Psicologia: Teoria e Pesquisa
2022, v.38, e38417

DOI: https://doi.org/10.1590/0102.3772e38417.en

Perception of family members of people with eating disorders about treatment: a metasynthesis of the literature[*],[**]

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ABSTRACT – Family relationships seem to have a relevant contribution to the etiopathogenesis of eating disorders (EDs), which makes the international treatment guidelines recommend family participation. This study aimed to synthesize and reinterpret the findings of primary qualitative studies about the perception of family of people with EDs about treatment. The search strategy was organized using the SPIDER tool, and the analyzes were carried out by two independent reviewers. From 1115 studies originally retrieved from six databases (CINAHL, LILACS, PsycINFO, PubMed, Scopus and Web of Science), 19 articles were selected. The results converge to the recognition that the family is part of the process and also needs to be considered as a care recipient, not just as a coadjuvant/companion for the patient. Since family dynamics have a relevant contribution in the development and maintenance of EDs, it is necessary to invest in the transformation of family relationships so that more effective and lasting gains in treatment can be obtained.

KEYWORDS: eating disorders; anorexia nervosa; bulimia; family, treatment.

Percepção de familiares de pessoas com transtornos alimentares acerca do tratamento: uma metassíntese da literatura

RESUMO – Relações familiares parecem ter uma contribuição relevante na etiopatogenia dos transtornos alimentares (TAs), o que faz com que as diretrizes internacionais de tratamento recomendem a participação da família. Esta metassíntese teve como objetivo sintetizar e reinterpretar os resultados de estudos qualitativos primários sobre a percepção de familiares de pessoas com TAs acerca do tratamento. A estratégia de busca foi organizada utilizando-se a ferramenta SPIDER e as análises foram realizadas por dois revisores independentes. A partir de 1.115 estudos originariamente recuperados de 6 bases de dados (CINAHL, LILACS, PsycINFO, PubMed, Scopus e Web of Science), foram selecionados 19 artigos. Os resultados convergem para o reconhecimento de que a família é parte do processo saúde-doença e precisa ser considerada como destinatária de cuidados, não apenas como coadjuvante/acompanhante no cuidado à pessoa acometida. Como a dinâmica familiar tem contribuição relevante no desenvolvimento e na manutenção dos TAs, é necessário investir na transformação das relações familiares para que se possam obter ganhos mais efetivos e duradouros no tratamento.

PALAVRAS-CHAVE: distúrbios do ato de comer; anorexia nervosa; bulimia; família; tratamento.

Eating Disorders (EDs) are psychopathological conditions that are characterized by a persistent pattern of eating behavior disorders, which are accompanied by several behavioral and physiological changes (World Health Organization [WHO], 2018). The DSM-5, fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association [APA], 2014), describes six types of ED: anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), pica, rumination disorder and preventive eating disorder. The most common symptoms of this type of psychopathology are: intense fear of gaining weight or becoming obese; emission of inappropriate behaviors to avoid this event, such as restriction of caloric intake and adoption of purgative behaviors; disturbance in the experience of

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[*] Acknowledgements: CNPq, Research Productivity Scholarship (PQ-1A) and CNPq, Master's Scholarship.

[**] This article was based on the first author's Master's Thesis.

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■ Submetido: 30/12/2020; Aceito: 19/04/2021.

one's own weight or body shape, characterized by a distorted self-image (American Psychiatric Association [APA], 2014).

Among the factors considered to trigger and/or maintain the symptoms are: personality characteristics, socio-cultural environment – due to social pressure for a thin body – and family dynamics (Fava & Peres, 2011). There is already a reasonable body of evidence in the literature that suggests that in the families of people with EDs, parents generally exhibit overprotective behavior and exercise strict control over the behavior of their children, making it difficult or even inhibiting the development of their social skills and their autonomy schemes (Canetti et al., 2008; Jauregui-Lobera et al., 2011; Leonidas & Santos, 2015a, 2015b; Oliveira & Santos, 2006; Santos et al., 2016).

Family relationships are often unstable and marked by conflicts, tensions and dissatisfaction, with ill-defined or blurred borders between individuals (Attili et al., 2018; Souza & Pessa, 2016; Treasure et al., 2015). The bonds often oscillate between emotional entanglement and emotional distance, which offers a psychological and relational substrate conducive to the onset of symptoms (Leonidas & Santos, 2015a, 2015b; Santos et al., 2016). Once the multifactorial nature of the etiopathogenesis of EDs is recognized (Siqueira et al., 2020), the therapeutic plan must prioritize the multiprofessional format and focus on the comprehensive rehabilitation of the sick person, considering their needs in clinical, nutritional, psychological, psychiatric, family and socio-cultural aspects involved (American Psychiatric Association [APA], 2006).

The treatment involves coordinated actions supported by a multidisciplinary health team, whose basic structure consists of a psychologist, nutritionist, psychiatrist and general practitioner or nutrologist. This is the minimum format recognized as the most suitable for monitoring EDs today (Pinheiro et al., 2010; Scorsolini-Comin & Santos, 2012; Sicchieri et al., 2006). The services specialized in the treatment of EDs are in different health establishments, and can be found in medical, pediatric and psychiatric units. They vary depending on the type of treatment offered, such as outpatient care, day hospital and full hospitalization. The modality to be followed will depend on the clinical, emotional, psychiatric and social-family support conditions of each patient (Cabrera, 2006).

In Brazil, diagnosed cases of ED that are followed by public health are organized by the Psychosocial Care Network (RAPS). Established through Ordinance 3.088 / 2011 of the Ministry of Health, RAPS materializes the National Policy on Mental Health, Alcohol and Other Drugs and the principles of Psychiatric Reform, a movement that gained strength in the country in the 1970s, with the aim of modifying the system of clinical treatment of mental health issues. RAPS consists of components that aim to guarantee comprehensive care and the health rights of people with psychopathologies (Ramos & Pedrão, 2013).

