Model Driven Educational Assistance for Patients

RADHAKRISHNAN RAMACHANDRAN

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ABSTRACT

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Radhakrishnan Ramachandran

Benefits of patient education in improving patient's compliance to treatment and self management are well recognized by the health care community. Such benefits contribute to the growing interest in the use of computers to complement traditional means such as providing leaflets, instruction by the nurse and patient-doctor dialogue. Over the years a number of systems have been developed for patient education addressing the personalization and information needs of patients. Most of those systems focus mainly on personalizing the contents to be presented and give lesser importance to usability or user interface design of the software. As a result, many such systems are not deployed in hospitals. The primary focus of this thesis is to propose a patient education framework that can be successfully deployed and used in a typical hospital setting. We have explored the avenues that are identified important to have personalization in a patient education system. Model Driven Educational Assistance (MDEA) framework uses a combination of XML Topic Maps and the Learning Unit Classes (LUC) model for flexible knowledge organization. A simple and intuitive user interface was designed to help patients learn easily from the system. A functional prototype has been developed to assist transplant patients as they learn about their post transplant care. The pilot test was conducted over a period of six months at the transplant center of a Montreal hospital. The results of the evaluation were promising indicating that the software was easy to learn and to use.

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- Radhakrishnan Ramachandran

Dedicated to Appa and Amma

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Nomenclature

ADL - Advanced Distributed Learning

AICC - Aviation Industry Computer-based training Committee

ASTCAI - Asthma educational system with Computer Assisted Instruction

CHESS - Comprehensive Health Enhancement Support System

CO-ED - Computer assisted Education

CMI - Computer Managed Instruction

CNS - Clinical Nurse Specialist

HCP - Health Care Professional

ISO - International Standards Organization

ITS - International Transplant Society

IMS - Instructional Management Systems

LEAF - Layman Education and Activation Form

LMS - Learner Management System

LTSC - Learning Technology Standards Committee

LUC - Learning Unit Classes

MDEA - Model Driven Educational Assistance

PIES - Prostate Interactive Education System

PIGLET - Personalized Intelligent Generator of Little Explanatory Texts

PS - Patient Selection

SCORM - Sharable Content Object Reusable Model

SS - System Selection

UCD - User Centered Design

Chapter 1

Introduction

The importance of providing health information to patients has been widely recognized and practiced in the hospitals. Patient education has shown significant results in improving quality of treatment, and quality of life by reducing the hospital admissions, and length of stay in the hospital [Morris et al., 1989]. Educating patients regarding their disease and treatments gives them the essential knowledge for self-management, and creates awareness regarding their health condition. Traditionally, patients are educated in the hospitals by Health Care Professionals (HCP) through direct dialogue such as one to one tutoring, written leaflets, and audio-visual materials. However leaflets and audio-visual materials lack the personalization required by a patient, as they provide general information not specific to the patient's conditions, needs and preferences [Bental et al., 1999]. Instructions provided by the HCP are personalized, however, considering the health condition of patients, more instructions as well as additional time of HCP may be required to impart essential knowledge to the patients effectively. Computers are well suited for supporting patient education because of their anytime availability, repetitive instructional facility, and greater prospects for personalization in presentation.

In our work, we consider computer based education of patients to be a complement to the traditional means of patient education and not as a total replacement to them. The leaflets, audio-visual resources as well as the instructions can be transformed into digital resources for providing instruction to patients. A major problem with most of the available computer based patient education systems is that the information provided is general and not personalized for a specific patient [Bental et al., 1999]. Studies on patient education suggest that patients would prefer to view information that is tailored to their own disease and conditions [Osman et al., 1994]. This affirms that personalization is a crucial factor for the success of such systems. Personalization, viewed over a wide spectrum could range in its trivial or simplest form of inserting a patient's name and title during presentation to adapting the presentation of contents based on an elaborate dynamic model of a patient. Adaptive systems for patient education build a model of the patient and update the model as the patient progresses in learning with the system. Such a model is used as a primary source for personalization and adaptation.

Adaptive educational hypermedia is a new area of research combining intelligent tutoring systems and hypermedia systems, the two major approaches in computer assisted learning [Papanikolaou et al., 2003]. Such systems can be used for patient education and adaptations can be incorporated to accommodate different patient's needs and abilities, maintaining the appropriate context for interaction, and increasing the usability of the hypermedia by making it personalized. Personalization in educational software requires understanding of the learner as well as the tasks that are important to learning. Thus the design of the patient model influences the system's adaptation and such a model addresses significant characteristics of the patients associated with learning. Given the success of adaptive educational hypermedia systems, it is believed that their application in the area of patient education will be beneficial [Bental et al., 2000]. Patients can be considered as a special case of learners but a lot of issues have to be considered before defining a patient model such as motivation to learn, varying educational background, and current emotional status of a patient in dealing with his/her disease. Patients with chronic diseases require a lifetime of education and therefore such a patient model should consider not only different types of patients but also the change in the same patient with respect to the disease as time progresses. The patient model may also include the preferences of the patients, concerning the presentation and navigation of contents, or monitoring and alerting, for personalizing the user interface.

A good user interface facilitates effective communication between the user and the software. The design of such an interface is vital for the success of any computer based patient education system. One of the major requirements in the design of patient education software is a simple and intuitive user interface. The major objective in developing computerized patient education software is to provide patients with a personalized tutor minimizing the hospital staff involvement so that the overall efficiency of healthcare services can be improved. A complex and difficult to understand interface may consume more of patient's time in learning the software as well as the HCP's time in learning to use the software and in explaining to the patient about how to use the software. The acceptance of the HCP in using the software is important for the healthcare domain [Lapointe and Rivard, 2006]. This presents a key challenge to design a simple and intuitive user interface for patient education systems.

Content creation and knowledge engineering are labor intensive. They require much effort and time from the domain experts. Clear understanding of the goals and objectives are needed. A flexible method of knowledge representation may help reduce the complexities involved in modifications and maintenance of the existing contents. Sharing and reuse of such knowledge is beneficial for the healthcare community. Effective knowledge sharing and collaboration can help minimize development cost, and promote sharing of experiences and contents. It is clear that without a systematic approach to content creation, knowledge reuse and maintenance may be difficult. Standards such as learning objects (IEEE LTSC [IEEE LTSC Website]) and SCORM [ADL SCORM Specification] are recent international standardization attempts in the educational domain. Their emphasis is on packaging of 'content chunks' with reusability as the primary objective. Topic map [Topic Map Specification] is an ISO standard for the representation and interchange of knowledge. Topic maps, based on the concept of the index of a book, are recently gaining popularity in areas of knowledge organization, sharing and management.

1.1 Problems addressed and Contributions of this thesis

Most of the existing computer based patient education systems focus mainly on the information presented to patients and use suitable natural language techniques for personalizing the information [Bental et al., 1999; Cawsey et al., 1997; Cawsey and Jones, 1996]. Many such systems are not deployed in hospitals. The major factors that contribute to the success of computerized patient education systems are cost effectiveness, acceptability to medical professionals, amount of information needed about the patients, and the risk and impact of mistakes in adaptation [Reiter and Osman, 1997]. The focus of this thesis is to develop a model based framework for patient education that can be successfully deployed and used by patients as well as the HCPs.

In this direction, the following are the contributions of this thesis:

- Systematically studied and summarized the issues involved in developing interactive patient education systems.
- Proposed a model based framework for the development of patient education systems driven by a content model, patient model and disease model.
- Investigated significant factors such as personalization, UI design, and flexible knowledge organization, and proposed solutions to their design.
- Developed and evaluated a prototype at a Montreal hospital keeping usability and simplicity as the focus for use by patients and HCPs.

1.2 Thesis outline

This thesis is organized into six chapters, each addressing specific concerns of this thesis. Chapter 2 explains the difference between patient education and conventional learning. It also reviews existing patient education systems published in the literature. The challenges in building successful patient education systems are discussed, and design objectives that are set as the scope of this thesis are outlined. Chapter 3 describes the architecture of the proposed patient education system MDEA. The models driving the MDEA system are then discussed. The knowledge representation framework used for sharing and maintaining the contents is then explained. The design of a simple user interface used in the prototype is discussed. Chapter 4 explains the significance of patient education in organ transplant domain for which the prototype was developed. The design of the prototype is then discussed. It also elaborates on the efforts applied in deploying the prototype in the hospital for pilot testing and also the problems faced in such deployment. Chapter 5 provides the evaluation of the prototype by the patients as well as the domain experts. Chapter 6 includes conclusion and future works that can be done based on this work.

Chapter 2

Background and Related Literature

Over the last few decades the healthcare community has stressed the importance of providing more education to patients. Increasing emphasis on such an education is based on the belief that it will lead patients to a better understanding of their disease and help them make better informed decisions [Lewis, 2003]. Patients also have indicated that they want more information than what they get from their physicians [Tang et al., 1997]. With both patients and the medical community pushing for improved patient education there has been significant awareness in using computers to address these educational needs over the last 20 years. Today, in the domain of e-learning, software systems have undergone a significant change from simple static instructions to more dynamic and personalized instructions [Beck et al., 2000]. Computers have been extensively used for providing education in a wide range of disciplines such as mathematics, algebra, data structures and so on. There has been significant progress in the development of such systems in order to make them intelligent, adaptive and personalized to a person's needs and preferences [ACM Communications, 2002]. Such systems are designed based on some key assumptions about the user such as common level of background knowledge they possess on the subject, motivation to learn, and attentiveness. The learning goals and course contents are usually well defined, and that remains the same for all learners taking that lesson. The sources from which the instructional materials are derived are considered less important by the learners and they focus more on instructional materials than their sources. Patients, on the other hand, differ significantly from conventional learners as they comprise of a wider range of population with respect to different educational backgrounds, and varying motivation levels. Also, in case of patients, the source from which the instructions are derived is considered very important. These factors are supportive of the fact that patients as learners are quite different from conventional learners and such factors should be considered while designing any educational software to be used by patients. In this chapter, before reviewing the interactive patient education systems published in literature, we will outline some of the critical issues that differentiate patients as learners from conventional learners to provide a better understanding of relevant issues.

2.1 Differences between patients and conventional learners

The purpose of learning by students in general is to gain more knowledge or to develop skills that might be useful for them in their future studies or career. Patient education, on the other hand, has more specific goals such as: (a) to educate the patient on selected narrower topics such as self-medication and personal care, (b) to teach them how to monitor their own health conditions for managing chronic diseases, (c) to train them on home care after major hospitalization, (d) to provide them more information on their disease and treatment options. There are several benefits that can arise from an effective patient education. In [Osman et al., 1994] the authors report how computer supported education of asthma patients has resulted in reduced hospital admission. Patient education might take place in the hospital setting, in home setting, while waiting in clinics, or in any other suitable locations.

Patients can be considered as a special category of learners and modeling patients draws a number of interesting differences from conventional learners.

1. *Motivation to learn*: In most computer based education systems, learners are often assumed to have a certain level of motivation to be educated. This may not be true with respect to patients, who may be in a state of shock, or may be suffering from physical pain or in great anxiety. Under such circumstances, the motivation to learn about their disease condition is generally very low.
2. *Heterogeneity*: Considering the widely varying educational background and knowledge of patients about the disease, it is quite evident that patients form a more heterogeneous group as compared to a group of conventional students.
3. *Emotional status*: Emotional status is also an important factor that will affect how an individual assimilates the presented information. In conventional systems, students usually learn in environments of personal stability, whereas patients may be learning in situations of concerns and anxiety. Then they may not be able to assimilate information in the same capacity as they may under normal conditions.
4. *Cognitive or physical disability*: An impairment of the cognitive or physical function of the patient can also have an impact on the patient's ability to be attentive and to interact while using a system. In conventional systems, it is assumed that the learners have the ability to pay attention and interact with an interactive presentation. However with a patient this may or may not be true depending on the conditions and situations.
5. *Evaluation*: It is also important to note that the evaluation model has to be modified for patients. The evaluation of patient learning would be different from

the evaluation of a student's learning in an academic environment. The objective of patient learning is not excelling in comparison to other learners but is to improve the opportunities for improving personal health care and management of personal health.

In summary, personalization and well 'carved' patient models could play a far greater role in addressing differences and building successful patient education systems.

2.2 Interactive Patient Education Systems

Computers have the advantage of providing information that is personalized thereby addressing a number of key issues faced by both patients as well as HCPs. With regard to the impact of these systems to date, a number of studies have borne out that computer applications have improved patients' education. A systematic review of randomized clinical trials was conducted to evaluate the acceptability and usefulness of computerized patient education interventions [Krishna et al., 1997]. The results suggested that computerized educational interventions can lead to improved health status in several major areas of care, and appear not to be a substitute for, but as a valuable supplement to face-to-face interaction with physicians. The growing acceptance of computers having a positive impact on patient education, patient satisfaction and disease outcomes, has spurred an abundance of interest into research and development of computer applications for patient education [Tang et al., 1997]. As a result many specialized educational softwares are being created and used in teaching centers such as diabetes and asthma teaching centers.

As compared with other educational domains, personalization can be viewed from a wider perspective in the patient education domain. One such personalization arises from the changing information needs of patients. Patients are not static figures and their need for information changes as they progress with the disease. A particular disease may consist of a large set of topics covering the different stages of the disease. The set of topics that are of interest to a patient can be identified through their stage in the disease from an electronic patient record based on which the information can be tailored to reduce information overload. The preferences of a patient in learning the desired set of topics may vary based on whether the patient prefers to learn through question answering or to allow the system to present topics in an organized manner as planned by the content developers. Another important personalization is in the presentation of information on a selected topic based on the learning ability of the patients. For instance, based on a patient's preference, the amount of information or the multimedia used for contents may vary in the presentation of a particular topic. Such adaptive presentations might help the patients to comprehend the information in an effective manner. Evaluation is an indispensable component of any educational system as it helps to monitor the fact that the learner was able to comprehend the presented information or not. Evaluation in patient education needs to be personalized based on the preferences of the patient and the objectives of the patient education. In the next sub-section, we review a number of interactive patient education systems published in the literature. This helps provide a deeper insight into the factors that are important to make such systems acceptable and usable by the health care community.

2.2.1 Migraine system

The migraine system provides customized information to patients suffering from chronic or acute migraine headaches. It uses natural language generation techniques to tailor the explanations provided to individual patients [Buchanan et al., 1995; Mittal et al., 1994]. The patient model used in Migraine consists of symptoms of disease, past treatments, relevant habits of the patient and current medical treatments. Information about the patient is gathered using a questionnaire on their first visit to the system and is stored in the patient model. Subsequent visits are recorded in the patient model and used appropriately. The system provides only textual information to the patients; multimedia elements are not used to improve interactivity and comprehension of the patients. The only language used is English; multiple languages are not considered in the system design. Learning takes place in the hospital setting during the visit to the physician in a clinic. Such learning is incorporated based on the fact that patients need more information than what they generally obtain from visiting their physician. Such a restricted learning environment in a clinical setting might not gain the advantage of anytime availability of computers for learning. One of the major constraints with the system is that the information to be presented is determined based on the patient's visit to the clinic and additional information outside the current treatment is not available for the patients. The system consists of a library of possible questions determined from an ethnographic analysis of doctor-patient interactions. An ethnographic study can broadly be described as the qualitative description of human social phenomena based on fieldwork [Hammersley and Atkinson, 1994]. The system aids the patient in formulating a question, and at the same time constraints him/her from asking questions that the system cannot answer. The system does not include an evaluation component to assess the comprehension of the patients in the information presented.

2.2.2 PIGLET

Personalized Intelligent Generator of Little Explanatory Texts (PIGLET) provides patients with personalized explanations of their medical record [Binsted et al., 1995]. The explanations are text-based only; multimedia elements are not used for presentation. The patient records are hand-built from real paper records from diabetes clinics consisting of information such as a set of personal information, a list of problems, a list of treatments, and a list of tests and measurements. PIGLET uses a simple patient model which is based on categories of patients derived from the type of chronic problem. The information is presented in English and the system does not consider multiple languages which is usually necessary for non-English speakers. The system assumes that the patient is interested in all the topics mentioned in their health record and therefore does not personalize the topics that might be of specific interest to patients. The system does not conduct an evaluation to assess comprehension of the patients in the presented information about their medical record.

2.2.3 Cancer patient education

The cancer patient education system is an improvisation of PIGLET and particularly adapted for teaching patients with cancer [Cawsey et al., 2000; Bental et al., 2000]. The system is hypertext based and multimedia is not used for presentation. The system is based on 'coping theory' which is based on the premise that patients wish to know and are able to absorb different kinds of information at different times - at diagnosis time, during different phases of treatment, and during post treatment period. A simple patient model is used which is entirely derived from the patient's medical record. The patient record consists of information such as current and past problems, treatments, test results and personal details such as age. Information is personalized according to the type of cancer and stage of illness, the treatments offered to or undergone by the patient and the time frame in which the patient is seeking information. The system does not include an evaluative component to assess the patient's understanding. The system does not adapt to the patients within a session and such adaptation is more coarse grained and might not be effective during long learning sessions. The system does not consider using multiple languages to tailor information to the patients.

2.2.4 CO-ED

The CO-ED (COmputer assisted EDucation) project is developed as an interactive computer based educational program for a variety of chronic conditions and other health related topics [Finkelstein et al., 2002]. The patient model used in CO-ED consists of disease history, patient cognitive profile, patient behavioral profile and personal preferences of the patient. Information to be presented to the patients is organized as sections with each section consisting of one or more educational messages. Each educational message is followed by a multiple choice question and patients cannot proceed to the next message unless they give the right answer. The major drawback of this approach is that patients are forced to take a lot of tests and might lose their interest with the system. The system performs a closed evaluation to assess the learning but is not flexible for the patients to avoid the evaluation or skip to particular evaluation process. Thus the presentation and evaluation are combined in a precompiled manner and offers no flexibility for the patients to learn as desired. The system design does not address multiple languages which might not be advantageous to patients whose mother tongue is not English.

2.2.5 LEAF

The "Layman Education and Activation Form (LEAF)" project extends the usual activity of filling in a medical history form to include educational activities that help patients understand the terminology of the form and allows suggesting topics that they might want to discuss with their doctor [McRoy et al., 1998]. The patient model in LEAF consists of gender, age, reported illnesses and immunizations, and illnesses of family members. The model is initialized with the help of a questionnaire at the beginning. It is an interactive system which tailors its interaction with each patient by using the information provided by them. The information is presented as text and multimedia presentation is not available in the system. The system does not include an evaluative component to assess the knowledge gained by patients in the presented information. The information is presented in English and multiple languages capability is not supported by the system design.

2.2.6 ASTCAI

ASThma educational system with Computer Assisted Instruction (ASTCAI) was developed to assist patients with bronchial asthma regarding disease management and techniques for using instruments such as a peak flow meter [Takabayashi et al., 1999]. It is an educational tool that can be used as a quiz where correct answers are scored, and the time required to complete the question–answer drill is measured for each patient. The system does not contain the model of a patient and presents the precompiled quiz in the same way for every patient. Therefore the quiz provided by the system is common to each patient and is not adapted to the patient's need and preferences. Learning occurs through testing and patients learn through answers to the questions. Such a system might not be of interest to patients who would not prefer evaluations and prefers only a learning session. Also patients are not allowed to select the desired questions and thus might reduce the interest of the patients with the system in learning the required information.

