Using a Pen-Based Computer to Collect Health-Related Quality of Life and Utilities Information

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We have developed a system that uses the Newton MessagePad technology as part of a client-client-server paradigm to collect health-related quality of life information from breast cancer patients attending an outpatient clinic at the Dana-Farber Cancer Institute. Patients are asked to fill out an electronic questionnaire on the Newton, which then uploads the information into the institution's Oracle database. The program consists of a separate questionnaire engine and question base, facilitating questionnaire design and allowing us to give different questionnaires to different patients dynamically. The results of a preliminary trial show excellent user-acceptance of the device. Finally, we present a general framework for such systems and discuss issues that developers must consider when implementing a pen-based computer project.

INTRODUCTION

Information on the effect of disease and treatment on patients' health-related quality of life (HRQOL) is essential to rational delivery of health care services and outcomes management. We wished to introduce routine, serial collection of patient self-reported HRQOL data into the operations of a large, multidisciplinary breast cancer clinic. Potential benefits could include: more informed decision-making by providers and hence improved patient care, enhanced patient satisfaction, and incorporation of patient quality of life measures into clinical research studies. However, to achieve these goals we needed to overcome the major practical barrier to widespread collection of HRQOL data in the routine clinical care setting, the need for a technology that is acceptable to patients, minimizes data entry tasks and generates reports for providers in real time without disrupting the functioning of a busy clinic.

Several approaches to HRQOL data-collection are available. The most commonly used method of data-input is transcription from written records (1, 2) . This approach suffers from high labor costs and poor turnaround time. In addition, transcription is prone to errors. These errors stem from a variety of sources, including typographical errors, the inherent difficulty of the task, inadequate instructions to data-entry personnel, lack of quality control, and lack of continuous monitoring (2-4) . Optically scanning specially formatted questionnaires minimizes the cost of data-entry, but does not eliminate poor turnaround time. Direct entry of information by patients at a terminal has been shown to be a feasible means of data-collection (5-7) and dissemination (8, 9) . However, this method is not portable, can intimidate users with little computer experience, and requires some facility with keyboard and/or mouse input devices.

Pen-based computers offer an appealing alternative to computer terminals because they are portable and do not require the subject to have any facility with a keyboard or mouse. They have already been used in both medical and non-medical projects (10-13) . Questionnaire administration is a simple application of this technology. It relies on the use of standard gestures such as "tapping" and does not require interpretation of free text, a function that has not yet been implemented in an acceptable fashion. Thus, we chose to develop our questionnaire program on a hand-held computing device - specifically the Newton MessagePad.

SYSTEM OVERVIEW

We have completed the development of a pen-based application for routine HRQOL data collection. The design of the fully integrated system is as follows. Breast cancer patients are asked to complete a questionnaire on the Newton each time they come to the clinic for a visit. The components of the questionnaire are two widely used, validated, cancer-specific quality of life instruments, the FACT-B and the Quality of Life Index (14, 15) . The patient fills out the questionnaire and returns the Newton to the computer Operator. Next, the Operator uploads the responses into a desktop Macintosh through a wireless infrared connection. The program on the Macintosh confirms the identity of the patient with the Operator, and then updates a database

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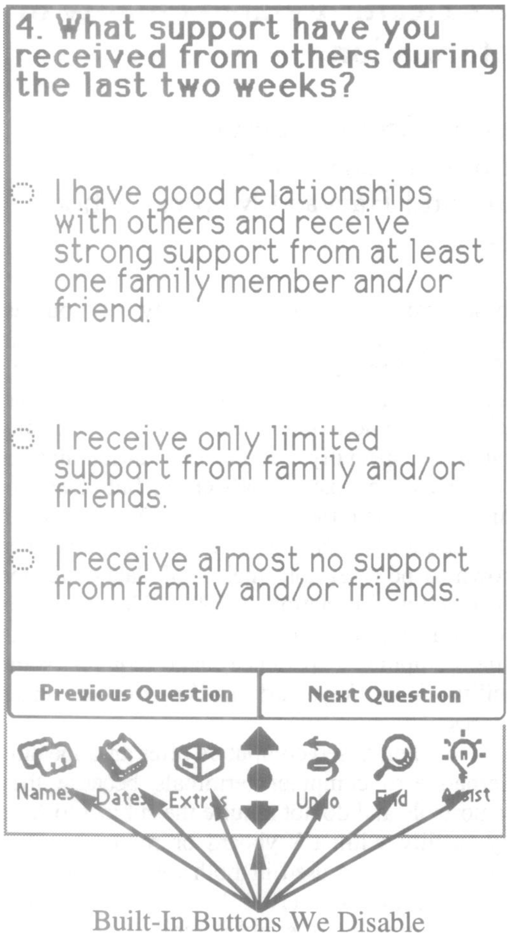

Figure 1
Sample Question Screen

with the new entry. Automatically, the updated history of the patient's responses is printed out for the Operator to attach to the patient chart. Thus, current and previous quality of life scores are made available to the doctor and nurse seeing the patient that day.

