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## Just a click away... E-mental health for eating disorders

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### Citation

Aardoom, J. J. (2016, December 7). *Just a click away.. E-mental health for eating disorders*. Retrieved from <https://hdl.handle.net/1887/45091>

Version: Not Applicable (or Unknown)

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**Note:** To cite this publication please use the final published version (if applicable).

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**Title:** Just a click away... E-mental health for eating disorders

**Issue Date:** 2016-12-07

# Chapter 10

## E-health interventions for eating disorders: Emerging findings, issues, and opportunities

Published as:

Aardoom J.J., Dingemans A.E., van Furth E.F. (2016). E-health for eating disorders: Emerging findings, issues, and opportunities. *Current Psychiatry Reports*, 18, 42.

## **Abstract**

This study aimed to review the emerging findings regarding E-health interventions for eating disorders and to critically discuss emerging issues as well as challenges for future research. Internet-based cognitive behavioral therapy and guided self-help have demonstrated promising results in terms of reducing eating disorder psychopathology. Emerging findings also suggest that E-health interventions reach an underserved population and improve access to care. The use of smartphone applications is becoming increasingly popular and has much potential although their clinical utility and effectiveness is presently unknown and requires investigation. Important challenges include the diagnostic process in E-health interventions, the optimization of E-health within existing health care models, and the investigation and implementation of blended care. More high-quality research is needed to bring the field forward and to determine the place for E-health in our health care service delivery systems.

## Introduction

Eating disorders (ED) are severe psychiatric disorders characterized by serious disturbances in attitudes and behaviors around eating, body weight, and body shape (American Psychiatric Association, 2013). Hudson et al. (2007) estimated the lifetime prevalence of anorexia nervosa (AN) among women in the United States to be roughly 0.9%, and estimated 1.5% and 3.5% lifetime rates for bulimia nervosa (BN) and binge eating disorder (BED), respectively. Eating disorders have high rates of comorbidity with other psychiatric disorders (Hudson et al., 2007) and have one of the highest mortality rates of any psychiatric disorder (Arcelus et al., 2011). Patients with an ED (Agh et al., 2015; De Jong et al., 2013) and their relatives (de la Rie, van Furth, de Koning, Noordenbos, & Donker, 2005; Zabala et al., 2009) demonstrate marked impairment in their quality of life. Hence, the economic costs of ED are substantial (Stuhldreher et al., 2012) and they represent a serious public health problem.

Despite their severity, ED are frequently undetected and many individuals do not seek or receive treatment for their ED symptoms (Hart et al., 2011; Hudson et al., 2007; Keski-Rahkonen et al., 2007). Perceived barriers to care include social barriers such as feelings of shame, or fear of stigma and social stereotyping, as well as barriers related to financial constraints and limited availability of specialized care (Becker et al., 2010; Cachelin et al., 2006). A study in the Netherlands (de la Rie et al., 2006) found that it took patients on average 3.6 years to recognize and acknowledge that they were suffering from an ED, and 4.2 to 6.3 years to seek treatment (i.e., patient delay). After seeking treatment, more than half of the community-based sample reported delays (1.1 years) in receiving treatment as well, due to waiting lists or a delay of referral (i.e., doctor/system delay) (de la Rie et al., 2006). These delays in seeking and receiving treatment are unfortunate, as studies have indicated that a shorter duration of the ED symptoms is associated with better outcomes and higher chances of recovery (Berkman, 2007; Fichter et al., 2006; Keel et al., 1997; Reas et al., 2000).

There is a need for interventions for ED that decrease barriers to care, are more widely available, and more easily accessible. Internet-based interventions have the potential to address these challenges and provide promising ways to enhance health care for patients with an ED. The number of studies investigating Internet-based and mobile interventions for ED is rising. In parallel, there is a growing number of reviews available regarding this area of research (Aardoom et al., 2013; Ambwani, Cardi, & Treasure, 2014; Bauer & Moessner, 2013; Dolemeier, Tietjen, Kersting, & Wagner, 2013; Fairburn & Rothwell, 2015; Juarascio, Manasse, Goldstein, Forman, & Butryn, 2015; Loucas et al., 2014; Schlegl, Burger, Schmidt, Herbst, & Voderholzer, 2015; Shingleton, Richards, &

Thompson-Brenner, 2013). In the current study, we will update our previous review (Aardoom et al., 2013) and critically evaluate published literature over the past 1-3 years (January 2013 – September 2015) with respect to E-health interventions for individuals with ED symptoms. Furthermore, we will critically discuss some emerging issues in this field and several areas for future research in order to bring the field forward.

