Anorexia Nervosa’s Meaning to Patients: A Qualitative Synthesis

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Abstract

Background: We carried out a qualitative synthesis of international literature to provide insight into the patient’s experience as a means to help clinicians recognize symptoms of anorexia nervosa. Method: International publications from 1990 to 2005 were searched for relevant qualitative investigations, and meta-ethnography was employed to identify common themes across studies. Databases included were PubMed, ISI, PsycINFO, EMBASE, LILACS and SciELO. Results: 24 studies were included from a total of 3,415 papers. The second-order interpretation process using reciprocal translation allowed the identification of two concepts: (1) symptom identification (disease representation, self-concept, development of anorexia) and (2) disease interpretation (positive aspects, negative aspects, areas of life affected). Third-order constructs emerged revealing the disease as connected with identity and control. Conclusion: Knowledge of patients’ efforts to interpret the illness as a part of their own identity and sense of control have a key role in physician understanding of the disorder by allowing physicians to bring structure to the patients’ lives generally and to their help-seeking behavior specifically. The study has some limitations. Most of the results come from B-grade studies (as classified by the Critical Appraisal Skills Programme) that used qualitative methodology, implying the need for caution in data interpretation. Moreover, study populations were almost exclusively female, and no comparison was attempted concerning the severity of the condition between studies.

Introduction

Qualitative research has been recognized as a legitimate way to obtain knowledge that might not be accessible by other methods and to provide extensive data on how people interpret and act upon their illness symptoms. Recently, qualitative research has found increasing recognition within health-related fields as a reliable and important source of knowledge about health and healthcare. The proliferation of empirical studies using qualitative methods has led to an accumulation of a substantial body of qualitative health research. At the same time, there has been a growth of interest in evidence-based policy [1, 2].

Qualitative research obtained from purposeful samples – such as clinical cases and focus groups as well as those obtained via semistructured interviews and participant observation – seek to investigate the meaning of anorexia nervosa and patient experiences with the disease through patient interviews. The results of this research reveal a complex structure characterized by the
presence of many variables, outstanding among which are various ways of understanding the disease, peculiarities of personal history, emotional difficulties, and the structure of family dynamics [3–5]. Other studies have identified experiences related to rejection, low self-esteem, insecurity, and autoevaluation centered on the body [6–8]. As would be expected, most research has involved small samples, generally from 1 to 12 patients [3, 9–11].

The understanding of the clinical manifestations of anorexia nervosa has been enhanced by psychodynamic and cognitive investigations. The psychodynamic theories were enriched by the work of Bruch [12–15], Boris [16], Skårderud [17], Farber et al. [18], and others. Among various considerations, anorexia nervosa is seen as a multidetermined symptom, in which appear attempts to create a new identity, deal with counterattacks to the self, give birth to a true self, come up with defense mechanisms to cope with parental conflicts, manage annihilation anxieties, and develop ‘emotional metaphors’ to articulate where emotions are materialized in the body. The cognitive theories, including those put forth by Kleinfeld et al. [19], are supported by two basic assumptions. The first is that avoiding food is primary for the maintenance of the disorder. The second is that anorexia nervosa would have a positive function in the patient’s life, thus offering a way out of the difficulties faced at different stages of the development of the disorder, in addition to the cognitive distortions that accompany the disorder. In this sense, the disorder to which the patient is attached is constantly being reinforced.

