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

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Chapter 1

General introduction

This introductory chapter begins by providing the reader with a theoretical background and context of the research presented in this dissertation: E-mental health for eating disorders. Furthermore, this chapter provides a rationale for the research, explaining why E-mental health for eating disorders is worth investigation and how this research can help to address some important gaps in research and clinical practice. At the end of this chapter, the aims and outline of this dissertation are presented.

Eating disorders

Diagnostic classifications

Eating disorders are psychiatric disorders characterized by persistent disturbances of eating or eating-related behaviors that significantly impair physical health and psychosocial functioning (American Psychiatric Association, 2013). The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013) specifies several distinct eating disorders, including anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), and their variants. Anorexia nervosa is characterized by significantly low body weight due to a restriction of energy intake, intense fear of gaining weight or of becoming fat, and disturbances in self-perceived weight or shape. Two subtypes of AN can be distinguished: the restricting and the binge eating/purging type. Patients with the former subtype accomplish their weight loss primarily through food restricting and/or excessive exercise, whereas patients with the latter subtype engage in binge eating and purging behaviors such as self-induced vomiting or the misuse of diuretics, laxatives, or enemas. Patients with BN have recurrent binge eating episodes and inappropriate compensatory behaviors, both at least once a week for three months, and their self-evaluation is unduly influenced by their body weight and shape. Recurrent binge eating episodes are also a feature of BED, but patients with BED do not engage in inappropriate compensatory behaviors as do patients with BN. The diagnosis of other specified feeding or eating disorder (OSFED) captures clinically severe symptoms of a feeding or eating disorder that do not meet the diagnostic criteria for another feeding or eating disorder, and distinguishes five subtypes: atypical AN, subthreshold BN, subthreshold BED, purging disorder, and night eating syndrome. For example, the criteria for atypical BN and BED are met when individuals experience a low frequency or limited duration of binge eating episodes and/or compensatory behaviors. The diagnosis of OSFED was formerly referred to as eating disorder not otherwise specified (EDNOS) (American Psychiatric Association, 1994), that included BED as a subtype of this diagnostic category.

Prevalence

The lifetime prevalence of an eating disorder can be defined as the proportion of a population that had an eating disorder at any point in life. Lifetime prevalence estimates of DSM-5 diagnoses of AN have been found to vary between 0.8% and 4.2% (Smink, van Hoeken, & Hoek, 2013), and for BN between 1.6% and 2.6% (Keski-Rahkonen et al., 2009; Stice, Marti, & Rohde, 2013; Trace et al., 2012). Studies investigating the lifetime prevalence of BED on a community-level are scarce, but have been estimated at around 1.9% across several countries according to DSM-4 criteria, and somewhat higher according to the DSM-5 criteria: 2.3% (Smink, van Hoeken, Oldehinkel, & Hoek, 2014) and 3.0% (Stice et al., 2013). Preliminary data regarding the prevalence of OSFED shows varying results. More specifically, two studies have found estimates of around 0.6% (Allen, Byrne, Oddy, & Crosby, 2013; Smink et al., 2014), whereas the results of a study by Stice et al. (2013) demonstrated much higher estimates: 2.8% for atypical AN, 4.4% for subthreshold BN, 3.6% for subthreshold BED, and 3.4% for purging disorder.

Eating disorders are often developed during adolescence and early adulthood (Hudson, Hiripi, Pope, & Kessler, 2007; Kessler et al., 2013). The majority of patients with AN and BN are female (Bulik et al., 2006; Hudson et al., 2007; Kessler et al., 2013); the proportion of men has been found to vary from less than 10% (Hoek & van Hoeken, 2003) to up to 25% (Hudson et al., 2007). With respect to binge eating behaviors however, the gender differences in prevalence are less pronounced (Striegel-Moore et al., 2009) and recent literature even suggests that the number of males and females who experience binge eating behaviors is roughly equal (Mitchison & Mond, 2015).

Course and outcome

The course and outcome varies among the type, nature and severity of the eating disorder, but can be considered unsatisfactory. A large review of 119 studies covering 5,590 patients with AN found that less than half (i.e., 46%) of the patients fully recovered, one-third showed improvements with only partial or residual symptoms of AN, and 20% remained chronically ill (Steinhausen, 2002). For patients with BN the remission rates are somewhat higher, around 70% (Keel & Brown, 2010), and these patients tend to achieve remission faster as compared to patients with AN (Clausen, 2008; van Son, van Hoeken, van Furth, Donker, & Hoek, 2010). Nevertheless, a large review by Steinhausen et al. (2009) found the long-term chronicity rates of AN and BN to be quite comparable. Remission rates for BED seem to be more favorable than for AN and BN, with most estimates varying between 55% and 80% (Keel et al., 2010). The literature with respect to EDNOS/OSFED is scarce and requires further investigation, although preliminary results suggest that remission rates of the bulimic subtype are comparable to those of BN (Keel et al., 2010).