The literature indicates that if the treatment of an ED is not started early, the course of the disease tends to be prolonged and induce associated physical and psychological damage, in addition to a high mortality rate, especially in patients with AN (Scorsolini-Comin & Santos, 2012; Treasure et al., 2015). Despite recognizing the importance of multiprofessional care for patients with ED, it is known that these disorders have a high chronicity index and that the treatment abandonment rates by the affected population are high, reaching 73% depending on the follow-up modality and the health care unit where the specialized care is located. (Fassino et al., 2009; Souza & Pessa, 2016). However, little is known about the factors and variables involved in this phenomenon, which places adherence to treatment as a critical point in the continuity of care (Souza et al., 2019).

The literature has documented the systemic repercussions of EDs. It is important to note that family members of affected people also feel the impacts of the disease (Souza & Santos, 2009, 2012). The daily contact with these diseases has been associated with physical and mental health problems, as well as with the depreciation in quality of life. Studies show that parents of people with ED experience personal, social, occupational and economic losses, and that the levels of stress and *burnout* associated with care are similar to those observed in the care of individuals with psychotic disorders (Hillege et al., 2006; Zabala et al., 2009).

In view of this scenario, it is understandable that the international guidelines for the treatment of EDs recommend family participation to obtain better therapeutic results (APA, 2006). Working on parents' anxiety and the coping resources they must develop to deal with their children's symptoms can be crucial if they are to understand the nature of psychological distress and provide greater autonomy to patients. The inclusion of the family as a care unit can increase the chances of successful long-term treatment (Leonidas et al., 2019; Scorsolini-Comin & Santos, 2012; Sibeoni et al., 2017). The guidelines recognize the relevance of listening and welcoming these family members, who as a rule do not have as much space in the services as what is reserved for patients. It is established by the literature that support for the family of people with EDs is usually limited to specific orientations, lacking continuous and prolonged support, as is usually offered to affected individuals (McFarlane, 2016; Vall & Wade, 2015). In contrast to what is observed in clinical practice, in the perception of health professionals, the inclusion of family members in the treatment of their sick ones can result in benefits both for themselves and for patients (Souza & Santos, 2012).

Family participation in the treatment of EDs should not be justified just as a result of the emotional impact of daily living with an affected person. Engagement is fundamental above all because the level of family involvement in this process is related to the patient's prognosis, due to the influence of family dynamics on the development and maintenance of symptoms (Siqueira et al., 2020; Valdanha et al., 2013). A study proved that including families in the treatment of ED brings benefits not only in terms of quality of life and well-being of those involved, but also in reducing the days of hospitalization and the need for patients to use hospital resources, which makes treatment costs less (Treasure et al., 2020).

The scientific literature already has meta-syntheses that address the perception of treatment for EDs from the perspective of patients (Espíndola & Blay, 2009) and family members (Sibeoni et al., 2017), however, limited to the field of AN. There are also systematic reviews, such as a study that includes health professionals (Johns et al., 2019). However, meta-synthesis studies were not identified in order to gather qualitative evidence about the perception of treatment for EDs from the perspective of relatives of affected patients. Considering the above, this study aimed to synthesize and reinterpret the results of primary qualitative studies about the perception of family members of people with ED about treatment.

METHOD

Metasynthesis is a methodological tool that seeks to systematize, analyze and reinterpret the results obtained by other primary qualitative studies, recovered from a systematic literature review (Carvalho et al., 2019; Lopes & Fracolli, 2008). For this reason, it is considered an appropriate strategy to achieve the objective proposed by this study. It is structured around an organizing argument and transcends the mere compilation of research already carried out. It is proposed to operationalize a critical evaluation of qualitative studies published in the scientific literature available on a given topic. This interpretative synthesis generates original knowledge expanded from a comparison, translation and new interpretation that the researcher performs on the results of primary studies (Sandelowski & Barroso, 2006).

Data Collection Procedure

This meta-synthesis was registered in the International Prospective Register of Systematic Reviews – PROSPERO (Davies, 2012), protocol number [omitted to preserve the blind review]. The checklist ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research), which establishes the essential elements that a qualitative review must contemplate, was used for the preparation of this study (Tong et al., 2012).

The six steps proposed by Sandelowski and Barroso (2003) for the elaboration of a meta-synthesis were followed, which consist of : 1) Definition of the research question, the parameters and the search strategy; 2) Retrieval of qualitative evidence: systematic searches in databases; 3) Selection of articles to be analyzed; 4) Methodological evaluation of the selected articles; 5) Extraction and analysis of data from articles; 6) Elaboration and presentation of a qualitative synthesis. At the end of the process, the purpose is to create a new analysis based on the integration of the selected qualitative findings.

To achieve the proposed objective of this study, the following guiding question was outlined: "What is the qualitative evidence from the scientific literature on the perception of family members of patients with EDs about treatment?". To structure the search strategy, the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research Type) tool was used, designed especially to identify qualitative studies by combining descriptors, including synonyms and keywords, linked by the Boolean operators AND and OR (Methley et al., 2014) (Table 1).

The systematic searches were carried out by two independent reviewers (MA; MI), in the month of April 2020, in six databases: CINAHL, LILACS, PsycINFO, PubMed, Scopus and Web of Science. These bases were chosen from reading other literature reviews and meta-synthesis studies, and because of the prestige and suitability of each to the objective of the present study.

The descriptors and keywords were listed from the CINAHL Subject Headings, Browse Emtree, Descritores em Ciências da Saúde (DeCS), APA Thesaurus and Medical Subject Headings (MeSH), and with the Boolean operators (AND, OR), respecting the specifics of each database. As an example of a track/set of MeSH terms used to capture the articles: "Feeding and Eating Disorders" AND "Therapeutics" AND "Focus Groups" AND "Perception/psychology" AND "Qualitative Research". There was no limitation on the search period, and articles published on any dates were considered eligible. The search was limited to articles published in Portuguese, English or Spanish, due to the fluency of the researchers.

