Providing psychosocial support to young cancer patients through an online virtual world

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The use of online communities in providing health support has increased with the emergence of online virtual worlds over the past decade [1]. We are developing a personalized online virtual world to facilitate psychosocial support to young cancer patients who are between six and fourteen years old. Salient details from the patients records are stored in an ontology which is provided to a reasoning engine as input. Based on these details patients are provided with suggestions and resources about their ongoing treatment, for example what they might follow up on with their doctors. Commonalities between patients (for example treatments, type of cancer, age, interests) can also be used to facilitate productive interactions in the world between the patients. In this paper we describe the architecture of our system, describe our current prototype implementation, and discuss how our system may be used in combination with physical co-located support groups.

Keywords
Psychosocial support, Cancer, Personalized Self-management, Virtual World, Semantic Web

1. INTRODUCTION

While online virtual worlds have been predominantly used in gaming, they provide an interesting alternative to face-to-face healthcare encounters between patients and care providers. The virtual world renders a realistic world environment in which the individual can immerse him/herself and interact with meaningful objects for work, entertainment and education. Healthcare environments are at times perceived as ‘cold’ and health care encounters within these environments are perceived as ‘uncomfortable’ in some clinical situations. Young patients who on the one hand are particularly sensitive to clinical environments and encounters, and on the other hand are attuned to the gaming environments are therefore prime candidates for exploring the potential of virtual healthcare environments for delivering psychosocial support and disease-specific programs. Young patients may not able to communicate their problems with the health professionals in the physical world as freely as they can through virtual world.

A virtual world based patient support environment has many potential advantages over other mediums in supporting patients. For example, patients can chat with each other through text, voice, and gesture using mobile phones, but a virtual world provides the feeling of sharing a ‘living’ space which arguably gives it an edge over other mediums of digital communication [2]. A virtual world provides an opportunity to
introduce new techniques and spaces of social interaction, participation and collaboration to deliver realistic and vivid health experiences [1]. Given that in a virtual world, patients can make themselves anonymous through the use of an avatar it is possible to maintain privacy and yet still interact with care providers, fellow patients and educators without feeling the pressure of stigma or embarrassment. As a “safe” social environment, young cancer patients may be more comfortable discussing psychosocial issues. Patients can engage in interactive activities and seek certain types of help in the world which they cannot easily do in a clinical setting. Since the virtual world can be accessed from anywhere, it can facilitate connectedness even when patients cannot coordinate or are unable to travel to support centers and healthcare facilities. From a design perspective, one of the major advantages of using a virtual world is the vast amount of virtual space one can devote to developing personalized virtual worlds according to the needs, intent and interest of patients.

In this paper we present an investigation into the development of a psychosocial support framework that aims to (a) develop a ‘virtual’ psychosocial support environment to deliver personalized educational interventions to youth cancer patients, (b) model psychosocial content using a formal representation scheme—in our case ontologies; (c) provide a rule-based personalization approach that selects relevant educational content based on the patient profile, and (d) identify commonalities between patients and bring patients with common characteristics together in the virtual world for peer psychosocial support.. For our current work we are focusing on young cancer survivors (aged 6-16 years) to whom we are providing follow-up care, psychosocial support and self-management educational messages based on their therapeutic regime (in particular to their cancer drugs). Youth cancer patients undergoing intensive therapies tend to get isolated due to the effects of the therapy, yet at such a tender age they need to socialize and enjoy their youth. It is for this purpose, we believe that a virtual world for youth cancer patients not only provides an alternative social environment where they can meet other cancer patients of their age, but it also provides a viable medium for delivering psychosocial support and educational interventions as part of social interactions. In our work, we establish similarities between different cancer youths and can potentially introduce them to each other so that they can socialize and share their experiences and provide peer-level support.

We present a Youth Cancer Patient Support World (YouCan-World) that features a virtual world that (a) allows patients to develop their own personalized avatars and; displays personalized educational messages to patients at strategic points in the world; and (b) navigates the patients through their long-term care process by delivering them appropriate educational and psychosocial resources. We have developed an ontology-based personalization module that features a large set of SWRL rules that take as input the patient’s profile—currently, the patient drug therapy and other clinical characteristics—and in turn generates a set of drug-related messages relevant to the patient’s profile. These educational messages and psychosocial support mechanisms are then presented within the patient’s virtual world. Although, the literature presents systems that use virtual worlds to support patients, the novelty of our work is the fine-grained personalization approach that not only delivers patient-specific messages and interactions with patients, but at a technical level offers a scalable knowledge-base to which new personalization rules and messages can be readily added to enhance the patient experience and support relationships between patients. YouCan-World is developed using Open Wonderland as the virtual world and a suite of semantic web technologies as the personalization module. The personalization rules and
the associated messages are derived from clinical guidelines and validated by pediatric oncologists at the IWK hospital in Halifax. The virtual world and personalization components of YouCan-world are integrated using the TwinSpace framework [3], which also provides support for multiple input and display configurations, and we discuss how this will allow YouCan-world to support a wider range of use-contexts in future work. Our current YouCan-World prototype is accessible through a URL, which loads a Java-based client. YouCan-world is still under development and not fully evaluated for its efficacy in terms of user interactions and psychosocial support.

