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USER INVOLVEMENT OF PATIENTS WITH EATING DISORDER – THE DESIGN PROCESS FROM USER NEEDS TO PROTOTYPE

First Author Name, Second Author Name

Institute of Problem Solving, XYZ University, My Street, MyTown, MyCountry
f_author@ips.xyz.edu, s_author@ips.xyz.edu

Third Author Name

Department of Computing, Main University, MySecondTown, MyCountry
t_author@xy.mu.edu

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Abstract: The aim of this work was to investigate different methods for involving patients with eating disorders in the design process. According to the specific needs of this group of patients four main design goals were set up for the system. These were: Providing an artificial case manager able of answering questions and of interacting with the patient; Increasing motivation to get well; Providing distraction from the disease; Providing an appealing environment that the patients find interesting enough to use for a longer period of time. To meet these requirements several methods for involving end-users were used including “Cultural Probes”, “Repertory Grid Technique” and ”Wizard of Oz”. This paper describes our experiences of using these methods when developing a system for patients with eating disorders. The methods and the tasks used in the different studies also turned out to be a distraction away from the disease, which shows the potential of making the development process a part of the actual usage. The patients’ enthusiasm regarding the tasks in the studies also showed the importance of using methods suitable with respect to the symptoms of the disease and tasks that the specific group of patients find interesting and meaningful.

1 INTRODUCTION

There is a great need for treatment of eating disorders with lasting effects. For a long period of time the recovery rate among patients has been low. For example, a patient with anorexia has less than 50 percent chance of recovery within 10 years (Södersten, Bergh & Zandian, 2006). Eating disorders are also quite common, The National Institute of Mental Health (NIMH) estimates that 5 to 10% of the U.S. population has an eating disorder of one sort or another. In addition to the suffering on a personal level, the existing treatments are very time consuming and expensive. These patients suffer from a disease that has taken over their entire life, and all their daily activities are centred on eating and

dieting. They are also ambiguous towards getting cured since they have strong fear of gaining weight. The fear leads to a constant desire to have certain questions answered in terms of assurances related to weight and eating. This need of assurance and information could be provided for in new complementary ways, in addition to traditional treatment. The use of computers and the Internet along with traditional treatment is a growing phenomenon that could provide extended help to people suffering from different psychological disorders. These electronic environments could also provide complementary benefits in terms of giving the patients help and information around the clock every day of the week. They could also contribute with pleasant experiences in terms of providing rich

and enjoyable design that the patients could explore or find distraction within.

Computer supported treatment has previously been used within, for example, cognitive therapy (Klingberg et al., 2002; Carlbring, 2004). One further way to extend this therapy and to provide treatment can be through the use of rich interactive environments inspired by applications related to entertainment, such as computer games. These environments consist of, for example, 3D-animations and artificial characters. Artificial characters can also have motivational effects since they create a sense of confidence (Berry et al., 2004; Coyle & Matthews, 2004). DeRosis et al. (2005) have explored the use of artificial characters within the domain of eating disorders. Their system consists of an artificial counsellor that through a dialogue with patients gives advice about healthy eating habits. However, their efforts have mostly been geared towards creating an emotional presentation of information in order to increase the sense of believability in the artificial character.

The work described in this article has been a co-operation between a research institute for computer science (SICS, Swedish Institute of Computer Science) and a clinic that treats patients suffering from eating disorders (the Mandometer clinic in Stockholm). The aim has been to develop an interactive environment for patients with eating disorders. The interactive environment and the functionalities are based on the treatment at AB Mando. This treatment has its main focus on re-educating patients how to eat properly and on motivational talks held on a regular basis with a personal case manager. The method has been successful and the probability of recovering at the clinic is 75% (Bergh et al., 2002).

The purpose of this work has been to develop a prototype that could be a part of treatment of eating disorders. The design was based on a 3D-environment consisting of artificial characters. The game-like approach was chosen since we wanted to make the environment appealing to the intended user group. If a system like this should be useful it is important that the patients find motivation and joy in using it and return to it on a regular basis.

