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Development of a Multimedia Interactive Education System for Prostate Cancer

Michael A. Diefenbach[1*], PhD; Brian P. Butz[2], PhD; Nihal Mohamed, PhD[1]

[1] Mount Sinai School of Medicine, Department of Urology, New York, USA
[2] Temple University, College of Electrical Engineering, Philadelphia PA, USA

Prostate cancer is the most commonly diagnosed cancer and the second leading cause of cancer-related deaths among American men (American Cancer Society [ACS], 2007). It is estimated that 218,890 men will be diagnosed with prostate cancer and 27,050 men will die from this disease in the United States in 2007 (ACS, 2007). Treatment options for localized disease (i.e., confined to the prostate, without metastases or nodal involvement) include radical prostatectomy, external beam radiation, radioactive seed implantation, and watchful waiting. Although either of these treatments is quite effective with an average 5-year survival rate of 95%, each treatment option brings risks of long term adverse physical effects (e.g., sexual, bowel, and urinary dysfunction) that have the potential to severely impact a patient's disease-specific and general quality of life. In addition, treatment information is often presented in unfamiliar medical terms, fraught with probabilistic information that many patients have difficulties understanding. Patients are therefore in the difficult situation to make potentially far-reaching health decisions under heightened levels of distress and uncertainty (Diefenbach et al., 2002).

The Prostate Interactive Education System

We developed The Prostate Interactive Education System (PIES), an interactive multimedia expert system, to create a forum where patients receive trusted information, presented in easy-to-understand language. The overall goal was to educate patients about their treatment options and to assist them in their treatment decision by including a decision aid. PIES provides the patient with a multitude of treatment information and encourages patients to obtain the kind of information that they desire about the disease. PIES is envisioned as an important step in the treatment-decision process. The software will prepare a factual report for the patient who will meet with a physician or a psychologist if needed following his interaction with the software. PIES provides information and does not preclude a second opinion. In fact, a patient might have received a second or third opinion before using PIES.

In addition, PIES includes an expert system that will be operating in the background. The expert system will analyze prostate cancer and treatment information that the patient obtains and determine if the patient is getting enough information to make an informed decision. The expert system will not make any decision for the patient. It will only follow and evaluate the completeness of the process of obtaining information that enhance treatment decision (e.g., survival, treatment side effects). If the expert system becomes concerned that the patient is not being thorough in his examination of alternatives, it will make suggestions to view information that has not been accessed and about where the patient might find it. The patient can follow or ignore the expert system's suggestions.

Michael Diefenbach
Associate Professor Urology
Associate Professor Oncological Sciences
Mount Sinai School of Medicine

Prof Diefenbach will be a facilitator at the 2007 Synergy Workshop (12-14 August 2007)

Design of PIES and Contained Information

The identification and development of the information contained in PIES is a multi-step process. A starting point for compiling information is a review of current information on prostate cancer treatment (e.g., the PDQ), that is approved by the National Cancer Institute (NCI, 2004) and the Cancer Information Service (CIS, 2004). Regular Medline searches (Diefenbach & Butz, 2004) supplement this information and ensure that it stays current. Second,

*Corresponding Author: Michael A Diefenbach; email: Michael.Diefenbach@mountsinai.org

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the research team summarizes this information and identifies and develops appropriate visual materials. Third, medical expert consultants vet all materials for accuracy. Fourth, a health educator and a cancer-information specialist adopt the information to a 6th- to 7th-grade reading level. Last, information is then adopted for high and low information seekers.

An overview of the PIES architecture is shown in Figure 1. The patient interacts with the CD-ROM based system on a personal computer. The system is CD-ROM based but could be made available over the Internet. A CD-ROM delivery system was chosen so that those patients without a high-speed connection to the Internet would not experience delays caused by downloading videos. The information is developed and presented using Macromedia's Authorware (2004). Authorware is able to communicate with other software and can transmit information in real time or near real time. Authorware will allow the patient to have access to other programs such as a notebook to record information, and various applicable medical-applications software.

