



A systematic review of the impact of carer interventions on outcomes for patients with eating disorders

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Received: 10 September 2021 / Revised: 18 November 2021 / Accepted: 19 November 2021 / Published online: 1 December 2021
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Abstract

Purpose Eating disorder (ED) prevalence and illness severity is rapidly increasing. The complicated interplay of factors contributing to the maintenance of EDs, including family/carer influences, highlights the importance of carer interventions within ED treatment. Carer interventions demonstrate positive outcomes for carers themselves, though are also hypothesised to benefit the patient indirectly. A systematic review was conducted to greater understand the impact of carer interventions on ED patient outcomes.

Methods Eight databases, including CINAHL, MEDLINE and PsychINFO, were systematically searched. Intervention studies for parent(s)/carer(s) of a patient with an ED were included, provided they reported outcomes for the patient. No publication date restrictions were set. Included studies were quality appraised.

Results Twenty-eight studies met inclusion for the review; all of which varied in intervention type, duration, content and setting. Patient diagnosis and treatment setting were mixed across studies, though the majority focused on Anorexia Nervosa within outpatient settings. Intervention content broadly included consideration of relationship issues and interactional patterns, psychoeducation, skill development, behavioural management, and peer support. Therapeutic models utilised were diverse, including but not limited to: family, interpersonal, cognitive, and psychodynamic approaches.

Conclusion Several carer interventions showed positive outcomes for patients with EDs, with small group treatment formats being commonly used and proving effective through intervention content alongside a peer support element. Separate family therapy was suggested to be of equal efficacy, if not better, than family therapy alongside the patient. Recommendations for clinical practice and future research are considered.

Level of evidence 1. Systematic review, evidence mostly obtained from randomised controlled trials.

Keywords Eating disorders · Carer · Family · Anorexia nervosa

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Background

Eating disorders, including anorexia nervosa (AN) and bulimia nervosa (BN), have the highest mortality rate among psychiatric conditions [1], and are extremely prevalent with an estimated global total of 5.5 million people suffering from eating conditions [2]. Additionally, recent figures show a 104% rise in children and young people (CYP) with AN requiring hospital admission [3], demonstrating an increase in severity of cases.

The role of family, carer, parent, and friends is important in supporting those with an eating disorder (ED) towards recovery [4]. For this review, we will refer to these roles as ‘carers’. Furthermore, as AN and BN typically onset during early adolescence and young adulthood [5], intensive support for carers and carer involvement is typically encouraged in clinical and treatment guidance, e.g., National Institute for Health and Care Excellence [6] and The New Maudsley Model [7]. Additionally, EDs are often associated with elevated caregiver burden and distress [8] and intense emotions can create an entanglement between caregiver responses to the illness and inadvertently the maintenance factors of the illness [9], so the need to offer support is key. As a result, together with carers, a range of interventions delivered to carers have been developed to assist with those they support, including self-help materials, facilitated groups and telephone coaching [10]. These interventions tend to focus on AN and BN because they present the greatest medical risk, with patients most likely to be hospitalised. However, most of the knowledge, understanding and skills that are helpful for carers of loved ones with AN and BN are applicable across the full range of eating disorder diagnoses, e.g. communication, assertiveness, developing resilience and motivation (4). Some differences in approach for the type of eating disorder and age of the patient are necessary; the advice and guidance given to carers does not always make this clear.

Carer outcome measures have also been generated to support the exploration of coping strategies within clinical practice and to assess the effectiveness, of carer interventions for EDs. For example, the Accommodation and Enabling Scale for Eating Disorders (AESED) [11] developed by clinicians and caregivers, measures 5 subscales specific to accommodating family behaviours and thoughts expressed by caregivers including: Avoidance and Modifying Routine, Reassurance Seeking, Meal Ritual, Control of Family and Turning a Blind Eye. Additionally, the Carers Skills Scale (CASK) [12], has been introduced within the literature. This CASK questionnaire is designed to measure care caregiver skills based on the interpersonal mechanisms of the cognitive interpersonal maintenance model for eating disorders [13]. Finally, the Experience

of Caregiving Inventory (ECI) [14] measures the experience of caring for a relative with a serious mental illness and conceptualises caregiving within a “stress-appraisal-coping” framework, rather than “caregiver burden”. These outcome measures reflect the nature of difficulties and challenges caregivers of ED’s face and can be valuable within both the clinical and research setting when understanding effective treatment for EDs.

