

Clinical study on the acceptance of a Web-based self-help guide for bulimia

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Abstract

Eating disorders are a common source of psychiatric morbidity among young women. In order to respond to such problems, it is urgent to develop and evaluate more accessible treatment methods. Self-help manuals could bring a solution. Research on self-help manuals for the treatment of bulimia has already been conducted in Anglo-Saxon countries, where efficiency of such methods is recognised. These manuals are based on cognitive and behavioural therapy and provide step-by-step methods to face eating disorders by progressively recovering self-control over one's food behaviour.

The study is part of Salut! (IST-2000-25026), a 39-month project funded by the European Commission under the 5th Framework Programme and by the Swiss Federal Office for Education and Science (OFES). This project, started in January 2001, aims at developing Web-based and mobile tools for diagnosis, treatment, and prevention of eating disorders. One of the main developments of the project is a Web-based self-help guide for bulimia. Several European countries are participating in clinical trials aimed at evaluating this guide developed by the liaison psychiatry unit of the University Hospitals of Geneva and by NetUnion in Lausanne.

Project description

Salut! uses advances in information and telecommunication technology to design, prototype and validate innovative tools and cost effective strategies for the prevention, diagnosis and treatment of eating disorders.

The project has two main objectives: (a) to develop and validate online tools and mobile components for supporting the prevention and treatment of bulimia; (b) to

facilitate the exchange of reliable information about eating disorders between health professionals, researchers and the general public.

A main project component is the implementation of an online multi-lingual "self-help" guide (SHG) for outpatient treatment of bulimia. This guide contains evaluation and treatment modules designed to progressively deliver users techniques to get through their illness by themselves. The main modules of the SHG are expanded to form the basis of a more generic platform for supporting other online and mobile applications based on Cognitive Behavioural Therapy (CBT).

Salut! also set up a network of regional Web portals to facilitate the access and exchange of information between health professionals, researchers and the general public. These portals [1], launched in 2002, seek to encourage the dissemination of unbiased information about eating disorders, listing of current events, and local resources for people searching for information about eating disorders.

Self-help guide for bulimia

The online version of the "Self-Help Guide" [2], developed by the *University Hospitals of Geneva* (HUG) and *NetUnion*, is composed of seven sequential steps (cf. figure 1): (1) preparing yourself for change, (2) observing yourself, (3) changing your behaviour, (4) changing the way you think, (5) identify and solve your problems, (6) self-assertion, and (7) conclusion.

Steps are composed of lessons, exercises and several examples illustrated by a virtual character called Sarah. One of the most important exercises of the SHG is the food diary and its weekly summaries: users have to record their meals, binges, binge triggers, etc. daily. At the end of each week, they are invited to analyse their eating behaviour

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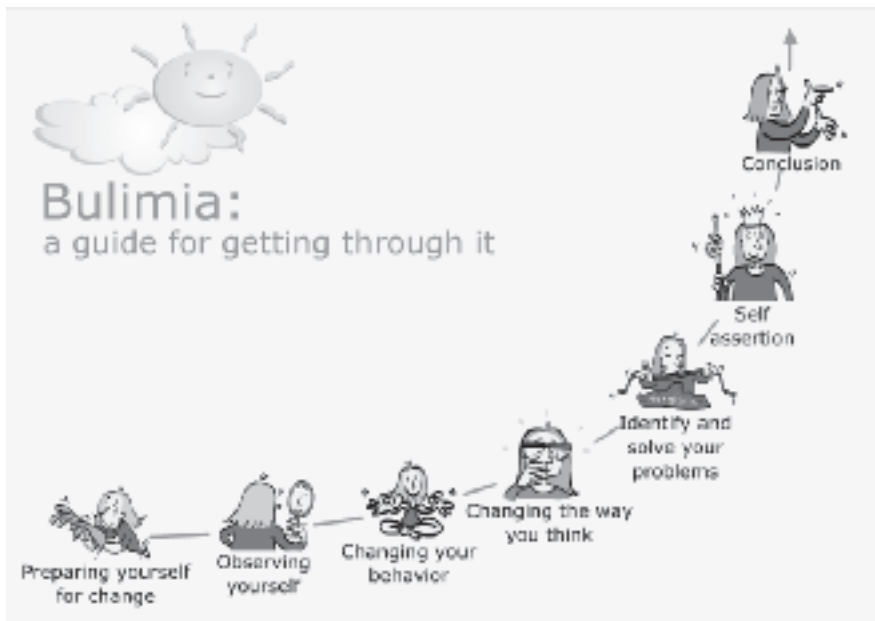


