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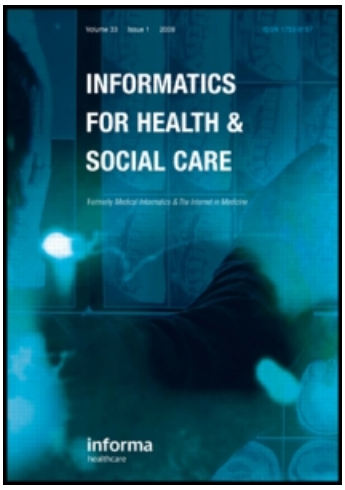

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Design and development process of patient-centered computer-based support system for patients with schizophrenia spectrum psychosis

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Design and development process of patient-centered computer-based support system for patients with schizophrenia spectrum psychosis

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Abstract

Background. Schizophrenia is a serious mental illness requiring self-management skills and information about the illness, its treatment, and where to get help with daily routines. Despite the systematic development of computer-based approaches in mental health, less systematic development of such methods can be found for patients with schizophrenia or psychosis.

Objective. The aim is to describe the design and development process of patient-centered computer-based support system (Mieli.Net portal) for patients with schizophrenia spectrum psychoses.

Methods. The process with a mixed methods approach includes four phases: analysis of users' needs, development of key patient information areas, development of a software prototype and to pilot the portal, and user evaluation by health care staff.

Results. The computer-based patient support system is a promising health-promoting service to schizophrenic patients. It is important, that users of technology are involved in the development process, which will ensure that sites are user-friendly, information can be personalized, and mental patients' voices are heard in the development of patient education.

Conclusions. The effectiveness needs to be evaluated carefully in future clinical trials. This will offer valuable information for policymakers, organizations and health care practitioners about the usability of web-based patient education in the area of mental health care.

Keywords: *Development process, computer, support system, schizophrenia, mixed methods approach*

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1. Introduction

Schizophrenia is among the most severe mental disorders [1]. Its prevalence is approximately 1% throughout the world [1] and in population terms, around 24 million people suffer from schizophrenia worldwide [2]. Schizophrenia is characterized by profound disruptions in thinking, affecting language, perception and sense of self. It may include psychotic experiences such as hearing voices or delusions. Schizophrenia can impair functioning through the loss of an acquired capability to earn one's own livelihood or the disruption of studies [2]. Defects in cognitive functioning such as problem-solving ability, explicit memory, knowledge and general intellectual capacities have been mentioned [3,4]. Other demanding issues are patient complaint [5], relapses [6], lack of insight [7] or non-compliance with treatment [8,9]. Due to their illness patients also suffer from isolation and loneliness [7,10,11]. Among patients with schizophrenia the risk of suicide is 5 to 9 times higher than in normal population [12,13]. Patients' willingness to follow through with their treatment plans is related to their perception and understanding of their illness [14].

Atypical antipsychotic agents have been found to be effective in the treatment of patients with schizophrenia and related psychoses [15]. Through guidelines and textbooks, most patients with schizophrenia benefit from the combined use of antipsychotic drugs and psychosocial treatment [16,17]. In addition to medication and cognitive behavioral therapy [18], patients and their families should be educated about schizophrenia [16]. Patient education has been found to be an effective way to increase patients' understanding of their mental health problems [19,20], ability to cope more effectively in daily lives, compliance in treatment, and reduction of relapse or readmission rates [21]. It may also help people to evaluate their mood, self-esteem and negative beliefs about themselves and others, which are to be considered when designing interventions [22]. Further, those clinical interventions that foster appraisals of recovery may improve emotional well-being in people with psychoses [23].

In the past 20 years there has been a growing tendency for treatments that support social relations of everyday life through information technology [24,25]. Researchers have examined the role of computers in improving patients' understanding of their illness and its treatment [25,26]. Moreover, many Internet users have also turned to the web to provide the information they need because of the fear of stigmatization [27,28]. Recent studies have reported that the Internet has shown promise in patient education when diverse illustration is needed [29]. Websites seem to be a practical and promising intervention for preventing mental health problems such as depression and anxiety in the general public. Randomized controlled trials in computerized interventions showed that computer-delivered interventions resulted in improvement in depression, anxiety, work, social adjustment or general psychopathology [30,31]. However, the reliability of the health information is a concern: the content of information varies and many health-related sites lack scientific evidence and references [32,33].