2.2.7 CHESS

Comprehensive Health Enhancement Support System (CHESS) is designed for patients facing life-threatening illnesses such as breast cancer, HIV infection, heart disease, Alzheimer's disease, and alcoholism [Gustafson et al., 1999]. The system provides different types of services such as help, and referral directory for the patients to learn the desired information. The system does not have a patient model and the information is not personalized based on the patient's needs and conditions, rather the system acts as a reference library where patients can access the desired information. Patients can read brief answers to questions, as well as articles and descriptions of services they may need. It also helps the patients in making decisions by providing information about the decisions and its consequences. The system design does not include an evaluation component to assess the understanding of the patients on the learnt information and does not address the multiple languages which might assist in better comprehension of presented information for patients who are not fluent in English.

2.2.8 PIES

The Prostate Interactive Education System (PIES) is an interactive multimedia expert system to help patients who have been diagnosed with early-stage of prostate cancer [Diefenbach and Butz, 2004]. The system design is narrowed down by focusing on a particular stage of the prostate cancer disease. The system provides the patient with information regarding treatments and allows patients to obtain the kind of information they need about the disease. The information is tailored to the patients but does not offer personalization in the topics to be learnt by the patient. One of the major drawbacks in the design of PIES is that when the user decides to exit the software, the system presents the information that are required for the patient to have a balanced knowledge on the presented topics. Such a system design might annoy the user when he/she wants to quit the software. The system also does not address the presentation on multiple languages restricting it to only English.

2.3 Challenging problems in building successful patient education systems

In computer science and educational technology there is a considerable body of literature for computer based education systems. These systems focus on educating students in domains such as algebra, introduction to UNIX operating systems or data structures to name a few. Such systems can be used by the industries or educational institutions to provide individualized tutoring. Their acceptance would be mainly based on the quality of the software, its features and functionalities. In the health care domain, there is still averseness in the usage of computers for health care applications [Lapointe and Rivard, 2006]. A significant reason for this reluctance might be based on the fact that it is a very sensitive domain involving human life and any error in the deployment of software might have a huge impact in the health care services.

Although there are many computer based patient education systems, only a few have been used by the hospitals [Diefenbach and Butz, 2004]. The important factors that influence the success of such systems are the cost effectiveness, and their acceptability by patients as well as the HCP for content creation [Reiter and Osman, 1997]. Significant cost and time are involved in creating the knowledge required for presentation and evaluation during the development of software for patient education. The usability of the software plays a very important role in gaining the acceptance of the patients as well as HCP in using the software [Diefenbach and Butz, 2004]. Creating a dynamic patient model that contains the required information about patients and its use for right personalization are two big challenges in the development of such systems.

The challenging design issues in building successful patient education systems can be summarized as follows:

1. Creation, maintenance, and sharing of the contents.
2. Creating, improving, and maintaining a dynamic patient model for its application.

3. Designing an adaptive and intuitive interface for the software following suitable design techniques like User Centered Design (UCD).
4. Personalizing the multimedia presentation of the learning materials with the help of the patient model addressing the context and needs of the patient.
5. Conducting a personalized evaluation of the learnt material tuned to the preferences of the patient.
6. Providing flexibility to the patients in learning the required information about the disease.
7. Supporting collaborative learning among a 'support group' of patient population with due considerations to individual's needs for sharing and maintaining privacy.

In this chapter, we outlined the significant factors differentiating patients from conventional learners and discussed their impact on the design of computerized patient education systems. Some of the existing interactive patient education systems were then reviewed which helped us get a good insight into the challenging issues involved in building successful deployable patient education systems. The next chapter will discuss how this thesis proposes to address many of the challenges listed above. Collaborative learning is a future work of this research and will not be discussed in this thesis.

Chapter 3

Model Driven Educational Assistance (MDEA) for Patients

Computer based patient education is an active research and development area. Benefits of such an education have been widely recognized by the healthcare community [Morris et al., 1989]. With the advancement in technology, the world has moved its horizons in the patient education domain, looking forward to personalization that the technology today promises. To name a few of its many advantages, a personalized system might assist patients to acquire better knowledge on the subject relevant to their illness and make informed decisions [Cawsey et al., 2000]. In short, such an approach could be an adjunct to the education they receive in a hospital or a clinical environment.

Over the last few years, several adaptation techniques have been proposed to personalize softwares based on the learner's needs and preferences. Application of such techniques to the patient education domain is still a challenging research issue [Bental and Cawsey, 2002]. A brief review of the technologies used for incorporating intelligence and adaptivity provides an insight into their applications in the patient education domain. Adaptive educational hypermedia is a combination of the two traditional methods of learning: intelligent tutoring systems and adaptive hypermedia. On one hand, intelligent tutoring systems focus more on being a tutor and provide less flexibility to the learner whereas on the other hand, adaptive hypermedia systems focus more on the learner and give less flexibility to the tutor [Papanikolaou et al., 2003].

Intelligent technologies in education can be categorized into curriculum sequencing and problem solving support [Brusilovsky, 1999]. The goal of the 'curriculum sequencing' technology is to provide the learner with the most suitable and individually planned sequence of 'knowledge units' to learn and also to sequence the learning tasks. Illustrations, questions, and problems are some examples in support of the learning tasks. Curriculum sequencing technology assists the learner to find an optimal path through the learning material. On the other hand, 'problem solving support' technology is used to provide assistance to the learner while solving a problem or at the end of solving a problem. It analyzes the path of the learner while solving the problem and provides hints or recommendations in correlation with the optimal path to solve the problem.

Adaptive hypermedia is relatively a new research area as compared to the intelligent tutoring systems. Adaptive systems use different forms of user model to adapt the content and links of hypermedia pages to the user. The two major technologies in adaptive hypermedia are 'adaptive presentation' and 'adaptive navigation' support [Brusilovsky, 1996]. The goal of the 'adaptive navigation support' technology is to support the learner in a hyperspace orientation and navigation by changing the appearance of visible links. The goal of the 'adaptive presentation' technology is to adapt the content of a hypermedia page to user's goals, user's knowledge and other information stored in the user model. One such example of an 'adaptive presentation' technology is that expert learners receive more detailed and deep information whereas novice learners receive more helpful information.

The implications of adaptive and intelligent technologies for patient education would be based on the requirements of the hospitals and acceptance by the healthcare industry [Lapointe and Rivard, 2006]. The selection of the technology must be made after a careful review of the requirements making sure that the incorporated technology is acceptable by the hospitals.

3.1 MDEA architecture framework

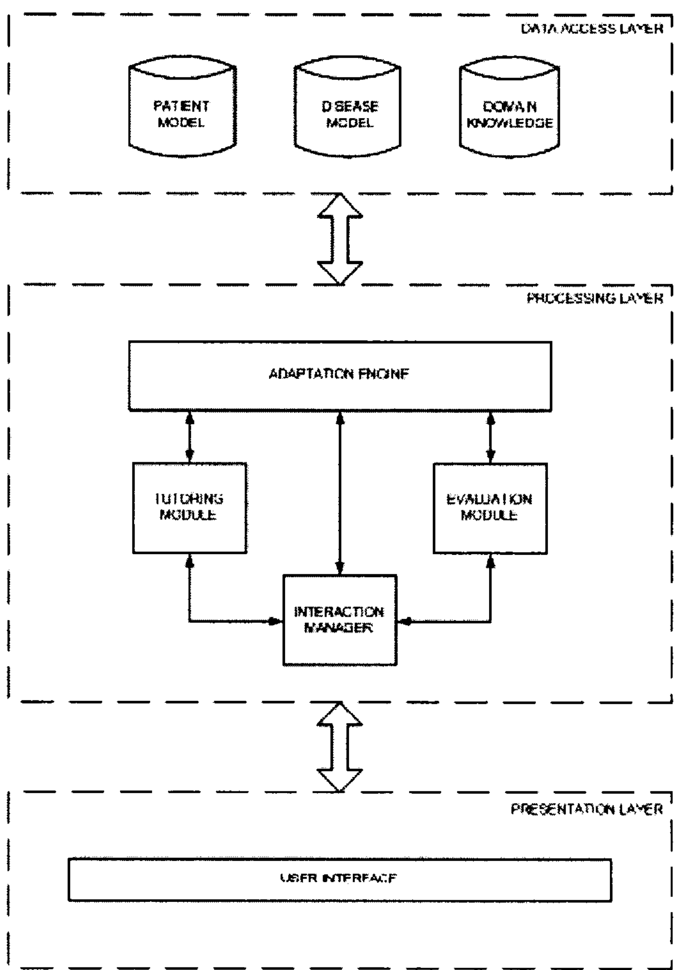

Figure 3.1: Three-tier architecture of MDEA

The architecture of MDEA (Figure 3.1) is three-tier architecture with the presentation, processing and data access components separated into independent tiers. The three tier architecture is used when an effective distributed client/server design is needed that provides increased performance, flexibility, maintainability, reusability, and scalability, while hiding the complexity of distributed processing from the user [Sadoski, 2005]. These characteristics have made three-tier architectures a popular choice for internet applications and net-centric information systems. Three-tier architecture enforces a general separation between the three parts: client tier or user interface, middle tier or business logic, and data storage tier. The third tier provides database management functionality and is dedicated to data and file services that can be optimized without using any proprietary database management system languages. The middle tier provides process management services such as process development, process enactment, process monitoring, and process resourcing that are shared by multiple applications. The middle tier server, also referred to as the application server, improves performance, flexibility, maintainability, reusability, and scalability by centralizing process logic. Centralized process logic makes administration and modifications easier by localizing system functionality so that changes must only be written once and placed on the middle tier server to be available throughout the systems. The first tier consists of the user interface to present the contents and taking care of user interactions with the software. A significant advantage with the three-tier architecture is that any of the three tiers can be upgraded or replaced independently as requirements or technology change [Braude, 2004].

Data access tier

The data access tier consists of the information required to drive the software. The three categories of information required by a patient education system similar to MDEA can be grouped into: (a) patient model, (b) disease model and (c) content base. The patient model is important for personalizing the system to each patient and consists of information pertaining to the needs, preferences and conditions of patients. The disease model is used to represent the state of the patient in the disease, its treatment and the corresponding learning materials that will be required for patient education corresponding to the disease state. Domain knowledge or the content base needed for patient education is usually organized in a flexible manner such that it can be adapted or personalized based on the underlying models that drive the patient education process.

Processing tier

The learning contents in the database are grouped based on topics that might be of interest/help for the patients in learning about the disease. Some examples of topics are preparing the medications, identifying side effects, life style changes after surgery and so on. The processing tier provides functionalities to assist the learning process such that only the relevant topics are to be learnt by the patient. The processing tier consists of functional modules to select, adapt, and present the contents, evaluate the knowledge of patients on the presented contents, manage interactions of the patient, and to provide adaptation to the patients. The processing modules corresponding to the above tasks are tutoring module, evaluation module, interaction manager and the adaptation engine. The tutoring module is used to select the topics and the level of details to be presented to the patients. The evaluation module is used to test the knowledge of the patient on the topics. The interaction manager is used to manage the user interface events such as presentation and navigation. The adaptation engine monitors the activities of the patients based on a pre-determined set of monitoring variables and provides the necessary adaptations to personalize the session to the patient.

Presentation layer

The presentation layer consists of the user interface for patients to interact with the MDEA system. To increase the system's usability, it is important for such an interface to be simple and intuitive and the interface be designed after a careful analysis of patients and the required tasks in learning the topics from the software. The major goals of the interface would be learnability, ease of use, and simplicity.

3.2 Model-based knowledge representation

Knowledge can be represented using a model, and systems can reason based on those models. Model-based knowledge is efficient where it would be very difficult to represent the information as a set of rules and very inefficient to represent the data as a set of facts [Gonzalez and Dankel, 1993]. In such systems, it is normal to represent the information simply using models and to work with the knowledge in that form. Such a model can be represented in a variety of ways, depending on the characteristics of the problem and the manner in which the inference engine is to operate on the knowledge represented as per the model.

The significant advantages [Walters and Nielsen, 1988] of model-based knowledge are

- *Generality of the representation:* The model-based representation provides a clear specification and in the absence of some evidences, the inference mechanism can reason by applying some general principles to the model's representation.
- *Compatibility of the representation with inferencing tools:* Models can be made compatible with the existing inferencing tools available. Models can also be shared between different applications that address a common system.
- *Economy afforded by the representation:* The model-based knowledge can facilitate greater understanding, minimize errors, and facilitate easy maintenance. A model can be simply validated by verifying whether it holds all the relevant information required to drive the system.

The type of model(s) required by the system depends on the application domain and the knowledge requirements. User model is a commonly used model to store the information about a particular user. Such a user model captures information about the user's characteristics that are used to adapt the system for a particular user. User models may or may not contain complete information about the user but includes necessary information to adapt the system for a particular user. The information contained in the user model may be static or dynamic. Static information includes age, gender and so on whereas dynamic information includes data about user's interaction with the system. Such user models can be constructed using various methods such as stereotypes, overlay, machine learning, logic based, Bayesian and so on [Tsiriga and Virvou, 2004]. The other models that are used in interactive systems are domain model, interaction model and so on. The usages of such models differ based on applications and the system requirements.

3.2.1 Models driving the MDEA system

There are many complexities involved in fulfilling the goal of an interactive system for patient education. The first complexity is in adapting the system for patients in order to maintain the interest of the patients with the system. Adaptability in patients can be viewed from two distinct perspectives: (1) the capabilities and limitations of the patients to learn from the system and (2) with respect to the constraints arising from the learning situation. The second complexity arises because of the diverse group of patients e.g., age factor, learning abilities, varying backgrounds, prior knowledge, and so on. The third type of complexity arises out of the constraints faced by patients in learning due to the disease condition and environment. The same learner could exhibit different aptitudes, retention ability and behavior patterns depending on their condition during the stages of illness and the learning environment such as hospital or home.

Personalization should be cautiously incorporated into the patient education system after careful analysis of the needs and preferences of the patients. A brief review of the various kinds of personalization that can be incorporated is necessary to understand their significance.

- The set of topics to be learnt by the patient can be personalized based on the patient model and disease model in order to reduce information load on patients.

Such a personalization might help patients to learn necessary and relevant information based on their conditions as well as the state of the disease.

- The instructional strategy can be personalized based on whether patients would like to learn the preferred topics or to request the system to select topics in an orderly manner as determined by HCP and present it to them.
- Presentation can be personalized to patients at two levels: one with respect to the level of detail and the other is with respect to the multimedia contents to be included in the presentation. A topic might be presented at the basic level or at the enhanced level. The basic level contains only the essential information regarding a topic whereas enhanced level includes additional information for patients who are interested in learning the topics in more detail. Presentation of a topic might consist of one or more pages and the content of a page might be a combination of one or more multimedia elements. Such a personalization in presentation would help patients to learn topics in their preferred multimedia.
- Evaluation is important to test the understanding of the patients in the topics. Such an evaluation is based on the belief that by identifying deficiencies, the system can address them by providing more information to improve the patient's understanding of the topics. Personalization in testing can also be viewed from two different dimensions: one with respect to when to test and the other with respect to how to test. In a sensitive domain such as patient education, tests might lessen the motivation of the patients in learning from the system and personalization in evaluation is important to maintain the patient's motivation.

Though the above list of personalization might help patients in learning from the system, there can be a lot of complexities involved in implementing all such personalization at a finer level in a hospital environment. During the development of this research project, there have been a lot of constraints that are imposed due to the hospital domain.

Some of the constraints are listed below:

- The contents used for presentation have to be approved by the hospital authorities,
- The set of topics to be learnt by each patient was pre-determined,
- Personalization in presentation is not possible as the learning content used for the presentation of topics was only available at a very simple and low level of detail,
- Curriculum sequencing cannot be personalized as the order to present the topics was pre-determined.

Such constraints exist in most of the hospitals and the design of patient model and disease model in MDEA addresses such constraints.

3.2.2 Patient model

Personalization in MDEA is mainly guided by the patient model which captures various aspects of the patients such as the knowledge level, patient's progress, preference in learning, presentation type, and evaluation preference. Such a patient model is initialized as the patient enters the system and will be updated as they progress with the system.

The patient model used in MDEA has the following characteristics:

- It uses an overlay model following the domain structure representing the knowledge of the patient in the domain. User's knowledge on the subject is most often represented by an overlay model, which is based on the structural model of the subject domain. The idea of the overlay model is to represent user's knowledge of the subject as an overlay of the domain knowledge. For each domain knowledge topic, individual overlay models store some value which is an estimation of the learner's knowledge level on this topic. This can be just a binary value (known-unknown), or a qualitative measure (good-average-poor), or a quantitative measure such as the probability that the user knows the topic.
- It stores general information such as name, patient id etc for system operations like login and personalization in system messages.
- It stores information such as age and education for initialization purposes based on stereotypes.
- It stores the current medication list containing list of medications taken by the patient, their dosages and the time to take the medications which can be used to personalize the learning of medications and preparing them.
- It stores information regarding the preferred instruction type, multimedia elements, and evaluation preferences.
- It records patient's interactions with the system to monitor and remember the preferences of the patients in learning. One example is to maintain the preference of the patient in multimedia presentation.

- It dynamically updates the patient's progress with the system so that the current state of the patient with the system is stored and hence facilitates learning in successive sessions. A session ends when the user pauses or stops temporarily for resuming at a later time.