Figure 1. SHG steps

using a series of reports generated from their food diary (cf. figure 2).

Clinical trials

Medical partners in France, Spain, Sweden, and Switzerland are conducting clinical trials on the SHG using a common research protocol accepted by the psychiatry department's ethical committees of Swiss partners. Participants in the study are selected according to strict inclusion criteria. The main goals of this first study are the evaluation of acceptance and efficiency of the SHG in a population of patients suffering from bulimia, purging type (and more precisely "vomiting type").

Trials in Switzerland are currently being conducted by HUG and IPVR (Institutions Psychiatriques du Valais Romand) in the French speaking part of Switzerland. German and Italian versions of the SHG are being prepared to anticipate extension of the trials in other Swiss cantons.

The clinical trials have a six-month cycle (four months self-treatment, two months follow-up). All trial participants maintain regular contact with their assigned coaches. Coaches can monitor patient progress via the result analysis module of the SHG and by using standardized questionnaires (EDI-2 [3], SCL-90(R) [4]) administered in

person during pre-, post-treatment, and follow-up evaluation sessions.

Technical aspects

The online version of the SHG is based on a modular and multi-lingual e-health/e-learning platform developed by NetUnion in Java (JSP/Servlets) and XML with a PostgreSQL database backend. The current release contains six main modules: (1) user management, (2) editing/publishing, (3) evaluation, (4) program, (5) results analysis, and (6) messaging.

The user management module was designed in order to provide flexible, hierarchical and compartmented administration of users. The different user types have restricted rights according to their role(s). The overriding design criterion is to maintain confidentiality between coaches and participants.

The editing module is a powerful tool that allows rapid deployment of multi-lingual versioning of the SHG. This module includes interfaces for editing program content (lessons, exercises, examples), user interfaces (menus, buttons, etc.), evaluation questionnaires and the online help. Using this module, researchers can publish new program content directly on a pre-production server, setup new or edit existing research questionnaires (based on an XML template) to support clinical research and data collection. Other questionnaire-specific parameters – dimensions and norms – can also be edited using this interface. Questionnaires can be viewed and printed using XSL style sheets.

The result analysis module enables easy monitoring of patient progress by providing up to the minute results of participant response to questionnaires and exercise results. Results from questionnaires and exercises are presented graphically by creating SVG (Scalable Vector Graphics) files dynamically and rendering it on the fly as PNG images.

The usage analysis module also provides managerial and administrative information tailored to hospital administrators, program directors, coaches, and researchers. Information from this module is intended to help monitor information such as clinical workload, and potential impact on health care

delivery.

Prototyping of specific mobile components is ongoing. The aim is to provide anytime / anywhere access to specific exercises or components of the SHG.

Privacy and security

During the evaluation process, access to the SHG is restricted to users who participate in the clinical trial. Otherwise, the lessons, exercises, and other program modules are not made available to the general public.

A main design concern is protecting the confidentiality of the coach / patient relationship. Several steps were taken to assure this. For example, only coaches have access to the following information: patient responses to questionnaires and exercises, patient contact information, and messages exchanged between patient and coach.

These measures were achieved using technical and procedural solutions. The participants are only identified by a pseudonym. Real name and patient files are kept separately under lock and key. An internal messaging module allows coaches and patients to exchange messages without exposing their

e-mail address. The messaging module also implements rules restricting who can receive messages from whom. For example, coaches can only write to participants in their own groups. The message is written using the pseudonym.