Despite the systematic development of computer-based approaches in mental health services, less systematic development of such methods can be found for patients with schizophrenia or psychosis [26,34,35]. Computer-based methods used by patient groups who show poor compliance have received less attention even if they are able to recruit patients and maintain their participation [34]. Information is formatted based on the target audience, so that information is easy to understand and help patients to better understand their sickness [36]. Throughout the design and development process it has been of great importance that the content is understandable and navigable and provides an alternative description for an image object [37]. In addition, the national view should take account of the usefulness of services; approximately 86% of the web pages produced are in English [38].

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Finnish is a very rare language, with about 6 million speakers in the world [39] and a part of population of Finland is not able to use English. Thus, it was necessary to develop computer-based support systems in the field of mental health for Finnish language users. Furthermore, to guarantee a patient-centered development process, both patients and patient advisory groups should be actively engaged in the design and development process. The aim of this article is to describe the design and development process of a patient-centered computer-based support system for patients with schizophrenia spectrum psychoses

2. Methods

2.1. The development process of the computer-based support system

Our goal was to create computer-based self-management system for patients with schizophrenia spectrum psychosis. The main principles in the development of information technology application were patient-centered, health-oriented, supportive self-care abilities and self-management and being independent of time and place. It aimed to support practice improvement initiatives by offering a basis for patient education and online support, which are seen as a useful approach to coping with the alienation and isolation of patients with schizophrenia [40]. It aims to support self-management among patients with chronic illness by offering: (1) evidence-based, easily understandable, clear and organized information for patients on their illness, its treatment, the daily and social support available, and information about patients' rights; (2) a channel for peer support for patients; (3) a tool for counseling; and (4) interaction between clients and staff by means of a question-and-answer column. Nurses have also an opportunity to use the support system to update their knowledge of schizophrenia spectrum psychoses and their treatment.

The development process of the support system aimed to offer user-friendly services in the field of mental health services where patients and their carers may be inexperienced in using computers [41]. The process with a mixed methods approach [42] included four phases: (1) analysis of users' needs, (2) development of informational areas, (3) development of prototype, and (4) user evaluation. The development process of the user-friendly web based support system is described in Figure 1.

3. Results

3.1. Analysis of users' needs

The analysis of users' needs was conducted from different perspectives to develop the main key areas of interest in patient information: national analysis of the developmental areas in Finnish psychiatric hospitals; a 1-year patient satisfaction survey, and interviews with patients and relatives. Furthermore, a literature review was conducted.

First, a survey for administrative personnel was conducted in the year 2000 to ascertain the needs for development of patient education in Finnish psychiatric hospitals. It was sent to 55 psychiatric hospitals; 36 hospital organizations with 58 different wards participated in this survey. The analysis showed that patient information is a central intervention used in all the study hospitals. The most common method for information delivery for patients was oral information (100%), leaflets (84%) or videos (43%), and information technology applications were used less often (9%). In general, challenges in patient information were ensuring that patients' informational needs were satisfied (48%), clarity and intelligibility of the information (33%), and information received by patients' relatives and significant others (33%) [43].

