

REVIEW

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

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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

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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; Sonnevile & Lipson, 2018; Strand et al., 2017; Thapliyal et al., 2020; Thomson et al., 2014; Tipton et al., 2021;

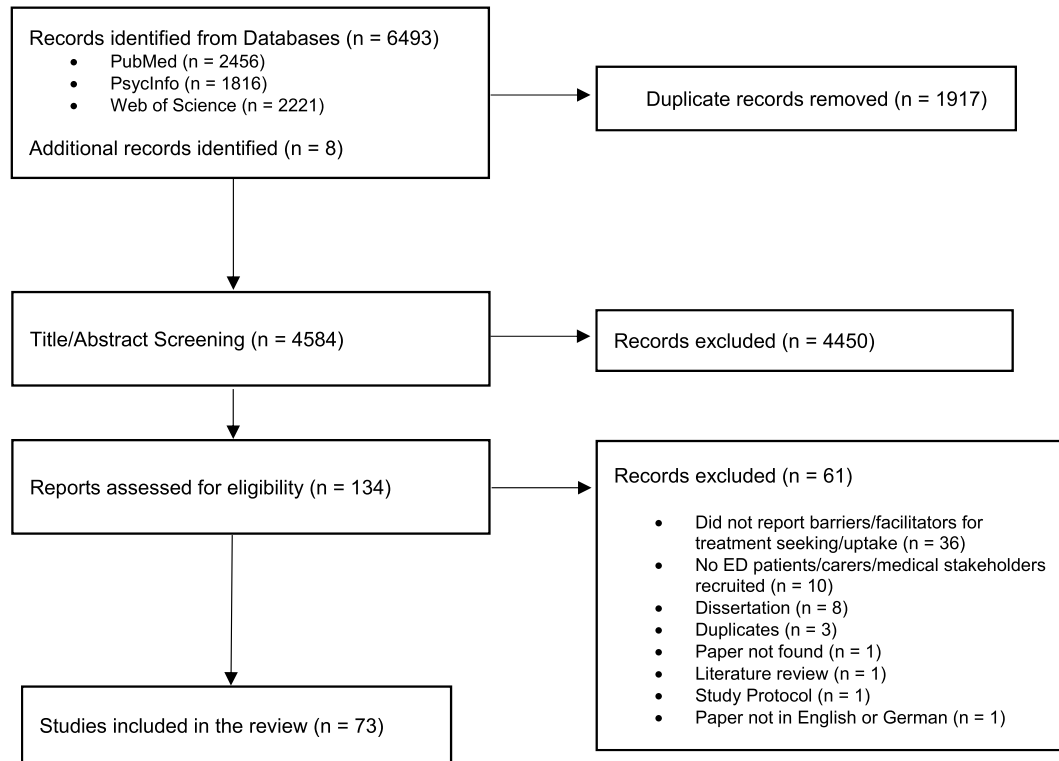


FIGURE 1 Study selection flow chart.

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 to 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.

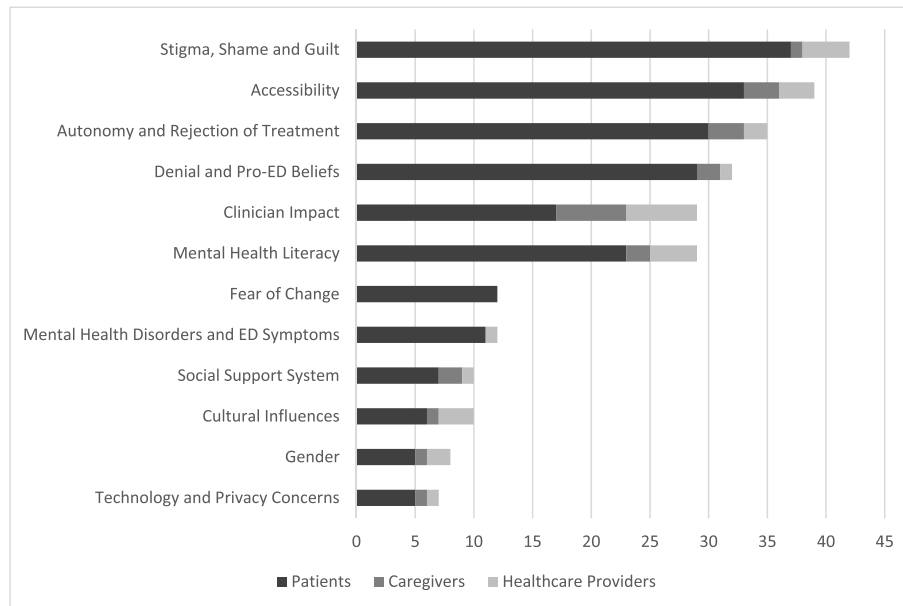


FIGURE 2 Barriers preventing treatment uptake, reported by patients, caregivers, and healthcare professionals ($n = 65$). ED, eating disorder.