The mortality rate of AN ranks amongst the highest mortality rates of all psychiatric disorders (Chesney, Goodwin, & Fazel, 2014; Harris & Barraclough, 1998). Arcelus et al. (2011) in a meta-analysis demonstrated elevated mortality rates not only for patients with AN, but for patients with other eating disorders as well. Mortality rates were almost twice as high for individuals with an eating disorder as compared to the general population, whereas nearly six times higher for individuals with AN. It is estimated that suicide accounts for approximately 1 in 5 deaths in individuals with AN and BN (Smink et al., 2013).

Recovering from an eating disorder is a challenging and complex process (Federici & Kaplan, 2008; Keski-Rahkonen & Tozzi, 2005), and relapse is a common problem, even after successful treatment. Mostly, reported relapse rates following treatment of AN and BN range between 30 to 50% (Carter, Blackmore, Sutandar-Pinnock, & Woodside, 2004; Carter et al., 2012; Grilo et al., 2007; Halmi et al., 2002; Herzog et al., 1999; Keel & Mitchell, 1997; Keel, Dorer, Franko, Jackson, & Herzog, 2005; Olmsted, Kaplan, & Rockert, 1994; Olmsted, Kaplan, & Rockert, 2005; Richard, Bauer, Kordy, & COST Action B6, 2005; Strober, Freeman, & Morrell, 1997). Investigations of relapse in BED and EDNOS is limited, although rates for EDNOS might be similar to that of BN (Grilo et al., 2007), whereas three studies suggest somewhat lower relapse rates (10-28%) for BED (Agras, Telch, Arnow, Eldredge, & Marnell, 1997; Hilbert et al., 2012; Safer, Lively, Telch, & Agras, 2002).

Burden and costs

The vast majority of individuals with an eating disorder also meet the diagnostic criteria for one or more other psychiatric disorder, the most common being mood, anxiety, behavioral, and substance use disorders (Hudson et al., 2007; Kessler et al., 2013; Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011). Individuals with eating disorders are furthermore at elevated risk for medical complications and physical illnesses (Johnson, Cohen, Kasen, & Brook, 2002; Kessler et al., 2013; Mitchell & Crow, 2006), such as cardiovascular diseases, chronic fatigue, diabetes, obesity, chronic pain, musculoskeletal conditions, gastrointestinal complications, and metabolism problems. The burden of eating disorders is furthermore reflected in significant role impairments regarding work, household, and social relationships (Hudson et al., 2007; Kessler et al., 2013; Swanson et al., 2011). Also, eating disorders are known to negatively impact various important aspects of individuals' life, hence are associated with a poor quality of life (Engel, Adair, Las, & Abraham, 2009; Jenkins, Hoste, Meyer, & Blissett, 2011). Not only the wellbeing of patients is impaired, but the wellbeing of caregivers is also negatively affected as presented by high levels of psychological distress and burden amongst caregivers (Schmidt et al., 2016; Zabala, Macdonald, & Treasure, 2009), as well as impaired quality of life (de la Rie, van Furth, De, Noordenbos, & Donker, 2005).

The economic burden of eating disorders upon patients (Gatt et al., 2014) and society (Stuhldreher et al., 2012) is substantial. Cost-of-illness studies have shown the annual direct medical costs (e.g., health care and pharmaceutical costs) per patient to range between 1,288 to 8,042 US$ (Stuhldreher et al., 2012). On top of this direct medical costs there are indirect costs, that is, costs due to sickness absence or losses in productivity at work. Currently, only two studies have attempted to estimate the indirect costs for patients with AN, with resulting estimates of a total of 4,445 US$ (Krauth, Buser, & Vogel, 2002) per patient, and an estimated mean 3-month cost of €2,492 per patient (Stuhldreher et al., 2015). The indirect costs for patients with BN have only been estimated in one study, at 1,528 US$ per patient (Krauth et al., 2002).