From a research perspective the aim with the system developed was to investigate how interactive environments like this could be used in the treatment of eating disorders, and how an interactive environment and the use of artificial characters could be used with the aim to answer questions about a disease, contribute to distraction away from the disease and to enhance motivation to get well.

Another aim with this work was to explore how to apply methods for user-centred design in situations where the user group is suffering from a

disease affecting their participation in the process. User-centred design is well established, however, the methods had to be adjusted, and other methods had to be used as well, when designing for user groups with disease related behaviours. Certain demands are placed on the methods used, for example, it is important to use methods that the patients find interesting when lack of motivation is a part of the disease.

2 DESIGN GOALS

Based on the specific needs of patients with eating disorders four main goals were set up for the system.

During the entire process the design goals were taken into consideration to ensure that they were met by the final version of the prototype.

1) *Providing an artificial case manager:* The most important aspect of the system was that it should contain an artificial case manager able to answer questions in a trustworthy way. Since the patients have constant worries about their weight and what they should eat it was also important that the case manager could disrupt ruminating questions and thinking.

2) *Increasing motivation:* Motivational aspects could further be affected by mixed feelings towards getting well due to the unfounded fear of the patients that getting well also will mean that they will become fat. The use of computers could, due to illness, also be affected by the decreased motivation to participate in different every-day tasks. The challenges for a system like this were to both find ways to motivate the patients to use the system, and to include aspects and functionalities that within themselves could provide an overall motivation to fight the disease, to get well and to look at life in more positive way.

3) *Providing distraction:* The life for this group of patients has become very narrow due to the disease and everything has become focused around eating and dieting. One way of supporting these patients is to provide them with tasks and things to do that serves as distraction away from thoughts related to the disease. The challenge related to this design goal was to find functionalities to include in the system that the patients found interesting enough to actually serve the purpose of distraction.

4) *Providing an appealing environment:* In order to make a system like this capable of providing support and actually work as a complement to the treatment it will, of course, be crucial that the patients find the system appealing and that they use

it repeatedly over a period of time. To meet this goal with this group of patients, mainly young girls with reduced motivation, the environment has to be entertaining and fun to be in and to use. The environment should therefore have traits similar to other interactive environments that these patients normally use, such as games and on-line communities.

3 DESIGN PROCESS

The need for supporting the treatment through an interactive environment and the problem description that served as a starting point for this work were given in a broad sense. The design challenges consisted of narrowing this down to functionalities and design demands that actually could be implemented, but at the same time meet all the design goals mentioned earlier. One aim with this work was to investigate and study a set of methods, which situations to apply them in and how; and also how these methods should be applied with respect to this particular user group. Based on the design goals an iterative design process was conducted, and the entire work was conducted in close cooperation with the patients that also provided us with feedback on the methods that we used. The design methods used in the project included or was inspired by: Cultural probes (Gaver et al., 1999), Repertory Grid Technique (Fallman & Waterworth, 2005) and Wizard of Oz (Dahlbäck, Jönsson, & Ahrenberg, 1993).

3.1 Investigating user needs by the use of Cultural probes

The design goals of providing functionalities that could provide motivation and distraction in an appealing environment were addressed by a study using the method “Cultural Probes” (Gaver et al., 1999). With this method the participants are given probe packages with items encouraging them to be creative and playful when solving tasks in a self-reporting manner. This is an engaging method to involve users in the design process in areas where it can be difficult to research by other means. We chose this method since it would capture issues in the patients’ lives that are positive and that will contribute to their recovery. In contrast using for example observations, would have given us documentation describing their current situation where they were still struggling with the disease, with lack of social life and still suffering from all the behaviour related to the disease.

Seven females patients participated in the study. The patients were selected on the criterion of getting a mixed group of patients from the clinic and that the patients should be in-care patients or frequent day-care visitors.

In the study the patients got a cardboard box wrapped as a present. The box contained a disposal camera, a blank diary, a glue stick, a pair of scissors, a set of colour pens, pens, pencils, stickers, a newspaper and a magazine (see figure 1).



Figure 1: The material in the box

The patients were given one task every day for four days, which was handed to them by their case manager at the clinic. During the study, we changed the cameras and gave the patients previously taken photographs back printed on paper.