For the inclusion of articles in the meta-synthesis, the following criteria were outlined: (a) primary qualitative studies; (b) studies that presented the perception of family members about the treatment for EDs. The exclusion criteria were: (a) qualitative studies that did not include human beings (such as theoretical and/or reflective studies); (b) qualitative studies in which there was no participation of family members (such as those that contained only the perception of patients and/or professionals); (c) studies of mixed methods, in which the qualitative results could not be separated from the quantitative findings; (d) quantitative method studies; (e) gray literature; (f) articles published in languages other than Portuguese, English or Spanish.

Table 1
Description of the Spider strategy for literature search

Acronym	Descriptors/Entry terms/keywords
S Sample	“Feeding and Eating Disorders”[Mesh] OR “Feeding Disorders” OR “Disorder, Feeding” OR “Disorders, Feeding” OR “Feeding Disorder” OR “Eating Disorders” OR “Disorder, Eating” OR “Disorders, Eating” OR “Eating Disorder” OR “Appetite Disorders” OR “Appetite Disorder” OR “Feeding and Eating Disorders of Childhood”[Mesh] OR “Anorexia Nervosa”[Mesh] OR “Bulimia Nervosa”[Mesh]
Pi Phenomenon of interest	“Therapeutics”[Mesh] OR “Therapeutic” OR “Therapy” OR “Therapies” OR “Treatment” OR “Treatments” OR “ Psychotherapy, Group”[Mesh] OR “Therapy, Group” OR “Group Therapy” OR “Self-Help Groups”[Mesh] OR “Group, Self-Help” OR “Groups, Self-Help” OR “Self Help Groups” OR “Self-Help Group” OR “Support Groups” OR “Group, Support” OR “Groups, Support” OR “Support Group” OR “Psychodrama”[Mesh] OR “Drama Therapy” OR “Therapy, Drama” OR “Dramatherapy” OR “Art Therapy”[Mesh] OR “Therapy, Art” OR “Art Therapies” OR “Therapies, Art” OR “Psychotherapy”[Mesh] OR “Psychotherapies” OR “Psychotherapists” OR “Psychotherapist” OR “Psychotherapeutic Processes”[Mesh] OR “Process, Psychotherapeutic” OR “Psychotherapeutic Process” OR “Processes, Psychiatric Therapeutic” OR “Therapeutic Processes, Psychiatric” OR “Psychiatric Therapeutic Process” OR “Psychiatric Therapeutic Processes” OR “Therapeutic Process, Psychiatric” OR “Process, Psychiatric Therapeutic” OR “Processes, Psychotherapeutic” OR “Counseling”[Mesh] OR “Helping Behavior”[Mesh] OR “Health Facilities”[Mesh] OR “Facilities, Health” OR “Facility, Health” OR “Health Facility” OR “Group Structure”[Mesh] OR “Structure, Group” OR “Structures, Group”
D Design	“Focus Groups”[Mesh] OR “Focus Group” OR “Group, Focus” OR “Anthropology, Medical”[Mesh] OR “Medical Anthropology” OR “Grounded Theory”[Mesh] OR “Theory, Grounded” OR Culture OR “Thematic synthesis” OR “Hermeneutics”[Mesh] OR Hermeneutic OR Ethnographic OR “ethnographic research” OR Phenomenology OR “phenomenological research” OR Narrative OR “Interviews as Topic”[Mesh] OR Interviewers OR Interviewer OR Interviewees OR “Group Interviews” OR “Group Interview” OR “Interview, Group” OR “Interviews, Group” OR “in-depth interview” OR “qualitative interview” OR “content analysis” OR “semantic analysis”
E Evaluation	“Experience” OR “Experiences” OR “Sense” OR “Senses” OR “Meaning” OR “Meanings” OR “Life Change Events”[Mesh] OR “Event, Life Change” OR “Events, Life Change” OR “Life Change Event” OR “Life Experiences” OR “Experience, Life” OR “Experiences, Life” OR “Life Experience” OR “perspective” OR “perspectives” OR “Subjectivities” OR “Perception/psychology” [Mesh]
R Types of research	“Qualitative Research”[Mesh] OR “Research, Qualitative” OR “Qualitative studies” OR “Qualitative” OR “Empirical Research”[Mesh] OR “Research, Empirical”

To organize primary studies and eliminate duplicates, the Rayyan reference manager was used. The evaluators reviewed the titles and abstracts according to the established inclusion/exclusion criteria. At first, duplicate studies and those that did not meet the inclusion criteria were removed. The lists drawn up by the reviewers were systematically ordered with the help of the software and subsequently compared. The result of this selection carried out by the two evaluators was validated by the Kappa Test, obtaining an inter-judge agreement index of 0.87, which indicates an almost perfect agreement (Viera & Garrett, 2005). The procedures operationalized in this stage were represented by means of a flowchart, according to the model recommended by the PRISMA strategy – Preferred Reporting Items for Systematic Reviews and Meta-Analyzes (Mohan et al., 2009).

Data Analysis Procedure

The scientific quality of the selected studies was assessed according to the quality checklist of the Critical Appraisal Skills Program (CASP, 2018). This instrument consists of 10 questions with the possibility of answering YES (ü); NO (X) and CAN´T TELL (?), Which make it possible to operate a systematic analysis of the quality of a qualitative study. The instrument groups the questions into three major analysis themes: study validity (section A); results (section B) and utility (section C). In case of doubts about the eligibility of the article, the author (MA) and the independent reviewer (MI) made the decision in mutual agreement, after reviewing the article and discussing it with a group of researchers. The studies met most items: eight met all items (42.1%), five studies met nine items (26.3%), four studies met eight items (21.1%) and two studies met seven items (10.5%).

To analyze the data extracted from the studies, the procedure recommended by Thomas and Harden (2008) was used. The authors describe the analysis of the data according to the following steps: 1) Reading of the qualitative primary studies for the identification and creation of free-codes related to the objectives of the thematic synthesis; 2) Systematic grouping of free-codes by related areas, for the construction of descriptive themes; 3) Development of the analytical theme. The constructed themes are presented in the results in the form of meta-synthesis.