Psychological treatments

What is the current evidence-base for psychological treatments of eating disorders? For children and adolescents with AN, family-based treatment that focuses on empowering the family to help restore the patient's weight, is the treatment of choice (Kass, Kolko, & Wilfley, 2013; National Institute for Clinical Excellence, 2004; Watson & Bulik, 2013; Wilson, 2005; Zipfel, Giel, Bulik, Hay, & Schmidt, 2015). For adults with anorexia nervosa there is no superior treatment approach, although specialized psychological treatment approaches such as cognitive behavior therapy, interpersonal psychotherapy, and specialist supportive clinical management, have been found to reduce symptoms in a considerable amount of patients (Kass et al., 2013; National Institute for Clinical Excellence, 2004; Watson et al., 2013).

The evidence-base for cognitive behavioral therapy for the treatment of bulimia nervosa and binge eating disorder is strong (National Institute for Clinical Excellence, 2004; Kass et al., 2013; Shapiro et al., 2007). Furthermore, there is emerging evidence that interpersonal psychotherapy could be equally effective as cognitive behavior therapy for these disorders, although treatment with interpersonal psychotherapy takes longer to achieve a similar result (Kass et al., 2013; National Institute for Clinical Excellence, 2004). Finally, there is preliminary evidence that self-help programs could be effective as a first step in the treatment of bulimia nervosa and binge eating disorder, and that such programs might even be as effective as cognitive behavior therapy when incorporated as a first step in a stepped-care model for the treatment of these disorders (Crow et al., 2013; Thiels, Schmidt, Troop, Treasure, & Garthe, 2001; Treasure et al., 1996; Perkins, Murphy, Schmidt, & Williams, 2006; Sysko & Walsh, 2008).

Given that eating disorders are characterized by high symptom fluctuation and considerable rates of diagnostic cross-over (Tozzi et al., 2005), and given that the different eating disorder subtypes share overlapping core psychopathology, there has been an

increasing interest in the investigation of enhanced cognitive behavior therapy (CBT-E): a transdiagnostic treatment for eating disorders (Fairburn, Cooper, & Shafran, 2003). This treatment focuses primarily on psychological and behavioral mechanisms that underlie and account for the maintenance of eating disorder psychopathology, such as clinical perfectionism, low self-esteem, mood intolerance, or interpersonal difficulties. The results of some recent studies investigating CBT-E are promising and suggest CBT-E to produce comparable effects as existing psychological treatments (Fairburn et al., 2015; Wonderlich et al., 2014; Zipfel et al., 2014).

Unfortunately, all above mentioned treatments for eating disorders still fail to help a substantial proportion of patients. Wilson et al. (2005) estimated that cognitive behavior therapy resulted in abstinence from binge eating and purging behaviors in approximately 30% to 50% of the cases with bulimia nervosa, and remission from binge eating in over 50% of the cases with binge eating disorder. Rates on abstinence, remission, and recovery rates for CBT-E in various eating disorder populations vary between 20% and 69.4% (Fairburn et al., 2015; Wonderlich et al., 2014; Zipfel et al., 2014).

Unmet need for mental health care

Despite the severity and burden of eating disorders, they often go undetected and the majority of individuals does not seek or receive mental health care for their eating disorder problems (Hart, Granillo, Jorm, & Paxton, 2011; Keski-Rahkonen et al., 2007; Keski-Rahkonen et al., 2009; Swanson et al., 2011). A systematic review by Hart et al. (2011) found that on average as few as 23.2% of patients with an eating disorder seek treatment. Several barriers to help-seeking have been identified, including amongst other things financial reasons (Cachelin, Rebeck, Veisel, & Striegel-Moore, 2001; Cachelin & Striegel-Moore, 2006; Hepworth & Paxton, 2007; Evans et al., 2011), as well as feelings of shame or fear of stigmatization (Becker, Hadley Arrindell, Perloe, Fay, & Striegel-Moore, 2010; Cachelin et al., 2006; Evans et al., 2011; Griffiths, Mond, Murray, & Touyz, 2015; Hepworth et al., 2007). Another important reason that prevents individuals from seeking help is the belief that one's eating disorder problems are not significant enough, or even non-existent, despite the presence of significant eating disorder psychopathology (Cachelin et al., 2001; Cachelin et al., 2006; Hepworth et al., 2007). Along similar lines, a study conducted in the Netherlands (de la Rie, Noordenbos, Donker, & van Furth, 2006) found that it took patients on average 3.6 years to recognize and acknowledge that they were suffering from an ED, and a further 4.2 to 6.3 years to seek treatment.

