



Revista Mexicana de Trastornos
Alimentarios

E-ISSN: 2007-1523

editorrmta@campus.iztacala.unam.mx

Universidad Nacional Autónoma de
México
México

Unikel, Claudia; Sánchez, Marisol; Trujillo, Eva; Bauer, Stephanie; Moessner, Markus
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Revista Mexicana de Trastornos Alimentarios, vol. 6, núm. 1, enero-junio, 2015, pp. 64-69
Universidad Nacional Autónoma de México
Tlalnepantla Edo. de México, México

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REVISTA MEXICANA DE TRASTORNOS ALIMENTARIOS

MEXICAN JOURNAL OF EATING DISORDERS

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CASE REPORT

Internet-based aftercare program for patients with bulimia nervosa in Mexico – A pilot study



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Received 4 March 2015; accepted 12 May 2015

Available online 18 June 2015

KEYWORDS

Eating disorders;
Aftercare;
Internet based;
ACTUA;
Mexico

Abstract High rates of relapses are common in eating disorder patients after achieving the status of remission. The lack of support after completing a treatment can contribute to relapse. Therefore aftercare programs are needed to maintain the benefits of treatment, to reduce the risk of relapse, and to stabilize patients' well-being. This paper describes the Internet-based aftercare program ACTUA (Continued Support for Eating Disorders) developed to support patients with bulimia nervosa in Mexico. ACTUA is an adaptation of the program EDINA (Internet-based maintenance treatment for eating disorders) which was developed and evaluated in Hungary. In this paper we first describe the intervention which consists of different modules including a monitoring and feedback tool, forums, and counseling chat with a clinician. In the second part, we report on first experiences following the introduction of the program in two treatment centers in Mexico (Monterrey and Mexico City). Fifteen patients participated in a semi-structured interview assessing perceived benefits of participating in ACTUA as well as barriers that prevented patients from joining the program. Implications for the implementation of Internet-based interventions in Mexico are discussed.

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PALABRAS CLAVE

Trastornos de la conducta alimentaria;

Programa de seguimiento en línea para pacientes con trastornos de la conducta alimentaria en México – Estudio piloto

Resumen Las elevadas tasas de recaída son comunes en los pacientes con trastornos de la conducta alimentaria una vez que se les ha dado de alta de un tratamiento. La falta de apoyo

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Peer Review under the responsibility of Universidad Nacional Autónoma de México.

<http://dx.doi.org/10.1016/j.rmta.2015.05.004>

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Seguimiento de
pacientes;
Programa en línea;
ACTUA;
México

después de terminado el tratamiento puede contribuir a las recaídas. Por lo tanto, los programas de seguimiento son necesarios para mantener los beneficios obtenidos en el tratamiento, para reducir el riesgo de recaídas y para estabilizar el bienestar de los pacientes. Este trabajo describe el programa de seguimiento en línea ACTUA (Apoyo Continuo para Trastornos Alimentarios), desarrollado para dar apoyo a pacientes con bulimia nervosa en México. ACTUA es una adaptación del programa EDINA (Programa de seguimiento en línea para trastornos alimentarios), que fue desarrollado y evaluado en Hungría. En este trabajo se describe primero la intervención, que consiste en diferentes módulos, incluyendo una herramienta de monitorización y retroalimentación, foro y un chat con un clínico para obtener supervisión. En la segunda parte se reportan las primeras experiencias después de la introducción del programa en 2 centros de tratamiento en México (Monterrey y Ciudad de México). Quince pacientes participaron en una entrevista semi-estructurada, que evaluó la percepción de los beneficios obtenidos de participar en ACTUA, así como las barreras que impidieron que los pacientes participaran en el programa. Se discuten las implicaciones que tiene en México la implementación de un programa en línea.