## **Methods**

We searched four electronic databases (Medline, Embase, PsycInfo, Web of Science) for studies and study protocols published between January 2013 and September 2015. Search terms included 'online', 'web-based', 'Internet-based', 'e-health', 'e-mail', 'technology-based', 'mobile', 'smartphone' combined with 'eating disorders', 'bulimia', 'anorexia', 'binge eating'. The reference lists of retrieved papers were also checked for other relevant studies. Studies were included if they examined an Internet-based or mobile intervention for individuals with ED symptoms, or included at least one internet-based or mobile component. Studies evaluating Internet-based prevention programs were excluded.

## **Results**

### **E-health for eating disorders: Emerging findings**

#### *Treatment and self-help interventions*

Three large randomized controlled trials investigated Internet-based cognitive behavioral therapy (CBT) (Ruwaard et al., 2012; ter Huurne et al., 2015a; Wagner et al., 2013). Generally, these trials consist of a structured CBT program including different modules (e.g., monitoring, cognitive restructuring) that individuals have to work through sequentially, accompanied by assignments and homework. Therapist support is provided on at least a weekly basis via email. Ter Huurne et al. (2015a) found that for individuals with BN, BED, and eating disorder not otherwise specified (EDNOS), an Internet-based CBT was more effective than a waiting list control in terms of ED psychopathology, body dissatisfaction, physical health, symptoms of depression, self-esteem, and social functioning (range Cohen's  $d=0.20-1.28$ ). Two other studies investigated Internet-based CBT in individuals with BN (Ruwaard et al., 2012; Wagner et al., 2013). Ruwaard et al. (2012) demonstrated Internet-based CBT to be more effective than both a waiting list control ( $d=1.20$ ) and unguided self-help ( $d=0.90$ ). This may suggest superiority of guided interventions over unguided interventions, which would be in line with emerging findings of E-health studies in the field of mental health (Baumeister et al., 2015). Finally, Wagner

et al. (2013) found Internet-based CBT to be equally effective as conventional guided self-help, in which participants received a self-help book and e-mail support from a therapist.

A pilot study by Hogdahl et al. (2013) supported the findings of Wagner et al. (2013) that a self-help book with e-mail support can significantly improve ED psychopathology ( $d=0.78$ ) over time. Regarding unguided self-help, results of an open trial of an unguided Internet-based self-help program showed that participants experienced improvements in their motivation to change, ED psychopathology, and symptoms of depression and anxiety (Leung, Ma, & Russell, 2013a; Leung, Ma, & Russell, 2013b). However, no comparison condition was used and almost 60% of the study samples reported that they were receiving treatment. Hence, positive results may have been caused by general treatment participation or other factors rather unspecific of the unguided self-help program.

A large ( $N=212$ ) trial conducted by Hötzel et al. (2014) examined guided Internet-based motivational enhancement therapy for individuals with AN or BN. In six online sessions of approximately 45 minutes, participants were asked to complete writing assignments which were based on principles of motivational interviewing. For example, writing about the pros and cons of the ED and change, or writing about the impact that the ED has concerning patients' life goals and quality of life. Individualized feedback was provided after each assignment. Results demonstrated the Internet-based motivational enhancement therapy to be superior to a waiting list in enhancing motivation to change and self-esteem, as well as in reducing restraint (Hotzel et al., 2014). This suggests the Internet to be a potentially useful means to deliver interventions targeting individuals with an ED who are ambivalent towards change, which eventually may help to increase the number of individuals entering treatment for their ED.

Finally, two preliminary studies by Cardi et al. (2013) investigated the use of short video clips ('vodcasts') as a self-help intervention in order to support meal intake for patients with AN and BN. The vodcasts included auditory and visual content including amongst other things music, psychoeducation, and content based on motivational interviewing principles. Participants generally evaluated the vodcasts as being helpful, motivating and practical to use (Mohr et al., 2012). Nevertheless, the effectiveness of the vodcasts in terms of reducing meal distress and increasing meal consumption remains to be evaluated, as no control conditions were included.