The tasks that the patients got during the four days were:

- Day 1: “Use the camera to get pictures of, and the diary to describe things you enjoy or find distracting.”
- Day 2: “Use the camera to get pictures of, and the diary to describe things you miss or long for.”
- Day 3: “Use the camera to get pictures of, and the diary to describe things making you fight the disease.”
- Day 4: “Choose some of your previously taken pictures and paste them in the diary where you think they best illustrate your previously written text and possibly add some comments.”

In order to solve the tasks the patients were encouraged to fill the diary by using the material in the cardboard box and also to take pictures with the cameras. The patients were encouraged to solve the tasks in their own personal way. The only obligation was to paste the note describing the task of the day as a headline, on a blank sheet in the diary and to take at least five pictures with the camera to illustrate the headline.

The patients had devoted large amounts of time on the tasks and their diaries contained many creative and colourful entries describing important issues in their lives. The most frequently mentioned

items in the diaries, regardless of task, were the family, friends, travelling, reading, sports, pets, health and music.

Based on the results from the Cultural Probes study a brainstorming session was held. The aim with this session was to develop a number of design suggestions for different functionalities that could meet the design goals in terms of providing motivation for recovery and distraction away from the disease. However, it should be pointed out that this method aims to capture the participants' subjective experience of different issues and situations, which in turn provide input to design of artefacts and interfaces.

Many ideas came up during the brainstorming and only a few of them could be described or implemented. One idea that was kept all the way into the final version of the prototype was the need for having more than one character. The diversity of the design goals, in terms of providing answers and convey trust, enhance motivation to get well and to provide distraction away from thoughts related to the disease, made it impossible to incorporate all these in one character or functionality.

3.2 Appearance of the characters and the use of the method RGT

To meet the design goals of provide a trustworthy artificial case manager, and appealing artificial characters for motivation and distraction a method inspired by "Repertory Grid Technique" (Fallman & Waterworth, 2005) was used. The method is based on a selective process where different types are compared and described according to their similarities and dissimilarities. This method was chosen since it provided the opportunity for the patients to describe their subjective experiences regarding how they perceived the characters.

As a starting point we produced a wide range of different types of drawn characters to test on the patients. A professional illustrator produced the characters as black and white hand-drawn sketches.

Five patients were shown 24 characters, divided into four categories, three categories of human-like characters (women over the age of 30, women 20-30 years old and men over the age of 60), and one category of animal-like characters. Beside asking the patients to describe the characters, the patients were asked to rate how much they liked each character (scale 1-9), and to which extent they would prefer talking to the character (scale 1-3).

The results regarding the human-like female characters women over the age of 30 seemed to be

most appealing. However, the characters of this category were getting the lowest score on "the want to talk to rating". Thus, it seemed as even though the patients fancied the characters visualised as women over 30 years of age, they preferred to talk to the younger ones between 20 and 30 years of age.

This results was also supported in the discussion with the patients, and the conclusion was that a good artificial case manager should not be too young (over 30 years of age), which would guarantee experience and knowledge, but look as up-to-date as the younger category (women between 20 and 30 years of age), which would guarantee that you would like to talk to her about anything. The best-liked women from the case manager categories are presented in figure 2.

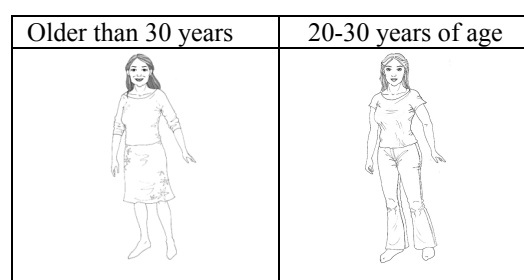


Figure 2: Best liked case manager characters

The comments regarding the category of older men (category 3) were that they seemed friendly. They were ascribed traits and discussed in terms of being nice, wise and as interesting storytellers. The most popular man is presented in figure 3. The group of elder men seemed about equally popular as potential talking partners ($m=1.8$) as the group of women over 30 years of age.