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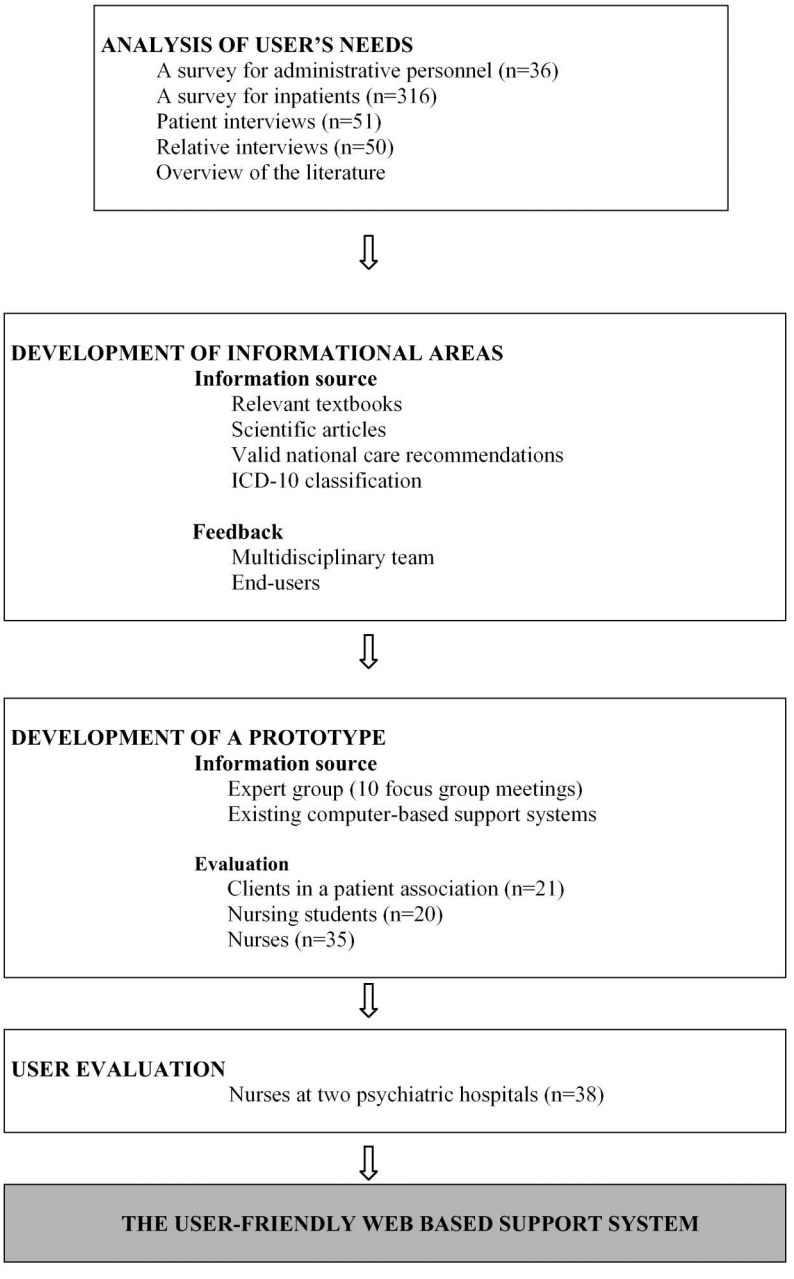

Figure 1. The development process of the user-friendly web-based support system.

Second, a survey of inpatients' satisfaction with care was conducted. The data were collected in inpatient settings using a self-rating patient satisfaction questionnaire. A total of 316 patients discharged from acute wards during a 1-year period were recruited to the study. Although in general patients were quite satisfied with their care, they reported most dissatisfaction in the areas of information, restrictions and compulsory care [44].

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Third, the interviews with patients were conducted to ascertain spheres of information rated important by patients, realization of information supply, and the methods through which patients wanted to access information. Patients also described the problems of information supply in their own words and offered suggestions for the development of successful information supply. Data were collected through interviews with patients ($n = 51$) using both structured and open-ended questions. The interviews showed that patients considered access to information about illness, care, patients' rights and different kinds of support to be important. They wanted to receive information in parallel ways through discussions with staff and other methods, such as leaflets, literature and the Internet. They also wanted to have different options for independent information seeking [45].

Fourth, 50 interviews with relatives were carried out to explore their informational needs, realization of information supply, and the methods through which relatives wanted to receive information. Relatives also described problems related to information supply and offered suggestions for the development of successful information supply. The results of this phase showed that relatives considered information provision important. They emphasized the meaning of receiving information related to the patient's illness, the different treatment methods, daily issues related to patient well-being, social security and social benefits. Patients' security issues and relatives' own rights were also important topics for relatives. They also wanted to have parallel options to receive information.

Finally, to ensure high-quality content of the information included in the support system, existing solutions at national and international levels were overviewed. A literature review concerning patients' needs for information and different solutions were described and analyzed to find the most effective and appropriate methods. The literature concerned patients' needs for access to information, realization of information supply and items related to patients' information supply.

