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Binge-eating disorder in the Arabic world and the Netherlands, assessment, etiology, efficacy, effectiveness and economic evaluation of psychological interventions

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1. Chapter 1 General introduction

Background

Eating disorders have a significant impact on the psychological, social and physical well-being and quality of life of affected patients (Agh et al., 2015; Hay et al., 2015; Rojo-Moreno et al., 2015) including anxiety, depression, and even high rates of mortality (Smink et al., 2012; Watson et al., 2012). The conceptualization of eating disorders has expanded over the last 10 years (Hay, 2020). The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM 5) specifies four types of eating disorders: anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED) and otherwise specified feeding or eating disorder (OSFED). The OSFED category comprises patients who do not meet the behavioral frequency or all other criteria of AN, BN or BED (APA, 2013). However, until 2013 BED was a provisional diagnosis and therefore not included in the DSM. Therefore, BED is the most recently acknowledged eating disorder. Main reason for the revision of the DSM was the high frequency of eating disorder not otherwise specified (EDNOS) diagnoses. All other eating disorders of clinical significance that did not meet the criteria of AN or BN received the diagnosis EDNOS, even patients that barely missed the diagnostic threshold for AN or BN, or patients that met the criteria for BED (Smink et al., 2013; Walsh et al., 2015). Consequently, the diagnostic criteria for AN and BN were elaborated upon, and new disorders, such as BED were added in the DSM-5 (APA, 2013). The broader criteria of eating disorders are more likely to increase the clinical utility of the DSM-5 (Hay, 2020).

Eating disorders can either be approached from a diagnostic perspective, stipulating the differences among the various eating disorders, or from a transdiagnostic perspective. The transdiagnostic model for eating disorders assumes that all disorders share the same maintaining mechanisms (Fairburn et al., 2003), rather than each having a unique underlying

factor. The core overarching mechanism of all eating disorders is evaluating one's self-worth predominantly in terms of control over weight, shape and eating (Cooper & Fairburn, 2011; Fairburn et al., 2003). The diagnostic approach states that the differences among the various eating disorders are that AN is characterized by a severely restrictive food pattern, malnourishment, being underweight and sometimes the occurrence of binges followed by compensatory behavior such as laxative misuse and purging behavior. In contrast, BN is characterized by a normal weight, binges followed by compensatory behavior and a restrictive, irregular food pattern. Lastly, BED is characterized by an irregular food pattern, recurrent episodes of binge eating accompanied by a sense of lack of control, marked distress and absence of compensatory behavior. The binges are followed by feelings of shame, guilt and disgust (APA, 2013; Hay, 2020). Finally, OSFED refers to eating disorders which do not meet the criteria for AN, BN or BED, such as atypical AN, atypical BN, atypical BED, purging disorder or night eating syndrome. Life-time prevalence of AN is estimated at 0.16% and 0.63% for BN (Qian et al., 2021). BED and OSFED are the most common eating disorders with estimated life-time prevalence of 2% (Kessler et al., 2013) and 5% (Hay, 2020), respectively. However, these numbers might be outdated as recently, and related to the Covid-19 crisis, the estimated prevalence of BED has increased and patients seeking help display more severe symptoms (Termorshuizen et al., 2020).

Though BED is the most common eating disorder, BED remains underrecognized in comparison to AN and BN (Mitchison & Hay, 2014) leading to undertreatment of this disorder in clinical practice in the Netherlands. At the Novarum center for eating disorders we regularly admit patients who suffer from BED complaints for decades. Usually, they have been referred for weight loss treatments in the past. Consequently, the number of binges increase which leads to weight gain (Fairburn, 2008).

In conclusion, there is still a lack of sufficient data about clinical characteristics and the clinical course of BED. Moreover, due to its recent acknowledgement, data regarding BED examining the etiology, prevalence, correlates, and response to treatment are scarce. Therefore, this dissertation will focus on BED. It will focus on several knowledge gaps regarding assessment, prevalence, and correlates of BED. Another focus area will be treatment for BED: its efficacy, effectiveness, and cost-effectiveness. In short, three main subjects will be addressed in this dissertation: assessment, correlates and treatment.