2. RELATED WORK

Virtual worlds have been used previously for giving social support to patients. Sawyer et al. (2011) mainly concentrated on the social issues of older patients, and developed a virtual environment to meet their needs [2]. In our application we are trying to support young cancer patients, not only socially but also psychologically by addressing their questions about therapies and treatments. Becker and Pentland [4] used a virtual environment to educate cancer patients about relaxation and self-imagery. In their work they used patient gestures to navigate them through the blood stream as white cells killed the malignant cells, which gave a feeling of relaxation to the patients [4]. This experience gave the patient the required inspiration for going through the treatment with a more positive attitude. While our current prototype assumes mouse and keyboard input, the TwinSpace framework on which we are building a YouCan-world supports a broad range of natural inputs and immersive displays. We also provide similar experiences by deploying interactive 3-D models (e.g., of a chemotherapy machine) and videos of young cancer patients undergoing treatment in the virtual world. By interacting with such models and watching the videos, we hope to provide support to young patients as they prepare for or are undergoing treatments.

Virtual worlds are also used for providing online role-play, which is a technique for engaging individuals in various tasks, for example, team building [5]. Also in many universities, virtual worlds are considered as a tool for providing education especially in the medical field. Baker et al. (2009) argued about the use of virtual world as an education tool [6]. They proposed that the virtual world has an advantage for learning psychology and skills, as the student can create environments and objects in the world. Welbourne et al. (2009) discussed the use of the virtual world as a tool for online supportive communication in infertility groups [7]. They proposed that the virtual environment is suitable for discussions and sharing queries for infertile women. Virtual worlds are also being used for providing healthcare support for people with intellectual disabilities [8]. People with intellectual disabilities find it hard to understand information from brochures and booklets. Lack of access to healthcare information will also cause poor access to healthcare facilities. Virtual worlds provide a 3-D computer generated environment that can be used for providing information to such people.

Young people are often attracted to virtual worlds, as many like to play video games. Since virtual worlds have been used before for providing healthcare support to people, they should also be effective in providing support to young cancer patients [9]. Second Life has been considered as a tool for providing
medical-related education in a virtual environment [10]. Research has been done in using virtual worlds as a classroom which will allow large number of students and teachers to participate at the same time [11]. In our application, we are using Open Wonderland as a virtual environment due to its extendable nature and flexibility. Using Open Wonderland, we can create a virtual world suitable for young cancer patients very easily, and control access and deployment. Our approach builds on the Twinspace infrastructure [3]. Twinspace’s core feature is to support the integration of virtual environments with physical collaborative environments, which we discuss in future work. It provides a rudimentary reasoning engine, which has been used to respond to virtual world events (including when someone logs in, or speaks) by updating how the virtual world is presented to a group of viewers (for example, a virtual world client might pop up a screen that shows an avatar while they are speaking). In our approach we considerably extend the functionality and intent of the reasoning engine of TwinSpace to work in a medical context. Specifically, we reason about patient information in order to tailor the virtual world experience for young cancer patients.

The Semantic web technology has been used before for providing support based upon the information stored in the OWL ontologies. Bouamrane et al discussed about using semantic web technology for building an adaptive patient information modeling and providing clinical decision support system [12]. They used ontology to store the domain knowledge of preoperative assessment which includes classification of procedures and guidelines for various tests. Based on the information stored in the ontology, they provided the personalized patients’ reports consisting of relative preoperative tests. In our system, we are also using semantic web technology to store the background information about the patients and will be logically inferencing information from it. We will use this inferred information in our system to provide messages and recommendations for the patients.