Given the seriousness of EDs and as carer distress may both inadvertently lead to the maintenance of EDs [15] and be a protective factor, it is necessary that treatment plans consider the skills and knowledge required for carers supporting those with EDs and are involved in their care. Typically, family therapy and family-based interventions which include the involvement of both the carer/s and the patient are advocated for young people with an ED and the involvement of carers encouraged when delivering MANTRA (Maudsley Model of Anorexia Nervosa Treatment for Adults) for adults [6]. Previous studies on the interventions for carers of patients with EDs demonstrate positive outcomes for carers themselves, including decreased carer psychological distress [16, 17]; decreased carer burden [18, 19]; decreased carer expressed emotion [18–20]; and increased carer self-efficacy [21]. However, due to the reported positive impact on carer outcomes, it is also hypothesised that there may also be an indirect effect on patient outcomes. In a systematic review and meta-analysis investigating outcomes of guided self-help for carers and patients with EDs [22] clinical improvements in BMI, depression, anxiety and quality of life were not found, this may be due to the limited number of studies included and heterogeneity between studies. The authors conclude that guided self-help interventions have the potential to increase patients’ treatment engagement and carers’ skills; however, further work is needed to fully understand this better.

To our knowledge, no systematic review has been conducted on the impacts of carer interventions alone on patient outcomes in EDs. This is an important consideration given that carers have reported subjective improvements in those they care for.

This piece of work aims to undertake a systematic review of the available literature on the impact of carer interventions on outcomes for patients with eating disorders. Additionally, it aims to apply the knowledge to inform policy, service delivery and support given to carers of patients with EDs. It is important to note that the review defines “carer interventions” as interventions for carers alone (i.e., where the patient was not involved). Evidence for family therapy, involving the patient, is already well established [23].

Methods

Search strategy

The systematic review protocol was developed and conducted in accordance with the “Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA1)”. The protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO; <https://www.crd.york.ac.uk/prospero> Registration Number: CRD42020207685).

We conducted systematic searches across eight electronic databases: AMED, BNI, CINAHL, EMBASE, HMIC, MEDLINE, PsycINFO and PubMed. Searches were conducted on 19th August 2020, due to COVID 19 NHS staff demands

authors spent time supporting colleagues in late 2020 and early 2021. A second and final re-run of the search strategy was, therefore, completed on 10th August 2021 to check the results remained accurate. The two search approaches are reflected in Figs. 1 and 2. No publication date restrictions were set. Limits applied to papers published in English due to lack of resources for translation.

Search terms

parent* OR carer* OR “care giver”

AND

intervention OR treatment OR therap* OR education OR psychoeducation* OR “self-help”

