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Internet-based treatment for eating disorders: bridging the treatment gap

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Chapter 1

Introduction



Introduction

A question that has sparked interest since the rapid progress in computer and internet technology, is whether the sector of mental health care can be improved using such technology. Indeed, especially since the COVID-19 pandemic, technological innovations have been creatively implemented in many mental health institutions to keep patient care on track. Examples are therapy through video conferencing and using online modules or smartphone applications to help patients work on recovery even when possibilities for direct contact are limited. However, to confidently use such innovations it is necessary to investigate if they work, under what conditions they work most effectively and how they compare to alternatives, such as regular face-to-face treatments. The question of how to optimally use technology in the mental health sector should therefore be broken down into smaller pieces that can individually be researched. In this thesis, eating disorders will be the topic of interest. Not only are these disorders burdensome on both an individual and societal level, but some distressing characteristics coinciding with eating disorders, such as high levels of shame and a reluctance to seek appropriate care, might be well targeted by technology-based interventions.

Eating Disorders

Eating disorders are mental disorders, indicating that they are characterized by dysfunctional behavioral or mental patterns (centered around eating) that cause considerable distress or impaired functioning. Eating disorders frequently lead to severe psychiatric and somatic complications, reductions in quality of life or even death (Smink et al., 2013). There is evidence to suggest that the lifetime prevalence of eating disorders (i.e., the proportion of the population that will experience an eating disorder at some point in their life) has been growing and is now around 7.8% (Galmiche et al., 2019). The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) recognizes four distinct eating disorder diagnoses: binge eating disorder, bulimia nervosa, anorexia nervosa and other specified feeding and eating disorders. A short account on each disorder is presented in Table 1.

It must be noted that while differences between the diagnoses exist, there are many common factors, such as a negative self-image, over-evaluation of weight and shape and disturbances in regulating mood and impulsivity (Lampard et al., 2013). Moreover, over 70% of people with an eating disorder also experience other psychiatric difficulties, such as self-harming behaviors, anxiety and depressed mood (Keski-Rahkonen & Mustelin, 2016). These comorbid psychiatric problems as well as physical problems that coincide with the eating problems, such as chronic pain, diabetes or problems with weight, result in more frequent use of health care services of individuals with an eating disorder compared to those without (Ágh et al., 2016; Weissman & Rosselli, 2017). However, they often do not seek or get help specifically for their eating problems (Hart et al., 2011). Indeed, it may take up to 68 months before individuals with an eating disorder receive targeted help for their problems (Austin et al., 2021). This discrepancy between developing eating disorder symptoms and not receiving appropriate care is referred to as the treatment gap. Bridging this treatment

gap, or in other words getting people with an eating disorder into appropriate care more quickly, will go a long way in making eating disorder treatment more effective on a systemic level (Moessner & Bauer, 2017). But how do we go about bridging this treatment gap?

Table 1. Description of the four eating disorder diagnoses

Disorder	Description	Lifetime prevalence estimates (Galmiche et al., 2019)	Recovery rates after treatment (Eddy et al., 2017)
Binge eating disorder	Recurring episodes of eating an objectively large quantity of food (compared to most others in a similar situation) in a short period of time (within two hours) and simultaneously feeling out of control or unable to stop.	2.8% for women, 1.0% for men	Estimated between 19-77%
Bulimia nervosa	Frequent binge eating episodes that are compensated, for instance by self-induced vomiting, use of laxatives, fasting and excessive movement or exercise.	1.9% for women, 0.6% for men	Estimated between 55% and 68%
Anorexia nervosa	Restricted food intake (and weight loss) driven by an intense fear of gaining weight or being fat. The self-image of people with anorexia nervosa is distorted, so that they believe they are heavy even when they are (severely) underweight.	1.4% for women, 0.2% for men	63% recovery (after 22 year follow-up)
Other specified feeding and eating disorder	Diagnosed when behavioral or psychological patterns similar to that of other eating disorders are present, but symptoms do not fit one of the three other diagnoses.	4.3% for women, 3.6% for men	Unknown