For data analysis, the qualitative analysis software QDA MINER LITE® (version 2.07) was used independently by the two reviewers from the previous step, which facilitated the visualization of the codes created, helped in the organization of the codes in a tree structure and allowed to add comments throughout the coded project. The data were extracted from the articles included in the meta-synthesis and transferred to the software. After reading all the data in full, the first stage of coding was initiated according to the line-by-line technique, which initially resulted in eight themes that brought together 45 different codes. In the second stage of codification, the codes were grouped by common themes, rescuing the research question and taking into account those codes that answered it directly, which resulted in four themes with 16 codes, as well as in the descriptive themes.

The author and an evaluator (MA; MI) performed all phases of the data analysis independently. In cases in which divergences were observed in the appreciation of the material, the evaluators discussed it punctually and entered into a consensus. As recommended in the method, the final analysis was discussed and validated by a group of five researchers, who followed the complete process of producing the meta-synthesis. The extraction of data from the articles and their detailed characterization, as well as their reference numbers used throughout this article, are systematized in Table 2.

RESULTS AND DISCUSSION

Figure 1 details the search and selection process for studies eligible for the elaboration of this meta-synthesis. Of the 1115 studies identified, 449 were excluded because they were duplicates (present in more than one consulted database), leaving 666 articles. Then, the titles and abstracts of these studies were read independently by the author and a reviewer (MA; MI), following the previously established inclusion and exclusion criteria. At this stage of the search refinement process, another 640 references were excluded. The remaining 26 articles were retrieved and read in their entirety, of which seven were excluded from this total because they did not meet the inclusion criteria. Thus, the final sample consisted of 19 articles.

Descriptive Theme 1: Family Members' Perceptions of the Relationship with Health Workers

This descriptive theme consists of seven codes – lack of specialization in EDs (8), communication problems (6), exclusion (3), blaming (6), positive aspects in the relationship with professionals (9), universalization (7) and need for information (9). These codes delineate the perception of family members about the services and health professionals responsible for the treatment of their loved ones affected by EDs, as well as the perception about the way they relate to these elements.

The lack of specialization and knowledge about EDs, a code identified in eight of the selected articles (studies number 1, 2, 3, 11, 14, 17, 18 and 19), reflects the perception of family members participating in the studies that, since the beginning of their search for help, health professionals had difficulties in identifying that the symptoms presented referred to a possible diagnosis of ED. Difficulties and barriers were also encountered in finding and accessing specialized services in EDs. A participant's statement illustrates this perception: "My experience is that the initial contact with the primary care professional is not good, simply because he has no experience in dealing with many people who suffer from eating disorders" (study 1, p. 406).

Regarding the relationship between family members and the health professionals responsible for the treatment, six studies (1, 3, 11, 17, 18, and 19) report conflicts and difficulties in communication, either by the team with the family, or by the professionals among themselves. Family members regretted the lack of feedback from professionals about the progress of their loved ones affected by EDs Parents of adolescents with the disorder complained that psychologists and other professionals who cared for their children maintained a good relationship with patients, but not with family members, especially with regard to the failure to provide information about psychological status or needs of the patient. The report of the mother of a patient with ED illustrates these gaps in the communication between family member and health agent: "I was already freaking out at this stage ... I met the doctor on the golf course... he said that I was just a neurotic mother and that it was to get out and leave it to people who know what they are doing" (study 18, p. 71).

Feelings of guilt and exclusion on the part of the professional team responsible for the treatment were present in six (1, 2, 3, 5, 14 and 18) and three articles (7, 17 and 18), respectively. Parents of adolescents and young people with ED, in particular, reported realizing that the professionals attributed the diagnosis of the disorder to the lack of parental skills and failures in the relationship between parents and children, failing to make these family members feel welcomed in their difficulties. This can be illustrated with the excerpt of a mother's speech: "I felt that she was blaming me, you know, that my daughter had an eating disorder because of me" (study 1, p. 407).

Family members also reported feeling isolated and, in some cases, explicitly discouraged from being involved in the treatment of their loved ones affected by EDs, which generated feelings of exclusion (study 17). In some cases, parents even associated their exclusion from treatment with blaming, realizing that being removed from the care that the team dedicated to their children made them feel as part of the problem and, therefore, responsible for it, thus establishing a dynamic and interdependent between the two aspects. This can be illustrated with the excerpt of a mother's statement: "Moving away and leaving her there was one of the worst things I have ever had to do. Looking back now, I wonder if that really was the right thing to do" (study 18, p. 70).