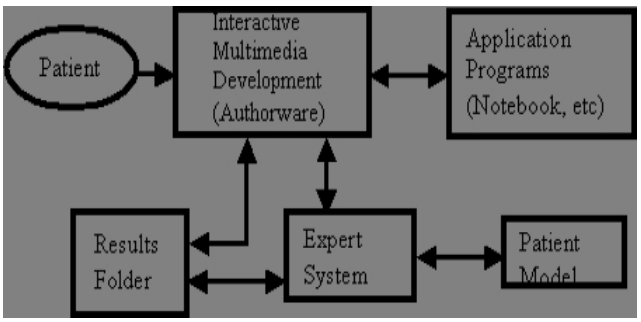

Figure 1 Overview of the PIES architecture

The metaphor used in PIES to organize information is that of a virtual health center. When the patient enters the health center, he is greeted by an information specialist (see Figure 2). The information specialist welcomes the patient and shows him around the PIES Health Center. The Health Center consists of a reception area, a library, and a group meeting room on the first floor, and physician offices on the second and third floors, connected through an elevator. Each room is interactive and the patient is shown how to use the room's facilities when he first chooses to enter the room. After showing the patient the layout of the Health Center, the information specialist asks the patient to provide some clinical data and to state initial information seeking and treatment preferences by filling a needs assessment questionnaire. This information allows the expert system to tailor the information contained in the program to the patient's information seeking needs. For example, if the patient states that he is leaning towards surgery, the expert system will suggest surgery-related information as the patient uses different rooms' facilities. After filling the questionnaire, the patient is free to visit any room of his choosing.

Figure 2 PIES Virtual Information Specialist

The Library

If the patient would like to learn about prostate cancer and all its treatment options, he is referred to the library. To get to the library, or any other room, the patient would click with the mouse on the door that leads to the desired area. The library is a highly interactive area (see Figure 3) in which the patient may obtain, and interact with, educational material and other information. The library consists of a wall of shelves with many books to choose from. The

Figure 3 PIES Virtual Library

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books are sorted in alphabetical order; by "rolling over" a book with a mouse, its title is revealed. For example, a book entitled Brachytherapy (see Figure 4) contains information about radioactive-seed implant treatment.

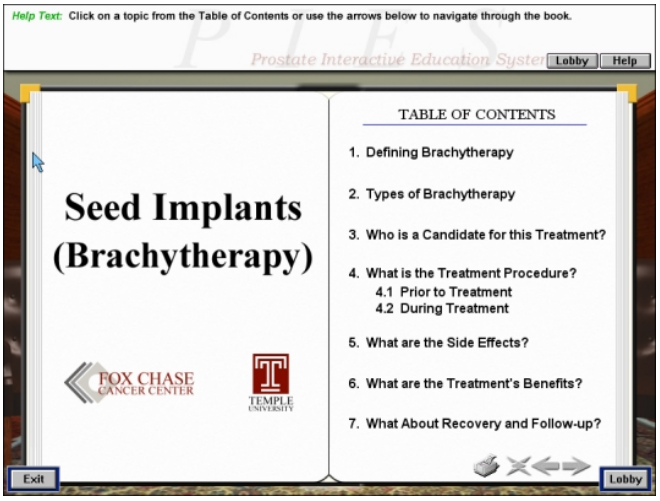

Figure 4 PIES Virtual Library – Book Example

A chapter gives an overview of brachytherapy; another chapter focuses on side effects, while another one describes the rationale behind a particular treatment regimen. Other books available contain information about psychosocial functioning, such as how to deal with impotence and incontinence, the use of alternative medicine, clinical trials, and the impact of prostate cancer on the family. In sum, the library is a place that has a comprehensive collection of disease- and treatment-related materials that not only address the momentary concerns of the patient, but also assist in the preparation for future prostate-cancer and treatment-related consequences.