AND

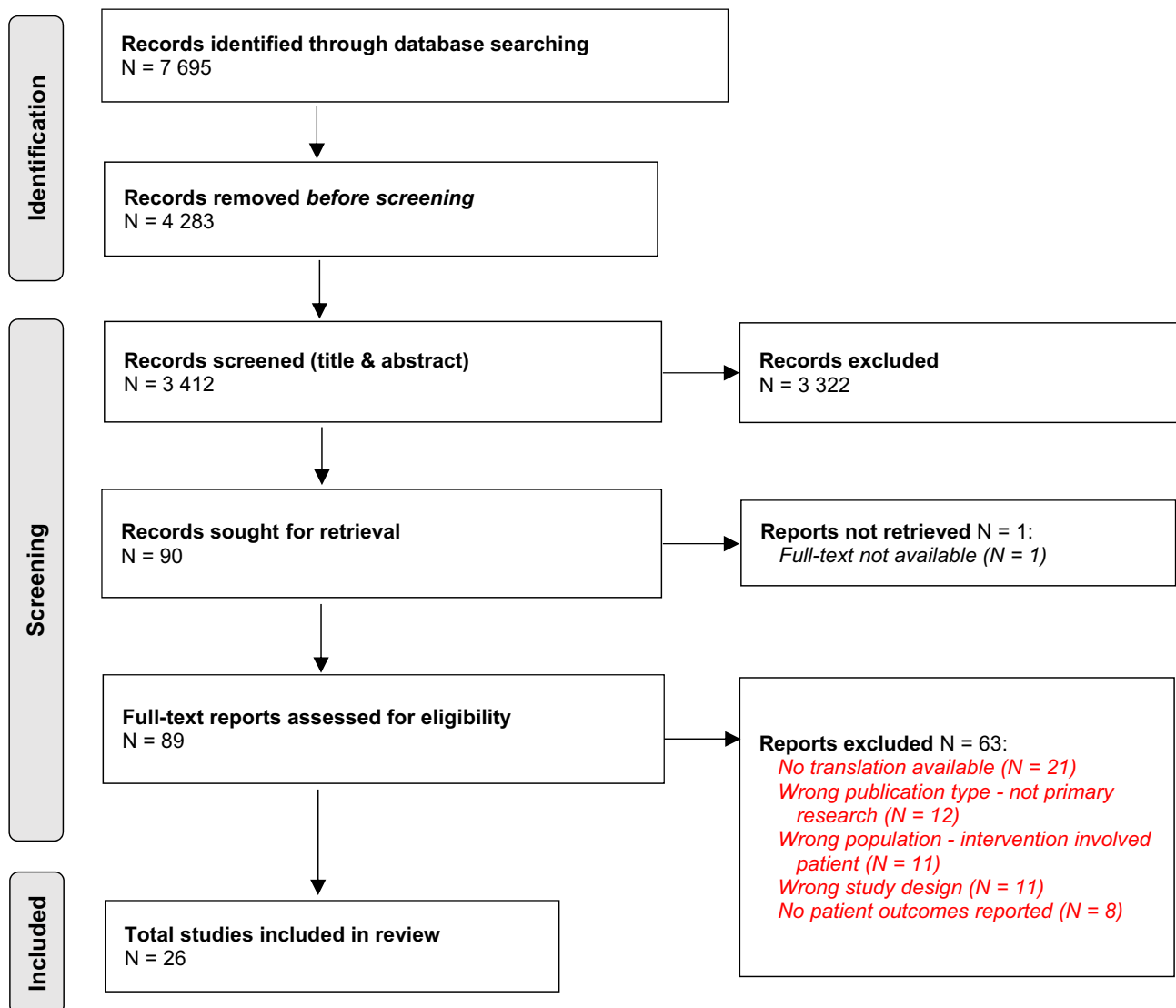


Fig. 1 Aug 2020 search

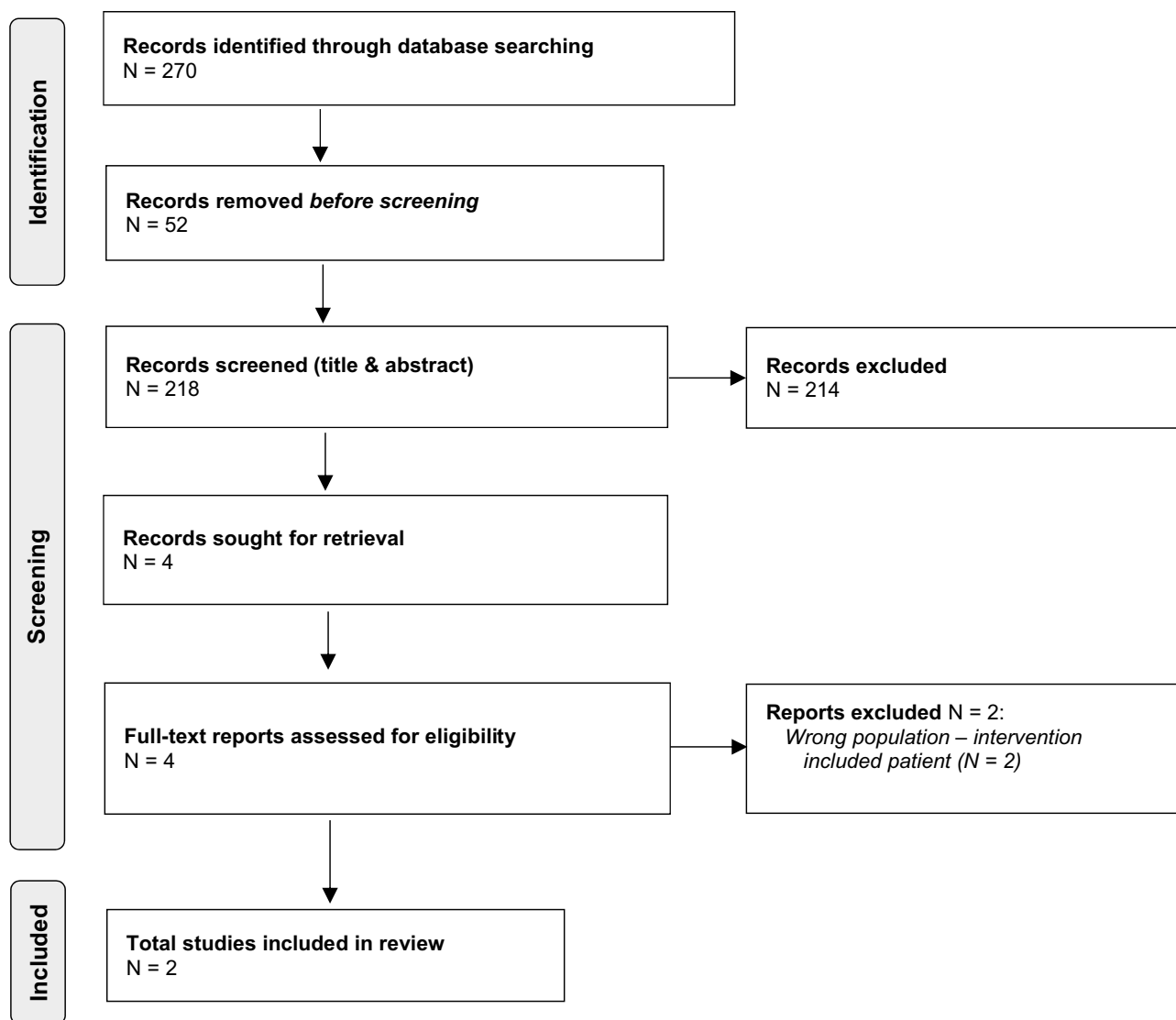


Fig. 2 Aug 2021 search

anorexia OR bulimia OR “binge eating disorder” OR ednos OR “eating disorder*”.

The search term “patient outcomes” was not used as many studies report both patient and carer outcomes and it was important to capture the patient outcomes in all studies.

Eligibility criteria

The inclusion criteria employed were as follows: (1) intervention for parent/carer of a patient with an ED (including randomised and non-randomised controlled trials); and (2) reported outcomes of the ED patient. Quantitative and qualitative studies were included. Studies that met any of the following criteria were excluded: (1) not published in or translated to English; (2) intervention involved the patient (e.g. family therapy, although separate family therapy that

involved carers only was included); (3) reported carer outcomes only (i.e. does not look at patient outcomes); (4) not primary research (book chapters, literature reviews, conference proceedings, commentaries with no primary data, descriptive studies of intervention without pre-/post-outcome data). Case reports were included, provided they met the inclusion criteria. Patients being referred to clinical services was not part of the inclusion criteria and studies were eligible when patients reported a diagnosis of ED.

Study selection and data extraction

Search results were merged across databases and duplicates removed. Remaining papers were uploaded to online software “Rayaan QCRI2” [24]. Screening (title and abstract, and full text) was conducted by one author (LH, MC, HB or

SA) with 10% double screened independently by an additional author; any conflicts were resolved in team discussion (LH, SA, MC, HB and TC). Screening of the second search was undertaken by MC, with 10% double screened by TC. Quantity of articles and exclusion reasons at each stage were documented (see Fig. 1).