3. FUNCTIONAL AND TECHNICAL ARCHITECTURE OF YOUCAN-WORLD

We have defined some key functionalities to be provided to the young cancer patients in order to provide psychosocial support. OpenWonderland already provides facilities for voice and text chat, for creating and modifying virtual environments, for sharing media of various kinds (video, web pages, pdfs, images, etc.), and for participating in online collaborative activities (e.g., brainstorming, exploring interactive 3D models). The functionalities that we add to OpenWonderland in our work involve using knowledge management to a) display recommendations for activities in the world; b) identify commonalities between patients currently visiting the world; and c) dynamically adapt the world to accommodate the needs and activities of those currently visiting. Currently we are able to determine and display recommendations based upon the SWRL rules and data stored in the ontology as soon as patient logs into the world. These recommendations are determined based on the details of patient records stored in an ontology which will help the patient to follow-up with the doctors. Certain recommendations will be presented to the patient based on their location in the world (i.e if the patient is in a virtual therapy room then messages about the relevance of the therapy to the patient will be displayed).
The second key functionality on which we are working on is to identify the commonalities between patients, and indicate these commonalities in such a way that patients can have useful encounters with each other when online. At present we are merely displaying commonalities outright on each patient’s virtual world client screen, but we anticipate iterating on this implementation after consultation with patients and experts. The main motive behind displaying the commonalities is to attract the attention of a patient towards other patients who are undergoing the same therapy so they can share their experiences and doubts regarding therapies and treatments. These commonalities will be based on the information stored in our ontology. For example if two patients are taking a same drug or they are of same age, this similarity will be displayed, which can provide reasons for communication between them. We also have various models of rooms, furniture inserted in the world for the patients to give a real world experience to patients. We also inserted pdf’s and web documents about various cancer treatments and therapies in the world, and informative videos or lectures by experts or specialists. The main objective of having informative material in the virtual world is to educate the young patients about cancer treatments and therapies.

At the system level YouCan-World mainly consist of 3 main components: (1) the Personalization Module, which is comprised of a knowledge base encapsulating the content personalization rules and a reasoning engine designed to select the relevant messages based on the satisfaction of a personalization rule; (2) the Virtual World Integration Module, which contains YouCan-world’s script and space elements used to affect changes in the virtual world based on personalization data; (3) the Open Wonderland Server, which provides the necessary virtual world operational components; and (4) the Event Heap Server, which is used for communications between the integration module and the personalization module. OpenWonderland is itself built on an MMO (Massively Multiplayer Online) model, which is a variant of the client-server architecture concerned with creating a synchronized experience across a number of simultaneous clients. When patients login via a wonderland client (see Figure 1), they have to enter their username for identification, after which they will find themselves able to explore the virtual world using their selected avatar. Within the virtual world, patients are able to receive personalized educational messages, navigate through the world to learn about the care process and to interact with other patients using voice or text.

The personalization module is responsible for generating the ‘right’ messages which are then displayed in the YouCan-World at strategic locations which the patient would notice as he/she is navigating through their YouCan-World. The personalization module resides in the back end, where any information needed about the patients is received by querying the ontology using the reasoning engine. Data transfer between wonderland server and reasoning module is done through EventHeap server which acts as a connection between the wonderland and the reasoning module. Event heap is an infrastructure specially developed for ubiquitous environments. It allows communication between mobile devices as well as embedded devices which can be situated anywhere [3]. Any data which is to be transferred has to be encapsulated into event heap events which are then added to the event heap server. Any device or program who wants the data has to register for that event and for registering for the event it should have the template of that event. We are using twinspace in our approach, which is a flexible infrastructure for combining interactive workspace with the virtual world [13]. We are using the modules or capabilities of

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twinspace that are useful to connect the wonderland server to the reasoning engine. We cover the details of the personalized module and Virtual world components in the following subsections.

3.1 PERSONALIZATION MODULE

The personalization module consists of a knowledge base and it is responsible for firing the rules based on the patient’s profile. We are using a patient ontology and SWRL rules for building our knowledge base. The ontology consists of three main classes, ‘Drug’, ‘Patient’ and ‘Decision’, where Decisions are the suggestions which will be given to patients depending upon the firing of the personalization rules. We developed the patient ontology using a standard database of drugs, and the ontology captures the drugs being taken by a patient along with other personal health attributes. There are around 19 drugs which we have in our patient ontology each of them having its own effects and side-effects. Also we have rules based on the drugs and the details of the patient to give recommendation out. Table 1 describes the part of the database for drug Bleomycin which we have used for building our knowledge base. In the table we can see that parameters like age of the patient, the amount of the dose are considered along with the drug. The suggestions are the guidelines for the patient when they will meet their doctors for follow up.