The application respects prevailing European and local legislation on privacy and data protection [5]. However, a balance between security and ease of use had to be found in order to provide a reasonable level of security without asking too much IT knowledge from users. Again, appropriate technical and policy solutions were developed to meet this challenge.

Collected information is transmitted over a secured connection (SSL). Safe password rules are implemented to request users to choose "more secured" passwords. User passwords are stored as MD5 hash in the database.

Intermediate results and conclusion

The online version of the SHG was released in September 2002 and is currently available in French, Spanish, Swedish, and English. German and Italian versions, as

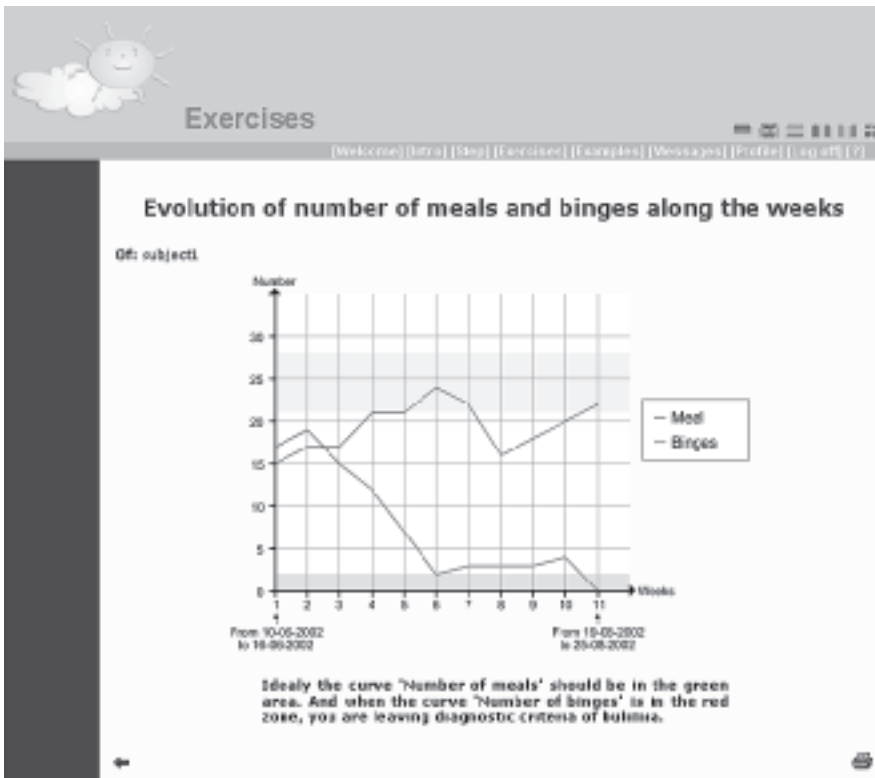


Figure 2. Evolution of number of meals and binges along the weeks



well as, prototypes of mobile components, will be available first quarter 2003. Clinical trials were launched in October 2002 and will continue throughout 2003 in four countries. Final results are expected by first quarter 2004.

The Self Help Guide research is already providing interesting feedback on the use of online tools for collaborative research, and novel cost effective treatment strategies.

The multi-lingual scope of the application gives us the opportunity to deploy the SHG in most European countries and to easily expand its use to other languages.

nation of health-related information.

The opportunity for providing service to a minority population is also perceived to be an unexpected benefit (e.g. providing the Spanish version of the SHG to the Spanish speaking communities in Sweden).

Moreover, the CBT platform, by its modularity, allows the creation of other self-help applications based on cognitive behavioural therapy and a similar clinical framework.

Insuring and promoting trust was also an issue. The project chose the strategy of using HON Code of Conduct (HON-code) [6] accreditation, an external quality benchmark indicating compliance to prevailing best practice [7] for online dissemi-