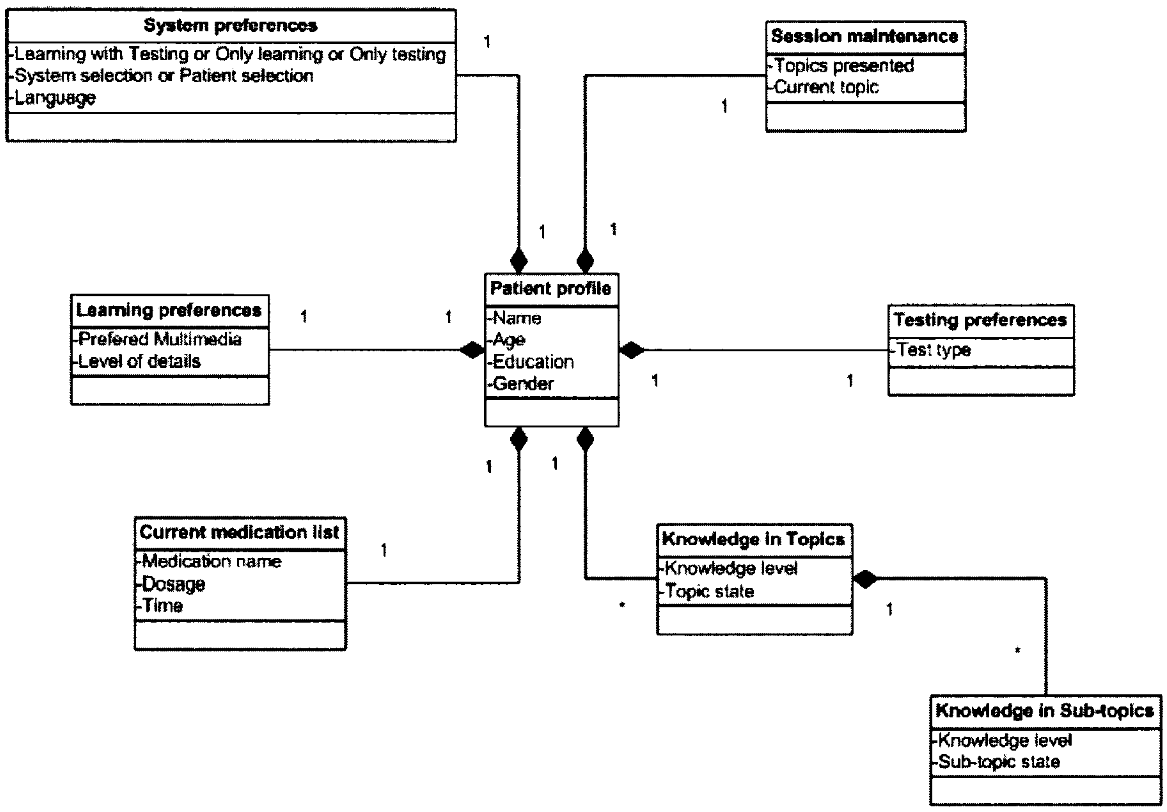

Figure 3.2: MDEA Patient Model Structure

During patient's interaction with the system, a patient model is constructed for each patient based on the structure shown in Figure 3.2. This structure represents current state of the patient with the system and is used for personalizing the session for the patient. Learning preferences store information regarding patient's preferences in learning such as the multimedia preferences. Testing preferences include preferences regarding testing such as when and how to test. System preferences include preferences such as the preferred language. Patient information, preferences and medication list can be initialized with the help of a questionnaire. The knowledge level of the patient on each topic is initialized with the help of 'stereotypes'. In a stereotype initialization, users are classified into categories based on some parameters such that the system can apply the information that is true for a particular category (stereotype). The progress of the patient with the system is stored to facilitate learning in sessions and to keep track of the learnt topics to avoid redundancy. Patient preferences can be changed dynamically and the system keeps track of the preferences while presenting the information to the patient.

3.2.3 Disease model

Patients with chronic diseases require a lifetime of education incrementally to cope up with the changes in their disease status. Diseases at different stages may require patients to know different levels of details of information based on their own situation as well as the process of treatment and illness state [Radhakrishnan et al., 2005]. This leads to the need for a model that can take care of the changes in the disease state within the context of a single patient. The 'disease model' represents the stages involved in a disease as well as the information about patient's stage in the disease. The disease model may contain information regarding the phase/duration of his/her illness, location of the patient and his/her level of anxiety or duress. To further illustrate the importance of a disease model let us consider the case of a transplant patient over time in the following three stages: diagnosis (pre-transplant), transplant (in-hospital) and post-transplant. During pre-transplant phase patients may be at home or may be hospitalized which could be an indicator of the severity of the disease and how they may interact with the system. In addition his/her level of duress will generally tend to be high given the stage of the disease, particularly in the setting of a recent diagnosis and the uncertainty in getting an organ in time. Considering this phase/duration of illness which will be fairly new and this will dictate what needs to be taught to the patients at this level. During the next phase of the transplant namely the in-hospital or transplant phase, the element of duress remains the same as pre-transplant but will focus on what happens to them now right after the transplant surgery in the hospital as well as after they are discharged from the hospital. The phase/illness of transplant will have changed and the focus of education will be mostly regarding managing themselves after the organ transplant surgery particularly with respect to medications. The last stage of transplant is the post-transplant stage with the location being home or the clinic and the clinical support lesser than when they were in the previous stage. The level of duress will be lower with time and the progress of the disease. The phase/ duration of illness have also been progressed and the educational focus must be on reinforcing the topics rather than the assimilation of new topics. Such a case gives a wider perspective of the change in a patient with the progress in the disease and the importance of disease model in personalization for patients.

3.3 Knowledge organization and sharing

Content creation and knowledge engineering are labor intensive tasks and require a lot of effort and time from the domain experts. Clear understanding of the goals and objectives are needed. The objectives for creating and maintaining contents for patient education should be properly defined to enable reusability and sharing of contents. There are a large number of resources available with the medical fraternity and in the open domain on the Internet. For example, in the case of transplant medicine a wide amount of information is available on the web, medical literature, on-line medical dictionaries, transplant centers and from the International Transplant Society (ITS). The design and implementation strategy should be able to benefit from these wide resources. A flexible method of content (knowledge) representation is necessary that can be suitably adapted for presentation and maintained easily. Applicable standards must be used to enable reusability of the created contents and appropriate 'version control' techniques must be used to facilitate sharing of contents created, updated and maintained. It is clear that without a systematic approach to the process of content creation, the above objectives are difficult to meet.

3.3.1 E-learning standards for knowledge organization and sharing

Several standards have been proposed for representing and sharing contents in the e-learning domain. In this section we will review some of the well known standards in the domain of e-learning. The important organizations working for standardization in e-learning are Advanced Distributed Learning (ADL) [ADL Website], Aviation Industry Computer-based training Committee (AICC) [AICC Website], Instructional Management Systems (IMS) [IMS Website], and IEEE Learning Technology Standards Committee (LTSC) [IEEE LTSC Website].

ADL SCORM Standards

SCORM (Sharable Content Object Reusable Model) [ADL Specification] is initiated by ADL which is a U.S. government-sponsored organization that researches and develops specifications to encourage the adoption and advancement of e-learning. SCORM is a set of standard web-based technologies and protocols that allow application developers to share content and learner data between diverse LMSs. SCORM utilizes XML and JavaScript as standards to define a protocol to help application developers wanting to create instruction that can be shared between learning systems utilizing different technologies and structures. Fundamental objectives of the SCORM standard are easy portability of learning content from one LMS to another as well as the reusability of learning objects. An important advantage of SCORM compliant LMS is that they are basically interoperable with all other SCORM compliant LMSs. In addition, they can exchange important user data, metadata, and a variety of interaction data (e.g. scores) in a standardized way with SCORM compliant LMSs.

AICC CMI (Computer Managed Instruction) Standards

CMI [AICC CMI Specification] standards are developed by AICC which was originally developed for the aerospace industry and gradually expanded its scope to become one of the most widely used standards for e-learning. AICC recommendations are fairly general to most types of computer based training and, for this reason they are used outside of the aviation training industry. The standard recommends guidelines that promote the interoperability of CMI systems. Interoperability means the ability of a given CMI system to manage computer based training lessons from different origins. It also includes the ability for a given training lesson to exchange data with different CMI systems. The content is divided into assignable units in LMS often termed lessons. As concerns the LMS, this is a unit that cannot be divided any further. These assignable units usually contain a comprehensive overview assembled from several pages, chapters, etc. In addition to the actual content, it has integrated into it the controls for navigation through the lesson. For easy storage of AICC courses in the LMS, the course should contain (the LMS should be able to import) files describing the course structure, lesson parameters and progress conditions.

IMS Standards

IMS [IMS Specification] is a consortium of vendors and implementers who focus on the development of XML-based specifications. These specifications describe the key characteristics of courses, lessons, assessments, learners and groups. In addition, they provide a structure for representing e-learning meta-data defined as data about the data. The most widely acknowledged IMS specifications are IMS Meta-data, IMS Content Packaging and IMS QTI (Question and Test Interchange). IMS Metadata specification is a primary source of input to the IEEE Learning Object Meta-data (LOM) standardization process, and has also been adopted by ADL as part of SCORM. The content packaging specification creates standardized packages of learning objects, files referenced by the objects, and instructions for a LMS to organize the learning objects in the package. The question and test interoperability specifies an XML format for encoding online questions, tests, and test banks and enables transport of such objects between learning systems.

IEEE Learning Technology Standards Committee (LTSC) Standards

The IEEE LTSC [IEEE LTSC Website] produces accredited open standards, reports, and guides as the result of projects authorized by the IEEE Standards Association. The most widely acknowledged IEEE LTSC specification is the Learning Object Metadata (LOM) specification, which defines element groups and elements that describe learning resources. The IEEE LOM standard specifies the syntax and semantics of learning object metadata required to fully and effectively describing a learning object. The LOM standard focus on the minimal set of attributes needed to allow the learning objects to be managed, located, and evaluated and can be extended or added. Some attributes of learning objects that can be captured in metadata include type of object, description of the object, creator or author of the object, technical format of the object, and the technical location of the object. LOM may also include pedagogical attributes such as teaching or interaction style, grade level, mastery level, and prerequisites.

3.3.2 Implications of e-learning standards for adaptive learning systems

The e-learning standards are proposed to facilitate reusability and portability among the Learning Management Systems following the specifications of those standards. Such standards deal with the most of the sections of the e-learning system providing specifications for the learner model, content data, communication and so on. Such standards are still emerging and might not be directly applicable for adaptive learning systems [Modritscher et al., 2004].

The implications of e-learning standards for the adaptive learning systems [Santos et al., 2003] are summarized below:

1. Current standards in the e-learning domain are aimed to store the organization and sequencing of courses or lessons by just taking into account previous actions and the 'knowledge' acquired by the student in the course. They do not consider other factors such as students' learning style to assist dynamic sequencing of courses or lessons.
2. Most vocabularies proposed for many of the different elements within the e-learning standardization process have a reduced value space set that do not properly cope with adaptation needs. Also, the defined vocabularies as described in the specifications are too ambiguous. Thus, it is difficult for an adaptation engine to fully understand issues like students previously acquired knowledge or their preferred learning style.
3. Lack of explicit relationships among the different proposals. For example, it is not straightforward to match the 'competency' element category from the IMS learner specification to the LOM metadata elements.

3.3.3 ISO topic map standard

Proposed as an ISO standard 13250, the idea of topic maps [Topic Map Specification] is gaining popularity for knowledge management. The three main concepts involved in topic maps are topics, associations and occurrences. Topics describe the subjects and they can be physical, logical or conceptual entities. An occurrence could be an article in the encyclopedia, a picture, a video depicting the topic, a simple mention of that topic in some context, a commentary on the topic, etc. An 'association' describes the relationship between topics or between a topic and the occurrences. The associations are typed. This facility gives a lot of flexibility to the topic maps approach. The topic and the occurrences involved in an association both play 'roles'. The occurrences may be assigned certain metadata called 'facet'. Facet provides a mechanism to assign <property-value> pair to the information resource. Examples of facets are language of description, media type, security level, last time updated etc. Facets can be used by the system to personalize the delivered content using the patient model.

3.3.4 Combining the 'Learning Unit Class' (LUC) methodology with 'Topic maps'

The LUC methodology described in [Mudur et al., 2002] is an integrative design process model that integrates the learning modalities dictated by the different learning theories proposed by Merrill [Merrill, 1983], Gagne [Gagne, 1985] and Reigeluth [Reigeluth, 1999]. An LUC is an organized collection of learning primitives that are required to achieve the learning of a particular concept. Each LUC has two attributes <i,k> based on two sets; in the parlance of the LUC methodology they are: 'learning objective or learning level' and 'knowledge type'. The LUC model has been successfully applied in the creation of contents for teaching subjects like 'data structures' to computer science students. Various learning primitive types have been defined, such as, goal, instruction, example, non-example, demonstration, simulation, exercise, hint, etc. An LUC is much like IEEE LTSC learning object, except that the emphasis is more on defining the purpose of the content than on packaging for reusability. The LUC methodology models the learning content as a graph of LUC instances, where each LUC is derived as an element of a 4 x 4 matrix representing the combination of learning objective *(memorize, comprehend, apply, problem solve in increasing levels of difficulty)* and the knowledge type *(part-of/fact, kind-of/classification, procedure, principle)*. Clearly, an LUC with the same knowledge type but with a higher learning objective corresponds to learning of the concept in a greater detail.

LEARNING OBJECTIVE → / ↓ KNOWLEDGE TYPE	MEMORIZE	COMPREHEND	APPLY
PART-OF/FACT	Recall or state fact	Recognize/Identify fact	Use/apply fact in carrying out the task
KIND OF/CLASSIFICATION	Recall examples or non-examples	Recognize example or non-examples	Use correct example
PROCEDURE	Recall rule or procedure	Select or identify the appropriate procedure	Use or apply procedure

Table 3.1: Adapted version of LUC model for patient education

(Pictograms are used to denote an $(i,j)^{th}$ element in the Table)

In MDEA, we used a combined approach of the notions of the topic map with an abridged version of the LUC methodology proposed in [Radhakrishnan et al., 2005]. The 4x4 matrix used in the LUC model was appropriate for a subject like data structures but for patient education an abridged version of LUC sub-model which is a 3x3 matrix is used as shown in Table 3.1. In MDEA, we excluded the problem solving from the *learning objective* and principle from the *knowledge type.*

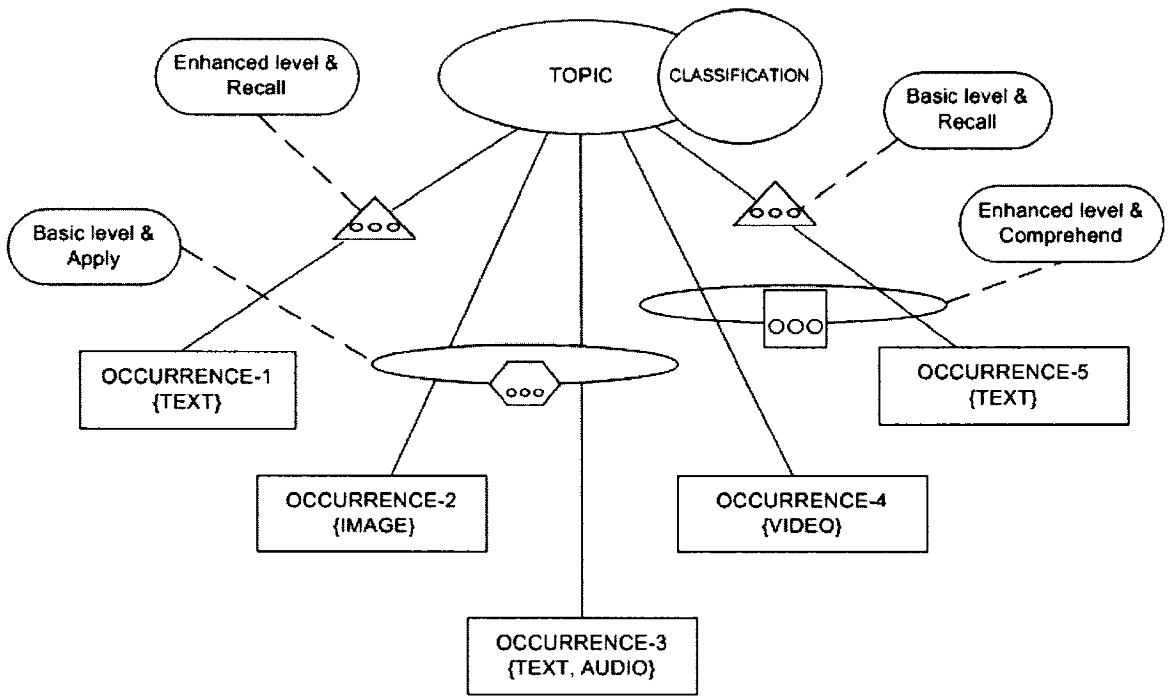

Figure 3.3: Combination of Topic maps and LUC model

The combination of topic maps and LUC model is explained using Figure 3.3. Each topic is related to a knowledge type such as fact, classification or procedure. The topic is associated with the occurrences which may be one or more of the multimedia elements such as text, image, audio, video etc. The association of the occurrences to topics is defined by the <content level, learning level> tag (facet). The content level can be basic or enhanced level of details and the learning level may be one of recall, understand and apply. The associations can also be grouped together to form the <content level, learning level> tag and will be used for personalizing the presentation according to the patient model. The intellectual process of developing the learning and test materials will be guided by the domain specialist's expertise in choosing appropriate media type (text, audio, video, or animation etc.) for the resources or occurrences, for organizing the content (knowledge) as per the standards of the topic map, and then by appropriately tagging the topic map representation of various topics.

3.4 User Interface Design

Usability is an important feature of patient education software in order to gain acceptance by the target community [Spallek and Schleyer, 2003]. The design goals for user interface have to be defined properly to achieve both usability and acceptability by the healthcare professionals.

3.4.1 UI design goals

The design goals for the user interface are listed as follows:

(a) Patients must be able to learn information related to their health condition easily and concisely.

(c) Patients must learn how to prepare their own medications as per their medication list.

(c) The design must cater to different navigation preferences of patients in learning from the software.

(d) The design should take into account of the patient's limitations in learning from the software.

3.4.2 Task specifications

High-level task: Learn a topic relevant to his/her disease condition, needs and preferences.

T1: List of topics. A disease might contain a large set of topics that might help patients coping with the disease. Not all the topics might be relevant for a particular patient and a patient would only be interested in topics related to his/her condition.

T2: Selecting a topic. Different patients might prefer different ways of learning. Some patients would like to learn the preferred topics whereas some patients would request the system to present the topics in an orderly manner as determined by the HCP.

T3: Learning or testing the topic. The main objective of patients in using the system is to learn the topics that might help in coping with the disease. Testing would assist the patients as well as the teacher to evaluate how well the patients understood those topics. Some patients might be confident about their knowledge on certain topics and would like to avoid a 'test' whereas some patients might prefer to take tests. Some other patients might prefer to take a test without learning from the software because they may already know these things.

T4: Presenting a topic. Presentation is an important part of learning in computerized patient education. Patients might have different preferences on multimedia contents used in a presentation. Proper navigation mechanisms are also required for the patients to go through the presentation with ease.

T5: Feedback on performance. Patients would like to know their progress with the system at any point of time. These include performance on a given test, topics that are learnt/not learnt and so on. Such a feedback will help patients to determine their status with the system.

T6: Learning in sessions. Patient education is a continuous process. Patients might log in, learn some topics and then log off. After some point of time, they might again log in and the whole process continues. Thus storing the state of patients with the system is important to resume learning from the point it is left.

T7: Pause or exit. A patient would like to take breaks during learning sessions. Some breaks might be short whereas some might be lengthy. A pause option might be suitable for short breaks whereas quit might be suitable for lengthy breaks. The decision to select between pause/quit will be taken by the patient.

3.4.3 Task analysis: problems and solutions

The main objective of developing a patient education system is to educate the patients regarding the topics concerned with his/her state in the disease. Patients use the system to learn information regarding the topics related to their health condition. The domain knowledge might vary a lot depending on a lot of factors such as the previous experience, education level, age and so on. The attitude of the patients towards such an education might vary based on the level of motivation to be educated. Most of the patients might have a positive attitude of using computers for education provided that the information is authorized by their HCP.

T1: List of topics. The disease might consist of a lot of topics that would help patients in learning to cope up with the disease.