With regard to the clinical and theoretical considerations concerning the topic, there is a consensus among health professionals involved with the care for patients presenting with anorexia nervosa that the treatment is difficult independent of the theoretical concept used [20–23]. In addition, the treatment is not limited to weight gain, but is also related to personality disorders. Westen and Harnden-Fisher [24] assessed the functioning of the personality of patients with eating disorders. From this study, three categories were observed: (1) a group showing little emotional control, (2) a group with excessive control, and (3) a group of perfectionists. Patients with the purgative subtype of anorexia tend to be more impulsive than restrictive, from which the latter would be more perfectionist and obsessive. The key psychological characteristics with which these patients commonly present are low self-esteem, feeling of hopelessness, unsatisfactory development of identity, tendency to seek external approval, hypersensitivity to criticism, and conflicts referring to issues regarding autonomy and/or independence. According to the results obtained, the authors considered these distinctions to be relevant to the etiology, prognosis, and treatment of anorexia nervosa. Because interventions in this population are known to be difficult and involve the way patients experience the disease, a study summarizing the results to date may be useful. In as much as we have not found literature reviews on the subject, the present work presents a systematic review and metasynthesis concerning the meaning of anorexia nervosa from the patient’s perspective. The integration of findings from different qualitative studies about anorexia nervosa is important in order to extend our understanding in this field. In addition, we aim to develop a hypothesis about the nature of this disorder and how it relates to more effective therapeutic interventions.

**Methods**

The research comprehended three distinct phases: (1) systematic literature review, (2) critical analysis of the papers, and (3) metasynthesis.

**Systematic Review**

**Search Sources.** An exhaustive electronic bibliographic search was carried out. The following databases were used as search sources: PubMed, LILACS, SciELO, ISI, PsycINFO and EMBASE.

**Search Strategy for Electronic Databases.** This research used the following descriptor terms: eating disorder, anorexia nervosa AND qualitative research, qualitative study, phenomenology, perspective, perception, experiences, and comprehension, respecting the peculiarities of each database.

**Selection of Qualitative Studies.** The selection of manuscripts is not free from debate. As proposed by Dixon-Woods et al. [1], we opted for a quality inclusion strategy.

Inclusion criteria were as follows: (a) Studies had to have been published in English, Spanish, French, or Portuguese in the last 15 years (from 1990 to 2005). (b) Papers had to report qualitative research about patient experiences with anorexia nervosa, according to DSM-IV criteria. We focused on patients with anorexia nervosa independent of the degree of severity and with adolescents and adults only. (c) Papers had to report the following methodological structure: original study, clear theoretical framework, and purposeful sample with sample size defined by saturation; papers also had to report on analyses based on qualitative methods of data extraction and results obtained through text-based transcriptions and interpretations.

Exclusion criteria were as follows: (a) chapters or books, as well as master’s theses or dissertations; (b) studies focused on psychiatric disorders or comorbidity other than eating disorders; (c) investigations assessing children or the elderly; or (d) secondary analyses of previous studies.
Critical Assessment of Papers. The adopted quality criteria were assessed by the standardized form Critical Appraisal Skills Programme (CASP) [25], which traces lines for quality appraisal of qualitative research. CASP consists of 10 items that allow the classification of papers in categories pursuant to the methodological structure. The studies were classified in categories A and B.

Category A studies have a low risk of bias. They meet at least 9 of the 10 criteria proposed, which comprise the following: (1) objectives are clear and justified; (2) methodological design is adequate to the objectives; (3) methodological procedures are presented and discussed; (4) sample selection is purposeful; (5) data collection is described with explicit instruments and saturation process; (6) relationship between researcher and interviewee is considered; (7) ethical care is taken; (8) dense and well-based analysis is carried out; (9) results are presented and discussed, point to the credibility aspect, and use triangulation, and (10) the analysis is carried out; (9) results are presented and discussed, considering the contributions and implications of the knowledge generated by the research, as well as its limitations, are discussed.

Category B studies meet at least 5 of the 10 items proposed, meaning that they partially meet adopted criteria and thus present risk of moderate bias. Case studies and convenience samples belong to this category.

There were no disagreements between the two researchers regarding study categorization, and studies were deemed to fit the inclusion criteria for the review.