Table 2
Characterization of the studies included in the meta-synthesis

Ref No.	First author, Year, country	Study objectives	Research design / data collection / data analysis	Number of family members participating	Relationship of participants	Type of treatment or intervention to which the study refers
1	McArdle, 2019, Ireland	Explore parents 'experiences after contacting health services to treat their daughters' eating disorders	Generic qualitative study; focus groups or semi-structured individual interviews; interpretative thematic analysis	N = 15	12 mothers and 3 fathers	Multiprofessional outpatient treatment or hospitalization
2	Mitrofan, 2019, United Kingdom	Explore the perspectives of patients and parents on positive and negative aspects of the care offered to young people with eating disorders	Generic qualitative study; *online* focus groups; thematic content analysis	N = 11	9 mothers and 2 fathers	Multiprofessional outpatient treatment or hospitalization
3	Sun, 2019, China	To analyze the search for help and the results of treatment for anorexia nervosa in a sample of family members.	Generic qualitative study; semi-structured group interview; content analysis	N = 6	4 mothers and 2 fathers	Multiprofessional outpatient treatment or hospitalization
4	Toubøl, 2019, Denmark	Examine the perception of parents of patients with eating disorders about their new skills after participating in skills-based training inspired by Maudsley's New Method.	Generic qualitative study; focus groups; deductive thematic content analysis	N = 21	11 fathers and 10 mothers	Skills training for parents of outpatient patients
5	Wufong, 2019, Australia	Build an understanding of how parents of people with eating disorders assign meaning to their experiences and negotiate their identities in the context of multifamily therapy.	Generic qualitative study; semi-structured interviews; critical discursive analysis	N = 13	9 mothers and 4 fathers	Family therapy
6	Berends, 2018, The Netherlands	Understand how patients and their parents experience work with *Guideline Relapse Prevention*, a guide to relapse prevention designed for the context of treatment of eating disorders.	Generic qualitative study; semi-structured interviews; thematic content analysis	N = 12	6 mothers and 6 fathers	Use of a relapse prevention guide at a center specializing in eating disorders
7	Langenberg, 2018, Australia	Explore the experience of families about the involvement of sisters and brothers in the treatment of eating disorders, from the perspective of siblings, patients and parents.	Generic qualitative study; semi-structured interviews; thematic analysis	N = 26	13 mothers, 12 siblings and 1 father	Outpatient family treatment
8	Prior, 2018, United Kingdom	Gain insight into the perspectives of those who may use or refer others to use an eating disorder telephone helpline, to identify the requirements and potentials of this service.	Generic qualitative study; focus groups and individual interviews; inductive thematic analysis	N = 4	Not specified	Telephone lines to support family members and patients with eating disorders
9	Wallis, 2017, Austrália	To investigate the process of change in family relationships of adolescents with anorexia nervosa and their parents, who participated in a family treatment.	Constructionist approach; individual interviews; analysis according to data-based theory	N = 27	15 mothers and 12 fathers	Family post-hospitalization treatment of patients with eating disorders
10	Engman-Bredvik, 2016, Sweden	To investigate the experience of parents of patients with anorexia nervosa in multifamily therapy.	Generic qualitative study; individual interviews; phenomenological analysis	N = 12	6 mothers and 6 fathers	Multifamily therapy for families of patients in multi-professional outpatient or inpatient treatment

Table 2
Cont.

Ref No.	First author, Year, country	Study objectives	Research design / data collection / data analysis	Number of family members participating	Relationship of participants	Type of treatment or intervention to which the study refers
11	Macdonald, 2014, United Kingdom	Explore the perception of patients and their caregivers about the quality of the relationship between them after the caregivers have received a skills training intervention.	Generic qualitative study; written questionnaires; thematic content analysis	N = 115	Unspecified (mostly mothers)	Skills training for caregivers of people with eating disorders undergoing hospitalization
12	Patel, 2014, USA	Understand how a child's eating disorder affects the parents' life and well-being; understand the main barriers and motivations that parents experience to engage in adaptive coping behaviors; determine what are the reactions to messages that encourage self-care.	Generic qualitative study; focus groups; comparative analysis	N = 19	15 mothers and 4 fathers	Self-care messages for parents of people with eating disorders undergoing outpatient or hospital treatment
13	Ma, 2012, China	Identify the symptomatic cycle of family interactions that maintained the symptoms of the eating disorder; find out if the family therapist, in his role as facilitator, promoted contextual changes in the family; understand the roles of the family and the therapist in these changes.	Generic qualitative study; semi-structured family interviews and transcription analysis of recorded therapeutic sessions; content analysis	N = 20	10 mothers and 10 fathers	Family therapy offered at a family treatment center for eating disorders
14	Whitney, 2012, United Kingdom	Explore the perception of the effectiveness of treatment, caregiver satisfaction and the change process in caregivers of people with anorexia nervosa who participated in individual family work or in multi-family workshops	Generic qualitative study; individual interviews; Interpretative Phenomenological Analysis	N = 23	17 parents, 4 siblings, 1 husband and 1 daughter	Family therapy or multifamily workshops for families of patients in hospital
15	Ma, 2006, China	Explore the perception of patients with anorexia nervosa and their families about family therapy	Generic qualitative study; family interviews; thematic analysis	N = 24 families	Parents (unspecified quantities)	Family therapy at a treatment center for eating disorders
16	Highet, 2005, Australia	Identify the experiences and difficulties of caregivers of people with eating disorders throughout the disease process up to the point of accessing treatment	Generic qualitative study; focus groups and individual interviews; thematic analysis	N = 24	Parents and partners (unspecified quantities)	Treatment in specialized services for eating disorders
17	Tierney, 2005, United Kingdom	Investigate the perspective of parents of people with eating disorders on treatment	Generic qualitative study; semi-structured interviews; thematic analysis	N = 14	8 mothers and 6 fathers	Multiprofessional outpatient treatment or hospitalization
18	McMaster, 2004, Australia	Explore the interactions between parents of people with eating disorders and health professionals	Generic qualitative study; individual interviews; thematic analysis	N = 22	19 mothers and 3 fathers	Multiprofessional outpatient treatment or hospitalization
19	Winn, 2004, United Kingdom	Determine the extent to which health services meet the support needs of caregivers of people with bulimia nervosa and whether they feel the need to seek help for themselves.	Generic qualitative study; telephone interviews; thematic content analysis	N = 20	14 Mothers, 1 father and 5 emotional partners	Multiprofessional outpatient treatment or hospitalization

