office of X" reassures the patient. When the clinician indicates need for more closely monitoring of a symptom, the computer can also alert the patient with a statement such as: "Your doctor was concerned about your fever and wanted us to call this morning to verify that it has subsided."

4 Pilot Study

We are in the process of testing the ability of these innovations in improving computer-patient interactions. In particular, we have designed a system to collect the symptoms in the Therapy-Related Symptom Checklist (TRSC) for oncology patients [16]. The current computer system was developed cognizant of earlier experiences using the TRSC at distant clinics through two-way video communications [17, 18]. The current system works on an Interactive Voice Response telephone system. It has extensive orientation statements, alerting the patient of passage from one section to another. It reviews symptoms reported in past calls one-by-one and provides a summary of its findings at end of the section. It then groups remaining symptoms into cohesive categories or clusters and asks about both individual symptoms and clusters. It ends with an open question: What other symptoms have you experienced since our last

call?" It matches responses to keywords and acknowledges the responses selectively. The system is built on progressive error messages that transfer the call to human operator if the system fails to address the error. It uses active listening techniques to solicit more symptoms after open ended questions. It reports to the patient the extent to which symptoms have been reported to his/her clinicians. It asks leading questions towards the end of the interview. It changes the format of asking questions and the words used to describe a symptom. It explores details of symptoms asking for severity or other features of the symptom. We believe we are approaching a computer interview that mimics a real conversation with undertones and meaning not only in what is said but what is not said as well.

5 Conclusions

We acknowledge that we do not yet have data on the impact of these innovations on patients' health care outcomes. We also acknowledge that the methods we are using are not comprehensive. We lack a comprehensive theory on what makes a computer interview more empathetic. We have a list of innovations that we believe will make a difference but both a theoretical model and data on their impact are missing. As we move beyond the empirical development of an operating clinical system, we will capture information that will help us and others generate theories that identify meaningful patient-machine interactions that can improve patient care and treatment outcomes.

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