Extraction and Data Synthesis. Metasynthesis is a method involving induction and interpretation that provides an alternative to traditional synthesis methods by allowing the researcher to understand and transfer ideas, concepts and metaphors across different studies. Meta-ethnography is one of the most well-developed and frequently used methods for synthesizing findings of qualitative studies [26–29]. Part of the appeal of meta-ethnography to qualitative researchers is its potential to preserve the properties of primary data and facilitate the identification of themes that run both within and across studies. Also, it is one of the few methods to lay out explicit guidelines for conducting a synthesis. Unlike traditional review work, meta-ethnography aims to derive new insights. The meta-ethnographic method involves selecting relevant empirical studies to be synthesized and then reading them repeatedly and noting key concepts. These key concepts become the raw data for the synthesis. The synthesis is achieved through three techniques: (1) Reciprocal translation analysis, which entails examining the key concepts across each study. An attempt is made to translate the concepts into each other. Judgments about the ability of the concept of one study to capture concepts of others are based on the attributes of themes themselves, including cogency, economy and scope. The concept that is ‘most adequate’ is chosen. (2) Refutational synthesis, in which the key concepts and themes in each study are identified and contradictions between the reports are characterized. The ‘refutations’ are examined and an attempt is made to explain them. (3) Lines of argument synthesis, which involves building a general interpretation grounded on the findings of the separate studies (similar to comparative analysis of the Grounded Theory).

Although these translations allow comparisons between different studies, they preserve the structure of relations between concepts. The translation process goes through two stages as suggested by Noblit and Hare [30]. The first is called second-order interpretation and is based purely on original results when the synthesis itself is done. The contexts and concepts relevant to each study are registered for a better understanding of interpretations. Text re-readings are done to standardize terminology and incorporate new concepts. The start of the synthesis process translates the findings from an individual study to provide an understanding of how this work interrelates with others. Each new concept is examined through convergent and divergent cases through a process called reciprocal translation.

The second stage is called third-order interpretation. In this stage, interpretation goes beyond the meaning of the original results and interpretations, advancing conceptually and bringing out a new reading of the original categories synthesized. As a result, third-order interpretation can constitute a new construction of hypotheses or theories concerning the area of study.

The reading and extraction of categories were carried out by two independent reviewers (C.R.E. and S.L.B.). Categories used in assessment and metasynthesis were obtained through a consensus among appraisers. One of the articles [10] was used as a reference for organizing the comparison process between the different investigations.

Results

The search turned up 3,415 documents. Those in which the title and summary agreed with our interests were selected for complete reading. Out of these, 24 fulfilled the inclusion criteria. According to the quality criteria applied, 3 studies were classified as Category A and 21 as Category B. Tables 1 and 2 show study characteristics. Table 1 includes papers that exclusively considered patients with anorexia nervosa, while table 2 includes studies with mixed disorders, i.e., anorexia nervosa and bulimia.

The papers read in this study yielded a total sample of 369 female patients and 13 male patients. Patient ages in the studies ranged from 13 to 63 years, with most studies focusing on samples around the age of 18 years. Regarding assessment instruments, 19 investigations used semi-structured interviews with patients, 2 used case studies, 2 used focal groups, and 1 used letters addressed to anorexia nervosa as if a ’friend‘ or an ’enemy‘.

The articles appeared in journals from the following countries: 6 from the USA, 2 from Canada, 2 from China, 2 from New Zealand, 1 from Australia, 1 from Israel, 1 from Spain and 1 from Brazil.

The editorial foci of the journals were eating disorders (n = 8), general psychiatry (n = 3), clinical medicine (n = 3), qualitative research methodology (n = 3), and nursing (n = 3). Although the publications had different purposes and the studies were carried out in different contexts, various similarities were found in the experiences related for anorexia nervosa.
Second-Order Interpretation

Through the reading and saturation process, various concepts emerged from the works. The process of second-order interpretation used in the reciprocal translation allowed the identification of two concepts: (1) symptom identification (disease representation, self-concept, development of anorexia) and (2) disease interpretation (positive and negative aspects, areas of life affected). The concepts and second-order interpretations can be seen in Table 3.

At this stage, the results for each text were submitted to operations that allowed highlighting of information. This construction work was processual, involving a series of approximations to reach the central categories.