Table 1 Rules in text format

<table>
<thead>
<tr>
<th>Sr No</th>
<th>Drug Name</th>
<th>Decision Points</th>
<th>Suggestions</th>
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<tbody>
<tr>
<td>1</td>
<td>Bleomycin</td>
<td>IF age &gt; 10 yrs at treatment AND dose &lt;400 units/m2</td>
<td>Ask your doctor to check your lung symptoms (cough, wheeze, shortness of breath) and do a physical exam every year.</td>
</tr>
<tr>
<td>2</td>
<td>Bleomycin</td>
<td>IF age &lt; 10 years at treatment</td>
<td>Ask your doctor to do a baseline breathing test (including peak flow, diffusion capacity and spirometry). Ask your doctor to check your lung symptoms (cough, wheeze, shortness of breath).</td>
</tr>
</tbody>
</table>

Figure 1 Block diagram of YouCan-World
wheeze, shortness of breath) and do a physical exam every year. Ask your doctor to repeat your breathing test every 5 years or so - or when he or she thinks there is a clinical need.

<p>| | | |</p>
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<tbody>
<tr>
<td>3</td>
<td>Bleomycin</td>
<td>IF dose ( \geq 400 ) units/m(^2)</td>
</tr>
<tr>
<td>4</td>
<td>Bleomycin</td>
<td>IF received chest irradiation</td>
</tr>
<tr>
<td>5</td>
<td>Bleomycin</td>
<td>IF received Busulfan, BCNU or CCNU</td>
</tr>
</tbody>
</table>

In the patient ontology the patient’s attributes like ‘age at time of treatment’, ‘isoverweight’ and are represented as datatype properties (around 50 datatype properties). We converted our text rules from the database into SWRL rules to be used for reasoning. All the SWRL rules have a consequent part as these suggestions and the antecedent as the decision points from the above database. The following are some of the SWRL rules which are for the patient who is taking Bleomycin drug.

- Patient(?x) \( \land \) isTaking(?x, Bleomycin) \( \land \) hasAge(?x, ?z) \( \land \) swrlb:greaterThan(?z, 10) \( \land \) drugDose(?x, ?w) \( \land \) swrlb:lessThan(?w, 400) \( \rightarrow \) askTheDoctor(?x, D-1).
- Patient(?x) \( \land \) isTaking(?x, Bleomycin) \( \land \) hasAge(?x, ?y) \( \land \) swrlb:lessThan(?y, 10) \( \rightarrow \) askTheDoctor(?x, D-2) \( \land \) askTheDoctor(?x, D-1) \( \land \) askTheDoctor(?x, D-3).
- Patient(?x) \( \land \) isTaking(?x, Bleomycin) \( \land \) drugDose(?x, ?y) \( \land \) swrlb:lessThan(?y, 500) \( \rightarrow \) askTheDoctor(?x, D-1).

As you see in the above rules, the Antecedent part (before implication) are the conditions to be satisfied about the patient and the consequent part (after implication) are the recommendations. For example consider the first rule from the above listed rules. The patient is taking Bleomycin, has age greater than 10 and has a drug dose less than four hundred then the rule is fired giving out the recommendation D-1. We are maintaining a text file where we have mapped D-1 to D-142 to the actual recommendation sentences. We will retrieve these sentences from the text file when needed. Based on the patient’s treatment data and their details rules are fired. We can find similarities between two or more patients by querying the ontology. For example we can find the patients who are currently logged in the virtual and taking the drug Carboplatin. We are using pellet reasoner along with Jena to query the SWRL rules. The recommendations which will result from the querying of SWRL rules are added to event heap server in the form of events.

### 3.2 Virtual World

The YouCan-World we have created is built using Open Wonderland, a framework for creating collaborative virtual environments. We have built an environment based on the ‘Meeting Complex’ world, which is a standard template provided by Open Wonderland. We have modified it by inserting models of buildings for different purposes and objects like tables and sofas for patients to sit and have a
conversation. Open Wonderland provides support at the user level for sharing websites, images, videos and documents for collaborative viewing or editing, as well as support for asynchronous communication by leaving notes, and for communicating in real-time with others using voice or text chat.

Open Wonderland is a module based system which allows new modules with additional features to be added as necessary. Open Wonderland modules exist for many purposes, including connecting sensor inputs to control events in the virtual world and for connecting with standard video-conference tools. We used this feature of the wonderland framework to build our system by developing custom modules which serve our objective of supporting young cancer patients.