#### *Aftercare and maintenance treatment*

Two randomized controlled trials reported on an Internet-based maintenance treatment for individuals with ED (Fichter, Quadflieg, & Lindner, 2013; Gulec et al., 2014; Unikel, Sánchez, Trujillo, Bauer, & Moessner, 2015). Fichter et al. (2013) reported on the 9-month

follow-up of an Internet-based CBT relapse prevention program for individuals with AN ( $N=210$ ) after discharge from inpatient treatment. Although participants showed improvements over time regarding measures of ED psychopathology, no significant differences were found between the relapse prevention and the control condition for the majority of outcome measures.

Gulec et al. (2014) investigated the effectiveness of an Internet-based maintenance intervention for individuals with BN or EDNOS ( $N=105$ ). The intervention comprised psychoeducation, weekly group chat sessions, a forum, and a fully automated monitoring and feedback system. The intervention was demonstrated to be feasible and acceptable, but the intervention was not more effective in reducing psychopathology than a waiting list. However, the study had methodological shortcomings and limitations when assessed with the Cochrane risk of bias tool (Higgins et al., 2011). For example, the timing of the intervention could be considered too late as participants were enrolled when they had completed treatment for their ED within the past 12 months, whereas the highest risk for relapse is between four and twelve months after discharge (Carter et al., 2004; Carter et al., 2012; McFarlane, Olmsted, & Trottier, 2008). Furthermore, the 4-month timeframe of the study period may have been too short to detect an effect.

A recent pilot study in Mexico by Unikel et al. (2015) used an adapted version of the above described intervention of Gulec et al. (2014). Preliminary results of 15 participants demonstrated the intervention to be feasible and acceptable, although there were also concerns about data security. Participants furthermore reported on ways to improve the program, for example by using videos and photos in the program, or offering more flexible hours for the group chat sessions. Flexibility is an important factor to consider when developing and implementing E-health interventions, as flexibility may be one of the key reasons for individuals to prefer E-health interventions over face-to-face interventions.

#### *Predictors of outcome and dropout*

To our knowledge, only two studies examined predictors of outcome in an Internet-based interventions for ED. Within a guided self-help program for individuals with BN, it was found that higher motivation to change, higher harm-avoidance, higher drive for thinness, lower binge eating, and lower body dissatisfaction at baseline predicted better outcomes (Wagner et al., 2015). Another study (Hogdahl, Birgegard, & Bjorck, 2013) investigating guided self-help for individuals with BN, identified lower baseline body mass index and higher self-esteem as predictors of good outcome.

What about predictors of dropout? Higher baseline levels of depression and ED psychopathology (i.e., shape concerns, self-induced vomiting, and binge eating episodes)



were shown to predict dropout within an Internet-based motivational enhancement therapy (von Brachel et al., 2014). Lower self-directedness was found to predict dropout in a guided self-help program (Wagner et al., 2015).

### **Smartphone applications in the treatment of eating disorders: emerging findings**

In the last few years, there has been an explosive growth in the availability of health-related mobile applications. Recently, two reviews on mobile applications ('apps') for individuals with ED have been published (Fairburn et al., 2015; Juarascio et al., 2015). Both reviews aimed to identify the available apps, and to evaluate their functions and clinical utility. The effectiveness of these apps could not be reviewed as research studies in this field are currently lacking. Juarascio et al. (2015) identified 20 apps. Five apps provided psychoeducation, whereas 9 incorporated a variety of functions such as self-assessment tools, tools for finding referrals, and supportive pro-recovery material. Six apps were aimed at the treatment of patients with an ED or could be used as an adjunct to existing treatments. These 6 apps were reviewed in detail, and the authors concluded that most of these apps only made limited use of evidence-based treatment strategies, such as principles based on CBT, interpersonal therapy, or acceptance and commitment therapy. Moreover, the app functionality and the degree to which the apps utilized recent advances in smartphone technologies (e.g., ecological momentary assessment) appeared to be limited (Juarascio et al., 2015).

A similar conclusion regarding the status of apps for ED was reached by another review (Fairburn et al., 2015). Furthermore, in that review, Fairburn and Rothwell (2015) concluded that the majority of apps included variable or misleading information with respect to the provision of information, advice, treatment, and self-assessment. In addition, 5 apps were identified that were developed for clinicians. Three apps included scientific articles, an e-book, and events sponsored by a recovery center for ED respectively. Another app included diagnostic information on ED, as well as some information on assessment and screening tools. Finally, one app ('Recovery Record') links clinicians to their patients. With the use of this app, clinicians can access monitoring data of their patients and patients and clinicians can communicate directly with each other.