Table 1. Studies with anorexia nervosa (n = 17)

<table>
<thead>
<tr>
<th>Group</th>
<th>Study location</th>
<th>Sample</th>
<th>Qualitative design/data analysis method</th>
<th>Study quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgenor et al. [3]</td>
<td>New Zealand</td>
<td>7 women</td>
<td>Interview</td>
<td>B</td>
</tr>
<tr>
<td>Chan and Ma [4]</td>
<td>China</td>
<td>1 patient and family</td>
<td>Interview</td>
<td>B</td>
</tr>
<tr>
<td>Hardin [5]</td>
<td>USA</td>
<td>12 women</td>
<td>Interviews</td>
<td>B</td>
</tr>
<tr>
<td>Guzman et al. [8]</td>
<td>Brazil</td>
<td>7 patients (20–42 years old)</td>
<td>Case study</td>
<td>B</td>
</tr>
<tr>
<td>Lamoureux and Bottorff [9]</td>
<td>Canada</td>
<td>9 women (19–48 years old)</td>
<td>Interview-grounded theory</td>
<td>B</td>
</tr>
<tr>
<td>Colton and Pistrang [10]</td>
<td>UK</td>
<td>19 women (12–17 years old)</td>
<td>Semistructured interviews</td>
<td>A</td>
</tr>
<tr>
<td>Hsu et al. [31]</td>
<td>UK</td>
<td>6 patients (17–44 years old)</td>
<td>Case study</td>
<td>B</td>
</tr>
<tr>
<td>Serpell et al. [32]</td>
<td>UK</td>
<td>18 women (mean age = 24.1 years old)</td>
<td>Letters</td>
<td>B</td>
</tr>
<tr>
<td>Thomsen et al. [33]</td>
<td>USA</td>
<td>28 women (18–43 years old)</td>
<td>Interview</td>
<td>B</td>
</tr>
<tr>
<td>Tozzi et al. [34]</td>
<td>New Zealand</td>
<td>69 women (mean age = 32.3 years old)</td>
<td>Interview</td>
<td>B</td>
</tr>
<tr>
<td>Tan et al. [35]</td>
<td>UK</td>
<td>10 women (13–21 years old)</td>
<td>Interview</td>
<td>B</td>
</tr>
<tr>
<td>Tan et al. [36]</td>
<td>UK</td>
<td>10 women (13–21 years old)</td>
<td>Interviews</td>
<td>B</td>
</tr>
<tr>
<td>Tan et al. [37]</td>
<td>UK</td>
<td>10 women (13–21 years old)</td>
<td>Interviews</td>
<td>B</td>
</tr>
<tr>
<td>Williams et al. [38]</td>
<td>USA</td>
<td>28 women (18–43 years old)</td>
<td>Interviews</td>
<td>B</td>
</tr>
<tr>
<td>Bacher-Melman [39]</td>
<td>Israel</td>
<td>4 women (23–40 years old)</td>
<td>Interview</td>
<td>B</td>
</tr>
<tr>
<td>Weaver et al. [40]</td>
<td>Canada</td>
<td>12 women (14–63 years old)</td>
<td>Interview-grounded theory</td>
<td>B</td>
</tr>
</tbody>
</table>

Table 2. Studies with mixed eating disorders: anorexia/bulimia (n = 7)