Eating disorders occur globally

Though data regarding efficacy and cost-effectiveness of treatments for BED are scarce in the western world, etiology, prevalence, and correlates are unknown of several Arab countries such as Saudi Arabia. This may be because traditional Arab notions of beauty differ from the western ideal, with a curvy body being associated with fertility and wealth (Ford et al., 1990). However, since the rise of the thin ideal (Gordon, 2001) there are indications that also evaluation of self-worth predominantly in terms of control over weight and shape is increasingly prevalent in Saudi Arabia. After observation of the large diet (Imarcgroup, 2023) and cosmetic surgery (Bell, 2019) industries and from personal communications, it could cautiously be concluded that overevaluation of shape and weight is present in modernized Saudi Arabia. In addition, recent studies show that eating disorders occur globally (Keel & Klump, 2003; Thomas et al., 2016). However, research regarding eating disorders including BED is still in its infancy in Saudi Arabia. In addition, the lack of popular knowledge about eating disorders leads to stigmatization, and delayed help seeking (Griffiths et al., 2015). Since it is culturally unacceptable to discuss personal matters with non-family members, only 0.3% of Saudis with an eating disorder seek help, compared to 20% of eating disorder patients in western countries (Latzer et al., 2009). Saudis are more prone to seek help when they

experience physical complaints, such as diabetes mellitus or kidney failure. Furthermore, eating disorders are not perceived as diseases of primary care and therefore barely recognized in Saudi Arabia (Alkhadari et al., 2016). Saudi Arabia faces an absence of assessment tools and specialized treatment centers (Darcy et al., 2012; Qadan, 2009). Moreover, Saudi Arabia is a widespread country, covering 2,150,000 km², including large desert plains. Therefore, even when specialist facilities would be available, Saudis would potentially deal with geographical barriers for treatment (Abrahamsson et al., 2018). Research regarding eating disorders in Saudi Arabia is further complicated by Saudi being a relatively culturally reclusive society, hard to access, and dealing with several taboos regarding mental health problems. Moreover, Saudi citizens are very sensitive to how they are viewed by others, and therefore, less likely to participate in surveys, questioning them on their personal beliefs and values (Al-Darmaki, 2003). It is challenging to build stepping stones for the investigation of eating disorder pathology in Saudi Arabia. It is deemed necessary to increase awareness on eating disorders in the Saudi community (Thomas et al., 2014).

Correlates of eating disorder pathology

The Saudi culture is currently undergoing rapid changes. Since the oil boom of the 1970's Saudi Arabia is dealing with an increased affluence resulting in rapid sociocultural and socioeconomic changes (Pike et al., 2014; Thomas et al., 2018). Furthermore, research shows that countries dealing with rapid sociocultural changes are impacted by an increase in eating disorder prevalence (Gordon, 2001; Pavlova et al., 2010). Various explanations have been put forth. Sociocultural changes come along with a sedentary lifestyle (WHO, 2006), and a dietary shift towards western types of foods, higher in salt, sugar and fat, all instrumental in the rise of excess weight (Hawks et al., 2004; Madanat et al., 2007). Currently, Saudi Arabia has one of the highest prevalence rates of excess weight (WHO, 2006), which is known to be