Most recently, Tregarthen et al. (2015) described the development, characteristics, and user- and utilization statistics of Recovery Record. With over 108,000 downloads over a 2-year timeframe, the app has become increasingly popular. The acceptability of the app was demonstrated by high user ratings; approximately 97% of the users rated the app with 4 or 5 stars out of 5. However, the effectiveness of this smartphone app remains to be evaluated. Collectively, the emerging literature suggests that the use of smartphone applications in the treatment of ED has much potential and is

becoming increasingly popular. However, the effectiveness, validity, and clinical utility of these apps have not yet been established and warrants further investigation.

### **Development and implementation of E-health interventions**

Internet-based treatment could be offered instead of face-to-face treatment but the development and implementation of E-health interventions is challenging. Moreover, most E-health interventions have not been developed as a replacement, but rather to use before, after, or as a supplement to existing treatments. Internet-based self-help interventions, for example, may particularly be of interest within a stepped-care approach for the treatment of ED. Such self-help interventions can be used to provide low-intensity care in case of mild ED symptoms and for individuals who have never received treatment. Individuals who do not respond to self-help, can then easily ‘step up’ to more intensive treatments (Mitchell et al., 2011). Guided or unguided Internet-based self-help could similarly be offered to individuals whose symptoms have improved after receiving treatment, but are still in need of support to work on their recovery and in consolidating and maintaining treatment gains.

Another issue related to the development and implementation of E-health interventions is the combination of face-to-face and online components into a blended care intervention. Unfortunately, well-designed studies investigating blended care for ED are lacking. Blended care is a promising innovation as it could provide the best of both worlds. That is, online components can reduce travel time and stimulate self-management. Face-to-face sessions can in turn be more personal and may enhance the therapeutic relationship. Importantly, patients seem to prefer face-to-face sessions in combination with online sessions in the treatment of mental problems (McClay, Waters, Schmidt, & Williams, 2014; van der Vaart et al., 2014). By blending online and face-to-face components however, one of the main goals of blended care is to reduce the number of face-to-face sessions, instead of being a substitution of, at least some, face-to-face sessions. The latter has been demonstrated in a study comparing face-to-face treatment with blended treatment for individuals with anxiety and depression (Kenter et al., 2015). Thus, implementation seems to be key; ideally, blended care should improve efficiency (e.g., reduction traveling time, more flexibility) and reduce costs.

### **Diagnostics in E-health interventions**

In daily clinical practice, the “gold standard” for determining a psychiatric diagnosis per classification systems such as the DSM (American Psychiatric Association, 1994; American Psychiatric Association, 2013) is a face-to-face clinical interview. The DSM establishes consistent and reliable diagnoses and furthermore provides a ‘common language’ to

communicate about these disorders. Importantly, a face-to-face clinical interview allows for clinical intuition and could lead to more detailed information on patients' experiences and symptoms as compared to self-report assessments. Clinicians can furthermore observe and take into account patients' nonverbal behaviors and responses.

Yet, a face-to-face interview may be at odds with the aims or clinical evaluation of anonymous E-health interventions or applications. If so, is the lack of a face-to-face diagnostic classification problematic? Should we always aim to include a face-to-face clinical interview? A DSM-based psychiatric diagnosis (American Psychiatric Association, 2013) is essential if the treatment is to be reimbursed by a health insurance company. However, the incorporation of a face-to-face diagnostic interview can be in conflict with the goals and advantages of using new technologies as delivery mode of interventions. These goals often pertain to lowering the threshold of seeking help, improving health outcomes, and/or improving the efficiency, accessibility and availability of health care services. Potentially, E-health interventions improve our reach to underserved populations; individuals who would otherwise not have been reached. Face-to-face appointments could limit or eliminate the above-mentioned advantages that often serve as one of the main goals of choosing E-health over more traditional delivery modes. In both research and everyday clinical practice, this is an undesirable situation especially because the majority of individuals with an ED does not seek or receive mental health care (Keski-Rahkonen et al., 2007; Hart et al., 2011; Hudson et al., 2007) due to perceived barriers including a fear of stigma, feelings of shame, and limited availability of specialized care (Becker et al., 2010; Cachelin et al., 2006).