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Introduction

Bulimia nervosa (BN) is a severe and in many cases a chronic mental illness which is associated with substantial impairment on the psychological, physical, interpersonal, and social levels (APA, 2000). According to the national survey of psychiatric epidemiology in Mexico, in the population over 18 years, 0.6% of males and 1.8% of females suffer from BN (Medina-Mora et al., 2003). However, the prevalence of partial syndromes is substantially higher (Hoek & van Hoeken, 2003).

According to the National Institute for Clinical Excellence (2004) Cognitive Behavior Therapy (CBT) is considered the treatment of choice for BN. Despite the efficacy of CBT, relapse is frequent in eating disorder patients (Keel & Mitchell, 1997; Olmsted, Kaplan, & Rockert, 1994). Frank et al. (1991) defined relapse as “a return of symptoms satisfying the full syndrome criteria for an episode that occurs during the period of remission, but before recovery”. Keel and Mitchell’s (1997) review showed that approximately 50% of the women initially diagnosed with BN recovered from their disorder, but 30% of the women experienced a relapse.

At the end of treatment, eating disorder patients are confronted with the stresses of everyday life again. It has been reported that the risk for relapse is particularly high within the first 6–7 months after discharge from hospital (Richard, Bauer, & Kordy, 2005). Taking into account the high rates of relapse, offering an aftercare support in this critical time should help to stabilize the patient’s well-being and thus reduce relapses.

Psychosocial interventions based on Information and Communication Technology (ICT) became more common over the past ten years. They promise many benefits such as (1) to extend services for economically disadvantaged populations and individuals living in rural areas, (2) to improve self-management competences, (3) to provide support at relatively little cost. ICT-based interventions have demonstrated their potential for anxiety disorders (Anderson, Jacobs, & Rothbaum, 2004), post-traumatic

stress disorder (PTSD), smoking cessation, body image, drinking, weight loss, depression and anxiety (Barak, Hen, Boniel-Nissim, & Shapira, 2008).

So far, four review articles have been published on the use of ICT in the prevention and treatment of eating disorders (ED) (Aardoom, Dingemans, Spinhoven, & Furth, 2013; Bauer & Moessner, 2013; Dölemeyer, Tietjen, Kersting, & Wagner, 2013; Loucas et al., 2014). In the field of aftercare promising findings on the efficacy of 3 interventions have been published so far (Bauer, Okon, Meermann, & Kordy, 2012; Fichter et al., 2012; Gulec et al., 2014).

As in most other countries, the use of Internet and new technologies has increased in Mexico over the last years. The Mexican Association of Internet (AMIPCI, 2007) carried out several investigations from 2003 to 2007. The main objective was to evaluate the habits of Internet users in México. AMIPCI reported an increase of Internet users of 12.75% (9 millions) during these years. The users’ main activities on the Internet were sending or reading emails and chatting with other people.

Mental health resources in Latin America are very scarce. In Mexico an epidemiological study reported a prevalence of 28.6% for mental disorders (Medina-Mora et al., 2003). Despite this high burden of illness, resources are mostly devoted to chronic cases, so that outpatient treatment and aftercare services are massively under-financed (Alarcón, 2003). In the light of this lack of aftercare interventions despite the high risk of relapse, we developed and implemented an online aftercare program to support patients who finished inpatient treatment.

The present paper has two aims: (1) to introduce the online aftercare program ACTUA (Continued Support for Eating Disorders) and (2) to explore factors that patients consider relevant for participation (i.e. perceived benefits and barriers).

In order to explore factors that are important for participation and adherence to the aftercare program, interviews were conducted with three groups: (1) individuals still participating, (2) individuals who quit early, and (3) individuals not willing to participate.

