

Chapter 56

Patient Centered Design: Challenges and Lessons Learned from Working with Health Professionals and Schizophrenic Patients in e-Therapy Contexts

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ABSTRACT

Patient-Centered Design (PCD) is a particular type of User-Centered Design (UCD), where the end-user is a patient that will use an Information and Communications Technology (ICT) solution for healthcare. It focuses on needs, wants, and skills of the product's primary user and implies involving end-users in the decision-making and development process of the solution. e-Therapy aims to provide support to therapy sessions through ICT solutions. It has grown in the last years, and in the mental health arena is being used for specific therapeutic contexts. It is an especially difficult environment due to specificities of the patients' conditions and the physical access to patients being restricted and, sometimes, not even possible. Thus, a PCD approach can be accomplished through the health professionals involved, applying some of the most well known methods of UCD: interviews, questionnaires, focus groups, and participatory design. eSchi is an e-Therapy tool that complements traditional practices for the cognitive rehabilitation and training of schizophrenic patients. It was successfully developed using a PCD approach.

INTRODUCTION

Any software solution should comply with two major traits: fulfill its functioning goals and, also, be usable by its end-users. Thus, it is mandatory to adopt software development techniques that

ensure a better outcome for both aspects. User Centered Design (UCD) is one of those techniques. Its practices focus mainly on needs, wants, and skills of the end-users of the software solution.

In the mental health context, and more specifically when considering a disorder such as

DOI: 10.4018/978-1-4666-6339-8.ch056

schizophrenia, patients display rather extreme and serious symptoms. Schizophrenia has no known cure and its chronic condition is usually addressed with proper medication – drugs – and cognitive rehabilitation training - therapy. Nowadays, therapy is already being provided in an electronic format (e-Therapy) and being used in the field as a support and complement to traditional therapy.

eSchi is a successful example of an e-Therapy tool used by schizophrenia patients as a complement to traditional therapy. The system was applied to two distinct environments: a closed psychiatric institution and a public mental health specialized hospital, and in two different countries: Portugal and Spain. eSchi was developed using a particular approach of UCD called Patient Centered Design (PCD) since the system refers to the health context and the end-users of the system are patients. This software development method allows a distinctive end-user involvement usually pointed out as responsible for the successful outcome of the software solution. It is considered as the leading factor for the successful adoption of eSchi.

This chapter provides a background on the mental health context and the specific conditions endured by schizophrenia patients and corresponding caretakers. A brief overview of the UCD software development approach is provided and the benefits and issues of applying a PCD approach in the mental health context are presented.

The eSchi case study is explained according to the PCD approach used in its development and the challenges and lessons learned in the process are depicted.

BACKGROUND

Mental disorders such as schizophrenia are amongst the 20 leading causes of disability worldwide (World Health Organization, 2004). Schizophrenia is one of the disorders identified as a priority. Currently, it affects about seven per thousand of the world adult population, mostly

in the age group 15-35 years, summing up to almost 24 million people worldwide. Although the incidence rate is rather low, three per 10.000 inhabitants, the prevalence is high due to chronicity (2008) and (World Health Organization, 2007).

Schizophrenia is a severe mental disorder usually detected in the early adulthood and characterized by disruptions in thinking. People find difficult “to tell the difference between real and unreal experiences, to think logically, to have normal emotional responses, and to behave normally in social situations” (MedlinePlus, 2008). Someone that endures this condition sees his/her language, perception, and sense of self, affected. Seldom, the condition includes psychotic experiences, such as hearing voices or delusions, and can impair functioning through the loss of an acquired capability, disabling the person to earn a living or continue with its studies.

There is no known cure for schizophrenia, but it is treatable and allows some of those who suffer from it to have an adequate and productive life, enabling them to integrate fully into society. Severe cognitive deficits such as memory loss are a reality for schizophrenia patients, regardless of the schizophrenia’ subtype considered: paranoid; hebephrenic or disorganized; catatonic; undifferentiated or residual (Elvegag, Maylor, & Gilbert, 2003).

Current national policies are especially dedicated to prevent and improve mental health assistance, considering mental disorders as a public health case. One of these policies includes the digital provision of mental health (e-Mental Health) information and services through Mental Health Information Systems (MHIS) (World Health Organization, 2009) and (World Health Organization, 2008).

e-Therapy is a subsystem of an MHIS that enables the electronic provision of an already existing and specific health service: therapy. It “is a new modality of helping people resolve life and relationship issues. It uses the power and convenience of the Internet to allow simultaneous

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