Aus der

Medizinischen Universitätsklinik und Poliklinik Tübingen
Abteilung Innere Medizin VI
Psychosomatische Medizin und Psychotherapie

# Improving Motivation and Treatment Uptake Behaviours of Patients with Eating Disorders

**Inaugural-Dissertation**
**zur Erlangung des Doktorgrades**
**der Humanwissenschaften**

**der Medizinischen Fakultät**
**der Eberhard Karls Universität**
**zu Tübingen**

**vorgelegt von**

**Daugelat, Melissa-Claire**

**2026**

Dekanin: Professorin Dr. S. Y. Brucker

1. Berichterstatter: Professorin Dr. K. Giel
2. Berichterstatter: Professor Dr. M. Hallschmid

Tag der Disputation: 27.07.2026

# Table of Contents

# List of figures

# List of abbreviations

| | |
|---|---|
| ED | Eating disorder |
| AN | Anorexia nervosa |
| BN | Bulimia nervosa |
| BED | Binge eating disorder |
| DUED | Duration of untreated eating disorders |
| CBT | Cognitive Behavior Therapy |
| CBT-E | Enhanced Cognitive Behavior Therapy |
| FPT | Focal Psychodynamic Therapy |
| MANTRA | Maudsley Model of Anorexia Nervosa Treatment for Adults |
| TTM | Transtheoretical Model of Health Behavior Change PPI Patient and public involvement |
| RCT | Randomised controlled trial |
| DSM-5 | Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition |
| ICD-11 | International Classification of Diseases, 11$^{th}$ Revision |
| EDE-Q | Eating disorder examination questionnaire |
| URICA-S | University of Rhode Island Change Index Assessment – Short Version |
| PHQ | Patient Health Questionnaire |
| PROSPERO | International Prospective Register of Systematic Reviews |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| NEON | Narrative Experiences Online Intervention |

# 1. Theoretical Background

A persistent and significant treatment gap exists between the number of persons affected by eating disorders (ED), and those seeking and receiving treatment services. More precisely, it is estimated that only around 30% of persons who are experiencing symptoms of an ED are currently receiving any form of treatment (2025). This leaves an all too large number of patients who are struggling with these disorders on their own, often due to patients' ambivalence toward treatment. Peer support programs foster the interactions between current and former patients. Patients report a series of positive outcomes based on these interactions including feelings of being understood and validated (Peebles et al., 2022), as well as hope that recovery is possible (Ramjan et al., 2024). Patient narratives are personal stories of persons currently or previously affected by ED. When presented in a safe and responsible manner, patient narratives may provide the same feelings of hope toward recovery as peer support programs (Dawson et al., 2018), and could therefore be an innovative adjunct to early intervention practices for patients with ED.

This dissertation aims to contribute to the understanding of treatment motivation and treatment uptake behaviours of patients with ED by focusing on the barriers and facilitators that either prevent or encourage engagement with treatment services. Further, this dissertation aims to understand the potential of patient narratives as a low-threshold intervention to improve treatment motivation and treatment uptake behaviours for patients with ED.

## 1.1. Eating Disorders

Eating disorders (ED) are debilitating mental disorders that significantly impair the physical and psychological wellbeing of those affected (American Psychiatric Association, 2013; Schmidt et al., 2025; Treasure et al., 2020). These disorders are characterised by maladaptive cognitions and behaviours regarding the consumption of food and/or weight management (Schmidt et al., 2025; Treasure et al., 2020). The global lifetime prevalence for any ED ranges from 2.6-8.4% in females and 0.7-2.2% in males (Hay et al., 2023), depending on the diagnostic

criteria and assessment materials used. Although EDs can affect persons of any age or gender (Treasure et al., 2020), the prevalence of EDs is highest in adolescents and young adults, with evidence suggesting the age of onset is decreasing (Hay et al., 2023). A further examination of geographic location found that the prevalence of EDs in Western countries is between 2-21 times higher than in Asian countries (Qian et al., 2022). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5; (American Psychiatric Association, 2013)) currently contains diagnostic criteria for eight EDs, of which the most prevalent are Anorexia nervosa (AN), Bulimia nervosa (BN), and Binge-Eating-Disorder (BED).

### 1.1.1. Anorexia Nervosa

AN is characterised by severe dietary restriction and significantly low body weight (American Psychiatric Association, 2013; Treasure et al., 2020; Zipfel et al., 2015). Persons with AN further report an overevaluation in the importance of body shape and weight, disturbances in the perception of body shape and weight, and an intense fear of weight gain (American Psychiatric Association, 2013). Based on the behaviours used to achieve weight loss, AN is further divided into two subtypes: the restrictive type and the binge-eating/purge type (American Psychiatric Association, 2013; Gradl-Dietsch et al., 2024). AN is perhaps the most well-known ED, due in part to its representation in the media - often through images of young, emaciated girls (Himmerich et al., 2024). While it is true that symptoms of AN typically begin in adolescence or young adulthood (Schmidt et al., 2016), the disorder can affect persons of any age or gender (Treasure et al., 2020; Zipfel et al., 2015). If left untreated, AN can have significant impact on all major body systems due to the effects of malnutrition, sudden weight loss, and purging behaviours (Gibson et al., 2019). AN further has one of the highest mortality rate of all mental disorders (Lai et al., 2025) , attributable both to suicide and medical complications such as sudden cardiac death (Gibson et al., 2019; Sullivan, 1995).

### 1.1.2. Bulimia Nervosa

BN is defined by reoccurring episodes of binge eating, which is the consumption of an objectively large amount of food coupled with the experience of loss of control over eating behaviour (American Psychiatric Association, 2013; Gradl-Dietsch et al., 2024; Treasure et al., 2020). In order to counteract any potential weight gain, persons with BN will also engage in compensatory behaviours, the most common of which include self-induced vomiting, abuse of laxatives and other medications, and excessive exercise (Gradl-Dietsch et al., 2024; Treasure et al., 2020). While persons with BN are typically of normal weight or overweight, the disorder is nevertheless characterised by a similar overevaluation of the importance of shape and weight as seen in AN (Treasure et al., 2020), accompanied by secrecy and shame on behalf of its sufferers (Gradl-Dietsch et al., 2024). The medical effects of BN are dependent on the type and frequency of the compensatory behaviours that are employed and could include dental erosion, gastroesophageal reflux, and rectal prolapse (Gibson et al., 2019).

### 1.1.3. Binge-Eating-Disorder

BED is also characterised by recurrent episodes of binge eating, during which a large amount of food is consumed together with a loss of control over eating (American Psychiatric Association, 2013; Giel et al., 2022). In addition, persons may report eating more rapidly than during regular mealtimes, eating until uncomfortably full, eating despite a lack of physical hunger, eating alone due to shame and embarrassment regarding the amount of food consumed, or experiencing negative feelings such as guilt after eating (American Psychiatric Association, 2013). Persons with BED do not engage in regular compensatory behaviours, and as a result BED is frequently associated with overweight or obesity (Gradl-Dietsch et al., 2024; Kessler et al., 2013).

## 1.2 Treatment of Eating Disorders

The treatment of ED is complex and may occur in one of three settings including inpatient, partial inpatient, and outpatient treatment. Treatment setting is commonly determined based on the level of care required for each patient, with many patients experiencing treatment across multiple settings throughout their illness (Monteleone et al., 2022).

For patients with AN, the German S3 Guidelines (Zeeck et al., 2019) currently recommend the use of psychotherapeutic treatments regardless of treatment setting. Psychotherapeutic treatments should include a strong focus on weight restoration, normalising eating behaviours, and treatment of the physiological effects of starvation and underweight, as well as addressing the emotional, cognitive, and social difficulties that often accompany this disorder (Zeeck et al., 2019). Numerous manualised psychotherapies have been developed for the treatment of AN including Focal Psychodynamic Therapy (FPT), Enhanced Cognitive Behavior Therapy (CBT-E), and the Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA) (Zipfel et al., 2015). Each of these psychotherapies have shown considerable success in the treatment of AN, however, there is no evidence to suggest that any one of these treatments is superior to the rest (Zeeck et al., 2018). There is currently no evidence to support the use of psychotherapeutic medications for the treatment of AN, apart from the treatment of psychiatric comorbidities (Monteleone et al., 2022; Zeeck et al., 2018).

Meanwhile, Cognitive Behavior Therapy (CBT) is currently recommended as the first line of treatment for adult patients with BN (Svaldi et al., 2019). CBT has been shown to be particularly effective in managing both specific and general symptoms of BN, with both short and long-term effects (Monteleone et al., 2022). Treatments for BN should include a focus on the reduction of symptoms including binge eating and compensatory behaviours, a reduction of body image issues associated with the importance of body weight, and treatment of the psychological issues and conflicts associated with this disorder, as well as any comorbid disorders (Svaldi et al., 2019). Currently, Fluoxetine is the only

psychopharmaceutical medication which has approval for the treatment of BN in Germany. The use of Fluoxetine is recommended only in combination with psychotherapy (Svaldi et al., 2019).

Lastly, psychotherapy (including CBT) has been shown to be most effective for patients with BED, and is therefore recommended as the first line of treatment in Germany (Hilbert et al., 2019). Treatments for BED should focus on reducing binge eating episodes and ED psychopathology, the treatment of further psychological symptoms including low self-esteem und emotion regulation, as well as the treatment of comorbid psychiatric disorders (Herpertz et al., 2019). No psychopharmaceutical medications are currently approved for the treatment of BED in Germany (Hilbert et al., 2019).

### 1.3 The Current Treatment Gap Related to Eating Disorders

Despite the availability of evidence-based treatment services, a large number of patients with ED are not currently receiving treatment. A recent systematic review by Ali et al. (2025) shows that only approximately 30% of patients who are experiencing symptoms of an ED will actively seek treatment, a number which has remained relatively stable over the last fifteen years despite the development of various novel treatment options (Ali et al., 2025; Hart et al., 2011). Among those patients who receive treatment, the amount of time that elapses between onset of symptoms and the receival of treatment, also known as the duration of untreated ED (DUED), is substantial and ranges from 29.9 months for patients with AN, to 53 months for patients with BN, and even 67.4 months for patients with BED (Austin et al., 2021). Shorter DUED are typically associated with better rates of remission, while delays in treatment uptake and the subsequently longer DUED are associated with increased psychological distress and a chronic progression of ED symptoms (Andres-Pepina et al., 2020; Austin et al., 2021).

## 1.4 Understanding Treatment Motivation for Patients with Eating Disorders: The Transtheoretical Model of Health Behaviour Change

In order to better understand the current ED treatment gap, it is important to understand patients' motivation toward treatment, or lack thereof. A large number of patients with ED report high levels of ambivalence toward treatment, resulting in their failing to seek the assistance of treatment services until they are no longer able to manage the symptoms of their ED on their own (Stadler et al., 2025). An understanding of the processes of change which must be conquered by patients throughout their treatment journey is therefore crucial for the development of new intervention strategies which encourage patients with ED to seek treatment sooner.

The Transtheoretical Model of Health Behaviour Change (TTM; (Prochaska & DiClemente, 1982; Prochaska & Velicer, 1997)) proposes that change is gradual and that individuals will typically progress through a series of stages of willingness to change in order to modify a health behaviour. Six stages of change have been proposed by the authors, namely precontemplation, contemplation, preparation, action, maintenance, and termination (Prochaska & Velicer, 1997), an overview of which can be seen in Figure 1:

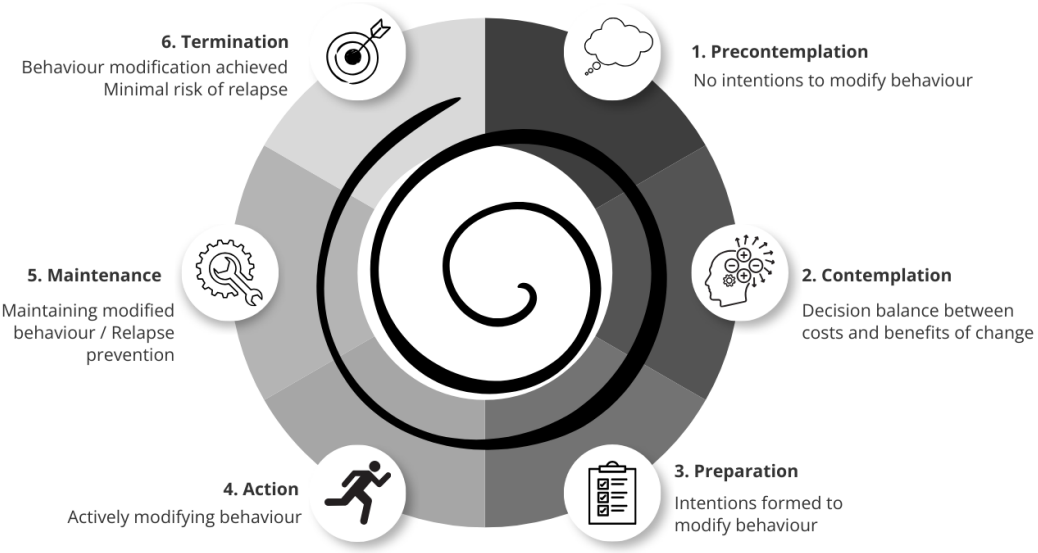



**Figure 1.** Stages of change proposed by the Transtheoretical Model of Health Behaviour Change. Adapted from Prochaska and Velicer (1997).

**Precontemplation:** this first stage of change refers to individuals who currently have no intentions to modify their behaviour, and have therefore undertaken no actions to initiate change. As a result, these individuals are often classified as unmotivated or treatment-resistant if forced into treatment too soon (Prochaska & Velicer, 1997).

**Contemplation:** individuals in this second stage of change have begun thinking about the pros and cons of changing their behaviour, however, the balance between costs and benefits typically results in their remaining ambivalent in their motivation to change (Prochaska & Velicer, 1997).

**Preparation:** in this next stage of change, individuals develop intentions to modify their behaviour in the near future. This includes researching the necessary parameters needed for change or talking to a general practitioner about possible treatment pathways. Prochaska and Velicer (1997) recommend waiting until individuals have reached the preparation stage of change before beginning action-oriented intervention programs.

**Action:** this stage of change refers to individuals who are actively working on modifying their behaviour (Prochaska & Velicer, 1997). There is great variability on what this stage might entail based on the type of behaviour that is being changed. For individuals with EDs this could include implementing changes in the environment in order to improve eating behaviours (Hasler et al., 2004).

**Maintenance:** individuals in the maintenance stage of change have to some extent succeeded in modifying their behaviour and are working on strategies to prevent relapse. This is perhaps the longest stage of change, with the risk of relapse decreasing gradually with each year that elapses (Prochaska & Velicer, 1997).

**Termination:** this last stage of change refers to individuals who are certain they have mastered the behaviour they were wishing to change, with very little risk of relapse. The viability of attaining this stage of change is largely dependent on the type of behaviour that is being modified (Prochaska & Velicer, 1997).

Individuals wishing to change a health-related behaviour typically progress through all six stages, however, this progression is not always linear and relapses or regressions are common at every stage (Prochaska & DiClemente, 1982; Prochaska & Velicer, 1997). While the TTM was initially proposed for high-risk health behaviours such as smoking, alcohol and other substance abuse (Prochaska & DiClemente, 1982), its relevance has since spread to a myriad of other health and mental health behaviours and disorders including depression, anxiety, and EDs (Krebs et al., 2018). Particularly in regards to ED, lower pre-treatment stages of change have been associated with a reduced likelihood of patients seeking or engaging with treatment services, as well as an increased likelihood of treatment drop-out or relapse (Dray & Wade, 2012; Geller et al., 2004). Meanwhile, higher pre-treatment stages of change have been found to positively predict treatment outcomes for patients with ED including eating pathology and changes in BMI (Dray & Wade, 2012), as well as increased treatment acceptance (Geller et al., 2004). These results demonstrate the importance of addressing patients' treatment motivation in order to increase treatment uptake behaviours.

## 1.5 The Role of Social Support in Increasing Treatment Motivation for Patients with Eating Disorders

When designing interventions to increase the treatment motivation of patients with ED, it is important to also consider the environment and the resources which patients may rely on, such as the availability of social support. ED most commonly begin in adolescence and early adulthood (Solmi et al., 2022), a period marked by the influences of social interactions. Patients with ED report craving emotional connections throughout their illness, and that a large part of their recovery was dependent on the social supports they received (Ali et al., 2017; Linville et al., 2012; Radunz et al., 2023; Robinson et al., 2024). Unfortunately, social withdrawal is common among patients with EDs and often results in a lack of social connections outside of the immediate family environment (Linville et al.,

2012; Quiles Marcos & Terol Cantero, 2009). Instead, many patients report turning to online ED communities, despite their potential for containing triggering content or hostile interactions, in the hopes of finding support, acceptance, and a feeling of belonging among other patients with shared experiences (Albano et al., 2025; Ransom et al., 2010; Sharpe et al., 2011). Peer support mentoring with "recovered" former patients provide an alternative approach to help foster positive social connections and increase treatment motivation. This engagement of patients at various stages of recovery is well accepted by both current and former patients (Beveridge et al., 2019), with both groups reporting a series of benefits. For current patients, this includes the validation of individual experiences (Peebles et al., 2022), as well as the feeling of hope that recovery is possible (Albano et al., 2021; Beveridge et al., 2019; Fogarty & Ramjan, 2016; Hanly et al., 2020; Ramjan et al., 2024). Meanwhile, former patients report satisfaction in utilising their negative experiences to help others (Beveridge et al., 2019; LaMarre et al., 2025). Reciprocity is essential in these relationships, with studies reporting higher patient engagement rates in programs with peer mentors in comparison to student or general social support mentors (Albano et al., 2021; Ranzenhofer et al., 2020). Similarly, information shared by peers has been reported by patients as being significantly more empowering than the same information shared by healthcare professionals (Lock et al., 2005). There are, however, a number of difficulties in setting up and sustaining peer support mentoring. For instance, Beveridge et al. (2019) found that while current patient "mentees" showed improvements in BMI and ED psychopathology as a result of the peer support interactions, the former patient "mentors" experienced an increase in ED symptoms. This is not to say that peer support should not be implemented, but instead, care should be taken to ensure adequate supports are in place for mentees and mentors alike. Ramjan et al. (2024) therefore propose the implementation of controlled and moderated peer support.

## 1.6 Patient Narratives as an Example of Social Support and Adjunct to Early Interventions for Eating Disorders

Patient narratives can best be defined as personal stories from current or former patients with a physical or mental disorder, and can offer an easy to disseminate alternative to traditional peer-to-peer support. Common characteristics of patient narratives might include discussions of the challenges and successes that might accompany patients' experiences of illness and/or treatment (Llewellyn-Beardsley et al., 2019; Yeo et al., 2021). Patient narratives are an essential part of peer-to-peer support, but can also be found in a variety of different modalities including books, poems, films, and artwork. Patient narratives can also be found on most popular social media platforms including Instagram, TikTok, and Youtube, often in the form of so-called "recovery accounts" (Wenig & Janetzke, 2022; Yeo et al., 2021), making access to patient narratives easier than ever before. Reading, watching, or otherwise engaging with patient narratives can have a variety of positive outcomes including increased self-efficacy (McLeod et al., 2022; Williams et al., 2018) and feelings of support, connection, and belonging (Bientzle et al., 2024; Rennick-Egglestone, Ramsay, et al., 2019; Wenig & Janetzke, 2022; Yeo et al., 2021), as well as decreased self-stigma (Rennick-Egglestone, Morgan, et al., 2019; Sheens et al., 2016) and feelings of social isolation (Dawson et al., 2018). Patient narratives demonstrate first-hand that recovery is possible, and as a result currently affected patients report feeling hopeful and motivated toward their own recovery (Dawson et al., 2018). Meanwhile, in an online intervention featuring a database of over 600 patient narratives for patients with a variety of non-psychosis mental disorders, Slade et al. (2025; 2024) further showed that patients who engaged with at least one patient narrative reported significant increases in self-reported quality of life and meaning of life ratings. This effect appeared to be moderated by the perceived authenticity of the narrator and how well the viewer could relate to his/her experiences (Ng et al., 2022; Rennick-Egglestone, Ramsay, et al., 2019).

The use of patient narratives in the field of EDs is a relatively new methodological approach and findings from previous studies are inconclusive. Patient narratives such as those found online may easily contain information that is triggering for

persons with ED, and engagement with these narratives may therefore be harmful (Nikolova & LaMarre, 2023). In a retrospective study assessing patients' previous engagement with patient narratives, Shaw and Homewood (2015) found that patients who were not receiving treatment at the time of engagement were at an increased risk of replicating harmful ED behaviours, as they were described in the patient narratives. In an attempt to combat this effect, Dawson et al. (2018) produced a series of written patient narratives from which all potentially triggering contents were removed. These patient narratives were well accepted by patients with AN, who reported an increase in thoughts regarding their own recovery after reading the patient narratives. These patients further confirmed that they would recommend patient narratives to other patients with ED, despite the study finding no short-term effects in regards to patients' self-efficacy or treatment motivation (Dawson et al., 2018). Most recently, Gumz et al. (2023) completed interviews with adolescent patients with AN to determine the predictors of DUED among this patient group. The results of this study showed that among only a handful of other factors, previous self-reported engagement with patient narratives was associated with significantly shorter DUED for adolescent patients with ED (Gumz et al., 2023).

# 2. Aims of the Present Work and Project Overview

This dissertation aims to investigate what factors contribute to the treatment motivation and treatment uptake behaviours of patients with ED. In addition, this dissertation aims to develop a series of evidence-based patient narrative videos and to evaluate their acceptability and feasibility as a potential intervention to increase treatment motivation and treatment uptake behaviours for patients with ED. In order to address these aims, this dissertation consists of three projects and four corresponding publications (see Figure 2):

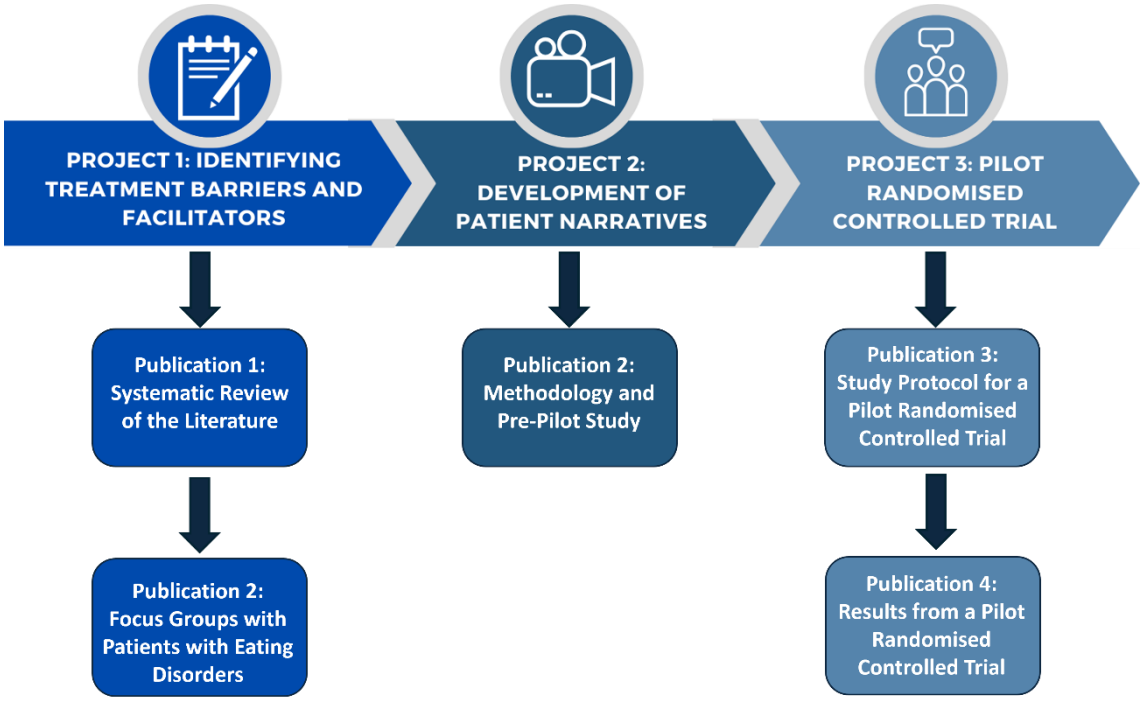



**Figure 2.** Overview of the projects and publications included in this dissertation

Project 1 identifies the barriers and facilitating factors that influence patients with EDs to seek and/or engage with treatment services. This includes a systematic review synthesising the perspectives of patients themselves, their caregivers, and healthcare professionals, as well as a series of focus groups with patients affected by ED and residing in Tübingen, Germany.

Project 2 describes the methodological approach used to create a series of evidence-based patient narrative videos for patients with ED. This project uses a collaborative process with a lived experience expert to combine their personal experiences with the findings of the systematic review completed in Project 1 and the findings of a series of focus groups with patients with ED. Particular care is taken in this project regarding the inclusion of Patient and Public Involvement (PPI). PPI is defined as the participatory collaboration between researchers and persons with lived experience (Dudley et al., 2015) and has been increasingly advocated in all aspects of planning, implementing, interpreting, and publishing clinical research (Giel et al., 2023; Musić et al., 2022; Price et al., 2022; Sangill et al., 2019). The inclusion of PPI promotes the development of research which is both significant and applicable to real-world situations (McCarron et al., 2021; Musić et al., 2022), while giving power back to those with lived experiences (Giel et al., 2023). Project 2 further reports the results from an initial pilot study of the patient narrative videos with a sample of students and employees without a (current) eating disorder. Assessed data includes participants' evaluations of the authenticity, empathy, and usefulness of the videos.

Project 3 comprises the design, methodology, procedures, and results of a pilot RCT with a clinical sample of patients with ED. Within this study, patients are randomly assigned to either watch one of the patient narrative videos created in Project 2, or else to watch no video. Patients are assessed at baseline, immediately after watching the video (if applicable), as well as at one-week and three-months follow-up. Data collected includes patients' self-reported treatment motivation and treatment uptake behaviours, ED psychopathology, hope and confidence toward recovery, and patients' evaluations of the authenticity, empathy, and usefulness of the videos.

# 3. Summary of Results

This dissertation consists of four publications investigating the factors contributing to treatment motivation and uptake behaviours of patients with ED, as well as the development and implementation of patient narrative videos for patients with ED. A detailed description of each of these publications and a discussion of the results is presented below.

## 3.1 Publication 1: Barriers and facilitators affecting treatment uptake behaviours for patients with eating disorders: A systematic review synthesising patient, caregiver and clinician perspectives (Daugelat et al., 2023).

Full citation: *Daugelat, M.C., Pruccoli, J., Schag, K., & Giel, K. E. (2023). Barriers and facilitators affecting treatment uptake behaviours for patients with eating disorders: A systematic review synthesising patient, caregiver and clinician perspectives. European Eating Disorders Review. https://doi.org/ 10.1002/erv.2999.*

Many patients who are affected by ED show ambivalence toward treatment services, often due to a variety of both individual and environmental reasons. A systematic review was therefore completed to identify the barriers and facilitators that may affect an individual's engagement with ED treatment services, with particular emphasis on the different experiences reported by patients, their caregivers, and healthcare professionals. This systematic review was pre-registered on the international prospective register of systematic reviews (PROSPERO, Submission ID 313447), and was completed in accordance to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA 2020) guidelines (Page et al., 2021).

A systematic search of the electronic databases PubMed, PsycInfo, and Web of Science was completed in August 2022 and yielded an initial number of 6,493 studies. These studies were screened and assessed by two independent raters, resulting in a total of 73 studies which were deemed eligible for inclusion in the systematic review. Thematic analysis (Liamputtong & Ezzy, 2005) was used to

determine 12 barriers and 13 facilitators to treatment based on the results reported by the included studies. The results were further divided into subgroups to compare 1) the different barriers and facilitators reported by patients, their caregivers, and healthcare professionals, 2) transdiagnostic differences regarding barriers and facilitators to treatment, and 3) the different barriers and facilitators reported for face-to-face vs digital interventions.

Across all studies, a variety of motivational, pragmatic, and socio-culturally oriented barriers to treatment were reported. Subgroup analyses showed that patients themselves most frequently reported motivational barriers such as stigma, shame, and guilt to be responsible for their not seeking and/or engaging with treatment services. This included feeling personally responsible for the disorder, feeling like a failure for needing treatment, or else feeling that they are not worthy of receiving treatment. Patients further reported fears of the reactions of others and possible discrimination as a result of disclosing symptoms. Meanwhile, caregivers and healthcare professionals most frequently reported pragmatic barriers including the behaviours and knowledgeability of the treating clinician. For caregivers, this included negative experiences with clinicians who dismissed or misdiagnosed their child or loved one's ED, resulting in delayed treatment and a feeling of mistrust of the capabilities of the clinician. For healthcare providers, this included a general lack of knowledge and available resources regarding the diagnosis and treatment of ED. All subgroups reported the patient's social support system as the most important facilitator for treatment uptake. Transdiagnostic comparisons were not able to be completed, due to the lack of studies reporting on the experiences of patients with BN or BED. An analysis of studies reporting the experiences of AN showed that these patients most frequently reported motivational barriers including difficulties acknowledging the ED and pro-ED beliefs, and the need for autonomy and subsequent rejection of external treatment. Similarly, only six studies (Cavazos-Rehg et al., 2020; Linardon et al., 2021; Linardon, Rosato, et al., 2020; Linardon, Shatte, et al., 2020; Moessner et al., 2016; Venkatesh et al., 2021) reported barriers regarding the uptake of digital treatment services, including concerns surrounding technology and data privacy, and a lack of accessibility.

The results of this systematic review showed that patients, caregivers, and healthcare professionals report a wide variety of barriers to ED treatment uptake. In particular, patients most frequently reported stigma, shame, and guilt as a barrier to treatment, while caregivers and healthcare professionals reported the (lack of) training and knowledge of the treating clinician. Meanwhile, patients, caregivers, and healthcare professionals collectively reported positive social support as the foremost facilitator for treatment uptake. These findings suggest that anti-stigma campaigns are urgently needed to help combat patients' fears of disclosure and the impact of stigma on treatment uptake behaviours, while the reinforcement of positive social support, for instance through the establishment of peer-support programs could help foster treatment motivation.

Received: 24 March 2023 | Revised: 22 May 2023 | Accepted: 4 June 2023

DOI: 10.1002/erv.2999

REVIEW

WILEY

# Barriers and facilitators affecting treatment uptake behaviours for patients with eating disorders: A systematic review synthesising patient, caregiver and clinician perspectives

**Melissa-Claire Daugelat**[1,2] | **Jacopo Pruccoli**[3,4] | **Kathrin Schag**[1,2] | **Katrin Elisabeth Giel**[1,2]

[1]Department of Psychosomatic Medicine and Psychotherapy, Medical University Hospital Tübingen, Tübingen, Germany

[2]Centre of Excellence for Eating Disorders Tübingen (KOMET), University of Tübingen, Tübingen, Germany

[3]IRCCS Istituto delle Scienze Neurologiche di Bologna, Regional Center for Feeding and Eating Disorders in the Developmental Age, Pediatric Neuropsychiatry Unit, Bologna, Italy

[4]Department of Medical and Surgical Sciences, University of Bologna, Bologna, Italy

**Correspondence**
Melissa-Claire Daugelat, Department of Psychosomatic Medicine and Psychotherapy, Medical University Hospital Tübingen, Osianderstr. 5, Tübingen 72076, Germany.
Email: melissa-claire.daugelat@med.uni-tuebingen.de

**Handling Editor**: Tchanturia, Kate

**Funding information**
Hans Böckler Stiftung; Ministerium für Wissenschaft, Forschung und Kunst Baden-Württemberg

**Abstract**

**Objective:** A significant treatment gap exists between persons affected by eating disorders (ED), and those engaging with treatment services. This systematic review aims to provide a thorough understanding of the barriers and facilitators affecting eating disorder treatment engagement, including a synthesis of the perspectives of patients, caregivers and healthcare professionals.

**Method:** This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. Studies were retrieved from three databases (PubMed, PsycInfo, Web of Science) and were screened and assessed independently by two raters. A thematic analysis was completed to determine the key barriers and facilitators reported by the included studies.

**Results:** A total of 73 studies were included. From these studies, 12 barriers and 13 facilitators were identified. Patients reported stigma, shame and guilt as the most prominent barrier affecting their engagement with treatment services. Meanwhile, caregivers and healthcare professionals reported a lack of eating disorder knowledge of clinicians as the most important barrier. Positive social support was cited as the most prominent facilitator to promote help-seeking.

**Discussion:** Patients, caregivers and healthcare professionals experience a variety of barriers and facilitators to treatment uptake for ED. Interventions addressing barriers and facilitators could increase treatment engagement, including anti-stigma campaigns and positive peer-support interventions.

**KEYWORDS**
barriers, eating disorders, facilitators, help-seeking, treatment

**Highlights**

- Patients with eating disorders (ED) report stigma, shame and guilt as the most prominent barriers affecting their engagement with treatment services.
- A lack of eating disorder knowledge among healthcare providers is reported by caregivers and healthcare professionals as an important barrier for the treatment of ED.
- Positive social support is the most prominent facilitator to promote ED treatment.

## 1 | INTRODUCTION

Currently, there exists a significant treatment gap in people affected with eating disorders (ED) between those needing help and receiving help. A large screening study reports that up to 85.9% of individuals who screened positive for an ED, never received treatment (Fitzsimmons-Craft et al., 2019). Similar results were found by a population-based study in Finland, wherein only 13% of male and 30% of female patients with an ED stated they received treatment (Silén et al., 2021). Meanwhile, a recent systematic review reported that the average duration of untreated ED (DUED) ranges from 2.5 years for Anorexia Nervosa, to 4 years for Bulimia Nervosa, and almost 6 years for Binge-Eating Disorder (Austin et al., 2021). Delays in treatment and the resulting DUED may be associated with adverse outcomes, including significant psychological distress and progression of the ED (Andres-Pepina et al., 2020; Austin et al., 2021). Meanwhile, rates of remission from ED have been shown to be most strongly predicted by a shorter DUED, thereby highlighting the importance of early detection and intervention (Andres-Pepina et al., 2020). Therefore, it is important to investigate and understand the reasons contributing to this 'treatment gap' which may be manifold: partly rooted in circumstances of the health care system, partly rooted in society, and partly rooted in the individual. Previous studies further found that up to 50% of individuals affected by ED were unaware that they had a problem (Ali et al., 2017). Meanwhile, those individuals that did receive treatment in the USA waited an average of 12 months after recognition of their ED symptoms before seeking professional help (Kazdin et al., 2017).

A systematic review by Ali et al. (2017) found that former patients with ED frequently reported stigma, shame and denial of the severity of the ED as the most prominent barriers to help-seeking. A recent meta-analysis completed by the same research group similarly showed denial of the ED and the perceived inability of others to provide help as significantly correlated to reduced help-seeking (Radunz et al., 2023). Both studies provide an excellent overview of the quantitative studies published on barriers preventing treatment uptake among patients with ED. However, a significant number of qualitative studies exist which may contribute to our understanding of this complex area of research. The current systematic review therefore provides an in-depth overview and analysis of all available literature, so as to include this wealth of information.

Moreover, to the best of our knowledge, this review will provide for the first time a synthesis of the barriers to receiving ED treatments from different perspectives: (a) patients affected by an ED, (b) their caregivers and (c) healthcare professionals treating patients with ED. Additionally, we aim to compare the experiences of patients with different ED diagnoses, so as to ascertain if different barriers are preventing patients with various ED from engaging with treatment services.

Lastly, since the publication of the former review by Ali et al. (2017), the use of digital interventions, namely the use of digital technology (e.g. smartphones) to deliver medical and mental health services (Kazdin et al., 2017) has skyrocketed. Numerous studies have reported positive endorsements from both patients and clinicians regarding the use of digital technologies for the treatment of ED (e.g. Basterfield et al., 2018), with up to 61.9% of current ED patients reporting intentions to utilise digital psychotherapeutic interventions (Linardon, Shatte, et al., 2020). Nevertheless, in comparison to traditional face-to-face therapies, the engagement rates with digital interventions remain low (Torous et al., 2018). The current review will therefore ascertain the different barriers reported by patients with ED regarding their engagement with face-to-face therapies versus digital interventions.

In summary, the current systematic review aims to provide a thorough understanding of the barriers and facilitators which may either prevent or encourage an individual to engage with ED treatment services, with a particular focus on the following research aims:

1. to identify and compare the barriers and facilitators affecting treatment uptake behaviours experienced and reported by patients with ED, their caregivers, and healthcare professionals
2. to determine transdiagnostic differences of the barriers and facilitators reported by patients with various types of ED when seeking treatment services
3. to compare the different barriers and facilitators that apply to standard face-to-face ED treatments in comparison to digital interventions.

## 2 | METHOD

This systematic review was completed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (Page et al., 2021). The systematic review protocol was pre-registered on the PROSPERO international prospective register of systematic reviews (Submission ID 313447).

### 2.1 | Data sources

A systematic search of the databases PubMed, PsycInfo and Web of Science was completed in August 2022. The database searches were not restricted according to the time of publication of studies. The following search terms and Medical Subject Headings (MeSH) were developed in consensus by the research team: (anore* OR bulimi* OR eating disorder OR disordered eating OR binge eat* OR feeding and ED [MeSH]) AND (uptake OR help seek* OR treatment OR health behaviour [MeSH] OR Help-Seeking Behaviour [MeSH]) AND (barrier* OR facilitat* OR accept* OR motivation [MeSH]).

### 2.2 | Inclusion/exclusion criteria

Inclusion criteria were established prior to the screening process, based on the 5 PICOS criteria: Population, Intervention, Comparison, Outcome, and Study Decision. Studies were included if they assessed participants of any age or gender that met the criteria for a (sub-) clinical ED diagnosis or displayed signs of disordered eating, caregivers of patients with ED, or healthcare professionals working with patients with ED. Studies were not required to provide treatment services or active interventions for participants. Similarly, there was no requirement for a control condition or active comparison group. Studies were required to report the barriers/facilitators that either hinder or foster treatment uptake for patients with ED. The study design was not restricted based on methodology, so that quantitative, qualitative and mixed-method studies could be included, with the following exceptions: literature reviews, systematic reviews, meta-analyses, dissertations, study protocols, book chapters, book reviews, case studies, and animal studies.