- Problem: Patients would like to learn information that is relevant to their own conditions.
- Solution: The list of topics to be presented can be customized using the patient model as well as the disease model and displayed to the patients in an easy and simple to select format.

T2: Selecting a topic. A topic would be selected to be presented to the patient.

- Problem: Patient wants to learn the preferred topics.
- Solution: A customized list of topics can be shown to the patient, from where he/she can select a topic.

- Problem: When the patient is learning the topics based on his/her own interest, they want to see the list of available topics.
- Solution: Functionality must be provided for the patients to navigate to the customized list of topics while they are selecting their preferred topics.

- Problem: Patients do not want to select the topics.
- Solution: Topics can be presented by the system based on the patient model and the disease model. The order of presentation would be the same as recommended by the HCP.

- Problem: Patients would like to switch between different modes of learning the topics.
- Solution: Functionality must be provided for the patients to dynamically change the way a topic is selected.

T3: Learning or testing the topics. Patients would like to learn the topics and/or take a test on them to assess their knowledge.

- Problem: Patients would like to learn or test topics based on their interest.
- Solution: Functionality should be provided for the patients to select both learning and testing, or only learning, or only testing.

- Problem: Patients would like to have a flexible testing schedule based on his/her preference.
- Solution: The tests shall be customized based on the patient's preference in taking a test at the end of each topic, or for a set of topics, or a complete test for all the topics.

T4: Presenting a topic. Patient would like to view the information on the selected topic based on his/her preference.

- Problem: Patient would like to go through the pages presented for a topic.
- Solution: Proper navigation controls have to be provided to ensure that the patients can easily learn the information presented on the topic.

- Problem: Patients would prefer to have presentation in their preferred multimedia contents.
- Solution: The multimedia contents involved in the presentation shall be customized based on the preferences of patients.

- Problem: Patients would like to select the multimedia contents involved in a presentation depending on their preference.
- Solution: Functionality shall be incorporated for dynamic selection of multimedia contents during a presentation.

T5: Feedback on performance. Patients require proper feedbacks to monitor their progress with the system.

- Problem: Patients would like to monitor the topics that are learnt so that they can learn the remaining topics.
- Solution: Functionality shall be provided for patients to clearly recognize the 'learnt' topics.

- Problem: Patient would like to know his/her performance on the tests.
- Solution: Proper feedbacks should be provided based on the performance of patients on tests.

T6: Learning in sessions. Learning is a continuous process especially when it comes to patient education.

- Problem: Patients would like to resume learning from where they left last time.
- Solution: The system shall facilitate learning in sessions so that the patients can resume their learning each time they login.

T7: Pause or Exit. Patients might require breaks during a learning session.

- Problem: Patient wants to take a small break during a learning session.
- Solution: 'Pause' functionality shall be provided which freezes the system temporarily and allow patients to resume learning after sometime.

- Problem: Patient would like to quit the software during a learning session.
- Solution: 'Quit' functionality shall be provided to allow patients to exit the system anytime.

3.4.4 UI design solutions

Based on the above task analysis, the UI design solutions for the MDEA patient education software have been listed below.

1. Customized list of topics to be displayed and/or presented.
2. Two modes for selecting topics: patient selection, in which the patients select their desired topic to learn and system selection, in which the system presents the topics to the patient.
3. Learning options: learn and test; only learning; directly to testing.
4. The test can be customized based on whether the patient would like to take test at the end of each topic, or for a set of topics, or a complete test for all topics.
5. The presentation can be customized based on the preference of the patients on multimedia elements involved in a presentation.
6. Proper and simple navigation controls to be provided for the presentation.
7. Proper feedbacks to be provided to inform the patient regarding his/her progress in the system.
8. The system will facilitate learning in sessions so that the patients can resume their learning from the last time.
9. The system must provide simple functionalities for the patients to pause or exit the system.

In this chapter, we presented the three-tier architecture framework of MDEA. The significance of model-based knowledge representation was elaborated and the models driving the MDEA system were discussed. Then we reviewed some of the popular e-learning standards, and discussed their implications for adaptive learning systems. The knowledge sharing model, a combination of topic maps and LUC model, used for representing the contents (knowledge) in MDEA was explained. Finally we discussed the user interface design along with the analysis of the various goals to be focused by the design and summarized the UI design solutions to achieve those goals. The implemented MDEA prototype for organ transplant patients is discussed in the next chapter.

Chapter 4

MDEA Prototype for Organ Transplant Patients

Patient education is a necessary part of the care of transplant patients. An ongoing goal in the care of this population is to develop strategies to improve the process of patient education. As part of this thesis, a functional prototype has been developed to assist liver, kidney, and pancreas transplant patients as they learn about their post transplant care. Such a prototype has been developed with the belief that it would help to experiment with many of the issues discussed and proposed in this thesis. We have focused on a specific sub-class of patients, the post organ transplant patients who have undergone a recent organ transplant surgery and are in the hospital after their surgery. Our emphasis was to develop a simple interactive tutoring system that can be deployed for pilot testing in a Montreal hospital setting for post organ transplant patients and study the issues from that experience. After an organ transplant surgery, it is vital for patients to learn about changes in their lifestyle in order to lead a healthy life by lessening the chances of rejection and complication thereafter. Before discussing the design of the MDEA prototype, in this chapter we will discuss the significance of the transplant domain and highlight the importance of education specifically for organ transplant patients.

4.1 Significance of patient education in organ transplant

Over the years, organ transplant is gaining its acceptance as a way of treatment for certain end-stage diseases. Organ transplants are primarily performed when all other avenues of treatment are not possible. Today, with the advancement in medical science, transplantation of different organs is in practice and examples include kidney, liver, pancreas, heart, lung etc. Transplantation, as a process, proceeds in three stages:

(1) *Pre-transplant stage* is when the preparation and medical examinations take place.

(2) *Transplantation stage* includes surgery and hospitalization for a certain period that may last for several weeks,

(3) *Post-transplant stage* is when the patients are followed up in a clinical setting as 'out patients'.

Patient education can take place in all three stages. For the patient and their family, going through these stages is a very emotional and stressful experience. In the midst of their emotions, different people who are waiting or those who have undergone an organ transplant react differently when it comes to learning about the transplant process. This learning is necessary. Learning is more important when patients are in the hospital because that is when the healthcare team prepares the patient and assures itself that the patients are well prepared to take care of themselves once they are home. Transplant rejection is the most important topic to be learnt. It may occur when the immune system of the recipient of a transplant attacks the transplanted organ or tissue. Episodes of infection and rejection may occur even if the patients take good care of themselves and more so in the early periods following the transplant. Education is important for them to take appropriate and timely steps when such episodes occur, so that they can apply those concepts to handle complications that may lead to the rejection of the transplanted organ [Bass et al., 1999].

To minimize the risk of rejection, transplant patients have to take medications throughout their life and such medications include a combination of immuno suppressive and other medications to minimize the risks of rejection and other risks. Administering these drugs is sort of an optimization process, as too much immuno suppression would put the patient into the risks of weakening the immune system beyond limits and the consequent susceptibility for infections and on the other hand too little immuno suppression would put the patient's immune system working against the transplanted organ to induce rejection. This optimization process depends on multiple factors and there are wide variations from one patient to another. Hence, patient education could be of great help to act in a timely fashion and in minimizing their post transplant hospitalizations. In clinical research it has been observed by several researchers that *'non-compliance of prescribed medication'* has significant negative impact on the survival of transplant patients as the years progress after transplantation [Russell et al., 2003]. The causes for non-compliance of medication could be many, but lack of education is certainly one of them.

Generally, patient education at the hospital setting will be coordinated by a Clinical Nurse Specialist (CNS). We envisage that he/she will choose the right time after the transplantation for each patient to go through the learning process. The software prototype developed can be used by the patients in a personalized manner in a convenient location to learn the 'pre-determined' set of essential topics before they are discharged from the hospital.

The prototype was suitably restricted in consultation with the CNS as getting acceptance of the hospital authorities to deploy it for pilot testing is a long and complex process. The following technical challenges are observed from the point of view of developing the educational assistant:

- Need to have a flexible and effective knowledge representation technique to create and manage the contents. Content creation being an expensive task, we should be able to use and re-use the already available or newly developed and validated 'content resources' effectively.
- Creating and maintaining an appropriate model of the patient who is using the software for learning. The main use of this model would be in the interactive and adaptive presentation of the learning materials and in the assessment of the patient's learning and retention.

4.2 Design of MDEA Prototype

In this section, we will discuss the design of the MDEA prototype as per the requirements and constraints posed in a hospital environment.

4.2.1 Domain model

In every transplant center of major hospitals, there are 'information booklets' created in print form that are not personalized to the individuals [Tang et al., 1997]. In this prototype, we made use of the existing learning materials available in the form of such booklets and customized them to be used with the software. The first step in creating the domain model is to identify the set of topics to educate the patients. The domain model is developed with a minimal set of the most essential topics. In determining the minimal set, priority is given to the immediate needs of the patients that will be faced in the days and weeks following discharge from the hospital. Once the minimal set of topics is determined, the analysis is focused on the minimal level of details that absolutely every post organ transplant patient should learn about these topics. Details refer to the depth of information to be presented on each topic. On each of the topics in the minimal set, one might be able to learn the relevant facts and procedures about the disease to varying levels of details based on their interest, and needs. In the design of our system we have identified two levels (basic level and enhanced level) in which the topics can be presented for learning purposes. All topics will be presented at the basic level whereas some of the topics can be presented at both levels to satisfy the eagerness of the patients whose capability of learning is much higher than the average. Accordingly, at the content or knowledge organization level, the Learning Materials (called LM) and Test Materials (called TM) associated with each topic are appropriately created or grouped together based on the level of details.

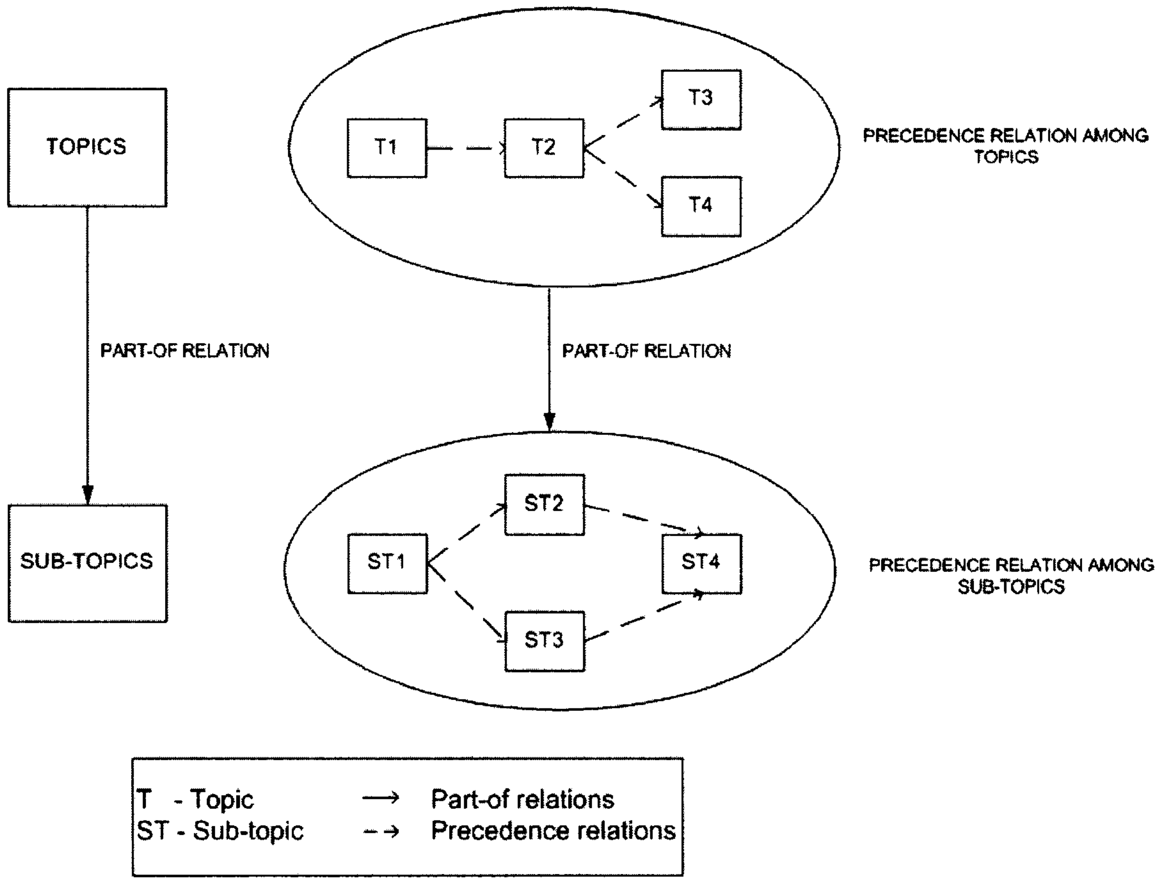

Figure 4.1: Topics, Sub-topics and their Relationships

The knowledge base of MDEA prototype is a two layer hierarchy (Figure 4.1) that consists of topics and sub-topics. Sub-topics have a part-of relation with topics, where each part-of relation is assigned a weight that indicates the relative importance of the sub-topic to the topic. One more relation that exists in the knowledge base is the precedence relation. Precedence relations exist within the topics as well as sub-topics. The precedence relation is also assigned a weight that indicates the strength of the precedence within topics (sub-topics). The topics, sub-topics and their relationships are represented using the topic maps technology [Topic Map Specification]. The presentation occurs at the sub-topic level, and learning as well as test materials corresponding to sub-topics are stored as XML files (Figure 4.2). The learning materials may be made up of text, audio, video, images, and animation. The test materials may contain evaluation questions such as choose, true or false, fill up and perform an action. A sub-topic can be presented at any combination of the <content level, learning level>. Content level can be basic or enhanced and learning level can be one of memorize, understand and apply. Thus the presentation can be one of the following six combinations of the content level and learning level.

1. <Basic, Memorize>
2. <Basic, Understand>
3. <Basic, Apply>
4. <Enhanced, Memorize>
5. <Enhanced, Understand>
6. <Enhanced, Apply>