<table>
<thead>
<tr>
<th>Group</th>
<th>Study location</th>
<th>Sample</th>
<th>Qualitative design/data analysis method</th>
<th>Study quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Woods [6]</td>
<td>USA</td>
<td>16 women and 2 men (18–21 years old)</td>
<td>Interviews by e-mail</td>
<td>B</td>
</tr>
<tr>
<td>Keski-Rahkonen and Tozzi [7]</td>
<td>USA</td>
<td>155 women and 3 men (13–53 years old)</td>
<td>Internet messages</td>
<td>B</td>
</tr>
<tr>
<td>Nevonen and Broberg [41]</td>
<td>Sweden</td>
<td>125 women (18–25 years old)</td>
<td>Grounded theory</td>
<td>A</td>
</tr>
<tr>
<td>Drummond [42]</td>
<td>Australia</td>
<td>8 men</td>
<td>Interviews</td>
<td>B</td>
</tr>
<tr>
<td>Etxeberria et al. [43]</td>
<td>Spain</td>
<td>12 patients</td>
<td>7 focal groups</td>
<td>A</td>
</tr>
<tr>
<td>Redenbach and Lawler [44]</td>
<td>Australia</td>
<td>5 women (above 18 years old)</td>
<td>Interviews</td>
<td>B</td>
</tr>
<tr>
<td>D’Abundo and Chally [45]</td>
<td>USA</td>
<td>20 women</td>
<td>Interviews; focal groups; participant observation</td>
<td>B</td>
</tr>
</tbody>
</table>
problematic and involves living without a part of the subject’s own identity. Certain uniformity is highlighted in relation to the descriptions:

‘It’s part of me now (…) it’s my identity’ [35].

‘Everything would be different. My personality would be different. I know it is a big part of me, I think I cannot live without it, get rid of the feelings, you will always have part of it in you.’ [35].

‘Even when my mother tried to force me to buy new clothes, I refused. That’s because I didn’t need them nor wanted to change my clothes. I only thought about my size number’ [11].

(b) Anorexia Nervosa as a Coping Strategy [10, 11, 32, 35–38, 45]. Several accounts from patients show anorexia nervosa as a way of coping, of handling psychological suffering and controlling external events and demands as well as adolescent transformations. Some descriptions from patients are as follows:

‘It was my way of coping. It was not a very effective way of escaping reality. It was my way of coping. It was not a very effective way because it was just ignoring what was going on… but I guess at the time, that was the only thing I had.’ [38]

(c) Denial of Disease [3, 5–7, 11]. This eating behavior is considered normal by some patients, since they do not consider themselves mentally ill. They recognize some symptoms, but do not accept the disease itself and provide a wealth of personal interpretations while exhibiting a notorious lack of consciousness of the disease.

‘Only my loss of weight has something to do with anorexia nervosa.’ [3]

Self-Concept

Identity issues were studied in this category. Self-concept is related to the perception that people have about themselves. The concept of those perceptions is everything the person recognizes as part of himself. Findings revealed an outstandingly negative self-image, with anorexia patients’ self-appraisal being excessively focused on the body, its shape and weight. The second-order interpretation, solely based on the original results, is where the synthesis itself is done.

(a) Low Self-Esteem [9, 31, 33–34, 39, 44]. Self-esteem was included as part of self-concept and expresses a feeling or an attitude of approval or repulsion towards the self. Self-esteem is a personal value judgment expressed in the attitudes a person has about himself or herself. Six