associated with eating disorder pathology, especially with recurrent binge eating and BED (Unikel Santoncini et al., 2018; Van der Horst et al., 2019; Van Son et al., 2013). Moreover, excess weight appears to be associated with body-shape dissatisfaction, and Saudis who are dissatisfied with their bodies have an increased risk for unhealthy dietary habits (Stice & Shaw, 2002), which may increase the risk of developing eating disorder pathology (Cooper et al., 1987). Other consequences of the rapid sociocultural changes in Saudi Arabia are associated with eating disorder pathology as well. The arrival of western companies, western expatriates (Thomas et al., 2018; Zeeni et al., 2013), increased exposure to western cultures (Pike & Dunne, 2015), and western social media (Madanat et al., 2007; Musaiger & Al-Mannai, 2013, 2014) led to a rise in the popularity of the “thin ideal” (Ford et al., 1990; Thomas et al., 2014). Consequently, levels of dieting, body-shape dissatisfaction and eating disorder pathology increased (Gow et al., 2020; Haines & Neumark-Sztainer, 2006; Pike & Dunne, 2015). Furthermore, rapid sociocultural changes might be accompanied by low self-esteem and increased stress. Both appear associated with eating disorder pathology (Gow et al., 2020; van der Valk et al., 2018; Yoneda et al., 2021). In addition, excess weight strengthens the association between eating disorder pathology and its correlates (Friedman et al., 2002; Madanat et al., 2007; Musaiger & Al-Mannai, 2013). However, since Saudi Arabia deals with a high prevalence of excess weight it is unclear whether media use, body-shape dissatisfaction, low self-esteem, increased socio-economic status, westernization and perceived stress are still correlates of eating disorder pathology after controlling for the effect of body mass index (BMI, kg/m^2) (Gow et al., 2020; Haines & Neumark-Sztainer, 2006; van der Valk et al., 2018; Yoneda et al., 2021). The prevalence of eating disorder pathology could potentially be predominantly associated with the rates of excess weight (Unikel Santoncini et al., 2018). Identification of correlates of eating disorder pathology, including BED and the covarying role of high BMI may facilitate the identification of individuals at risk for

developing an eating disorder and who may benefit from participation in prevention programs (Stice et al., 2010; Stice et al., 2007). Consequently, reliable and valid assessment tools adapted to the Saudi language and culture are needed, in order to detect Saudis at high risk of eating disorders and body-shape dissatisfaction (Latzer et al., 2009; Musaiger et al., 2013). Therefore, this dissertation will first focus on assessment of eating disorder pathology.

Assessment

Various interview and self-report measures are developed to screen for eating disorders and body-shape dissatisfaction . The Eating Disorder Examination (EDE), a semi-structured interview is the most widely used assessment tool to assess eating disorders and eating disorder symptoms such as binge eating and shape concern (Cooper & Fairburn, 1993). The EDE is generally considered reliable and valid, has good internal consistency (Cooper et al., 1989), test-retest reliability (Rizvi et al., 2000), and discriminative and concurrent validity are supported (Rosen et al., 1990). However, as administration of the EDE is time consuming and the instrument needs to be administered by trained professionals, self-report measures can be a less time consuming and more practical alternative. The Body Shape Questionnaire (BSQ) (Cooper et al., 1987) is most often used to measure body-shape dissatisfaction (Rosen et al., 1996). The original British BSQ (Cooper et al., 1987) is translated and adapted to various western cultures, such as Sweden, Norway, Portugal, Spain, Italy and various Latin-American countries such as Brazil, Colombia and Mexico (Ayensa et al., 2002; Castrillón Moreno et al., 2007; da Silva et al., 2014; Kapstad, 2015; Pook, 2008; Rosen et al., 1996; Stefanile et al., 2009; Welch et al., 2012). In addition, the Eating Disorder Examination-Questionnaire (EDE-Q) (Fairburn & Beglin, 1994) is a self-report measure based on the EDE (Cooper & Fairburn, 1993). The EDE-Q and EDE show acceptable levels of agreement, and therefore, when necessary, the EDE-Q can be used instead of the EDE (Reas et al., 2006).