SYSTEM WALK-THROUGH

When a patient comes into the clinic, an Operator enters the patient's unique hospital number into the Newton, starts the application, and hands the Newton to the patient. The Newton displays a title screen, then two screens with directions on how to navigate through the questionnaire. Next come the question screens - one question per screen. [See Figure-1]. The patient picks her response by "tapping" in the circle next to the desired response. The action of picking a response automatically displays the next question. The patient also has the use of "Next Question" and "Previous Question" buttons that allow her to move between questions, skip questions, and change her responses to previously viewed questions.

Once the patient has finished the last question of the questionnaire, the Newton offers her the choice of going back to review or change her answers. If she chooses to continue, the program checks the patient's responses. If she has not skipped any questions, the program displays the End Screen, which asks the patient to return the Newton to the Operator. However, if the patient has skipped one or more questions, the Newton notifies her of this fact and asks if she would like to go back and answer them. If she chooses to go back, the program displays the unanswered questions according to the same procedures used in the initial administration of the questionnaire. If she chooses not to go back, the program displays the End Screen.

When the patient returns the Newton to the Operator, the Operator brings up a Control Screen which is inaccessible to the patient. The Operator is then able to upload the responses into an Oracle database running on a desktop Macintosh. The communication occurs through a wireless infrared connection between the Newton and a device attached to the Macintosh. The accuracy of the transmission is ensured through an error-checking protocol. On the Newton side, the information remains in memory until it is specifically removed at the end of each day.

A Hypercard application runs on the desktop Macintosh, and manages the communications and Oracle SQL queries. The Hypercard application receives the patient hospital number and queries the institute's Oracle database to get the patient's name. If the name is correct, the Operator hits a button to record the questionnaire results into the database. If the name is incorrect, the Operator can either try a new hospital number or accept the number in the Newton as the overriding identification.

Once the upload is complete, the Operator resets the Newton to prepare it for the next patient. At the same time, the Hypercard application prints out the patient's current and previous HRQOL scores and responses. This history is attached to the patient chart and delivered to the doctor or nurse seeing the patient that day.

DESIGN GUIDELINES AND CONSTRAINTS

Our experiences in designing prototypes of this system and looking at other Newton applications have given us some general insights into the design of hand-held computer applications. We present these guidelines as well as design-specific constraints which affected our application.

Hand-held computers are not desktop computers. Memory, computing power, and display space are at a premium. When using a hand-held computer as a client to a server, the server should perform all computationally intensive and memory-intensive tasks. It has been recognized that portable computers should be part of a larger system, with appropriate functions placed on each device (16) . Furthermore, a pen-based application should maximize display area by only displaying pertinent information. If possible, text should be broken down into relevant pieces that are displayed one at a time.

The application should minimize the amount of writing required to complete an input. While the handwriting recognition capability of the Newton has improved, it's usefulness is limited. Since the recognition relies upon knowledge of the writing style of the user and often forces the user to adapt his/her writing, it becomes tailored to an individual user. In cases where very few individuals interact with the Newton, relying on limited handwriting recognition is feasible. However, if a large number of people will be using it, especially if only for brief periods of time, then there should be almost no handwriting recognition required. The interface should only require the user to use standard gestures such as "tapping" the desired choices.

In developing our application we faced a number of additional design constraints, the solutions to which are reflected in the ultimate design. In order to ensure that a unique patient identifying number is associated with every set of responses, the Operator is required to enter the patient's hospital number into the Newton before handing it to the patient. We maximize usable screen space because we have a text-intensive application and ill subjects who may be unable to tolerate a complex display. Since the primary users of the Newtons are not technically trained, we made the Newton into a dedicated device by disabling the built-in function buttons on the Newton. This eliminates the possibility that the patient might accidentally start up one of the built-in applications. Theft is another major concern in our design. We require that the patient return the Newton to the Operator, who will be present in the room, before seeing the physician. Another theft-deterrent is the fact that disabling the functional buttons on the Newton prevents its normal use as a personal digital assistant.

Our particular wireless connection configuration between the Newton and desktop computer has many benefits. By choosing the wireless connection, we eliminate the need to connect and disconnect the Newtons each time a questionnaire is filled out. Not only does this save time and energy, but it also reduces wear and tear on the device. Second, since the connection is made via the Newton's built-in infrared transceiver, we don't need to attach bulky third-party transceivers to the Newton. While the built-in connection is low-level and has a limited range (approximately 1 meter between the Newton and the desktop device), our application doesn't require more range and we have implemented an error-detection protocol on top of the connection to ensure uncorrupted transmissions. The limited range of the infrared beam also helps ensure the security of the information being sent.