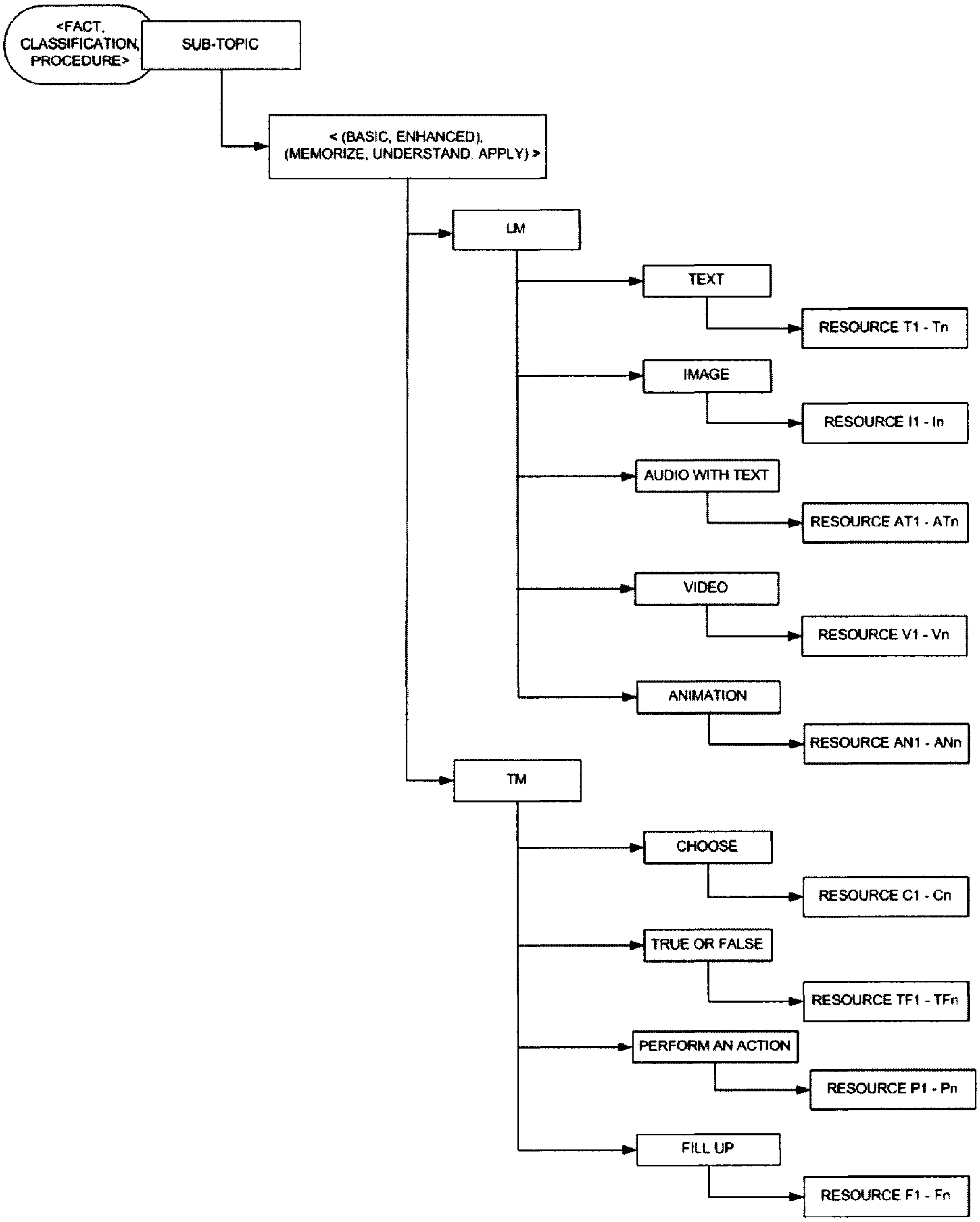

Figure 4.2: XML Format for Learning and Test materials

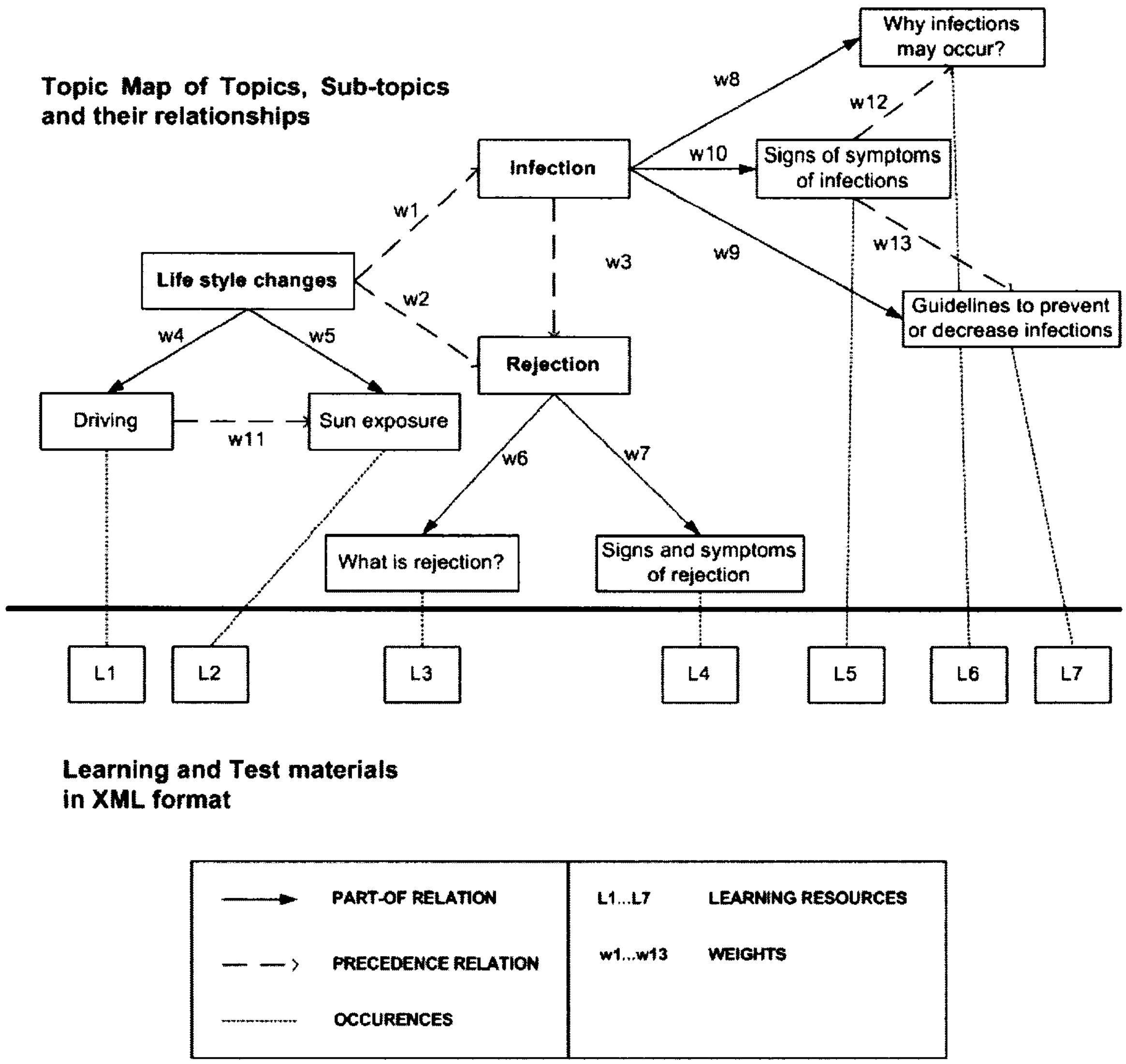

Figure 4.3: Knowledge Representation in MDEA

4.2.2 Patient model

MDEA uses a patient model containing information relating to the patient's needs, and preferences in order to assist the patient in learning post transplant care. MDEA uses different stereotypes of patients for initializing the patient model. A stereotype refers to a specific category of patients based on a set of parameters. An example of a parameter is "patients having previous medical experience". These stereotypes have been organized in the form of a class-hierarchy. The parameters characterizing the patient model can be classified into three parts: (a) Initialization attributes (ID, gender, occupation, transplant category); (b) Slowly varying attributes (disease progress, new complications, medication-changes); (c) Attributes that change and that are monitored one or more times a day in the hospital setting (e.g. vital signs, blood-sugar level, blood test results, immuno-suppression-drug level in the blood). The patient model is updated and maintained by the MDEA and is used for customizing the system based on the preferences of patients in presentation and evaluation. The interactive software system MDEA will be initialized by the CNS with the patient profile which is the data needed for personalization. Patients can then use it at bedside with the help of a laptop or in a patient-family room computer. The simplest form of personalization is to tailor the stored knowledge and present the details that are relevant to that patient based on <patient's language preference>, <patient's current medication list>, <the kind of organ transplant done on that patient>, <one of the two learning skill levels>, and <age determining – child or adult>. In order to deploy this prototype, we used a simple patient model storing the information about the patient as well as their preferences in learning.

The patient model used in the MDEA prototype consists of a list of parameters that can be used to customize the software for the patient. The list of parameters used in MDEA patient model regarding an organ transplant patient is specified below:

1. First name and Last name,
2. Hospital identification number,
3. Transplantation type (liver, kidney, pancreas etc),
4. Gender,

5. Age and Education,
6. Learning skill level (basic or enhanced),
7. Current medication list,
8. Competence value (knowledge) on topics (0-1),
9. Preferred learning mode (Patient Selection (PS) or System Selection (SS)),
10. Preferred presentation type (Text or Text with audio etc),
11. Preferred test type (sub-topic, topic or at the end),
12. Past history in learning during the previous sessions. The learning activities in each session such as topics and sub-topics that are presented, tested and learnt are stored and used suitably to enable learning in sessions.

First name and last name are used for addressing the patients. Hospital identification number is the primary key for the patient model and is unique for each patient. Patients are authorized using the hospital identification number. The transplantation type is used to present the topics that are relevant to their condition and needs. Gender is used for the title in addressing the patients. Age and education is used for classifying the patients into stereotypes and to initialize the level of details and knowledge on topics. The current medication list is used to teach patients to prepare their medications and consists of medication name, dosage, and time(s) to take the medication. The knowledge level on topics indicates the proficiency of patients in the topics. The preferred learning mode is used by the software to present/test the topics based on their desired learning mode. The preferred presentation type is used to store the preference of the patients in multimedia contents used for the presentation. Tests can be customized by storing the preference of the patients on tests. The patient's interaction with the software is used to store the state of the patient with the system and in resuming the learning sessions.

The patient model used in MDEA is an overlay patient model in the sense that the knowledge of the patient on each topic (sub-topic) is overlaid on the corresponding topic (sub-topic). The knowledge of patients on topics (sub-topics) is represented as a value (0-1) and is used to assess the progress of the patient on topics (sub-topics). Overlay models are powerful and flexible as they can independently measure patient knowledge on different topics (sub-topics) [Brusilovsky, 1996]. The patient model is initialized with the help of stereotypes. Stereotype [Tsiriga and Virvou, 2004] is coarse-grained which classifies users into categories based on some parameters. In MDEA, stereotypes are used for initializing the knowledge of patient on topics as well as the learning skill level. The remaining fields in the patient model are initialized with the help of a questionnaire that is filled by the CNS while registering patients with the system.

4.2.3 Tutoring module

Tutoring module is used to assist the learning process by selecting the next topic (sub-topic) to be presented including the level of details (basic or enhanced) based on the patient model and the disease model. The disease model is not present in the prototype as it is intended to be used by a specific sub-class of post organ transplant patients.

*** The term 'tutoring' used in this prototype implies selecting an appropriate topic (sub-topic) for presentation based on the patient model.**

The learning contents created for the prototype consists of only basic level of details for all the topics (sub-topics). A selection algorithm is used in the prototype that selects the next available sub-topic to be presented based on the patient model.

Selection algorithm

Topics or sub-topics can have one of three states: 'learnt', 'marked' and 'not learnt'. Learnt topics (sub-topics) are the ones tested with patients and the results of the evaluation are satisfactory. 'Marked topics (sub-topics)' are the ones that are tested with patients and the results of the evaluation are not satisfactory. A 'marked' topic will consist of one or more 'marked' sub-topics. 'Not learnt topics (sub-topics)' are not tested with patients.

<u>Algorithm:</u>

Input:

Topics, sub-topics, and their states

Output:

Sub-topic to be presented

Process:

1. Identify the current topic that is presented.
2. Identify the sub-topics in the current topic that are 'learnt', 'not learnt' and 'marked'.

3. If all the sub-topics in the current topic are 'learnt', label the current topic as 'learnt'. Else if some sub-topics in the current topic are 'marked', label the current topic as 'marked' and do the following to select next topic:
    a. Consider only the 'not learnt' topics and identify those topics for which all the preceding topic(s) are 'learnt' or 'marked' and move them to the 'ready topics' vector.
    b. Select the topic with the lowest knowledge value in the 'ready topics' vector and make it as the 'current' topic and go to step 4.
    c. If the 'ready topics' vector is empty, check if any 'marked' topics exists. If yes, change all the 'marked' topics as 'not learnt' and go to step a. If there are no 'marked' topics, the patient has learnt all the topics successfully.
4. For each sub-topic that are 'not learnt' in the 'current' topic, if all the preceding sub-topic(s) are 'learnt' or 'marked', move it to the 'ready sub-topics' vector.
5. Select the sub-topic which has the lowest knowledge value in the 'ready' vector for presentation.

The tutoring module uses the selection algorithm to facilitate automatic tutoring of topics (sub-topics).

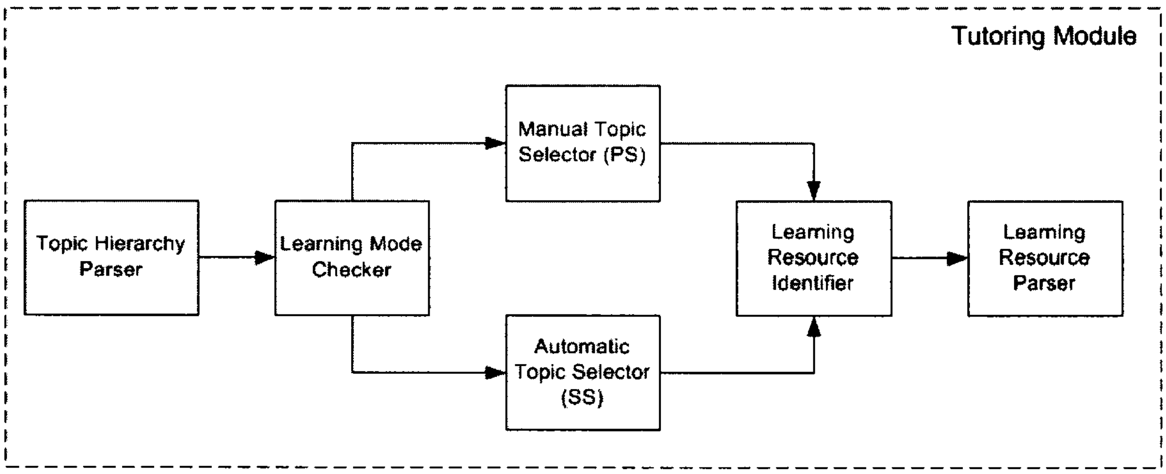

Figure 4.4: Design of Tutoring Module

Topic hierarchy parser: The topics, sub-topics and their relationships are stored as topic maps and this parser is used to extract them from the XML topic map.

Learning mode checker: Two learning modes are available in the system. In the Patient Selection (PS) mode, patients select their desired topic (sub-topic) to learn and in System Selection (SS) mode, the system selects the topic (sub-topic) to be presented to patients. The learning mode checker is used to identify the preferred mode of learning for the patient to assist in the learning process.

Manual topic selector (PS): The manual topic selector is used for the Patient Selection (PS) mode to present the available topics (sub-topics) to patients with guidance relating to the 'learnt' and 'not learnt' topics (sub-topics) to assist patients in selecting the desired topic (sub-topic) to learn/test.

Automatic topic selector (SS): The automatic topic selector is used for the System Selection (SS) mode to select the next topic (sub-topic) to be presented to the patient using the given selection algorithm.

Learning resource identifier: The sub-topic to be presented consists of learning and test materials. The learning materials for the sub-topic are stored as XML files and the learning resource identifier is used to locate the XML file that contains the learning materials for the sub-topic to be presented.

Learning resource parser: The sub-topic consists of learning materials that are made up of text, image and audio stored in XML format. The learning resource parser extracts the learning materials from the XML file and such learning materials are then used for presenting the sub-topic to the patients based on their preferences.

The design of the tutoring module provides details on how the tutoring process is carried out by the prototype.

4.2.4 Evaluation module

Evaluation module is used to facilitate the testing process in the prototype and provides customization in tests. Testing can be done in three levels (1) for each sub-topic, (2) for each topic, and (3) Complete test for all topics. The evaluation module is also used to select the test type suitable for a patient such as true or false, fill up etc. The MDEA prototype incorporates customization in the testing process based on when to give the test to the patient.

Testing algorithm

The topics (sub-topics) can have one of the three states: 'learnt', 'marked' and 'not learnt'. Learnt topics (sub-topics) are the ones tested with patients and the results of the evaluation are satisfactory. 'Marked topics (sub-topics)' are the ones that are tested with patients and the results of the evaluation are not satisfactory. A 'marked' topic will consist of one or more 'marked' sub-topics. 'Not learnt topics (sub-topics)' are not tested with patients.

<u>Algorithm:</u>

Input:

Topics, sub-topics, and their states

Output:

Sub-topic(s) to be tested

Process:

(1) Identify the current topic (sub-topic) that is presented.

(2) Identify the patient's preference in taking the test: 'sub-topic level', or 'topic level' or 'complete test'.

(3) If the test preference is 'sub-topic level', check if the current sub-topic is 'learnt', 'marked' or 'not learnt'. If the current sub-topic is 'learnt' continue with the

presentation of the next sub-topic, else if it is 'not learnt' or 'marked' then present the test on the sub-topic.

(4) If the test preference is 'topic level', do the following:

- Identify the sub-topics in the current topic and check if all the sub-topics are presented.
- If all the sub-topics are not presented, continue with the presentation of the next sub-topic.
- If all the sub-topics are presented, identify the sub-topics that are 'not learnt' or 'marked' and present the test on those sub-topics.

(5) If the test preference is 'complete test', do the following:

- Determine all the available sub-topics and check if all the available sub-topics are presented.
- If all the available sub-topics are not presented, continue with the presentation of the next sub-topic.
- If all the available sub-topics are presented, identify the sub-topics that are 'not learnt' or 'marked' and present the test on those sub-topics.

The evaluation module uses the testing algorithm to carry out the test on topics (sub-topics).

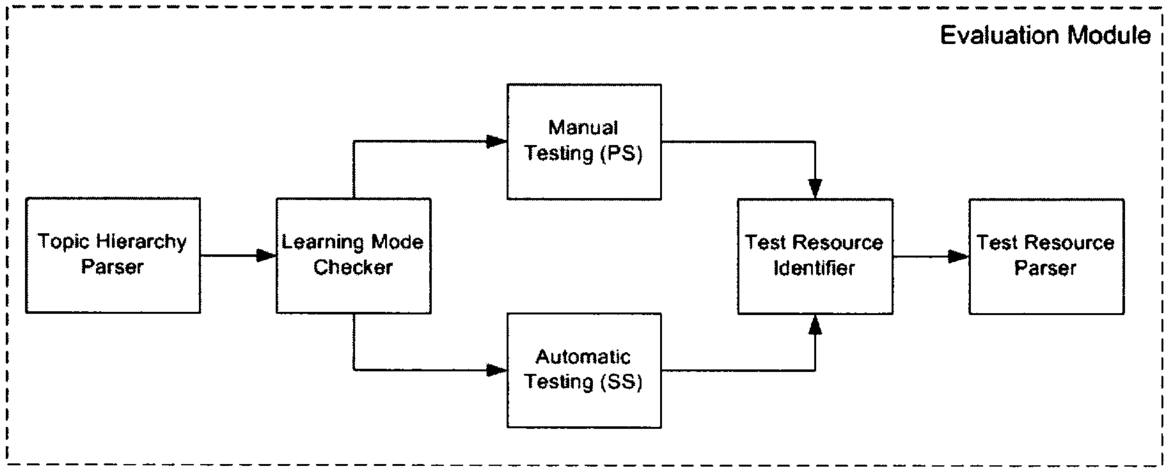

Figure 4.5: Design of Evaluation Module

Topic hierarchy parser: The topics, sub-topics and their relationships stored in the topic map format are parsed using the topic hierarchy parser to extract the available topics, sub-topics and their relationships.

Learning mode checker: Evaluation takes place differently in the Patient Selection (PS) mode and the 'System Selection' (SS) mode. The learning mode checker identifies the preferred mode of learning for the patient that will be used to determine the evaluation type.

Manual testing (PS): The manual testing is used for the Patient Selection (PS) mode to customize the test for patients such that they can select their preferred set of topics (sub-topics) to be tested.

Automatic testing (SS): Automatic testing is used for the System Selection (SS) mode to select the test type for patients. Tests can be given at the end of each sub-topic, or at the end of each topic, or a complete test of all topics (sub-topics). Testing algorithm is used to present tests based on the preference of patients.

Test resource identifier: The test materials for the topics (sub-topics) are stored as XML files and the test resource identifier is used to locate the XML file containing the test materials for the topics (sub-topics) to be tested.

Test resource parser: The test resource parser extracts the test materials associated with the topics (sub-topics) from the XML file that is used to present the test and to evaluate the knowledge of patients on topics (sub-topics).

The design of the evaluation module elaborates the evaluation process used in the prototype and explains how it is carried out by the prototype.

4.2.5 Interaction manager

Interaction manager handles the user interface events and makes the system interactive by responding to user's actions. It manages the presentation of sub-topics in terms of multimedia to be presented, highlights the corresponding text when audio is played, and provides navigation within pages in the sub-topics. It also handles the preference of patients that can be changed at run time such as the learning mode (PS/SS), and the learning preferences (learn with test, or only learn, or only test). It also manages the functionalities that allow patients to navigate between the previous and next topics. It updates the patient model to maintain the state of the patient with the system.