Data were extracted by a single author (LH, MC or HB) using a pre-formatted data extraction Microsoft Excel spreadsheet, recording study characteristics (authors, title, publication year, country, setting [inpatient/community], ED of focus, study design), carer demographics, intervention details (with control if applicable), patient outcomes, summary of results and limitations (Supplementary Material: Table 1).

Quality assessment

The methodological quality of each included study was assessed by two authors (LH, MC or HB) using Critical Appraisal Skills Programme (CASP) Checklists [25–27]. The checklist used for each study was dependent on study design, and each checklist comprised of ten/eleven questions in which validity, relevance and results were covered. Once completed, answers were cross-referenced, and discrepancies discussed among authors. Conclusions were made as to whether articles were “Low”, “Moderate” or “High” in quality, based on frequency of “Yes”, “No” and “Can’t Tell” answers and answers provided within the broader questions of the checklist. “High” quality was assigned to papers achieving 80% or more of “Yes” answers on the checklist, “Moderate” quality was classified as papers recording between 60 and 80% “yes” on the checklist and papers scoring 60% “Yes” or lower were categorised as “Low” quality. Quality assessment was used to inform data synthesis and analysis; influencing the weight each study had within our findings, whilst helping to interpret and explain differences across studies.

Narrative synthesis

A formal narrative synthesis was performed based on guidance by Popay et al. (2006) [28]. This consisted of 4 main elements: developing a theory, developing a preliminary synthesis, exploring relationships in the data, and assessing robustness of the synthesis. The elements were applied iteratively and integrated into the results.

Results

Twenty-eight studies met inclusion for the review (see Fig. 1). Information about the studies, including type of study, setting, type of ED and intervention details are given

in Table 1 (Supplementary Material). The studies included varied in design: randomised controlled trials (RCT; $N=17$), non-randomised ($N=3$), feasibility ($N=4$), qualitative ($N=2$), matched control ($N=1$) and case series ($N=1$). Most studies originated from the United Kingdom ($N=11$), followed by Australia ($N=6$); United States of America ($N=3$); Spain ($N=2$); Canada, Belgium, Italy, Iceland, Austria ($N=1$ each); and a mixed study across Australia and UK ($N=1$).

Sixteen studies involved carers of patients with AN exclusively; the remainder studies recruited participants with a range of EDs. None of the studies focused exclusively on BN or Binge Eating Disorder. The majority of studies were within outpatient settings ($N=22$), though a selection observed inpatients alone ($N=3$), both inpatients and day patients ($N=2$), and inpatients and/or those awaiting inpatient ($N=1$).

Study quality is provided in Table 1 (Supplementary Material). Most were classified as high quality ($N=19$) with the remaining being moderate quality. RCT studies were generally rated higher quality than those utilising a non-randomised design.

Carer demographics

The number of recruited carers per study ranged from 6 to 268 (mean = 120); however, only sixteen studies reported the number of carer participants with others reporting number of patient participants alone. Other carer demographics (i.e. age/gender) were only reported in 7 of the 28 studies (see Supplementary Material: Table 1 for details). It is important to note, over half of the studies ($N=15$) examined interventions for adolescents (< 18 years), whilst others examined both adults and adolescents ($N=6$), and adults alone ($N=6$). One study did not report patient age. Most carers were likely to be parents and interventions targeted more towards a younger demographic; potentially experiencing a shorter duration of illness comparatively to those older in age. 19 studies reported parents as primary caregivers and of the remaining 9 most caregivers were parents.

Intervention type

A range of interventions were identified, in which their content included the need for carers to take control of re-nutrition at the beginning and gradually transferring responsibility; disentangling individual psychological and family relationship factors from the ED and interactional patterns that have developed; psychoeducation around EDs themselves; skill development; behavioural management; and peer support.

Nine studies compared a style of conjoined family therapy (CFT) to either separated family therapy (SFT)

[29–33], parental-focused therapy [34–36], or intensive parental coaching (IPC) [37]. One study compared family therapy with additional IPC to family therapy alone [38].