The animal-like characters (category 4) were the most popular category in the study ($m=7.2$). To meet the design goal of providing distraction, it was important to create a character that the patients fancied and enjoyed to interact with, otherwise it would not provide the intended distraction. The most popular individual of all categories was the sheep (see figure 3)

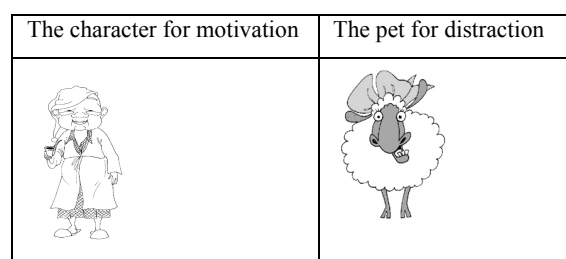


Figure 3: The characters for motivation and distraction

3.3 Developing the dialogue for the artificial case manager using WoZ

To meet the design goal of providing an artificial character that could provide trustworthy answers to the patients questions the Wizard of Oz (WoZ) method was used. It is a method used to test device design and techniques and functionality before it is implemented in a system (e.g. Dahlbäck, Jönsson & Ahrenberg, 1993). The method is based on using a human to simulate the response of a system. The "wizard" sits in a back room and simulates the system's responses to the user.

Based on the WoZ method we wanted to collect material to a database in terms of frequently asked questions as well as examples of how patients would be expressing themselves when "chatting" to an artificial case manager. Based on ethical reasons we informed the patients prior to the WoZ session that the replies were not automatically delivered by the computer but written by a real case manager sitting in another room. However, neither patient nor case manager were informed about the other persons identity.

Sixteen patients were participating, 2 males and 14 females. The patients were told to ask anything they wanted by writing freely phrased questions in a "chat window". They were also asked to imagine that they were talking to the artificial case manager seen on the computer screen. Further, they were informed that the questions would be saved in a log-file to be used in the design of a dialogue system for clinical use. No time limits were set for the session.

After the session the patient was interviewed. In the interviews, the patients expressed their appreciation of being able to ask questions anonymously. They felt that this fact made it easier for them to ask about things they considered being embarrassing and private.

The case managers acting like wizards were also asked about their opinions. Everyone had enjoyed this new way of communicating with the patients. Several had experienced the patients as being more attentive and interested than during regular eye-to-eye talks. They also thought it was useful for the patients to be able to "hear" similar instructions and exhortations from somebody else than their "own" case manager.

4 THE FINAL VERSION OF THE PROTOTYPE

As mentioned, the results from the Repertory Grid study showed that the patients wanted the case

manager to combine features from the two categories of female characters. That is, a woman with an age over 30 years of age but with a trendy look. Based on this the illustrator draw a new selection of case managers, looking young enough for enabling the patients to identify themselves, but not too young since it was important to give the impression of being trustworthy and resolute. From this new selection the patients preferred the character shown in figure 4.



Figure 4: The most preferred character

Based on this version of the case manager character, a 3D-model was developed. However, due to limitations, both related to the used software and to limited resources, some simplifications had to be made. The 3D-model was also discussed several times with patients at the clinic and the appearance was changed according to their suggestions. The final version of the artificial 3D case manager is presented in figure 5A. The character with the function of a case manager was placed in the living room of an apartment.

Based on the design goals regarding developing an appealing environment and due to the patients frequent reluctance against hospital environments and medical clinics a 3D-environment looking like an apartment was developed, see figure 5B. The apartment consisted of two rooms, a hall and a balcony.

The diversity of the design goals, in terms of providing answers and convey trust, enhance motivation to get well and to provide distraction away from thoughts related to the disease made it, as mentioned, necessary to include several characters within the system, each of them with functionalities meeting some of the design goals, but not all of them.

Beside the case manager a character for providing motivation was realised by a character looking like an old wise man. The man, who was placed on the balcony delivered encouraging quotations when clicking on him, see figure 5C. The aim was that the character should say thoughtful things about life that gives hope and encourages people look at their lives in a positive way. The quotations were selected by a group of users that

ranked 40 aphorisms on a scale. The 23 most liked aphorisms were chosen as material for the character.