eHealth for eating disorders

eHealth refers to the use of technologies such as the internet and smartphone applications in health care. Internet interventions can act as stand-alone intervention or as addition to face-to-face treatment, and they differ regarding their content and technical features. For example, they can be completely self-guided (no guidance, automated) or have some form of guidance. Many internet interventions contain email or telephone contact with a health professional (e.g., a psychologist) in addition to an automated part of the intervention, such as online modules with information and tasks a user can complete. Internet interventions

have been proposed as a possible solution for challenges in mental health care, such as long waiting lists, financial pressure and reaching underserved populations (Aardoom, Dingemans, & Van Furth, 2016). Indeed, eHealth might be especially useful to target eating disorders. For example, internet interventions can be made anonymous so that feelings of shame and unsafety might be more easily overcome (Bachner-Melman et al., 2018; McClay et al., 2014). Consequently, individuals with an eating disorder can arguably be reached more quickly through the internet than through gatekeepers such as the general practitioner. Successful implementation of internet interventions to improve access to psychological treatment has already been reached for other mental disorders, such as depression and anxiety (Titov et al., 2018). While implementation of online interventions for eating disorders in society is not yet common, multiple trials have been conducted to investigate the feasibility and effectiveness of internet interventions (Aardoom et al., 2013b; Beintner et al., 2012; Dölemeyer et al., 2013; Linardon et al., 2020; Loucas et al., 2014; Melioli et al., 2016; Pittock et al., 2018; Schlegl et al., 2015; Taylor et al., 2021; Wade & Wilksch, 2018; Zeiler et al., 2021a). Overall, internet interventions for eating disorders have been found to be effective in reducing eating disorder symptomatology, such as disordered eating behaviors, body dissatisfaction and fear of weight gain. An online self-help program that has been developed and researched in the Netherlands is Featback. It contains an automatic monitoring and feedback system to help users become aware of (the severity of) their eating problems and seek support, either from within their close surroundings or professionally. It has been found to be effective in reducing eating disorder related problems and feelings of anxiety and depression (Aardoom, Dingemans, Spinhoven, et al., 2016).

Guidance

Across mental disorders, there is evidence to suggest that incorporating guidance increases the effectiveness of internet-based interventions (Baumeister et al., 2014). However, for eating disorders, mixed results on the effectiveness of adding guidance were found (Yim & Schmidt, 2019b). For example, a meta-analysis investigating individual components of eHealth interventions for eating disorders, found that guidance did not moderate intervention effectiveness (Barakat et al., 2019). This is surprising given that online guidance is repeatedly found to be highly valued (Galmiche et al., 2019; Yim & Schmidt, 2019a). Accordingly, Aardoom, Dingemans, Spinhoven, et al. (2016) showed that while adding online chat or email support by a psychologist increased satisfaction with the Featback intervention, it did not result in increased effectiveness. An explanation for lacking effectiveness of psychologist support could be that individuals with an eating disorder still experienced barriers to fully engage with the offered support, such as shame, fear to be stigmatized and feeling misunderstood. These barriers may be lower when guidance is offered by experts by experience. Such expert patients have a lived experience of an eating disorder, are fully recovered and have been trained to use their own experience to help others who are currently struggling with eating problems. Expert patients might inspire hope of recovery because they are proof that recovery is possible (Simoni et al., 2011), and a shared background with current sufferers could help to bond more quickly compared to other health professionals (Montoya & Horton, 2012). There is some evidence to suggest that support from expert patients has beneficial

effects for both the individual with an eating disorder and the expert patients themselves (Fogarty et al., 2016). For example, when providing support expert patients are affirmed in what they have already accomplished, the challenges they have overcome and how well they are doing currently. For individuals receiving support from an expert patient, findings cautiously suggest that the support can enhance quality of life, relationships and adherence to an intervention (Cardi et al., 2019; McCarroll, 2012; Perez et al., 2014; Ramjan et al., 2017). In summary, expert-patient support might be a strategic alternative to support from other health professionals, especially in the context of low-threshold interventions (like Feedback), aimed at individuals who do not yet receive fitting professional care. However, more high-quality research establishing its effectiveness is warranted.