Six examined the “Experienced Carers Helping Others” (ECHO) intervention [39–44], by the Maudsley group: a skill sharing and training approach using books, DVDs and at times telephone coaching. The ECHO approach is based on a cognitive interpersonal model for AN and encourages caregivers to reflect on their own response to the illness and how these behaviours could be maintaining, accommodating, and enabling the ED. The model supports caregivers with positive communication skills, education of the illness and how to demonstrate compassion, self-care, and adaptive coping strategies.

One study adapted the interpersonal model, tailoring it more specifically to CYP, designing “Supporting Carers of Children and Adolescents with Eating Disorders” (SUCCEAT) [45]. This encompassed aspects of the cognitive interpersonal maintenance model, transtheoretical model of change and antecedent–behaviour–consequence model. Researchers compared mode of delivery (face-to-face workshop vs online equivalent); both yielded medium-to-high effect sizes, with full or partial remission observed in 72% and 87% of patients, respectively.

Seven studies reviewed “Carer Skills Workshops” [16, 17, 46–50]; two of which were in conjunction with family therapy [48, 50]. These workshops ranged in duration from a one three-hour session to six two-hourly sessions. Their content often included psychoeducation and some incorporated “guest speakers”—other carers whose loved one has recovered. The group workshops also enabled carers to share their caregiver experiences and thus incorporated a peer support element.

Two online only interventions were reported: “Overcoming Anorexia Online” [18]—which combined systemic and cognitive behavioural principles, and a parental guided self-help intervention [51]—which involved videos of expert clinicians instructing parents on the principles and application of family-based therapy, whilst emphasising parental empowerment and reframing parental criticism.

One study assessed the effectiveness of Adlerian Parental Counselling (APC) [52], an approach derived from psychodynamic therapy, which aimed to provide parents with cognitive and emotional tools to better understand their child’s feelings and behaviours and to respond to them in a supportive manner. Parents were also invited to participate in a counselling group.

Finally, one study measured the effect of Acceptance-based Separated Family Treatment [53], which aimed to prepare parents with acceptance-based strategies to target negative reinforcement for symptom expression and increase behavioural flexibility.

Carer interventions in outpatient settings

Twenty-two of the examined studies were conducted within outpatient settings. Content of these interventions included: SFT (carer only), in some cases compared with CFT (patient and carer; $N=9$); Skills-based/psycho-education ($N=6$); ECHO with and without telephone coaching ($N=3$); APC ($N=1$); SUCCEAT ($N=1$); ‘Overcoming Anorexia Online’ ($N=1$); and, acceptance-based treatment ($N=1$).

SFT was found to be at least as effective, and in some cases more effective, than CFT. Eisler [30, 31] found SFT more effective than CFT for those with high levels of maternal criticism, which was maintained at five-year follow-up. Large effect sizes were also reported for weight gain ($z=1.2$), BMI ($z=1.2$), Nutrition ($z=1.8$), Mental State ($z=1.0$), Depression ($z=0.9$), and ED behaviour and cognitions [EDI ($z=1.0$); EAT ($z=1.3$)]. These studies were classified as high quality. Furthermore, two studies found higher levels of ED remission at the end of SFT treatment compared to CFT [34, 36]; however, the differences between the two treatments did not persist into the 6- or 12-month follow-up.

Three studies examined the addition of carer sessions to family therapy [37, 38, 48]. Ganci et al. [48] tested a one-off, 3-h group workshop in the early stages of family therapy treatment. Whilst there was no difference in length of treatment or ED psychopathology, BMI at week 4 had greater increases compared to treatment as usual (TAU), though this difference was not maintained at week 12 or end of treatment. Lock and colleagues [37] held 3 parenting coaching sessions in addition to TAU; there were no differences between the groups. Rhodes et al. [38] found an additional 20 parent sessions led to a small improvement in weight restoration compared to TAU, but this was a small sample ($N=20$ families).

There was mixed evidence for the effectiveness of the ECHO intervention. Keshen et al. [41] found no statistically significant differences in symptomology severity between ECHO (without telephone coaching) and TAU, whilst Hodsoll et al. [40] found the ECHO group showed improved BMI and fewer inpatient admissions. These differences may be understood when considering Keshen et al. [41] included patients with BN; ECHO’s content is tailored more towards AN symptomology. Furthermore, with reference to telephone guidance Hodsoll et al. [40] reported that the ECHO treatment group with telephone guidance had no positive impact on BMI outcomes and rather in the ECHO treatment group without telephone guidance BMI was higher at both 6 and 12 months, with small-to-medium effect size.