Therefore, the EDE-Q is the most widely used self-report assessment tool to screen for eating disorder pathology and to assess its severity (Fairburn & Beglin, 1994). The EDE-Q is currently available in the Netherlands, Finland, Spain, Australia, Malaysia, Japan, Mexico and Israel, and various other countries (Aardoom et al., 2012; Calugi et al., 2017; Isomaa et al., 2016; Peláez-Fernández et al., 2012; Unikel Santoncini et al., 2018; Zohar et al., 2017). Although the BSQ and EDE-Q are valid and reliable assessment tools with good psychometric properties, such as high internal consistency and test-retest reliability, factorial and convergent validity (da Silva et al., 2014; Isomaa et al., 2016; Kapstad, 2015; Luce et al., 2008; Pook, 2008; Rosen et al., 1990; Welch et al., 2012), the BSQ and EDE-Q are currently not available in an Arabic version adapted for use in Saudi Arabia. Absence of assessment tools to measure body-shape dissatisfaction and eating disorder pathology may lead to overlooking or underdiagnosing BED and other eating disorders, which hampers timely proper treatment (Alkhadari et al., 2016). In addition, the ability to screen for body-shape dissatisfaction is an important first step to help prevent eating disorders through intervention programs, since targeted programs are more effective than universal preventative programs (Stice et al., 2019). Due to cultural differences, norms for Western and Arabic populations may differ (Welch et al., 2011). Therefore, the present thesis aims to adapt the BSQ and EDE-Q to the Saudi language and culture and evaluate its psychometric properties. In addition, valid assessment tools could also be used to measure reduction of eating disorder symptoms after eating disorder treatment, and therefore to assess efficacy and effectiveness of the various eating disorder treatments across the globe. This dissertation will also focus on efficacy and effectiveness of eating disorder treatment.

Treatment

Data regarding efficacy, effectiveness and cost-effectiveness of treatments for BED are scarce in the western world. Currently there is a range of treatments available for BED and other eating disorders, such as Dialectical Behavioral Therapy, Interpersonal Therapy and Cognitive Behavioral Therapy (ANZAED, 2014; Fairburn, 2008; NICE, 2017). Treatments for eating disorders based on cognitive behavioral principles display superior treatment outcomes (Agras et al., 2000). However, in 2003 Fairburn suggested that eating disorder pathology is maintained by a set of common mechanisms and that treatments addressing these mechanisms should be effective for various eating disorder presentations (Fairburn et al., 2003). Therefore, Fairburn modified the most leading evidence-based treatment for BN (CBT-BN) (Cooper & Fairburn, 1993) to make it suitable for treatment of all eating disorders. This resulted in Enhanced Cognitive Behavioral Therapy (CBT-E) (Fairburn, 2008), of which efficacy is proven in several randomized controlled trials. CBT-E appeared effective among transdiagnostic samples and for adult patients suffering from BN and atypical AN (Fairburn et al., 2003). In addition, CBT-E appeared also effective among adolescents with BED. Therefore, the Dutch national guideline recommends “Cognitive Behavioral Therapy-Enhanced” (CBT-E) (Zorgstandaard, 2021). However, data are scarce on how adult patients diagnosed with BED respond to CBT-E when offered individually (Berg et al., 2020; Fairburn et al., 2015; Fairburn et al., 2009; Wade et al., 2017). In addition, efficacy of CBT-E is mostly examined in randomized controlled trials, conducted under ideal circumstances, while effectiveness studies involve a naturalistic design and measure the degree of beneficial effect in real world, clinical settings (Andrews, 1999; Nordon et al., 2016). Therefore, as efficacy of CBT-E is well documented, its effectiveness among patients suffering from BED should be investigated. Furthermore, comparing the effectiveness of CBT-E between various eating disorders could potentially confirm its transdiagnostic nature. Moreover, determination of factors predicting CBT-E treatment outcome would provide prognostic information about for

whom CBT-E is likely to be beneficial and for whom less so. Treatment outcomes can potentially be maximized by understanding its predictors as more targeted treatments can be offered and potentially add-ons can be developed, thus improving clinical decision making (Kraemer, 2013).