Costs of eating disorders

The search for innovative interventions, such as internet interventions and expert-patient support, continues in an effort to improve the overall effectiveness of eating disorder treatment, but also to reduce treatment related costs. Indeed, the impact of mental illness on society is huge, ranking the top 3 of causes of global burden (Vigo et al., 2016). The worldwide economic costs of mental disorders was estimated to be 2.5 trillion US dollars in 2010 and might be as high as 6 trillion dollars by the year 2030 (Marquez & Saxena, 2016). These costs are considerable, but most countries spend a disproportionately small amount of their yearly health budget on mental health and fail to provide people with the mental health services they need (World Health Organization, 2021), warranting both policy changes and continued effort to find effective and inexpensive treatment options.

Looking more specifically at costs associated with eating disorders, health care costs for people with eating disorders were estimated to be 48% higher compared to people in the general population (Van Hoeken & Hoek, 2020). Expected annual health care costs for individuals with eating disorder were estimated to be between €888 and €55K (Ágh et al., 2016). According to a study in the US, the additional yearly costs of eating disorders might be as high as \$12K per person with an eating disorder when also considering costs outside of health care, such as reduced work productivity and caregiver costs (Deloitte Access Economics, 2020). Consequently, timely, effective and inexpensive treatment might not only reduce the burden on the individual, but on society as a whole. E-mental health has been proposed as a cost-effective alternative to usual care (F. Griffiths et al., 2006), but economic evaluations are necessary to substantiate this (Hedman et al., 2012; Tate et al., 2009).

Economic evaluations in mental health care

Economic evaluations can help to determine whether the benefits of an intervention outweigh the costs associated with the intervention compared to an alternative (e.g., doing nothing, care as usual or another intervention). The goal is to inform on the extent to which treatment options are worth their costs, so that patients and society pay a fair price. Specifically, there is a scarcity of financial resources in the mental health care sector, so economic evaluations are important for clinicians and policy makers to aid decisions about which interventions or treatments should receive funds in order to provide the best possible care.

Utilities

Economic evaluations can take several forms, one of which is the cost-effectiveness analysis. With this method, costs and effects, such as the extent to which certain symptoms are reduced, of an intervention of interest are compared to the costs and effects of a different course of action. In a specific form of cost-effectiveness analyses (called cost-utility analyses), the effectiveness is operationalized by quality-adjusted life years (QALYs). QALYs help to determine a fair price for a treatment based on how well it works. Basically, the QALY is an established measure of all the benefits and detrimental effects of a certain course of action. For example, a cream for toenail fungus might have a small benefit for people, producing some QALYs. Possibly, an EMDR trauma treatment and a drug treatment for insomnia lead to more significant benefits such as enhanced quality of life or even life prolongation, producing more QALYs. However, the drug treatment for insomnia has some bad side-effects, reducing its QALYs. Consequently, courses of action across disorders can be compared in how much QALYs they produce, which can inform resource allocation decisions (e.g., spending more money on EMDR trauma treatment and less on toenail fungus cream). To calculate QALYs of an intervention, a group of people receiving an intervention are inquired after their appreciation of their life quality, referred to as utility, over a period of time during and after the intervention. Utility can vary from 0 (death) to 1 (perfect life quality). QALYs produced by an intervention, then, equals the utility value multiplied by the years lived with this utility.

Generally, utility values are derived from quality-of-life scores obtained from generic health questionnaires such as the EQ-5D (EuroQol Group, 1990) or Short-Form-Six-Dimensions (Brazier et al., 1998). Such questionnaires approach quality of life as one's perception of their position in relation to their life goals, which is affected by one's physical health, psychological state, level of independence, social relationships, and environmental factors (WHOQOL Group, 1995). Therefore, they assess different domains of functioning that are found to be important contributors to one's quality of life, like physical functioning, vitality, pain, social participation, and mental health. Nevertheless, although the use of utilities (and corresponding QALYs) is widespread in economic evaluations, generic health questionnaires are criticized for not capturing all relevant domains of quality of life (Coast, 2004; Pietersma et al., 2013). Certain aspects of quality of life that fall beyond (physical) health might be underestimated, such as experienced social support, psychological resilience and the capability to cope with illness. As a result, the effectiveness of an intervention might be underestimated in economic evaluations, especially for interventions outside of the traditional health care model, such as social care, public health, general well-being, chronic illness, elderly care and mental health (Goranitis et al., 2016; Mitchell et al., 2017).