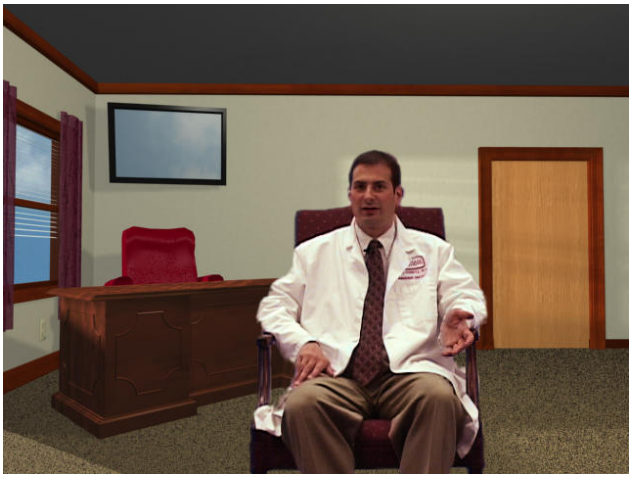

Figure 5 PIES Virtual Physician

Interacting with a physician

The physician offices are on the second and third floor of the virtual health center. The physician offices are reached through an elevator, which contains a large sign that allows the user to click on the desired office. Experts of a particular treatment specialty (i.e., surgeons, radiation oncologists, a physician specializing in brachytherapy) are available to provide information about different treatment modalities. After entering the office (see Figure 5), the patient interacts with the physician by selecting different video clips from a clipboard that contains over 30 frequently asked questions. Each video clip answers a specific question about the treatment, providing anatomical and technical information. In addition, physicians discuss issues such as who is a candidate for a particular treatment, the likelihood of side effects, success rates, recovery time, and expected quality of life.

Figure 6 PIES Virtual Group Meeting Room

The Group Meeting Room

The patient may choose to participate in a group meeting of prostate cancer survivors. There are four groups representing the different treatment options (i.e., external beam radiation, surgery, brachytherapy, and a combination of the previous options). The patient may listen to the group members discuss with one another aspects of their treatment decision-making such as how they found out that they had prostate cancer, how they felt when they found they had the disease, and how they chose a treatment. Figure 6 shows members of the group discussing a wide-ranging array of topics that include sexual and

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incontinence problems, issues with intimacy, the effect of the disease on the partner, the influence of the spouse on treatment decision-making, experience with different treatments, and the use of alternative therapies.

The Notebook

If the participant wants to take notes or jot down a comment during his exploration of the Health Center, he can call up an electronic notebook, which is available from any room. The notebook will also be helpful to jot down notes when visiting the doctor's office. These notes might be helpful to the patient when he consults with physicians about prostate cancer. All notes will be incorporated in the final printed report that will be generated upon exiting the program.

The Expert System

Research has identified two main profiles of information processing: high monitoring (i.e., information seeking) and low monitoring (i.e., information distracting) (Miller, 1995). When confronted with medical information, high monitoring patients typically process information very attentively and amplify its threatening aspects. In contrast, low monitoring patients are more likely to minimize threatening cancer-related information that diverges from their belief that they will be fine (Miller, 1995, Diefenbach & Butz, 2004). Based on the patient's scores on the needs assessment questionnaire, the expert system determines if the patient is a low information seeker (i.e., a low monitor), one who wants only the important facts about a treatment, or a high monitor (i.e., a high information seeker), one who wants considerable detail about a treatment therapy. The expert system directs the interactive multimedia program to provide the amount of information that the patient desires. The expert system realizes that a patient might want to be a high monitor in some areas and a low monitor in others. For example, a patient may be very interested in knowing all about the side effects of external beam radiation while wanting only the essentials about the procedure itself. To our knowledge, PIES is unique in that it allows such dynamic tailoring. Consequently, as patients proceed through PIES, its expert system determines how much information patients desire about a topic and provides it.

Exiting the Software

When participants decide to exit, the software calculates which information had been accessed and offers information that has not been viewed to patients. For example, if a patient only inquired about surgical treatment for prostate cancer, the program offers information on external beam radiation and brachytherapy for reviewing. Thus, the software will ensure that all patients are offered a balanced amount of information. If the patient desires, he can complete a decision aid, designed to elicit his values and goals with regard to prostate cancer treatment (O'Conner et al., 1999) and thus assist him in making a treatment decision that is right for him. After completing the decision aid, the software will also ask the patient if he wants to return to PIES. If the answer is yes, the expert system will update the patient's results folder before the program is closed. When a participant re-enters the software he is placed in the reception area to decide which part of the health center he wishes to visit. If the participant does not intend to revisit the software, it updates the results folder, and then generates a report for the patient. This report contains a synopsis of accessed information, notes that were taken, areas the participant has not visited, and types of available information that he has not yet accessed. Information about the evaluation of PIES is available at <http://www.jmir.org/2004/1/e3/>.

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