Salerno and colleagues [44] also compared ECHO (with and without telephone coaching) to TAU. The results suggest that in both ECHO groups parents were able to regulate emotions better post-intervention, thus preventing mirroring

and maladaptive caregiver responses and reducing illness maintenance and patient distress. Furthermore, patients with improved distress were more likely to report a better outcome after 12 months (BMI) in the ECHO condition. Their findings continue to suggest no increased positive impact from the addition of telephone coaching [44].

Two RCT studies compared skills training and psychoeducation workshops for carers [47, 49]. Skills training was found to be more effective at reducing patient psychological distress than the psycho-educational programme: (effect size $\eta = 0.73$), anxiety ($\eta = 0.38$) and depression ($\eta = 0.32$) from baseline to 3-month follow up [47]. Oppositely, the second study suggested that both workshops were similarly efficacious in reducing patient psychological distress and ED psychopathology [49].

Carer interventions in inpatient and day patient settings

Interventions within inpatient and day patient settings were also evaluated ($N = 6$). Multi-family group, without the patient, was suggested to be similarly effective in reducing ED symptoms than multi-family group with the patient [29]. Another found a 3-day “family workshop” with two families was as effective as 18 h of 1–1 individual family sessions [16]. Furthermore, a high-quality, qualitative study within an inpatient setting found that a skills training workshop for carers had positive impacts on patient outcomes [17].

Two studies reporting on one large RCT ($N = 238$); [39, 43] found positive impacts of ECHO on patient outcomes, including ED psychopathology, distress and quality of life; all persisting 24 months post-intervention. These studies were classified as high quality. Supporting this, qualitative research within inpatient and day patient populations also suggests that the ECHO treatment enhances patient wellbeing [42].

Discussion

The aim of the study was to systematically review and synthesise the literature on the impact of carer interventions on outcomes for patients with EDs, and how this information can be applied to inform clinical practice. Twenty-eight studies were evaluated; findings suggested there is potential benefit in bringing some carers and families together in small groups for such interventions [30, 39, 40, 42, 43, 46, 47, 51–53]. This is especially the case for families with high levels of maternal criticism [30] and patients who have been unwell for less than a year [37]. The positive outcomes on patients themselves align with carer views of the benefits of peer support and feeling more equipped to manage the disorder.

The results from the ECHO interventions demonstrate long-term positive outcomes within both inpatient and outpatient settings [39, 40, 42–44]. However, there was a stronger effect size within inpatient and day patient settings than outpatient settings, suggesting the intervention is perhaps more suited to accompany intensive treatment and by those who require further support to manage the disorder within the home environment. These results, plus the success of SFT, also imply that carer interventions may be more effective when carers are able to spend time away from the patient and reflect on what has been discussed and taught in the sessions. Given the clinical and economical success of the ECHO intervention, which is relatively low in cost, it would be worth developing it further to include digital/virtual features that support remote working.

The age of the patients within the ECHO trails ranged from adolescents as young as 13 years to adult populations with a mean age of 27 years, crossing both CAMHS and adult services, reflecting on this, it would be interesting to look closer at the effect of age on the outcomes of the interventions. Further understanding is needed to recommend when and how a carer intervention should be utilised. For example, future research is needed to identify which interventions work best with specific groups and contexts, including place of treatment (outpatient or inpatient), patient age, and stage of illness, factors that may determine suitability towards certain interventions. Furthermore, carer characteristics should also be considered. Some models of support may be better matched to parents and others to spouses acting as carers. Work exploring carer capabilities should be developed to determine efficacy and potential implications, raising the question: can we expect all carers to be equally effective? Sibling involvement is another aspect of carer intervention that has not been mentioned in this review, however, is worth exploring given the influence of family dynamics and EDs.