Towards more efficiency: Guided self-help treatment

CBT-E is effective, but it is a time consuming treatment, requesting intense therapist involvement. In order to offer more efficient treatments, several new technologies are implemented, such as online guided self-help interventions or eMental Health (Donker & Kleiboer, 2018; Eysenbach, 2001). Therefore, the availability of eMental Health interventions has grown extensively over the past years. During eMental Health interventions patients will complete home assignments and upload them in an interactive treatment platform. eMental Health interventions can be unguided or therapist guided. During guided interventions patients and therapist interact through telephone calls, videoconferencing or chat. In addition, guided eMental Health interventions are more effective than unguided eMental Health interventions (Andersson & Cuijpers, 2009; Palmqvist et al., 2007; Spek et al., 2007). Furthermore, eMental Health interventions are effective for alcohol abuse (Cunningham et al., 2009; Eysenbach et al., 2010), depression (Andersson & Cuijpers, 2009; Andrews et al., 2010; Spek et al., 2007) and anxiety disorders (Andrews et al., 2010; Palmqvist et al., 2007; Spek et al., 2007). However, it is yet unknown whether CBT-E is effective and indeed efficient when offered by an online treatment modality. In addition, many authors mention the present gap between treatment needs and treatment provision (Abrahamsson et al., 2018; Becker et al., 2010; Fairburn & Patel, 2017; Shafran et al., 2009). There is a lack of specialized therapists and consequently, eating disorder patients have to deal with long waiting time to commence treatment (Fairburn & Peveler, 1990; Shafran et al., 2009). For instance, over all treatment

facilities in Amsterdam, the average wait time for an initial intake session is 11 weeks, and a further 20 weeks for treatment (NZA Nederlandse zorg autoriteit). Thus, there is a need to increase access for patients to specialized eating disorder treatment (Abrahamsson et al., 2018). The shortage in treatment availability can be covered by offering treatment as eMental Health. eMental Health offered as a guided self-help intervention may reduce the amount of intensive therapy, the amount of specialists time invested in a single treatment and, therefore, potentially reduce waiting time duration (Abrahamsson et al., 2018; Fairburn & Peveler, 1990; Shafran et al., 2009). Furthermore, guided self-help increases access to specialized treatment (Abrahamsson et al., 2018), which may improve quality of life (Fairburn & Peveler, 1990; Shafran et al., 2009). Guided self-help has also several additional advantages for the patient, such as the removal of geographical barriers, the possibility to hold sessions within the patient's own environment, reduced travel costs and travel time, and to communicate with their therapist wherever they are (Abrahamsson et al., 2018; Becker et al., 2010; Evans et al., 2011). Furthermore, according to a stepped care principle (Bower & Gilbody, 2005), guided self-help should be the first treatment of choice for patients diagnosed with BED, as preferably, the least resource-intensive treatment is delivered first (Mitchell et al., 2011). As international guidelines recommend guided self-help based on cognitive behavioral principles for BED (ANZAED, 2014; NICE, 2017), offering a guided self-help version of CBT-E including 12 weekly brief telephone sessions first might be an efficient treatment modality for BED.

Responding to the absence of a CBT-E based guided self-help treatment in Dutch, Novarum, Center for Eating Disorders in the Netherlands, developed a guided self-help version of CBT-E, based on the self-help section (Part two) of *Overcoming Binge Eating, The Proven Program to Learn Why You Binge and How You Can Stop* (Fairburn, 2013; Fairburn, 2016). As a first step of evaluating this treatment modality for BED, its efficacy should be

examined in a randomized controlled trial by comparing outcomes of an experimental treatment group to a waiting list control group. Thus, efficacy will be examined in comparison to a delayed treatment control condition. It is hypothesized that guided self-help CBT-E is superior to the control condition with regard to a decrease in binges, full recovery and diminished clinical impairment. Guided self-help CBT-E is also expected to be superior to the waiting list with regard to an increase in self-reported quality of life.

When the efficacy of guided self-help CBT-E is demonstrated, it could potentially mitigate the scarcity of specialized therapists, since guided self-help CBT-E requires less therapist involvement. In addition, if proven efficacious guided self-help CBT-E could be a cost-effective alternative compared to treatment as usual (ANZAED, 2014; NICE, 2017). Guided self-help CBT-E is briefer than in-person CBT-E and therefore potentially associated with lower costs of offering treatment. For example, costs of offering guided self-help based on regular CBT vary between €630- €900, whereas the costs for in person CBT-E are around €3,500 (Berg et al., 2020; Jenkins, 2021; König et al., 2018). In addition, guided self-help CBT-E potentially decreases societal burdens (Weissman, 2017), since BED is associated with non communicable diseases such as hypertension and diabetes mellitus (Eapen et al., 2006) and decreased work place productivity (Jenkins, 2021).