One approach to deal with the criticism on generic health questionnaires is to assess quality of life in terms of capabilities (i.e., the extent to which someone is capable of doing what one wishes to do) instead of current functioning (i.e., what or how someone is actually doing in one's life). Several instruments to measure capabilities are used (Helter et al., 2020). In the Netherlands the ICECAP questionnaire (Al-Janabi et al., 2012) is recommended to be used alongside established generic health questionnaires when benefits of an intervention are expected that not only involve (physical) health, but a broader sense of well-being (Zorginstituut Nederland, 2015). While such a recommendation is understandable given the criticism on generic health questionnaires, capability instruments such as the ICECAP require

further examination to be used confidently. Ultimately, capability instruments might help to make economic evaluations in areas outside the traditional (somatic) health care context more valuable.

Costs

Economic analyses involve effectiveness measures, but also an assessment of costs. Costs that are considered depend on the perspective of the economic evaluation. A health care perspective includes intervention costs (e.g., personnel and used materials to execute an intervention) and health care costs, such as costs related to visits to a hospital or general practitioner. In the case of a societal perspective, non-health care costs, such as sick days from work, reduced productivity while at work and caregiver costs, are added to the health care costs. Generally, a societal perspective is preferred over narrower perspectives, as it gives a better understanding of the costs involved for all parties affected by the (medical) decisions that might follow from an economic evaluation (Fahkri et al., 2017).

Cost-effectiveness

We have established how, in the context of economic analyses, benefits (mostly QALYs) and costs (health care and non-health care) of treatments are assessed. One more ingredient is required to determine whether one course of action is cost-effective over an alternative. Indeed, in the easy case that an intervention is more effective and less costly compared to a different course of action, it is considered dominant. However, if it is more effective, but also more costly, it is harder to evaluate whether the intervention is considered cost-effective over the alternative: is the added benefit worth the extra costs? To answer this question, we require information on how much society values the benefits. This value is indicated by society's willingness to pay (WTP). In the Netherlands, acceptable WTP values for one QALY have been estimated to range between €20,000 for interventions in the context of 'low disease burden' to €80,000 in the context of severe diseases (Zwaap et al., 2015). With all three ingredients (i.e., intervention effectiveness, associated costs and WTP value per QALY), a cost-effectiveness analysis can be conducted to compare different courses of action. Cost-effectiveness analyses can complement effectiveness research, as they can guide decisions on how money should be distributed over various treatment options. Moreover, especially for innovative treatments that promise good effectiveness at low costs (e.g., internet interventions), cost-effectiveness research helps to determine the added value of such interventions to established treatment options.

Dissertation outline

The general aim of this dissertation is to investigate whether and how internet-based interventions are a valuable addition to the existing pallet of available treatment options for eating disorders. Ultimately, results obtained throughout this dissertation could help to make treatment options available for individuals with eating disorders who are currently not reached. Low threshold online interventions with appropriate guidance show promise in reaching this goal, but further corroboration is necessary (Aardoom, Dingemans, & Van Furth, 2016).

A first step is to demonstrate their effectiveness, to establish that individual patients are likely to experience a reduction in eating disorder symptoms or other important outcomes when participating in such internet-based interventions. However, effectiveness results do not tell the full story. Considering their cost-effectiveness compared to different courses of action is also important to help policy makers with resource allocation decisions and to better understand their impact when implemented in real-world settings.

In order to reach this aim, first, the effectiveness of two internet-based interventions and their combination for eating disorders in the Netherlands were investigated: 'Featback', a fully automated monitoring and feedback system, and expert-patient support. Second, the evidence of cost-effectiveness of e-mental health in general (not only for eating disorders) compared to care as usual was reviewed to verify the often made claim that e-mental health brings good effectiveness at low costs. Additionally, possible improvements in cost-effectiveness research were considered. Specifically, the criticism on using QALYs in cost-effectiveness analyses of interventions outside the area of (physical) health was addressed, by exploring the ICECAP-A and preparing it for economic evaluations in the Netherlands. Finally, returning to the area of eating disorders, the cost-effectiveness of Featback, expert-patient support, their combination and a waiting list control condition were compared. The content of the various chapters in this dissertation is detailed here.