Table 3. Synthesis: second-order interpretation

<table>
<thead>
<tr>
<th>Symptom identification</th>
<th>Disease interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disease representation</strong></td>
<td><strong>Positive aspects of the disease</strong></td>
</tr>
<tr>
<td>Anorexia nervosa as part of identity [10, 35, 37, 39, 40]</td>
<td>Safety [3, 10–11, 32, 38–40, 42].</td>
</tr>
<tr>
<td>Anorexia nervosa as a coping strategy [10, 11, 32, 35–38, 45]</td>
<td>Feeling of self-control [3, 4, 6, 11, 32, 39, 40, 44]</td>
</tr>
<tr>
<td><strong>Self-concept</strong></td>
<td>Feeling special [3, 5, 6, 9, 11, 32, 40]</td>
</tr>
<tr>
<td>Low self-esteem [9, 31, 33, 34, 39, 44]</td>
<td>Beauty [6, 8, 11, 32, 38].</td>
</tr>
<tr>
<td>Distortion of the body image [8, 11, 40]</td>
<td><strong>Negative aspects of the disease</strong></td>
</tr>
<tr>
<td>The feeling of not belonging to the family [10, 31, 40]</td>
<td>Presence of obsessions [3, 8, 9, 11, 32, 33, 38, 43]</td>
</tr>
<tr>
<td><strong>Development of anorexia nervosa</strong></td>
<td>Loneliness [32, 43, 45].</td>
</tr>
<tr>
<td>Factors triggered by anorexia nervosa</td>
<td>Feeling controlled by the disease [3, 32, 36, 40]</td>
</tr>
<tr>
<td>School stress [9, 11, 41, 43]</td>
<td><strong>Affected areas in life</strong></td>
</tr>
<tr>
<td>External critical comments [3, 6, 33]</td>
<td>Schoolwork [6, 8, 37, 43, 45]</td>
</tr>
<tr>
<td>Losses [34, 38, 40]</td>
<td>Work [8, 32, 43, 45]</td>
</tr>
<tr>
<td>Dissatisfaction with appearance [6, 33, 41]</td>
<td>Family relationships [4, 33, 38, 43, 45]</td>
</tr>
<tr>
<td>Adolescence [34, 40]</td>
<td>Social relationships [32, 37, 43, 45]</td>
</tr>
<tr>
<td>Sexual abuse [6, 34, 40]</td>
<td>Health [6, 11, 32, 40, 43]</td>
</tr>
<tr>
<td><strong>Improper practices to get thinner</strong></td>
<td></td>
</tr>
<tr>
<td>Severe diets [8, 9, 33, 38]</td>
<td></td>
</tr>
<tr>
<td>Use of laxatives [8, 33, 40]</td>
<td></td>
</tr>
<tr>
<td>Excessive exercise [8, 33, 40]</td>
<td></td>
</tr>
<tr>
<td>Vomiting [8, 33, 40]</td>
<td></td>
</tr>
<tr>
<td>Rational attitude towards food [3, 8, 33]</td>
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</tr>
</tbody>
</table>

Anorexia Nervosa: A Qualitative Synthesis

studies integrate this subcategory. Studies show lowered self-esteem expressed in feelings of depreciation, impotence and ineffectiveness, while anorexic patients obsessively consider their body shape and weight.

‘I didn’t feel like I was good enough to eat and I felt so guilty every time I … took in anything… I thought I shouldn’t feel the feelings but I did… so I decided I was a bad person.’ [39]

(b) Distortion of the Body Image [8, 11, 40]. Body image can be understood as a mental portrait the person has of himself or herself, based on recent experiences, existence and present stimulations and future expectations. In anorexia nervosa, there is a failure in proper perception of body size or part proportions, with body parts seen as either larger or more voluminous than they really are. Subjects’ resolute wish to continue to get thinner despite all opposing opinions is outstanding.

(c) The Feeling of Not Belonging to the Family [10, 31, 40]. Some accounts show that some patients with anorexia nervosa, since the beginning of their illness, did not feel understood by others, mainly by close associations, such as family. According to Bacher-Melman [39], this feeling of not belonging is followed by a strong compensatory wish of being fully accepted by several social groups.

‘I felt like nobody understood me… and it wasn’t like I was alone, many people were around me, but I felt as if I wasn’t communicating.’ [9]

Development of Anorexia Nervosa
Development of anorexia nervosa usually results from a diet that reflects dissatisfaction with weight or body image. Anorexia nervosa starts with changing eating habits by eliminating food considered fattening, and as time passes food restrictions get progressively worse.

(a) Factors Triggered by Anorexia Nervosa. Issues repeatedly raised by interviewed patients as triggering factors for anorexia nervosa are associated with some specific situations such as school and professional stress. Experiences of sexual abuse, loss, and separation or death of parents are also mentioned frequently.

School stress [9, 11, 41, 43]. Pressure for good school performance appears as one of the usual triggers of the disorder:

‘The exams were responsible for my weight loss. After each exam, I lost weight.’ [11]

External critical comments [3, 6, 33]. Intolerance towards criticism and comments related to physical shape set off the disease.