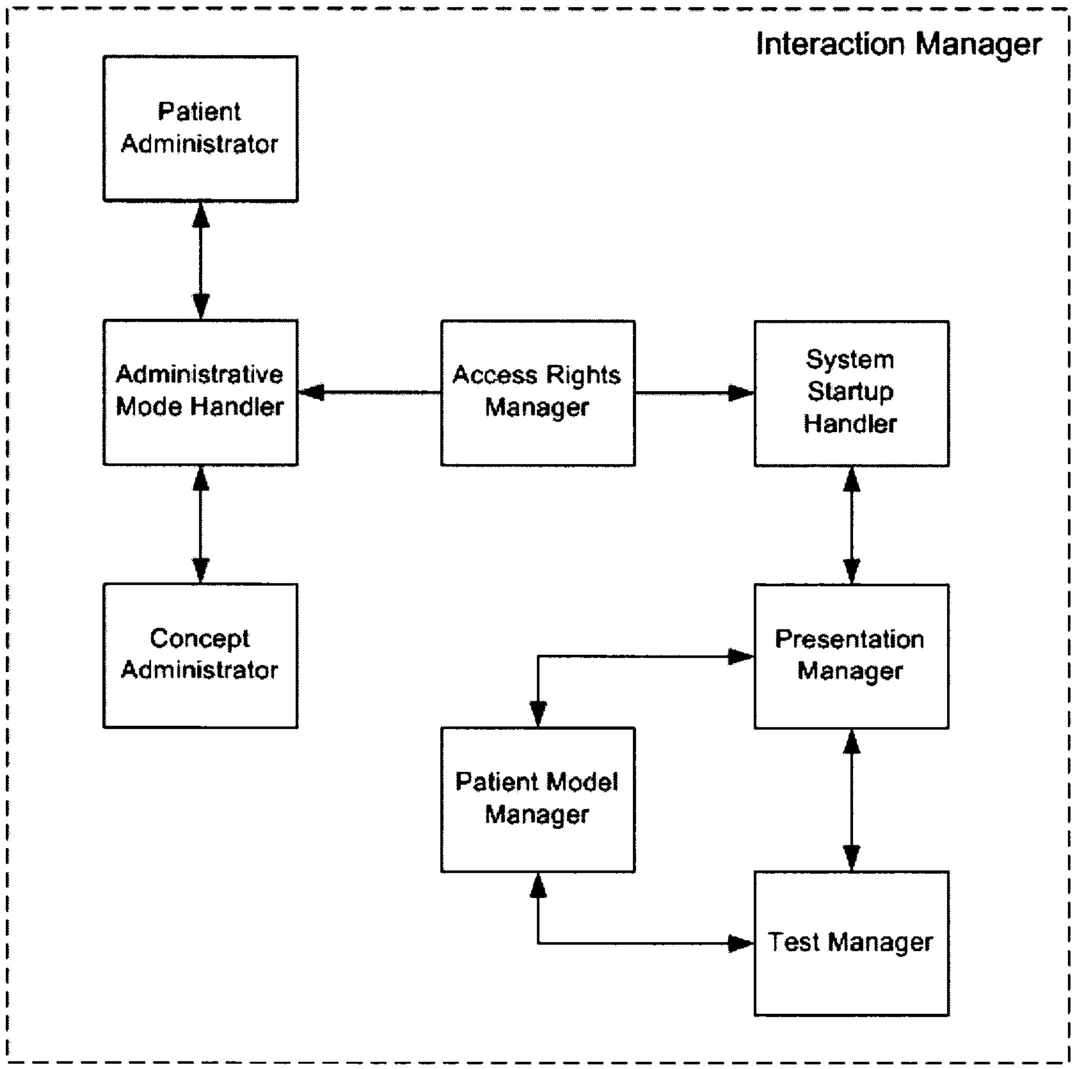

Figure 4.6: Design of Interaction Manager

Access rights manager: Ensuring secured access to the system is important and the access rights manager checks for the username and password and provides secured access to the system. It also distinguishes between the patient and the CNS/administrator to present the tasks based on their category.

Administrative mode handler: Administrative tasks involve managing patients as well as the learning contents. The administrative mode handler provides administrative operations based on the request of the HCP/administrator. It directs them to the concept administrator or the patient administrator based on their request.

Concept administrator: The learning contents to be presented to the patients might change with time. The concept administrator is used to manage the learning contents and is not implemented in this prototype.

Patient administrator: The patient administrator provides functions to manage patients such as adding new patients, view/edit existing patient information or deleting patients from the system.

System startup mode handler: The system startup mode handler provides initial operations in the learning session such as welcome messages and learning mode explanation. It also loads the state of the patient and directs them to learn/test the topics (sub-topics).

Presentation manager: Presentation of topics (sub-topics) involve multimedia elements such as text, image, audio and preferences in learning such as learn with test, or only learn, or only test. The presentation manager provides such functionalities using the patient model.

Test manager: Preferences in evaluation such as the evaluation type is handled by the test manager. The test manager provides such functions in order to test the patient and to evaluate patient's performance in the test.

Patient model manager: The patient model manager updates the patient model as patients' progress with the system. The knowledge value on the sub-topic is updated based on the evaluation results. Each sub-topic consists of a set of questions and weights are associated with each question. The weights indicate the knowledge value reflected by the question on the sub-topic. The final knowledge value on the sub-topic is calculated by using a weighted mean of the questions. The knowledge value on the topics is also updated based on the weighted mean of its sub-topics using the weights associated with each sub-topic in the topic. In addition, it maintains the state of topics (sub-topics) that are 'not learnt', 'marked' (non-satisfactory performance in test) and 'learnt' by patients. It keeps track of the current topic (sub-topic) that is presented to the patient in order to resume learning in the next session.

4.2.6 User interface design

User interface is an important component of any interactive system. In our case, since the motivation level of patients in such learning will not be high, the interface has to be simple and intuitive for the patients to maintain their interest in the system. Before designing the main interface of the MDEA prototype, a review of the list of functions to be included in the interface is important. The previous chapter analyzed the tasks involved in learning from the system and proposed solutions based on the analysis of such tasks to be performed by patients. The proposed UI solutions provide the list of functions to be incorporated in the user interface of MDEA prototype. The functions to be included in the interface are listed below:

1. Quit the system
2. Selection of learning/testing
3. Switching learning modes between PS/SS mode
4. Navigate to the list of sub-topics (sub-topics) in PS mode
5. Repeat the presentation of the current sub-topic
6. Navigate to the next and previous sub-topics
7. Pause the system
8. Selection of multimedia elements used in presentation

The user interface of the MDEA prototype has been designed keeping in mind the fact that the above list of functionalities should be easily accessible. The main interface is designed to incorporate such functions and made available to the patients to be used at any point. The UI design of the MDEA prototype is explained below. The numbers correspond to those shown in Figure 4.7 (user interface of MDEA prototype).

1. Patients would like to exit the system at any time within the session. The **Quit** button is used to end or exit the program at any point of time within a session.
2. Patients would like to select or change the learning options within a session. The **Learn** and **Test** buttons are used for selecting one of the learning options. There are 3 options available: **Learn with Test, Learn alone and Test alone.**

- In order to learn from the software and take the test, both **Learn** and **Test** have to be selected.
- In order to learn from the software without taking the test, only the **Learn** button have to be selected and **Test** button should not be selected.
- In order to take the test without learning from the software, only the **Test** button has to be selected and **Learn** button should not be selected.

3. Patients would like to change the learning mode within a session. Patients can learn and/or take test on topics on their preferred way of learning. There are 2 options: **SS** (System Selection) and **PS** (Patient Selection)
   - In **SS** mode, the system selects the relevant topics and presents it to patients.
   - In **PS** mode, the patient can select his/her preferred topic to learn/test.

   The toggle button is used to switch between **PS** and **SS** modes.
4. Patients would like to change or select another topic to learn/test in the Patient Selection (PS) mode. In **PS** mode, patients can view the list of available topics (sub-topics) to learn/test. The **List of sub-topics** button is used to display the list of topics (sub-topics) in the **PS** mode.
5. Patients would like to replay the presentation of the current sub-topic. The **Repeat** button is used to replay the presentation of the current sub-topic.
6. Patients would like to navigate through the previous or next topic (sub-topic) during the course of learning. The following navigation options are available:
   - **Prev** is used to go to the previous sub-topic,
   - **Pause** is used to stop the program for a short period,
   - **Next** is used to go to the next sub-topic.

7. Patients would like to change or select their preferred multimedia during a presentation. The multimedia options available for learning are:
   - In order to read the text in the program and listen to audio at the same time, patients must select the first button for the Text and the second button for the Audio.
   - In order to read only, patients must select on the first button for the Text.
   - In order to hear the audio only, patients must select the second button for the Audio.

   Images are used on buttons to indicate their functionality. Such visual representations will help patients to easily recognize and select their preferred multimedia. Video contents are not available in the present prototype.
8. Patients would like to know their status such as the current learning mode in the system at any point of time. The page title indicates whether the patient is in **SS (System Selection Mode)** or in the **PS (Patient Selection Mode)**.

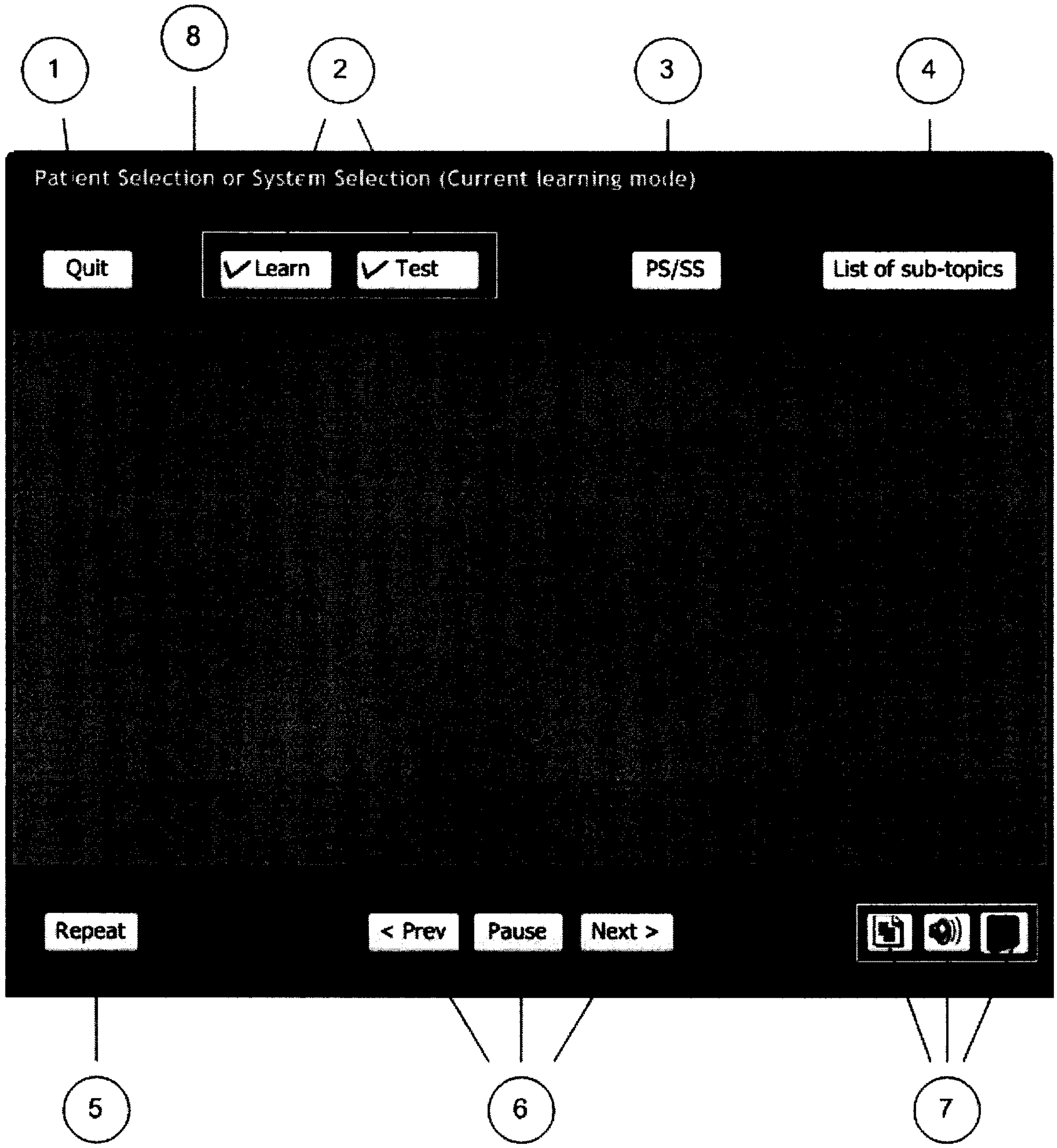

Figure 4.7: User Interface of MDEA Prototype

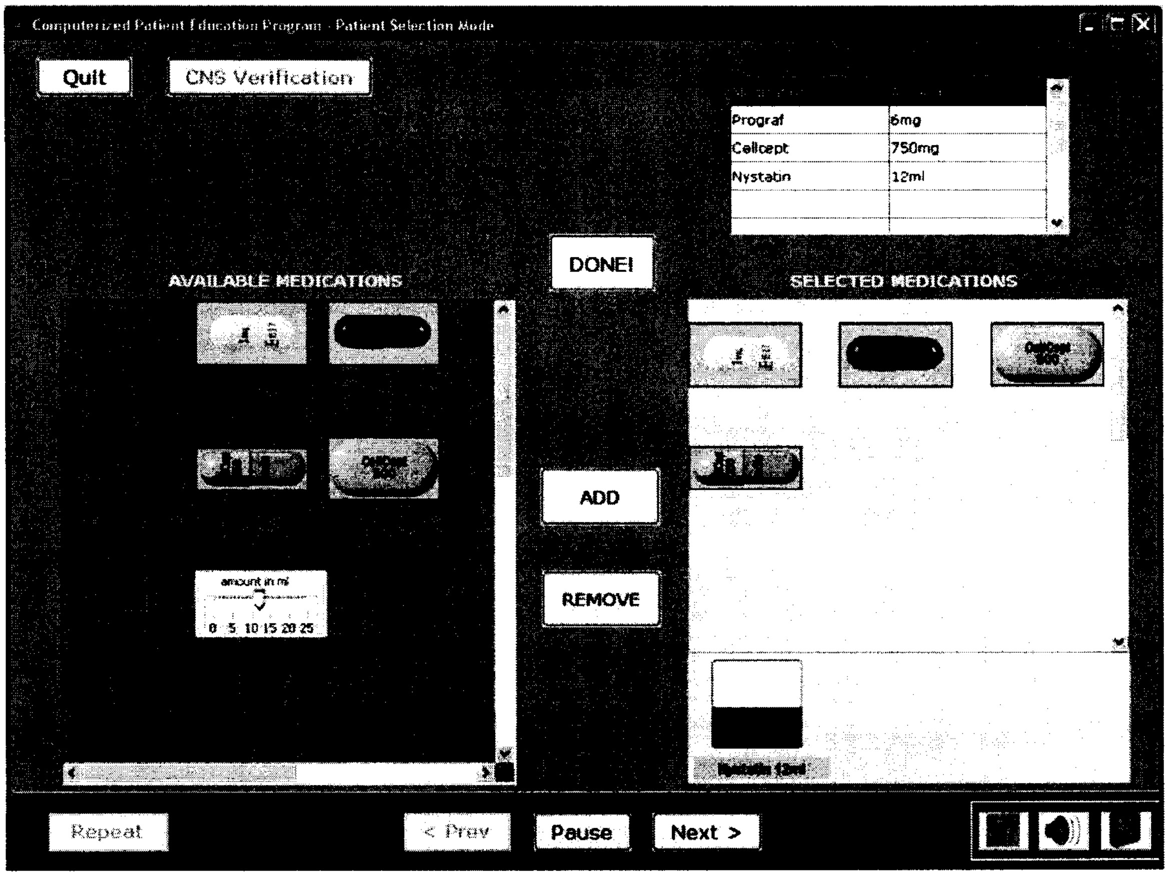

Figure 4.8: Medication Preparation Screen in MDEA Prototype

4.3 Complexities/Problems faced in the healthcare domain

As patients are the central focus in a healthcare system, the success or failure of a patient education system depends on whether the physicians, hospital authorities and patients accept or resist its implementation [Lapointe and Rivard, 2006]. The MDEA prototype was developed with the goal to deploy it in the hospital and made available to patients to learn with ease about the topics related to their post transplant care. The process though necessary does give rise to quite a few complexities/problems and eventually placed some limitations on the software design. Here we discuss some of the complexities/problems faced during the phase of development and deployment of the software prototype.

Currently patients are educated in the hospital by a nurse or CNS on a one to one basis. As such there is no educational software that has been used in the hospital for educating organ transplant patients. There were frequent changes in the requirements and such changes are accommodated in the proposed prototype. The software was developed with the motivation of using it as a complement to the current means of educating patients and not as a complete substitute.

Since the intended users of the prototype are patients, confidentiality and privacy issues are vital. To avoid concerns related to confidentiality, the information obtained from the patients as well as the information stored by the software about their interaction with the system are made confidential and known only to the CNS. The patient model is designed with the minimal required information to drive the prototype and sensitive information such as previous medical history are not considered in the design of the patient model for the prototype.

In the development of such learning systems for patients, knowledge engineering (content creation and management) is a time consuming process. Though there is vast amount of information available on the web, the knowledge created and used for presenting the topics need to be verified and approved by the hospital authorities. A major constraint in creating such contents is that the language used for presentation has to be simple and should be suitable for people at a grade-4 level (specification given by the hospital authorities). The knowledge engineering process went through lots of iterations with the domain specialist (CNS) to make sure that the contents are suitable for the patients as well to check whether it conforms to the hospital standards.

The prototype though it is developed and used by patients in the hospital for several months, delay was there in getting evaluation of patients as an approval from the ethics committee of the hospital is required. We were restricted in the list of topics as well as the contents and the wordings that we can use to describe them. We were also restricted in the questions we can ask of the patients in the way of evaluating our software system. A significant time has been spent in deploying the MDEA prototype in the hospital and to get evaluation results from patients. More time is required to have a comprehensive study of the usability and acceptability issues involved in the deployment of such software considering multiple places of application.

In this chapter, we discussed the significance of patient education in the organ transplant domain. The design of the MDEA prototype was then elaborated. Finally the problems/complexities faced in the development and usability testing of the MDEA prototype was explained. Usability testing of the MDEA prototype conducted at a Montreal hospital is discussed in the next chapter.

Chapter 5

Pilot Testing of MDEA Prototype

In order to test the usability of the MDEA software prototype, we conducted a pilot test at a Montreal hospital. This chapter starts with an introduction to the methods and techniques used for usability evaluation and then discusses how the evaluation was conducted in a hospital setting. The pilot testing results are analyzed and discussed. We also discuss the process of introducing the patient education software in a hospital setting.

5.1 Overview of usability evaluation methods and techniques

Usability is the capability of a product that enables the users to learn it easily and use it at ease to accomplish their tasks [Geraci, 1991]. Usability aspects are integrated into the system throughout its development cycle in a systematic approach known as 'usability engineering'. This includes identifying users, analyzing tasks, setting specifications, developing and evaluating prototypes, and the iterative cycles of development and evaluation. Usability evaluation is performed during different stages of the product to provide feedback to the iterative process of system development. Such evaluations involve measuring the usability of the product and identifying the user interface problems.

5.1.1 Usability evaluation

Usability evaluation is concerned with collecting data about the usability of a design or a product by observing a group of users performing particular activities within a specified test environment or work context [John and Marks, 1997]. Many techniques and methods have been developed to evaluate the usability in different stages of software lifecycle. They can be classified into three different categories:

1. Usability inspection based,
2. Usability inquiry based,
3. Experimental/empirical testing based.

5.1.2 Usability inspection

Usability inspection methods involve usability experts examining the software user interface to identify usability problems. In this technique, usability specialists, software developers, users and other professionals examine and judge whether each element of a user interface follows the established usability principles. Most of the inspection methods are used early in the software lifecycle to discover the usability problems, and some others are used addressing the overall system usability based on the final prototype.

Some of the important techniques for usability inspection [Nielsen and Mack, 1994] are:

1. *Heuristics evaluation:* It involves usability specialists to examine whether each dialogue element follows established usability principles.