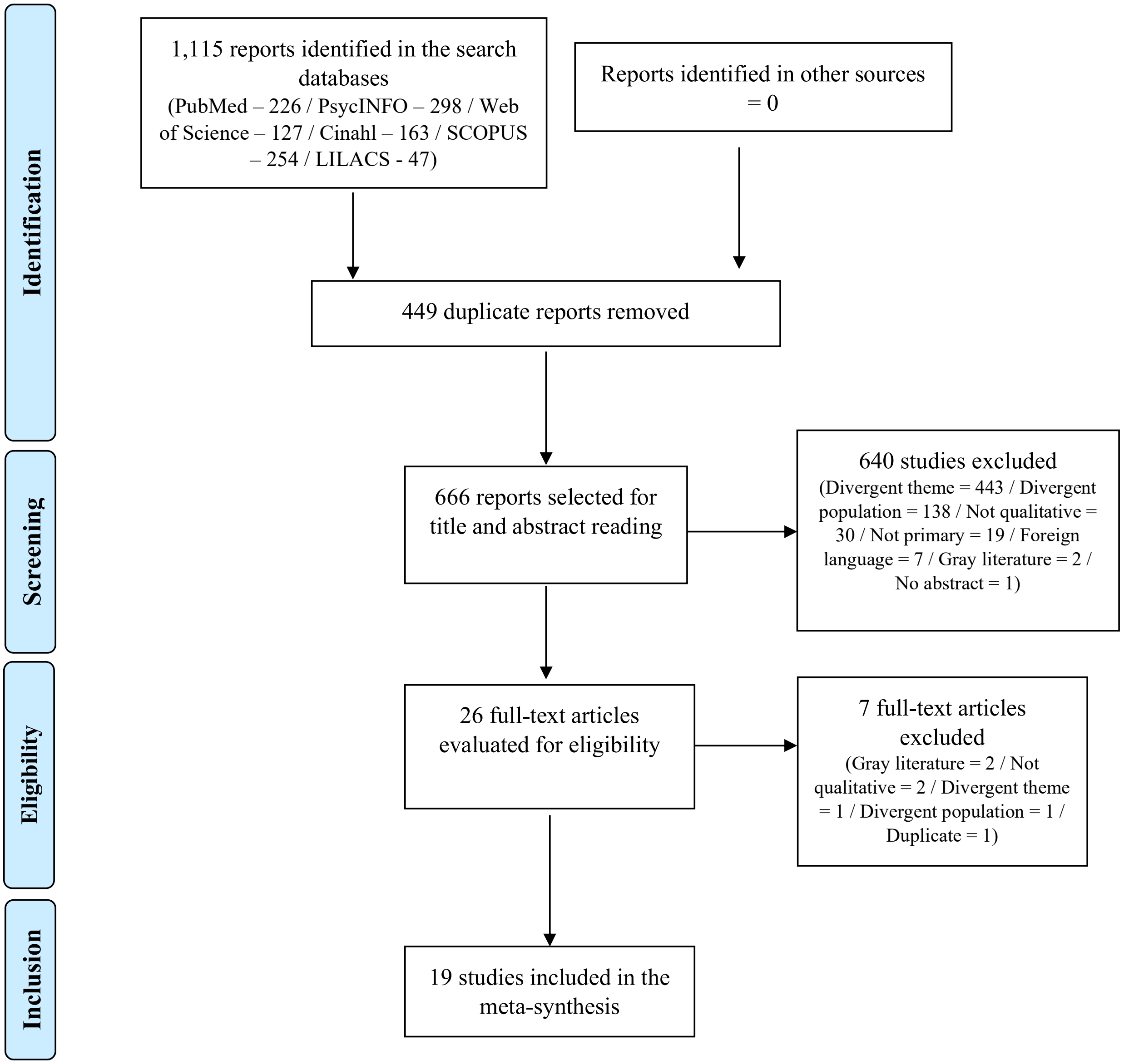

Figure 1. Flowchart with the steps for selecting the meta-synthesis articles
Source: prepared by the authors.

Despite the conflicts experienced in the relationships and the communication difficulties mentioned, positive aspects of the relationships between family members and health professionals appear in nine articles (1, 6, 8, 9, 13, 14, 15, 17 and 18), that is, in half of the sample of meta-synthesis. The participants are grateful for the empathy with which some professionals addressed them, as well as associating the permanence or even success in the treatment with the relationship established with the health agents, as well as the confidence and support inspired by them in the directions and tips offered. “The most important point for us, as parents, was to have someone to turn to when things were not going well. The relationship with the health professional, that back-up, gave us the confidence to go through it” (study 6, p. 1550).

Seven articles (2, 10, 11, 12, 14, 16, and 19) contemplate the code referring to universalization, that is, to the importance attributed by the family to the spaces of exchange and sharing with other people who are going through or have gone through similar situations, which commonly occurs in support groups. Participants refer that the dialogue with other relatives of people with ED helps to reduce feelings of isolation and guilt, increases hope, helps in better understanding of the disease and also allows learning from the experiences of others, as illustrated by a mother : “I went to some of the support groups, which were fantastic because I didn't know enough about it, and I said 'she does this and she does that', and they said, 'yes, yes, they do that too' , so they were fundamental to overcome the whole situation, because I knew that everyone else was going through the same as me"(study 16, p. 339). A study by Souza and Santos (2010) showed that, for the relatives of people with ED, the support group works as a space that favors the production of meanings about the disorder, thus allowing its members to deconstruct and reconstruct the meanings of their experiences.

Another code, present in nine articles (1, 2, 3, 7, 8, 15, 16, 18, 19), expresses the family members' need for more qualified information about the disorder, the details of the treatment, and the health status of the affected patient, evidencing their perceptions regarding an insufficient supply of clarification by the services and professionals involved in the treatment. Only a few participants report having obtained sufficient information regarding the mentioned aspects, as shown by three studies included in the meta-synthesis (articles 10, 14 and 19). In these cases, family members point out that they were offered an adequate amount of clarification, with answers to their doubts and explanations about the treatment. One statement suggests how a mother felt satisfied with the information received, while showing the importance of an active attitude on the part of her to seek the literature indicated by the health service where she performed her daughter's treatment.

Descriptive Theme 2: Family Members' Perception of the Format and Structure of Treatment

This descriptive theme consists of four codes: treatment focus (6), treatment structure (5), understanding of the objectives (2), everyone's voice (4), which show the perception of relatives of people with EDs regarding of the format and structure of the treatments offered to their affected loved ones.

The focus of treatment, a topic that appears in six studies (2, 3, 5, 14, 17 and 19), highlights the opinions of family members about the aspects that they consider to be prioritized by health services and professionals in the care of their loved ones with EDs. Several reports from the participants question or criticize the exaggerated importance that health care units attribute to body weight and physical symptoms in general, defining them as admission criteria for treatment or even as reliable measures of patient improvement, as can be seen in the statement of a mother: "The focus seems to be all on the dietary aspects, but from my point of view as a mother, food is the end product of the whole problem. What's going on underneath that? What is causing all this?"(study 5, p. 9). When family members criticize the focus that is placed on the progress of physical symptoms to the detriment of, for example, emotional/psychological progress, some express their opinion about what could or should have been considered in the treatment, such as behavioral and psychological patterns, underlying difficulties, family conflicts, or even the need for family welcoming.