The design goal set up to enhance the patients' distraction also was included in the system. It was a pet that had been designed based on the users suggestions, and it had the appearance of a sheep. It was kept in an enclosure of glass looking like an aquarium to make the users curious, see figure 5D. The pet had the function of a small game where the user could take care of and play with the sheep. During the work with this part of the system, the patients were very engaged and came with many suggestions. Some of these were implemented in a sub-application.

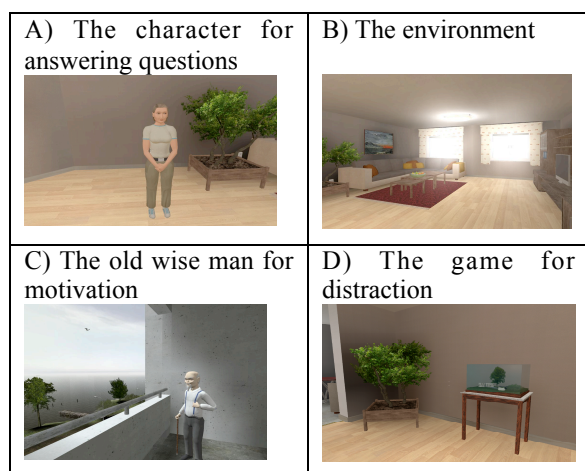


Figure 5: The final version of the prototype

5 USER FEEDBACK OF THE PROTOTYPE

A user feedback study was conducted at AB Mando during three weeks of time. During this phase the patients had free access to computers located at the clinic. The only criterion for inclusion in the study was that the patient should visit the clinic frequently (everyday or at least almost everyday) during the weeks for the study.

Six patients participated in the study, they were all young women and their average age was 17 years. Before the study started the patients were given instructions to use the prototype at least twice a week during the test phase, and also to write down comments about the prototype while they were using it. After the three weeks test phase, the patients was interviewed and the data from the log-files were analysed.

5.1 Usage and overall opinions

The overall attitudes during the interviews were positive. All patients in the evaluation thought that the prototype was easy to use and that it worked well without technical problems.

All patients in the evaluation, except for one, said that they would like to have access to the system on a permanent basis. They also wanted to have access to the system both at the clinic and at home. However, the purpose with the usage would be different depending on location. At the clinic the main purpose would be for distraction, but on the other hand at home the system would be used for asking questions to the artificial case manager.

5.2 The artificial case manager and the dialogue system

None of the patients in the evaluation made any judgements regarding the artificial case manager's appearance since they had not paid these aspects that much attention. However, during the interviews, it was pointed out that the visualisation of the artificial case manager was important since it would have been boring to just get answers delivered in a textbox.

With respect to the dialogue system and its capacity to provide correct answers to the patients' questions, there was a hit rate of .35. Of the .65 answers that were wrong .19 was explained by the fact that the question did not exist in the database and .46 was explained by failure to interpret the question.

Regarding the content of the answers, the patients thought that they had an appropriate length and that they consisted of much relevant information. However, it was also mentioned that the answers sometimes were too medical and too general. The patients thought that the dialogue lacked the possibility to talk in a deeper way of feelings and emotions, and that the system/dialogue should provide comfort when feeling sad.

5.3 Motivation and distraction

The two other characters within the application, the sheep and the old wise man, were included in the system to provide distraction and motivation. The patients in the evaluation liked the appearance of both these characters.

The old wise man that provided the patients with quotations for motivation was, for some of the patients, difficult to find since he was located at the balcony. However, the things he delivered/said was

very much liked by the patients, even though the number of quotations was found to be too low. This was not surprising as the aim of the work was not to deliver large amounts of content to the system.

When trying to provide distraction it is important that the content of the application is well suited for the particular target group. This sub-application and the appearance of the character were developed in close cooperation with the patients. As a result of this, the patients also liked the character and found the sub-application enjoyable to use. The interaction with the sheep-game provided distraction as far as the limited amount of content could do.

The 3D-environment that was developed for the final version of the prototype had been redesigned extensively to convey a feeling of a home environment. All patients in the evaluation found the environment attractive, however they thought that it could be more colourful and that it should have more soft decorations such as pillows and blankets.