### 2.3 | Study selection

The selection of included studies can be found in Figure 1. The initial database search returned a total of 6493 abstracts, following which 1917 duplicates were removed. An additional eight studies were found by hand searching previous systematic reviews, key studies and key journals. Two independent raters screened 4584 abstracts according to the inclusion and exclusion criteria provided above. Following abstract screening, the full texts of 134 studies were retrieved and screened by two independent raters. Studies that both raters mutually agreed upon were included in the review with 97% agreement between raters. Disagreements were settled by a third, independent rater. In total, 73 studies were deemed eligible to be included in the current review (Ali et al., 2020; Andersen et al., 2021; Becker et al., 2003; Becker et al., 2010; Bye et al., 2018; Byrom et al., 2022; Cachelin & Striegel-Moore, 2006; Cachelin et al., 2001; Cavazos-Rehg et al., 2020; Chowbey et al., 2012; Ciao et al., 2020; Coelho et al., 2021; Couturier et al., 2013; Dayal et al., 2015; Dearden & Mulgrew, 2013; Del Valle et al., 2017; Elran-Barak et al., 2018; Escobar-Koch et al., 2010; Evans et al., 2011; Fitzsimmons-Craft, Balantekin, et al., 2020; Fitzsimmons-Craft, Eichen, et al., 2020; Fitzsimmons-Craft, Krauss, et al., 2020; Forrest et al., 2017; Goodwin & Fitzgibbon, 2002; Gorse et al., 2013; Grammer et al., 2022; Griffiths et al., 2015; Griffiths et al., 2018; Grillot & Keel, 2018; Gulliksen et al., 2015; Hamilton et al., 2022; Hartman-Munick et al., 2021; Hepworth & Paxton, 2007; Herman et al., 2014; Javier & Belgrave, 2019; Kanakam, 2021; Kästner et al., 2021; Lazare et al., 2021; Leavey et al., 2011; Lebow et al., 2021; Linardon, Shatte, et al., 2020; Linardon, Rosato, et al., 2020; Linardon et al., 2021; Lipson et al., 2017; Liu et al., 2022; Ma et al., 2021; Maier et al., 2014; Malova & Dunleavy, 2021; Martin-Wagar et al., 2021; McClay et al., 2016; Meyer, 2001; Moessner et al., 2016; Mond et al., 2009; Neyland & Bardone-Cone, 2019; Pettersen et al., 2016; Plateau et al., 2017; Potterton et al., 2020; Ranta et al., 2017; Reyes-Rodríguez et al., 2013; Robinson et al., 2020; Schoen et al., 2012; Smalec & Klingle, 2000; Sonneville & Lipson, 2018; Strand et al., 2017; Thapliyal et al., 2020; Thomson et al., 2014; Tipton et al., 2021;

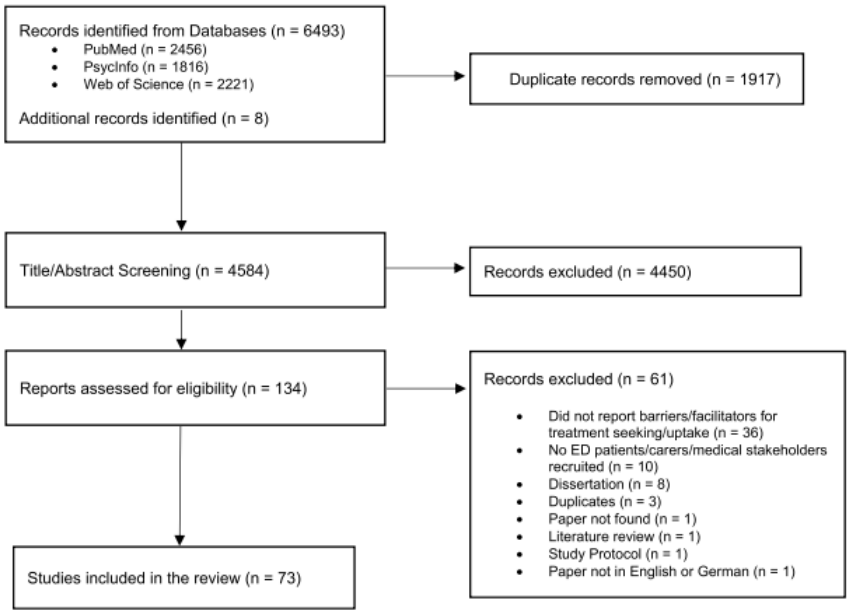



FIGURE 1 Study selection flow chart.

Tsong et al., 2022; Venkatesh et al., 2021; Wacker, 2018; Wales et al., 2017; Weigel et al., 2014; Yim et al., 2021).

## 2.4 | Coding of studies

Each of the 73 included studies was coded independently by two raters using a predetermined rating sheet according to the following criteria: author name, year of publication, country in which the study was conducted, sample size, participant characteristics (patients, caregivers, healthcare professionals), type of ED diagnosis assessed, age of participants, gender, study design (quantitative, qualitative, mixed methods), assessment tools used, types of intervention assessed (face to face vs. digital treatment), reported barriers to treatment, and reported facilitators to treatment.

## 2.5 | Data analysis

A thematic analysis (Liamputtong & Ezzy, 2005) was completed, wherein the key barriers and facilitators reported by each of the included studies were extracted and compiled into key themes. This was completed through discussions with the entire research team, until a consensus was reached. Where possible, the original terms used by the authors were maintained. In total, 12 key barrier themes and 13 key facilitator themes were identified (see Tables 1 and 2). The included studies were then examined by two independent raters so as to calculate how often each barrier and facilitator was reported. The results of these analyses were then compiled with 75% agreement between raters. Disagreements were settled through discussions between the raters. The included studies were further divided into subgroups to compare the differences in experience for (1) patients versus caregivers versus healthcare professionals, (2) transdiagnostic differences across the various ED diagnoses, and (3) the comparison of standard face-to-face care and digital interventions.

## 2.6 | Quality assessment/risk of bias

An evaluation of the methodological quality of the included studies was completed by one author. Qualitative studies were evaluated using the Critical Appraisal Skills Programme (CASP) Quality Assessment Tool (Critical Appraisal Skills Programme, 2022). The CASP Quality Assessment Tool uses 10 questions to assess qualitative studies according to their research methodology, credibility and relevance. There is currently no official rating scale provided for this tool. For the

TABLE 1 Key barriers preventing treatment uptake, as determined through thematic analysis.

| Barriers | Examples |
|---|---|
| Accessibility | Lack of time; treatment costs; lack of health insurance; availability of treatment services; geographic location; opening hours of treatment services; wait times |
| Autonomy and rejection of treatment | Preference for self-management; ambivalence; lack of motivation; disbelief that others can help; mistrust/fear of treatment services; negative treatment experiences |
| Clinician impact | Dismissal of symptoms by clinician; misdiagnosis/delayed diagnosis; clinician bias; mistrust of clinician; clinician lack of experience in treating ED; lack of resources |
| Cultural influences | Cultural norms regarding weight, food, mental illness and help-seeking; immigration background; language barriers |
| Denial and Pro-ED beliefs | Minimising/normalising symptoms; 'I'm not sick enough'; weight stigma; pride; positive appraisal of symptoms; ED identity |
| Fear of change | Fear of losing control over eating/weight; fear of losing ED identity; fear of weight gain |
| Gender | Male gender; transgender identity; ED seen as a female/gay issue |
| Mental health disorders and ED symptoms | Comorbid mental health disorders; lower BMI; severe symptoms; binge/purging behaviours |
| Mental health literacy | Lack of awareness about ED; lack of awareness about ED treatment services |
| Social support system | Lack of social/familial support; feelings of social isolation; not wishing to burden others |
| Stigma, shame and guilt | Fear of disclosure; fear of discrimination; not wanting others to know; self-blame; feelings of failure; feelings of guilt about symptoms; not feeling worthy of treatment |
| Technology and privacy concerns | Cost of technology; concerns about treatment content; lack of accountability in digital treatments; concerns about privacy/confidentiality/security of data |

Abbreviations: BMI, body mass index; ED, eating disorder.

purposes of this systematic review, the scoring system devised by Butler et al. (2016) was used, wherein items answered with 'Yes' are awarded 1 point, items answered with 'Can't Tell' 0.5 points, and items answered with 'No' 0 points. Studies achieving a score of 9–10 points are considered 'high quality', 7.5–9 points 'moderate quality', and less than 7.5 points 'low quality' (Butler et al., 2016). Quantitative studies were evaluated using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool (Effective Public Healthcare Panacea Project, 2010). The EPHP Quality Assessment Tool measures studies according the criteria of selection bias, study design, confounders, blinding, data collection methods, and drop-outs. Each item is coded as 'Strong', 'Moderate' or 'Weak', and a global rating is calculated based on the inclusion of no 'Weak' items ('Strong' Global rating), one 'Weak' item ('Moderate' Global Rating), or more than one 'Weak' item ('Weak' Global Rating) (Effective Public Healthcare Panacea Project, 2010). Mixed Methods studies were assessed using both tools, as both the qualitative and quantitative results reported by these studies were extracted for analyses.

## 3 | RESULTS

### 3.1 | Study characteristics

Detailed characteristics of the included studies are provided in the Supporting Information S1. The following section provides an overview of the year and country in which studies were published, the methodologies employed, and a description of sample and patient characteristics.

#### 3.1.1 | Publication year and origin

All 73 studies were published between 2000 and 2022. The majority of studies were completed in the USA

TABLE 2 Key facilitating factors of treatment uptake, as determined through thematic analysis.

| Facilitators | Description |
|---|---|
| Acceptance/motivation | Awareness of ambivalence; admitting the problem; wanting to make a different choice |
| Accessibility | Easily accessible and convenient; flexible business hours of treatment services; limited travel required to attend appointments; available during crisis situations; flexible payment scales; availability of financial resources |
| Clinician impact | Clinician advertising lived experience with ED; highly specialised qualifications; clinical experience managing ED; Clinician's personal belief in the treatment; supportive interactions; collaboration between clinicians; clear referrals to other services |
| Cultural/religious influences | Multi-generations in one household; acculturation to dominant white society; religious influences |
| Gender | Female gender |
| General patient characteristics | Caucasian; older age; affluent socioeconomic background; higher parental education |
| Mental health disorders and ED symptoms | Comorbid mental health disorders; somatic/physiological symptoms; health concerns; feeling physically uncomfortable; eating/weight concerns; poor body image; binge/purging behaviours; increase in symptom severity |
| Mental health literacy | Improved understanding of ED and the recovery process |
| Privacy | More privacy possible in digital treatment; ability to remain anonymous in digital treatment |
| Social support system | Positive/supportive relationships; treatment initiated by others; practical assistance from others |
| Stigma | Positive familial attitudes towards help-seeking; feelings of being ignored when job hunting; less shame engaging in digital treatments; no fear of dismissal by digital treatments |
| Subjective ED severity and emotional distress | Loss of control of symptoms; persistence of symptoms despite efforts to control them; awareness of negative consequences; increased 'costs' of the ED; impact on social functioning; emotional distress; environmental changes; important life events |
| Treatment factors | Previous mental health service use for an emotional or behavioural problem; utilising self-help resources; short-term and direct treatments; personalised care |

Abbreviation: ED, eating disorder.

($n = 35$), the UK ($n = 16$) or Australia ($n = 13$). All studies were published in English.

### 3.1.2 | Methodology

The included studies varied greatly in regards to the methodology used to assess treatment barriers and facilitators. The majority of studies were qualitative ($n = 43$) in nature, using methods such as semi-structured interviews, focus groups, thematic analyses of online discussion boards or open-ended survey responses. In contrast, the included quantitative studies ($n = 26$) utilised online questionnaires, medical records, and structured clinical interviews. The remaining studies were mixed methods ($n = 4$), thereby employing methods used by both qualitative and quantitative studies.

### 3.1.3 | Risk of bias

The majority of qualitative studies ($n = 26$) received a 'high' quality rating, according to the CASP Quality Assessment Tool and the guidelines proposed by Butler et al. (2016). The remaining studies ($n = 17$) received a 'moderate' quality rating, while no studies received a 'low' quality rating. One mixed methods study received a 'high' quality rating, with the remainder ($n = 3$) receiving a 'moderate' quality rating for the qualitative

elements of their study design. Most quantitative studies were cross-sectional or cohort studies and thus could not fulfil all quality criteria proposed by the EPHPP Quality Assessment Tool. Only a few studies ($n$ = 3) received a 'Strong' quality rating, while the majority of studies ($n$ = 14) received a 'Moderate' quality rating. The remaining studies ($n$ = 9) received a 'Weak' quality rating, predominantly due to their cross-sectional and descriptive design. One mixed methods study received a 'Moderate' quality rating, while the majority ($n$ = 3) received a 'Weak' quality rating in regards to the quantitative elements of their study design. The decision was made to include all studies, regardless of quality rating. A more detailed overview of the quality ratings of each individual study can be found in the Supporting Information S1.

#### 3.1.4 | Sample size and description

Sample sizes ranged from 5 to 353,117 (median = 63) participants across all studies. The majority of studies ($n$ = 65) recruited patients with ED. A smaller number of studies examined the perspectives of caregivers of patients with ED ($n$ = 7) or healthcare professionals working with patients with ED ($n$ = 9). Studies which included the perspectives of more than one participant group (e.g. Yim et al., 2021) were included more than once in the analyses, provided the responses from each group were clearly differentiated in the results.

#### 3.1.5 | Age and gender

The included studies examined treatment barriers and facilitators pertaining to adolescent ($n$ = 16) and adult ($n$ = 56) patients with ED. There was a clear gender bias among the studies included, with the majority of studies examining exclusively female participants ($n$ = 27), or else containing an uneven distribution of genders favouring female participants ($n$ = 38). A total of $n$ = 1 study examined the treatment barriers pertaining to transgender participants.

#### 3.1.6 | ED diagnoses

The majority of studies recruited participants with elevated ED psychopathology ($n$ = 44), or else failed to differentiate results from participants with different ED diagnoses ($n$ = 13). A total of $n$ = 11 studies reported treatment barriers and facilitators from the perspectives of patients with Anorexia Nervosa, while $n$ = 2 reported the perspectives of patients with Bulimia Nervosa and $n$ = 3 reported the perspectives of patients with Binge-Eating Disorder.

#### 3.1.7 | Type of intervention

In total, $n$ = 6 studies reported the barriers/facilitators patients face when accessing digital interventions, while $n$ = 8 studies reported barriers/facilitators pertaining solely to face-to-face therapies. A total of $n$ = 4 studies examined both digital and face-to-face interventions, however, the results of these studies did not specify which barriers/facilitators were relevant for which type of intervention/therapy. The remaining $n$ = 55 studies did not specify the type of intervention/therapy they examined.

### 3.2 | Barriers and facilitators to treatment

#### 3.2.1 | Barriers to treatment

The majority of studies included in this review ($n$ = 65) provided information regarding the barriers reported by participants to either prevent or delay treatment uptake. A thematic analysis of each included paper revealed a total of 12 barriers that prevented patients with ED to engage with treatment services (see Table 1). The most frequently reported barrier was stigma, shame and guilt ($n$ = 42), followed by accessibility ($n$ = 39), and autonomy and rejection of treatment ($n$ = 35). The frequency with which the remaining barriers were reported can be seen in Figure 2.

#### 3.2.2 | Facilitators for treatment

Only $n$ = 42 studies included in this review identified facilitators which promoted treatment uptake. A total of 13 facilitating factors which encouraged patients with ED to engage with treatment services were identified by thematic analysis (see Table 2). The most frequently cited facilitator was the patient's social support system ($n$ = 27), followed by subjective ED severity and emotional distress ($n$ = 22), and comorbid mental health disorders and specific ED symptoms ($n$ = 21). A summary of the frequency of the remaining facilitating factors can be seen in Figure 3.

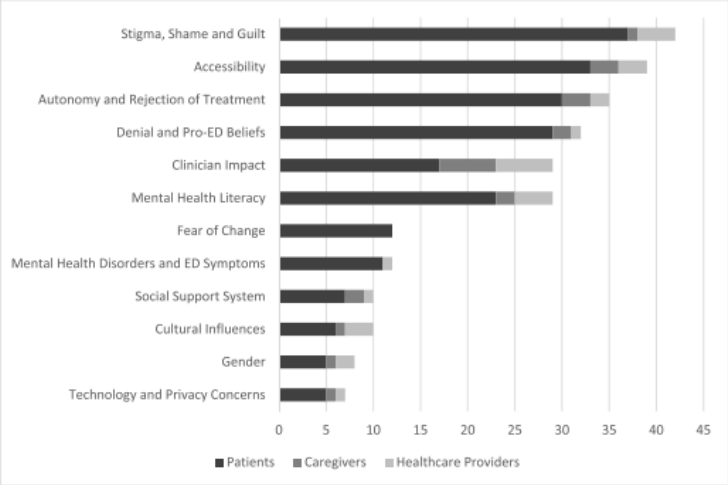



**FIGURE 2** Barriers preventing treatment uptake, reported by patients, caregivers, and healthcare professionals ($n = 65$). ED, eating disorder.

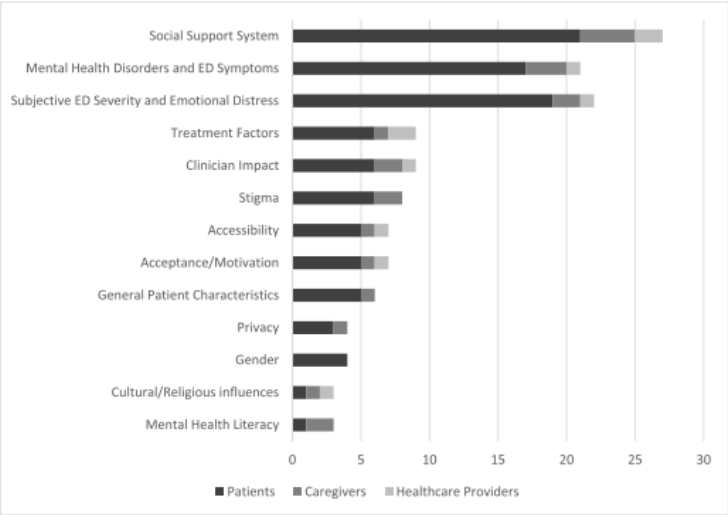



**FIGURE 3** Facilitating factors promoting treatment uptake, reported by patients, caregivers, and healthcare professionals ($n = 42$). ED, eating disorder.

## 3.3 | Subgroup comparisons of barriers and facilitators

### 3.3.1 | Patients versus caregivers versus healthcare professionals

Figure 4 provides an overview of the most frequently reported barriers that prevented engagement with treatment services, divided according to the perspectives of patients, caregivers, and healthcare professionals. Stigma, shame and guilt was reported as one of the most predominant barriers to treatment by both patients (65%) and healthcare professionals (44%), but only minimally important by caregivers (14%). Meanwhile, inadequate accessibility to treatment services and the need for autonomy or the rejection of treatment

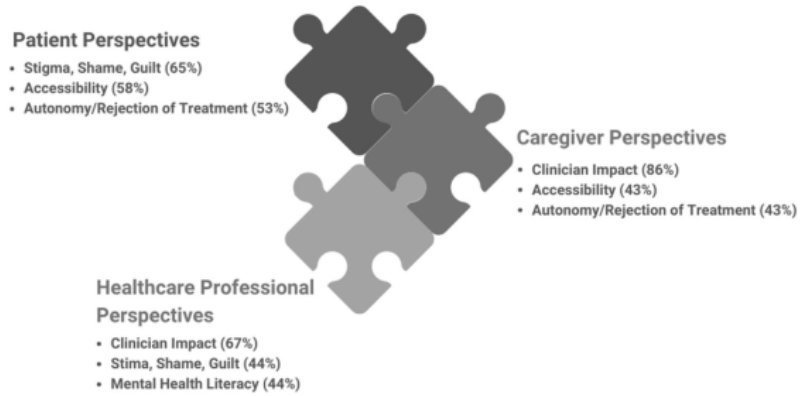



FIGURE 4 Most prominent barriers preventing treatment uptake, as reported by patients, caregivers, and healthcare professionals.

were reported as equally important by patients (58% and 53% respectively) and caregivers (43% and 43% respectively). Clinician impact was reported to be the most important barrier to treatment according to caregivers (86%) and healthcare professionals (67%). Only healthcare professionals (44%) reported a lack of mental health literacy to be a noteworthy barrier. In examining the facilitating factors which prompted treatment uptake, the patient's social support system was cited as the most prominent facilitator by patients with an ED (55%), caregivers of patients with an ED (67%), and healthcare professionals working with patients with an ED (40%).

### 3.3.2 | Type of ED diagnosis

Most studies included report data on mixed samples with multiple or unspecified ED diagnoses. Given the small number of studies that examined the treatment barriers/facilitators from the perspectives of patients with Bulimia Nervosa ($n = 2$) and Binge-Eating Disorder ($n = 3$), the decision was made to only report the barriers and facilitators reported by patients with Anorexia Nervosa ($n = 11$). The most frequently reported barriers to hinder treatment by patients with Anorexia Nervosa included denial and pro-ED beliefs (80%), autonomy and rejection of treatment (70%), clinician impact (60%), and stigma, shame and guilt (60%). The most prominent facilitators reported by patients with Anorexia Nervosa to have fostered their treatment included the patient's social support system (88%), comorbid mental health disorders and ED symptoms (75%), and subjective ED severity and emotional distress (75%).

### 3.3.3 | Digital interventions

A small number of studies ($n = 5$) examined the barriers pertaining to digital interventions. The most prominent barriers reported to prevent the use of digital interventions included technology and privacy concerns (80%), accessibility (60%), and stigma, shame and guilt (40%). Only $n = 2$ studies examined facilitators promoting the use of digital interventions, with the most frequently reported facilitator being stigma associated with face-to-face therapies (100%).

## 4 | DISCUSSION

The aim of this systematic review was to provide an in-depth overview of the barriers and facilitators affecting the treatment uptake behaviours of patients with ED, with a special emphasis being placed on the inclusion of the perspectives of patients themselves, as well as their caregivers and healthcare professionals. The majority of barriers reported were motivational (e.g., stigma, shame, guilt; denial of the ED) or pragmatic (e.g., accessibility; clinician impact) in nature, while only a few barriers were socio-culturally oriented (e.g., cultural influences, gender). Similarly, the most frequently reported facilitators were also motivational in nature, including positive social supports, specific ED symptoms, and emotional distress due to the severity of the ED.

A closer look at the barriers reported by the different subgroups showed that patients affected by ED reported predominantly motivational barriers, with feelings of self-blame, failure and not being worthy of treatment, as well as a fear of disclosure and discrimination frequently preventing patients from engaging with treatment

services. These results mirror those reported by previous reviews focusing on the experiences of patients with ED (e.g. Ali et al., 2017; Gulliver et al., 2010; Regan et al., 2017), wherein feelings of stigma and shame were reported to be some of the strongest barriers to treatment uptake. Internalised self-stigma has been previously shown in the literature to prevent individuals affected by various mental health disorders from seeking mental health information, a vital first step in the process of treatment uptake (Lannin et al., 2016). Stigma, shame and guilt was also reported as an important barrier to treatment by healthcare professionals. Prior studies have shown that individuals affected by ED are often perceived as being personally responsible for their illness by both themselves (Griffiths et al., 2014) and healthcare professionals (McNicholas et al., 2016), and that the cessation of symptoms is believed to be within the person's own control (Griffiths et al., 2014). It is therefore not surprising that a fear of discrimination by others, or else an internalisation of the stigmatised views regarding ED, may prevent individuals from engaging with treatment services. Meanwhile, caregivers typically did not report stigma, shame or guilt as being a barrier to treatment, but rather reported retrospective feelings of guilt regarding their own (lack of) actions which may have prevented their loved one from seeking treatment sooner (Coelho et al., 2021). Particularly parents of adolescents with ED reported high motivation to seek specialised treatment (Thomson et al., 2014), and it is possible that in these situations fear of stigma was overridden by fear for the adolescent's health and wellbeing. Barriers reported by caregivers and healthcare professionals were generally more pragmatic in nature, with an emphasis being placed on the behaviours and (lack of) ED knowledge of the treating clinician. Caregivers reported that actions such as a dismissal of ED symptoms, misdiagnoses and a mistrust of the capabilities of the treating clinician resulted in delayed treatment of their child or loved one. Meanwhile, healthcare professionals reported a lack of knowledge and/or experience in treating ED, as well as a lack of available resources as barriers to treatment. Healthcare professionals such as general practitioners are among the first professionals to have contact with patients with ED, and are therefore ideally suited to provide early intervention services for patients who may be unaware of their ED or else ambivalent about seeking further treatment (Gulliksen et al., 2015). However, studies have shown that if healthcare professionals have not received adequate training, they will be less confident and willing to identify these individuals and provide proper treatment (Linville et al., 2010). As a result, up to 92% of frontline medical workers in the USA reported they had failed to diagnose at least one patient with an ED (Linville et al., 2010). These results mirror those reported in the current review, that is, that the knowledge and skills of the healthcare professional regarding ED can have a major impact on the likelihood of patients engaging with treatment services. As this is the first systematic review that has incorporated the perspectives of caregivers and healthcare professionals, a direct comparison is not possible. However, previous reviews found the role of clinician impact to be equally important from the perspectives of patients affected by ED, wherein the characteristics of the clinician (Gulliver et al., 2010) and their perceived credibility and trustworthiness were reported as deterrents to treatment engagement (Ali et al., 2017). Whilst not as strongly reported in the studies included in the current review, previous reviews further found that positive past experiences with healthcare providers could be a significant facilitator of treatment uptake (Gulliver et al., 2010).

The patient's social support system was cited as the most prominent facilitator to treatment uptake by patients with an ED, caregivers, and healthcare professionals. Patients affected by ED crave social and emotional connections throughout their illness, and the recovery process is largely influenced by the social supports patients can rely upon during this time (Wacker, 2018). The importance of social support as a facilitator of the help-seeking process is also mirrored in previous reviews which found positive social support to be reinforcing of treatment uptake (Regan et al., 2017), while a lack of social support, encouragement and understanding from others was reported to be a significant treatment barrier (Ali et al., 2017; Radunz et al., 2023).

### 4.1 | Type of ED diagnosis

The majority of included studies were either completed with patients with early symptoms of ED (i.e. no formal ED diagnosis), or else did not specify which ED diagnoses were included in the study. Among those studies which specified the type of ED they examined, an overwhelming number of studies focused on patients with Anorexia Nervosa. Studies examining ED as a whole reported stigma, shame and guilt to be the most predominant barrier preventing patients from engaging with treatment services. While this barrier was also reported by studies examining patients with Anorexia Nervosa, other motivational barriers including denial of the ED and pro-ED beliefs, as well as the need for autonomy and rejection of treatment were reported to more significantly impact the decision to engage with treatment services. In attempting to understand why this particular group of patients appears to be so ambivalent towards treatment,

the Cognitive-Interpersonal Maintenance Model of Anorexia Nervosa is very helpful (Schmidt & Treasure, 2006). This model posits that a rigid, detail-oriented thinking style, an avoidant emotion processing and relational style, positive beliefs pertaining to the disorder, and an enabling/accommodating response of the patient's social support network are key in the maintenance of Anorexia Nervosa (Schmidt et al., 2014). It is therefore unsurprising that studies examining patients with Anorexia Nervosa report failed engagement with treatment services due to difficulties in perceiving the seriousness of the disorder, positive beliefs and/or benefits regarding the ED identity, and the strong need for autonomy.

### 4.2 | Digital interventions

Previous systematic reviews and meta-analyses (e.g. Melioli et al., 2016) have shown small to moderate effects for the use of digital interventions in the treatment of ED. However, low uptake and retention rates are common among digital interventions. A relatively small number of studies included in the current review provided information regarding the barriers of digital interventions (Cavazos-Rehg et al., 2020; Linardon, Shatte, et al., 2020; Linardon, Rosato, et al., 2020; Linardon et al., 2021; Moessner et al., 2016; Venkatesh et al., 2021). Among the most prevalent barriers reported were concerns regarding technological requirements and data privacy, as well as the accessibility of digital interventions. These results mirror those of prior studies, in which the accessibility, usability and visual design of digital interventions were among the key factors in the decision to engage with services (Jarman et al., 2022). Among the included studies in the current systematic review, the use of digital interventions was associated with significantly less stigma than face-to-face therapies. In fact, the reduced possibility of dismissal from healthcare professionals was reported to be a major facilitator in an individual's decision to engage with digital interventions (Linardon, Shatte, et al., 2020; Linardon et al., 2021). These findings are similar to those of prior studies examining treatment preferences, in which patients without a confirmed ED diagnosis demonstrated significantly higher preference rates for digital treatment options, than patients with an ED diagnosis, thereby reflecting the fear of stigma which prevents patients from initially seeking treatment (Griffiths et al., 2018). However, while the use of digital interventions has been associated with less stigma than standard face-to-face therapies, the fear of stigma nevertheless remained a predominant barrier for engagement. In particular, patients with ED stated that they were concerned that others may see the intervention app/website on their digital device(s) and thereby know that they are receiving ED treatment.

### 4.3 | Strengths and limitations

The current review provides an in-depth overview of the barriers and facilitators affecting treatment uptake among patients with ED. In doing so, the current review provides, to the best of our knowledge, the most comprehensive assessment of a large number of studies researching this topic. Our review further includes the perspectives of caregivers and healthcare professionals working with patients with ED, as opposed to focusing solely on the perspectives of the patients themselves. However, in doing so, the studies included in the current review are heterogenous in nature and a direct comparison between studies is difficult. It was therefore not possible to complete a meta-analysis or calculate effect sizes for the included studies. Risk of bias assessments showed that the majority of qualitative studies included were of a high quality. The included quantitative studies were of a more moderate quality, largely due to the cross-sectional and descriptive research designs employed. Most studies were completed in the USA, UK, or Australia, and only studies published in English were included. Further, few of the included studies researched the perspectives of patients with the diagnoses Bulimia Nervosa or Binge-Eating Disorder or of male patients with ED. Consequently, the results of this review may not be generalisable to other countries or to these neglected patient populations.

### 4.4 | Implications for research and treatment

The results of the current review reveal two major points of focus for the provision of treatment for patients with ED: the reduction of personal and public stigma and the strengthening of positive social supports. Fear of stigma was one of the most frequently reported barriers to treatment among studies included in the current review. The reduction of stigma is therefore necessary in order to encourage patients with ED to engage with treatment services. Nationwide awareness campaigns may be useful to increase mental health literacy surrounding ED and their treatment, while challenging the stigma surrounding these disorders. Similarly, mental health recovery narratives, that is, personalised stories of persons previously affected by mental health disorders, have been shown to reduce self-stigma of ED in student populations (Sheens et al., 2016). While this area of research is still relatively new and unexplored, particularly among

patients with ED, it could be a promising approach to 'normalising' ED and encouraging treatment among affected individuals.

Meanwhile, positive social support from others was reported as the most prominent facilitator for treatment by patients, caregivers and healthcare professionals. However, as social withdrawal is also frequently reported among patients with ED, active interventions are needed to enable the positive effects of this facilitator. One possible approach to provide more social support to patients with ED could be the inclusion of previously affected persons such as the implementation of peer mentoring support programs (e.g. Ranzenhofer et al., 2020). Preliminary evidence has shown that peer mentoring programs with recovered ED patients resulted in significantly higher treatment retention rates, as well as improved mood, quality of life, and feelings of hope that recovery is possible (Pellizzer & Wade, 2023).

The majority of studies completed to date have focused on individuals with unspecified ED symptoms, or in the case of a specified diagnosis, on individuals with Anorexia Nervosa. More research is needed to understand the needs of patients with Bulimia Nervosa and Binge-Eating Disorder, so as to ascertain if a transdiagnostic approach to early intervention is warranted, or if individual needs-based approaches are required. Similarly, while the studies included in the current review represented patients of various ages and ethnic backgrounds, the majority of studies were nevertheless completed with female patients. Studies have shown that ED continue to be viewed as a 'female disorder', resulting in a significant stigma both among male patients with ED and the healthcare professionals treating them (Dearden & Mulgrew, 2013; Malova & Dunleavy, 2021; Thapliyal et al., 2020). More studies are therefore needed to understand the needs of male patients with ED, in particular the barriers which may be preventing these patients from engaging with treatment services. Lastly, the current review provides a limited overview of the barriers preventing patients with ED from engaging with digital interventions. As the popularity of digital interventions continues to increase among the mental health care sector, it is important for future studies to research what factors may be inhibiting patients with ED from engaging with these services.

## 5 | CONCLUSION

Understanding the barriers and facilitators affecting the help-seeking behaviours of patients with ED is crucial for improving access to effective treatments for this patient group. The results of this review show that affected patients perceive stigma, shame and guilt as major barriers to treatment, while caregivers and healthcare professionals report more pragmatic barriers such as the knowledge and training of the treating clinician. More research is needed to determine the individual needs of specific patient populations, in particular male patients and patients with Bulimia Nervosa and Binge-Eating Disorder. Anti-stigma programs are needed to reduce the impact of stigma on preventing individuals from seeking treatment services. Meanwhile, the amplification of positive peer-support programs could help boost treatment motivation among affected individuals.

## AUTHOR CONTRIBUTIONS

Conceptualization: Melissa-Claire Daugelat, Kathrin Schag, Katrin Elisabeth Giel; Methodology: Melissa-Claire Daugelat, Kathrin Schag, Katrin Elisabeth Giel; Formal analysis: Melissa-Claire Daugelat, Jacopo Pruccoli; Writing – original draft: Melissa-Claire Daugelat; Writing – review & editing: Melissa-Claire Daugelat, Jacopo Pruccoli, Kathrin Schag, Katrin Elisabeth Giel; Visualization: Melissa-Claire Daugelat; Supervision: Kathrin Schag, Katrin Elisabeth Giel; Funding acquisition: Melissa-Claire Daugelat, Katrin Elisabeth Giel.

## ACKNOWLEDGEMENTS

We thank Daniel Barth for his contribution in the screening process. Melissa-Claire Daugelat receives a PhD scholarship from the Hans-Böckler Foundation. Kathrin Schag is funded by the Margarete von Wrangell Program by the Ministry for Science and Education Baden-Württemberg.

Open Access funding enabled and organized by Projekt DEAL.

## CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

## DATA AVAILABILITY STATEMENT

All data used to support the findings of this review are available from the corresponding author upon reasonable request.

## ORCID

*Melissa-Claire Daugelat* https://orcid.org/0000-0003-3772-4478

*Katrin Elisabeth Giel* https://orcid.org/0000-0003-0938-4402

## REFERENCES

Ali, K., Farrer, L., Fassnacht, D. B., Gulliver, A., Bauer, S., & Griffiths, K. M. (2017). Perceived barriers and facilitators towards help-seeking for eating disorders: A systematic review.

*International Journal of Eating Disorders*, *50*(1), 9–21. https://doi.org/10.1002/eat.22598

Ali, K., Fassnacht, D. B., Farrer, L., Rieger, E., Feldhege, J., Moessner, M., Griffiths, K. M., & Bauer, S. (2020). What prevents young adults from seeking help? Barriers toward help-seeking for eating disorder symptomatology. *International Journal of Eating Disorders*, *53*(6), 894–906. https://doi.org/10.1002/eat.23266

Andersen, S. T., Linkhorst, T., Gildberg, F. A., & Sjögren, M. (2021). Why do women with eating disorders decline treatment? A qualitative study of barriers to specialized eating disorder treatment. *Nutrients*, *13*(11), 4033. https://doi.org/10.3390/nu13114033

Andres-Pepina, S., Plana, M. T., Flamarique, I., Romero, S., Borràs, R., Julià, L., Gárriz, M., & Castro-Fornieles, J. (2020). Long-term outcome and psychiatric comorbidity of adolescent-onset anorexia nervosa. *Clinical Child Psychology and Psychiatry*, *25*(1), 33–44. https://doi.org/10.1177/1359104519827629

Austin, A., Flynn, M., Richards, K., Hodsoll, J., Duarte, T. A., Robinson, P., Kelly, J., & Schmidt, U. (2021). Duration of untreated eating disorder and relationship to outcomes: A systematic review of the literature. *European Eating Disorders Review*, *29*(3), 329–345. https://doi.org/10.1002/erv.2745

Basterfield, A., Dimitropoulos, G., Bills, D., Cullen, O., & Freeman, V. E. (2018). "I would love to have online support but I don't trust it": Positive and negative views of technology from the perspective of those with eating disorders in Canada. *Health and Social Care in the Community*, *26*(4), 604–612. https://doi.org/10.1111/hsc.12557

Becker, A. E., Franko, D. L., Speck, A., & Herzog, D. B. (2003). Ethnicity and differential access to care for eating disorder symptoms. *International Journal of Eating Disorders*, *33*(2), 205–212. https://doi.org/10.1002/eat.10129

Becker, A. E., Hadley Arrindell, A., Perloe, A., Fay, K., & Striegel-Moore, R. H. (2010). A qualitative study of perceived social barriers to care for eating disorders: Perspectives from ethnically diverse health care consumers. *International Journal of Eating Disorders*, *43*(7), 633–647. https://doi.org/10.1002/eat.20755

Butler, A., Hall, H., & Copnell, B. (2016). A guide to writing a qualitative systematic review protocol to enhance evidence-based practice in nursing and health care. *Worldviews on Evidence-Based Nursing*, *13*(3), 241–249. https://doi.org/10.1111/wvn.12134

Bye, A., Shawe, J., Bick, D., Easter, A., Kash-Macdonald, M., & Micali, N. (2018). Barriers to identifying eating disorders in pregnancy and in the postnatal period: A qualitative approach. *BMC Pregnancy and Childbirth*, *18*(1), 114. https://doi.org/10.1186/s12884-018-1745-x

Byrom, N. C., Batchelor, R., Warner, H., & Stevenson, A. (2022). Seeking support for an eating disorder: A qualitative analysis of the university student experience-accessibility of support for students. *Journal of Eating Disorders*, *10*(1), 33. https://doi.org/10.1186/s40337-022-00562-5

Cachelin, F. M., Rebeck, R., Veisel, C., & Striegel-Moore, R. H. (2001). Barriers to treatment for eating disorders among ethnically diverse women. *International Journal of Eating Disorders*, *30*(3), 269–278. https://doi.org/10.1002/eat.1084

Cachelin, F. M., & Striegel-Moore, R. H. (2006). Help seeking and barriers to treatment in a community sample of Mexican American and European American women with eating disorders. *International Journal of Eating Disorders*, *39*(2), 154–161. https://doi.org/10.1002/eat.20213

Cavazos-Rehg, P., Min, C., Fitzsimmons-Craft, E. E., Savoy, B., Kaiser, N., Riordan, R., Krauss, M., Costello, S., & Wilfley, D. (2020). Parental consent: A potential barrier for underage teens' participation in an mHealth mental health intervention. *Internet Interventions*, *21*, 100328. https://doi.org/10.1016/j.invent.2020.100328

Chowbey, P., Salway, S., & Ismail, M. (2012). Influences on diagnosis and treatment of eating disorders among minority ethnic people in the UK. *Journal of Public Mental Health*, *11*(2), 54–64. https://doi.org/10.1108/17465721211236363

Ciao, A. C., Lebow, J., VandenLangenberg, E., Ohls, O., & Berg, K. C. (2020). A qualitative examination of adolescent and parent perspectives on early identification and early response to eating disorders. *Eating Disorders*, *30*(3), 249–266. https://doi.org/10.1080/10640266.2020.1805960

Coelho, J. S., Suen, J., Marshall, S., Burns, A., Lam, P. Y., & Geller, J. (2021). Parental experiences with their child's eating disorder treatment journey. *Journal of Eating Disorders*, *9*(1), 92. https://doi.org/10.1186/s40337-021-00449-x

Couturier, J., Kimber, M., Jack, S., Niccols, A., Van Blyderveen, S., & McVey, G. (2013). Understanding the uptake of family-based treatment for adolescents with anorexia nervosa: Therapist perspectives. *International Journal of Eating Disorders*, *46*(2), 177–188. https://doi.org/10.1002/eat.22049

Critical Appraisal Skills Programme. (2022). CASP qualitative checklist. [cited 2023].https://casp-uk.net/casp-tools-checklists/

Dayal, H., Weaver, K., & Domene, J. F. (2015). From shame to shame resilience: Narratives of counselor trainees with eating issues. *Qualitative Health Research*, *25*(2), 153–167. https://doi.org/10.1177/1049732314551988

Dearden, A., & Mulgrew, K. E. (2013). Service provision for men with eating issues in Australia: An analysis of organisations', practitioners', and men's experiences. *Australian Social Work*, *66*(4), 590–606. https://doi.org/10.1080/0312407x.2013.778306

Del Valle, G., Belloch, A., & Carrió, C. (2017). The long and complex road in the search for treatment for mental disorders: An analysis of the process in five groups of patients. *Psychiatry Research*, *253*, 1–8. https://doi.org/10.1016/j.psychres.2017.03.024