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3.2. Development of informational areas

Based on the analysis of users' needs, five general informational areas were identified: illness, treatment, well-being, daily activities and patients' rights. Illness covered information about schizophrenia and related psychoses in general, its etiology, prognosis and symptoms. Treatment covered information about the treatment options available, treatments to be continued and rehabilitation options. Well-being covered different areas dealing with way of life such as nutrition, exercise, medications and sexuality. Daily activities included information about different types of support options which may be needed during hospitalization and afterwards. For example, they wanted knowledge about social benefits, opportunities to reorganize education, activities of voluntary organizations and different areas of interest. Patients' rights included information about patients' rights in general, focusing on patient status and rights. Further, it included information about the rights of patients in mental hospitals to be based on the Mental Health Act. Additional information was included about patient ombudsman and patients' rights to appeal about circumstances related to their treatment.

The content for the information areas was produced on the basis of a user needs analysis and using the ICD-10 classification [46], relevant textbooks, scientific articles and valid national care recommendations [47]. These were included because they exist in clinical care as care practices and concepts. In addition, the references were estimated to be reliable enough to use as resources for information content.

The next step was to evaluate and produce the text material developed for each content area. The multidisciplinary team consisted of nursing directors, psychiatrists, nursing

teachers, mental health nurses, researchers and experts in the field of technology. The members of the team had expertise in psychiatric adult care and psychosis. The goal of the multidisciplinary team was to allow multiple perspectives and minimize profession-specific biases. The team convened regularly during the development process and they were expected to give clinical experience to the development process. The evaluations were conducted by 10 focus group meetings during the process. In cases where the team noticed any problems or had concerns related to the content of the portal text, these were immediately rectified. Moreover, end-users in patient associations were actively involved in the development process and their feedback on the portal was systematically collected.

The material produced for the content was processed to be better suited for the computer-based support system. The same prepared material was once more processed by the expert groups. The result was sent for comments to the members of the expert group. The material was revised further according to the experts' comments. Further, health-oriented, patient-centered and community-based orientation was supported in the content of the text. The aim was to avoid traditional hospital-based treatment philosophy.

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3.3. Development and evaluation of a prototype

A prototype of the computer-based support system was developed on the basis of the recommendation of the health care experts, users and experts in the field of technology. At that point the outward appearance of the support system and its information structure were designed. The expert group helped to prepare the content and its structure to be most suitable for the target group.

The appearance of the computer-based support system was finalized with regard to the colours, text font size, pictures, links to other information sources and tool bars. Photos, voice clips, texts and Internet links were used to illustrate the content of the information keeping in mind the simplicity of its appearance. No moving pictures or diagrams were used to avoid disturbing patient concentration.

Every information area began with a scheme to show the user the specific content. The amount of text was kept to a minimum to keep the appearance of the page as clear as possible. This meant that one informational theme was presented on one portal page at a time; there were no rolling tool bars. Further, attention was paid to increasing the interactivity and usefulness of the system. Interaction between the users and developers was ensured by means of an online feedback system.

The content, structure, visual appearance and usability of a prototype of the computer-based support system were evaluated by clients in a patient association, nursing students and nurses. The data were collected using a questionnaire developed for the study. The viewpoint was usability evaluation [48] by looking at the content, structure and visual appearance of the portal. The content of the questionnaire was based on the quality criteria for health-related websites [49]. Altogether 36 items with a five-point scale (1 = totally agree, 2 = almost agree, 3 = no opinions, 4 = almost disagree, 5 = totally disagree) focused on the usability of the portal. Altogether 76 informants (20 nursing students, 35 nurses and 21 clients) were recruited to evaluate the preliminary version of the portal. The analysis showed that in general the portal was evaluated to be usable and reliable. The clients were more positively disposed to the portal than were the nurses. The visual realization of the portal was successful, while the content and structure needed further improvement. The results of the pilot study were used for the further development of the portal.

On the basis of the prototype evaluation some changes were made to the structure of the portal. Multimedia applications developed together with clients were integrated into the

support system. Applications included voices with clients' life stories, drawings and pictures. In addition, personal diary, peer-support, and eSupport systems were integrated into the system.

3.4. User evaluation

To ensure system usability from the nurses' perspective as well, we conducted a preliminary usability evaluation among nursing staff ($N = 76$, $n = 38$) working at two psychiatric hospitals in Finland. In this phase, the focus was health care professionals' opinions regarding the portal. The evaluation provided hints for the further development of the portal and for actual portal testing on patients with schizophrenia and psychosis. Before the evaluation process nurses were educated in small groups in computer, Internet and Mieli.Net portal use.