The interventions included in this review have a clear programme structure, in comparison other, more fluid, interventions, such as “Peer Support Groups”, where carers meet on a regular basis to share their lived experience and learn from each other in a more organic manner, have not fully been fully explored or reported in the literature. Such groups often have a professional facilitator, but their membership is flexible and are different to the “Programmes” described in the current review. Carers report how helpful attending these groups are to them and enable them to provide better support, and hopefully better patient outcomes; however, they have not been picked up in our review, therefore further empirical evidence on patient outcomes using this method would add more value and insight to our clinical recommendations.

Most of the studies featured in this review focused on AN and young people aged under 18, with parents acting

as carers. Therefore, it would be beneficial to have a greater awareness of how other types of EDs, including BN and Binge Eating Disorder (BED), across the lifespan may be influenced by carer interventions. The results of this review, including the types of interventions, could be used to develop effective carer interventions for patients with BN or BED. It would be constructive to compare the specific needs and reports of carers of different types of EDs and use this to inform adaptations of successful carer interventions for ED.

Finally, it is important to highlight the quality of future research and what would be beneficial to guide future treatment; previous work has used relatively small sample sizes, warranting a need for more RCTs with larger sample sizes in this area.

Strengths and limits

In terms of strengths, there were a relatively large number of RCTs (although many of these were pilot trials) with active control groups. All studies came from high-income countries, including 10 from the UK, making it more likely to be applicable to the NHS context. Limitations included small sample sizes and non-randomised designs (see Supplementary Material: Table 1). It was not always clear whether the carer intervention was the only treatment accessed by the patient, which makes it difficult to separate out whether the effectiveness is due to the carer intervention, particularly in non-randomised studies. Additionally, there was a lack of sufficient evidence regarding the effectiveness of carer interventions for BN and BED. The lack of quantitative synthesis limits the results; a full meta-analysis would be useful to support this evidence.

Conclusion

Due to the positive impact on both patient and carer outcomes, plus the increasing severity, duration, and high risk of relapse with eating disorders carer interventions are a crucial and sustainable part of treatment, clinicians and commissioners should therefore consider this when developing and transforming services. The evidence suggests carer support can be more effective on patient outcomes if it is provided away from the patient, further research is required to understand which groups this works best for. Evidence for family therapy is well established within the literature. However, more work is needed to understand if adding carer sessions to this leads to improved patient outcomes; therefore, carer support needs to be appropriate to the treatment pathway.

What is already known on this subject?

Support for carers of those experiencing an eating disorder is an important part of inpatient and outpatient treatment. It is well established within the literature that current carer interventions induce positive impacts on the carers themselves; however, a systematic review has never been undertaken focusing on the outcomes of the patients themselves. This paper will provide a greater understanding of the impact of carer interventions on ED patient outcomes, alongside evidence and clinical recommendations for the use of them.

What this study adds?

A range of carer interventions demonstrate positive outcomes for patient with EDs, including weight gain, ED psychopathology and quality of life. Intervention shared content included: responsibility of re-nutrition, relationship issues and interactional patterns, psychoeducation, skill development, behavioural management, and peer support. Therapeutic models utilised were diverse and incorporated: family, interpersonal, cognitive, and psychodynamic approaches. Separate family therapy was suggested to be of equal efficacy, if not better, than family therapy alongside the patient. Several carer interventions showed positive outcomes for patients with EDs, with small group treatment formats being commonly used and proving effective through intervention content alongside a peer support element. This is especially the case for families with high levels of maternal criticism and patients who have been unwell for less than a year. It is important to note that the majority of effective carer interventions included patients with AN and future research should investigate how other EDs can be employed. Due to the positive impact on both patient and carer outcomes, plus the increasing severity, duration, and high risk of relapse with eating disorders carer interventions are a crucial and sustainable part of treatment, clinicians and commissioners should, therefore, consider this when developing and transforming services.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s40519-021-01338-7>.

Acknowledgements The team would like to thank the librarians of Norfolk and Suffolk NHS Foundation Trust, Robert Kelly and Jill Waters, for their assistance with the database searches.

Funding Not applicable.

Availability of data and material Available upon request.

Code availability Not applicable.

Declarations

Conflict of interest Not applicable.

Ethical approval Not applicable.

Informed consent Not applicable.

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