Conclusion

While studies regarding eating disorders are in their infancy in Saudi Arabia, knowledge in the Netherlands is more advanced. The Netherlands has several validated assessment tools available, such as the EDE (Cooper & Fairburn, 1993) and the EDE-Q (Fairburn & Beglin, 1994) as well as several kind of evidence based psychological treatments for eating disorders. Example of such an effective treatment is CBT-E (Berg et al., 2020; Fairburn et al., 2015).

However, effectiveness of CBT-E for BED is currently unknown, as well as efficacy and cost-effectiveness of the recently developed guided self-help version of CBT-E.

Saudi Arabia currently deals with an absence of culturally validated assessment tools and specialized treatment centers. It is of importance to increase awareness regarding eating disorders since Saudi Arabia currently deals with rapid sociocultural changes, which is associated with eating disorder pathology (Pike et al., 2014; Thomas et al., 2018). Cautiously, it can be concluded that the current state of knowledge concerning eating disorders in Saudi Arabia appears comparable to those of eating disorders in the Netherlands around the 1980's (Alkhadari et al., 2016; Qadan, 2009).

Aims

In this dissertation several knowledge gaps of aspects of eating disorders, mainly BED in the Netherlands and Saudi Arabia will be investigated. However, due to the major differences regarding the current state of knowledge, studies in the Netherlands will focus on different aspects of BED than in Saudi Arabia. Each chapter in this thesis focuses on different aspects of eating disorders which include screening, identification of correlates and therefore individuals at potential risk, treatment effectiveness, treatment efficacy, and cost-effectiveness.

Aim of the studies in Saudi Arabia is two-fold: (1) to adapt and examine psychometric properties of the two most used assessment tools to examine body dissatisfaction and eating disorder pathology: the BSQ and EDE-Q; (2) to investigate potential correlates of eating disorder pathology.

Main purpose of the studies in the Netherlands is to examine the effectiveness and efficacy of two treatment modalities of CBT-E for BED. The first treatment modality will be

in-person CBT-E for BED. As several trials showed that the efficacy of CBT-E is well documented among BN and transdiagnostic samples, its effectiveness in clinical practice using ROM data will be evaluated for patients with BED. Through a naturalistic design, outcome predictors of CBT-E will also be examined. The second treatment modality for BED will be eMental Health, offered as an online guided self-help version of CBT-E. Therefore, next efficacy of guided self-help CBT-E for BED will be examined through a randomized controlled trial (RCT) and an economic evaluation alongside the RCT will be undertaken.

Outline of this thesis

Chapter 2 reports on the evaluation of an adapted version of the EDE-Q in order to make it suitable for use among Saudis.

Chapter 3 describes the development of a Saudi version of the BSQ.

Chapter 4 presents a comprehensive synthesis regarding rapid sociocultural changes in Saudi Arabia and its consequences, including correlates and risk factors for BED. It will offer guidance for further studies investigating correlates of eating disorders.

Chapter 5 investigates the associations between expressions of sociocultural changes and eating disorder pathology in Saudi Arabia.

Chapter 6 will examine the effectiveness of CBT-E in everyday clinical practice. It investigates and compares effectiveness of CBT-E among patients with BED to patients diagnosed with BN and OSFED. Furthermore, predictors of treatment outcome are evaluated.

Chapter 7 will present the study protocol of the study described in Chapter 8.

Chapter 8 reports on the efficacy of online guided self-help CBT-E in a randomized controlled trial.

Chapter 9 will focus on cost-effectiveness and cost-utility of guided self-help CBT-E utilizing the outcome data of the randomized controlled trial.

Finally, **chapter 10** contains a summary and general discussion of the main findings.

Furthermore, the strengths and limitations will be discussed, and directions for future studies will be considered. Last, implications of the findings of the studies for clinical practice will be presented.

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