Effective Public Healthcare Panacea Project. (2010). EPHPP quality assessment tool for quantitative studies. [cited 2023].https://www.ephpp.ca/quality-assessment-tool-for-quantitative-studies/

Elran-Barak, R., Barak, A., Cohen-Ashkenazi, S., & Schifter, T. (2018). Barriers to hospital admission among people with eating disorders: A qualitative internet-based study. *International Journal of Mental Health Nursing*, *27*(6), 1784–1792. https://doi.org/10.1111/inm.12485

Escobar-Koch, T., Banker, J. D., Crow, S., Cullis, J., Ringwood, S., Smith, G., van Furth, E., Westin, K., & Schmidt, U. (2010). Service users' views of eating disorder services: An international comparison. *International Journal of Eating Disorders*, *43*(6), 549–559. https://doi.org/10.1002/eat.20741

Evans, E. J., Hay, P. J., Mond, J., Paxton, S. J., Quirk, F., Rodgers, B., Jhajj, A. K., & Sawoniewska, M. A. (2011). Barriers to help-

seeking in young women with eating disorders: A qualitative exploration in a longitudinal community survey. *Eating Disorders*, *19*(3), 270–285. https://doi.org/10.1080/10640266.2011.566152

Fitzsimmons-Craft, E. E., Balantekin, K. N., Graham, A. K., DePietro, B., Laing, O., Firebaugh, M., Smolar, L., Park, D., Mysko, C., Funk, B., Taylor, C. B., & Wilfley, D. E. (2020). Preliminary data on help-seeking intentions and behaviors of individuals completing a widely available online screen for eating disorders in the United States. *International Journal of Eating Disorders*, *53*(9), 1556–1562. https://doi.org/10.1002/eat.23327

Fitzsimmons-Craft, E. E., Balantekin, K. N., Graham, A. K., Smolar, L., Park, D., Mysko, C., Funk, B., Taylor, C. B., & Wilfley, D. E. (2019). Results of disseminating an online screen for eating disorders across the U.S.: Reach, respondent characteristics, and unmet treatment need. *International Journal of Eating Disorders*, *52*(6), 721–729. https://doi.org/10.1002/eat.23043

Fitzsimmons-Craft, E. E., Eichen, D. M., Monterubio, G. E., Firebaugh, M. L., Goel, N. J., Taylor, C. B., & Wilfley, D. E. (2020). Longer-term follow-up of college students screening positive for anorexia nervosa: Psychopathology, help seeking, and barriers to treatment. *Eating Disorders: The Journal of Treatment & Prevention*, *28*(5–6), 549–565. https://doi.org/10.1080/10640266.2019.1610628

Fitzsimmons-Craft, E. E., Krauss, M. J., Costello, S. J., Floyd, G. M., Wilfley, D. E., & Cavazos-Rehg, P. A. (2020). Adolescents and young adults engaged with pro-eating disorder social media: Eating disorder and comorbid psychopathology, health care utilization, treatment barriers, and opinions on harnessing technology for treatment. *Eating and Weight Disorders*, *25*(6), 1681–1692. https://doi.org/10.1007/s40519-019-00808-3

Forrest, L. N., Smith, A. R., & Swanson, S. A. (2017). Characteristics of seeking treatment among U.S. adolescents with eating disorders. *International Journal of Eating Disorders*, *50*(7), 826–833. https://doi.org/10.1002/eat.22702

Goodwin, R. D., & Fitzgibbon, M. L. (2002). Social anxiety as a barrier to treatment for eating disorders. *International Journal of Eating Disorders*, *32*(1), 103–106. https://doi.org/10.1002/eat.10051

Gorse, P., Nordon, C., Rouillon, F., Pham-Scottez, A., & Revah-Levy, A. (2013). Subjective motives for requesting in-patient treatment in female with anorexia nervosa: A qualitative study. *PLoS One*, *8*(10), e77757. https://doi.org/10.1371/journal.pone.0077757

Grammer, A. C., Shah, J., Laboe, A. A., McGinnis, C. G., Balantekin, K. N., Graham, A. K., Smolar, L., Taylor, C. B., Wilfley, D. E., & Fitzsimmons-Craft, E. E. (2022). Predictors of treatment seeking and uptake among respondents to a widely disseminated online eating disorders screen in the United States. *International Journal of Eating Disorders*, *55*(9), 1252–1258. https://doi.org/10.1002/eat.23760

Griffiths, S., Mond, J. M., Li, Z., Gunatilake, S., Murray, S. B., Sheffield, J., & Touyz, S. (2015). Self-stigma of seeking treatment and being male predict an increased likelihood of having an undiagnosed eating disorder. *International Journal of Eating Disorders*, *48*(6), 775–778. https://doi.org/10.1002/eat.22413

Griffiths, S., Mond, J. M., Murray, S. B., & Touyz, S. (2014). The prevalence and adverse associations of stigmatization in people with eating disorders. *International Journal of Eating Disorders*, *48*(6), 767–774. https://doi.org/10.1002/eat.22353

Griffiths, S., Rossell, S. L., Mitchison, D., Murray, S. B., & Mond, J. M. (2018). Pathways into treatment for eating disorders: A quantitative examination of treatment barriers and treatment attitudes. *Eating Disorders*, *26*(6), 556–574. https://doi.org/10.1080/10640266.2018.1518086

Grillot, C. L., & Keel, P. K. (2018). Barriers to seeking treatment for eating disorders: The role of self-recognition in understanding gender disparities in who seeks help. *International Journal of Eating Disorders*, *51*(11), 1285–1289. https://doi.org/10.1002/eat.22965

Gulliksen, K. S., Nordbø, R. H. S., Espeset, E. M. S., Skårderud, F., & Holte, A. (2015). The process of help-seeking in anorexia nervosa: Patients' perspective of first contact with health services. *Eating Disorders: The Journal of Treatment & Prevention*, *23*(3), 206–222. https://doi.org/10.1080/10640266.2014.981429

Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: A systematic review. *BMC Psychiatry*, *10*(1), 1–9. https://doi.org/10.1186/1471-244x-10-113

Hamilton, A., Mitchison, D., Basten, C., Byrne, S., Goldstein, M., Hay, P., Heruc, G., Thornton, C., & Touyz, S. (2022). Understanding treatment delay: Perceived barriers preventing treatment-seeking for eating disorders. *Australian and New Zealand Journal of Psychiatry*, *56*(3), 248–259. https://doi.org/10.1177/00048674211020102

Hartman-Munick, S. M., Silverstein, S., Guss, C. E., Lopez, E., Calzo, J. P., & Gordon, A. R. (2021). Eating disorder screening and treatment experiences in transgender and gender diverse young adults. *Eating Behaviors*, *41*, 101517. https://doi.org/10.1016/j.eatbeh.2021.101517

Hepworth, N., & Paxton, S. J. (2007). Pathways to help-seeking in bulimia nervosa and binge eating problems: A concept mapping approach. *International Journal of Eating Disorders*, *40*(6), 493–504. https://doi.org/10.1002/eat.20402

Herman, B. K., Safikhani, S., Hengerer, D., Atkins, N., Kim, A., Cassidy, D., Babcock, T., Agus, S., & Lenderking, W. R. (2014). The patient experience with DSM-5-defined binge eating disorder: Characteristics, barriers to treatment, and implications for primary care physicians. *Postgraduate Medical Journal*, *126*(5), 52–63. https://doi.org/10.3810/pgm.2014.09.2800

Jarman, H. K., McLean, S. A., Rodgers, R., Fuller-Tyszkiewicz, M., Paxton, S., O'Gorman, B., Harris, E., Shatte, A., Bishop, K., Baumann, T., Mahoney, D., Daugelat, M. C., & Yager, Z. (2022). Informing mHealth and web-based eating disorder interventions: Combining lived experience perspectives with design thinking approaches. *JMIR Formative Research*, *6*(10), e38387. https://doi.org/10.2196/38387

Javier, S. J., & Belgrave, F. Z. (2019). "I'm not white, I have to Be pretty and skinny": A qualitative exploration of body image and eating disorders among Asian American women. *Asian American Journal of Psychology*, *10*(2), 141–153. https://doi.org/10.1037/aap0000133

Kanakam, N. (2021). Therapists' experiences of working with ethnic minority females with eating disorders: A qualitative study.

*Culture Medicine and Psychiatry*, *46*(2), 414–434. https://doi.org/10.1007/s11013-021-09721-w

Kästner, D., Weigel, A., Buchholz, I., Voderholzer, U., Löwe, B., & Gumz, A. (2021). Facilitators and barriers in anorexia nervosa treatment initiation: A qualitative study on the perspectives of patients, carers and professionals. *Journal of Eating Disorders*, *9*(1), 28. https://doi.org/10.1186/s40337-021-00381-0

Kazdin, A. E., Fitzsimmons-Craft, E. E., & Wilfley, D. E. (2017). Addressing critical gaps in the treatment of eating disorders. *International Journal of Eating Disorders*, *50*(3), 170–189. https://doi.org/10.1002/eat.22670

Lannin, D. G., Vogel, D. L., Brenner, R. E., Abraham, W. T., & Heath, P. J. (2016). Does self-stigma reduce the probability of seeking mental health information? *Journal of Counseling Psychology*, *63*(3), 351–358. https://doi.org/10.1037/cou0000108

Lazare, K., Mehak, A., & Telner, D. (2021). Exploring the primary care experiences of adult patients with eating disorders: A qualitative analysis. *Eating Disorders*, *29*(1), 1–16. https://doi.org/10.1080/10640266.2019.1605778

Leavey, G., Vallianatou, C., Johnson-Sabine, E., Rae, S., & Gunputh, V. (2011). Psychosocial barriers to engagement with an eating disorder service: A qualitative analysis of failure to attend. *Eating Disorders*, *19*(5), 425–440. https://doi.org/10.1080/10640266.2011.609096

Lebow, J., Narr, C., Mattke, A., Gewirtz O'Brien, J. R., Billings, M., Hathaway, J., Vickers, K., Jacobson, R., & Sim, L. (2021). Engaging primary care providers in managing pediatric eating disorders: A mixed methods study. *Journal of Eating Disorders*, *9*(1), 11. https://doi.org/10.1186/s40337-020-00363-8

Liamputtong, P., & Ezzy, D. (2005). *Qualitative research methods*. Oxford University Press.

Linardon, J., Messer, M., Lee, S., & Rosato, J. (2021). Perspectives of e-health interventions for treating and preventing eating disorders: Descriptive study of perceived advantages and barriers, help-seeking intentions, and preferred functionality. *Eating and Weight Disorders*, *26*(4), 1097–1109. https://doi.org/10.1007/s40519-020-01005-3

Linardon, J., Rosato, J., & Messer, M. (2020). Break binge eating: Reach, engagement, and user profile of an Internet-based psychoeducational and self-help platform for eating disorders. *International Journal of Eating Disorders*, *53*(10), 1719–1728. https://doi.org/10.1002/eat.23356

Linardon, J., Shatte, A., Tepper, H., & Fuller-Tyszkiewicz, M. (2020). A survey study of attitudes toward, and preferences for, e-therapy interventions for eating disorder psychopathology. *International Journal of Eating Disorders*, *53*(6), 907–916. https://doi.org/10.1002/eat.23268

Linville, D., Benton, A., O'Neil, M., & Sturm, K. (2010). Medical providers' screening, training and intervention practices for eating disorders. *Eating Disorders*, *18*(2), 110–131. https://doi.org/10.1080/10640260903585532

Lipson, S. K., Jones, J. M., Taylor, C. B., Wilfley, D. E., Eichen, D. M., Fitzsimmons-Craft, E. E., & Eisenberg, D. (2017). Understanding and promoting treatment-seeking for eating disorders and body image concerns on college campuses through online screening, prevention and intervention. *Eating Behaviors*, *25*, 68–73. https://doi.org/10.1016/j.eatbeh.2016.03.020

Liu, L., Hay, P., & Conti, J. (2022). Perspectives on barriers to treatment engagement of people with eating disorder symptoms who have not undergone treatment: A qualitative study. *BMC Psychiatry*, *22*(1), 239. https://doi.org/10.1186/s12888-022-03890-7

Ma, R., Zhang, M., Oakman, J. M., Wang, J., Zhu, S., Zhao, C., Hu, Z., & Buchanan, N. T. (2021). Eating disorders treatment experiences and social support: Perspectives from service seekers in mainland China. *International Journal of Eating Disorders*, *54*(8), 1537–1548. https://doi.org/10.1002/eat.23565

Maier, A., Ernst, J. P., Müller, S., Gross, D., Zepf, F., Herpertz-Dahlmann, B., & Hagenah, U. (2014). Self-perceived stigmatization in female patients with anorexia nervosa--results from an explorative retrospective pilot study of adolescents. *Psychopathology*, *47*(2), 127–132. https://doi.org/10.1159/000350505

Malova, E., & Dunleavy, V. (2021). Men have eating disorders too: An analysis of online narratives posted by men with eating disorders on YouTube. *Eating Disorders*, *30*(4), 437–452. https://doi.org/10.1080/10640266.2021.1930338

Martin-Wagar, C. A., Boswell, R. G., Bennett, B. L., Perelman, H., & Forrest, L. N. (2021). Psychological and eating disorder symptoms as predictors of starting eating disorder treatment. *International Journal of Eating Disorders*, *54*(8), 1500–1508. https://doi.org/10.1002/eat.23538

McClay, C. A., Waters, L., Schmidt, U., & Williams, C. (2016). A survey of attitudes towards computerized self-help for eating disorders within a community-based sample. *Behavioural and Cognitive Psychotherapy*, *44*(1), 65–78. https://doi.org/10.1017/s1352465814000484

McNicholas, F., O'Connor, C., O'Hara, L., & McNamara, N. (2016). Stigma and treatment of eating disorders in Ireland: Healthcare professionals' knowledge and attitudes. *Irish Journal of Psychological Medicine*, *33*(1), 21–31. https://doi.org/10.1017/ipm.2015.24

Melioli, T., Bauer, S., Franko, D. L., Moessner, M., Ozer, F., Chabrol, H., & Rodgers, R. F. (2016). Reducing eating disorder symptoms and risk factors using the internet: A meta-analytic review. *International Journal of Eating Disorders*, *49*(1), 19–31. https://doi.org/10.1002/eat.22477

Meyer, D. F. (2001). Help-seeking for eating disorders in female adolescents. *Journal of College Student Psychotherapy*, *15*(4), 23–36. https://doi.org/10.1300/j035v15n04_04

Moessner, M., Minarik, C., Özer, F., & Bauer, S. (2016). Can an internet-based program for the prevention and early intervention in eating disorders facilitate access to conventional professional healthcare? *Journal of Mental Health*, *25*(5), 441–447. https://doi.org/10.3109/09638237.2016.1139064

Mond, J. M., Hay, P. J., Darby, A., Paxton, S. J., Quirk, F., Buttner, P., Owen, C., & Rodgers, B. (2009). Women with bulimic eating disorders: When do they receive treatment for an eating problem? *Journal of Consulting and Clinical Psychology*, *77*(5), 835–844. https://doi.org/10.1037/a0015336

Neyland, M. K. H., & Bardone-Cone, A. M. (2019). Treatment experiences of Latinas with current or past binge eating disorder and/or bulimia nervosa. *Eating Disorders*, *27*(2), 253–265. https://doi.org/10.1080/10640266.2019.1591827

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A.,

Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, *372*, n71. https://doi.org/10.1136/bmj.n71

Pellizzer, M. L., & Wade, T. D. (2023). The effectiveness of lived experience involvement in eating disorder treatment: A systematic review. *International Journal of Eating Disorders*, *56*(2), 331–349. https://doi.org/10.1002/eat.23847

Pettersen, G., Wallin, K., & Björk, T. (2016). How do males recover from eating disorders? An interview study. *BMJ Open*, *6*(8), e010760. https://doi.org/10.1136/bmjopen-2015-010760

Plateau, C. R., Arcelus, J., Leung, N., & Meyer, C. (2017). Female athlete experiences of seeking and receiving treatment for an eating disorder. *Eating Disorders*, *25*(3), 273–277. https://doi.org/10.1080/10640266.2016.1269551

Potterton, R., Austin, A., Allen, K., Lawrence, V., & Schmidt, U. (2020). "I'm not a teenager, I'm 22. Why can't I snap out of it?": A qualitative exploration of seeking help for a first-episode eating disorder during emerging adulthood. *Journal of Eating Disorders*, *8*(1), 46. https://doi.org/10.1186/s40337-020-00320-5

Radunz, M., Ali, K., & Wade, T. D. (2023). Pathways to improve early intervention for eating disorders: Findings from a systematic review and meta-analysis. *International Journal of Eating Disorders*, *56*(2), 314–330. https://doi.org/10.1002/eat.23845

Ranta, K., Väänänen, J., Fröjd, S., Isomaa, R., Kaltiala-Heino, R., & Marttunen, M. (2017). Social phobia, depression and eating disorders during middle adolescence: Longitudinal associations and treatment seeking. *Nordic Journal of Psychiatry*, *71*(8), 605–613. https://doi.org/10.1080/08039488.2017.1366548

Ranzenhofer, L. M., Wilhelmy, M., Hochschild, A., Sanzone, K., Walsh, B. T., & Attia, E. (2020). Peer mentorship as an adjunct intervention for the treatment of eating disorders: A pilot randomized trial. *International Journal of Eating Disorders*, *53*(5), 497–509. https://doi.org/10.1002/eat.23258

Regan, P., Cachelin, F. M., & Minnick, A. M. (2017). Initial treatment seeking from professional health care providers for eating disorders: A review and synthesis of potential barriers to and facilitators of "first contact". *International Journal of Eating Disorders*, *50*(3), 190–209. https://doi.org/10.1002/eat.22683

Reyes-Rodríguez, M. L., Ramírez, J., Davis, K., Patrice, K., & Bulik, C. M. (2013). Exploring barriers and facilitators in eating disorders treatment among Latinas in the United States. *Journal of Latina/o Psychology*, *1*(2), 112–131. https://doi.org/10.1037/a0032318

Robinson, I., Stoyel, H., & Robinson, P. (2020). "If she had broken her leg she would not have waited in agony for 9 months": Caregiver's experiences of eating disorder treatment. *European Eating Disorders Review*, *28*(6), 750–765. https://doi.org/10.1002/erv.2780

Schmidt, U., & Treasure, J. (2006). Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology*, *45*(3), 343–366. https://doi.org/10.1348/014466505x53902

Schoen, E. G., Lee, S., Skow, C., Greenberg, S. T., Bell, A. S., Wiese, J. E., & Martens, J. K. (2012). A retrospective look at the internal help-seeking process in young women with eating disorders. *Eating Disorders*, *20*(1), 14–30. https://doi.org/10.1080/10640266.2012.635560

Sheens, E., Rhodes, P., & Dawson, L. (2016). Encountering anorexia: Challenging stigma with recovery stories. *Advances in Eating Disorders*, *4*(3), 315–322. https://doi.org/10.1080/21662630.2016.1217495

Silén, Y., Sipilä, P. N., Raevuori, A., Mustelin, L., Marttunen, M., Kaprio, J., & Keski-Rahkonen, A. (2021). Detection, treatment, and course of eating disorders in Finland: A population-based study of adolescent and young adult females and males. *European Eating Disorders Review*, *29*(5), 720–732. https://doi.org/10.1002/erv.2838

Smalec, J. L., & Klingle, R. S. (2000). Bulimia interventions via interpersonal influence: The role of threat and efficacy in persuading bulimics to seek help. *Journal of Behavioral Medicine*, *23*(1), 37–57. https://doi.org/10.1023/a:1005468220077

Sonneville, K. R., & Lipson, S. K. (2018). Disparities in eating disorder diagnosis and treatment according to weight status, race/ethnicity, socioeconomic background, and sex among college students. *International Journal of Eating Disorders*, *51*(6), 518–526. https://doi.org/10.1002/eat.22846

Strand, M., Bulik, C. M., von Hausswolff-Juhlin, Y., & Gustafsson, S. A. (2017). Self-admission to inpatient treatment for patients with anorexia nervosa: The patient's perspective. *International Journal of Eating Disorders*, *50*(4), 398–405. https://doi.org/10.1002/eat.22659

Thapliyal, P., Conti, J., Bandara, R. S. L., & Hay, P. (2020). 'It exists': An exploratory study of treatment experiences in men with eating disorders. *Australian Psychologist*, *55*(5), 534–545. https://doi.org/10.1111/ap.12455

Thomson, S., Marriott, M., Telford, K., Law, H., McLaughlin, J., & Sayal, K. (2014). Adolescents with a diagnosis of anorexia nervosa: Parents' experience of recognition and deciding to seek help. *Clinical Child Psychology and Psychiatry*, *19*(1), 43–57. https://doi.org/10.1177/1359104512465741

Tipton, M. V., Terrell, A. L., & Becnel, J. N. (2021). Understanding treatment-seeking behavior among female survivors of eating disorders. *Family and Consumer Sciences Research Journal*, *49*(3), 270–283. https://doi.org/10.1111/fcsr.12393

Torous, J., Nicholas, J., Larsen, M. E., Firth, J., & Christensen, H. (2018). Clinical review of user engagement with mental health smartphone apps: Evidence, theory and improvements. *Evidence-Based Mental Health*, *21*(3), 116–119. https://doi.org/10.1136/eb-2018-102891

Tsong, Y., Ward, M. L., Dilley, A., Wang, S. C., & Smart, R. (2022). To seek help or not: Asian American women mental health services utilization for disordered eating and body image concerns. *Asian American Journal of Psychology*, *14*(2), 155–165. https://doi.org/10.1037/aap0000270

Schmidt, U., Wade, T. D., & Treasure, J. (2014). The maudsley model of anorexia nervosa treatment for adults (MANTRA): Development, key features, and preliminary evidence. *Journal of Cognitive Psychotherapy*, *28*(1), 48–71. https://doi.org/10.1891/0889-8391.28.1.48

Venkatesh, A., Chang, A., Green, E. A., Randall, T., Gallagher, R., Wildes, J. E., & Graham, A. K. (2021). Perceived facilitators and barriers to engaging with a digital intervention among those with food insecurity, binge eating, and obesity. *Nutrients*, *13*(7), 2458. https://doi.org/10.3390/nu13072458

Wacker, E. C. (2018). Barriers and facilitators to seeking treatment for subclinical eating disorders: The importance of supportive relationships. *Journal of Family Psychotherapy*, *29*(4), 292–317. https://doi.org/10.1080/08975353.2018.1471946

Wales, J., Brewin, N., Raghavan, R., & Arcelus, J. (2017). Exploring barriers to South Asian help-seeking for eating disorders. *Mental Health Review Journal*, *22*(1), 40–50. https://doi.org/10.1108/mhrj-09-2016-0017

Weigel, A., Rossi, M., Wendt, H., Neubauer, K., von Rad, K., Daubmann, A., Romer, G., Löwe, B., & Gumz, A. (2014). Duration of untreated illness and predictors of late treatment initiation in anorexia nervosa. *Journal of Public Health*, *22*(6), 519–527. https://doi.org/10.1007/s10389-014-0642-7

Yim, S. H., Spencer, L., Gordon, G., Allen, K. L., Musiat, P., & Schmidt, U. (2021). Views on online self-help programmes from people with eating disorders and their carers in UK. *The European Journal of Public Health*, *31*(31 Suppl 1), i88–i93. https://doi.org/10.1093/eurpub/ckab046

## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Daugelat, M.-C., Pruccoli, J., Schag, K., & Giel, K. E. (2023). Barriers and facilitators affecting treatment uptake behaviours for patients with eating disorders: A systematic review synthesising patient, caregiver and clinician perspectives. *European Eating Disorders Review*, 1–17. https://doi.org/10.1002/erv.2999

### 3.2 Publication 2: Participatory Development of Evidence-Based Patient Narrative Videos for Patients with Eating Disorders: A Methodological Approach and Pilot Data (Daugelat et al., 2024).

Full citation: *Daugelat, M.-C., Gregg, B., Adam, S.H., Schag, K., Kimmerle, J., & Giel, K. E. (2024). Participatory Development of Evidence-Based Patient Narrative Videos for Patients with Eating Disorders: A Methodological Approach and Pilot Data. Journal of Eating Disorders. https://doi.org/10.1186/s40337-024-01146-1*

The targeted use of patient narratives for mental disorders is a relatively new methodological approach in mental health care and to date, only a handful of studies have examined the use of patient narratives for patients with ED (e.g., (Dawson et al., 2018)). Meanwhile, information regarding the development of patient narratives remains scarce. This publication therefore describes the methodological approach used to develop a series of evidence-based patient narrative videos for patients with ED, as well as the results of a pilot study with a group of healthy participants without a (current) ED to determine the acceptability and feasibility of these videos, and their suitability for use in a clinical trial with patients with ED. The video development process described in this study consisted of four stages: a systematic review (results published separately, see Publication 1), focus groups with affected persons with ED, participatory narrative development with a lived experience representative, and a pilot study with persons without a (current) ED.

Two focus groups were completed with male and female participants with self-reported ED. Participants were asked to read and rate a list of barriers and facilitating factors that were previously identified by the systematic review as affecting treatment uptake. Participants were asked which barriers and facilitators in particular were relevant to their own illness and treatment journey, and the frequency with which each barrier and facilitator was reported was documented by the research team. Participants most frequently reported comorbid mental health disorders and ED symptoms, feelings of stigma, shame and guilt, and clinician impact as barriers to their seeking and/or engaging with treatment

services. Meanwhile, subjective ED severity and emotional distress was reported by all participants as facilitating their decision to seek and/or continue treatment.

A collaborative approach was used between the research team and a lived experience representative to create six (patient) narrative videos, the contents of which were based on the personal experiences of the lived experience representative, as well as the results of the systematic review and the focus groups with currently affected persons. While the content of each video remained the same, this was adapted slightly to feature the perspectives of a) the lived experience representative speaking about her experiences with an ED, b) a psychotherapist speaking about the experiences of her patients with ED, and c) the lived experience representative speaking about her experiences with a somatic condition (i.e., torn knee ligament). Further, the level of emotionality was manipulated so that two videos were created for each perspective featuring either a lower or a higher variation of the level of emotionality of the content (see Figure 3).

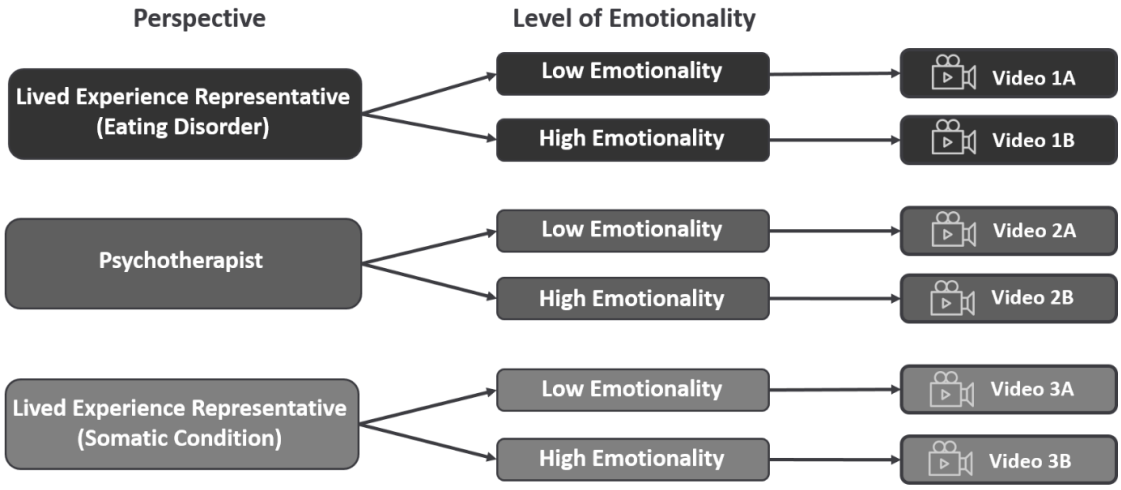



**Figure 3.** Overview of the Patient Narrative Videos Created

N = 19 female participants without a (current) ED participated in a pilot study to assess the feasibility and acceptability of the patient narrative videos. While participants rated all videos positively, the videos in which the lived experience representative spoke about her experiences with an ED were rated as

significantly more authentic than the videos in which the lived experience representative spoke about a somatic condition. The lived experience ED videos were further rated as more empathic and useful, and received better overall ratings than the videos featuring the perspective of the psychotherapist, or the videos featuring a somatic condition. A clear preference was reported by participants for the videos featuring a higher level of emotionality of the content. This publication provides one example of how evidence-based patient narrative videos can be created for patients with ED. An initial pilot study with participants without a (current) ED showed that these videos are feasible and acceptable for piloting with a larger clinical population of patients with ED (see Publications 3 and 4).

Daugelat *et al. Journal of Eating Disorders* (2024) 12:188
https://doi.org/10.1186/s40337-024-01146-1

Journal of Eating Disorders

METHODOLOGY

Open Access

# Participatory development of evidence-based patient narrative videos for patients with eating disorders: a methodological approach and pilot data

Melissa-Claire Daugelat[1,2*], Bettina Gregg[3], Sophia Helen Adam[1], Kathrin Schag[1,2], Joachim Kimmerle[4,5] and Katrin Elisabeth Giel[1,2,6]

**Abstract**

**Background** Patient narratives can best be defined as personal stories of persons previously or currently affected by a physical or mental health disorder. The collaborative development and implementation of such narratives reflects a participatory approach between researchers, patients, and members of the public towards the development of new interventions. Patient narratives can foster feelings of support and belonging, as well as increase hope and motivation towards recovery. Aims of this pilot study were (a) the collaborative development of a series of evidence-based patient narrative videos about eating disorders, (b) their initial evaluation with a group of participants without (current) eating disorders, and (c) to provide a reproducible documentation of this methodological approach.

**Method** A multi-stage participatory process was used including a) a systematic review, b) focus groups with affected persons, c) the participatory narrative development, and d) an initial pilot study with participants without (current) eating disorders. A former and currently recovered patient was recruited as a lived experience representative, while a psychotherapist provided the same information from a professional perspective. Control group videos featured the lived experience representative discussing a somatic condition unrelated to eating disorders (i.e., torn knee ligament). Two videos were created for each perspective with varying degrees of emotionality of the content.

**Results** Nineteen female participants without (current) eating disorders were recruited for the pilot study. All videos received positive ratings, however, participants rated videos in which the lived experience representative discussed her eating disorder as significantly more authentic than the control group videos, as well as significantly more empathic, useful, and better overall than the psychotherapist and control group videos. Participants further indicated a clear preference for videos with higher emotionality, regardless of which perspective or disorder was being presented.

**Discussion** The use of patient narratives for eating disorders is a relatively new methodological approach. This paper provides one example of how evidence-based patient narratives can be constructed. The patient narratives created in this study received positive feedback from participants without (current) eating disorders and are currently being tested in a 4-arm randomised controlled pilot study with patients affected by eating disorders.

*Correspondence:
Melissa-Claire Daugelat
melissa-claire.daugelat@med.uni-tuebingen.de
Full list of author information is available at the end of the article

**Keywords** Eating disorders, Motivation, Help-seeking, Lived experience, Patient involvement, Patient narratives, Recovery stories, Treatment

## Introduction

The treatment of eating disorders (ED) is influenced by a myriad of personal, social, and environmental factors. In particular, a systematic review completed by our research group showed that patients most frequently report stigma, shame, and guilt as barriers to treatment, while caregivers and healthcare professionals report a lack of training for clinicians regarding ED to be a hindrance to effective treatment [1]. Meanwhile, one of the most prominent factors influencing the initiation of ED treatment is social support, or rather the lack of positive social support commonly found among persons affected by ED [1, 2]. Patients with ED typically report relying on the social support of their immediate family, however, some patients may also seek social support through friends, co-workers, or by engaging with other affected persons and their stories (e.g. [3]).

Patient narratives can be defined as personal stories presented by persons previously or currently affected by a physical or mental health disorder, and frequently comprise insights into the narrator's challenges, struggles, and ultimately successes as they navigate treatment for their disorder [4, 5]. Patient narratives may be live, such as in peer-to-peer relationships, or else may be documented in a variety of mediums, including written texts such as books or blogs, documentary films, or videos posted on various social media platforms [5–7], and are therefore easily accessible to affected persons. Patient narratives can foster empathy and feelings of support and belonging [5, 8, 9], while showing that recovery is possible and providing currently affected persons with feelings of hope regarding their own recovery [10]. To date, only a handful of studies have examined the effects of patient narratives for patients with ED. A recent study by Gumz et al. [11] assessing factors influencing treatment uptake found that patients with anorexia nervosa who had reported reading and/or viewing patient narratives also reported significantly shorter durations of untreated ED (DUED), i.e. the amount of time that elapses between the onset of ED symptoms and treatment engagement [12]. Another study which retrospectively asked female patients with ED about their experiences with written patient narratives found that while patients in recovery benefited from engagement with patient narratives, patients who were not receiving treatment at the time of engagement were increasingly at risk for developing harmful social comparisons or "copy-cat" behaviours on the basis of the narratives [13]. Dawson et al. [10] further used patient interviews to create a series of written patient narratives, in which such possibly triggering or adverse contents were eliminated. Women with anorexia nervosa were recruited for the study and sent the patient narratives to read over a two-week period. While the results of this study showed no short-term effects on current patients' motivation or self-efficacy, qualitative results showed that the patient narratives were well accepted and that participants would recommend their use for other patients [10].

Studies examining the use of patient narrative videos for other mental disorders, including depression and anxiety, found that engaging with at least one patient narrative video resulted in significant long-term increases in participants' reported quality of life and meaning of life [14]. Similar results have also been found in the field of psychosis, where viewing patient narrative videos resulted in increased self-efficacy and hope towards one's own recovery [15, 16]. Interestingly, when presented with nearly identical content from a healthcare professional's point of view, these effects remained but were significantly reduced [15], suggesting that while content itself may evoke positive effects, the peer element of patient narratives appears to be an important component of these videos.

The process of developing patient narratives videos is a relatively new methodological approach and little information has been documented regarding how patient narratives should be developed in order to be most beneficial for the target population of affected persons. Previous work completed by LaMarre and Rice [17] focused on a digital storytelling workshop, in which participants co-created a series of videos focusing on ED recovery. These workshops consisted of five key components, including an introduction to the context, a story circle to develop and share ideas, technical introductions, an open studio for content production, and a screening and reflection of the videos. The videos created in the workshop were later used by participants for a variety of personal and/or public purposes (e.g., sharing on social media platforms) [17]. This paper aims to further develop the methodology of patient narratives and to document the process of developing evidence-based patient narrative videos for persons affected by ED.

## Study aims

Patient and Public Involvement (PPI) refers to the collaboration between researchers, patients, and members of the public when planning, conducting, or disseminating clinical research studies [18]. Through the use of PPI, affected individuals actively contribute to the development of new interventions that are relevant to the target patient group [19, 20]. The current study therefore incorporated PPI throughout the development and assessment of a series of evidence-based patient narrative videos for patients with ED. The videos featured three varying perspectives from a) a lived experience representative discussing her experiences with an ED (Video 1A and Video 1B), b) a psychotherapist (Video 2A and Video 2B), and c) the lived experience representative reporting on a somatic condition unrelated to ED (Video 3A and Video 3B). The videos further varied based on the level of emotionality of the content presented, with one half of the videos (i.e., video versions A) featuring content with a low degree of emotionality, and the other half of the videos (i.e., video versions B) featuring content with a higher degree of emotionality. A pre-pilot study with a student population was completed to gain initial insights into the possible acceptability and feasibility of these patient narrative videos, as well as to determine which videos would be most suitable for a larger pilot study with affected persons with ED.

## Method/design

Ethical approval for completion of this study was obtained from the ethics committee of the Medical Faculty at the University Hospital Tübingen (reference 417/2022BO2, 418/2022BO2). An overview of the five stages of the video development process can be seen in Fig. 1, while a detailed explanation is provided below.

### Stage 1: systematic review

A systematic review was completed to determine the most common barriers and facilitators affecting ED treatment uptake and engagement, including a synthesis of the perspectives of patients with ED, their caregivers, and healthcare professionals. Further information and results of the systematic review have been published elsewhere (see [1]).

### Stage 2: focus groups with affected persons

#### *Participants*

Recruitment e-mails were sent to approximately 60 participants of previous ED research studies completed by the University Hospital Tübingen. A total of n = 8 participants attended one of two 90-min focus-group appointments at the University Hospital Tübingen.

#### *Procedure*

Following a short round of introductions, participants were provided with a list of barriers and facilitating factors regarding treatment uptake for EDs, as identified by the systematic review [1]. Participants were asked to identify which of these barriers and facilitators were relevant to their own treatment journey. A semi-structured group discussion followed, during which participants provided further insights into the most important barriers and facilitators of their treatment journey. Participants were further asked if there were any other important barriers and/or facilitating factors which were not included in the list. Written informed consent was obtained from all participants prior to begin of the focus groups. Participants received a compensation for their participation.

#### *Analysis*

A list of the barriers and facilitators that were reported as being important by participants was compiled and documented by the research team to determine how frequently each barrier and facilitator was identified. The group discussions were recorded and transcribed manually by a member of the study team. Selected quotes were chosen from the transcripts; however, the content of the transcripts has not been further analysed.

### Stage 3: participatory narrative development

#### *Participants*

A former and currently recovered patient with an ED was recruited as a lived experience representative to ensure that the patient narratives would remain relevant and relatable for affected persons.


**Fig. 1** Overview of the five stages of the video development process

***Procedure***

The current study utilised a collaborative approach to develop a series of evidence-based patient narratives. The methodological approach used here was created by the study team and has been detailed to provide one example of how patient narrative videos may be developed. In order to gain further insight into her personal experiences, the lived experience representative was initially asked to summarise her ED journey in a letter to her "former self", including what motivated her to seek treatment and what information she wished she would have known prior to treatment. During a series of collaborative discussions, four key categories were developed on the basis of the lived experience representative's personal experiences and the results of the systematic review [1] and focus groups (see Results). Using these four categories, two scripts were developed in cooperation with the lived experience representative with identical content, but with a variation of the intensity of the emotionality of the content, as defined by the lived experience representative. Throughout this process, it was decided that the lived experience representative would not disclose which ED symptoms or diagnosis she previously experienced in the scripts, but that she would instead discuss those aspects of the treatment journey which are shared by most patients with ED. Two further scripts were developed in cooperation with a psychotherapist with professional ED experience. The scripts for the psychotherapist contained the same content as those of the lived experience representative but were adapted to reflect a more professional point of view. In order to increase comparability, the psychotherapist was the same age and gender as the lived experience representative. Finally, two additional scripts were developed in which the lived experience representative discussed the same content presented in her initial two ED-focused videos, but with regard to a somatic condition unrelated to ED (i.e., a torn knee ligament). These scripts contained the same content as the lived experience representative's scripts regarding her ED, however, the content was adapted to reflect the concerns, treatments, and need for social support of patients receiving treatment for this somatic condition.

A professional videographer was hired to film all six videos in June, 2023. Further editing was completed to ensure that all videos were comparable regarding duration, with the final videos being approximately six minutes in length. The lived experience representative received travel and accommodation reimbursement for the duration of the filming process.

**Stage 4: pilot study with participants without (current) eating disorders**

***Participants***

Participants were recruited via the online mailing systems of the University Hospital Tübingen and the Eberhard Karls University Tübingen. Female students and employees of the University and University Hospital were invited to participate, provided they fulfilled the following inclusion criteria: minimum age of 18 years, sufficient German language skills, no current acute psychiatric disorder (e.g., suicidal ideation or psychosis).