Methods

The present pilot study was conducted by collaborators at the Center for Psychotherapy Research in Heidelberg (Germany) and at two clinical institutions in Mexico: the centre for eating disorders Comenzar De Nuevo A.C. (Monterrey) and the National Institute of Psychiatry Ramón de la Fuente Muñiz (Mexico City). During their inpatient treatment in these institutions, patients were invited to participate in ACTUA once they got discharged from the clinic. Those who agreed, signed the informed consent form and chose a pseudonym as their username in ACTUA and a password received an introduction into the program before their discharge from the clinic. Participation in ACTUA was offered for 4 months following discharge. Patients had received a multidisciplinary inpatient or outpatient treatment with medical, psychiatric, nutritional and psychological approaches, of diverse length in relation to the illness characteristics. The psychotherapeutic approach included CBT and individual or family therapy when needed.

Intervention

ACTUA stands for “to make an action” and is an Internet-based aftercare program that allows providing support to patients after they terminate face-to-face professional treatment in a treatment center. ACTUA is an adaptation of the program EDINA (Internet-based maintenance treatment for eating disorders) which was developed and evaluated in Hungary. The main objective is to maintain the benefits achieved during inpatient treatment and to prevent relapse.

The Internet-based program includes various components of varying intensity: (1) psychoeducation, (2) supportive monitoring and feedback, (3) forum, (4) group chat sessions, (5) individual chat sessions, and (6) referral to face-to-face treatment.

The module on psychoeducation provides comprehensive information related to eating disorders. In addition to a general section that includes basic facts, risk factors and treatment options for eating disorders, the processes of recovery and relapse are described in detail to support participants in managing the transition from acute treatment to aftercare support successfully. The online forum offers peer-to-peer support. Participants can introduce themselves to other participants and they can express or discuss their opinions on various topics. The content of the postings is continuously checked by a member of the ACTUA team to promote positive communication among participants and delete insulting and potentially harmful content if necessary.

The supportive monitoring and feedback system is the central module of ACTUA. Every week, participants receive an email as a reminder to fill in their weekly monitoring assessment. Participants can access the assessment via a link in the email or directly via the ACTUA webpage. The monitoring questionnaire contains questions related to participants' wellbeing and eating behaviors in the past week. The three monitoring domains are: frequency of binge eating, frequency of compensatory behavior, and body dissatisfaction. After completing the questionnaire, based on their answers, participants receive a feedback message,

which refer to the individual symptom status and course. Week by week a participant can change in each domain in four different ways: improve (from the dysfunctional range to the functional range), deteriorate (from the functional to the dysfunctional range), stay in the functional range or stay in the dysfunctional range. Therefore, there are $4 \times 4 \times 4$ possible combinations of how a patient state can change from week to week. The evaluation is based on the SMS-based aftercare program introduced by Bauer, Percevic, Okon, Meermann, and Kordy (2003). The feedback includes reinforcing statements in case of positive changes. In case of deteriorations they suggest strategies to counteract such deteriorations and remind the participants of healthy behaviors they learned during treatment. In addition to the questions assessing the monitoring domains, the Short Evaluation of Eating Disorders (SEED, Bauer, Winn, Schmidt, & Kordy, 2005) is used in the weekly monitoring questionnaires to assess ED symptoms and identify severe impairment. In case of severe impairment, a clinician is informed automatically via email and then the patient is contacted (see below).

The weekly group chat guided by a clinician allows for both, interaction with a therapist and communication among participants. The 90-minute sessions provide the opportunity to discuss diverse topics with the clinician and with other participants. Participation in the weekly sessions is mandatory and participants are reminded of the sessions via email.

The individual chat is based on voluntary participation. Participants can reserve an appointment to discuss individual problems they would like to share with a clinician in a one-to-one setting. In addition, clinicians encourage those patients who reported severe impairment in the monitoring to utilize such individual chat counseling to clarify the need of more intense intervention. If a participant's status continues to deteriorate, the clinician refers the participant to a face-to-face treatment facility. Referral to a face-to-face treatment facility is a crucial component of the program as participation in ACTUA is not considered a sufficient intervention for patients with a full blown ED. As most of the components are automatized, the program requires only little resources and can be offered at no cost for patients. In addition to the provision of group and one-to-one chats, a clinician has to take care of participants developing severe symptoms.