2. *Cognitive walkthrough:* It uses a detailed procedure to simulate task execution at each step through the dialogue, determining if the simulated user's goals and memory content can be assumed to lead to the next correct action.
3. *Feature inspection:* It lists the sequences of features used to accomplish typical tasks, checks for long sequences, cumbersome steps, steps that would not be natural for a user to try, and steps that require extensive knowledge in order to assess a proposed feature set.
4. *Pluralistic walkthrough:* It involves group meetings where users, developers, and usability experts step through a learning scenario, discussing each dialogue element.
5. *Standards inspection:* It involves experts to inspect the interface for compliance with certain standards. This can involve user interface standards as well as domain-specific software standards etc.

Among the above inspection methods, heuristic evaluation is one of the least expensive and popular methods used for usability testing from early design stage to functional prototype evaluation [Nielsen and Mack, 1994]. It is an informal method where a small set of evaluators find usability problems by checking them against a set of heuristics or principles. The most commonly used heuristics are to be found in the set of interface design principles proposed by Jacob Nielsen [Nielsen and Mack, 1994]. Heuristic evaluation does not involve any end users; for this reason it is fast, cheap, and easy, but the problems discovered from this method are not always significant [Nielsen and Mack, 1994]. Heuristic evaluation can preferably be used early in the development process to reveal design problems. Given the constraints in evaluating the prototypes with patients, heuristic evaluation suited our needs for usability inspection better. In the development of MDEA prototype, heuristic evaluations were conducted on early stage prototypes, including paper mockups, as well as later-stage electronic prototypes, with and without all of the backend functionality implemented. Table 5.1 summarizes the results of heuristics evaluation conducted and the changes suggested in early interfaces of the MDEA prototype.

Prototype Interface Version	**Changes suggested after heuristics evaluation**	**Evaluators**
Version 0.8:beta	1. Display the current 'learning mode' (Patient Selection or System Selection) in the interface. 2. Changes in feedback messages to keep it simple and readable for patients. 3. Make a consistent and standard interface for all screens and provide important functionalities using buttons on the interface. 4. Changes in the names of buttons	Supervisors and Graduate students working on usability research

	and labels to keep them simple and intuitive.	
Version 0.9:beta	1. Changes in the names of buttons and labels in the interface. 2. Changes in feedback messages to speak patient's language.	CNS

Table 5.1: Heuristics evaluation of MDEA prototype interface

As can be seen from Table 5.1, heuristics evaluation was conducted on the beta version 0.8 of the prototype interface by thesis supervisors and graduate students working on usability research. The beta version 0.9 of the prototype interface was designed after correcting usability problems on the beta 0.8 version. The final prototype interface (Version 1) was designed after correcting the usability problems identified by the heuristics evaluation by CNS on the beta version 0.9 of the MDEA prototype interface.

5.1.3 Usability inquiry

Usability inquiry requires usability evaluators to obtain information about users' likes, dislikes, needs and understanding of the system by talking to them, observing them using the system in real work, or letting them answer questions verbally or in written form.

Some of the important techniques used for usability inquiry [Nielsen, 1993] are:

- *Field observation:* It involves going to users' workplace and observe them work to understand how the users are using the system to accomplish their tasks and what kind of mental model the users have about the system.
- *Focus groups:* It consists of a group of potential users or stakeholders in a product who are brought together to gather information as input to the design process.
- *Interview:* It involves formulating questions about the product based on the kind of issues of interest.
- *Logging:* It involves having the computer automatically collect statistics about the detailed use of the system.
- *Questionnaires:* They have long been used to evaluate user interfaces. Questions are specifically designed to assess aspects of usability, validity and/or reliability of software.

Questionnaires are especially good for collecting subjective data (e.g. "how easy is it to use this software?") [Nielsen, 1993]. Questionnaire is one of the widely used methods for evaluating usability of desktop and web based applications [Nielsen, 1993]. The pilot testing of MDEA prototype uses questionnaire to obtain evaluation from patients regarding the ease of learning and ease of using the prototype.

Interviews involve gathering information by talking directly to the users. An interview can typically gather more information than a questionnaire and go into a deeper level of detail [Nielsen, 1993]. Interviews are good for getting subjective reactions, opinions, and insights into how people reason about issues. Interviews may happen in person or over the phone. "Structured interviews" are ones with a pre-defined set of questions and responses. A structured approach can provide more reliable, quantifiable data than an open-ended interview, and can be designed rigorously to avoid biases in the line of questioning. "Open-ended interviews" permit the respondent (interviewee) to provide additional information, ask broad questions without a fixed set of answers, and explore paths of questioning which may occur to the interviewer spontaneously during the interview. An open-ended approach allows for an exploratory process to uncover the unexpected information, used especially when the exact issues of interest have not been identified yet. Structured and open-ended approaches may be combined. For instance, an interview can begin with structured questions, and once the quantifiable data is covered, discussion with the interviewee into other areas may be opened up. A combination of structured and open ended interviews has been used in our pilot testing process to obtain evaluation of the prototype.

5.1.4 Experimental / Empirical testing

The empirical testing approach requires representative users to work on typical tasks using the system or a prototype. A prototype models the final product that allows testing of the attributes of the final product even if it is not ready yet. The evaluators use the results to see how the user interface supports the users to do their tasks.

Some of the important empirical testing [Soken et al., 1993] methods are:

- *Coaching method:* It can be used for usability test, where the participants are allowed to ask any system-related questions to an expert coach who will answer to the best of his or her ability.
- *Performance measurement:* It is used to obtain quantitative data about test participants' performance when they perform the tasks during usability test.
- *Question asking protocol:* It prompts the users by asking direct questions about the product in order to understand their mental model of the system and the tasks, and where they have trouble in understanding and using the system.
- *Thinking aloud method:* It allows the test users to verbalize their thoughts, feelings, and opinions while interacting with the system.

Most of the above methods are used to collect qualitative data except performance measurement method, which is used to collect quantitative data. The widely used methods in empirical testing are performance measurement method and thinking aloud method [Bental et al., 2000]. We could not use the empirical methods for testing the MDEA prototype due to restrictions imposed by the hospital authorities on us for contacting the patients in the hospital. However we conducted interview with the CNS who has talked to the patients who evaluated the MDEA prototype.

5.2 Usability testing of the prototype

This section addresses the evaluation study conducted with the patients and CNS who has expertise in educating patients in the hospital. The evaluation by patients is used to assess the ease of learning and using the prototype. The CNS evaluation is used to evaluate the interface and the usefulness of the software in a hospital environment. The overall testing process focused on patient satisfaction as well as the satisfaction of the CNS in using such software.

The prototype developed for educating patients was packaged in a laptop computer so that patients can use it at their bedside to learn about self medication, immunosuppression, and other important topics to prepare them for the post transplant lifestyle. An approval from the ethics committee was obtained prior to pilot testing process in the hospital. The pilot testing process had to be minimal due to the limitations/constraints imposed by the ethics committee. Only CNS is allowed to observe patients using the software and no other evaluators can observe patients using the software or interact with them during the whole evaluation process. Any information pertaining to patients must be kept confidential and available only to the hospital authorities. Hence we were not been able to conduct most of usability testing techniques such as think aloud method, logging etc to get quantitative results. In this pilot testing process, we used questionnaire to obtain patient's evaluation and interview to obtain CNS evaluation.

5.2.1 Evaluation of the software by Patients

Study Design

The patients' evaluation of the MDEA prototype has been made through a survey questionnaire. It contains eight questions: two questions to assess how familiar the patient is with using a computer and six questions to assess how comfortable the patient is in using the software and the educational content. The questionnaire along with a proposal was submitted for review by the ethics committee and their approval was obtained.

Sample

The participants were post liver, kidney, or pancreas transplant patients whose follow-up is done in the transplant program at the Montreal hospital. The survey sample includes English speaking men or women 18 years of age or older, who have recently had a transplant, have used the software to learn, and who agreed to participate.

Procedure

After approval by the Ethics committee, the CNS in transplant approached the transplant patients (men and women) who have recently undergone a transplant and have used the prototype. The patients were asked by the CNS if they would be interested in participating in an evaluation of this program. For those who agreed, the CNS explained the evaluation process and questionnaire in further detail. The patient was asked to sign an "informed consent form". The participant was informed that at any time during this process he or she can choose to withdraw. The only method of data collection was the questionnaire. The patient was given sufficient time to complete the questionnaire.

Data collection

The data for patient's evaluation is collected using the evaluation questionnaire that was intended to assess the ease of learning and ease of using the prototype.

The six questions shown in Table 5.2 are used in the questionnaire to assess the following:

1. Ease of use of the software
2. Ease of use after repeated usage
3. How patients find navigation mechanisms provided in the software?
4. How patients find the way information is presented?
5. How patients find instructions to use the software?
6. How patients find using the software independently without much help?

The two questions shown in Table 5.3 are used to assess the familiarity of the patient with computers. The first question is used to assess if the patient is a regular computer user. If the patient is not a regular computer user, the second question is used to find out if the patient has minimal experience in using computers.

The three answers for each question are AGREE, DISAGREE, or UNDECIDED

- AGREE means that patient generally have a positive feeling about this statement.
- DISAGREE means patient generally have a negative feeling about this statement.
- UNDECIDED means patient is unable to decide.

No	**Questions**	**Agree**	**Disagree**	**Undecided**
1	I found it easy to learn how to use this program.	☐	☐	☐
2	As I became more familiar with this program, I found it easier to use.	☐	☐	☐

3	I found it easy to move from one section to another section in this program.	☐	☐	☐
4	The information presented in each topic was easy to understand.	☐	☐	☐
5	I found the instructions on how to use this program were clear.	☐	☐	☐
6.	I did not have to ask for help frequently to be able to use this program.	☐	☐	☐

Table 5.2: Evaluation questionnaire for patients

The following two questions indicate how familiar patients are with computers.

No	Questions	Yes	No
1.	I use a computer at home.	☐	☐
2.	I have never used a computer before.	☐	☐

Table 5.3: Questions regarding patient's familiarity with computers

5.2.2 Evaluation of the software by CNS

The CNS is involved in educating patients in the hospital and has good expertise in the process of patient education. While patient's evaluation addresses the ease of using and learning the interface, CNS evaluation is focused on the usability, patient's acceptance to computer based learning, and usefulness of such software in a hospital environment.

Study design

The evaluation by CNS was conducted through a combination of a structured and open ended interview that consisted of several questions.

The goals of such an interview are to assess the following:

1. Use of the prototype as a supplement to the traditional means of teaching,
2. Interest of the patients in using computerized education software,
3. User interface evaluation ,
4. Overall satisfaction on the learning process using the prototype.

Procedure

The CNS was first contacted for an interview. On her permission the standard questions prepared to evaluate the prototype was asked. At the end of the structured interview, additional questions were asked based on the responses of the CNS. The interview was audio recorded to make sure that the answers were properly perceived.

Data collection

The interview with the CNS elaborates on usefulness and usability of the prototype. It also provides us feedback on issues involved in deploying the software in the hospital for educating patients. Such an evaluation is significant as the CNS is not only experienced in teaching patients in the hospital but has also observed and interacted with patients who used this prototype.

The questions prepared for the interview with CNS are given below:

1. What are the advantages of using this software for educating patients as compared to not using it?
2. Is testing of patient's knowledge in this software helpful to assess how they grasped the topics covered?
3. Are the functionalities (buttons and tasks) in the interface easy to learn and use? If not, please explain.
4. Are there any useful functionalities that are missing in the interface? If yes, please explain them.
5. Are there any redundant functionalities in the interface? If yes, please explain them.
6. Are you satisfied with the outcome of patient's learning by using the software?
7. What are your suggestions to deploy this software in the hospital for patient education in a continued basis?

Finally the CNS was asked to rate the software in terms of its usefulness in the process of patient education.

The rating is in a 1-4 scale as specified below:

- 1 being very useful,
- 2 being useful,
- 3 being moderately useful,
- 4 not being useful.

Such a rating gives an overall idea about the introduction of this computerized patient education with the current face to face teaching methodology for patients.

5.3 Analysis and Discussion of Results

A total of four patients evaluated the software and gave their responses to the evaluation questionnaire. One CNS from a Montreal hospital who is involved with teaching patients for some years and who was conducting this pilot testing process gave her evaluation through an interview. This section provides a summary of the evaluation of patients and the CNS and discusses the results of the evaluation in terms of contents, interface and the process of educating patients with the help of computers.

5.3.1 Patients' evaluation

Patients filled out the evaluation questionnaire consisting of eight questions to provide feedback about using the prototype. All the participating patients reported that they have used computers at home.

Total number of participating patients: 4

No	Questions	Total Agreed	Total Disagreed	Total Undecided
1	I found it easy to learn how to use this program.	4	0	0

2	As I became more familiar with this program, I found it easier to use.	**3**	**1**	**0**
3	I found it easy to move from one section to another section in this program.	**4**	**0**	**0**
4	The information presented in each topic was easy to understand.	**4**	**0**	**0**
5	I found the instructions on how to use this program were clear.	**4**	**0**	**0**
6.	I did not have to ask for help frequently to be able to use this program.	**3**	**0**	**1**

Table 5.4: Response of patients to the questionnaire

Table 5.4 shows the response of patients to the evaluation questionnaire. All the four patients participated in the evaluation agreed that the software is easy to use (question 1), easy to learn (question 5), presentation is clear (questions 4), and navigation provided by software is good (question 3). Three of four patients agreed that the software becomes easier to use when used again and again. One patient disagreed with this aspect and it is contradictory considering the patient's overall positive response and the fact that the patient agreed that the software is easy to use in question 1. Question 2 is used to assess ease of learning especially when a patient disagrees to question 1. Since the patient agreed to question 1, his/her disagreement to question 2 does not have a significant impact in the ease of use of the software. One patient was undecided about the level of help required to use the prototype. However, the patient indicated he/she did not require frequent help. Overall the results were positive indicating that patients have a positive feeling about using the prototype.

5.3.2 CNS Evaluation

The software was set up by the CNS and then given to patients to learn about their post transplant care. The CNS teaches patients regarding medications in a one to one tutoring process and then gives the laptop to patients to learn more on their own. The main intent of using the software is to learn issues such as life style changes, rejection, side effects and so on.

The following are the summary of evaluation by the CNS:

1. The CNS reported that approximately two-thirds of patients she contacted (including the four evaluated patients) prefer to use the software to learn about their post transplant care.
2. The CNS felt that the prototype is very useful in supplementing one to one traditional teaching and gives freedom for patients to learn at their own pace and convenience.
3. The CNS preferred laptop over a pocket pc for patient education as patients would prefer bigger fonts for reading.
4. The CNS also told to package the software in a CD for use in the family room computer. This would help her to avoid concerns regarding the safety of laptops used for pilot testing.

5. The CNS reported that since patients were familiar with computers, they have found the software very useful to learn and suggested that more navigational aids might be required for patients who do not have familiarity with computers.
6. The CNS also reported that there was no significant functionality missing in the interface and no redundant or unnecessary functions were found in the interface.
7. The CNS rated the usefulness of the software as **'2'** i.e. useful in educating patients.

5.3.3 Discussion

Since the contents are only in English and prepared for post transplant patients in the hospital, a total of only four patients evaluated the software prototype over a period of six months. It has been reported that most of the usability problems can be identified by employing three to five users for evaluation [Nielsen et al., 1993]. This is indicative of the fact that though the number of evaluated patients is small (four), it is a sufficient number to evaluate the usability of the software prototype. We were satisfied with the evaluation of the software prototype by four patients given the constraints in getting patients for evaluation. Also the CNS evaluation gave a lot of insights about the usability and usefulness of the software prototype. The results of pilot testing of the MDEA prototype were quite satisfactory in terms of usability as well as the acceptance by patients and the HCP.

Content evaluation

All the participated patients answered that the content is clear and can be easily understood. The contents were prepared in collaboration with the CNS and thesis supervisors.

Interface evaluation

Patients' evaluation of the prototype indicates that the prototype is easy to learn and use. This is also asserted by the CNS's evaluation of the interface. A suggestion from the CNS concerning the interface is that more navigational aids might be required for patients who do not have familiarity with computers.

Process evaluation

The software can be used in conjunction with the conventional teaching used by the CNS. This would contribute to the efficiency of healthcare services by lessening the time spent by the HCP to teach patients and allowing them to spend more time on other healthcare tasks. Also more patients are willing to use the computer to learn, as this gives them an opportunity to learn at their own pace at a convenient time and location.

Recommendations

In summary, the following work has been recommended to deploy the software prototype in the hospital based on CNS evaluation:

1. Removing simple bugs that exist in the highlighting of text during presentation.

2. Translate the English contents to French and also develop a French version of the software as the primary language in Montreal is French.
3. To package the software in a CD that can be used in the family room computer of the hospital.
4. To provide an interface that gives control to the CNS / administrator to make changes in the presentation such as changing font size and adjustments in the transition time from one screen to the next.

Chapter 6

Conclusion and Future work

Direct and indirect benefits of patient education are many. It can lead to medication compliance and better self management of health. Such benefits contribute to the growing interest towards the use of computers to complement the traditional means such as providing leaflets, instruction by the CNS and patient-doctor dialogue. The advantages of using computers for patient education as a supplement include anytime availability and better prospects for personalization in the learning process. Over the years a number of computer-based systems have been developed for patient education addressing the personalization and information needs of patients. Most of those systems focus mainly on personalizing the contents to be presented and give lesser importance to usability or user interface design of the system. Many such systems are only experimental and not deployed in hospitals.

The primary focus of this thesis was to propose a patient education framework that can be successfully deployed and used in a typical hospital setting. The MDEA architecture addressed significant factors such as personalization, knowledge organization, and UI design that would help in the deployment of such systems in hospitals. The architecture is flexible to develop patient education systems for different diseases. The models drive the learning as well as testing process and such models can be extended or modified to personalize the education process. A flexible knowledge representation framework was used to create, share and maintain the contents. Simple UI design solutions were proposed to assist patients to learn easily from the software. The prototype developed as part of this thesis was limited addressing the constraints of a hospital environment. The disease model is not present in the current prototype and the patient model could be extended further to include more personalization. The knowledge base used is small and can be made more extensive to study its effectiveness in the hospital domain.

In this thesis, we have explored avenues that are identified as being important for personalization in a patient education system. Primarily it includes the set of topics to be learnt by patients at a particular time, level of details to be presented on each topic, use of multimedia in the presentation, testing the patient's understanding, and the relevant features in the user interface.

The knowledge representation framework of MDEA is based on the topic map standard to create and manage the contents. The motivation for such a flexible content organization came from the fact that content creation and knowledge engineering are labor intensive tasks in the health care domain. We reviewed the existing e-learning standards for content creation, based on which this thesis recommends a combination of XML Topic Maps and LUC model for knowledge representation. Such a knowledge representation framework enables the contents created to be re-used and/or translated to any language and can be deployed at any hospital.

User interface is a significant aspect of a patient education system and a simple interface that is easy to learn and use, can greatly contribute to the success. The prototype developed as part of this thesis provides a simple and intuitive graphical user interface incorporating the functionalities that are easy to learn and use. The user interface requirements were identified based on extensive requirements analysis and discussions with the CNS.