4 WORKING SCENARIOS OF OUR APPLICATION

In the YouCan-world we have displayed messages for helping the patient to have a good and beneficial experience. Figure 2 shows an example of the messages that are displayed in the YouCan-world. Our reasoning engine can assess the patient information upon login and then provide a customized message to a patient. For example, we can suggest activities for the patient to engage in while in the world. We have created several places where relevant PDFs and other content is placed. Content that is specifically relevant to the patient can be dynamically placed in the world by the reasoning engine via a TwinSpace module called the DisplayEffector. We have also created a mock-up of a chemotherapy room (Figure 4), which contains 3-D models of chemotherapy equipment as well as educational materials about the procedure. This room can be explored by individuals or used by a healthcare practitioner to discuss and illustrate the procedure to one or more patients. We also provide a dedicated “movie room” in the world (Figure 5), which can be used to present educational videos or recorded messages from health specialists directed at individual patients or groups of patients. We have seating arrangements for patients in the world where they can have conversations with each other (see Figure 3).
Figure 2  A Patient has just logged into the YouCan-World sees the message in front of him.

Figure 3  Patients having interaction in the YouCan-world.
Figure 4 A patient is reading a pdf on eating hints for cancer patients.

Figure 5 Movie room where patients are watching an educational lecture from the doctor.
Figure 6 A patient standing in chemotherapy room.

Figure 7 A window pops at right-top corner displaying suggestions.
We are currently working on the functionalities of displaying suggestions and identifying commonalities between patients. Consider a scenario where “Steve” logs into the virtual world. When Steve enters the virtual world, he will see several messages displayed in the virtual world to help him to navigate in the virtual world. When he enters different spaces in the virtual world, recommendations will appear in a custom window (see Figure 7). For example, the recommendations window will help Steve when he meets doctors or specialists in the virtual world, by suggesting questions to ask regarding his treatment. The other scenario of our application on which we are working is that when 2 or more patients are present in the virtual world. If Steve and Mark are present in the virtual world, then when Mark’s avatar comes within a certain range of Steve’s avatar, the similarities between Steve and Mark in terms of their treatments or even interests are displayed on their screens. The intention is to help them to identify commonalities and to have fruitful interactions with each other. They can share their views and experiences about the treatment or ask questions about it.

5 Future Work

In future we will be evaluating our system by conducting two focus groups, one of around 5 to 10 people who are experts in oncology, and another group that match the target demographic of users. We have not decided yet the exact structure of our focus groups but we have some questions or factors to be considered. The questions will be more about usability and effectiveness of our system. The factors on which we will focus on are relevancy of the documents and the information displayed in the virtual world, how useful displaying the commonalities will prove to patients, what type and amount of content should be there in the virtual world, what more functionalities must be added or improvement should be done. Depending upon the feedback from the experts, we will update our system to make it more suitable for young cancer patients.

We also intend to build on the capabilities of the TwinSpace infrastructure to facilitate a broader range of usage scenarios. For example, we can combine the physical bricks-and-mortar treatment centers with the virtual world support systems. This will enable patients who are far away from the actual health care center to connect through the virtual world. In prior work TwinSpace was used to “fuse” an office working environment with a virtual workspace to allow remote and local people to collaborate together without needing to stay focused on a video-conference screen [11]. We believe this offers interesting possibilities for allowing bedridden or remote patients remain connected with a support group, for example.

Consider the scenario where 5 to 6 patients are having a conversation in a physical support group. Combining the physical world with the virtual world will allow remote patients to enter the conversation through the virtual world. In this scenario mapping of physical and virtual spaces can be done by using the reasoning of mapping rules. A seating area in the virtual world can be mapped to a seating area in the physical center to facilitate conversation – in this case a display in the physical room would show the virtual seating area, and a video feed of the physical room would be set up in the virtual space. If the group later moves to a chemotherapy room to discuss a treatment, participants in the virtual world could move to the virtual chemotherapy room. Through mapping rules, interactions with physical chemotherapy
equipment can be manifested in the 3-D models. An audio link will keep the physical and remote groups connected in the chemotherapy room.

As previously mentioned, TwinSpace also provides support for a range of input and output technologies. This can support alternative immersive approaches to treatment-based education as explored by Becker and Pentland [3], but can also provide alternative input modalities to support bedridden patients, or patients undergoing aggressive treatments. This creates a “level playing field” for accessing the virtual world and may extend the benefits of psychosocial support into more difficult phases of treatment and care.

6 CONCLUSION

In this paper we have proposed a personalized virtual world—i.e. YouCan-world—targeting psychosocial support for young cancer patients through the provision of personalized care recommendations and messages. YouCan World is still being developed as we plan to add additional functionalities to it. We plan a pilot study to get user feedback regarding the design and interactions offered to patients. Based on the feedback of the pilot study we will improve and finalize YouCan-World, following which we will evaluate it for usability and assess its impact on improving the isolation faced by youth cancer patients and its educational value. We believe that YouCan-world can potentially help patients to solve their concerns by interacting and discussing their psychosocial concerns with other patients and doctors or by going through educational materials in the world.

7 REFERENCES