Sample

Following the initial implementation of ACTUA, 15 patients were interviewed in order to explore the acceptability of the program as well as perceived benefits and barriers, that might prevent patients from participating. Interview candidates were contacted by the staff of the centre of eating disorders treatment Comenzar de Nuevo A.C., and asked to participate in a semi-structured interview about ACTUA. In order to obtain different perspectives, we included patients diagnosed with BN according to DSM-IV-TR diagnostic criteria (APA, 2000), who participated in ACTUA at the time of the interview ($n=6$) as well as BN patients who had ended their participation in ACTUA prematurely ($n=5$) and BN patients who declined to participate in ACTUA

($n=4$). The intervention was carried out by one therapist specialized in the treatment of eating disorders at the Comenzar de Nuevo A.C. clinic.

The semi-structured interview included questions regarding the utility of participating in the program, if the program satisfied their needs, if it was useful for problem solving, the use and usefulness of the different components of the program, their opinion in the program duration, difficulties and benefits.

Procedure

Participants were invited by the therapist in charge of the intervention to participate at the semi-structured interview. For those who accepted, an appointment was established at the Comenzar de Nuevo A.C. clinic to carry out the interview in a face-to-face manner. The interviewer took notes of the responses given by the participants, which were used afterwards to write a report on the benefits and barriers of the ACTUA program, in order to ameliorate the intervention and the usability of the program.

Results

First experiences

ACTUA was implemented in the clinical center in July 2010. About 20 patients had used the aftercare program at the time the pilot study was carried out. As most of the components are automatized, the program requires only little resources and can be offered at no cost for patients. In addition to the provision of group and one-to-one chats, a clinician has to take care of participants developing severe symptoms. Being a new intervention offered to patients, it was important to evaluate its feasibility and acceptance by patients, this being the main reason why we conducted this pilot study.

Semi-structured interviews

In order to get a first impression about the acceptance of the program and about the factors that prevent patients from participating in the program, fifteen patients were interviewed.

From the interview responses we could conclude that the intervention was well accepted by patients and could be easily implemented into the clinical routines of inpatient and outpatient treatment, although certain aspects have to be taken into account, such as internet access, good understanding of the web page performance, and providing accessible schedules for individual and group sessions.

The results of the interviews indicated that the use of the different components of the program gives benefits to the participants. The individuals still participating ($N=6$) reported that the components were user-friendly and the instructions from the program easy to understand, but three out of these six reported technical difficulties with opening the chats and loading the monitoring questionnaires. Regarding the chats (group and individual) the six participants felt the content very helpful as they could talk about

their experience with other patients and receive support from the clinician. For instance, they talked about the triggers of their illness and setting the homework between sessions. Three people reported that they wanted more different options to book appointments with the clinician. The individuals who quit in an early stage ($N=5$) reported the factors or reasons that influenced quitting the registration of the program: the burden of answering, the study related questionnaires and concerns about data security were important factors. One person reported that the feedbacks received after answering the monitoring assessments were too repetitive and not so personal. Also, two individuals felt that the group chats were not so well organized and found it difficult to interact with other participants. However, three individuals who quit early reported to consider the use of the Internet as a tool in the future and two individuals considered it as a complement with other treatment. The individuals who were not willing to participate ($N=4$) felt it was not so personal; they disliked the idea of online communication, and would prefer human contact. Two individuals also felt it difficult to talk about their illness with people they did not know. Regarding the online program itself, one person reported it was not so attractive and did not look professional enough.

As part of the interviews participants were also asked about ways to improve the program. Two individuals still participating said it would make the program more attractive by adding videos, photos and more people in the group chats. One person who quit early said that she would like to have more flexible hours for the chats. One person mentioned that she would not want to complete long questionnaires.

Discussion

This pilot study had the aim of introducing the online aftercare program ACTUA and to explore benefits and barriers that patients consider relevant for participation in an aftercare eating disorders program.