Regarding the structure and organization of treatment, five articles (1, 10, 14, 15 and 17) expose the family members' perspective on their own experiences. One of the attributes considered is the question of patients' participation or not during therapeutic or orientation sessions aimed at family members. Family members who did all the sessions in the presence of their loved ones affected by EDs expressed frustration associated with this *modus operandi*, reporting that they missed exclusive sessions for them, in order to make room for them to feel more comfortable to share their difficulties and unpleasant emotions, as the excerpt illustrates: "[We would have enjoyed] sessions in which we were alone ... when we could have been more honest in expressing our feelings" (study 17, p. 374). On the other hand, some family members who participated in meetings with and without the patient believe that it would be important for those affected by EDs to be present in more moments than they were in fact, so that there was more sharing of experiences and dialogue within the family itself. "A lot of work was done without [my daughter] being there and then she was brought as a patient, to participate ... to a certain extent her feeling was that she was excluded" (study 14, pp. 135-136).

Two studies (numbers 1 and 14) highlight the family members' perspective on the objectives and goals of family treatment for EDs. The participants presented different understandings regarding the objectives of the same treatment model, showing that this aspect had not been properly understood or had not been exposed with sufficient clarity to the family members, which, according to them, increases dysphoric feelings, such as anxiety and fear. While some believed that the main objectives were to better understand the disease itself and improve communication strategies, others believed that the goal was to identify problems and difficulties in each family and work on them in a specific way. Some understood that the objective was to create strategies to obtain weight gain for the person affected by ED, and there were still those who understood that the objective of family treatment was to learn care techniques used in the hospital or health unit to apply them in the home environment.

Family members report that they had difficulties in assessing whether the treatment was in fact being effective and consistent with what was proposed, precisely because the goals and objectives were not known to them with clarity and objectivity. In some cases, feelings of frustration were reported for realizing that their understanding of the objectives did not correspond to what was being offered or proposed in the health service.

Despite the unpleasant emotions experienced by family members during the treatment of their loved ones affected by EDs, four studies (5, 9, 15 and 17) report statements by family members that evoke positive perceptions of treatment, especially associated with a specific aspect: the experience of feeling that both their own and their family members' voices were heard during family therapy. The participants in these research expresses satisfaction and gratitude in relation to the fact that all family members were able, many of them for the first time, to have a place to talk and "vent" about the repercussions of ED in their daily lives.

Descriptive Theme 3: Family Members' Perceptions of Treatment Results

This descriptive theme is composed of five codes: no progress (4), improvement in symptoms (6), improvement in parenting style (8), improvement in self-care and coping (7), and awareness of the importance of their role (6). These codes expose family members' perspectives regarding treatment results, that is, their consequences, progress, and outcome, both for themselves and for their loved ones with ED.

Four articles (5, 11, 17 and 19) highlight the perception of family members that there has been no progress in the symptoms of the patient being treated. The perception of lack of improvement of the ED during the process was related to previous expectations about the treatment, the expected results, and the time needed to obtain the desired effects, as suggested by the words of a father: "I wasn't prepared for the time it took to get to where we are today. It has been a very gradual process" (study 17, p.376). Despite the dominant perspective that the expected progress in these cases has not been achieved, six studies (9, 11, 13, 15, 17 and 19) report the perception of improvements in general conditions and in the symptoms of the patient affected by ED. Some participants mentioned progress in psychological terms, such as mood stabilization, greater willingness, resilience and patients' self-confidence; other reports showed the perception of improvement in functionality and in observable symptoms, which are commonly associated with EDs; it was mentioned, for example, that the patient started to engage more in behaviors related to eating or to worry less about this aspect, opening space in his life to be interested in activities that were previously left out.

Regarding the effects of treatment perceived by family members in relation to themselves as participants in this process, eight articles (4, 5, 9, 10, 11, 13, 14 and 15) report improvement in parenting style. The family members identified positive changes in the relationship with the entities affected by EDs, managing to establish a more assertive and effective communication with them. They also noticed an improvement in the ability to offer space and encourage patient autonomy and independence. They claimed to have learned to communicate more positively, to express their feelings more authentically, and to listen more to what the patients had to say. They have also learned to identify, discern, and assume their responsibilities in the relationship, distancing themselves from anything that deviates from that scope.

Still in relation to the positive results of the treatment and its reflexes perceived in themselves, in seven articles (4, 9, 10, 11, 12, 15, 17) family members emphasize that there was an improvement in terms of self-care, which had a positive impact on the coping with adverse situations generated by living with patients' symptoms. Family members refer that the treatment for ED favored the acquisition of new skills by the sick person to deal with the problem in which they were involved, which contributed to the mitigation of unpleasant feelings, reducing stress and anxiety. They claim that they managed to distance themselves enough to also look at themselves with compassion and not only at the person affected by the disease and their suffering, thus being able to increase their continence and offer more effective support to the patient. They report observing, in themselves, more behaviors aimed at self-care compared to the moments prior to the treatment, when they perceived themselves completely absorbed by the care directed to the sick person. In general, the reports converge when they recognize that they have allowed themselves to change, adopting a more flexible attitude towards the dysfunctional behaviors of their children, which made it possible to deal more positively with the situations experienced and increase their levels of subjective well-being.