***Materials used***

Participants completed a short demographic questionnaire including items regarding age, gender, nationality, and if they had any previous experiences with ED. A new questionnaire was developed by the research team for this study consisting of 11 items, in which participants were asked to rate the authenticity (e.g., Item 3: "I believe that the person in this video was personally affected by an eating disorder") and empathy (e.g., Item 5: "I feel compassion for the person shown in this video") of the person featured in the lived experience representative videos re. ED, the psychotherapist videos and the lived experience representative videos re. a somatic condition. Participants also rated the usefulness of the lived experience expert and psychotherapist videos (e.g., Item 9: "I think this video is helpful for people with eating disorders") using a 5-Point Likert scale ranging from 1 = strongly disagree to 5 = strongly agree. Participants were further asked to provide an overall rating for each of the six videos using a 6-Point Likert Scale ranging from 1 = insufficient to 6 = very good. Participants completed the questionnaire immediately after watching each video. After watching both the low emotionality and high emotionality versions of each narrative video, participants were asked to indicate which version (low vs. high emotionality) they preferred. In addition, a subgroup of n = 5 participants was randomly selected by the study team and invited to participate in semi-structured interviews in order to gain additional insights into their perception of the videos, which may otherwise have been overlooked in the questionnaires, with particular focus on the authenticity, empathy, likeability, and usefulness of the videos as a whole, as well as which video/s they preferred the most.

***Procedure***

All data collection was completed in the Department for Psychosomatic Medicine and Psychotherapy at the University Hospital Tübingen. Participants were required to attend one study appointment with a duration of

approximately 60 min, for which they received a compensation. All participants were asked to view and rate all six patient narrative videos created for this study. Participants were not supplied with any information regarding the research aims or how the videos differed from one another (i.e., different perspectives or emotionality). The order in which the videos were presented was randomised for each participant, both in regards to which perspective was seen first (i.e. lived experience re. ED, psychotherapist, lived experience re. a somatic condition) and which level of emotionality was seen first (i.e. low emotionality, high emotionality).

#### *Statistical analyses*

Data analyses were conducted using statistical software IBM SPSS Statistics Version 28 [21]. Authenticity, empathy, and usefulness scores were determined by calculating the mean of the respective items included for each domain in the questionnaire. A series of four repeated measures analyses of variance (ANOVA) were completed, wherein the Video Perspective (3 levels) and Emotionality of the Video (2 levels) were included as within-subject factors, and the authenticity, empathy, usefulness, and overall ratings for each of the six videos were assessed as dependent variables. Post-hoc tests were completed to further investigate pairwise comparisons between the three levels of the within-subject factor Video Perspective. The semi-structured interviews were recorded and transcribed manually by a member of the study team. Selected quotes were chosen from the transcripts to highlight individual feedback points provided by participants; however, the content of these transcripts has not been further analysed.

## Results

### Results from focus groups

Two focus groups were completed between September and October 2022 with persons with ED residing in the area of Tübingen, Germany, so as to validate the results of the previously completed systematic review. The first focus group had a total of n = 5 participants, including both male and female patients with Binge Eating Disorder. The second focus group consisted of n = 3 female participants with Anorexia Nervosa or Bulimia Nervosa. A full overview of the results can be seen in Fig. 2. Participants of the focus groups reported that comorbid mental health disorders and ED symptoms (n = 5, 62.5%), feelings of stigma, shame, and guilt (n = 4, 50%), as well as the clinician impact (n = 4, 50%) were important barriers to seeking and/or engaging with treatment services. Participants further reported that a lack of social support (n = 4, 50%), as well as denial and pro-ED beliefs (n = 4, 50%) had a negative effect on their treatment. Meanwhile, all participants of the focus groups reported that the subjective ED severity and emotional distress were primarily responsible for their seeking and/or engaging with treatment services (n = 8, 100%). Other facilitators to treatment included comorbid mental health disorders and ED symptoms (n = 6, 75%), accessibility of treatment (n = 5, 62.5%), and clinician impact (n = 4, 50%).

Discussions in the focus groups allowed participants to elaborate on the individual barriers and/or facilitators which they experienced in their personal treatment journey. These discussions focused heavily on issues regarding accessibility and the local healthcare system, as well as experiences with stigma, shame, and guilt in relation to EDs. A selection of quotes from participants can be found in Table 1 to provide further insights.

### Results from the participatory narrative development

Six patient narrative videos were developed from the perspectives of a lived experience representative (Videos 1A and 1B), a psychotherapist (Videos 2A and 2B), and the lived experience representative reporting on a somatic condition unrelated to ED (Videos 3A and 3B; for an overview, see Fig. 3).

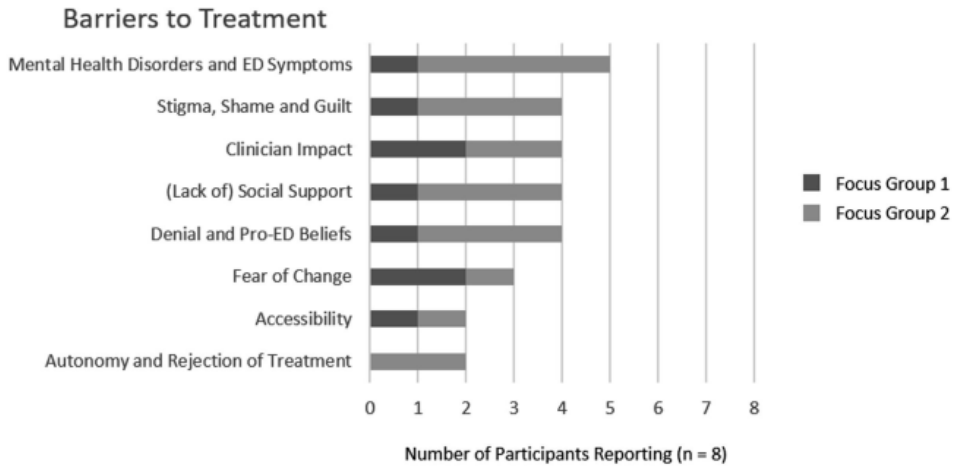
Each video consists of four key categories, based on a combination of the lived experience representative's personal experiences and the results of the systematic review [1] and focus groups with currently affected persons:

1. The role of stigma, shame, and guilt as a barrier to treatment
2. The role of subjective distress caused by the ED as a facilitator for treatment
3. The importance of social support before and during treatment
4. Overall advice and encouragement for currently affected persons.

The level of emotionality was varied across the videos, so that a lower and a higher emotionality version was created for each perspective. To better demonstrate this, Table 2 shows the same excerpt of the script and how it is presented according to the different perspectives and levels of emotionality.

### Results from the pilot study with participants without (current) eating disorders

In total, n = 19 participants were recruited for the initial pilot study. Participants identified as female (n = 18) or non-binary (n = 1), and ranged in age from 19 to 55 years ($M = 26.00$, $SD = 8.29$). The majority of participants were German citizens (n = 17), while the remaining participants were British (n = 1) or Chinese (n = 1) citizens residing in Germany. When asked about previous



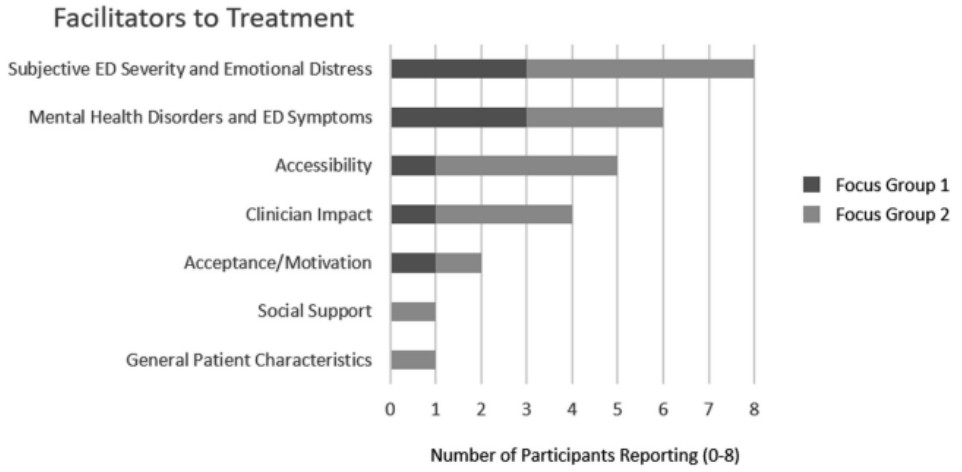




**Fig. 2** Barriers and Facilitators to Treatment, as reported by the Focus Groups (n = 8). Notes: ED = eating disorder

**Table 1** Selection of quotes from the focus groups discussing their experiences with "Stigma, Shame, and Guilt" in relation to their eating disorder

| |
|---|
| *"I somehow never managed to inform the people around me or get into those conversations, because for me I always saw it as a taboo subject and as a stigma"*<br>- Participant 1, currently affected by Anorexia Nervosa |
| *"In any case, with people who are overweight, it's always a case of, yes, it's your own fault, eat less, be more disciplined, erm, so in principle the blame is always put on the patient, so in my experience it's always the patient's fault"*<br>- Participant 2, currently affected by Binge Eating Disorder |
| *"It was a bit like, I wasn't sick enough, first of all through my own conviction, but also somehow from everyone else […] I don't know but there is such a hierarchy of eating disorders […] and as a man, now not only as a man but as a man in my personal experience I would hear 'well, he just likes to eat' or 'he just eats a bit too much' or things like that […]" - Participant 3, currently affected by Binge Eating Disorder* |

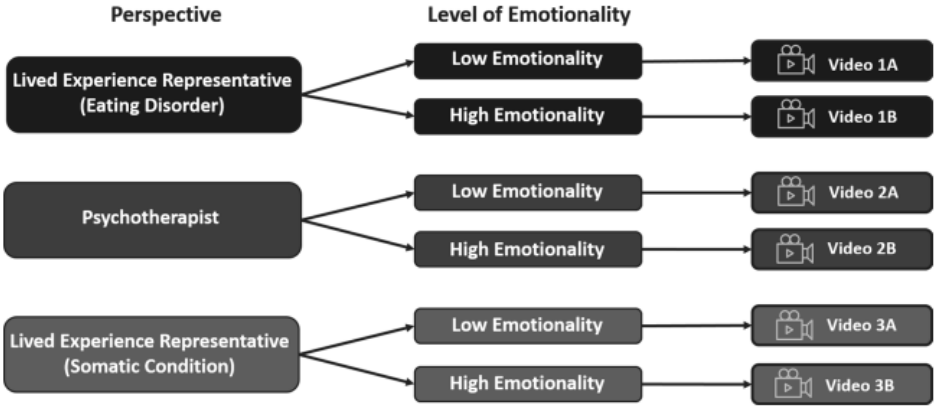



**Fig. 3** Overview of the six narrative videos

experiences with ED, n = 1 participant reported having had personal historical (but no current) experiences with an ED, while n = 9 participants reported having experiences through friends and/or family members.

#### *Perspectives of the videos*

*Authenticity* A significant main effect was found for the perspectives of the videos in regards to the authenticity ratings ($F(1, 18) = 6.909$, $p = 0.003$, $\eta^2 = 0.277$). Post-hoc analyses showed that the lived experience videos re. ED were rated as significantly more authentic than the lived experience videos re. a somatic condition ($p = 0.002$). No significant differences were found between the lived experience videos and the psychotherapist videos ($p = 0.106$) or the psychotherapist videos and the lived experience videos re. a somatic condition ($p = 0.060$).

*Empathy* A significant main effect was also found for the empathy ratings of the videos ($F(1, 18) = 9.301$, $p < 0.001$, $\eta^2 = 0.341$). Post-hoc analyses showed that the lived experience videos re. ED were rated as significantly more empathic than the psychotherapist videos ($p = 0.008$) and the lived experience videos re. a somatic condition ($p = 0.004$). No significant difference was found between the psychotherapist videos and the lived experience videos re. a somatic condition ($p = 0.767$).

*Usefulness* The results further showed a significant main effect for the usefulness ratings of the videos ($F(1, 18) = 25.095$, $p < 0.001$, $\eta^2 = 0.582$), wherein the lived experience videos re. ED were rated as significantly more useful than the psychotherapist videos.

*Overall ratings* Lastly, the results showed a significant main effect for the perspective of the videos regarding the overall ratings of the videos ($F(1, 18) = 6.018$, $p = 0.006$, $\eta^2 = 0.251$). Post-hoc analyses showed that the lived experience videos re. ED received a significantly better overall rating than the psychotherapist videos ($p < 0.001$) and the lived experience videos re. a somatic condition ($p = 0.011$). No significant difference was found between the psychotherapist videos and the lived experience videos re. a somatic condition ($p = 0.446$). A summary of these findings can be found in Fig. 4.

#### *Emotionality of the videos*

*Authenticity* No significant main effect was found for the emotionality of the videos regarding the authenticity ratings ($F(1, 18) = 1.704$, $p = 0.208$, $\eta^2 = 0.086$).

*Empathy* A significant main effect was found for empathy ratings of the videos ($F(1, 18) = 9.357$, $p = 0.007$, $\eta^2 = 0.342$), wherein the high emotionality videos were rated as more empathic than the low emotionality videos.

*Usefulness* A significant main effect was also found for the usefulness ratings of the videos ($F(1, 18) = 4.490$, $p = 0.048$, $\eta^2 = 0.200$), wherein the high emotionality videos were rated as more useful than the low emotionality videos.

*Overall ratings* Lastly, the results also showed a significant main effect for the overall ratings of the videos ($F(1, 18) = 5.586$, $p = 0.030$, $\eta^2 = 0.237$), wherein the high emotionality videos received a better overall rating than the low emotionality videos. When asked to explicitly state which level of emotionality they preferred, 68.4% of participants reported they preferred the videos with higher emotional content (i.e., Video 1B, Video 2B, and Video 3B). A summary of these findings can be found in Fig. 5.

#### *Interaction effects*

No significant interactions were found between the perspective and emotionality of the videos in regards to

**Table 2** Script excerpts according to perspective and level of emotionality

| | Lower emotionality | Higher emotionality |
|---|---|---|
| Perspective: lived experience representative re. eating disorder | *"I had been suffering from an eating disorder for a few months and didn't know how long I could continue living my life in this way, because I actually still had so many plans."* | *"It was only when the eating disorder had a big enough impact on my life that I realized that I might be "sick enough" for treatment. Over the course of a few months my symptoms worsened, and I suffered a lot due to the eating disorder and the associated fears, rules, and loneliness."* |
| Perspective: psychotherapist | *"Patients often spend several months struggling with the eating disorder, during which time they suffer increasingly and become unsure if they can continue living in this way."* | *"Patients report that they will only admit to suffering from an eating disorder and being "sick enough" to receive treatment when the eating disorder has had a sufficient impact on their life. This usually takes some time, during which the patient's physical health deteriorates and they suffer from the eating disorder and its associated fears, rules, and loneliness."* |
| Perspective: lived experience representative re. a somatic condition | *"I spent a few months struggling with the pain and restricted mobility, during which time the psychological suffering I experienced kept growing. I didn't know how I could continue living my life in this way."* | *"It was only when the suffering had a big enough impact on my life that I thought I might be "sick enough" and should perhaps have surgery. Over the course of a few months my symptoms worsened, and I suffered a lot due to the pain and mobility restrictions. I didn't know how I could continue living my life in this way."* |

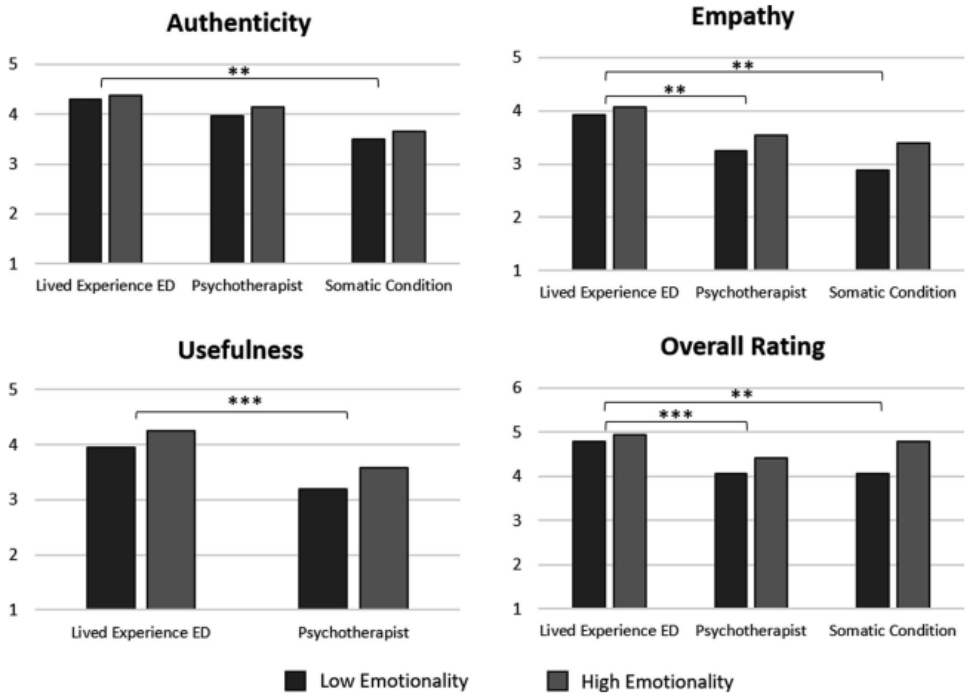



**Fig. 4** Comparison of the perspectives of the videos regarding authenticity, empathy, usefulness, and overall ratings. Note. For authenticity, empathy and usefulness y-axis scale: 1 = strongly disagree and 5 = strongly agree. For overall rating y-axis scale: 1 = insufficient and 6 = very good. *$p = .05$, **$p = .01$, ***$p = .001$

the authenticity ($F(1,18) = 0.191$, $p = 0.827$, $\eta^2 = 0.010$), empathy ($F(1,18) = 1.569$, $p = 0.222$, $\eta^2 = 0.080$), usefulness ($F(1,18) = 0.175$, $p = 0.681$, $\eta^2 = 0.010$), or overall ratings of the videos ($F(1, 18) = 2.661$, $p = 0.084$, $\eta^2 = 0.129$).

#### *Follow-up interviews*

Participants reported that the videos were generally authentic and empathic, and that they considered the videos as useful for patients with ED. Participants stated experiencing a variety of emotions while viewing the videos, including compassion, sympathy, and joy that the lived experience representative can present a positive outcome. When asked which videos they most preferred, n = 2 (40%) participants stated the lived experience videos re. ED, n = 1 (20%) stated the psychotherapist videos, and n = 2 (40%) stated they found both perspectives equally good. All participants reported that they found the lived experience videos to be more authentic than the psychotherapist videos. A selection of quotes from participants is provided in Table 3 to provide further insights.

## Discussion

The use of patient narratives for mental disorders, and especially ED, is a new methodological approach in clinical care and research. As such, it is difficult to find relevant information regarding the efficient development and implementation of patient narratives. The approach described in this paper is an example of how PPI can be effectively applied throughout the process of creating evidence-based patient narrative videos. This study combined five stages for the development of patient narrative videos: a systematic literature review, focus groups, participatory narrative development, and pilot studies evaluating the narrative videos.

Participants of the focus groups reported that in addition to the hindering effects of comorbid mental health disorders and individual ED symptoms, they experienced a considerable amount of stigma, shame, and guilt, which prevented them from seeking and/or engaging with treatment services. This confirms the findings of previously completed systematic reviews (e.g., [1, 2, 22, 23]), which also found that patients affected by ED most frequently reported stigma and shame as their biggest barriers to treatment. Participants of the focus groups further

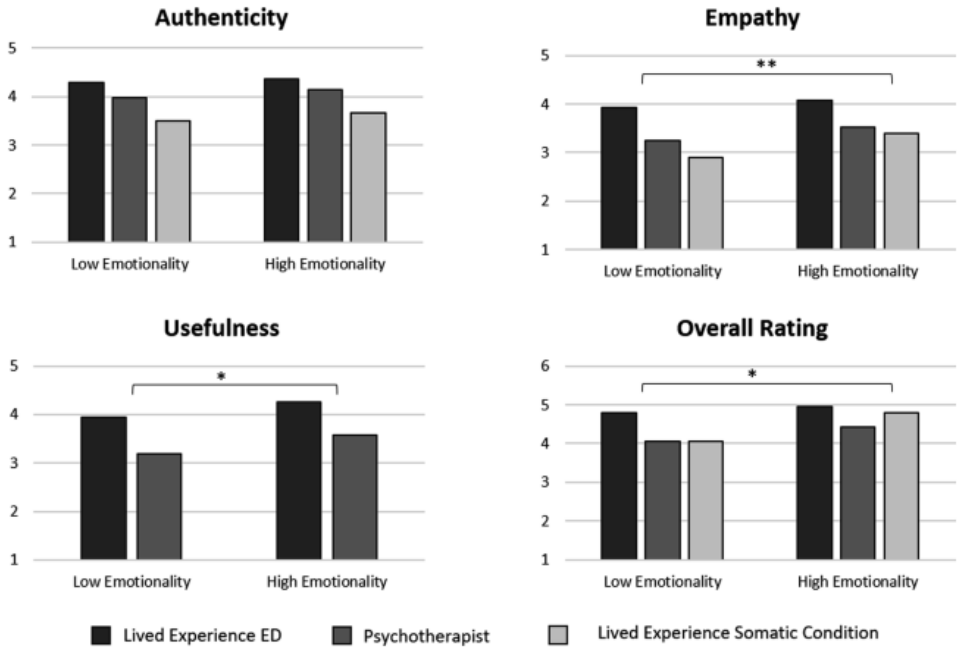



**Fig. 5** Comparison of the emotionality of the videos regarding authenticity, empathy, usefulness, and overall ratings. Note. For authenticity, empathy and usefulness y-axis scale: 1 = strongly disagree and 5 = strongly agree. For overall rating y-axis scale: 1 = insufficient and 6 = very good. *$p$ = .05, **$p$ = .01, ***$p$ = .001

**Table 3** Selection of quotes from participants of the pilot study

| |
|---|
| *"[The videos] certainly made it clear what a great deal of suffering affected persons experience […] they especially made the thought processes that affected persons have a little more relatable for me"* |
| - Participant 1, experiences with ED through friends/family |
| *"A lot of different emotions were mentioned [in the videos], um, and I think that, um, maybe not every emotion will apply to everyone, but since there were quite a few, I can imagine that there will be something for everyone, um, that they will be able to identify with"* |
| - Participant 2, no experiences with ED |
| *"As someone who once suffered from an eating disorder, I definitely felt heard and included […] especially when it's another patient talking to you, it's like, okay, she's talking to me right now, there are two of us in this boat so we're sitting in the same place, we're at eye level"* |
| - Participant 3, personal experiences with ED |
| *"I can imagine that not only patients with eating disorders will be able to identify themselves [with the videos], but also patients with psychosomatic disorders or disorders or illnesses that are not visible"* |
| - Participant 4, no experiences with ED |

discussed that a lack of positive social support was a significant barrier to treatment, with many participants stating that they felt the need to "hide" their ED from others. The previously completed systematic review found similar results, whereby patients, caregivers, and healthcare professionals reported that the establishment of positive social support networks was the most important facilitator for treatment uptake and/or engagement [1]. A recent systematic review by Robinson et al. [24] similarly demonstrated a clear positive correlation between social supports and motivation to change among patients with a variety of ED, while a systematic review by Ramjan et al. [25] found a variety of positive outcomes including motivation to change among young people aged under 25 years among interventions which included social support as an adjunct to treatment. Other systematic reviews have also reported that a lack of positive social support may be a significant barrier to treatment seeking and/or engagement among patients affected by ED [2, 26]. Meanwhile, the severity of individual ED symptoms,

and the resulting feelings of distress were discussed as primary motivation for treatment seeking among participants of the focus groups. Here the results varied somewhat from those of previous literature, in which the importance of individual ED symptoms as a barrier to treatment was represented, albeit significantly less pronounced [1]. This finding emphasises the importance of validating research results in the desired target population, to ensure that these remain relevant.

A total of six patient narrative videos were created on the basis of the results of the systematic review and the focus groups, using a collaborative approach with a lived experience expert. All six videos received positive ratings from a group of participants without (current) ED. Videos featuring the lived experience expert discussing her ED were rated as significantly more authentic than the lived experience videos re. a somatic condition, significantly more empathic than the psychotherapist videos and lived experience videos re. a somatic condition, and as significantly more useful than the psychotherapist videos and lived experience videos re. a somatic condition. The lived experience videos re. ED further received a significantly better overall rating than the psychotherapist videos and lived experience videos re. a somatic condition. The results of the interviews greatly mirror those of the post-intervention questionnaires. Although the majority of participants in this study had no personal experiences with ED, these findings nevertheless reflect those of prior studies in which content presented by former patients or "peers" was reported as significantly more empowering than the same content presented from the perspectives of healthcare professionals [15, 27]. Additionally, videos with higher emotionality were rated as more empathic and useful and received a better overall rating in comparison with videos with lower emotionality, indicating that high emotionality may be more empowering as well.

#### Strengths and limitations

One of the greatest strengths of this study was its focus on collaborative approaches and inclusion of PPI. The lived experience representative featured in the patient narrative videos not only actively constructed the content of the videos, but has also been included as a co-author of this paper, thereby following current recommendations [28] to integrate lived experience authors into the research process. It should also be outlined that implementing PPI in mental health research is complex and requires the consideration of many issues, including ethical aspects and power dynamics within participatory research teams. For instance, a recent position paper by individuals engaging in PPI outlines the importance of reciprocity for positive outcomes in participatory research, including an active involvement of PPI representatives in the research process, reimbursement for time and expertise, and to be valued for contributions to the project [29]. Reciprocity in various ways can also prevent "pseudo-participation" of individuals with lived experience, however, for this to be avoided, there needs to be a structural foundation of PPI in society and research, including the opportunity to acquire funding for PPI [20].

A further strength of this study is the versatility of the patient narrative videos that were developed. The videos discuss aspects which may be relevant to all ED, so that affected persons can identify with them regardless of their ED diagnosis. Similar to the written narratives created by Dawson et al. [10], any possibly triggering content was removed, so that the videos remained purely motivational. Nevertheless, the videos are primarily focused on the experiences of one person and may therefore not be applicable to everyone. Consequently, there is a need for more diversity in future videos with regard to both the content and the person featured in the video.

A healthy sample of participants with no (current) ED was chosen for this initial pre-pilot for several reasons. As the patient narrative videos created for this study were brand new, the research team felt it was necessary to assess their feasibility and potential for any triggering content with an unaffected population, before showing these videos to currently affected persons. While the majority of these participants could not provide any personal ED experiences, they nevertheless provided a fresh perspective regarding the authenticity, empathy, and usefulness of the videos, and their feedback was used to determine whether these videos were ready for use in a clinical population. While this work underlines the high potential of authentic patient narratives, their evaluation by persons affected by ED remains unknown. Therefore, a further pilot study is currently being completed, this time with patients with EDs, to assess the effects of the patient narrative videos developed in this study on the treatment motivation and uptake of treatment services for patients EDs [30]. In this pilot study, the very same questionnaires are being used that were previously implemented in the present study with participants without a (current) ED, therefore allowing for a comparison of experiences between the groups (e.g. perceived authenticity of the videos).

Lastly, it should be noted that the qualitative methods utilised in this study were merely explorative. This pilot study was not intended to be a qualitative study per se. Rather, the purpose of the included focus groups and semi-structured interviews were to include the important insights of PPI to generate new hypotheses and ideas, as well as to ensure that no important feedback regarding the newly created materials were overlooked by relying

solely on the results of quantitative surveys. Further studies with a stronger focus on qualitative methodology may therefore be useful to better reflect the experiences of viewing patient narrative videos such as those created in this study.

## Conclusion & perspectives

A series of evidence-based participatory patient narrative videos detailing the experiences of patients with ED were created in this study by utilising a multistep development process. An unaffected pilot sample rated the created videos as generally positive, with a clear preference for videos with content with higher emotionality. Based on these pilot results, the decision was made to utilize only those videos with higher emotionality (i.e., video Versions B) for a larger 4-arm pilot RCT that is currently being completed with persons currently affected by eating disorders [30].

The use of patient narratives for mental disorders, and especially ED, is a relatively new methodological approach in clinical care and research. As such, it is difficult to find relevant information regarding their efficient development and implementation. The approach used in this pilot study was one developed by the research team, and an example of how an evidence-based patient narrative may be constructed. We believe that it is important to document and share this process, so that other research groups may be able to use these findings for their own implementation and in order to stipulate more research in the field of patient narratives for clinical research on mental disorders.

**Acknowledgements**
We would like to thank Larissa Schubert for her assistance in transcribing the focus group and interview materials. We acknowledge support from the Open Access Publication Fund of the University of Tübingen.

**Author contributions**
Conceptualization: MCD, KS, KEG; Methodology: MCD, BG, SHA, KS, JK, KEG; Writing—Original Draft: MCD; Writing—Review & Editing: MCD, BG, SHA, KS, JK, KEG; Visualization: MCD; Supervision: KS, KEG; Funding acquisition: MCD, KEG.

**Funding**
Open Access funding enabled and organized by Projekt DEAL. MCD receives a PhD scholarship from the Hans-Böckler Foundation. KS is supported by the Ministry of Science, Research and the Arts Baden-Württemberg.

**Availability of data and materials**
No datasets were generated or analysed during the current study.

## Declarations

**Ethics approval and consent to participate**
This study is conducted in accordance with Good Clinical Practice (GCP-ICH guidelines). Ethical approval was obtained from the ethics committee of the Medical Faculty of the University Hospital Tübingen (reference 417/2022BO2, 418/2022BO2). All participants provided written informed consent prior to participating in this study. Participants could withdraw from the study at any time without disadvantage.

**Consent for publication**
Consent for publication was obtained from both persons displayed in the videos.

**Competing interests**
The authors declare no competing interests.

**Author details**
[1]Department of Psychosomatic Medicine and Psychotherapy, Medical University Hospital Tübingen, Osiander str. 5, 72076 Tübingen, Germany. [2]Centre of Excellence for Eating Disorders Tübingen (KOMET), Tübingen, Germany. [3]Lived Experience Representative, Tübingen, Germany. [4]Department of Psychology, Eberhard-Karls-University Tübingen, Tübingen, Germany. [5]Leibniz-Institut Für Wissensmedien, Tübingen, Germany. [6]DZPG (German Centre for Mental Health), Tübingen, Germany.

**Received: 24 June 2024 Accepted: 1 November 2024**
Published online: 20 November 2024

**References**

1. Daugelat MC, et al. Barriers and facilitators affecting treatment uptake behaviours for patients with eating disorders: a systematic review synthesising patient, caregiver and clinician perspectives. Eur Eat Disord Rev. 2023;31(6):752–68.
2. Ali K, et al. Perceived barriers and facilitators towards help-seeking for eating disorders: a systematic review. Int J Eat Disord. 2017;50(1):9–21.
3. Sharpe H, et al. Pro-eating disorder websites: facts, fictions and fixes. J Public Ment Health. 2011;10(1):34–44.
4. Llewellyn-Beardsley J, et al. Characteristics of mental health recovery narratives: systematic review and narrative synthesis. PLoS ONE. 2019;14(3):e0214678.
5. Yeo C, et al. Uses and misuses of recorded mental health lived experience narratives in healthcare and community settings: systematic review. Schizophr Bull. 2021;48(1):134–44.
6. Rennick-Egglestone S, et al. Mental health recovery narratives and their impact on recipients: systematic review and narrative synthesis. Can J Psychiatry. 2019;64(10):669–79.
7. Eggeling M, et al. The impact of patient narratives on medical students' perceptions of shared decision making: a randomized controlled trial. Med Educ Online. 2021;26(1):1886642.
8. Wenig V, Janetzke H. "That you just know you're not alone and other people have gone through it too." Eating disorder recovery accounts on Instagram as a chance for self-help? A qualitative interview study among people affected and self-help experts. Int J Environ Res Public Health. 2022;19(18):11334.
9. Bientzle M, Eggeling M, Kimmerle J. Good reasons for bad behavior: a randomized controlled experiment on the impact of narrative reading and writing on empathic concern, perspective-taking, and attitude. Front Public Health. 2024;12:1343225.
10. Dawson L, et al. Are recovery stories helpful for women with eating disorders? A pilot study and commentary on future research. J Eat Disord. 2018;6:21.
11. Gumz A, et al. Factors influencing the duration of untreated illness among patients with anorexia nervosa: a multicenter and multi-informant study. Int J Eat Disord. 2023;56(2315):2327.
12. Austin A, et al. Duration of untreated eating disorder and relationship to outcomes: a systematic review of the literature. Eur Eat Disord Rev. 2021;29(3):329–45.
13. Shaw LK, Homewood J. The effect of eating disorder memoirs in individuals with self-identified eating pathologies. J Nerv Ment Dis. 2015;203(8):591–5.
14. Slade M, et al. Effectiveness and cost-effectiveness of online recorded recovery narratives in improving quality of life for people with non-psychotic mental health problems: a pragmatic randomized controlled trial. World Psychiatry. 2024;23(1):101–12.
15. McLeod B, et al. Do recovery-oriented messages improve self-efficacy and positive emotions amongst people with lived experience of psychosis? Experimental investigation. Psychol Psychother Theory Res Pract. 2022;95(4):1003–17.

16. Williams A, et al. Recovery after psychosis: qualitative study of service user experiences of lived experience videos on a recovery-oriented website. JMIR Ment Health. 2018;5(2): e9934.
17. LaMarre A, Rice C. Embodying critical and corporeal methodology: digital storytelling with young women in eating disorder recovery. In: Forum qualitative sozialforschung/forum: qualitative social research. 2016.
18. Dudley L, et al. What difference does patient and public involvement make and what are its pathways to impact? Qualitative study of patients and researchers from a cohort of randomised clinical trials. PLoS ONE. 2015;10(6): e0128817.
19. McCarron TL, et al. Patients as partners in health research: a scoping review. Health Expect. 2021;24(4):1378–90.
20. Giel K, et al. Enriching a randomized controlled treatment trial for anorexia nervosa by lived experience–chances and effects of a lived experience council in the SUSTAIN study. Int J Eat Disord. 2023;57:1300.
21. IBM Corp, IBM SPSS Statistics for Windows, Version 28. 2021, IBM Corp: Armonk, NY.
22. Gulliver A, Griffiths KM, Christensen H. Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. BMC Psychiatry. 2010;10(1):1–9.
23. Regan P, Cachelin FM, Minnick AM. Initial treatment seeking from professional health care providers for eating disorders: a review and synthesis of potential barriers to and facilitators of "first contact." Int J Eat Disord. 2017;50(3):190–209.
24. Robinson L, Flynn M, Cooper M. Individual differences in motivation to change in individuals with eating disorders: a systematic review. Int J Eat Disord. 2024;57:1069.
25. Ramjan LM, et al. Social support for young people with eating disorders—an integrative review. Int J Ment Health Nurs. 2024. https://doi.org/10.1111/inm.13363.
26. Radunz M, Ali K, Wade TD. Pathways to improve early intervention for eating disorders: findings from a systematic review and meta-analysis. Int J Eat Disord. 2023;56(2):314–30.
27. Lock A, et al. Resisting anorexia/bulimia: foucauldian perspectives in narrative therapy. Br J Guid Couns. 2005;33(3):315–32.
28. Yeo C, et al. Uses and misuses of recorded mental health lived experience narratives in healthcare and community settings: systematic review. Schizophr Bull. 2022;48(1):134–44.
29. Richmond L, et al. Creating positive experiences of involvement in mental health research. Lancet Psychiatry. 2023;10(3):220–7.
30. Daugelat M-C, et al. Improving motivation and treatment uptake behaviors of patients with eating disorders using patient narrative videos: study protocol of a pilot randomized controlled trial. J Eat Disord. 2024;12(1):1.

## Publisher's Note

### 3.3 Publication 3: Improving motivation and treatment uptake behaviors of patients with eating disorders using patient narrative videos: study protocol of a pilot randomized controlled trial (Daugelat et al., 2024).

Full citation: *Daugelat, M. C., Kimmerle, J., Hagmann, D., Schag, K., & Giel, K. E. (2024). Improving motivation and treatment uptake behaviors of patients with eating disorders using patient narrative videos: study protocol of a pilot randomized controlled trial. Journal of Eating Disorders. https://doi.org/10.1186/s40337-023-00960-3*

There currently exists very little empirical research on the effects of patient narratives. However, initial reports from the field of mental health research suggest that patient narratives are associated with a number of positive effects in patients currently affected by a mental health disorder, including increased feelings of support (Bientzle et al., 2024; Rennick-Egglestone, Ramsay, et al., 2019; Wenig & Janetzke, 2022; Yeo et al., 2021), self-efficacy (McLeod et al., 2022; Williams et al., 2018), and overall quality of life (Slade et al., 2024). Regarding ED, an even smaller number of studies have been completed using primarily retrospective assessments of patients' previous experiences with patient narratives (e.g. (Shaw & Homewood, 2015)). The exception to this is a study completed by Dawson et al. (2018), in which patients with ED were asked to read a series of written patient narratives. Although patients in this study reported no measurable effects on treatment motivation, qualitative interviews revealed that patients were inspired to think more about their own recovery after reading patient narratives (Dawson et al., 2018). Information regarding the potential effects of patient narratives on clinical outcomes such as treatment motivation and treatment uptake behaviours for patients with ED therefore remains lacking.

This study protocol provides an overview of the study design, methodology and procedures used in a clinical pilot RCT examining the effects of patient narrative videos on the treatment motivation and uptake of treatment services for patients with ED. Female patients with ED aged 15 years and older and attending an initial appointment at the Department of Psychosomatic Medicine and Psychotherapy

and the Child and Adolescent Psychiatry at the University Hospital Tübingen are invited to participate, with a recruitment target of n = 100 patients. Patients will be randomly allocated to one of four groups, three of which will watch one of three patient narrative videos, while the fourth group watches no video.

This study aims to assess the acceptability and feasibility of patient narrative videos for patients with ED, as well as to determine which outcomes are most suitable to assess the potential effects of patient narratives for this patient group. Primary outcomes of this study therefore include the effects of patient narrative videos on patients' self-reported treatment motivation and treatment uptake behaviours. Further outcomes include effects on patients' ED psychopathology, hope and confidence toward recovery, as well as patients' assessments of the perceived authenticity, empathy, and usefulness of the patient narrative videos.

Daugelat *et al. Journal of Eating Disorders* (2024) 12:1
https://doi.org/10.1186/s40337-023-00960-3

Journal of Eating Disorders

STUDY PROTOCOL Open Access

# Improving motivation and treatment uptake behaviors of patients with eating disorders using patient narrative videos: study protocol of a pilot randomized controlled trial

Melissa-Claire Daugelat[1,2*], Joachim Kimmerle[3,4], Daniela Hagmann[5], Kathrin Schag[1,2] and Katrin Elisabeth Giel[1,2,6]

**Abstract**

**Background** Patients with eating disorders (ED) typically report delays between the onset of symptoms and engagement with treatment services. Personal barriers including stigma, shame, and guilt, as well as the availability of social support may influence patients' decisions to engage with treatment services. Patient narratives are personalized stories discussing the illness and recovery of previously affected persons. Such narratives can reduce self-stigma and provide current patients with hope for their own recovery.