The pilot testing was conducted with a small group of patients at the transplant center of the Montreal hospital. The patient population for evaluation was very much narrowed because of constraints such as:

1) English speaking post transplant patients in the hospital
2) Who are willing to use a computer
3) Who are ready to answer certain evaluation questions
4) Over the period of six months from June 2006 to November 2006.

Four patients and one CNS evaluated the MDEA prototype and the results of the evaluation were positive implying that the software was easy to learn and to use.

From the experiences in deploying the software prototype for pilot testing in the hospital, we discovered that supervised patient education in a hospital setting has multitude of characteristics and requirements. We faced several challenges in the deployment process. Some of the challenges are:

1. Getting acceptance of the hospital authorities in terms of the contents presented for educating patients.

2. Presenting those contents to patients such that they can comprehend the presented information in a better way.
3. Identifying what can and cannot be done with patients as a way of education and evaluation.
4. To cope up with the limitations imposed by the ethics committee while dealing with patients.
5. Introducing the computer based patient education to the current one to one tutoring process as a supplement.

A significant time has been spent in deploying the MDEA prototype in the hospital and to get evaluation results from patients. More time is required to have a comprehensive study of the usability and acceptability issues involved in the deployment of such software considering multiple places of application. From our experience in the development of this prototype, it is clear that even though the healthcare community understands the advantages of using IT, such a transition should start from smaller goals to convince the healthcare professionals and finally might lead to the vision of deploying large scale educational systems in hospitals.

Future work

The software prototype developed as part of this thesis was well received in terms of the usability as well as the acceptability by the patients and CNS.

Future work could include the following:

- The present prototype can be extended to other stages of transplant such as pre-transplant and post transplant.
- For the continued use of MDEA in hospital, tools can be developed for the CNS to update and maintain the contents. An authoring tool can be developed to provide functionalities to the CNS/administrator to enable them to modify the contents, and to change presentation layouts.
- The overall system can be made web based such that patients can learn at any place and at any time. The MDEA system can be hosted in a web server from the hospital. The hospital database can be connected to the MDEA database such that the patient model can be automatically updated with the current treatments and medications of the patient.

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Appendix A

Proposal submitted to the ethics committee

Description of the Patient Education Project

Patient education is a vital part of the care of transplant patients. An ongoing goal in the care of this population is to develop strategies to improve the process of patient education. One strategy is to build on the existing patient education material. Over the past two years, an interactive computerized education program has been developed to assist liver, kidney, and pancreas transplant patients as they learn about their care post transplant. Mr.R.Ramachandran, a graduate student in Computer Science, researched and developed the interactive software system MDEA, (Model Driven Educational Assistance), as a part of his Master's thesis. Norine Heywood, Clinical Nurse Specialist (CNS) in Transplant, developed the education material for the program.

The content of the program includes information on medications, basic functions of the immune system, rejection, infection, prevention of infection, life style changes, and follow-up care. In this program patients are able to listen to the audio as they read the text, or, if they prefer, choose to only read the text or listen to the audio. They can choose to view the whole program at one time or select specific topics to review. An interesting feature of the program is that patients can simulate practicing preparing their medications using a simple graphical interface. Throughout the program there are questions to help the patients remember and reinforce what they have learned A useful feature of the program is that the nurses are also able to assess the patient's knowledge level, and, from this, identify if further education is needed.

Background and review of the literature

The purpose of health education is to increase an individual's knowledge, support their abilities to manage their situation or enhance their skills, and thus improve their health outcomes (Arora, Johnson, Gustfson, McTavish, Hawkins, & Pingree, 2002; Zernike & Henderson, 1998). Acquiring new skills is one of the challenges transplant patients face as they learn a complex medication regime, how to prevent infections, and how to recognize infection and rejection (Luk, 2004; Russell, Kilburn, Conn, Libbus, & Ashbaugh; 2003; Wainwright, Fallon, & Gould; 1999). It is important to recognize that patients have different learning needs and preferences, and learn best in ways that fit their needs (Lewis, 1999). Thus providing patient education material in different formats supports individual learning needs, and enhances the quality of care.

In recent years, with the rise in computer technology, computer-assisted learning has emerged as a valuable and useful method to provide patient education, and supplement information provided by nurses and physicians (Buchanan, Moore, Forsythe, Carenini, Ohlsson, & Banks, 1995; Krishna, Balas, Spencer, Griffin, & Boren, 1997; Lewis, 1999).

Lewis (1999), in a review of the literature, described the potential benefits of using computers in patient education. A number of studies cited described the advantages of using computer-assisted education programs to provide or reinforce information, and support skill development. A benefit of computer-based programs is that they can be designed in a format that encourages active participation in the learning process.

Interesting findings are reported in studies reviewed, (Lewis, 1999), which compared the use of computer education programs versus usual forms of education. In the groups that used the computer education programs there were initial improvements in knowledge scores, an increase in skill development, and improved clinical outcomes. In one study with diabetic patients, it was found that, when individuals were given basic information on how to use an insulin pen on a computer program, it decreased the amount of time the diabetes educator spent on providing basic information, and thus meant there was more time for individualized instruction.

The importance of developing programs that meet the needs of different age groups, socioeconomic backgrounds, literacy levels, and visual or hearing deficits, was emphasized. Studies done with different age groups found that even individuals with little computer experience were able to use the computer education programs, as long as they were designed to meet their needs. Individuals with low literacy skills indicated that they preferred this format of learning as they could go at their own pace (Lewis, 1999).

There is evidence to show that using computers as a mode of patient education has the potential to provide an effective means of patient education, and contribute to improved health outcomes and increased patient satisfaction. This has spurred an abundance of interest into further research and development of computer applications for patient education (Lewis, 1999).

Evaluation of the patient education program

An essential component of evaluating a patient education program is to gather information from patients. The objective of this evaluation process is to understand how patients find using the computer software. The question for the evaluation is:

"Is this computerized patient education program easy for patients to learn and to use?"

Methods

Design

A survey, in the form of a questionnaire, will be used to evaluate this computerized patient education program. The survey questionnaire contains ten questions. Eight of the questions are designed to assess how comfortable the patients are in using the software and the educational content in the program. Two of the questions are to assess how familiar the participant is with using a computer.

Sample/Informants

The participants will be post liver, kidney, or pancreas transplant patients who are followed by the Royal Victoria Hospital transplant program. The sample will include English speaking men or women 18 years of age of older, who have recently had a transplant, have used the computerized patient education program, and who agree to participate. (The program is only available in English now but will be translated into

French soon). Over the course of 6 months (June 2006 to November 2006) it is anticipated that a maximum of ten patients will be recruited to participate in the evaluation.

Procedure

After ethics approval, the Clinical Nurse Specialist (CNS) in transplant will approach transplant patients (men and women) who have recently undergone a transplant and have used the computerized patient education program. The patients will be asked if they would be interested in participating in an evaluation of this program, and if they agree, for permission for the graduate student to contact them. For those who give permission, the graduate student will explain the evaluation of the program and questionnaire in further detail. If the patient agrees to participate, he or she will be asked to sign an informed consent form. The participant will be informed that at any time during this process he or she can choose to withdraw.

The only method of data collection will be the questionnaire. The patient will be given sufficient time to complete the questionnaire. The graduate student and nurse will not be present while the participant is completing the questionnaire.

Data Analysis

The data will be analyzed using the statistical method of percentile distribution. For example, if 9 out of 10 patients answered that the program is simple to use, then the conclusion will be drawn that 90% of patients tested agreed that the program is simple to use. The published thesis will be available at the Webster Library of Concordia University.

Ethical considerations

The following steps will be taken to obtain informed consent. The graduate student will discuss the evaluation of the program and the questionnaire, and review the consent form with the participant. The CNS will also be available to discuss the evaluation of the program and the questionnaire, and review the consent form with the participant if they would like further information. The participant will be asked it they have any questions and will be informed that they may discuss their participation in the evaluation of the program with others before making a decision.

The following steps will be taken to maintain confidentiality and ensure anonymity. A list will be developed with the participants' names, and each participant will be given a fictitious name and numeric code. The code list will be kept in a locked cabinet separate from the rest of the data. After this step, participants will be only be identified by these fictitious names and numeric codes. The code list and data will be kept in a locked cabinet in Norine Heywood's office at the Royal Victoria Hospital (MUHC) for 5 years and then destroyed. The only people that will have access to the data will be Norine Heywood, CNS in Transplantation, the student, Mr. Mr. R.Ramachandran, and his supervisors, Dr. Dr. T.Radhakrishnan, and Dr. S.P.Mudur.

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Appendix B

Questionnaire for Computerized Patient Education Program

Dear Participant,

The purpose of this survey is to help us understand how you have found using this computerized patient education program.

Thank you for taking the time to complete this survey.

There are 8 statements, with 3 possible answers for each statement.

The three possible answers are AGREE, DISAGREE, or UNDECIDED

- AGREE means that you generally have a positive feeling about this statement.
- DISAGREE means that you generally have a negative feeling about this statement.
- If you are unable to decide, then mark UNDECIDED.

		Agree	Disagree	Undecided
1	I found it difficult to learn how to use this program.	☐	☐	☐
2	As I became familiar with this program, I found it easier to use.	☐	☐	☐
3	I felt I could move easily from one section to another.	☐	☐	☐
4	The information in each topic was easy to understand.	☐	☐	☐
5	The information in this program was helpful to me.	☐	☐	☐
6	The information was presented in a format that I could understand.	☐	☐	☐
7	I found it easy to follow the instructions on how to use the program.	☐	☐	☐
8	I had to ask for help frequently to be able to use this program.	☐	☐	☐

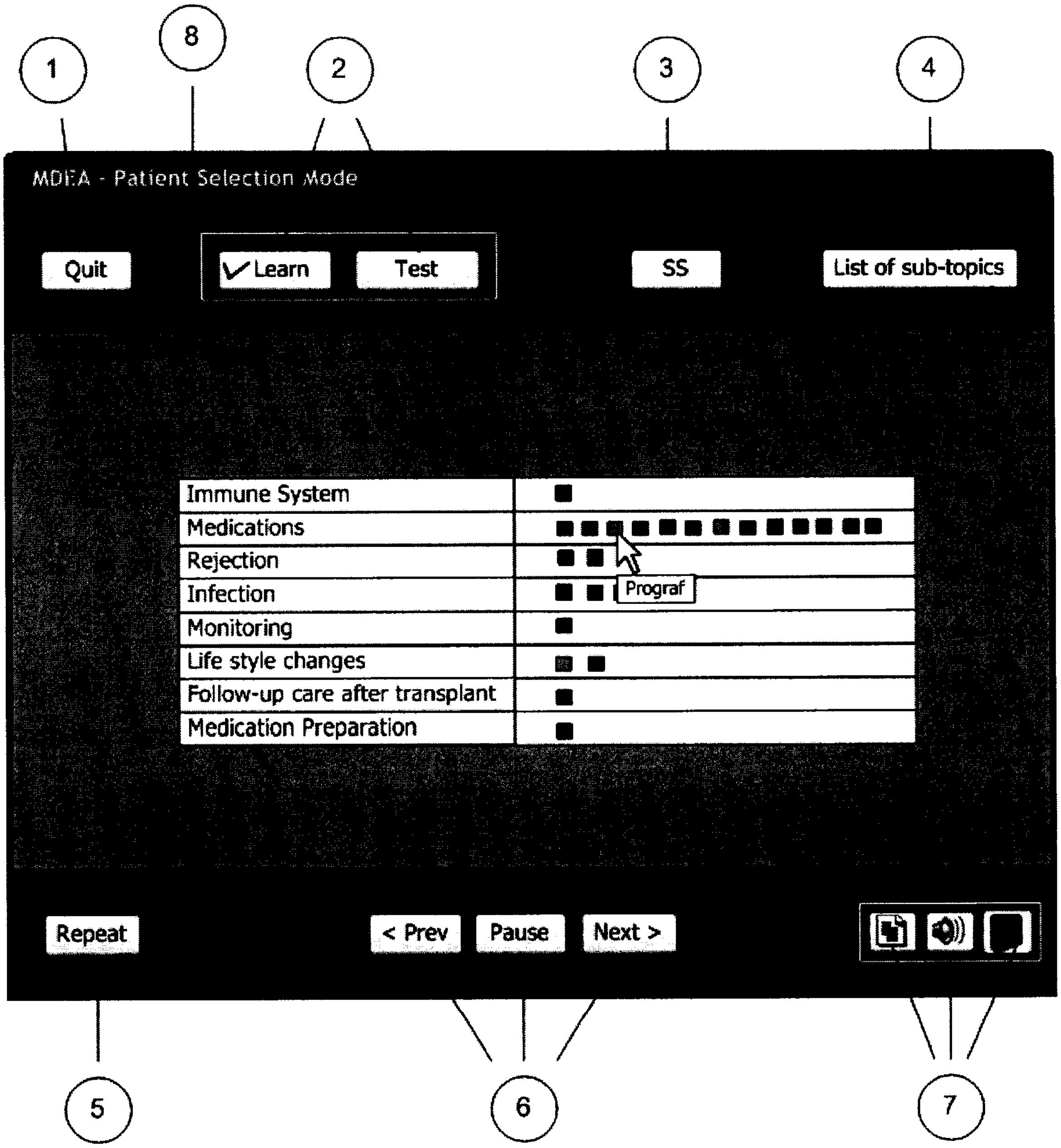
The following 2 questions will help us to understand how familiar you are with computers.

		Yes	No
1	I use a computer at home.	☐	☐
2	I have never used a computer.	☐	☐

Appendix C

User manual for MDEA prototype

DIAGRAM OF COMPUTER SCREEN



GUIDELINES FOR USING COMPUTER PROGRAM

This computerized patient education program is an interactive program, designed to help patients learn about their care after an organ transplant.

This program contains 8 topics. Each topic contains 2 or more sub-topics. At the end of each topic there is a short test. This test will help you to see if you have understood the information you have learnt.

This chart explains the buttons or modes on the computer screen

1	To end or exit the program, click on **Quit**
2	There are 3 options in this mode: **Learn with Test, Learn and Test** 1. If you would like to listen and learn from the program and take the test, then click on both **Learn** and **Test**. 2. If you would like to listen and learn from the program without taking the test then click on **Learn** 3. If you would like to take the test without listening to the program, then click on **Test**.
3	There are 2 options in this mode: **SS** (system selection) and **PS** (patient selection) 1. If you would like to go through the whole program, then select **SS**. 2. If you would like to go to specific topics or sub-topics, then select **PS**. Click on the button to switch between **PS** and **SS** modes.
8	This indicates whether you are in **SS (System Selection Mode)** or in the **PS (Patient Selection Mode)**.
4	This displays the list of sub-topics. To see this list, you need to be in the **PS** mode.
5	If you would like to replay a current sub-topic, then click on **Repeat**
6	Navigation options: • Click on **Prev** to go to the previous sub-topic, • Click on **Pause** if you want to stop the program for a short period, • Click on **Next** to go to the next sub-topic.
7	Multimedia options for learning: 1. If you would like to read the text in the program and listen to audio at the same time then click on the **first button for the Text** and the **second button for the Audio**. 2. If you would like to read only, then click on the **first button for the Text**. If you would like to hear the audio only then click on the **second button for the Audio**.

Appendix D

Participant consent form

Introduction

You are being invited to participate in an evaluation of the computerized patient education program that you have recently seen. This evaluation is being conducted by Mr. R. Ramachandran, a student doing a master's degree in computer science at Concordia University. The completion of this evaluation is a partial requirement of his master's thesis. The evaluation will be done under the guidance of Norine Heywood, Clinical Nurse Specialist (CNS) in Transplant, RVH site of the MUHC.

Before deciding to participate in the evaluation, you should clearly understand its requirements, risks, and benefits. This document provides information about the evaluation, and it may contain words you do not fully understand. Please read it carefully and ask any questions you may have. The student will discuss this evaluation with you in detail. You may take this form with you and discuss this evaluation with anyone else before making your decision. If you decide to participate, you will be asked to sign this consent form and a copy will be given to you.

Purpose

The purpose of this evaluation is to understand how you have found using the computerized patient education program designed for transplant patients. Having a transplant can mean many changes and challenges in your life. There are new things you will have to learn to be able to take care of yourself after the transplant. The purpose of this computerized patient education program is to help you learn more about your medications, basic functions of the immune system, rejection, infection, prevention of infection, life style changes, and follow-up care. Professionals would like to know how you have found using this program. The information we receive from you is important. This information will help us make changes and improvements in how we provide information to help patients learn about their care after the transplant.

Description of the evaluation

If you agree to participate in this evaluation, you will be given a short questionnaire to complete. The evaluation questionnaire will take about twenty (20) minutes to complete. You will be given the time you need to complete the questionnaire. Your name and personal information will not be on the questionnaire. The student will not be in the room while you are completing your questionnaire.

Risk and discomforts

There are no known harms to participants in this evaluation process.

Potential benefits

The only benefit from participating in this evaluation is that the information you provide will help the professionals improve this patient education program for future transplant patients.

Costs and compensation

You will not be offered any compensation for your participation in this evaluation.

Confidentiality

All personal information collected during this evaluation will be kept strictly confidential. Your name will be coded and the code list and data will be kept in a locked cabinet in Norine Heywood's office at the Royal Victoria Hospital (MUHC) for 5 years and then destroyed. The only people with access to the data will be Norine Heywood, CNS in Transplant, the student Mr. R. Ramachandran, and his supervisors, Dr. T. Radhakrishnan, and Dr. S. P. Mudur. The results of this evaluation will be written in a thesis, but your name will appear anywhere. The results of this evaluation may be published; however, your identity will not be revealed in the combined results. The findings of this evaluation can be made available to you upon request before any paper is published.

In order to verify the research study data, monitors from the MUHC Research Ethics Board may review these records containing your personal information. By signing this consent form, you give us permission to release your personal information regarding your participation in this evaluation to these entities, to other investigators participating in this evaluation, and for the purposes of publication, and to inform your treating physician of your participation in this project. Your confidentiality will be protected to the extent permitted by the applicable laws and regulations.

Voluntary participation and/or withdrawal

Your participation in this evaluation is strictly voluntary. If you decide to participate, you may refuse to discuss certain points or answer certain questions. You may refuse to participate or may discontinue your participation at any time without explanation, and without penalty or loss of benefits to which you are otherwise entitled. If you decide not to participate, or if you discontinue your participation, you will suffer no prejudice regarding your medical care.

Questions and contact information

If you have any questions regarding the evaluation you should contact the student Mr. R. Ramachandran or Norine Heywood.

Declaration of consent

I have read this consent form, and I agree to participate in this evaluation. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I have been given sufficient time to consider the above information and to seek advice if I choose to do so. I authorize Mr. Ramachandran to collect, exchange, communicate, and use my personal information for the purpose and in the manner mentioned above. I understand that I have a right to access my personal information and to make corrections, subject however, to the restrictions contained in the applicable laws and regulations. This consent is valid until such time the evaluation process is completed, which is the length of time need to achieve the purpose for which it was requested. I will be given a signed copy of this consent form. By signing this consent form, I have no given up any of my legal rights.

Participant	Print name	Date
Person conducting the informed Consent process	Print name	Date