The data were collected using a questionnaire focusing on the quality of online services [50]. Out of five evaluation areas, this study focuses on the quality of the functionality, content and benefits of the portal. The qualitative part of the questionnaire included written feedback on each of the three assessment areas mentioned above by an electronic evaluation form in the portal. The nurses were quite satisfied with the structure of the portal and they reported that it was easy to use and that its layout was pleasant. However, some reported that the portal required advanced information technology skills. According to the nurses the content of the information was relevant: the Mieli.Net portal contains essential, interesting and well-defined information. The text was understandable and easy to read. Further, the portal was seen to be beneficial to users, while the possible problems concerned users' lack of experience in using this new application. On the other hand, the nurses were concerned about the possible negative affects of decreased face-to-face contact and its impact on delivery of care [51].

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4. Discussion

The aim of this article was to describe how to produce high-quality health information for websites for individuals with schizophrenia spectrum psychoses. Although the amount of online health resources has grown dramatically in the last few years, there is still a need to develop health information on the Internet. Usefulness and quality of information were the main focus of the development project. The result of the project will be considered from the perspective of its impact on health care and society, particularly the impact of information in supporting the inclusion and participation of people in the information society, and in decreasing stigmatization.

People with mental health problems are the target group of the project because they are a growing segment in society and are at high risk for new inequality and exclusion from society. These sites are being specially developed for people with schizophrenia, which is a serious mental illness related to cognitive impairment. Accessibility in the information society means taking into account the different needs of disabled people. This includes the design of equipment and services [52]. In addition, to facilitate usability and enhance the accessibility of the sites, they are in Finnish. To ensure usefulness in our development process we took users and experts in the field of technology to develop and evaluate the prototype.

The aim of the project was to produce adequate information to support information access for patients with schizophrenia. This enables people with mental health problems to participate in society as active citizens instead of as passive patients. Participation and

independent living requires that people have enough information on mental illness, care, patients' rights and where to get help with daily routines [53]. This is one step to enable full participation in health care and moreover in society. The system is being developed to offer current information to both patients and their relatives and significant others. The aim is to decrease negative preconceptions and even incorrect images of mental health problems and care. Raising the profile of mental health at all levels of society is expected to reduce stigmatization related to mental health problems [53]. Besides medication and cognitive behavioral therapy [18], patients and also their families should be educated about schizophrenia [16].

When producing the content of the computer-based support system, quality was a concern. People with mental health problems are especially vulnerable to the varying availability and quality of Internet health information [54] and many studies have revealed the poor quality of health-related websites [33,55]. The deficiencies in existing sites have been taken into account. Quality of information was assured in two ways. Content was produced by using information that is consistent with the best available evidence on mental health issues. In addition, the collaboration with expert groups was essential to ensure the quality and usability of the content.

This project was a part of developing user-friendly information technology in mental health care. Managing information offered to clients is not enough when considering ways to support citizen participation in society. There are still many aspects of concern in reducing social marginalization and promoting equality for those people who can easily be excluded from society. Consumers need guidance and tools to navigate and select from the growing array of eHealth resources available [28]. In addition, products and services must be affordable to ensure that lack of income does not exclude from participation [52]. There is still a gap in computer and Internet access among certain population groups when segmented by income, educational level, age and disability [56]. There is a need to expand the opportunities to use Internet-based services in health care including economic considerations. Mental health problems are a high cost illness in society [57]. Thus, new methods should be developed to provide services in a situation of dwindling health care resources. One solution is to develop new innovative information and communication technologies. All those new methods should be developed and tested that may have potential with patients to foster appraisals of recovery and improve emotional well-being in people with psychosis [23]. It is important, however, that users of technology are involved in the development process of the technology. This will ensure that sites are user-friendly, information can be personalized, and mental patients' voices are heard in the development of patient education.

To evaluate the impact and the future possibilities of technology in mental health care the system will be tested in practice and its cost-effectiveness will be evaluated. This will offer valuable information for policymakers, organizations and health care practitioners about the usability of web-based patient education in the area of mental health care.

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