Finally, we needed the application maintainable by non-programmers. This constraint led us to choose a design where the questionnaire engine is separate from the text of the questions themselves. In this architecture, a person with almost no Newton programming knowledge can easily add, change, or remove questions or parts of questions. The application can also be loaded with many different questionnaires and allows the Operator to dynamically decide which questionnaire to give to a patient. We also collect auditing information about how long it takes to complete each questionnaire.

RESULTS

In a preliminary pilot test of the system, we asked 10 patients, randomly selected from the clinic waiting area at the Dana-Farber Cancer Institute, to take a sample questionnaire on the Newton. After being given a brief description of the goals of the pilot test, consenting patients were handed the device without any verbal instructions on its use. After they completed the questionnaire, they were asked to provide spontaneous feedback on the application and to answer a series of structures questions about it.

The patients ranged in age from 24 to 70 and included two men and eight women. Their computer experience ranged widely; one of them had never used any type of computer while another owned several computers. One patient had used a Newton once at a store display. Two of the patients only had the use of one hand.

All the patients completed the questionnaires quickly and easily, though two of them needed a brief demonstration about how to use the stylus (the utensil that is used to enter data on the Newton). The time to complete a nine item HRQOL questionnaire ranged from 149 to 372 seconds. The two patients who only had the use of one hand took 256 and 286 seconds, while the oldest patient took the longest time to complete the questionnaire. In response to structured questions about the application, all but two indicated that as a format for administration of a questionnaire, they would prefer the Newton over paper and pencil, a lap top computer or a personal interview. In each case, the two other subjects had no preference, but indicated that they felt the Newton was easier to use than the alternative. On a scale from one to five corresponding to "strongly agree" to "strongly disagree", the mean response to the statement "Using a Newton to complete a questionnaire is very easy," was 1.25.

Spontaneous comments about the application were uniformly positive. Subjects felt that it was very simple to use and suggested that their care would be improved by the feedback the application would introduce into clinic operations. Several patients also mentioned that enhanced privacy was a strength of the Newton over the other methods of administration. Surprisingly six respondents stated that taking a questionnaire on the Newton took less time than taking the equivalent questionnaire on paper. We suspect that using the Newton seems to take less time because the Newton is interactive and more fun, a response that might fatigue with repeated use.

DISCUSSION

The system that we have described has several advantages over traditional forms of data-collection. Like systems employing direct patient entry into a computer terminal, our system eliminates secondary data-entry, along with all the associated problems of paper storage, transcription costs, and mistakes in the transcription process. Our system also allows the design of "intelligent" questionnaires that selectively display questions based on the patient's responses to previous questions. For example, if a patient responds that she does not have any children, the program will not ask her questions about her children. The program also encourages completeness of the data-collection process by reminding the patient to go back to any skipped questions.

But our system has a number of advantages over direct patient entry at a computer terminal. First, the capacity is expandable. One Operator can take care of several Newtons at once, and each one only needs to be in communicating with the desktop computer long enough to upload its information. A busy clinic can have many Newtons running the questionnaire program, and no additional clinic space is required to accommodate the system. Furthermore, the Newtons are programmed to store all responses internally, until they are specifically erased. This allows the responses to be uploaded at any time, so the Newtons can continue data-collection while the desktop computer is busy or even not functioning. Therefore, in a clinic running with several Newtons, there is no single point-of-failure because each Newton can operate independently.

Our design also fares well in comparison to optically scanning of paper questionnaires. This only automates the data-entry portion of the questionnaire process. Scanning of responses does not allow you to give "intelligent" questionnaires, nor does it allow you to measure the amount of time spent on a particular question or the number of times a user goes back to a question to change an answer. All of these options are available with a questionnaire given on a pen-based computer.

Furthermore, our questionnaire application is just one of many applications that can be based on a pen computer and integrated into the clinical setting. We have already created the necessary building blocks of data-collection and wireless data-transfer to and from a networked computer. From there, we can collect and display almost any kind of information.

CONCLUSION

The system as outlined above is soon to be deployed in the breast cancer clinic of the Dana-Farber Cancer Institute. It will be an integral part of a comprehensive outcomes assessment program that will link data on medical history, treatment, and outcomes, including not only biological measures but also HRQOL. The resulting data base will be a tremendous resource for clinical research. But even more importantly, it is a first step toward overcoming one of the barriers to integrating quality of life considerations into the routine care of cancer patients. Changes in the health care delivery system are pushing physicians to see more patients in less time. One consequence is likely to be that attention is focused on the "disease" rather than the patient. This technology may offer one remedy.

All parties in the health care delivery system could benefit from a cost-effective method of quality of life data collection, storage and retrieval. Physicians will have better access to feedback on the outcomes of their care. Patients will benefit from any resulting improvements in their treatment. But more immediately, patients will be sent the reassuring message that their quality of life is seen as an important endpoint by their physicians and other providers. Finally, outcome data collected by this system will provide payors with critical information about the effectiveness of the health care services that they are buying with their limited resources.

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