‘The deprecative comments of the school teacher humiliated me.’ [33]

Losses [34, 38, 40]. Separation and parents’ death are included in losses as well as the break-up of emotional relationships.

‘Father’s sudden death.’ [34]

Dissatisfaction with appearance [6, 33, 41]. Many times anorexia starts as a diet to lose weight, but the diet then progressively becomes more restrictive until the person loses control and the condition becomes pathological.

‘I hated my body and thought I was fat since I was very young.’ [33]

Adolescence [34, 40]. Moving from childhood into adolescence requires a mental structure strong enough to bear contact with the new demands and responsibilities that arrive during this period. Anorexia nervosa can reflect difficulty dealing with these transformations.

‘I was unprepared to cope with adolescence.’ [34]

Sexual abuse [6, 34, 40]. The trauma of body violation can generate discomfort and aversion in relation to physical shape.

‘I was sexually abused by an uncle.’ [34]

(b) Improper Practices to Get Thinner. An exaggerated concern with looks, weight, diet, and body shape becomes an anorexic’s key focus in life. Within weight control practices, in addition to food restriction, physical activity, self-induced vomiting, laxatives, and appetite inhibitors were used.

Severe diets [8, 9, 33, 38]. In cases from the reviewed papers, typical eating behavior includes rigor concerning choice and quantity of food, with the exclusion of those considered ‘forbidden’. There is also an exaggerated use of vegetables and coffee to mask sleepiness and weakness.

Use of laxatives [8, 33, 40]. The use of laxatives as a purgative practice is often present in bulimic episodes.

Excessive exercise [8, 33, 40]. Exhausting exercises are considered one of the key factors in weight loss.

‘I used to overexercise and then I went to my room.’ [33]

Vomiting [8, 33, 40]. Self-induced vomiting emerges as one of the most common tactics for weight loss, becoming a habit after eating.

(c) Rational Attitude Concerning Foods [3, 8, 33]. The desire to eat does not appear, and food is consumed simply as a physiological necessity. These people show a great deal of knowledge about the nutritional and caloric value of food, revealing a rationalistic way of relating to food.

‘You have numbers in your head all the time…’ [3].
Disease Interpretation

Positive Aspects of the Disease

Within the synthesized studies, patients report a variety of positive aspects associated with anorexia nervosa. Anorexia nervosa is often described as a friend, providing feelings of safety, power, and well-being. Positive themes are important factors maintaining the state.

(a) Safety [3, 10, 11, 32, 38–40, 42]. In many accounts, anorexia nervosa is described as something that provides safety and protection on several levels.

‘Anorexia nervosa, my friend… You’re my source of safety, my guardian…’ [32]

‘I think for me it numbs a lot of my emotions, it protects me…’ [10]

(b) Feeling of Self-Control [3, 4, 6, 11, 32, 39, 40, 44]. Loss of weight is seen as a remarkable conquest and as a sign of extraordinary personal discipline, whereas weight gain is considered an unacceptable failure of self-control. Not eating gives patients a sensation of control over their own lives. They feel stronger when they do not eat and totally in control of the situation.

‘(…) I succeed when my body is in the shape I figure out. If I want to keep my weight each month and administrate it, I get happier than for anything else.’ [11]

‘(…) you can have control on all your body, you can do things that other people say you can’t.’ [3]

(c) Power [3, 39, 42, 45]. The thin body is considered a power symbol, a sign of willpower.

‘You get stronger and stronger when you don’t eat, you can have a greater opinion about yourself (…)’ [3]

(d) Feeling Special [3, 5–6, 9, 11, 32, 40]. Some accounts show a feeling of difference in relation to others, even superiority. Weaver et al. [40] describe anorexia nervosa used as a way of getting people’s attention and attaining popularity.

‘You make me feel special, by making me different. You give me something that nobody, family or friends have.’ [40]

(e) Beauty [6, 8, 11, 32, 38]. Thinness is shown as a synonym of beauty, health, and a way of feeling more attractive, a way to conquer men.