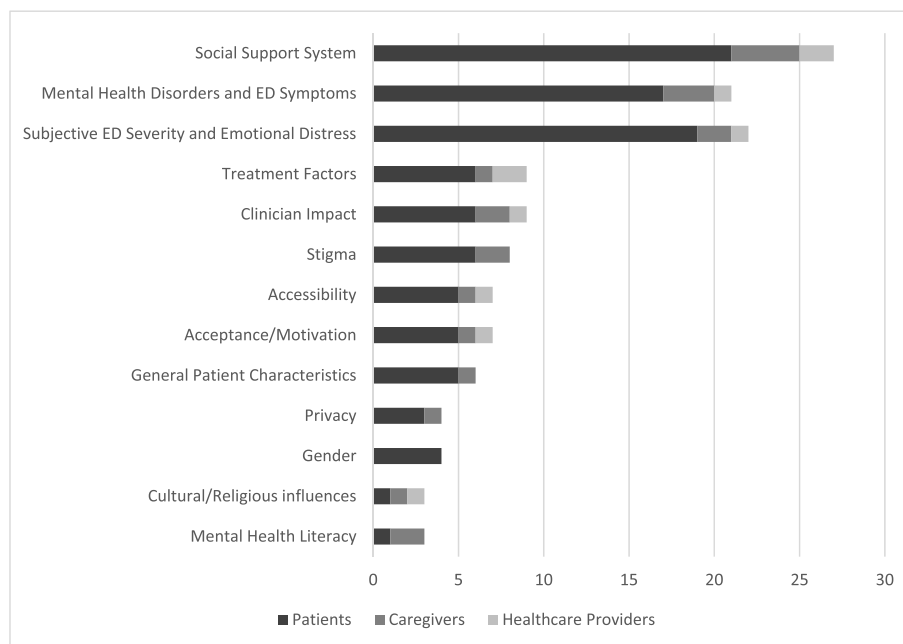


FIGURE 3 Facilitating factors promoting treatment uptake, reported by patients, caregivers, and healthcare professionals ($n = 42$). ED, eating disorder.

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

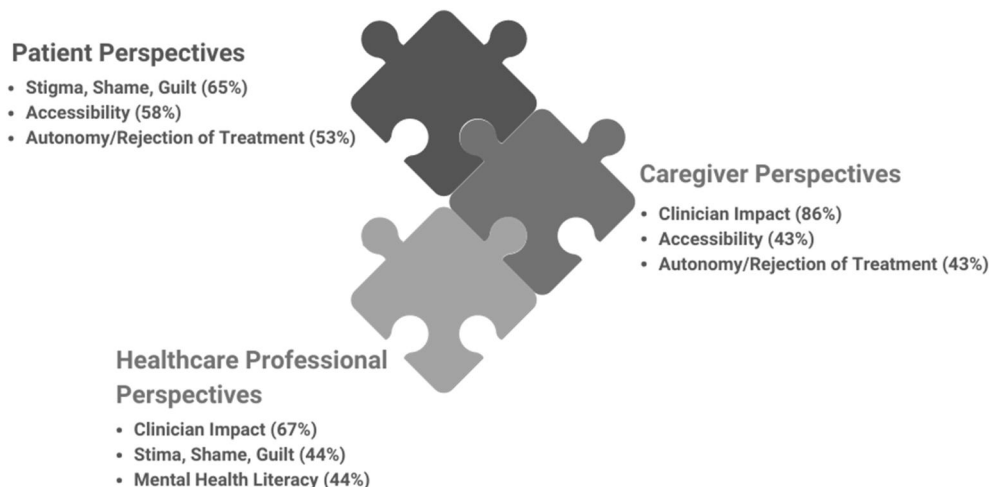


FIGURE 4 Most prominent barriers preventing treatment uptake, as reported by patients, caregivers, and healthcare professionals.

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 trans-diagnostic 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 Prucoli; Writing – original draft: Melissa-Claire Daugelat; Writing – review & editing: Melissa-Claire Daugelat, Jacopo Prucoli, Kathrin Schag, Katrin Elisabeth Giel; Visualization: Melissa-Claire Daugelat; Supervision: Kathrin Schag, Katrin Elisabeth Giel; Funding acquisition: Melissa-Claire Daugelat, Katrin Elisabeth Giel.

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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.

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SUPPORTING INFORMATION

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