In order to preserve the potential advantages that come with the Internet as delivery mode of the intervention, a valid and reliable online self-report questionnaire for diagnostic classification would be of great value. Keel et al. (2002) investigated the diagnostic agreement between face-to-face or telephone clinical interviews and self-report paper-based questionnaire data. Although the different assessment methods produced somewhat different results (i.e., higher rates of ED with questionnaire data), the authors concluded that the results challenge the use of a structured clinical interview as golden standard for the assessment of ED classifications. Both of the assessment methods have drawbacks, but possibly, the anonymity of self-report questionnaires leads to increased candor (Keel, Crow, Davis, & Mitchell, 2002).

This line of assessment research has been pursued by other researchers as well. Moessner et al. (2015) developed a self-report questionnaire for the online assessment of ED: the Clinical and Research Inventory for Eating Disorders (CR-EAT). The questionnaire showed good internal consistency and test-retest reliability, and showed promising results regarding construct and discriminant validity. The clinical utility of the CR-EAT requires

further investigation. Ter Huurne et al. (2015b) investigated the clinical utility and validity of an online self-report questionnaire (Eating Disorder Questionnaire-Online; EDQ-O) in diagnosing DSM-IV-TR (American Psychiatric Association, 1994) ED, in comparison to a face-to-face clinical interview. The degree to which these two assessment methods led to similar diagnoses ranged from acceptable to high, although the EDQ-O appeared to have low sensitivity in correctly classifying AN (0.44) and BED (0.66). The sensitivity rates for BN and EDNOS were moderate to high: 0.78 and 0.87 respectively. Thus, in E-health studies where a face-to-face clinical interview is in conflict with the primary goals of delivering the intervention by means of the Internet, the EDQ-O seems to be an acceptable instrument to provide a diagnostic impression of study samples. Nevertheless, it would be valuable to further assess and improve the diagnostic validity of the EDQ-O or comparable online self-report questionnaires, also in light of some revisions of the diagnostic criteria with the appearance of the fifth edition of the DSM (American Psychiatric Association, 2013).

### **Reaching an underserved population and improving access to care?**

Reaching an underserved population is often a goal or presumed potential advantage of E-health interventions. Is there evidence that E-health interventions actually reach underserved populations, or improve access to care? Several studies suggest that this is indeed the case. McClay et al. (2014) qualitatively examined the attitudes towards online self-help in a community sample of individual with symptoms of BN. They found that individuals often possessed negative attitudes towards accessing traditional treatments, due to fear, shame, embarrassment, long waiting lists and negative past experiences with such treatments. These difficulties may be solved by seeking help online, with reported advantages such as privacy, anonymity, convenience, and easy access (McClay et al., 2014).

In the three studies investigating an Internet-based CBT reviewed above (Wagner et al., 2013; ter Huurne et al., 2015a; Ruwaard et al., 2012), approximately 33% to 56% of the participants reported not having received any previous treatment for their ED. Similarly, Tregarthen et al. (2015) found that 46% of the users of an ED self-monitoring smartphone app reported that they were currently not receiving any treatment for their ED. A cross-sectional study (Aardoom, Dingemans, Boogaard, & van Furth, 2014) of the pro-recovery focused website and E-community 'Proud2Bme' showed that approximately one third of the study sample had never received treatment. In addition, results suggested that the E-community stimulated help-seeking behaviors. Of the visitors who received treatment at the time of the study, half reported having sought help as a result of visiting the website. Finally, a study by Wagner et al. (2013) further supported the idea that E-

health interventions improve access to traditional face to face care, as participants reported to be motivated to seek further treatment after receiving Internet-based CBT.

### **Challenges, research gaps and future directions**

There appears to be a research gap in comparing face-to-face and E-health interventions although three trials (Bulik et al., 2012; de Zwaan et al., 2012; Jenkins, Luck, Burrows, & Boughton, 2014) are ongoing. One trial is comparing the efficacy of Internet-based guided self-help with CBT for individuals with BED (de Zwaan et al., 2012), whereas another trial (Bulik et al., 2012) is comparing Internet-based group CBT with face-to-face group CBT for individuals with BN. In addition, Jenkins et al. (2014) are investigating the effectiveness of guided self-help delivered either face-to-face or via e-mail.