**Method** This pilot study will examine the effects of patient narrative videos on the treatment motivation and uptake of treatment services for patients with ED. Three narrative videos were developed from the perspectives of (a) a former patient with an ED, (b) an ED specialist, and (c) the same former patient discussing a somatic condition unrelated to ED. Patients will be randomized into three video viewing and one treatment-as-usual group. Effects on treatment motivation will be assessed using the University of Rhode Island Change Assessment Scale (URICA-S) immediately after viewing the videos, as well as one-week and three-month follow-ups. Treatment uptake will be assessed during follow-up using a questionnaire listing possible treatment interactions. A post-intervention questionnaire and semi-structured interviews will be used to assess the feasibility and acceptability of patient narrative videos for this population.

**Discussion** There is an urgent need to encourage patients with ED to engage with specialized treatments as soon as possible. Patient narratives may be a pivotal approach to implementing cost effective and easy to disseminate early intervention programs to future patients with ED.

**Keywords** Eating disorders, Motivation, Help-seeking, Lived experience, Patient narratives

*Correspondence:
Melissa-Claire Daugelat
melissa-claire.daugelat@med.uni-tuebingen.de
Full list of author information is available at the end of the article

## Public significance statement

Currently, there exists an urgent need to close the treatment gap and encourage patients with eating disorders (ED) to engage with specialized treatment services as soon as possible. Narrative videos featuring the experiences and perspectives of former patients could be a pivotal approach to implementing cost effective and easy to disseminate early interventions to patients currently affected by ED.

## Introduction

Treatment for eating disorders (ED) has been shown to be most effective when initiated shortly after the onset of symptoms [1]. Nevertheless, patients typically report a significant delay between the onset of ED symptoms and their engagement with treatment services. The duration of untreated ED (DUED), i.e., the time between onset of the ED and first contact with treatment, ranges from 2.5 years for Anorexia Nervosa to 6 years for Binge-Eating-Disorder [2]. Longer DUED is associated with a progression of ED symptoms, increased psychological distress, and increased mortality among patients with Anorexia [2, 3]. Patients with ED often report long wait times and/or a lack of specialized treatment services as contributing to the DUED they experienced [4, 5]. Interventions such as the First Episode Rapid Early Intervention for Eating Disorders (FREED) service model in the UK aim to reduce these healthcare-related delays by optimizing the referral process for tailored and evidence-based ED treatment services [6]. Meanwhile, feelings of ambivalence or a lack of motivation from patients to change their behaviors have also been reported as contributing to the DUED of most EDs [7]. In fact, many patients will wait up to 12 months after recognizing their ED symptoms before deciding to seek treatment [7]. The Transtheoretical Model of Health Behavior Change (TTM) by Prochaska and Di Clemente [8] can be used to understand patients' motivation (or lack thereof) to recover from their ED. The TTM proposes that when changing a health behavior, an individual will gradually progress through six stages of willingness to change, namely precontemplation, contemplation, preparation, action, maintenance, and termination. Evidence suggests that patients who have a higher motivation to change prior to commencing treatment (i.e., are further along the stages of change) will demonstrate better treatment outcomes, including reduced dietary restriction, binging, and purging behaviors [9, 10].

Engagement with treatment services may be influenced by the social support patients can rely upon [11, 12]. In fact, the presence [13, 14] or absence [15, 16] of social support may either facilitate or impede a patient's decision to seek and/or engage with treatment services. Unfortunately, a common theme among individuals with ED is a general lack of social connections outside the immediate family, with many individuals utilizing websites and online forums in the hopes of finding support, acceptance, and a place of belonging among fellow ED patients [17]. Currently, there is an increased use of peers in the care of various mental disorders, including ED (e.g., [18, 19]). Peer mentorship programs with former and currently recovered ED patients have shown high engagement rates, as well as increased mood, quality of life, and hope for a possible recovery [20]. Similarly, information shared by fellow ED patients has been reported by patients to be significantly more empowering than when the same information was presented by healthcare professionals [21].

Patient narratives, i.e., personalized stories of persons previously affected by a mental disorder detailing their illness and recovery, provide another promising adjunct to ED treatments. Patient narratives are available both as published books and in a variety of formats throughout the internet [22, 23]. Studies have shown that reading patient narratives may reduce the self-stigma associated with ED in student populations [24] and, when presented in a safe and responsible way, may shorten the duration of DUED [25] and provide current patients with feelings of hope for a possible recovery [22]. However, to date only a handful of studies have investigated the effects of patient narratives in ED care [26]. Studies on other severe mental disorders, such as psychosis (e.g., [27, 28]), suggest that viewing patient narrative videos can increase self-efficacy and provide hope toward recovery. These effects were strongest after viewing videos featuring former patients, in comparison to videos featuring healthcare professionals, despite the presentation of identical recovery-oriented content [27]. Patients with psychosis typically report similar levels of ambivalence toward treatment as patients with ED [29], and these findings suggest that perceptions of similarity/authenticity allow former patients with lived experience to inspire hope for recovery among persons currently affected by the disorder [27]. Three further clinical trials are currently being completed as part of the Narrative Experiences Online (NEON) Study [30], in which the effects of patient narrative videos are being examined for persons experiencing psychosis and other mental health problems. To the best of our knowledge, no prior studies have examined the effects of evidence-based and recovery-focused patient narratives presented as videos for patients with ED.

## Study aims

The proposed study will examine the effects of patient narratives provided in video format for patients with ED. In particular, the role of patient narrative videos on

patients' treatment motivation and uptake of treatment services will be assessed. The study further aims to ascertain the feasibility and acceptability of patient narratives, as well as establishing data to identify suitable outcomes and sample size calculations for a larger trial.

Patients will be randomly assigned to view one of three narrative videos, presented from the perspective of a former and currently recovered patient with an ED (Video A), an ED specialist (Video B), and the same former patient reporting on a somatic condition unrelated to ED (Video C). It is expected that patients who receive access to narrative videos from the perspective of a former patient with an ED (Video A) or an ED specialist (Video B) will show:

- stronger increases in treatment motivation (Hypothesis 1).
- and increased likelihood to engage in treatment uptake behaviors (Hypothesis 2).

compared to patients who receive access to a narrative video unrelated to ED (Video C) or patients who receive access to no videos.

It is further expected that patients who receive access to a narrative video from the perspective of a former patient with an ED (Video A) will show:

- stronger increases in treatment motivation (Hypothesis 3).
- and increased likelihood to engage in treatment uptake behaviors (Hypothesis 4).

compared to patients who receive access to a narrative video from the perspective of an ED specialist (Video B).

## Method/design

This study protocol is reported according to the recommendations of the SPIRIT checklist [31].

### Study participants

Female patients with EDs who attend a consultation appointment at the outpatient services of the Department of Psychosomatic Medicine and Psychotherapy at the Medical University Hospital Tübingen will be informed about the study and invited to participate. During such consultation appointments patients complete a variety of diagnostic assessments and are provided with recommendations for treatment. Patients do not receive any counselling or treatment at these appointments. Patients will be asked to provide information about any previous treatment(s) they may have received and will be excluded if their last treatment occurred within the last four weeks prior to the start of the study. As the majority of patients begin experiencing EDs already in late adolescence, patients aged 15 years and older will also be recruited from the Child and Adolescent Psychiatry at the Medical University Hospital Tübingen. Patients with any full-syndrome or subclinical ED diagnosis will be invited to participate in this study to gain a better understanding of any transdiagnostic differences that may affect for whom this intervention is best suited. In order to further increase reach and diversity, the study will also be made available to individuals who seek obesity treatment at the Medical University Hospital Tübingen, provided they also display symptoms of an ED.

### Inclusion criteria

Patients must comply with all of the following criteria in order to be eligible for the trial:

- Full-syndrome or subclinical ED according to DSM-5 (diagnosed by a trained clinician).
- Minimum age 15 years.
- Female gender.
- Written informed consent.

### Exclusion criteria

- Acute suicidality.
- Psychotic disorders (lifetime).
- Bipolar disorder (lifetime).
- Current moderate-severe substance use disorders.
- Currently receiving ED treatment(s).

### Materials used

#### *Self-report measures*

Demographic and diagnostic information, including ED diagnosis, will be obtained from patient files. Patients will be provided with a definition of patient narratives before being asked if/what experiences they may have had with patient narratives, and in what format. The following questionnaires will be used to determine ED psychopathology, comorbid mental disorders, treatment motivation, previous and current treatment uptake behaviors, and hope and confidence toward recovery:

- ED psychopathology will be assessed using the Eating Disorders Examination Questionnaire (EDE-Q [32]). The EDE-Q consists of 28 items measuring the cognitions and eating disturbances associated with ED, as well as diagnostically relevant behavioral features of ED. Items can be allocated to four subscales: Restraint, Eating Concern, Shape Concern, and Weight Concern. Mean subscale scores and a

mean global score are calculated in order to determine overall eating pathology [32]. The EDE-Q has high internal consistency ($\alpha \leq 0.97$) and is sensitive to change [33].

- Comorbid mental disorders will be assessed using the Patient Health Questionnaire (PHQ-D [34]). The PHQ-D consists of 15 items and is used to screen for symptoms of depressive disorders, panic disorder, and psychosocial functioning. The PHQ-D has excellent criterion validity and good internal consistency for depressive disorders ($\alpha = 0.88$) [34].
- Treatment motivation will be assessed using the University of Rhode Island Change Assessment Scale—Short Version (URICA-S [35]). The URICA-S consists of 16 items, measuring four of the six stages of change (i.e., Pre-contemplation, Contemplation, Action, and Maintenance) according to the TTM [8]. Readiness for change scores will be calculated for each patient by summing the mean contemplation, action, and maintenance subscale values of the URICA-S, before subtracting the mean precontemplation subscale value [36]. The URICA-S shows acceptable to good internal consistency ($\alpha = 0.61–0.85$), as well as strong criterion validity [35].
- Treatment uptake behaviors will be assessed using a short questionnaire developed for this study. Patients will be asked to select from a list which treatment services they have previously or currently engaged with, and to what extent (e.g., phone contact, appointment made/attended). ED treatment services are varied, including inpatient, partial inpatient, and outpatient treatment in psychiatric/psychosomatic clinics, outpatient psychotherapeutic and nutritionist services, and digital eHealth interventions. For the purposes of this study, treatment uptake will be defined as attending appointments at any of these treatment providers, however, preparatory actions such as researching treatment options and time spent on the wait list will also be assessed.
- Hope and confidence toward recovery will be assessed using two visual analogue scales. Patients will be asked to indicate how hopeful and confident they are regarding their own recovery. Each patient's scores will be calculated by measuring the distance (0-100 mm) on the visual analogue scales between the anchor (no hope/confidence) and the patient's selection, with higher scores indicating greater hopefulness and confidence toward recovery.
- A post-intervention questionnaire will be used to assess patients' feedback regarding the authenticity, empathy, and likeability of the person featured in the narrative video, as well as the usefulness of the video(s) as a whole. A subgroup of six patients (determined through Research Randomizer [37]) will also be invited to participate in a semi-structured interview to provide further insights into their perception of the authenticity, empathy, likeability, and usefulness of the video(s), so as to allow for a more thorough and qualitative understanding of how these are experienced by patients.

### *Interventions*

The narrative videos used in this intervention were developed collaboratively in a participatory research process with a former patient with an ED, while also being based on the results of a recent systematic review of barriers and facilitators for help-seeking in patients with ED [12]. Preliminary versions of these videos will be trialed in a pre-test study with a healthy student population. The final videos will be approx. six minutes in length (+/- 1 min difference) and feature a person of the same age and gender. The former patient featured in the video is a young woman with a healthy body weight, and it is not explicitly stated which symptoms or ED diagnosis she suffered from. Instead, EDs are discussed as a whole, and the content of the videos focuses on specific aspects of the former patient's treatment journey, including what motivated her to seek treatment and how her life has changed post-recovery. As part of the pilot study presented here, a parallel 4-arm pilot randomized controlled trial (RCT) approach will be used to evaluate the efficacy of patient narrative videos. Patients will be randomized into one of four groups for the intervention: one group (IG1) will receive access to a video featuring the personal experiences of a former patient with an ED regarding the barriers and facilitators she faced when seeking treatment, with particular focus on stigma, shame, and guilt, as well as the importance of social support. The second group (IG2) will receive access to a video featuring an ED specialist, in which the same barriers and facilitators to treatment presented by the recovered patient will be discussed, but from a professional perspective. The Control Group (CG) will receive access to a video in which the recovered patient will discuss the same barriers and facilitators to treatment, but for a somatic condition unrelated to ED (i.e., torn knee ligament). The remaining patients randomized in the Treatment-as-Usual Group (TAU) will not receive access to any videos.

### Procedure

An overview of the study plan and assessment materials are presented in Figs. 1 and 2, respectively. Following a baseline assessment (T0), patients will receive access to one of the three videos in a controlled setting at the Medical University Hospital Tübingen. After watching

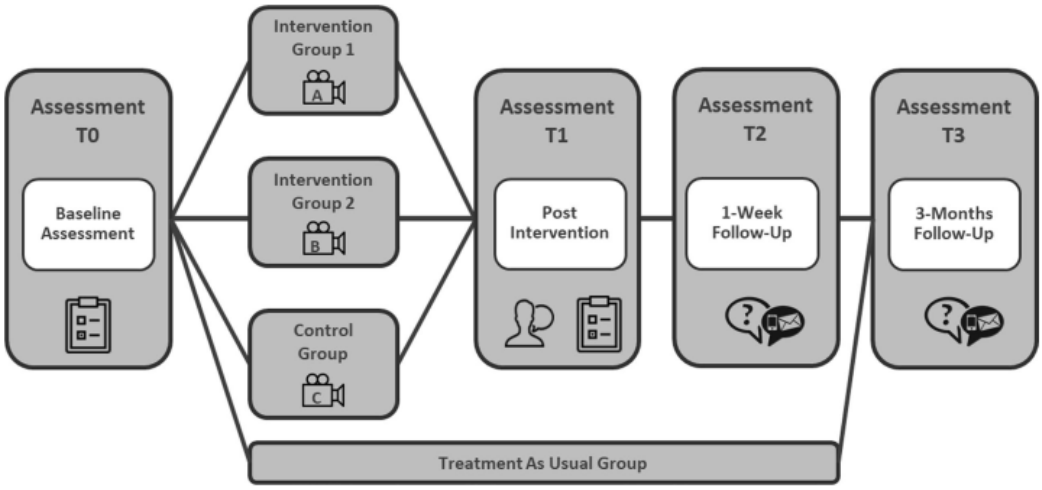



**Fig. 1** Study plan

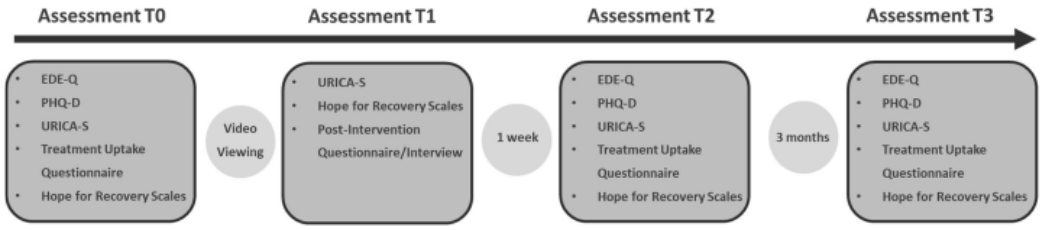



**Fig. 2** Overview of assessment materials

the videos (T1), patients will complete a series of questionnaires to assess any immediate changes in treatment motivation. A subgroup of patients will also be invited to participate in a semi-structured interview. Patients will be contacted for follow-up one week (T2) and three months (T3) after watching the videos. TAU patients will complete assessments at T0 and T3 but will not receive access to any videos.

## Outcomes

### *Main outcome measures*

Main outcome measures of this study will be changes in patients' treatment motivation and treatment uptake behaviors. Changes in treatment motivation will be measured by comparing patients' baseline (T0) readiness for change scores (URICA-S) to scores immediately after viewing the videos (T1), at one-week (T2) and three months follow-up (T3). Changes in treatment uptake will be measured by comparing the amount of treatment seeking activities indicated at baseline (T0), at one-week (T2) and three months follow-up (T3).

### *Secondary ED-related outcome measures*

Additional outcome measures will include changes in ED psychopathology, as measured by changes in the scores of the EDE-Q, and changes in patients' hopefulness and confidence for their own recovery, as measured by increased values in the visual analogue scales immediately after viewing the videos (T1) at one-week (T2) and three months follow-up (T3).

### *Evaluation of narrative videos*

The suitability of the narrative videos will be determined through a post-intervention questionnaire and qualitative interviews at T1, in which patients will be asked their views on the authenticity, empathy, and likeability of the person featured in the video, as well at the usefulness of the video(s) as a whole.

### Sample size

Currently, there is limited prior evidence on the effects of patient narratives on the treatment motivation of patients with ED. Existing studies are primarily qualitative in design (e.g., [22]). Further, no studies have previously used video narratives to examine their effect on treatment motivation. The proposed study is a pilot project and as such, its main aims are to investigate the usefulness of the narratives, and to identify a meaningful primary outcome and establish data to allow for sample size calculations for a larger trial. Analogous to similar pilot trials, it is planned to include 25 patients in each study group, resulting in a sample size of 100 patients. Dropout cases will be replaced until the proposed sample size has been recruited.

### Randomization/blinding

Patients will be randomized into one of four groups for the intervention. The study will be an open label study, meaning that neither the study team nor patients will be blind regarding group allocation. Randomization will occur following the receival of written consent to participate, using Research Randomizer [37].

### Statistical analyses

#### *Treatment motivation*

Generalized linear mixed effects models will be used to assess the relationship between patients' group allocation (IG1/IG2/CG/TAU) and their readiness for change scores at T0, T1, T2, and T3.

#### *Treatment uptake behaviors*

Pearson's chi-square tests of contingencies will be used to assess the relationship between patients' group allocation (IG1/IG2/CG/TAU) and treatment uptake behaviors at T0, T2, and T3.

#### *Hope for recovery*

Generalized mixed effects models will be used to assess the relationship between patients' group allocation (IG1/IG2/CG/TAU) and hope for recovery at T0, T2, and T3.

#### *Evaluation of narrative videos*

Pearson's chi-square tests of contingencies will be used to assess the relationship between patients' group allocation (IG1/IG2/CG) and their evaluation of the narrative videos at T1. Narrative/descriptive syntheses will also be completed, in which patients' evaluations of the videos will be extracted from interview transcripts and coded under themes.

### Data management and data monitoring

As part of this study, personal data will be collected, stored, and analyzed. All self-report questionnaires will be completed by patients online via UniPark (www.unipark.com/de). The UniPark data centers in Germany meet the highest security requirements including certifications according to ISO/IEC 27,001 and SOC II, as well as compliance with the requirements of the GDPR. Participant codes will be assigned, i.e., data storage will be pseudonymized. No external data monitoring will be implemented as this is a pilot trial.

### Ethical aspects

*Ethical approval* Ethical approval for completion of the trial has been obtained by the ethics committee of the Medical Faculty at the University Hospital Tübingen (reference 419/2022BO1). No known risks or negative side effects are expected to occur as a result of participation. Written informed consent will be obtained from all patients as well as the parents/guardians of patients under the age of 18. Patients may withdraw consent at any time, for any reason, without loss of benefit.

## Discussion

To date, a limited number of studies have examined the usefulness and influence of patient narratives in the recovery process of mental disorders in general [26], and even fewer studies did so for patients with ED. Among those studies who examined patients with ED (e.g., [22]), reading a selection of patient narratives, such as autobiographies by former patients, showed no measurable short-term effects on motivation or self-efficacy. Nevertheless, the majority of patients reported that reading patient narratives initiated feelings of hope regarding their own recovery [22]. Even less research has been completed regarding the use of patient narratives in an audio-visual format. To the best of our knowledge, this will be the first study to examine the effects of evidence-based and recovery-focused patient narratives presented as videos for patients with ED.

### Strengths and limitations

A strength of this study is the strong integration of lived experience into the intervention, which has been increasingly advocated [19, 38, 39]. A further strength is the inclusion of clinically relevant outcome measures, including treatment uptake behaviors at several time points in response to engagement with patient narratives. The inclusion of such measures will allow

the results of this study to more easily translate into and inform clinical practice. The long follow-up period of three months is roughly in accordance with the average wait times for psychotherapeutic treatment in Germany [40, 41], although this varies depending on region, disorder, and type of service. The study design will allow both short-term and long-term effects of this intervention to be examined. Limitations of this study include a selection bias, as the recruitment focuses on patients attending a diagnostic appointment at the Medical University Hospital Tübingen. Nevertheless, a large proportion of persons who attend such appointments fail to undertake any further actions, and therefore may benefit greatly from this intervention.

## Conclusion

There is currently an urgent need to encourage and assist patients with ED to engage with specialized treatments as soon as possible. If effective, patient narratives may be a pivotal approach to implementing cost effective and easy to disseminate early intervention programs to future patients with ED.

**Acknowledgements**
We acknowledge support from the Open Access Publication Fund of the University of Tübingen.

**Author contributions**
Conceptualization: MCD, JK, DH, KS, KEG; Methodology: MCD, JK, KS, KEG; Writing - Original Draft: MCD; Writing - Review & Editing: MCD, JK, DH, KS, KEG; Visualization: MCD; Supervision: KS, KEG; Funding acquisition: MCD, KEG.

**Funding**
Open Access funding enabled and organized by Projekt DEAL. MCD receives a PhD scholarship from the Hans-Böckler Foundation. KS is supported by the Ministry of Science, Research and the Arts Baden-Württemberg.

**Availability of data and materials**
All data used to support the findings of this study are available from the corresponding author upon reasonable request.

## Declarations

**Ethics approval and consent to participate**
Ethical approval was obtained from the ethics committee of the Medical Faculty of the University Hospital Tübingen (reference 419/2022BO1). All patients must provide written informed consent prior to participating in this study. Patients may withdraw from the study at any time without disadvantage.

**Competing interests**
The authors declare no competing interests.

**Author details**
[1]Department of Psychosomatic Medicine and Psychotherapy, Medical University Hospital Tübingen, Osianderstr. 5, 72076 Tübingen, Germany. [2]Centre of Excellence for Eating Disorders Tübingen (KOMET), University of Tübingen, Tübingen, Germany. [3]Leibniz-Institut für Wissensmedien, Tübingen, Germany. [4]Department of Psychology, Eberhard Karls University Tübingen, Tübingen, Germany. [5]Child and Adolescent Psychiatry, Medical University Hospital Tübingen, Tübingen, Germany. [6]DZPG (German Center for Mental Health), Tübingen, Germany.

Received: 15 September 2023 Accepted: 20 December 2023
Published online: 02 January 2024

**References**

1. Andres-Pepina S, et al. Long-term outcome and psychiatric comorbidity of adolescent-onset anorexia nervosa. Clin Child Psychol Psychiatry. 2020;25(1):33–44.
2. Austin A, et al. Duration of untreated eating disorder and relationship to outcomes: a systematic review of the literature. Eur Eat Disord Rev. 2021;29(3):329–45.
3. Franko DL, et al. A longitudinal investigation of mortality in anorexia nervosa and bulimia nervosa. Am J Psychiatry. 2013;170(8):917–25.
4. Lazare K, Mehak A, Telner D. Exploring the primary care experiences of adult patients with eating disorders: a qualitative analysis. Eating Disorders: The Journal of Treatment & Prevention; 2021.
5. Escobar-Koch T, et al. Service users' views of eating disorder services: an international comparison. Int J Eat Disord. 2010;43(6):549–59.
6. Austin A, et al. The first episode rapid early intervention for eating disorders-upscaled study: clinical outcomes. Early Interv Psychiat. 2022;16(1):97–105.
7. Kazdin AE, Fitzsimmons-Craft EE, Wilfley DE. Addressing critical gaps in the treatment of eating disorders. Int J Eat Disord. 2017;50(3):170–89.
8. Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. Am J Health Promotion. 1997;12(1):38–48.
9. Dray J, Wade TD. Is the transtheoretical model and motivational interviewing approach applicable to the treatment of eating disorders? A review. Clin Psychol Rev. 2012;32(6):558–65.
10. Krebs P, et al. Stages of change and psychotherapy outcomes: a review and meta-analysis. J Clin Psychol. 2018;74(11):1964–79.
11. Wacker EC. Barriers and facilitators to seeking treatment for subclinical eating disorders: the importance of supportive relationships. J Family Psychother. 2018;29(4):292–317.
12. Daugelat MC, et al. Barriers and facilitators affecting treatment uptake behaviours for patients with eating disorders: a systematic review synthesising patient, caregiver and clinician perspectives. European Eating Disorders Review; 2023.
13. Regan P, Cachelin FM, Minnick AM. Initial treatment seeking from professional health care providers for eating disorders: a review and synthesis of potential barriers to and facilitators of first contact. Int J Eat Disord. 2017;50(3):190–209.
14. Kästner D, et al. Facilitators and barriers in Anorexia nervosa treatment initiation: a qualitative study on the perspectives of patients, carers and professionals. J Eat Disord. 2021;9(1):28.
15. Ali K, et al. Perceived barriers and facilitators towards help-seeking for eating disorders: a systematic review. Int J Eat Disord. 2017;50(1):9–21.
16. Radunz M, Ali K, Wade TD. Pathways to improve early intervention for eating disorders: findings from a systematic review and meta-analysis. Int J Eat Disord. 2023;56(2):314–30.
17. Sharpe H, et al. Pro-eating disorder websites: facts, fictions and fixes. J Public Mental Health. 2011;10(1):34–44.
18. Ranzenhofer LM, et al. Peer mentorship as an adjunct intervention for the treatment of eating disorders: a pilot randomized trial. Int J Eat Disord. 2020;53(5):497–509.
19. Giel K et al. Enriching a randomized controlled treatment trial for anorexia nervosa by lived experience—chances and effects of a lived experience council in the SUSTAIN study. Int J Eating Disorders. 2023.
20. Pellizzer ML, Wade TD. The effectiveness of lived experience involvement in eating disorder treatment: a systematic review. Int J Eat Disord. 2023;56(2):331–49.
21. Lock A, et al. Resisting anorexia/bulimia: foucauldian perspectives in narrative therapy. Br J Guid Couns. 2005;33(3):315–32.
22. Dawson L, et al. Are recovery stories helpful for women with eating disorders? A pilot study and commentary on future research. J Eat Disord. 2018;6:21.
23. Wenig V, Janetzke H. That you just know you're not alone and other people have gone through it too. Eating disorder recovery accounts on instagram as a chance for self-help? A qualitative interview study among

people affected and self-help experts. Int J Environ Res Public Health. 2022;19(18):11334.
24. Sheens E, Rhodes P, Dawson L. Encountering anorexia: challenging stigma with recovery stories. Adv Eat Disord. 2016;4(3):315–22.
25. Gumz A, et al. Factors influencing the duration of untreated Illness among patients with Anorexia Nervosa: a multicenter and multi-informant study. International Journal of Eating Disorders; 2023.
26. Rennick-Egglestone S, et al. Mental health recovery narratives and their impact on recipients: systematic review and narrative synthesis. Can J Psychiatry. 2019;64(10):669–79.
27. McLeod B, et al. Do recovery-oriented messages improve self-efficacy and positive emotions amongst people with lived experience of psychosis? Experimental investigation. Psychol Psychother Theory Res Pract. 2022;95(4):1003–17.
28. Williams A, et al. Recovery after psychosis: qualitative study of service user experiences of lived experience videos on a recovery-oriented website. JMIR Mental Health. 2018;5(2):e9934.
29. Artaud L, et al. Adherence to treatment in first episode psychosis: Acceptance, refusal, or ambivalent process? Can J Community Mental Health. 2021;39(3):17–31.
30. Rennick-Egglestone S, et al. Impact of receiving recorded mental health recovery narratives on quality of life in people experiencing psychosis, people experiencing other mental health problems and for informal carers: narrative experiences Online (NEON) study protocol for three randomised controlled trials. Trials. 2020;21(1):1–34.
31. Chan A-W, et al. SPIRIT 2013 statement: defining standard protocol items for clinical trials. Ann Intern Med. 2013;158(3):200–7.
32. Fairburn CG, Beglin SJ. The assessment of eating disorders: Interview or self-report questionnaire? Int J Eat Disord. 1994;16:363–70.
33. Hilbert A, et al. Eating disorder examination-questionnaire. Diagnostica. 2007;53(3):144–54.
34. Gräfe K, et al. Screening psychischer Störungen Mit dem Gesundheitsfragebogen für patienten (PHQ-D). Diagnostica. 2004;50(4):171–81.
35. Mander J, et al. Stages of change, treatment outcome and therapeutic alliance in adult inpatients with chronic anorexia nervosa. BMC Psychiatry. 2013;13:111.
36. DiClemente CC, Schlundt D, Gemmell L. Readiness and stages of change in addiction treatment. Am J Addict. 2004;13(2):103–19.
37. Urbaniak GC, Plous S. Research Randomizer (Version 4.0). 2013; Available from: http://www.randomizer.org.
38. Sangill C, et al. Service user's actual involvement in mental health research practices: a scoping review. Int J Ment Health Nurs. 2019;28(4):798–815.
39. Musić S, Australian, et al. Valuing the voice of lived experience of eating disorders in the research process: benefits and considerations. New Z J Psychiatry. 2022;56(3):216–8.
40. von Wietersheim J, et al. Waiting times for admission into a psychotherapeutic inpatient treatment-results of a prospective study in south-Württemberg Psychotherapie. Psychosomatik Medizinische Psychologie. 2019;69(8):323–31.
41. Kammer BP. BPtK-Auswertung: Monatelange Wartezeiten be Psychotherapeut*innen. Corona-Pandemie verschärft das Defizit an Behandlungsplätzen. Funke-Kaiser K, editor; 2021.

## Publisher's Note

### 3.4 Publication 4: Improving motivation and treatment uptake behaviours of patients with eating disorders using patient narrative videos: results of a pilot randomised controlled trial (Daugelat et al., Manuscript).

Full citation: *Daugelat, M. C. Gregg, B., Adam, S.H., Kimmerle, J., Schag, K., & Giel, K. E. Improving Motivation and Treatment Uptake Behaviours of Patients with Eating Disorders using Patient Narrative Videos: Results of a Pilot Randomised Controlled Trial (Manuscript).*

To date, the effects of patient narratives for patients with ED remain largely unknown. This publication therefore aims to assess the feasibility and acceptability of patient narrative videos for patients with ED, as well as their effects on treatment motivation and treatment uptake behaviours.

A 4-arm RCT design was used to assess the effects of three patient narrative videos on the treatment motivation and treatment uptake behaviours of patients with ED. Patients were randomly assigned to watch 1) a patient narrative video featuring a lived experience representative speaking about her experiences with an ED, 2) a narrative video featuring a psychotherapist speaking about the experiences of her patients with ED, 3) a patient narrative video featuring a lived experience representative speaking about her experiences with a somatic condition (i.e., torn knee ligament), or 4) no video. Patients were asked to complete a series of questionnaires at baseline (T0) and post-intervention (T1), as well as one-week (T2) and three-months (T3) follow-up. Main outcome measures included the effects of watching patient narrative videos on self-reported treatment motivation and treatment uptake behaviours at one-week and three-months follow-up. Further outcomes measures included patients' ED psychopathology, as well as hope and confidence toward recovery. Patients who watched one of the patient narrative videos were also asked to complete a post-intervention rating in regards to the authenticity, empathy, and usefulness of the videos.

A total of n = 91 female patients with ED who attended an appointment at the Department of Psychosomatic Medicine and Psychotherapy at the University Hospital Tübingen but who were not currently receiving psychotherapeutic

treatment were recruited for this study. All patients reported an increase in treatment motivation over time, regardless of whether they watched a (patient) narrative video or not. Meanwhile, patients who watched any of the three (patient) narrative videos reported significantly increased treatment uptake behaviours at three-months follow-up in comparison to patients who watched no video. No significant differences were found between groups regarding ED psychopathology at any timepoint. Significant interaction effects were found between group and time in regards to patients' reported hope and confidence toward recovery. More specifically, patients who watched the patient narrative video featuring a lived experience representative discussing experiences with a somatic condition reported a significant increase in hope toward recovery from baseline (T0) to post-intervention (T1). While all three (patient) narrative videos received positive feedback, patients rated the video featuring the lived experience representative discussing her experiences with ED as significantly more authentic than the video in which she discusses her experiences with a somatic condition. In addition, patients rated the videos featuring the lived experience representative or psychotherapist discussing experiences with ED as significantly more useful than the video discussing a somatic condition.

These results suggest that watching (patient) narrative videos can have significant impacts on treatment uptake behaviours for patients with ED. Patients responded favourably to the themes of ambivalence addressed in all of the (patient) narrative videos developed for this study, while showing a preference for videos featuring lived experience of ED. The further development of evidence-based patient narratives could therefore prove to be a useful addition to early intervention approaches aiming to help combat the current treatment gap.

# Improving Motivation and Treatment Uptake Behaviours of Patients with Eating Disorders using Patient Narrative Videos: Results of a Pilot Randomised Controlled Trial

Melissa-Claire Daugelat[1, 2], Bettina Gregg[3], Sophia Helen Adam[1], Joachim Kimmerle [4, 5], Kathrin Schag*[1, 2, 6,] Katrin Elisabeth Giel*[1, 2, 6]

[1] Department of Psychosomatic Medicine and Psychotherapy, Medical University Hospital Tübingen, Germany
[2] Centre of Excellence for Eating Disorders Tübingen (KOMET), Eberhard-Karls-University Tübingen, Germany
[3] Lived Experience Representative, Tübingen, Germany
[4] Department of Psychology, Eberhard-Karls-University Tübingen, Germany
[5] Leibniz-Institut für Wissensmedien, Tübingen, Germany
[6] DZPG (German Centre for Mental Health), Tübingen, Germany

* Kathrin Schag and Katrin Elisabeth Giel contributed equally

Corresponding Author

Melissa-Claire Daugelat
Medical University Hospital Tübingen
Department of Psychosomatic Medicine and Psychotherapy
Osianderstr. 5, 72076 Tübingen, Germany
Email: melissa-claire.daugelat@med.uni-tuebingen.de

**Keywords:** eating disorders, motivation, help-seeking, lived experience, patient narratives

## Abstract

**Introduction:** There currently exists a tremendous treatment gap between persons experiencing eating disorders (ED) and those receiving treatment, in part due to ambivalences toward treatment. Patient narratives are stories of affected persons discussing their illness and recovery journeys. This study assessed the feasibility and acceptability of patient narrative videos, and their influence on treatment motivation and uptake in a clinical sample of patients with ED.

**Methods:** Using a 4-arm randomised controlled pilot trial, n = 91 female patients with an ED watched a (patient) narrative video featuring 1) a lived experience representative discussing her recovery from an ED, 2) a psychotherapist discussing the experiences of her patients with ED, 3) a lived experience representative discussing her recovery from a somatic condition, or 4) no video. Primary outcomes included treatment motivation and treatment uptake behaviours at one-week (T2) and three-months (T3) follow-up. Patients' evaluation of the videos was also assessed.

**Results:** Watching (patient) narrative videos was associated with increased treatment uptake behaviours at T3. Meanwhile, all patients reported increased treatment motivation over time, regardless of whether they watched a video or not. The video featuring lived experience with ED was rated more authentic, while videos featuring lived or psychotherapist experiences with ED were rated more useful than the video featuring a somatic condition.

**Conclusion:** The results of this study indicate that watching (patient) narrative videos can significantly affect treatment uptake behaviours. The development of further evidence-based patient narratives focusing on ambivalence could therefore be a useful adjunct to early intervention approaches.

## Plain Language Summary

Not all patients who are experiencing eating disorders are currently receiving treatment, which is partially due to ambivalence toward treatment. Patient narratives are stories about illness and recovery, told by the people who experienced them. This study looked at the suitability and impact of patient narrative videos for patients with an eating disorder. 91 female patients with eating disorders were divided into four groups: three groups were invited to watch a video featuring the perspective of a) a former patient talking about her experiences with an eating disorder, b) a psychotherapist talking about the experiences of patients with eating disorders, or c) a former patient talking about her experiences with a physical injury. The fourth group watched no video. Patients were asked how motivated they felt toward treatment, as well as what treatment services they had been in contact with one week and three months after watching the video. Patients were also asked about their evaluation of the videos. More patients who watched any of the patient narrative videos later reported attending treatment services than those who watched no video. Meanwhile, all patients reported increased treatment motivation over time, regardless of whether they watched a video or not. The patient narrative video featuring a former patient talking about her experiences with an eating disorder was rated more authentic than the video about a physical injury. Meanwhile, videos featuring the former patient or psychotherapist talking about experiences with eating disorders were rated more useful than the video about a physical injury.

## Introduction

Eating disorders (ED) are mental disorders characterised by persistent cognitions and behaviours which disrupt the consumption of food and significantly impair the physical and psychological wellbeing of its sufferers [1, 2]. There currently remains a significant treatment gap among those affected, with the latest screening studies showing that only around 30% of persons experiencing symptoms of an ED are receiving any sort of treatment [3, 4]. In addition, those who do seek treatment report a duration of untreated ED (DUED) ranging from 2.5 years for patients with anorexia nervosa, to 4.4 or even 5.6 years for patients with bulimia nervosa or binge eating disorder [5], despite a steady progression of symptoms and increased psychological distress [5, 6]. Fear of stigma and difficulties acknowledging the severity of symptoms often result in ambivalence toward treatment and are frequently described as contributing to the DUED by patients with ED [3, 7-9]. The Transtheoretical Model of Health Behavior Change (TTM) by Prochaska and Di Clemente [10] provides one way to examine motivation for change. According to the model, individuals wanting to change a health-related behaviour typically progress through six stages of change: precontemplation, contemplation, preparation, action, maintenance, and termination [10]. Higher stages of change represent a greater level of behavioural motivation, and the model can therefore be used to identify where interventions may be needed for a particular health behaviour. While a higher level of treatment motivation is associated with better treatment outcomes for patients with ED [11, 12], the majority of patients entering inpatient treatment report lower motivational stages of change such as precontemplation or contemplation [13].

Particularly for patients with ED, patient narratives could provide a much-needed source of inspiration that recovery is possible [14]. Patient narratives can be defined as personal stories from persons who are either currently or were previously affected by a physical or mental disorder. Patient narratives may focus on the experience of illness, or incorporate experiences with treatment services [15]. Patient narratives can appear in several mediums, including peer-to-peer support, or documented in books, blogs, films, or artwork. In an increasingly digital world, it makes sense that patient narratives have found their way online

as well. The popularity of so-called “ED recovery accounts” on social media platforms such as Instagram and YouTube [16, 17] shows that there is a desire from affected persons to connect with others experiencing the same struggles. Reading or otherwise engaging with patient narratives can have a range of positive effects, including a reduction of self-stigma [18] and perceived social isolation [14], as well as increased self-efficacy [19, 20], and feelings of support and belonging [16, 17]. A recent study investigating influences on DUED in anorexia nervosa found that the reception of patient narratives was one of the few factors among many investigated which were associated with a significantly shorter DUED [21].

Patient narrative videos, such as those found on social media platforms, have been assessed in only a handful of studies to date. The NEON and NEON-O trials recruited participants with psychosis, as well as a variety of other mental disorders, who received access to an online database featuring a collection of 659 patient narratives featuring a variety of mental disorders [22]. Results showed that participants with non-psychosis mental disorders reported significantly increased quality of life and meaning of life ratings after engaging with at least one patient narrative [23]. Further, engagement with the patient narratives was found to be highest when participants perceived the patient narratives as authentic and relevant to their own experiences [24]. Previous studies examining the use of patient narratives in the field of EDs have been predominantly observatory, i.e. these studies assessed patients’ self-directed consumption of patient narratives and not consumption within a treatment context [14, 25]. Finally, these studies neither reported the exact features of the patient narratives used nor systematically assessed treatment uptake rates after consumption versus non-consumption of these materials.