In *chapter 2*, a study protocol is presented to introduce the internet-based interventions Featback, expert-patient support and their combination. The chapter describes what the interventions entail, the design of the randomized controlled trial used to study its (cost-)effectiveness and the planning of data handling and analyses. Specifically, participants were randomly assigned to four conditions to compare (1) Featback (2) email or chat support by an expert patient, and (3) the combination of both with (4) care as usual for eating disorders. After an intervention period of eight weeks, participants were followed for a period of one year. In *chapter 3*, results on the effectiveness of the three active interventions are described. Findings include differences between the three active interventions and care as usual regarding changes in eating disorder symptoms, anxiety and depression, self-efficacy and experienced social support. The chapter also presents data on the satisfaction, intervention usage and whether the intervention stimulated people to seek (professional) help. The third chapter informs on whether and how internet-based interventions might incorporate online guidance in the form of chat and email support from an expert patient. Furthermore, it contributes to the understanding of the added value of Featback and expert-patient support to existing treatment options for eating disorders.

The number of studies on economic evaluations of internet-based interventions, covering many mental disorders, is rapidly growing, increasing the body of evidence to determine whether e-mental health interventions in general have a favorable balance between costs and effects. Therefore, in *chapter 4*, the existing evidence on cost-effectiveness of e-mental health interventions compared to usual care was systematically reviewed. Data from the reviewed studies were pooled together in a meta-analysis to capture the cost-effectiveness of internet-based interventions for various mental disorders compared to usual care. This is the first study to pool cost-effectiveness data in an aggregate-data meta-analysis in the area of psychiatry.

Chapter 5 presents research on validating the Dutch translation of the ICECAP-A instrument, a questionnaire that measures quality of life in terms of capabilities. This instrument might be especially useful in cost-effectiveness research on interventions that produce benefits beyond (physical) health, which includes e-mental health interventions such as Featback. Therefore, it is important to examine exactly what the ICECAP-A measures and whether it does so reliably.

Chapter 6 further prepares the ICECAP-A for economic evaluations in the Netherlands, by presenting the development of a tariff based on the Dutch general population. The ICECAP-A questionnaire assesses someone's capabilities in five areas, namely the extent to which someone is able to (1) feel settled and secure, (2) have love, (3) be independent, (4) achieve and progress, and (5) have enjoyment and pleasure. If someone indicates to improve in the area of enjoyment and someone else indicates to improve to a similar degree in the area of achievement, both individuals may not experience a similar increase in life quality. Developing an understanding of which capabilities people value more or less (i.e., contribute more or less to life quality) may lead to a more precise measurement of life quality when using the ICECAP-A. Such a mapping of the extent to which some capabilities are preferred over others are captured in a tariff. In other words, an ICECAP-A Dutch general population tariff is an operationalization of which capabilities are considered more or less important in the general Dutch population. It can be used to transpose all possible answers on the ICECAP-A questionnaire to better fit one's quality of life, putting more weight on items that were considered more important. These transposed ICECAP-A scores may vary between 0 (not at all capable to do what one wishes to do) and 1 (fully able to do what one wishes to do) and are referred to as capability values. Capability values can be compared to utility values, which are used when determining QALYs, and can be used in economic evaluations similar to QALYs.

The previous three chapters more broadly discuss cost-effectiveness of e-mental health interventions and possibilities for improvement of such economic evaluations. *Chapter 7* returns to eating disorders and compares the cost-effectiveness of Featback, expert-patient support, the combination of Featback and expert-patient support and care as usual. Data were captured alongside the randomized controlled trial described in chapter 2. The study gives insight in the produced benefits (in terms of quality of life), intervention costs, health care costs and societal costs involved with the investigated interventions. Consequently, the results help to inform clinicians and policy makers on whether implementing Featback and expert-patient support for eating disorders is worth the investment.

Finally, the results and implications of the previous seven chapters are summarized and discussed together in the *general discussion*. Study strengths and limitations are mentioned and future research directions and clinical implications are explored.