E-health research on the effectiveness of aftercare and relapse prevention of ED is still at an early stage. It is highly relevant to develop and study this area of research further, as relapse rates following treatment of AN and BN generally range between 35% and 50% (McFarlane et al., 2008), even after successful treatment. New technologies have potential for delivering easily accessible services that might help individuals to maintain and consolidate treatment gains, as well as prevent relapse. Online or mobile aftercare interventions may help to assist with the transition from treatment to daily life, as well as assist in the continuous process of recovery and early relapse detection (e.g., by monitoring ED behaviors and cognitions).

Currently, little is known about how and for whom E-health interventions work or who drop out from such interventions. A better understanding of predictors of dropout and outcome in E-health interventions could help to better implement and utilize such interventions. For example, the intensity, speed, and different components of an intervention might be tailored to the different needs of individual participants, thus moving towards personalized E-care. Similarly, individuals may vary in the extent to which they need and prefer therapist support in guided E-health interventions. Experimentally investigating the amount of therapist support within E-health interventions may lead to important insights on the duration and frequency of therapist support that is needed in order to improve participants' outcomes.

Previous reviews have concluded that the methodological quality and the level of evidence of conducted studies are both limited (Aardoom et al., 2013; Loucas et al., 2014; Schlegl et al., 2015). In the past 3 years, only six randomized controlled studies have been published on the effectiveness of an E-health intervention, of which four in 2013 (Fichter et al., 2013; Hotzel et al., 2014; Ruwaard et al., 2012; Wagner et al., 2013), only one in 2014 (Gulec et al.) and one in 2015 (ter Huurne et al.). More trials with good methodological quality and low risk of bias are needed in order to bring the field forward

and to establish a potential evidence-base of E-health interventions for individuals with ED. Risks of bias (Higgins et al., 2011) can be caused by different sources, one example being substantial amounts of missing data and methods in handling these. The studies included in this review had study dropout rates between approximately 4% and 43% (Gulec et al., 2014; Hotzel et al., 2014; Leung et al., 2013b; Ruwaard et al., 2012; ter Huurne et al., 2015a; Wagner et al., 2013). When facing substantial amounts of missing data, it is important to choose statistical techniques that handle missing data appropriately, for example multiple imputation approaches (Blankers, Koeter, & Schippers, 2010; Graham, 2009; Schafer et al., 2002).

Although it is often assumed that Internet-based interventions for ED are cost-effective in comparison to waiting lists or usual care, no studies have been published to substantiate this assumption. Fortunately, we identified several ongoing trials investigating the cost-effectiveness of Internet-based interventions for ED with a face-to-face alternative (Bulik et al., 2012; Jenkins et al., 2014). Furthermore, the cost-effectiveness of an Internet-based self-help intervention with or without therapist support in comparison to a waiting list is currently being investigated (Aardoom et al., 2013). Crow et al. (2013) investigated a stepped-care approach for individuals with BN, starting with offline self-help from which patients could ‘step up’ to more intensive treatment approaches. This stepped-care approach was more effective and less expensive, hence cost-effective when compared to CBT. Stepped care approaches in which low-intensity interventions are provided first, may well be delivered online. Possibly, effectiveness and efficiency will thus be increased and lead to even greater reductions in costs.

Furthermore, as described in previous sections of this paper, it would be relevant to develop and examine online diagnostic instruments focusing on the DSM-V (American Psychiatric Association, 2013) criteria for ED. Another future research direction includes focusing on the potential of E-health interventions within a stepped-care approach, as these may heighten the availability, accessibility and quality of health care for individuals with ED symptoms. Also, the potential of blended care, in which face-to-face sessions can be substituted by online modules and online therapist support, requires further investigation. Finally, there is a need to investigate the effectiveness, validity, and clinical utility of smartphone apps for individuals with ED and ED professionals.

## **Conclusions**

Emerging research suggests that Internet-based CBT and self-help interventions can be effective and have potential to help address various gaps in ED treatment although much more research is needed to address important uncertainties. The (cost-) effectiveness of aftercare and relapse prevention programs, as well as smartphone applications requires

investigation. E-health interventions seem to reach underserved populations and may improve access to care but important challenges remain regarding the diagnostic process, the optimization of E-health within existing health care models, and the investigation and implementation of blended care. E-health could help to enhance health care for patients with ED, potentially making it possible to treat more individuals, with an increased effectiveness, less intensive professional guidance, while reducing overall costs. E-health is here to stay, but more high quality research is needed to determine the place for E-health in our service delivery systems and to reach the full potential of E-health.