### Study Aims

This study aims to investigate the feasibility and acceptability of (patient) narrative videos, as well as to examine their effects on treatment motivation and uptake of treatment services in a clinical sample of patients diagnosed with ED. It was

hypothesised that patients who watched a (patient) narrative video from the perspective of a former patient with an ED or a psychotherapist would show:

- stronger increases in treatment motivation (Hypothesis 1) and
- increased likelihood to engage in treatment uptake behaviours (Hypothesis 2)

compared to patients who watched a (patient) narrative video unrelated to ED or patients who watched no video [26]. It was further hypothesised that patients who watched a video from the perspective of a former patient with an ED would show:

- stronger increases in treatment motivation (Hypothesis 3) and
- increased likelihood to engage in treatment uptake behaviours (Hypothesis 4)

compared to patients who watched a video from the perspective of a psychotherapist [26]. Further outcomes included the effects of the (patient) narrative videos on ED psychopathology and self-reported hope and confidence toward recovery. Lastly, patients' evaluations of the (patient) narrative videos were assessed to determine the suitability of patient narratives for this population.

## Method

The results of this study are reported according to the guidelines proposed by the CONSORT 2025 Checklist [27]. The study was performed in line with the principles of the Declaration of Helsinki [28]. Ethical approval was granted by the ethics committee of the Medical Faculty at the University Hospital Tübingen (reference 419/2022BO1), and the study was pre-registered with the German Registry for Clinical Studies (DRKS; reference DRKS00033709). A study protocol was also previously published [26].

### *Study Participants*

Recruitment for this study took place between February 2024 – April 2025, with follow-up assessments occurring until July 2025. A total of n = 97 patients were

recruited during their first appointment at the outpatient service of the Department of Psychosomatic Medicine and Psychotherapy, as well as the obesity treatment service at the University Hospital Tübingen. These initial appointments have the primary aim of diagnostic assessment and identifying future treatment needed. Female patients with a full-syndrome or sub-clinical ED as diagnosed by a trained clinician, as well as a minimum age of 15 years were informed about the study and invited to participate. Patients experiencing acute suicidality, psychotic disorders (lifetime), bipolar disorder (lifetime), or current moderate-severe substance-use disorders were excluded from the study. Similarly, patients who were currently receiving ED treatment (defined as receiving treatment in the last four weeks) were also excluded from the study. Patients received monetary compensation for their participation. Based on data from a pre-pilot study [29], it was not expected that any risks or negative side effects would occur as a result of participation. Written informed consent was obtained from all patients as well as the parents/guardians of patients under the age of 18. Patients could withdraw consent at any time, for any reason, without loss of benefit.

### *Materials Used*

**Self-report measures.** Patient files were consulted to obtain basic demographic and diagnostic information, including ED diagnosis and history of treatment.

The *Eating Disorders Examination Questionnaire (EDE-Q [30])* was used to assess ED psychopathology. The EDE-Q uses four subscales (Restraint, Eating Concern, Shape Concern, and Weight Concern) to measure the cognitive and behavioural disturbances typically associated with ED, as well as a mean global score to determine overall eating pathology [30]. The EDE-Q is sensitive to change and has a high internal consistency ($\alpha \leq .97$) [31].

The *Patient Health Questionnaire (PHQ-D [32])* was used to assess symptoms of depressive disorders, panic disorder, and psychosocial functioning. The PHQ-D shows excellent criterion validity, as well as a good internal consistency for depressive symptoms ($\alpha = 0.88$) [32].

The *University of Rhode Island Change Assessment Scale – Short Version (URICA-S [33])* was used to determine treatment motivation. The URICA-S provides a profile of an individual's readiness to change by calculating scores across four subscales: precontemplation, contemplation, action, and maintenance. In addition, a readiness to change (RTC) score can be calculated by subtracting the mean precontemplation score from the sum of the mean contemplation, action, and maintenance scores, wherein a higher score indicates a greater readiness to change [34]. The URICA-S has a strong criterion validity and shows acceptable to good internal consistency (α = 0.61-0.85) [33].

A short questionnaire was developed for this study in order to assess treatment uptake behaviours [26]. Specifically, patients were asked to select from a list which treatment services they had engaged with within a given time period including inpatient, partial inpatient, and outpatient psychotherapeutic/psychiatric treatment services, outpatient nutritionist services, homeopathic treatment services, and general practitioners. Treatment uptake was defined as attending at least one appointment at any of these treatment services. Patients could also indicate any preparatory actions such as researching treatment options and time spent on waiting lists.

Two visual analogue scales (VAS) measuring 0-100mm were used to assess how hopeful and confident patients felt toward their own recovery. Patients' scores were determined by measuring the distance in mm between the anchor (no hope/no confidence) and the patient's selection on the visual analogue scales. Higher scores were indicative of greater hopefulness and confidence toward recovery [26].

A post-intervention questionnaire was developed to determine patients' evaluation of the narrative videos, with particular emphasis on the perceived authenticity and empathy of the protagonist of each video, as well as the overall usefulness of the video [26].

**Interventions.** A lived experience expert was recruited for the development of the (patient) narrative videos used in this study. This process of development was

participatory as well as evidence-based, with the content of the videos deriving from an extensive review of the current literature [8], as well as the personal experiences of the lived experience expert [29]. Three (patient) narrative videos were used in this study: the first video (Patient ED Video) featured the lived experience expert discussing her personal experiences recovering from an ED, the second video (Psychotherapist Video) featured a psychotherapist discussing the experiences of her patients as they recover from ED, while the third video (Patient Other Video) featured the lived experience expert discussing her recovery from a somatic condition unrelated to ED (i.e., a torn knee ligament). All videos featured the same content and placed particular emphasis on the barriers defined as most important in the literature, namely the feelings of stigma, shame, and guilt that typically accompany treatment. The videos further discussed the importance of seeking treatment when symptoms become “too much”, the role of social support at various stages of recovery, and if treatment is “worth it” [8]. A pre-pilot trial was completed with a non-clinical sample of participants in order to determine ratings of authenticity, empathy, and usefulness [29]. All of the videos received positive ratings from participants, wherein the Patient ED Video was rated significantly more authentic than the Patient Other Video, as well as significantly more empathic, useful, and better rated overall than both the Psychotherapist Video and Patient Other Video [29].

### *Procedure*

This study followed the design of a 4-arm randomised controlled pilot study. Following informed consent, patients were randomised into four groups using Research Randomiser [35]: Intervention Group 1 (IG1) watched the Patient ED Video, Intervention Group 2 (IG2) watched the Psychotherapist Video, and Intervention Group 3 (IG3) watched the Patient Other Video, while the remaining patients in the Treatment-as-Usual (TAU) group did not watch any video. The study was an open-label study, and neither the patients nor the study team were blinded regarding group allocation. Patients initially completed a series of baseline assessments (T0), before patients in IG1, IG2, and IG3 watched the

(patient) narrative videos. Patients could choose to watch these videos at either an in-person appointment or online via video conference. All patients received the same instructions, namely that they would watch one of three videos featuring different disorders and perspectives. Immediately after watching the videos (T1), patients in IG1, IG2, and IG3 completed a series of questionnaires to assess any immediate changes in treatment motivation, hopefulness, or confidence toward recovery, as well as an evaluation of the video. Patients in IG1, IG2, and IG3 were contacted for follow-up assessments one week (T2) and three months (T3) after watching the videos (T1). Patients in TAU were contacted for follow-up assessments one week (T2) and three months (T3) after baseline (T0). An overview of the study plan and the assessment materials can be seen in Figure 1.

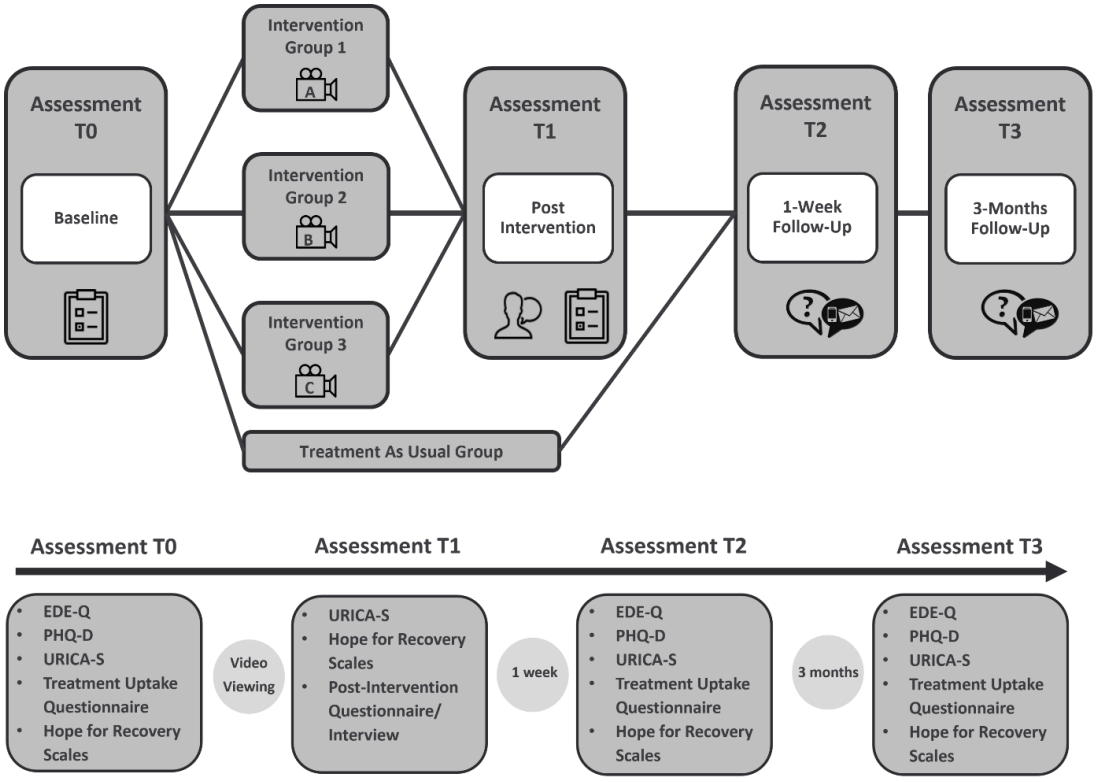



**Fig. 1. Study plan and overview of assessment materials.**
Note. EDE-Q = Eating Disorders Examination Questionnaire, PHQ-D = Patient Health Questionnaire, URICA-S = University of Rhode Island Change Assessment Scale – Short Version. Figure previously published in Daugelat et al. [26].

### *Sample Size*

This study was a pilot trial, aiming to investigate the feasibility and acceptability of patient narrative videos, as well as to collect sufficient data to determine sample size calculations for future larger clinical trials.

### *Outcome Measures and Statistical Analysis*

**Primary outcome measures.** As the effects of patient narrative videos have not been previously examined for this group of patients, this study aimed to identify a meaningful primary outcome. The main outcome measures of this study were therefore changes in patients' treatment motivation between T0, T1, T2, and T3, as well as their reported treatment uptake behaviours at T2 and T3. A mixed 3x4 analysis of variance (ANOVA) was used to assess the effects of group allocation on treatment motivation between T0, T2, and T3. Timepoint (3 levels) was included as the within-subject factor, group allocation (4 levels) was included as the between-subject factor, and the URICA RTC score was assessed as the dependent variable. Post-hoc pairwise comparisons were computed to further investigate the differences between the within-subject factor. Patients allocated to TAU did not complete T1 assessments. A further mixed 2x3 ANOVA was therefore used to assess the effects of group allocation on reported treatment motivation between T0 and T1 for patients in IG1, IG2, and IG3.

Treatment uptake was defined as attending a minimum of one appointment at any of the following treatment providers: general practitioner, nutritionist, outpatient psychotherapist, outpatient psychiatrist, inpatient services, partial inpatient services, or homeopathic services. Pearson's chi-square tests of contingencies were used to assess the relationship between patients' group allocation (IG1/IG2/IG3/TAU) and treatment uptake behaviours at T0, T2, and T3. Further exploratory analyses were completed using a Pearson's chi-square test of contingencies to determine the uptake of psychotherapeutic treatment services (outpatient psychotherapist, outpatient psychiatrist, inpatient services, partial inpatient services), as well as a mixed 3x4 ANOVA to assess the effects of group allocation on the intensity of treatment services, i.e. the total number of different

treatment providers patients engaged with between T0, T2, and T3. Post-hoc pairwise comparisons and planned contrasts were computed to further investigate the differences between the within-subject and between-subjects factors.

**Secondary outcome measures.** Additional outcome measures of this study included changes in patients' ED psychopathology, as well as changes in patients' reported hopefulness and confidence toward recovery between T0, T1, T2, and T3. A mixed 3x4 ANOVA was completed to assess the effects of group allocation between T0, T2, and T3 at these outcomes. Regarding hope and confidence toward recovery, the effects of intervention group allocation at T0 and T1 were further investigated to identify potential short-term changes. Post-hoc pairwise comparisons were computed to further investigate the differences between the within-subject and between-subjects factors. Additionally, authenticity, empathy, and usefulness scores of the videos assessed at T1 were determined by calculating the mean of the respective items included for each domain in the evaluation questionnaire. One-way between-group ANOVAs were calculated to assess the effects of group allocation on patients' ratings of the videos. The assumption of normality was violated in a few conditions regarding secondary outcomes. The decision was made to continue using the ANOVA, as this method has been proven in the literature to be robust against such violations [36, 37].

## Results

Of the 269 patients who attended an appointment at the University Hospital Tübingen, n = 109 did not meet inclusion criteria, and n = 63 declined the invitation to participate, resulting in n = 97 patients participating in the study (see Fig. 2). Regarding drop-out rates, n = 2 patients failed to complete the one-week follow-up assessment (T2), while n = 2 patients failed to complete the three-month follow-up assessment (T3). N = 5 patients were removed from all analyses due to a lack of an ED diagnosis, while n = 1 was removed due to being the only

patient under the age of 18. This resulted in a final sample of n = 91 patients at T0 and T1, and n = 87 patients at T2 and T3 (see Fig. 2).

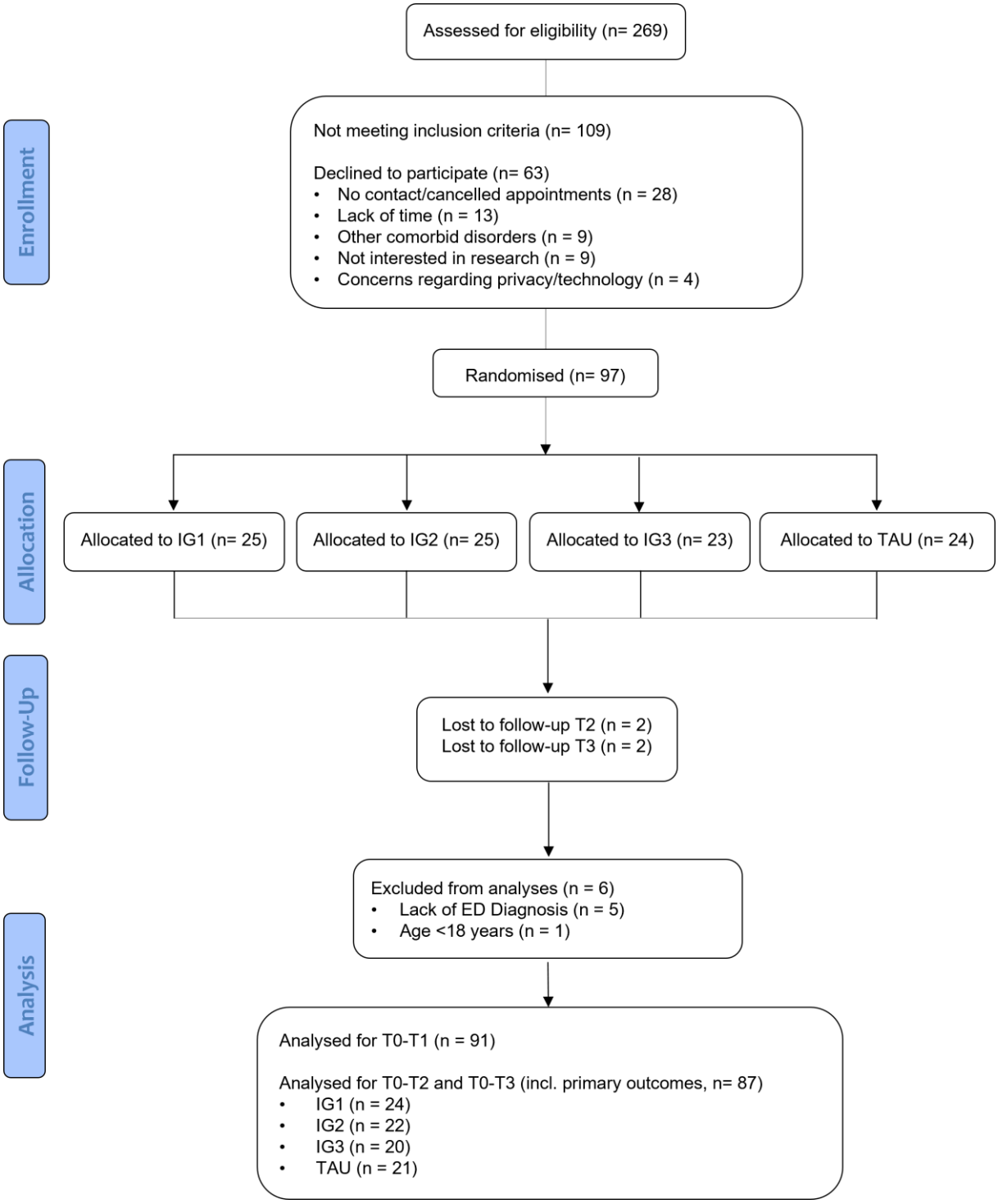



**Fig. 2. Patient Recruitment Flow Chart**
Note. IG = intervention group; TAU = treatment as usual; ED = eating disorder

### *Patient Demographics*

Patients ranged in age from 18 to 65 years (*M* = 31.77, *SD* = 12.17) and were diagnosed with either (atypical-) Anorexia Nervosa (n = 37), (atypical-) Bulimia Nervosa (n = 14), Binge Eating Disorder (n = 36), or Overeating Associated with other Psychological Disturbances (n = 4). These diagnoses were evenly distributed across the intervention/TAU groups (see Supplementary Materials). When asked about previous treatment experiences, 75% (n = 68) of patients indicated that they had previously sought any type of treatment for their ED, while 48% (n = 44) had previously sought psychotherapeutic treatments. Further information regarding baseline demographic variables can be found in Table 1.

**Table 1: Baseline Demographic Variables**

| | *n* | % |
|---|---|---|
| Participants | 91 | 100 |
| **Diagnosis according to ICD-10** | | |
| (Atypical-) Anorexia nervosa | 37 | 41 |
| (Atypical-) Bulimia nervosa | 14 | 15 |
| Binge Eating Disorder | 36 | 40 |
| Overeating Associated with other Psychological Disturbances | 4 | 4 |
| **Prior Treatment** | | |
| Any Treatment | 68 | 75 |
| Psychotherapeutic Treatment | 44 | 48 |
| | ***M*** | ***SD*** |
| **Age** | 31.77 | 12.17 |
| **URICA-S** | | |
| Readiness to Change Score (Range -2 - +14) | 8.57 | 2.28 |
| **EDE-Q** | | |
| Restraint Score (Range 0-6) | 4.31 | 1.81 |
| Eating Concerns Score (Range 0-6) | 4.32 | 1.32 |
| Weight Concern Score (Range 0-6) | 5.19 | 1.26 |
| Shape Concern Score (Range 0-6) | 5.53 | 1.30 |
| Total Score (Range 0-6) | 4.84 | 1.11 |
| **Hope toward Recovery** (Range 0-100) | 59.16 | 26.95 |
| **Confidence toward Recovery** (Range 0-100) | 55.30 | 24.70 |

Note. Note. URICA-S = University of Rhode Island Change Assessment Scale – Short Version; EDE-Q = Eating Disorders Examination Questionnaire

### *Primary Outcome: Treatment motivation*

No significant interaction effect was found between patient group allocation (IG1, IG2, IG3, TAU) over time from baseline (T0) to one-week (T2) and three months follow-up (T3) concerning patients' reported motivation to change, $F$ (6, 166) = 1.18, $p$ = .317, $\eta^2$ = .041. A significant effect was found for time, $F$ (2, 166) = 5.47,

$p$ = .005, $\eta^2$ = .062. Post-hoc pairwise comparisons showed that patients' motivation to change significantly increased from T0 to T2 ($p$ = .013), and from T0 to T3 ($p$ = .004), with no significant increases from T2 to T3 ($p$ = .377; see Fig. 3A). No significant effects were found for group allocation, $F$ (3, 83) = 0.60, $p$ = .619, $\eta^2$ = .021.

Similarly, no significant interaction effect was found between patient group allocation (IG1, IG2, IG3) over time from baseline (T0) to post-intervention (T1) concerning patients' reported motivation to change, $F$ (2, 65) = 2.09, $p$ = .132, $\eta^2$ = .060. A significant effect was found for time, $F$ (1, 65) = 18.12, $p$ < .001, $\eta^2$ = .218. Post-hoc pairwise comparisons showed that patients' motivation to change increased significantly from T0 to T1 ($p$ < .001; see Fig. 3B). No significant effects were found for group allocation, $F$ (2, 65) = 2.38, $p$ = .101, $\eta^2$ = .068.

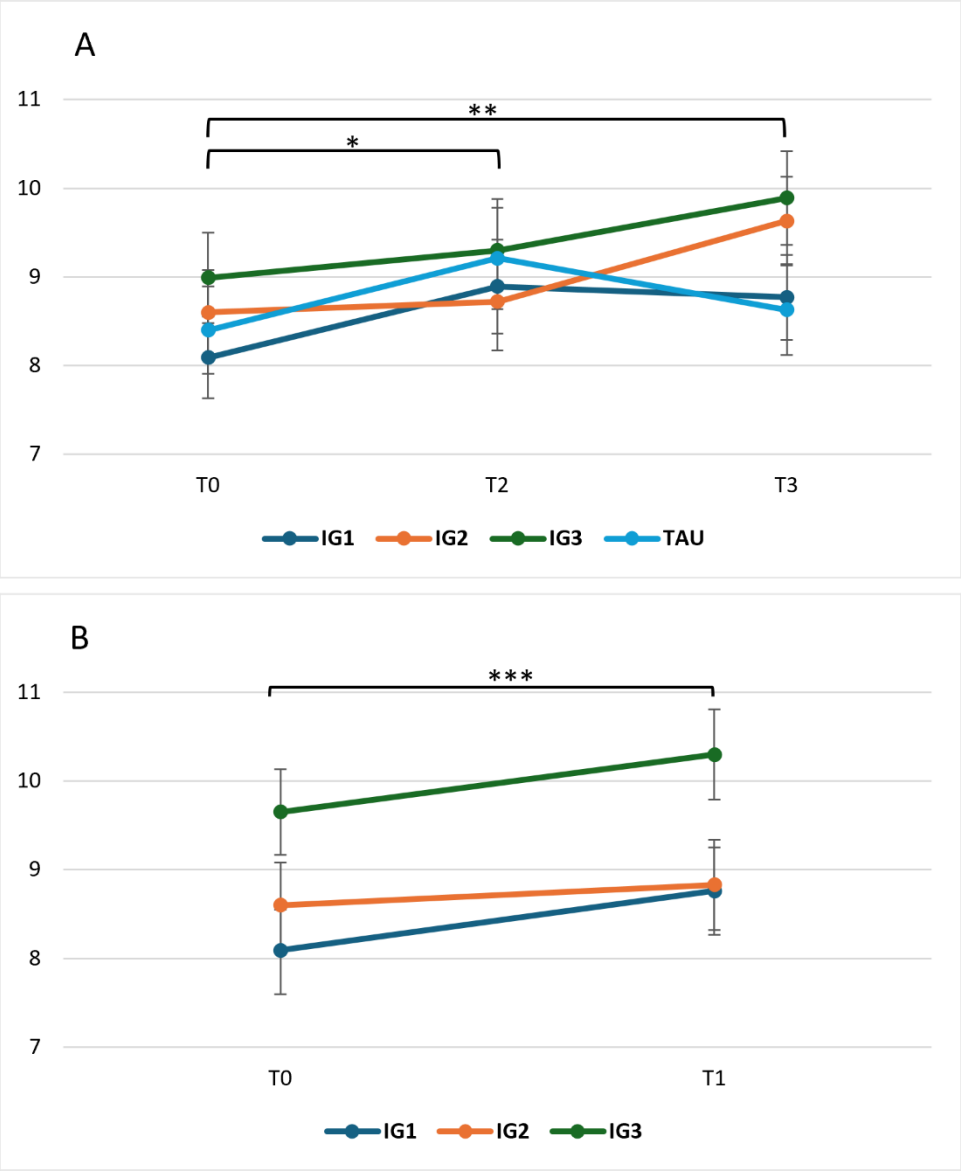



**Fig. 3. Treatment motivation reported at A. baseline (T0), one-week (T2) and three-months (T3) follow-up; and B. baseline (T0) and post-intervention (T1)**
Note. Range = -2 - +14. SE used. * p< .05, ** p< .01, *** p< .001
IG = intervention group; TAU = treatment as usual.
A. IG1: n = 24; IG2: n = 22; IG3: n = 20; TAU: n = 21.
B. IG1: n = 24; IG2: n = 22; IG3: n = 22

### *Primary Outcome: Treatment uptake behaviours*

No significant differences were found between patients' group allocation and the uptake of at least one treatment service at baseline (T0) or after one week follow-up (T2). Significant differences were found between patient groups at three months follow-up (T3), $\chi^2$ (3, $N$ = 88) = 10.58, $p$ = .014, with a moderate effect

size, $v$ = .35. Figure 4A shows that significantly more patients in IG1, IG2, or IG3 attended at least one treatment service (n = 21, 18, 16 respectively) than patients in TAU (n = 10). Explorative analyses show that these differences remained significant when treatment uptake was restricted to only psychotherapeutic (PT) services, $\chi^2$ (3, $N$ = 88) = 8.610, $p$ = .035, $v$ = .31 (see Fig. 4B).

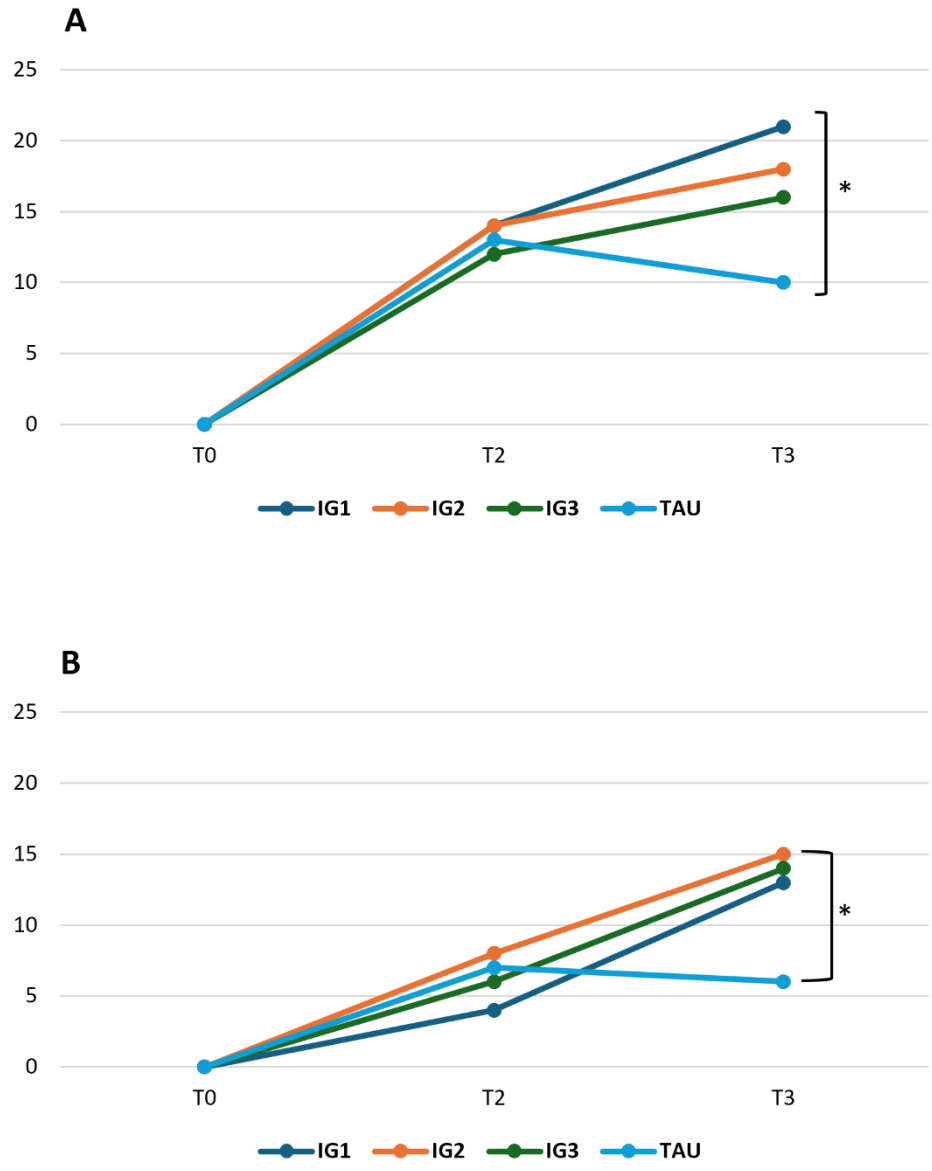



**Fig. 4. Treatment uptake behaviours reported at baseline (T0), one-week (T2) and three-months follow-up (T3) for A. all treatment services and B. psychotherapeutic treatment services**
Note. IG = intervention group; TAU = treatment-as-usual
T0: n = 91; T2: n = 89; T3: n = 87

Further exploratory analyses showed no significant interaction effect between patient group allocation (IG1, IG2, IG3, TAU) over time from baseline (T0) to one week (T2) and three months follow-up (T3) concerning patients' reported intensity of treatment, $F$ (6, 166) = 2.14, $p$ = .052, $\eta^2$ = .072. A significant effect was found for time, $F$ (2, 166) = 64.54, $p$ < .001, $\eta^2$ = .437. Post-hoc pairwise comparisons showed that patients' reported treatment intensity significantly increased from T0 to T2 ($p$ < .001), from T0 to T3 ($p$ < .001), and from T2 to T3 ($p$ = .002). Figure 5 illustrates these results. No significant effect was found for group allocation, $F$ (3, 83) = 1.86, $p$ = .142, $\eta^2$ = .063. A planned contrast indicated that patients in IG1 ($M$ = 0.86, $SE$ = 0.13), IG2 ($M$ = 0.97, $SE$ = 0.13) and IG3 ($M$ = 0.92, $SE$ = 0.14) reported significantly higher treatment intensity scores than patients in TAU ($M$ = 0.56, $SE$ = 0.14), with a mean difference of 1.08 ($SE$ = 0.47), $p$ = .024.

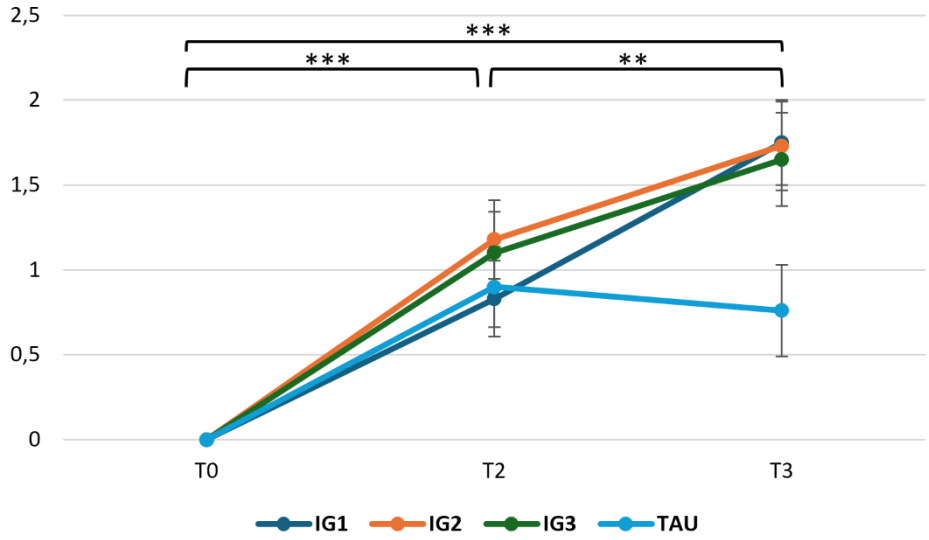



**Fig. 5. Treatment intensity reported at baseline (T0), one-week (T2), and three-months follow-up (T3)**
Note. Range = 0 - 7. SE used. * p< .05, ** p< .01, *** p< .001
IG = intervention group; TAU = treatment-as-usual
IG1: n = 24; IG2: n = 22; IG3: n = 20; TAU: n = 21.

### *Secondary Outcome: Changes in Eating Disorder Psychopathology*

No significant interaction effect was found between patient groups (IG1, IG2, IG3, TAU) over time from baseline (T0) to one-week (T2) and three months follow-up

(T3) concerning patients' reported ED psychopathology, Huynh-Feldt $F$ (6, 166) = 1.45, $p$ = .214, $\eta^2$ = .050. A significant effect was found for time, Huynh-Feldt $F$ (2, 166) = 22.64, $p$ < .001, $\eta^2$ = .214. Post-hoc pairwise comparisons showed that patients' ED psychopathology significantly decreased from T0 to T3 ($p$ < .001) and from T2 to T3 ($p$ < .001; see Table 2). No significant effect was found for group allocation, $F$ (3, 83) = .69, $p$ = .560, $\eta^2$ = .024.

### *Secondary Outcome: Hope and Confidence Toward Recovery*

**Hope toward recovery.** A significant interaction effect was found between patient group allocation (IG1, IG2, IG3, TAU) over time from baseline (T0) to one-week (T2) and three months follow-up (T3) concerning patients' reported hope toward recovery, $F$ (6, 166) = 2.22, $p$ = .044, $\eta^2$ = .074. Pairwise comparisons of the estimated marginal means of the model corrected using Bonferroni showed no significant differences between each group and timepoint combination. No significant effects were found for time, $F$ (2, 166) = 0.25, $p$ = .777, $\eta^2$ = .003, or for group allocation, $F$ (1, 83) = 0.56, $p$ = .642, $\eta^2$ = .020.

A significant interaction effect was also found between patient group allocation (IG1, IG2, IG3) over time from baseline (T0) to post-intervention (T1) concerning patients' reported hope toward recovery, $F$ (2, 65) = 4.61, $p$ < .013, $\eta^2$ = .124. Pairwise comparisons of the estimated marginal means of the model corrected using Bonferroni showed that patients in IG3 reported significantly higher hope toward recovery at T1 ($M$ = 68.64) in comparison to T0 ($M$ = 54.14; $p$ < .001).

**Confidence toward recovery.** A significant interaction effect was found between patient group allocation (IG1, IG2, IG3, TAU) over time from baseline (T0) to one-week (T2) and three months follow-up (T3) concerning patients' reported confidence toward recovery, $F$ (6, 166) = 2.55, $p$ = .022, $\eta^2$ = .084. Pairwise comparisons of the estimated marginal means of the model corrected using Bonferroni showed no significant differences between each group and timepoint combination. No significant effects were found for time, $F$ (2, 166) = 0.47, $p$ = .626, $\eta^2$ = .006, or for group allocation, $F$ (1, 83) = 0.86, $p$ = .465, $\eta^2$ = .030.

No significant interaction effect was found between patient group allocation (IG1, IG2, IG3) over time from baseline (T0) to post-intervention (T1) concerning patients' reported confidence toward recovery, $F$ (1, 65) = 2.59, $p$ = .083, $\eta^2$ = .074. No significant effects were found for time, $F$ (1, 65) = 2.88, $p$ = .095, $\eta^2$ = .042, or for group allocation, $F$ (2, 65) = 0.17, $p$ = .846, $\eta^2$ = .005.

**Table 2: Results from Self-Report Questionnaires**

| | *M (SD)* | | | |
|---|---|---|---|---|
| | **IG1** | **IG2** | **IG3** | **TAU** |
| **EDE-Q** | | | | |
| Restraint Score (Range 0 - 6) | | | | |
| T0 | 4.32 (1.57) | 4.97 (1.76) | 3.95 (1.90) | 4.01 (1.94) |
| T2 | 4.20 (1.95) | 4.72 (1.66) | 4.33 (1.81) | 4.14 (2.20) |
| T3 | 3.64 (1.66) | 4.15 (1.47) | 3.48 (1.76) | 3.56 (1.87) |
| Eating Concerns Score (Range 0 - 6) | | | | |
| T0 | 4.23 (1.37) | 4.43 (0.98) | 4.56 (1.29) | 3.77 (1.42) |
| T2 | 3.85 (1.22) | 4.06 (1.23) | 4.30 (1.27) | 4.20 (1.31) |
| T3 | 3.28 (1.40) | 3.72 (1.26) | 3.18 (1.41) | 3.68 (1.31) |
| Weight Concerns Score (Range 0 - 6) | | | | |
| T0 | 4.93 (1.56) | 5.31 (0.96) | 5.46 (0.91) | 4.97 (1.41) |
| T2 | 4.78 (1.28) | 5.25 (1.21) | 5.36 (0.99) | 4.93 (1.52) |
| T3 | 4.26 (1.56) | 4.97 (1.46) | 4.44 (1.24) | 4.72 (1.47) |
| Shape Concerns Score (Range 0 - 6) | | | | |
| T0 | 5.29 (1.58) | 5.56 (1.14) | 5.84 (0.89) | 5.32 (1.47) |
| T2 | 5.13 (1.50) | 5.51 (1.04) | 5.65 (0.99) | 5.32 (1.57) |
| T3 | 4.93 (1.67) | 5.32 (1.51) | 4.94 (1.09) | 5.08 (1.45) |
| Total Score (Range 0 - 6) | | | | |
| T0 | 4.69 (1.22) | 5.07 (0.91) | 4.95 (0.91) | 4.52 (1.35) |
| T2 | 4.49 (1.27) | 4.89 (1.02) | 4.91 (0.93) | 4.65 (1.46) |
| T3 | 4.03 (1.37) | 4.54 (1.25) | 4.01 (1.03) | 4.26 (1.40) |
| **Hope for Recovery** (Range 0 - 100) | | | | |
| T0 | 63.67 (25.63) | 62.41 (24.91) | 53.70 (27.71) | 56.33 (30.88) |
| T1 | 66.13 (24.48) | 63.23 (24.27) | 68.64 (23.72) | N/A |
| T2 | 61.13 (27.47) | 53.09 (23.52) | 62.70 (30.45) | 57.33 (30.36) |
| T3 | 65.54 (22.67) | 53.41 (24.07) | 67.50 (22.32) | 54.48 (28.94) |
| **Confidence for Recovery** (Range 0 - 100) | | | | |
| T0 | 59.50 (25.66) | 56.64 (24.05) | 51.70 (20.76) | 52.38 (28.91) |
| T1 | 59.92 (25.30) | 56.45 (23.38) | 60.00 (18.78) | N/A |
| T2 | 58.42 (28.24) | 49.73 (23.73) | 54.95 (25.71) | 55.10 (28.60) |
| T3 | 65.46 (22.61) | 48.05 (26.84) | 63.00 (19.76) | 49.71 (29.29) |

Note. EDE-Q = Eating Disorders Examination Questionnaire; IG = intervention group; TAU = treatment-as-usual

### *Evaluation of (patient) narrative videos*

**Authenticity.** A significant main effect was found regarding the authenticity ratings of the three videos, $F$ (2, 65) = 5.71, $p$ = .005, $\eta^2$ = .150. Post-hoc analyses with Tukey's HSD (using an $\alpha$ of .05) showed that patients rated the Patient ED Video ($M$ = 4.52) as significantly more authentic than the Patient Other Video ($M$ = 3.73), $p$ = .004.