Finally, a last outcome perceived by family members as a gain from the treatment is the fact that they begin to recognize the importance of their role both in the life of the person in distress and during treatment itself, a theme present in six of the studies that comprise this meta-synthesis (articles 3, 4, 5, 7, 9, and 13). Several parents of adolescents with ED have reported noticing, during the course of treatment, how their behavior influenced the onset or worsening of symptoms, as well as the possibility of alleviating them. Parents report that they started to observe themselves more frequently, perceiving themselves as active and essential agents in the search for resources to improve the health status of their daughters and sons, paying greater attention to their own behaviors and modes of interaction, and becoming more engaged in joint family work toward recovery. Some parents reported realizing that their responsibility in treatment was at least as relevant as the role they attributed to professionals, as the following excerpt exemplifies: "I think we are now very aware that the hospital lends a helping hand, but that the main things really happen in the family" (study 4, p. 963).

Analytical Theme: From Caregiver To (being) Cared

The analytical theme *From caregiver to (being) cared* was built from the interpretation of a constancy identified in the four descriptive themes about the perceptions of family members about the treatment for EDs of their affected loved ones. This construction reflects the perceived need to change the roles played as social actors in the treatment, gradually assuming a more important and leading role in the commitment to improvement.

In the family's understanding of treatment, the focus of the therapeutic process and the axis of action of health professionals still seem to fall predominantly on patients' symptoms. This centrality in the psychopathological dimension favors defensive attitudes. Participants in the analyzed studies reported feelings of exclusion and blame on the part of the health team responsible for the treatment (studies 1, 2, 3, 5, 7, 14, 17 and 18) and lack of support directed to family members (studies 2, 3, 16, 18 and 19). They criticized and questioned the focus of the interventions exclusively on the patient (studies 2, 3, 5, 14, 17, and 19), were unaware of the goals of the recovery process (studies 1 and 14), and had confusing perceptions about the progress, or lack thereof, in the evolution of the ED picture (studies 5, 9, 11, 13, 15, 17, and 19).

However, when the family member turns his attention to himself and to his perceptions about his own implication in the treatment process, there are reports about the relevance of maintaining a good relationship with health professionals (studies 1, 6, 8, 9, 13, 14, 15, 17 and 18), the importance of support groups and of contact with other families dealing with the same problem (studies 2, 10, 11, 12, 14, 16 and 19), the use of treatment for their own benefit as a space to listen (studies 5, 9, 15 and 17) and, finally, perceptions of good results only regarding their own progress within the treatment process (studies 4, 5, 9, 10, 11, 12, 13, 14, 15 and 17), besides a greater understanding about the real dimension and power of their role as family members of the person with ED (studies 3, 4, 5, 7, 9 and 13).

Taking these aspects into consideration, it is important that the family member is positioned in the treatment as the patient's caregiver, but can also be helped to evolve, throughout the process, to occupy a position of being (of) care, that is, someone who admits the need to receive care for himself and accepts the challenge of experiencing changes in his own functioning (Souza & Santos, 2012). In EDs, the etiological hypothesis rests, in part, on the contribution of factors related to family dynamics, which also has an influence on the maintenance of symptoms (Siqueira et al., 2020). For this reason, it is relevant that the family member understands himself as an active care agent, more than a companion in the treatment, and that he gradually understands that the process of appropriating his role implies assuming that the therapeutic action is also directed to him or that also makes him a beneficiary. In line with the present study, the empirical research developed by Treasure et al. (2020) and the literature reviewed by Valdanha et al. (2013) corroborate the need to expand the focus of treatment attention, in order to include the family in the therapeutic plan from the beginning. No research has been found in the scientific literature that contradicts this position.

This understanding, which involves changing the position initially assumed in relation to treatment, cannot be seen as the responsibility of the family alone, since it also depends on facilitating interventions instituted by the health team. Professionals need to position family members as healers, perceiving them as potential allies and offering care devices so that they can develop their resources (Souza & Santos, 2012). This may favor their involvement in the treatment and facilitate the acceptance of the fact that they become recipients of care actions. Thus, there can be a rotation of perspective when the family-caregiver understands that treatment is not a space offered only to the sick member, but also to himself, who will thus be able to experience changes as he actively gets involved in the other's change process.

FINAL CONSIDERATIONS

The results of this meta-synthesis show the different ways in which the relatives of people with ED perceive the treatment of the person affected. It remained clear that the eventual benefits obtained with the therapeutic intervention are not restricted to only mitigating the patients' symptoms, but also have positive effects on the feelings, attitudes and behaviors of the family members who accompany the treatment.

The analytical theme developed in this study highlights the need to recognize the emotional needs of the family-caregiver along the *healing* path, as he moves from a position from supporting the treatment of the person diagnosed with ED to a place of care receiver. This proposition is in line with the scientific evidences that family dynamics have an important contribution to the etiology, development and maintenance of EDs. It is understood that, in families in which a mental disorder of this type develops, it is necessary to invest in the transformation of family dynamics so that more effective and lasting gains can be obtained from the treatment.

This meta-synthesis has some limitations. Only studies carried out on the international stage were identified, and none of them came from Latin American countries, which are culturally closer to the Brazilian reality. This aspect limits the comparability of the results obtained by different studies.

In addition, not all selected studies contributed equally to the elaboration of the highlighted themes; some contributed more than others to the construction of certain categories, which makes the representativeness of each descriptive theme different.

The predominance of foreign articles is an obstacle to assess the cultural variability of the phenomenon and makes it difficult to generalize the results found for the Brazilian population and for Latin America and the Caribbean in general. Still, considering the findings obtained in the light of clinical practice and the experience accumulated over almost four decades uninterrupted in a reference service in the care of patients with anorexia and bulimia, one can bet on possible similarities with the national context.

In the national context, this meta-synthesis provides subsidies for the Brazilian public health service to appropriate this knowledge to plan assistance to patients with EDs within the scope of the Brazilian Unified Health System (SUS), so that they can be welcomed by the RAPS in the most appropriate way as effective and appropriate as possible. Raising awareness of the potential role of family members in the treatment response of individuals with EDs must be a joint undertaking, encompassing all those involved: patients, family members, and the healthcare team. It is expected that, with this understanding on the part of health professionals, there will be more space and encouragement for the family to take a stand, which means a more empowering appropriation of their place in the treatment.

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