6 DISCUSSION AND GENERAL CONCLUSIONS

6.1 Achievement of the design goals

Providing an artificial case manager: The most important aspect of the system was that it should contain an artificial case manager able to answer questions in a trustworthy way. With respect to this design goal we reached quite far, even if the systems dialogue section needs to be adjusted and improved. The patients trusted the answers even though they thought they, to some extent, were too medical and lacked emotions.

Increasing motivation: The design goal of enhancing the patients' motivation could both be long-term and short-term. The only aspect that was possible to investigate, at this stage, was short-term motivation and whether the character of an old wise man could make the patients look at life in a little more positive way for a short while when talking to him. However, the patients actually liked the things this character said and they felt encouraged and strengthened by his words of wisdom.

Providing distraction The design goal related to this aspect was to find interesting functionalities to include in the system. The functionalities had to be interesting enough to actually serve the purpose of distraction. For this design goal it was extremely important to take the profile of the user group into consideration. The sheep-game and the appearance of the character were developed in close cooperation

with the patients. As a result of this the patients also liked the character and found the sub-application enjoyable to use, even though it was not possible to provide a large amount of content within the framework of this project.

Providing an appealing environment: Within this work, much effort had been placed on actually finding functionalities and traits that are appreciated and liked by this user group. The work with the patients also provided much input about further functionalities to include in the system. The design goal of providing an appealing environment must be considered to be met to a quite great extent. The patients overall positive judgements about the system and its functionalities and the patients comments about wanting to have access to a system like this in their every-day life support this conclusion.

6.2 The use of different methods for investigating user needs

The first method we applied was based the use of "Cultural Probes" (Gaver et al., 1999). This method was selected to capture input to the design goals related to finding functionalities that would enhance the patients' motivation to fight the disease and to find things to do for the patients that could provide distraction from thoughts related to the disease. By asking the patients to describe good things in life and things they long for, instead of observing their present life or behaviour the material from this study could be used as positive input to the design process. Within this study the patients found the study tasks themselves also entertaining and therefore they also provided distraction away from the disease. One explanation to why this study worked so well even though that this group of patients normally lack the ability to engage in tasks not related to food intake might be that very clear instructions were given to the patients. These instructions made the tasks creative but they also provided enough information for the patients so that they could conduct the tasks without being affected by the disease related difficulties in engaging in new activities that demands a large amount of initiative from the individual.

The second study that investigated the appearance of the characters was conducted in a way that was inspired by the "Repertory Grid Technique" (Fallman & Waterworth, 2005). This method was chosen with the aim of letting the patients describe their own subjective way of perceiving the appearances and the different traits of the characters. Since the things to be described were humans or characters of different kinds a variety of

interpretations could be made, therefore an open method seemed to be a relevant choice. However, in our case it also turned out that this complexity contributed to difficulties in using the method. When asking people to group something complex as humans a more detailed instruction about what the grouping should be based on is needed, otherwise there is risk that the characters will be grouped or described upon very simple traits related to looks such as hair colour or hair style.

The WoZ method was appropriate to use for the purpose of gather dialogue. Besides providing material for the database, this study also showed the need among the patients for being able to ask questions anonymously. Despite the ethical considerations that made us reveal to the patients that there was a human on the other side, the study worked well and the patients forgot that they did not interact with a system or, at least, did not bother by this fact.

6.3 The prototype – lessons learnt for future development

It is important to state that the aim with this work only was to develop a prototype and to investigate different methods for user involvement. The knowledge gathered during this work was intended to serve as a starting point for the next phase of developing a system for patients with eating disorders.

One of the most important results regarding design of environments like this was the patients' opinion about the 3D-design/interface. The patients pointed out the importance of colours and homelike environments since several of them had spent time at hospitals against their own will. Further, the studies showed that it is important that when using an artificial character to answer questions as a complement to the treatment for this group of patients the character has to have an appearance and an age that conveys trust but also that it is young and modern enough to be someone that the patients feel that they would like to talk to. Finally, the positive results regarding the patients enthusiasm for the Cultural Probes study, the idea of using the development process as a direct means to an end (in our case as part of the treatment) would also be an aspect well worth investigating further.

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