**Empathy.** No significant main effect was found regarding the empathy ratings of the three videos, $F$ (2, 65) = 1.19, $p$ = .311, $\eta^2$ = .035.

**Usefulness.** A significant main effect was found regarding the usefulness ratings of the three videos, $F$ (2, 65) = 4.58, $p$ = .014, $\eta^2$ = .123. Post-hoc analyses with Tukey's HSD (using an $\alpha$ of .05) showed that patients rated the Patient ED Video ($M$ = 3.97) and the Psychotherapist Video ($M$ = 3.89) as significantly more useful than the Patient Other Video ($M$ = 3.33), $p$ = .018 and $p$ = .049 respectively.

**Overall rating.** No significant main effect was found for the overall ratings of the three videos, $F$ (2, 65) = 1.20, $p$ = .307, $\eta^2$ = .036. A summary of these findings can be found in Figure 6.

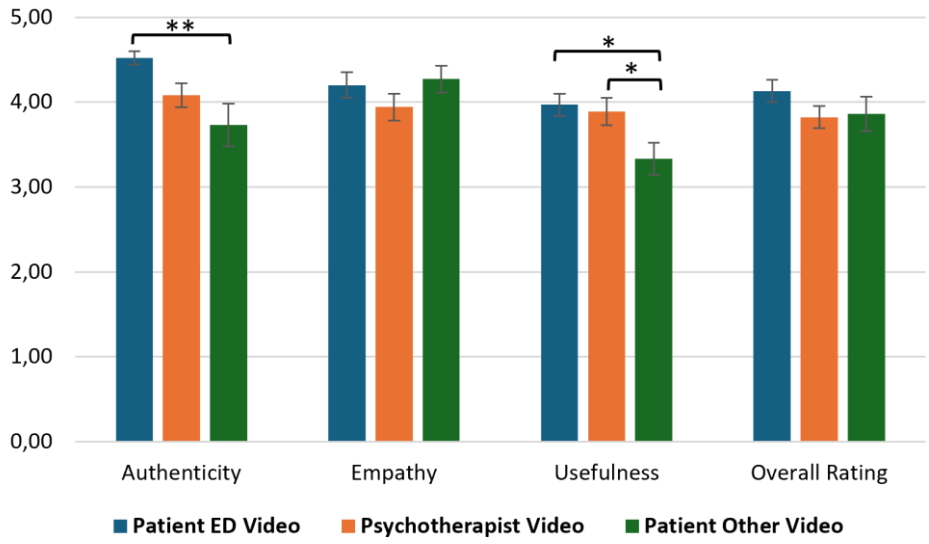



**Fig. 6. Video Ratings for Authenticity, Empathy, Usefulness, and Overall Rating**
Note. SE used. * p< .05, ** p< .01
Patient ED Video: n = 24; Psychotherapist Video: n = 22; Patient Other Video: n = 22.

## Discussion

The targeted use of patient narratives discussing mental disorders, and in particular ED, is a relatively new methodological approach. The current study piloted the use of three evidence-based (patient) narrative videos specifically developed for ED in order to evaluate the feasibility and acceptability of this methodology, as well as to assess the effects of such videos on the treatment motivation and treatment uptake behaviours of patients with ED. The results show that watching any of the (patient) narrative videos was associated with increased treatment uptake behaviours and treatment intensity in comparison to watching no video. Meanwhile, no significant differences were found between the intervention and control groups in regard to self-reported treatment motivation or ED psychopathology. Significant interaction effects were found between group allocation and time regarding patients' reported hope and confidence toward recovery, wherein patients who watched the patient narrative videos featuring a somatic condition reported significantly increased feelings of hope toward treatment immediately after watching the video (T1) in comparison to baseline (T0). All three (patient) narrative videos were deemed feasible and acceptable for this population. Patients rated the video featuring the lived experience expert discussing her recovery from an ED as more authentic than the video featuring a somatic condition, while videos featuring the lived experience expert or psychotherapist discussing experiences with an ED were rated as more useful than the video featuring a somatic condition.

### *Treatment motivation*

Patients reported a significant increase of treatment motivation over time, however, there were no significant differences between the different groups at any of the four time points. Treatment motivation as reported by patients in this study was comparable to that reported by another study examining treatment motivation of patients with anorexia nervosa [13], despite these patients having already begun inpatient treatment. These results highlight the persistent ambivalence of this patient population toward treatment services. It also poses

the question if the URICA questionnaire is truly the most suitable measure of treatment motivation for patients with ED, as it was developed to assess the motivation to change any health behaviour and is therefore quite broad. Individual items ask patients to indicate their willingness to change “the problem” in general, rather than naming individual symptoms or diagnoses. Dunn et al. [38] previously discussed the importance of asking patients about their motivation to change specific ED behaviours (e.g., binge eating episodes) as opposed to a motivation to change the ED in its entirety, as a patient’s readiness to change may be different for each ED related symptom and/or behaviour. There is therefore a need to develop more ED-specific instruments to measure treatment motivation, some of which are available for patients with Anorexia Nervosa (e.g., [39]) and Bulimia Nervosa (e.g., [40]), but which remain lacking for patients with Binge Eating Disorder or Other Specified Feeding and Eating Disorders.

### *Treatment uptake behaviours*

Significant differences were found between groups in relation to the reported treatment uptake behaviours. More specifically, significantly more patients who had watched any of the three (patient) narrative videos reported attending a treatment service than those patients who did not watch a video. No significant differences were found when comparing the three video groups with one another, despite these featuring different perspectives (i.e., lived experience vs. psychotherapist) and different diagnoses (ED vs. somatic condition). All patients further reported a significant increase in treatment intensity, i.e. the total number of treatment providers they engaged with over time, while patients who watched any of the videos reported higher treatment intensity compared to patients who watched no video. These results are in line with a previous study, in which shorter DUED were reported by patients with anorexia nervosa who reported reading or watching patient narratives by themselves [21]. Similar results were also found in the NEON-O trial, wherein participants with a variety of non-psychosis mental disorders had free reign to engage with any patient narrative featuring any diagnosis, regardless of whether this mirrored their own diagnosis or not.

Participants reportedly valued the diversity of patient narratives available to them [24], and participants who engaged with at least one patient narrative also reported significantly increased quality of life [23]. Though varied for the respective perspective and diagnosis, the content of each video was identical and based on the same four key categories, with a focus on the experiences of ambivalence toward treatment, fear of stigma, and the importance of social support (for more information see [29]). These results therefore suggest that focusing on ambivalence and its role in treatment motivation in (patient) narratives may be particularly effective in encouraging treatment seeking behaviours for patients with ED.

### *ED psychopathology*

While patients reported a significant decrease in ED psychopathology at three months follow-up, there were no significant group differences at any of the measured timepoints. This decline in ED psychopathology can be explained by the large proportion of the patients who also reported engaging with treatment services at three-months follow-up. These results are similar to those found by a previous study [14], wherein patients with ED reported no changes in ED psychopathology after reading five patient narratives. It is well known that EDs are complex disorders that typically require intensive therapeutic intervention [1, 2]. While patient narratives were never meant to replace psychotherapy, they may nevertheless be a useful adjunct, particularly for early intervention services and to foster treatment motivation.

### *Hope and confidence toward recovery*

Although significant interaction effects were found between group allocation and the progression from baseline (T0) to one-week (T2) and three-months follow-up (T3) regarding patients' hope and confidence toward recovery, the effect sizes were very small and subsequent pairwise comparisons and planned contrast analyses did not reveal any differences between all combinations of group and time. These results are partially in line with the findings of previous studies in

which patients with ED [14], psychosis [19, 20], and other mental disorders [41] reported increased feelings of hope, inspiration, and self-efficacy regarding their own recovery following their reading and/or watching of patient narratives. Nevertheless, the small effect sizes found in this study suggest that the sample size was insufficient to effectively analyse these effects. A significant interaction effect was further found between the three intervention groups and the progression from baseline (T0) to post-intervention (T1) regarding patients' hope toward recovery. However, only patients who watched the patient narrative video featuring the lived experience expert discussing her experiences with a somatic condition reported significantly higher hope toward their own recovery, in comparison to patients who watched the (patient) narrative videos featuring patient and psychotherapist experiences with ED. While all three (patient) narrative videos contain the same focus on ambivalence in recovery, the video featuring experiences with a somatic condition elucidates the treatment of a physical illness, whose recovery is perhaps easier to define than that from an ED. This video may provide patients with a certain degree of distance to their own ED diagnosis and the often-felt pressure of the "perfect recovery" [42]. The results of this study therefore highlight the continued complexity of ED recovery and how this is perceived by patients.

### *Evaluation of the (patient) narrative videos*

Patients rated the Patient ED Video, in which the lived experience expert discusses her ED treatment journey, as significantly more authentic than the Patient Other Video, which features the same lived experience expert discussing her experiences with a somatic condition. These results are not surprising, because although the lived experience expert did indeed receive treatment for an ED, she had no personal experiences with the somatic condition discussed in the Patient Other Video, a fact which patients seem to have noticed. While there were no significant differences between the videos regarding the empathy ratings, patients rated the Patient ED Video and the Psychotherapist Video as significantly more useful than the Patient Other Video. Again, this is not

surprising, as patients with ED were asked to indicate how useful the video which they watched would be for persons affected by an ED. While the Patient ED Video and the Psychotherapist Video both focused on the experiences of patients with ED, albeit from different perspectives, the Patient Other Video focuses on a somatic condition unrelated to ED.

### Strengths and Limitations

This is to the best of our knowledge the first study to investigate the usefulness of evidence-based (patient) narrative videos to influence treatment motivation and treatment uptake behaviours for patients with ED. A significant strength of this study was the collaborative approach used to combine evidence-based information with real lived experiences in order to create the (patient) narrative videos [29]. The lived experience expert featured in the videos has been actively involved in the entirety of this study, including the co-authoring of this and other publications. A further strength of this study was the versatility of the (patient) narrative videos, which focused on experiences that all patients with ED could relate to, regardless of their diagnosis, thereby including patients who may have experiences with more than one ED diagnosis, or whose symptoms may not be sufficient for a full clinical diagnosis. However, the diversity of the videos could also be regarded as a limitation of the study, as some patients remarked that they wished there had been more specific information about experiences with different treatment options. Due to the small sample sizes, we refrained from running subsample analyses based on ED diagnosis. The diagnoses were nevertheless well represented across the intervention and TAU groups. A further limitation of this study was the exclusion of male patients with ED who are equally as affected by barriers to treatment such as stigma [43]. The decision to include only female patients was made to maximise the feelings of kinship between patients and the women featured in the (patient) narrative videos. Future videos should therefore feature the perspectives of a diverse range of persons and treatment experiences.

## Conclusion and Perspectives

Patients who watched any of the (patient) narrative videos reported significantly more treatment uptake behaviours after three months than those who did not watch a video. Meanwhile, all patients reported increases in treatment motivation over time, irrespective of whether they watched a video or not. The non-judgemental discussion of themes of ambivalence and the reassurance that this is a “normal” experience seem to be very important elements to consider when supporting patients with ED who are making their first steps toward treatment. However, it should be noted that the patient narrative presented by the lived experience expert discussing recovery from an ED was experienced as more authentic, while the (patient) narratives presented by the lived experience expert and psychotherapist discussing recovery from an ED were rated as more useful than the patient narrative featuring a somatic condition. Given the current popularity of ED recovery videos on various social media platforms, the development of further evidence-based patient narratives which are free of triggering and possibly false information could provide a useful adjunct to current early intervention approaches overcoming ambivalence and motivation difficulties.

## Statements

**Ethical Approval:** This study was performed in line with the principles of the Declaration of Helsinki. Ethical approval was obtained from the ethics committee of the Medical Faculty of the University Hospital Tübingen (reference 419/2022BO1). All patients provided written informed consent prior to participating in this study. Patients could withdraw from the study at any time without disadvantage.

**Trial Registration:** This study was pre-registered on the 21.02.2024 with the German Registry for Clinical Studies (DRKS; reference DRKS00033709; https://www.drks.de/DRKS00033709).

**Study Protocol:** A study protocol was published on the 02.01.2024 in the Journal of Eating Disorders (https://link.springer.com/article/10.1186/s40337-023-00960-3).

**Conflict of Interest:** The authors declare no conflicts of interest.

**Funding Statement:** MCD receives a PhD scholarship from the Hans-Böckler Foundation. The funder had no role in the design, data collection, data analysis, and reporting of this study.

**Author Contribution Statement:** Conceptualization: MCD, JK, KS, KEG; Methodology: MCD, JK, KS, BG, SHA, KEG; Statistical Analysis: MCD, KS; Writing - Original Draft: MCD; Writing - Review & Editing: MCD, JK, KS, BG, SHA, KEG; Visualization: MCD; Supervision: KS, KEG; Funding acquisition: MCD, KEG

**Data Availability Statement:** The data that support the findings of this study are not publicly available due to privacy reasons but are available from the corresponding author upon request.

## References


1. American Psychiatric Association, *Diagnostic and statistical manual of mental disorders (DSM-5®)*. 2013: American Psychiatric Pub. .
2. Fairburn, C.G., Z. Cooper, and R. Shafran, *Cognitive behaviour therapy for eating disorders: a "transdiagnostic" theory and treatment.* Behaviour Research and Therapy, 2003. **41**(5): p. 509-528.
3. Ali, K., et al., *The Unmet Treatment Need for Eating Disorders: What Has Changed in More Than 10 Years? An Updated Systematic Review and Meta-Analysis.* International Journal of Eating Disorders, 2025. **58**(1): p. 46-65.
4. Stadler, J., et al., *Why Young People With Eating Disorder Symptoms Do Not Seek Help—Exploring Barriers to Help-Seeking.* International Journal of Eating Disorders, 2025.
5. Austin, A., et al., *Duration of untreated eating disorder and relationship to outcomes: A systematic review of the literature.* Eur Eat Disord Rev, 2021. **29**(3): p. 329-345.
6. Franko, D.L., et al., *A longitudinal investigation of mortality in anorexia nervosa and bulimia nervosa.* American Journal of Psychiatry, 2013. **170**(8): p. 917-925.
7. Kazdin, A.E., E.E. Fitzsimmons-Craft, and D.E. Wilfley, *Addressing critical gaps in the treatment of eating disorders.* Int J Eat Disord, 2017. **50**(3): p. 170-189.
8. Daugelat, M.C., et al., *Barriers and facilitators affecting treatment uptake behaviours for patients with eating disorders: A systematic review synthesising patient, caregiver and clinician perspectives.* European Eating Disorders Review, 2023.
9. Radunz, M., K. Ali, and T.D. Wade, *Pathways to improve early intervention for eating disorders: Findings from a systematic review and meta-analysis.* International Journal of Eating Disorders, 2023. **56**(2): p. 314-330.
10. Prochaska, J.O. and W.F. Velicer, *The transtheoretical model of health behavior change.* American Journal of Health Promotion, 1997. **12**(1): p. 38-48.
11. Dray, J. and T.D. Wade, *Is the transtheoretical model and motivational interviewing approach applicable to the treatment of eating disorders? A review.* Clin Psychol Rev, 2012. **32**(6): p. 558-65.
12. Krebs, P., et al., *Stages of change and psychotherapy outcomes: A review and meta-analysis.* Journal of clinical psychology, 2018. **74**(11): p. 1964-1979.
13. Martinelli, M.K., C.C. Schreyer, and A.S. Guarda, *Comparing hospitalized adult patients with chronic anorexia nervosa with versus without prior hospitalizations.* Journal of Eating Disorders, 2024. **12**(1): p. 132.
14. Dawson, L., et al., *Are recovery stories helpful for women with eating disorders? A pilot study and commentary on future research.* J Eat Disord, 2018. **6**: p. 21.
15. Llewellyn-Beardsley, J., et al., *Characteristics of mental health recovery narratives: Systematic review and narrative synthesis.* PloS one, 2019. **14**(3): p. e0214678.

16. Wenig, V. and H. Janetzke, *"That You Just Know You're Not Alone and Other People Have Gone through It Too." Eating Disorder Recovery Accounts on Instagram as a Chance for Self-Help? A Qualitative Interview Study among People Affected and Self-Help Experts.* International Journal of Environmental Research and Public Health, 2022. **19**(18): p. 11334.
17. Yeo, C., et al., *Uses and Misuses of Recorded Mental Health Lived Experience Narratives in Healthcare and Community Settings: Systematic Review.* Schizophr Bull, 2021.
18. Sheens, E., P. Rhodes, and L. Dawson, *Encountering anorexia: challenging stigma with recovery stories.* Advances in Eating Disorders, 2016. **4**(3): p. 315-322.
19. McLeod, B., et al., *Do recovery-oriented messages improve self-efficacy and positive emotions amongst people with lived experience of psychosis? Experimental investigation.* Psychology and Psychotherapy: Theory, Research and Practice, 2022. **95**(4): p. 1003-1017.
20. Williams, A., et al., *Recovery after psychosis: qualitative study of service user experiences of lived experience videos on a recovery-oriented website.* JMIR Mental Health, 2018. **5**(2): p. e9934.
21. Gumz, A., et al., *Factors influencing the duration of untreated illness among patients with anorexia nervosa: A multicenter and multi-informant study.* International Journal of Eating Disorders, 2023.
22. Slade, M., et al., *Recorded mental health recovery narratives for people with mental health problems and informal carers: the NEON research programme including 3 RCTs.* Programme Grants for Applied Research, 2025. **13**(9): p. 1-54.
23. Slade, M., et al., *Effectiveness and cost-effectiveness of online recorded recovery narratives in improving quality of life for people with non-psychotic mental health problems: a pragmatic randomized controlled trial.* World Psychiatry, 2024. **23**(1): p. 101-112.
24. Ali, Y., et al., *Perception and appropriation of a web-based recovery narratives intervention: qualitative interview study.* Frontiers in Digital Health, 2024. **6**: p. 1297935.
25. Shaw, L.K. and J. Homewood, *The Effect of Eating Disorder Memoirs in Individuals With Self-Identified Eating Pathologies.* J Nerv Ment Dis, 2015. **203**(8): p. 591-5.
26. Daugelat, M.-C., et al., *Improving motivation and treatment uptake behaviors of patients with eating disorders using patient narrative videos: study protocol of a pilot randomized controlled trial.* Journal of Eating Disorders, 2024. **12**(1): p. 1.
27. Hopewell, S., et al., *CONSORT 2025 statement: updated guideline for reporting randomised trials.* The Lancet, 2025. **405**(10489): p. 1633-1640.
28. World Medical Association, *World Medical Association Declaration of Helsinki: ethical principles for medical research involving human participants.* Jama, 2025. **333**(1): p. 71-74.
29. Daugelat, M.-C., et al., *Participatory development of evidence-based patient narrative videos for patients with eating disorders: a methodological approach and pilot data.* Journal of Eating Disorders, 2024. **12**(1): p. 188.

30. Fairburn, C.G. and S.J. Beglin, *The assessment of eating disorders: interview or self-report questionnaire?* International Journal for Eating Disorders, 1994. **16**: p. 363-370.
31. Hilbert, A., et al., *Eating disorder examination-questionnaire.* Diagnostica, 2007. **53**(3): p. 144-154.
32. Gräfe, K., et al., *Screening psychischer Störungen mit dem "Gesundheitsfragebogen für Patienten (PHQ-D)".* Diagnostica, 2004. **50**(4): p. 171-181.
33. Mander, J., et al., *Stages of change, treatment outcome and therapeutic alliance in adult inpatients with chronic anorexia nervosa.* BMC psychiatry, 2013. **13**(1): p. 111.
34. DiClemente, C.C., D. Schlundt, and L. Gemmell, *Readiness and stages of change in addiction treatment.* American journal on addictions, 2004. **13**(2): p. 103-119.
35. Urbaniak, G.C. and S. Plous. *Research Randomizer (Version 4.0)*. 2013; Available from: http://www.randomizer.org.
36. Blanca Mena, M.J., et al., *Non-normal data: Is ANOVA still a valid option?* Psicothema, 2017, vol. 29, num. 4, p. 552-557, 2017.
37. Schmider, E., et al., *Is it really robust?* Methodology, 2010.
38. Dunn, E.C., C. Neighbors, and M. Larimer, *Assessing readiness to change binge eating and compensatory behaviors.* Eating Behaviors, 2003. **4**(3): p. 305-314.
39. Rieger, E., S.W. Touyz, and P.J. Beumont, *The Anorexia Nervosa Stages of Change Questionnaire (ANSOCQ): information regarding its psychometric properties.* International Journal of Eating Disorders, 2002. **32**(1): p. 24-38.
40. Martinez, E., et al., *Assessing motivation to change in bulimia nervosa: the bulimia nervosa stages of change questionnaire.* European Eating Disorders Review: The Professional Journal of the Eating Disorders Association, 2007. **15**(1): p. 13-23.
41. Ng, F., et al., *How do recorded mental health recovery narratives create connection and improve hopefulness?* Journal of Mental Health, 2022. **31**(2): p. 273-280.
42. LaMarre, A. and C. Rice, *Recovering uncertainty: exploring eating disorder recovery in context.* Culture, Medicine, and Psychiatry, 2021. **45**(4): p. 706-726.
43. Lehe, M.S., et al., *Boys don't try? Gendered stigma specifically reduces help-seeking for disordered eating in men, but not women.* Journal of Eating Disorders, 2025. **13**(1): p. 1-15.

# 4. Discussion

This dissertation examined the factors contributing to treatment motivation and treatment uptake behaviours of patients with ED. This dissertation developed a series of evidence-based patient narrative videos for patients with ED and examined their use as a potential intervention to increase treatment motivation and treatment uptake behaviours of patients with ED. To do so, this dissertation consisted of three projects. Project 1 provided an overview of the barriers and facilitators affecting ED treatment uptake, including a systematic review synthesising the perspectives of patients, their caregivers, and healthcare professionals, as well as focus groups with patients affected by ED. Building on this knowledge, Project 2 described the collaborative methodology used to develop a series of (patient) narrative videos featuring the perspectives of a lived experience representative and a psychotherapist. This project also demonstrated the feasibility and acceptability of these (patient) narrative videos for participants without a (current) ED. Finally, Project 3 further built on these findings by designing and implementing a pilot RCT of the (patient) narrative videos among a clinical population of patients with ED. In combination, the results of these projects highlight the complexity of treatment motivation and the uptake of treatment services for patients with ED. The findings further suggest that patient narrative videos are feasible and acceptable among this patient population and may be useful as an adjunct to current early intervention treatment services.

## 4.1 Synthesis and interpretation of results

Only one third of persons affected by ED are receiving treatment (Ali et al., 2025), resulting in a significant treatment gap. Project 1 provides a comprehensive overview of the barriers and facilitators affecting the treatment uptake behaviours of patients with ED, including a synthesis of the perspectives of patients, caregivers, and healthcare professionals working with patients with ED. The results of the systematic review showed that patients themselves reported stigma, shame, and guilt as the most prominent barrier preventing their seeking

and engaging with treatment services. In particular, patients reported feeling personally responsible for their ED, as well as fears that others such as their healthcare providers would react with similar judgement and blame. As a result, patients reported they avoided disclosing their symptoms to others, preferring instead to try and manage the disorder on their own. These results were confirmed by participants of the focus groups, who reported that the impact of comorbid disorders as well as stigma, shame, and guilt most frequently prevented their uptake of treatment services. Meanwhile, a scoping review completed by Brelet et al. (2021) found that members of the general population reported feeling that patients with EDs were personally responsible for their disorder. In examining the different diagnoses, patients with AN were described as vain and as using their disorder to “get attention”, while patients with BN were perceived as self-destructive and patients with BED were seen as weak, lazy, and as lacking in self-discipline (Brelet et al., 2021). These stigmatising beliefs have also infiltrated the healthcare system, with some healthcare professionals describing patients with EDs as manipulative, deceitful, and non-compliant (Brelet et al., 2021; McNicholas et al., 2016). In addition to describing experiences of external stigmatisation (Maier et al., 2014), patients with EDs also report an array of self-stigmatising views including feelings that they alone are responsible for their symptoms and therefore are not “worthy” of support from others (Dayal et al., 2015; Fitzsimmons-Craft et al., 2020; Maier et al., 2014). These results show that interventions are needed to share the realities of living with an ED and to combat these preconceived views of patients with ED, in order to create an environment in which patients feel comfortable disclosing their symptoms without fear of judgement. Patient narratives could be one such solution, in which the stories of other patients could help normalise these experiences for patients currently affected by ED, as well as educating members of the general public and helping them to understand what it means to live with these disorders.

The results of the systematic review further showed that caregivers and healthcare professionals more frequently reported pragmatic barriers associated with the healthcare system. For caregivers, this included negative experiences with their loved ones’ treating physician, including misdiagnoses or outright

dismissal of ED symptoms which resulted in treatment delays and a lack of trust from caregivers regarding the capabilities of the physician. Healthcare providers further reported that a lack of knowledge, training, and resources was the biggest barrier to their treatment of ED. Patients experiencing symptoms of an ED will often consult a healthcare provider such as a general practitioner as their first step in seeking treatment. These initial experiences with the healthcare system are therefore vital for providing early interventions, or else encouraging patients to engage with specialised ED treatment services (Gulliver et al., 2010). Nevertheless, many healthcare providers report feeling unprepared to treat patients with ED, and are therefore reluctant to diagnose and treat these patients (Linville et al., 2010). Resources are urgently needed to ensure that all healthcare providers feel equipped to work with this patient group. Here too, patient narratives provide an opportunity for healthcare providers to learn about the experiences of patients with ED, in order to better support them throughout their treatment journey.

Regarding treatment facilitators, the systematic review showed that patients, caregivers, and healthcare professionals were unanimous in reporting positive social support as the most important treatment facilitator for patients with ED. These results were partially confirmed by participants of the focus groups, who reported negative social support as a significant barrier to their treatment journeys. Recent systematic reviews (Ramjan et al., 2024; Robinson et al., 2024) have demonstrated clear positive correlations between the social support experienced by patients with ED and their motivation to change. Nevertheless, many patients with ED report experiencing social withdrawal and isolation throughout their illness (Linville et al., 2012; Quiles Marcos & Terol Cantero, 2009), and this absence of positive social support may in fact hinder treatment uptake behaviours (Ali et al., 2017; Radunz et al., 2023). Social support is therefore an important catalyst for the treatment of ED, and strengthening sources of social support is vital.

Social support can be found in a variety of settings, including peer support and patient narratives. Project 2 provides one example of how patient narrative videos can be developed as an example of providing social support for patients with ED.

In a collaborative approach with a lived experience representative, a series of patient narrative videos were developed based on personal experiences and the findings from the systematic review and the focus groups completed in Project 1. A pre-pilot study assessing the feasibility and acceptability of the patient narrative videos for participants without a (current) ED showed that the patient narrative videos received positive ratings from participants. Videos featuring the former patient discussing her ED treatment journey were rated as significantly more authentic than the video featuring the former patient discussing her treatment for a somatic condition, as well as significantly more empathic, useful, and better overall than the (patient) narrative videos featuring the psychotherapist or the former patient discussing her treatment for a somatic condition. These findings show that despite containing the same information, not all patient narrative videos are rated equal, with videos featuring the experiences of a former patient with an receiving the best ratings from participants. Ali et al. (2024) found similar results in an examination of the patient narratives included in the NEON-O Trial, wherein participants reported that they were most likely to engage with patient narratives which were both authentic and relevant to their own experiences. While participants in Project 2 did not have a (current) ED themselves, they were asked to imagine the usefulness and relevance of the patient narrative videos for patients with ED. These results confirm the usability of the created patient narrative videos for use in further studies.

Project 3 therefore designed and implemented a pilot RCT using the patient narrative videos created in Project 2 in order to further ascertain the feasibility and acceptability of patient narrative videos for patients with ED. All patients reported a significant increase in treatment motivation over time, with no differences being found between patients who watched a (patient) narrative video and those who watched no video. Meanwhile, significantly more patients who watched a (patient) narrative video reported engaging in treatment uptake behaviours three months after watching the video, than patients who watched no video. This included engagement with treatment services in general, as well as engagement with psychotherapeutic services. Watching a (patient) narrative video was further associated with significantly higher treatment intensity, i.e., the

number of treatment services a patient engaged with, in comparison to watching no video. Interestingly, no differences were found between patients who watched one of the three (patient) narrative videos. While the (patient) narrative videos differed in regards to perspective and/or diagnosis, each video was based on the same content and featured discussions of ambivalence toward treatment, fear of stigmatisation, and the changing roles of social support throughout treatment. Few studies have examined the use of patient narratives in mental health care, meaning a direct comparison of these results is difficult. Some similarities can be seen, however, in the findings of Dawson et al. (2018), wherein patients with ED reported increased thoughts about their own recovery after reading a series of patient narratives. Similarly, participants with non-psychosis mental disorders who engaged with at least one patient narrative as part of the NEON-O Trial (Slade et al., 2024) reported significantly increased quality of life, in comparison to standardised care. Participants of this trial further commended the large variety of patient narratives made available to them, featuring different perspectives, experiences, and even diagnoses (Ali et al., 2024). It therefore appears that engaging with patient narratives can have a variety of positive effects for patients with mental disorders, including ED. In particular, the results of Project 3 suggest that patient narrative videos which include themes of ambivalence and how this may affect treatment motivation may be useful adjuncts to early interventions working to increase treatment uptake for patients with ED.

Project 3 further found that all patients with ED reported a significant decrease in ED psychopathology over the three months follow-up, regardless of whether they watched a (patient) narrative video or not. It should be noted however, that 75% of patients reported they were engaging with treatment services at three months follow-up, which could explain the reduction in ED psychopathology among these patients. Previous studies similarly reported no effects of reading patient narratives on ED psychopathology for patients with ED (Dawson et al., 2018). Patient narratives may therefore be a useful adjunct to intervention services; however, these results show that they are not a replacement for psychotherapeutic treatment services. Significant interaction effects were also found between patients' group allocation and time progression over three months

in regards to their self-reported hope and confidence toward recovery. In particular, follow-up analyses showed that patients who watched the patient narrative video featuring the former patient speaking about her treatment journey for a somatic condition reported significantly higher hope toward their own recovery immediately after watching the video, in comparison to baseline. No further differences were found between all combinations of group and time. These results only partially reflect those of previous studies completed with patients with ED (Dawson et al., 2018) and other mental disorders (Ng et al., 2022) wherein patients reported increased feelings of hope and inspiration following their engagement with patient narratives. It should be noted however, that the effect sizes found in Project 3 were very small, thereby suggesting an insufficient sample size for these analyses.

Patients in Project 3 provided positive ratings for all three (patient) narrative videos. In regards to authenticity, patients rated the patient narrative video in which the former patient speaks about her treatment journey for an ED as significantly more authentic than the patient narrative video featuring the former patient speaking about her treatment journey for a somatic condition. It should be noted, that although the content of the patient narrative video regarding treatment for a somatic condition was based on real-world experiences, these were not the personal experiences of the lived experience expert. A previous examination of patients' experiences with patient narratives by Ali et al. (2024) found that patients perceived videos as authentic when these recognised the difficulties of mental health disorders and described realistic experiences similar to their own. Project 3 was completed with patients with ED, and although some of these patients may have had prior experiences with the somatic condition discussed in the patient narrative video, it is unlikely that this applied to all patients. It is therefore understandable that the patient narrative video featuring a somatic condition was rated as least authentic by these patients. Patients further rated the (patient) narrative videos in which the former patient or the psychotherapist speak about treatment journeys for ED as significantly more useful than the patient narrative video featuring the former patient speaking about her treatment journey for a somatic condition. These results are also not surprising, as patients were asked

to rate the usefulness of the (patient) narrative videos for other patients with ED. Understandably, patients therefore questioned the relevance of the patient narrative video featuring treatment experiences for a somatic condition for this population. The results of Project 3 show that the (patient) narrative videos, and in particular the patient narrative video featuring a former patient discussing her ED treatment journey, were well liked by patients with ED. These results therefore confirm the acceptability of patient narratives for patients with mental health disorders, including ED, particularly when these include themes of ambivalence and how this may affect treatment motivation.

### 4.2 Strengths and Limitations

This dissertation is the first to examine the use of patient narrative videos specifically for patients with ED, and in doing so it contains a number of strengths and limitations.

A strength of this dissertation is the inclusion of PPI throughout. The lived experience representative recruited during Project 2 became an integral part in the co-creation, production, and piloting of the patient narrative videos, and was further included as a co-author for the publications of Projects 2 and 3. The inclusion of PPI in the research process significantly increases the quality and relevance of clinical research projects, and is increasingly recommended and required by government agencies and funding institutions (Price et al., 2022; Sangill et al., 2019).

A further strength is the combination of the personal experiences of a lived experience representative with the results of one of the largest and most comprehensive assessments of the barriers and facilitators that affect the uptake of ED treatment services (Project 1) to create a series of evidence-based patient narrative videos. As a result, these videos are authentic, motivational, and free of any information that may be triggering to persons currently affected by an ED. In addition, the videos refrain from reporting any information pertaining to one specific diagnosis of ED and instead focus on the aspects of ambivalence and

uncertainty which are experienced by most patients with an ED, thereby allowing these videos to be relevant to a wider audience. To aid future researchers to replicate these findings and to also work on patient narratives in mental health care, Project 2 provides a comprehensive overview of the exact processes used to create these patient narrative videos.

Several limitations should also be noted regarding the recruitment of participants and patients in Projects 2 and 3. First, only female participants and patients were recruited. As both protagonists of the patient narrative videos were young women, the decision was made to only include female participants and patients who may more easily identify with the perspectives and experiences discussed in the videos. While ED can affect persons of any age and gender, studies have historically centred around the experiences of women and girls. Further patient narrative videos are therefore needed which feature the perspectives and experiences of male, non-binary, and transgender patients with ED, in order to also support these patients.

A certain selection bias was also present in Project 3, as only patients who had attended an initial appointment at the University Hospital Tübingen were invited to participate. Patients were not provided with ongoing therapeutic services at this appointment, but rather received a diagnostic assessment and recommendations for treatment. While the patient narrative videos were designed with this particular group of patients in mind, further patient narrative videos and accompanying clinical studies are needed to assess the effects of patient narrative videos for patients who have not yet had any type of engagement with treatment services.

### 4.3 Practical Implications

The results of this dissertation highlight the importance of stigma, shame, and guilt as a barrier to treatment uptake for patients with ED. Meanwhile, the absence of social support further prevents treatment seeking, while positive social support is reported by patients, caregivers, and healthcare professionals

as most strongly facilitating treatment uptake. A combination of stigma reduction and positive social support interventions is therefore needed to reduce the current treatment gap. One example of such an intervention may be the targeted use of patient narratives. The results of this dissertation show that the use of evidence-based patient narrative videos is both feasible and acceptable for patients with ED. Patient narratives were further associated with positive effects, including an increase in treatment uptake behaviours. In particular videos featuring the perspective of a former patient were rated as authentic, empathic, and useful by patients with ED. Patient narrative videos should therefore be included as an adjunct to current early intervention practices. In addition, further patient narrative videos should be developed featuring a variety of perspectives from different ages, genders, and ED experiences, so as to be inclusive to as many patients as possible.

### 4.4 Conclusion

This dissertation contributes to the understanding of treatment motivation and treatment uptake behaviours of patients with ED, as well as the potential role of patient narrative videos in closing the current treatment gap of this patient group.

Project 1 provides an understanding of the barriers and facilitators affecting treatment uptake for patients with ED. The results of this project highlight the influences of stigma, shame, and guilt, as well as social support on patients' decisions to seek treatment. Patient narratives provide insights into the real-life experiences of patients with ED, and are therefore proposed in this dissertation as a potential adjunct to early intervention services in order to encourage treatment uptake behaviours for patients currently affected by ED.

Project 2 therefore describes the process used to develop a series of patient narrative videos in collaboration with a lived experience expert. A pre-pilot trial of these patient narrative videos with a sample of participants without a (current) ED showed that all of the videos received good ratings overall, with participants rating

the videos featuring a former patient discussing her treatment for an ED as most authentic, empathic, and useful.

Finally, Project 3 describes a pilot RCT completed with patients with ED in order to assess the feasibility and acceptability of the patient narrative videos created in Project 2. Patients who watched any of the patient narrative videos reported significantly more treatment uptake behaviours at three months follow-up, in comparison to patients who watched no video. These results suggest that patient narrative videos normalising themes of ambivalence throughout recovery can be particularly beneficial in supporting patients with ED who are commencing their treatment journey. It should be noted though that the patient narrative videos featuring a former patient discussing her treatment of an ED were rated as more authentic, and the (patient) narrative videos featuring a former patient or a psychotherapist discussing ED treatment were rated as more useful than the patient narrative video featuring a former patient discussing her treatment of a somatic condition.

Despite the popularity of patient narrative videos on social media platforms, the use of patient narratives in the treatment of mental disorders is limited. This dissertation is, to the best of our knowledge, the first to assess the usefulness of patient narrative videos for a clinical population of patients with ED. The results of this dissertation therefore contribute significantly to the understanding of the potential disseminations of patient narrative videos in early intervention practices in order to reduce the current treatment gap for patients with ED.

# 5. Summary

A significant treatment gap exists between the number of patients affected by eating disorders (ED) and those who are receiving professional treatment. This dissertation aims to understand the factors contributing to the treatment motivation and treatment uptake behaviours of patients with ED. This dissertation further aims to use these findings in order to develop a series of evidence-based patient narrative videos as a potential low-threshold intervention to increase treatment motivation and treatment uptake behaviours for patients with ED. A total of three projects were completed to address these aims.

Project 1 aims to determine the barriers and facilitators affecting treatment uptake for patients with ED. Results from a systematic review show that patients with ED most frequently report stigma, shame, and guilt as barriers to treatment, while caregivers and healthcare professionals more often report barriers within the healthcare system. Meanwhile, patients, caregivers, and healthcare professionals unanimously report positive social support as the most important treatment facilitator for patients with ED. These findings were confirmed by the results of a series of focus groups completed with patients affected by ED.

Project 2 describes the process of developing a series of six evidence-based patient narrative videos for patients with ED. A collaborative approach with a lived experience expert combined personal experiences with the results of the systematic review and focus groups completed in Project 1. These videos feature the perspectives of a former patient discussing her treatment of an ED, a psychotherapist discussing the treatment of her patients with ED, and a former patient discussing her treatment of a somatic condition (i.e., torn knee ligament). Project 2 further assesses the usability of the (patient) narrative videos in a pilot study with participants without a (current) ED. The results of this study show that participants rated the patient narrative videos featuring a former patient discussing her treatment of an ED as significantly more authentic than the patient narrative videos featuring a former patient discussing her treatment of a somatic condition, and as significantly more empathic, useful, and better overall than the

(patient) narrative videos featuring a psychotherapist or discussing treatment of a somatic condition.