On top of the delay between the onset of symptoms and seeking treatment, there are significant delays between seeking and actually receiving treatment. A delay of 1.1 years was reported for 50% of the patients in a Dutch community-based sample (de la Rie

et al., 2006), due to reasons such as waiting lists, delays in the referral process, or being sent from one institution to another. Other studies have also reported on the lack of, or limited availability of specialized eating disorder services (Escobar-Koch et al., 2010; Rosenvinge & Klusmeier, 2000) as barriers to access of care. The barriers in seeking and receiving health care are unfortunate, as these may lead to higher symptom severity at the start of treatment, in turn making treatment more difficult. Furthermore, studies have demonstrated that a longer duration of eating disorder symptoms is associated with both poor outcomes and lower chances of recovery (Berkman, 2007; Fichter, Quadflieg, & Hedlund, 2006; Keel et al., 1997; Reas, Williamson, Martin, & Zucker, 2000; Steinhausen, 2002; Zipfel, Lowe, Reas, Deter, & Herzog, 2000). E-mental health has the potential to address the unmet need for health care.

E-(mental) health

There has been an increasing pressure on the sustainability of healthcare systems all over the world, including the Netherlands, due to increasing health care costs (Deloitte, 2015). Consequently, there is an increasing demand for change and innovation in order to deliver health care services and available resources in a more cost-effective manner, while at the same time striving to maintain or improve the quality of health care and outcomes. One such innovation that holds promise in addressing these challenges, pertains E-(mental) health. E-(mental) health is commonly defined as the use of information and communication technologies to support and/or improve (psychological) health care (Riper et al., 2007). Eysenbach (2001) however, has defined E-health in a more dynamic manner: *"E-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology."*.

E-health services can encompass a wide variety of interventions and systems, including electronic health records, psychoeducational programs, self-assessment tools, e-consults with a mental health professional, and extensive treatment programs that individuals can work through with or without the help from a therapist or coach. It follows that E-health services can be applied in many areas of health care targeting a wide range of populations, and serving a wide range of different goals. For example, stimulating self-management and empowerment of patients, informing patients, improving communication between mental health care professionals and patients, improving access

to care, and prevention and early detection, as well as early intervention and treatment of (mental) health problems.

E-health has potential to help decrease the treatment gap of eating disorders by reaching more individuals more quickly. By offering anonymous interventions, barriers related to feelings of shame or fear of stigma and being judged can be reduced, thereby lowering the threshold for seeking help. The convenience and flexibility could be enhanced, as individuals can access interventions modules or information at any time and from any place. Potentially, health care services for eating disorders can be delivered in a more cost-effective manner.

Disease management and E-mental health at Rivierduinen Eating Disorders Ursula

Giving the need for decreasing barriers to care as well as to improve the accessibility, availability, efficiency, and quality of health care services for individuals with eating disorder problems, Rivierduinen Eating Disorders Ursula implemented a stepped-care disease management model in 2009. The former treatment model included day treatment, inpatient treatment, and outpatient treatment. With the introduction of the stepped-care disease management model, several low-threshold interventions have been added as options for care in order to bridge the gap between individuals with an eating disorder in the community and health care services. In addition, the inclusion of these low-threshold interventions could help to improve early detection and intervention of eating disorder problems, and to fast-track individuals to tailored care meeting the individuals' needs.

The website http://www.hulpbijeetproblemen.nl/ provides on overview of the health care services that are offered as part of the stepped-care program by Rivierduinen Eating Disorders Ursula. In the order of lowest to highest with respect to the intensity and degree of tailoring: website and e-community 'Proud2Bme', Internet-based self-help intervention 'Featback', e-mail support from expert patients ('Ervaringsdeskundigheid'), and treatment at our clinical program. This dissertation will focused on Proud2Bme and Featback. Proud2Bme (http://www.proud2bme.nl/) has been developed as a healthy alternative for pro-eating disorder websites and provides a safe, positive, fun, and pro-recovery focused environment. It offers a wide array of information and personal stories as well as platforms for interaction (i.e. forum and chat) with peers and professionals. Internet-based self-help intervention Featback (http://www.featback.nl) comprises psychoeducation and a fully automated self-monitoring and feedback system. By means of this system, individuals can monitor their eating disorder symptoms by means of a short weekly questionnaire, after which they receive a tailored feedback message that is automatically generated according to a pre-defined algorithm. The feedback messages

contain social support and advice on how to counteract on their reported symptoms. In case of severe symptoms, a psychologist from our clinical prorgram contacts the individual and will offer him/her a telephone, e-mail, or chat consult. In this consult, the individual is supported and helped where possible and is furthermore stimulated to seek further (professional) help when needed.