After the end of treatment, eating disorder patients are confronted with the stresses of everyday life again and relapse is a common event. Offering support in the critical time after discharge should help to stabilize patients' well-being and reduce the relapse rate. Offering an aftercare program via the Internet seems particularly promising because it may be used by patients independent of their place of living. Thus, aftercare support can be offered also to patients that do not have any face-to-face treatment options close to their residence after they complete treatment in a specialized institution. A conventional aftercare program that is not ICT-based would not be feasible for the majority of the patients due to the geographic distances between the hospital and the residence of the patients. Through programs such as ACTUA the provision of support after the end of inpatient treatment becomes a feasible option for hospitals that would not be able to provide this kind of aftercare support without ICT. For the provider of the program (the hospital), low costs and the resources needed can be estimated easily and – if necessary – adjusted to the personal resources that are available (e.g. by flexibly offering more or fewer chat appointments based on available therapeutic resources). ACTUA can offer support to a

high number of patients, as parts of the intervention are automated and do not require moderation.

ACTUA could be easily implemented into the organizational structure of the participating hospitals. The aftercare program is offering a new option to support ED patients during the critical transition period after the termination of inpatient treatment. For those with access to the Internet, the program provides anonymous support at low cost. The program does not follow a strict protocol. Participants have the flexibility to use some of the components of ACTUA (i.e., psycho-education, forum, individual chat) according to their needs and individual preferences. In this sense, the program offers individualized aftercare, aiming at concordance with participants' individual needs.

The central module of ACTUA is the continuous monitoring of the relevant ED symptoms. In addition to the positive effects of self-monitoring following treatment termination (Bauer et al., 2012) the monitoring allows early identification of patients' relapses and thus provides an opportunity for timely reaction. This identification is automated; a clinician is informed by the system as soon as a participant's impairment exceeds a predefined threshold. In that case, the clinician can refer the participant to more intense face-to-face treatment. The objective of ACTUA is twofold: The primary objective is relapse prevention, but in case of recurrence of severe symptoms and relapse, organizing a more intense form of support as soon as possible becomes the objective for this specific patient.

Conclusions

This is the first study investigating the feasibility of an online intervention for ED in Mexico. Although the sample size is small and the evidence is predominantly anecdotal, the interviews provided important insights, which will be of critical value for the future implementation of ICT-based psychosocial interventions in Mexico.

The present study is a pilot study with a small sample size. It does not provide any evidence that goes beyond feasibility and acceptance of the program. In order to be able to draw conclusions about its efficacy, an adequately powered randomized control trial is needed.

Some important considerations have to be taken into account for the release of an ICT-based intervention for the treatment of eating disorders in Mexico. Mexico occupies the 72nd place among a list of 190 countries around the world in the access to the Internet, which means many people in the country are not yet connected to the Internet on a regular basis, and there is still probably no great acceptance of a non face to face treatment of mental illnesses; nevertheless, there is great lack of low cost specialized treatment options, and as the scientific evidence reveals, ICT-based programs can be a low-cost effective tool for the treatment of eating disorder patients, which are two powerful reasons that justify the release of the ACTUA program to the scientific community in order to include a wider range of patients, reduce treatment costs and avoid relapses of eating disorder patients after discharge.

Responsibilities ethics

Protection of human and animal subjects. The authors declare that the procedures followed were in accordance with the regulations of the responsible Clinical Research Ethics Committee and in accordance with those of the World Medical Association and the Helsinki Declaration.

Confidentiality of data. The authors declare that they have followed the protocols of their work center on the publication of patient data and that all the patients included in the study have received sufficient information and have given their informed consent in writing to participate in that study.

Right to privacy and informed consent. The authors must have obtained the informed consent of the patients and/or subjects mentioned in the article. The author for correspondence must be in possession of this document.

Conflict of interest

The authors declare no conflict of interest.

Acknowledgements

This work was supported by the Research Training Network INTACT, funded by the European Commission in the Marie Curie Program (MRTNCT-2006-035988).

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