Project 3 reports the development and implementation of a pilot randomised controlled trial (RCT) assessing the feasibility and acceptability of three of the previously developed (patient) narrative videos in a clinical population of patients with ED. Patients in this study were randomised to one of four groups, three of which watched one of the videos while the fourth group watched no video. Significantly more patients who watched any of the (patient) narrative videos reported treatment uptake behaviours at three months follow-up, in comparison to patients who watched no video. All patients further reported a significant increase in treatment motivation and a significant decrease in ED psychopathology over time, regardless of whether patients watched a video or not. Patients provided positive ratings for all three (patient) narrative videos. Regarding authenticity, patients rated the patient narrative video in which a former patient discusses her experiences of treatment for an ED as significantly more authentic than the patient narrative video discussing treatment for a somatic condition. Meanwhile, patients rated the usefulness of (patient) narrative videos featuring a former patient or a psychotherapist discussing ED treatment as significantly higher than the patient narrative video discussing treatment for a somatic condition.

To the best of our knowledge, this dissertation is the first to investigate the targeted use of patient narrative videos for patients with ED. Patients who watched one of the patient narrative videos reported significantly more treatment uptake behaviours in comparison to those patients who did not watch a video. Further, patient narrative videos were deemed acceptable and feasible by patients with ED. These findings support the use of evidence-based patient narrative videos as an adjunct to early intervention services working to close the current treatment gap for patients with ED.

# 6. German Summary

Derzeit besteht eine erhebliche Behandlungslücke zwischen der Zahl derjenigen Menschen mit Essstörungen (ES), die eine Behandlung benötigen und derjenigen, die sie tatsächlich erhalten. Die vorliegende Dissertation hat das Ziel, die Faktoren zu verstehen, die Patient:innen mit ES dazu motivieren, eine Behandlung in Betracht zu ziehen bzw. diese schließlich in Anspruch zu nehmen. Diese Erkenntnisse sollen genutzt werden, um evidenzbasierte Patient Narrative Videos zu entwickeln, die als potenziell niederschwellige Interventionsmöglichkeit die Behandlungsmotivation und die Inanspruchnahme von Behandlungsangeboten von Patient:innen mit ES steigern sollen. Im Rahmen dieser Dissertation wurden drei Projekte durchgeführt.

Projekt 1 zielt darauf ab, die hemmenden und förderlichen Faktoren zu ermitteln, welche die Inanspruchnahme von Behandlungsangeboten beeinflussen. Die Ergebnisse einer systematischen Literaturarbeit zeigen, dass Patient:innen mit ES häufig Stigma, Scham und Schuldgefühle als Hindernisse für die Aufnahme einer Behandlung nennen, während Angehörige und Behandler:innen häufig Hürden im Gesundheitssystem aufführen. Alle drei Gruppen berichten, dass positive soziale Unterstützung der wichtigste Förderfaktor für die Behandlung einer ES ist. Die Ergebnisse einer Reihe von Fokusgruppen mit Patient:innen mit ES bestätigen diese Erkenntnisse.

Projekt 2 beschreibt die Entwicklung von sechs evidenzbasierten Patient Narrative Videos für Patient:innen mit ES. Diese wurden auf der Grundlage der systematischen Literaturarbeit und den Fokusgruppen in Zusammenarbeit mit einer Erfahrungsexpertin erstellt. In den Videos sprechen eine ehemalige Patientin über ihre Behandlung einer ES, eine Psychotherapeutin über die Behandlungserfahrungen ihrer Patient:innen mit ES, und eine ehemalige Patientin über ihre Behandlung einer somatischen Erkrankung (d.h. Kreuzbandriss). Projekt 2 überprüft zudem die Verwendbarkeit dieser Videos in einer gesunden Stichprobe von Teilnehmerinnen ohne (aktuelle) ES. Die Videos in denen die ehemalige Patientin über ihre ES berichtet wurden als deutlich authentischer bewertet als die Videos über eine somatische Erkrankung. Zudem

wurden die Videos in denen die ehemalige Patientin über ihre ES berichtet als deutlich empathischer, nützlicher und insgesamt besser bewertet als die Videos, in denen die Psychotherapeutin über ihre Patient:innen mit ES oder die ehemalige Patientin über eine somatische Erkrankung berichten.

Projekt 3 dokumentiert die Entwicklung und Durchführung einer randomisierten kontrollierten (RCT) Pilotstudie, in der die Akzeptanz von drei der zuvor entwickelten Patient Narrative Videos in einer klinischen Stichprobe von Patientinnen mit ES überprüft wurde. Patientinnen dieser Studie wurden zufällig einer von vier Gruppen zugeordnet, von denen je drei eines der Videos sahen, während die vierte Gruppe kein Video sah. Die Ergebnisse dieser Studie zeigen, dass deutlich mehr Patientinnen, die eines der Videos angesehen hatten, nach drei Monaten in Behandlung waren, als Patientinnen, die kein Video angesehen hatten. Gleichzeitig berichteten alle Patientinnen von einer deutlichen Zunahme der Behandlungsmotivation und einer deutlichen Abnahme der ES-Psychopathologie im Laufe der Zeit, unabhängig davon, ob sie eines der Videos angesehen hatten. Patientinnen bewerteten alle drei Videos als gut. Bezüglich der Authentizität der Videos, bewerteten Patientinnen das Video, in dem die ehemalige Patientin über ihre ES berichtet, als deutlich authentischer als das Video, in dem sie über eine somatische Erkrankung berichtet. Zudem bewerteten Patientinnen die Videos, in denen die ehemalige Patientin oder die Psychotherapeutin über ES berichten, als deutlich nützlicher als das Video, in dem die ehemalige Patientin über eine somatische Erkrankung spricht.

Diese Dissertation hat als eines der ersten Projekte gezielt den Einsatz von Patient Narrative Videos für Patientinnen mit ES untersucht. Die Dissertation liefert damit wertvolle Erkenntnisse über die Faktoren, welche die Behandlungsmotivation und das Behandlungsverhalten dieser Patientengruppe beeinflussen. Deutlich mehr Patientinnen, die eines der Videos gesehen hatten, berichteten die Inanspruchnahme einer Behandlung im Vergleich zu Patientinnen die kein Video sahen. Zudem wurden die Durchführbarkeit und Machbarkeit des Einsatzes von Patient Narrative Videos von Patientinnen mit ES bestätigt. Die Ergebnisse dieser Dissertation zeigen das Potenzial evidenzbasierter Patient Narrative Videos als Ergänzung zu derzeitigen Frühinterventionsansätzen.

# 7. Bibliography

Albano, G., Cardi, V., Kivlighan, D. M., Jr., Ambwani, S., Treasure, J., & Lo Coco, G. (2021). The relationship between working alliance with peer mentors and eating psychopathology in a digital 6-week guided self-help intervention for anorexia nervosa. *Int J Eat Disord*, *54*(8), 1519–1526. https://doi.org/10.1002/eat.23559

Albano, G., Teti, A., Gullo, S., & Lo Coco, G. (2025). Navigating an instagram community for eating disorder recovery: a qualitative study of users' motivation and confidence to change. *BMC Psychiatry*, *25*(1150). https://doi.org/https://doi.org/10.1186/s12888-025-07591-9

Ali, K., Farrer, L., Fassnacht, D. B., Gulliver, A., Bauer, S., & Griffiths, K. M. (2017). Perceived barriers and facilitators towards help-seeking for eating disorders: A systematic review. *Int J Eat Disord*, *50*(1), 9–21. https://doi.org/10.1002/eat.22598

Ali, K., Radunz, M., McLean, S. A., O'Shea, A., Mavrangelos, T., Fassnacht, D. B., & Hart, L. (2025). The Unmet Treatment Need for Eating Disorders: What Has Changed in More Than 10 Years? An Updated Systematic Review and Meta-Analysis. *International Journal of Eating Disorders*, *58*(1), 46–65. https://doi.org/ https://doi.org/10.1002/eat.24306

Ali, Y., Rennick-Egglestone, S., Llewellyn-Beardsley, J., Ng, F., Yeo, C., Franklin, D., Perez Vallejos, E., Ben-Zeev, D., Kotera, Y., & Slade, M. (2024). Perception and appropriation of a web-based recovery narratives intervention: qualitative interview study. *Frontiers in Digital Health*, *6*, 1297935. https://doi.org/https://doi.org/10.3389/fdgth.2024.1297935

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)* (5 ed.). American Psychiatric Pub. .

Andres-Pepina, S., Plana, M. T., Flamarique, I., Romero, S., Borras, R., Julia, L., Garriz, M., & Castro-Fornieles, J. (2020). Long-term outcome and psychiatric comorbidity of adolescent-onset anorexia nervosa. *Clin Child Psychol Psychiatry*, *25*(1), 33–44. https://doi.org/10.1177/1359104519827629

Austin, A., Flynn, M., Richards, K., Hodsoll, J., Duarte, T. A., Robinson, P., Kelly, J., & Schmidt, U. (2021). Duration of untreated eating disorder and relationship to outcomes: A systematic review of the literature. *Eur Eat Disord Rev*, *29*(3), 329–345. https://doi.org/10.1002/erv.2745

Beveridge, J., Phillipou, A., Jenkins, Z., Newton, R., Brennan, L., Hanly, F., Torrens-Witherow, B., Warren, N., Edwards, K., & Castle, D. (2019). Peer mentoring for eating disorders: results from the evaluation of a pilot program. *J Eat Disord*, *7*, 13. https://doi.org/10.1186/s40337-019-0245-3

Bientzle, M., Eggeling, M., & Kimmerle, J. (2024). Good reasons for bad behavior: a randomized controlled experiment on the impact of narrative reading and writing on empathic concern, perspective-taking, and

attitude. *Frontiers in Public Health*, *12*. https://doi.org/https://doi.org/10.3389/fpubh.2024.1343225

Brelet, L., Flaudias, V., Désert, M., Guillaume, S., Llorca, P.-M., & Boirie, Y. (2021). Stigmatization toward people with anorexia nervosa, bulimia nervosa, and binge eating disorder: a scoping review. *Nutrients*, *13*(8), 2834. https://doi.org/https://doi.org/10.3390/nu13082834

Cavazos-Rehg, P., Min, C., Fitzsimmons-Craft, E. E., Savoy, B., Kaiser, N., Riordan, R., Krauss, M., Costello, S., & Wilfley, D. (2020). Parental consent: A potential barrier for underage teens' participation in an mHealth mental health intervention. *Internet Interv*, *21*, 100328. https://doi.org/10.1016/j.invent.2020.100328

Dawson, L., Mullan, B., Touyz, S., & Rhodes, P. (2018). Are recovery stories helpful for women with eating disorders? A pilot study and commentary on future research. *J Eat Disord*, *6*, 21. https://doi.org/10.1186/s40337-018-0206-2

Dayal, H., Weaver, K., & Domene, J. F. (2015). From shame to shame resilience: narratives of counselor trainees with eating issues. *Qual Health Res*, *25*(2), 153–167. https://doi.org/10.1177/1049732314551988

Dray, J., & Wade, T. D. (2012). Is the transtheoretical model and motivational interviewing approach applicable to the treatment of eating disorders? A review. *Clin Psychol Rev*, *32*(6), 558–565. https://doi.org/10.1016/j.cpr.2012.06.005

Dudley, L., Gamble, C., Preston, J., Buck, D., Group, E. P. A., Hanley, B., Williamson, P., & Young, B. (2015). What Difference Does Patient and Public Involvement Make and What Are Its Pathways to Impact? Qualitative Study of Patients and Researchers from a Cohort of Randomised Clinical Trials. *PLoS One*, *10*(6), e0128817. https://doi.org/10.1371/journal.pone.0128817

Fitzsimmons-Craft, E. E., Eichen, D. M., Monterubio, G. E., Firebaugh, M.-L., Goel, N. J., Taylor, C. B., & Wilfley, D. E. (2020). Longer-term follow-up of college students screening positive for anorexia nervosa: Psychopathology, help seeking, and barriers to treatment. *Eating Disorders: The Journal of Treatment & Prevention*, *28*(5-6), 549–565. https://doi.org/10.1080/10640266.2019.1610628

Fogarty, S., & Ramjan, L. M. (2016). Factors impacting treatment and recovery in Anorexia Nervosa: qualitative findings from an online questionnaire. *J Eat Disord*, *4*, 18. https://doi.org/10.1186/s40337-016-0107-1

Geller, J., Drab-Hudson, D. L., Whisenhunt, B. L., & Srikameswaran, S. (2004). Readiness to change dietary restriction predicts outcomes in the eating disorders. *Eating Disorders*, *12*(3), 209–224. https://doi.org/https://doi.org/10.1080/10640260490490438

Gibson, D., Workman, C., & Mehler, P. S. (2019). Medical complications of anorexia nervosa and bulimia nervosa. *Psychiatric Clinics*, *42*(2), 263–274. https://doi.org/https://doi.org/10.1016/j.psc.2019.01.009

Giel, K., Bremer, J., Rieß-Stumm, S., Gregg, B., Fritz, A., Klemm, I., Daugelat, M.-C., Schag, K., & Group., S. S. (2023). Enriching a randomized controlled treatment trial for anorexia nervosa by lived experience – Chances and effects of a lived experience council in the SUSTAIN study. *International Journal of Eating Disorders*, *57*(6), 1300–1310. https://doi.org/https://doi.org/10.1002/eat.24050

Giel, K. E., Bulik, C. M., Fernandez-Aranda, F., Hay, P., Keski-Rahkonen, A., Schag, K., Schmidt, U., & Zipfel, S. (2022). Binge eating disorder. *Nat Rev Dis Primers*, *8*(1), 16. https://doi.org/10.1038/s41572-022-00344-y

Gradl-Dietsch, G., Föcker, M., & Hebebrand, J. (2024). Eating Disorders in the ICD-11 and DSM-5. In S. Herpertz, M. de Zwaan, & S. Zipfel (Eds.), *Handbook of eating disorders and obesity* (3rd ed., pp. 15–24). Springer.

Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry*, *10*(113), 1–9. https://doi.org/https://doi.org/10.1186/1471-244X-10-113

Gumz, A., Reuter, L., Löwe, B., Voderholzer, U., Schwennen, B., Fehrs, H., Wünsch-Leiteritz, W., Brunner, R., Kästner, D., & Zapf, A. (2023). Factors influencing the duration of untreated illness among patients with anorexia nervosa: A multicenter and multi-informant study. *International Journal of Eating Disorders*, *56*(12), 2315–2327. https://doi.org/https://doi.org/10.1002/eat.24069

Hanly, F., Torrens-Witherow, B., Warren, N., Castle, D., Phillipou, A., Beveridge, J., Jenkins, Z., Newton, R., & Brennan, L. (2020). Peer mentoring for individuals with an eating disorder: a qualitative evaluation of a pilot program. *Journal of Eating Disorders*, *8*(29). https://doi.org/https://doi.org/10.1186/s40337-020-00301-8

Hart, L. M., Granillo, M. T., Jorm, A. F., & Paxton, S. J. (2011). Unmet need for treatment in the eating disorders: a systematic review of eating disorder specific treatment seeking among community cases. *Clin Psychol Rev*, *31*(5), 727–735. https://doi.org/10.1016/j.cpr.2011.03.004

Hasler, G., Delsignore, A., Milos, G., Buddeberg, C., & Schnyder, U. (2004). Application of Prochaska's transtheoretical model of change to patients with eating disorders. *Journal of Psychosomatic Research*, *57*(1), 67–72. https://doi.org/10.1016/s0022-3999(03)00562-2

Hay, P., Aouad, P., Le, A., Marks, P., Maloney, D., Touyz, S., & Maguire, S. (2023). Epidemiology of eating disorders: population, prevalence, disease burden and quality of life informing public policy in Australia—a rapid review. *Journal of Eating Disorders*, *11*(23). https://doi.org/https://doi.org/10.1186/s40337-023-00738-7

Herpertz, S., Fichter, M., Herpertz-Dahlmann, B., Hilbert, A., Tuschen-Caffier, B., Vocks, S., & Zeeck, A. (2019). *S3-Leitlinie Diagnostik und Behandlung der Essstörungen* (2. Auflage ed.). Springer.

Hilbert, A., Herpertz, S., Kersting, A., Pietrowsky, R., Tuschen-Caffier, B., & Vocks, S. (2019). Binge-Eating-Störung. In *S3-Leitlinie Diagnostik und Behandlung der Essstörungen* (2. Auflage ed., pp. 275–302). Springer.

Himmerich, H., Keeler, J. L., Davies, H. L., Tessema, S. A., & Treasure, J. (2024). The evolving profile of eating disorders and their treatment in a changing and globalised world. *The Lancet*, *403*(10445), 2671–2675. https://doi.org/https://doi.org/10.1016/S0140-6736(24)00874-2

Kessler, R. C., Berglund, P. A., Chiu, W. T., Deitz, A. C., Hudson, J. I., Shahly, V., Aguilar-Gaxiola, S., Alonso, J., Angermeyer, M. C., Benjet, C., Bruffaerts, R., de Girolamo, G., de Graaf, R., Maria Haro, J., Kovess-Masfety, V., O'Neill, S., Posada-Villa, J., Sasu, C., Scott, K.,…Xavier, M. (2013). The prevalence and correlates of binge eating disorder in the World Health Organization World Mental Health Surveys. *Biol Psychiatry*, *73*(9), 904–914. https://doi.org/10.1016/j.biopsych.2012.11.020

Krebs, P., Norcross, J. C., Nicholson, J. M., & Prochaska, J. O. (2018). Stages of change and psychotherapy outcomes: A review and meta-analysis. *Journal of Clinical Psychology*, *74*(11), 1964–1979. https://doi.org/https://doi.org/10.1002/jclp.22683

Lai, E. T. H., Lai, B., Wong, C. S. M., Wong, L. Y., Cheng, K. S., Cheng, P. W. C., Heidi Ka-Ying, L., Tse, G., Chan, W. C., & Chang, W. C. (2025). Systematic Review and Meta-Analysis of Mortality in Patients With Anorexia Nervosa. *International Journal of Eating Disorders*. https://doi.org/https://doi.org/10.1111/eat.70002

LaMarre, A., Wozney, L., Obeid, N., Kumar, S., Jones, S., Dimitropoulos, G., & Couturier, J. (2025). Peer mentors' experiences of delivering peer support for individuals with eating disorders: giving back and supporting processes of change. *Eating Disorders*, *33*(6), 750–764. https://doi.org/https://doi.org/10.1080/10640266.2024.2420419

Liamputtong, P., & Ezzy, D. (2005). *Qualitative Research Methods*. Oxford University Press.

Linardon, J., Messer, M., Lee, S., & Rosato, J. (2021). Perspectives of e-health interventions for treating and preventing eating disorders: descriptive study of perceived advantages and barriers, help-seeking intentions, and preferred functionality. *Eat Weight Disord*, *26*(4), 1097–1109. https://doi.org/10.1007/s40519-020-01005-3

Linardon, J., Rosato, J., & Messer, M. (2020). Break Binge Eating: Reach, engagement, and user profile of an Internet-based psychoeducational and self-help platform for eating disorders. *Int J Eat Disord*, *53*(10), 1719–1728. https://doi.org/10.1002/eat.23356

Linardon, J., Shatte, A., Tepper, H., & Fuller-Tyszkiewicz, M. (2020). A survey study of attitudes toward, and preferences for, e-therapy interventions for eating disorder psychopathology. *Int J Eat Disord*, *53*(6), 907–916. https://doi.org/10.1002/eat.23268

Linville, D., Benton, A., O'Neil, M., & Sturm, K. (2010). Medical providers' screening, training and intervention practices for eating disorders. *Eating Disorders*, *18*(2), 110–131. https://doi.org/https://doi.org/10.1080/10640260903585532

Linville, D., Brown, T., Sturm, K., & McDougal, T. (2012). Eating disorders and social support: perspectives of recovered individuals. *Eat Disord*, *20*(3), 216–231. https://doi.org/10.1080/10640266.2012.668480

Llewellyn-Beardsley, J., Rennick-Egglestone, S., Callard, F., Crawford, P., Farkas, M., Hui, A., Manley, D., McGranahan, R., Pollock, K., & Ramsay, A. (2019). Characteristics of mental health recovery narratives: Systematic review and narrative synthesis. *PLoS One*, *14*(3), e0214678. https://doi.org/https://doi.org/10.1371/journal.pone.0214678

Lock, A., Epston, D., Maisel, R., & Faria, N. d. (2005). Resisting anorexia/bulimia: Foucauldian perspectives in narrative therapy. *British Journal of Guidance & Counselling*, *33*(3), 315–332. https://doi.org/10.1080/03069880500179459

Maier, A., Ernst, J. P., Müller, S., Gross, D., Zepf, F. D., Herpertz-Dahlmann, B., & Hagenah, U. (2014). Self-perceived stigmatization in female patients with anorexia nervosa--results from an explorative retrospective pilot study of adolescents. *Psychopathology*, *47*(2), 127–132. https://doi.org/10.1159/000350505

McCarron, T. L., Clement, F., Rasiah, J., Moran, C., Moffat, K., Gonzalez, A., Wasylak, T., & Santana, M. (2021). Patients as partners in health research: A scoping review. *Health Expect*, *24*(4), 1378–1390. https://doi.org/10.1111/hex.13272

McLeod, B., Meyer, C., Meyer, D., Nunan, C., Murray, G., Farhall, J., & Thomas, N. (2022). Do recovery-oriented messages improve self-efficacy and positive emotions amongst people with lived experience of psychosis? Experimental investigation. *Psychology and Psychotherapy: Theory, Research and Practice*, *95*(4), 1003–1017. https://doi.org/https://doi.org/10.1111/papt.12415

McNicholas, F., O'Connor, C., O'hara, L., & McNamara, N. (2016). Stigma and treatment of eating disorders in Ireland: healthcare professionals' knowledge and attitudes. *Irish Journal of Psychological Medicine*, *33*(1), 21–31. https://doi.org/doi:10.1017/ipm.2015.24

Moessner, M., Minarik, C., Özer, F., & Bauer, S. (2016). Can an internet-based program for the prevention and early intervention in eating disorders facilitate access to conventional professional healthcare? *J Ment Health*, *25*(5), 441–447. https://doi.org/10.3109/09638237.2016.1139064

Monteleone, A. M., Pellegrino, F., Croatto, G., Carfagno, M., Hilbert, A., Treasure, J., Wade, T., Bulik, C., Zipfel, S., & Hay, P. (2022). Treatment of eating disorders: A systematic meta-review of meta-analyses and network meta-analyses. *Neuroscience & Biobehavioral Reviews*, *142*, 104857. https://doi.org/https://doi.org/10.1016/j.neubiorev.2022.104857

Musić, S., Elwyn, R., Fountas, G., Gnatt, I., Jenkins, Z. M., Malcolm, A., Miles, S., Neill, E., Simpson, T., & Yolland, C. O. (2022). Valuing the voice of lived experience of eating disorders in the research process: Benefits and considerations. *Australian & New Zealand Journal of Psychiatry*, *56*(3), 216–218. https://doi.org/https://doi.org/10.1177/0004867421998794

Ng, F., Newby, C., Robinson, C., Llewellyn-Beardsley, J., Yeo, C., Roe, J., Rennick-Egglestone, S., Smith, R., Booth, S., & Bailey, S. (2022). How do recorded mental health recovery narratives create connection and improve hopefulness? *Journal of Mental Health*, *31*(2), 273–280. https://doi.org/https://doi.org/10.1080/09638237.2021.2022627

Nikolova, I., & LaMarre, A. (2023). “If I Unfollow Them, It's Not a Dig at Them”: A Narrative Analysis of Instagram Use in Eating Disorder Recovery. *Psychology of Women Quarterly*, *47*(3), 387–401. https://doi.org/https://doi.org/10.1177/03616843231166378

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S.,…Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *PLoS Med*, *18*(3).

Peebles, I., Brown, B., Juster, E., & Duffy, F. (2022). Thematic analysis of mechanisms underpinning email peer support for young people with eating disorders. *The Journal of Mental Health Training, Education and Practice*, *17*(1), 36–47. https://doi.org/10.1108/jmhtep-08-2020-0056

Price, A., Clarke, M., Staniszewska, S., Chu, L., Tembo, D., Kirkpatrick, M., & Nelken, Y. (2022). Patient and Public Involvement in research: A journey to co-production. *Patient Education and Counseling*, *105*(4), 1041–1047. https://doi.org/https://doi.org/10.1016/j.pec.2021.07.021

Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research & Practice*, *19*(3), 276–288. https://doi.org/https://doi.org/10.1037/h0088437

Prochaska, J. O., & Velicer, W. F. (1997). The transtheoretical model of health behavior change. *American Journal of Health Promotion*, *12*(1), 38–48. https://doi.org/https://doi.org/10.4278/0890-1171-12.1.38

Qian, J., Wu, Y., Liu, F., Zhu, Y., Jin, H., Zhang, H., Wan, Y., Li, C., & Yu, D. (2022). An update on the prevalence of eating disorders in the general population: a systematic review and meta-analysis. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*, *27*, 415–428. https://doi.org/https://doi.org/10.1007/s40519-021-01162-z

Quiles Marcos, Y., & Terol Cantero, M. C. (2009). Assesment of social support dimensions in patients with eating disorders. *Span J Psychol*, *12*(1), 226–235. https://doi.org/10.1017/s1138741600001633

Radunz, M., Ali, K., & Wade, T. D. (2023). Pathways to improve early intervention for eating disorders: Findings from a systematic review and meta-analysis. *International Journal of Eating Disorders*, *56*(2), 314–330. https://doi.org/https://doi.org/10.1002/eat.23845

Ramjan, L. M., Smith, B. W., Miskovic-Wheatley, J., Pathrose, S. P., & Hay, P. J. (2024). Social support for young people with eating disorders—An integrative review. *International Journal of Mental Health Nursing*, *33*(6), 1615–1636. https://doi.org/https://doi.org/10.1111/inm.13363

Ransom, D. C., La Guardia, J. G., Woody, E. Z., & Boyd, J. L. (2010). Interpersonal interactions on online forums addressing eating concerns. *Int J Eat Disord*, *43*(2), 161–170. https://doi.org/10.1002/eat.20629

Ranzenhofer, L. M., Wilhelmy, M., Hochschild, A., Sanzone, K., Walsh, B. T., & Attia, E. (2020). Peer mentorship as an adjunct intervention for the treatment of eating disorders: A pilot randomized trial. *Int J Eat Disord*, *53*(5), 497–509. https://doi.org/10.1002/eat.23258

Rennick-Egglestone, S., Morgan, K., Llewellyn-Beardsley, J., Ramsay, A., McGranahan, R., Gillard, S., Hui, A., Ng, F., Schneider, J., & Booth, S. (2019). Mental health recovery narratives and their impact on recipients: systematic review and narrative synthesis. *The Canadian Journal of Psychiatry*, *64*(10), 669–679. https://doi.org/https://doi.org/10.1177/0706743719846108

Rennick-Egglestone, S., Ramsay, A., McGranahan, R., Llewellyn-Beardsley, J., Hui, A., Pollock, K., Repper, J., Yeo, C., Ng, F., & Roe, J. (2019). The impact of mental health recovery narratives on recipients experiencing mental health problems: qualitative analysis and change model. *PLoS One*, *14*(12), e0226201. https://doi.org/https://doi.org/10.1371/journal.pone.0226201

Robinson, L., Flynn, M., & Cooper, M. (2024). Individual differences in motivation to change in individuals with eating disorders: A systematic review. *International Journal of Eating Disorders*, *57*(5), 1069–1087. https://doi.org/https://doi.org/10.1002/eat.24178

Sangill, C., Buus, N., Hybholt, L., & Berring, L. L. (2019). Service user's actual involvement in mental health research practices: a scoping review. *International Journal of Mental Health Nursing*, *28*(4), 798–815. https://doi.org/https://doi.org/10.1111/inm.12594

Schmidt, U., Adan, R., Böhm, I., Campbell, I. C., Dingemans, A., Ehrlich, S., Elzakkers, I., Favaro, A., Giel, K., & Harrison, A. (2016). Eating disorders: the big issue. *The Lancet Psychiatry*, *3*(4), 313–315.

Schmidt, U. H., Claudino, A., Fernández-Aranda, F., Giel, K. E., Griffiths, J., Hay, P. J., Kim, Y. R., Marshall, J., Micali, N., & Monteleone, A. M. (2025). The current clinical approach to feeding and eating disorders aimed to increase personalization of management. *World Psychiatry*, *24*(1), 4–31. https://doi.org/https://doi.org/10.1002/wps.21263

Sharpe, H., Musiat, P., Knapton, O., & Schmidt, U. (2011). Pro-eating disorder websites: facts, fictions and fixes. *Journal of Public Mental Health*, *10*(1), 34–44. https://doi.org/10.1108/17465721111134538

Shaw, L. K., & Homewood, J. (2015). The Effect of Eating Disorder Memoirs in Individuals With Self-Identified Eating Pathologies. *J Nerv Ment Dis*, *203*(8), 591–595. https://doi.org/10.1097/NMD.0000000000000347

Sheens, E., Rhodes, P., & Dawson, L. (2016). Encountering anorexia: challenging stigma with recovery stories. *Advances in Eating Disorders*, *4*(3), 315–322. https://doi.org/https://doi.org/10.1080/21662630.2016.1217495

Slade, M., Rennick-Egglestone, S., Ali, Y., Newby, C., Yeo, C., Roe, J., Hui, A., Charles, A., Hare-Duke, L., & Paterson, L. (2025). Recorded mental health recovery narratives for people with mental health problems and informal carers: the NEON research programme including 3 RCTs. *Programme Grants for Applied Research*, *13*(9). https://doi.org/https://doi.org/10.3310/PPOG2281

Slade, M., Rennick-Egglestone, S., Elliott, R. A., Newby, C., Robinson, C., Gavan, S. P., Paterson, L., Ali, Y., Yeo, C., & Glover, T. (2024). Effectiveness and cost-effectiveness of online recorded recovery narratives in improving quality of life for people with non-psychotic mental health problems: a pragmatic randomized controlled trial. *World Psychiatry*, *23*(1), 101–112. https://doi.org/https://doi.org/10.1002/wps.21176

Solmi, M., Radua, J., Olivola, M., Croce, E., Soardo, L., Salazar de Pablo, G., Il Shin, J., Kirkbride, J. B., Jones, P., & Kim, J. H. (2022). Age at onset of mental disorders worldwide: large-scale meta-analysis of 192 epidemiological studies. *Molecular Psychiatry*, *27*(1), 281–295. https://doi.org/https://doi.org/10.1038/s41380-021-01161-7

Stadler, J., Moessner, M., Becker, K., Hiery, A., Diestelkamp, S., Eschenbeck, H., Gillé, V., Kaess, M., Koenig, J., & Rummel-Kluge, C. (2025). Why Young People With Eating Disorder Symptoms Do Not Seek Help—Exploring Barriers to Help-Seeking. *International Journal of Eating Disorders*, *58*, 2147–2156. https://doi.org/https://doi.org/10.1002/eat.24515

Sullivan, P. F. (1995). Mortality in anorexia nervosa. *American Journal of Psychiatry*, *152*(7), 1073–1074. https://doi.org/https://doi.org/10.1176/ajp.152.7.1073

Svaldi, J., Hartmann Firnkorn, A., Legenbauer, T., von Wietersheim, J., de Zwaan, M., & Tuschen-Caffier, B. (2019). Bulimia Nervosa. In *S3-Leitlinie Diagnostik und Behandlung der Essstörungen* (2. Auflage ed., pp. 217–274). Springer.

Treasure, J., Duarte, T. A., & Schmidt, U. (2020). Eating Disorders. *Lancet*, *395*, 899–911. https://doi.org/https://doi.org/10.1016/S0140-6736(20)30059-3

Venkatesh, A., Chang, A., Green, E. A., Randall, T., Gallagher, R., Wildes, J. E., & Graham, A. K. (2021). Perceived Facilitators and Barriers to Engaging with a Digital Intervention among Those with Food Insecurity, Binge Eating, and Obesity. *Nutrients*, *13*(7). https://doi.org/10.3390/nu13072458

Wenig, V., & Janetzke, H. (2022). "That You Just Know You're Not Alone and Other People Have Gone through It Too." Eating Disorder Recovery Accounts on Instagram as a Chance for Self-Help? A Qualitative Interview Study among People Affected and Self-Help Experts. *International Journal of Environmental Research and Public Health*, *19*(18), 11334. https://doi.org/https://doi.org/10.3390/ijerph191811334

Williams, A., Fossey, E., Farhall, J., Foley, F., & Thomas, N. (2018). Recovery after psychosis: qualitative study of service user experiences of lived experience videos on a recovery-oriented website. *JMIR Mental Health*, *5*(2), e9934. https://doi.org/https://doi.org/10.2196/mental.9934

Yeo, C., Rennick-Egglestone, S., Armstrong, V., Borg, M., Franklin, D., Klevan, T., Llewellyn-Beardsley, J., Newby, C., Ng, F., Thorpe, N., Voronka, J., & Slade, M. (2021). Uses and Misuses of Recorded Mental Health Lived Experience Narratives in Healthcare and Community Settings: Systematic Review. *Schizophr Bull*. https://doi.org/10.1093/schbul/sbab097

Zeeck, A., Cuntz, U., Herpertz-Dahlmann, B., Ehrlich, S., Friederich, H.-C., Resmark, G., Hagenah, U., Haas, V., Hartmann, A., Greetfeld, M., Zipfel, S., & Brockmeyer, T. (2019). Anorexia Nervosa. In *S3-Leitlinie Diagnostik und Behandlung der Essstörungen* (2. Auflage ed., pp. 67–216). Springer.

Zeeck, A., Herpertz-Dahlmann, B., Friederich, H.-C., Brockmeyer, T., Resmark, G., Hagenah, U., Ehrlich, S., Cuntz, U., Zipfel, S., & Hartmann, A. (2018). Psychotherapeutic treatment for anorexia nervosa: a systematic review and network meta-analysis. *Frontiers in Psychiatry*, *9*, 158. https://doi.org/https://doi.org/10.3389/fpsyt.2018.00158

Zipfel, S., Giel, K. E., Bulik, C. M., Hay, P., & Schmidt, U. (2015). Anorexia nervosa: aetiology, assessment, and treatment. *The Lancet Psychiatry*, *2*(12), 1099–1111. https://doi.org/https://doi.org/10.1016/S2215-0366(15)00356-9

# 8. Declaration of Contributions

This dissertation was completed under the supervision of Prof. Dr. Katrin Giel in the Department of Psychosomatic Medicine and Psychotherapy at the Medical University Hospital Tübingen.

This dissertation contains four publications and/or submitted manuscripts. Each of these publications is listed below, together with a statement regarding the author's individual contributions and the contributions of each co-author.

**Study 1: Barriers and facilitators affecting treatment uptake behaviours for patients with eating disorders**

*Daugelat, M.C.,* Pruccoli, J., Schag, K., & Giel, K. E. (2023). Barriers and facilitators affecting treatment uptake behaviours for patients with eating disorders: A systematic review synthesising patient, caregiver and clinician perspectives. European Eating Disorders Review.

Contribution: This study was conceptualised by *MCD*, KS, and KEG. Funding was acquired by *MCD* and KEG. Formal analysis of the included studies was completed by *MCD* and JP, with KEG serving as a third rater in case of discrepancies. The original manuscript was written by *MCD*, and editing of the manuscript was completed by *MCD*, JP, KS, and KEG. Visualisation of results was completed by *MCD*. KS and KEG provided supervision for this study.

**Study 2: Participatory Development of Evidence-Based Patient Narrative Videos for Patients with Eating Disorders**

*Daugelat, M.-C.,* Gregg, B., Adam, S.H., Schag, K., Kimmerle, J., & Giel, K. E. (2024). Participatory Development of Evidence-Based Patient Narrative Videos for Patients with Eating Disorders: A Methodological Approach and Pilot Data. Journal of Eating Disorders.

Contribution: Conceptualisation of this study was completed by *MCD*, KS, JK, and KEG. *MCD*, BG, and SHA participated in the development of the patient

narrative videos. Funding was acquired by *MCD* and KEG. *MCD* recruited participants for this study. Data analysis was completed by *MCD* and KS, and results were interpreted by *MCD*, KS, JK, and KEG. Visualisation of results was completed by *MCD*. The original manuscript was written by *MCD*, and editing of the manuscript was completed by *MCD*, BG, SHA, KS, JK, and KEG. KS and KEG provided supervision for this study.

**Study 3: Improving motivation and treatment uptake behaviors of patients with eating disorders using patient narrative videos: study protocol of a pilot randomized controlled trial**

*Daugelat, M. C.,* Kimmerle, J., Hagmann, D., Schag, K., & Giel, K. E. (2024). Improving motivation and treatment uptake behaviors of patients with eating disorders using patient narrative videos: study protocol of a pilot randomized controlled trial. Journal of Eating Disorders.

Contribution: This study was conceptualised by *MCD*, JK, DH, KS, and KEG. Funding was acquired by *MCD* and KEG. Visualisations were completed by *MCD*. The original manuscript was written by *MCD*, and editing of the manuscript was completed by *MCD*, JK, DH, KS, and KEG. KS and KEG provided supervision for this study.

**Study 4: Improving motivation and treatment uptake behaviours of patients with eating disorders using patient narrative videos: results of a pilot randomised controlled trial**

*Daugelat, M.-C.,* Gregg, B., Adam, S.H., Kimmerle, J., Schag, K., & Giel, K. E. Improving Motivation and Treatment Uptake Behaviours of Patients with Eating Disorders using Patient Narrative Videos: Results of a Pilot Randomised Controlled Trial (Manuscript).

Contribution: Conceptualisation of this study was completed by *MCD*, JK, KS, and KEG. Funding was acquired by *MCD* and KEG. *MCD* recruited patients for this study. Data analysis was completed by *MCD* and KS, and results were

interpreted by *MCD*, JK, KS, and KEG. Visualisation of results was completed by *MCD*. The original manuscript was written by *MCD*, and editing of the manuscript was completed by *MCD*, BG, SHA, JK, KS, and KEG. KS and KEG provided supervision for this study.

I hereby confirm that I have independently written the manuscript and have used no sources other than those cited.

Tübingen, 13.03.2026

_____

Melissa-Claire Daugelat

# 9. Acknowledgements


# THANK YOU!

First and foremost, to the *Hans-Böckler-Stiftung* for their generous funding and support which made this research possible.

To *Katrin Giel*, for your guidance and encouragement in the development of my research ideas. I am deeply appreciative of the time and care you invested in every stage of this work.

To *Stephan Zipfel,* for allowing me to complete my research in the Department of Psychosomatic Medicine at the University Hospital Tübingen.

To my co-authors *Kathrin Schag, Joachim Kimmerle, Bettina Gregg, Sophia Adam, Daniela Hagman*, and *Jacopo Pruccoli*, for your collaboration and shared knowledge which enriched the work presented in this dissertation.

To the “Translational Psychotherapy Research” working group, for the discussions which played a crucial role in enhancing the quality of my research.

To my fellow pre-docs *Jana Throm, Marisa Schurr, Carla Schröpel, Anne Herschbach, Tatjana Korbanka*, and *Bea Klos*, and *Astrid Günther* for your camaraderie and encouragement throughout this shared experience.

To *Ulrike Schmidt, Helen Sharpe,* and the entire EDIFY team for generously welcoming me into your teams and allowing me to learn from your work.

To my parents, *Frank and Katja Daugelat*, for your unconditional support and for believing in me even when I didn’t believe in myself.

To *Jens Lang*, for your unwavering patience and understanding, and for being my constant source of love, encouragement, and motivation.

To *Emily Daugelat*, for quite literally being the reason I get up in the morning.

And finally, to every patient and participant who took part in the studies included in this dissertation - without you, none of this would have been possible!