To summarize

Eating disorders represent a significant public mental health concern, which places a large burden on patients, their relatives, and wider society. Unfortunately, there is a wide treatment gap: many eating disorders go undetected and the majority of patients does not seek and receive mental health care. Amongst the minority who does receive treatment, treatments appear to be only moderately effective. Hence, there is a need to improve the current health care services and to decrease barriers to care for eating disorders. Furthermore, there is a need to make health care services more widely available and more easily accessible. E-mental health has much potential in addressing these challenges and provides promising ways to enhance health care for patients with an eating disorder. In addition, E-mental health may also provide an answer to the increasing pressure to establish sustainable health care systems, by delivering innovative ways to increase the efficiency of health care services and to deliver interventions and resources in a more cost-effective manner.

Aims and outline of this dissertation

The aim of this dissertation is to investigate whether and how E-health can help to improve health care for individuals with eating disorder symptoms, thereby focusing on the evaluation of two of the E-health interventions of Rivierduinen Eating Disorders Ursula: the e-community Proud2Bme and the self-help intervention Featback. This aim is pursued by conducting several different studies, each with their own research aims and questions as presented below.

Chapter 2 contains a systematic review of the published literature up until 2013 with respect to the treatment of eating disorders over the Internet. What is the state-of-the-art of Internet-based treatment for disorders, and what are important directions for future research? This Chapter includes a critical evaluation of the methodology of conducted studies, and discusses the effectiveness, predictors of outcome, compliance and dropout rates, as well as the acceptability of Internet-based treatments. Also, directions for future research are presented.

In Chapter 3, we report on a cross-sectional study of the website and e-community 'Proud2Bme': a healthy alternative for pro-eating disorder websites that provides a safe, positive, and pro-recovery focused environment. Research aims are to investigate whether, and to what extent, participants experience empowering processes and outcomes as a result of visiting Proud2Bme. The second aim was to examine correlates of empowering processes and outcomes. More specifically, can certain user characteristics be identified that are related to the experience of empowerment?

Chapter 4 presents the study protocol of a randomized controlled trial investigating Internet-based intervention 'Featback'. Featback comprises psychoeducation, as well as a fully automated self-monitoring and feedback system. This Chapter includes a more detailed description of Featback, as well as the design and procedures of the research trial. Subsequently, Chapter 5 to 8 report on the results of different research questions as part of this randomized controlled trial.

Chapter 5 focuses on the question of whether Featback is effective in reducing eating disorder psychopathology and comorbid symptoms. Furthermore, the added value of different intensities of therapist support is examined, by comparing participants' symptom levels and satisfaction with the intervention when offered Featback without therapist support, Featback with low-intensity therapist support (once a week), and Featback with high-intensity therapist support (three times a week). Finally, participants' experiences with Featback are reported on.

In Chapter 6, potential moderators of intervention outcomes within the Featback trial are examined. Is Featback more effective for some individuals than others? Can subgroups of individuals be identified that show better outcomes when provided low-intensity of high-intensity therapist support on top of the fully-automated Featback intervention?

In Chapter 7, potential mediators of change in eating disorder psychopathology during the intervention period of Featback are examined, thus examining possible mechanism that might explain how or why Featback works.

Chapter 8 reports on the economic evaluation of Featback in comparison to a waiting list control condition, including cost-effectiveness and cost-utility analyses. What are the costs and health benefits of Featback in comparison to a waiting list, and is adding a certain amount of therapist support good value for money?

In Chapter 9, all digital therapist communication within the therapist support sessions of Featback is qualitatively examined. What do therapists actually do within the online support sessions as offered in addition to Featback? And can therapist behaviors predict participants' outcome and satisfaction?

In Chapter 10, we aimed to discuss the emerging findings, issues, and opportunities regarding E-health for eating disorders in the past few years (2013-2015). How effective are self-help interventions, treatment, and relapse prevention programs? What is the potential of Smartphone applications in treating eating disorders? Opportunities and challenges for the development and implementation of E-health for eating disorders are furthermore discussed.

Finally, Chapter 11 contains a summary and general discussion of the main findings. Furthermore, the strengths and limitations are considered, and implications and directions for future research as well as clinical practice are presented.