‘… I feel more men are interested in me and this has to do with you.’ [32]

Negative Aspects of the Disease

The experience of a person with anorexia nervosa is a tangle of feelings and ideas, interweaving positive and negative characteristics. The synthesized studies identify some negative sentiments in relation to anorexia nervosa. Those most often mentioned are presence of obsessions, loneliness, and feeling controlled by the disease.

(a) Presence of Obsessions [3, 8, 9, 11, 32, 33, 38, 43]. Some studies report the presence of constant thoughts related to food, with an obsession about food’s nutritional and caloric values taking a key place in the lives of those patients. Anorexia nervosa’s obsessive aspects include the inflexibility, strictness, stubbornness, and obstinacy associated with that pathology.

‘That became an obsession. A complete obsession.’ [33]

(b) Loneliness [32, 43, 45]. Accounts of loneliness and social isolation are found as well:

‘I feel sick and worried about your power over my life. You make me feel unhappy, anti-social and very lonely.’ [32]

(c) Feeling Controlled by the Disease [3, 32, 36, 40]. Patients experience anxiety; they feel controlled and dominated by the disease. Thus, anorexia nervosa passes from an effort to attain control to an entity controlling their lives.

‘It’s like a monster… something that holds you with its claws.’ [3]

Affected Areas in Life

The experience is not limited to eating and food, but involves the person as a whole, the way he or she relates to the world and others, as reflected in various areas of life.

(a) Schoolwork [6, 8, 37, 43, 45]. The search for perfection and discipline in studying is enhanced in anorexia nervosa, revealing bootstrap and obsessive study habits. The sicker the anorexic individual becomes, the less he or she produces. Concentration and memory are diminished, as in the following quote:

‘I need to study it literally. There’s a moment when it goes from perfection to total failure.’ [43]

(b) Work [8, 32, 43, 45]. Professional life is also neglected. Quitting a professional activity due to exhaustion or general malaise is very common. The passage below shows how the condition jeopardizes jobs and studies.

‘It’s awful to admit, but in general it’s the most important thing in my life… In comparison with relationships, it’s much more important than that, with university and work it’s a difficult decision, but as it goes I can’t say anything but that I did drop my university and that I was in pursuit of thinness at the time.’ [32]

(c) Family Relationships [4, 33, 38, 43, 45]. Family relationships are affected, causing estrangement, misunderstandings and worry, bringing trouble to the whole family.
‘They try to understand, but they don’t, it’s hard for them.’ [26]

d) Social Relationships [32, 37, 43, 45]. Social relationships appear as one of the most affected areas through deterioration and isolation. The quote below concerns this problem:

‘I hate you for what you have done: ruined friendships, relationships and career prospects.’ [32]

e) Health [6, 11, 32, 40, 43]. Studies report the appearance of several health problems related to the disorder, such as dry skin, hair loss, heart problems and gastric upset.

‘Were you responsible for the length of time it took me to get pregnant? The perforated gastric ulcer?’ [32]

The findings of second-order interpretations are reported in Table 3.

Third-Order Interpretation

Readings, comparison of texts and second-order categories allowed the definition of relationships between studies. Study findings did not oppose or refute the data from one study relative to another. This was true even when a specific category is present in one work but absent in another. In this sense, relations between studies are organized in a reciprocal manner yielding a line of interpretation. Third-order synthesis defines two new categories about how people with anorexia nervosa recognize and interpret their symptoms: (1) disease as identity and (2) systems of control. The category ‘disease as identity’ was generated based on the second-order category ‘symptom identification’ and its subcategories: disease representation, self-concept and development of anorexia. On the other hand, ‘systems of control’ emerges from ‘disease interpretation’ and its subcategories: positive and negative disease aspects, as well as affected areas of life.

Disease as Identity. The synthesis of data extracted from this review suggests that identity has a major role in the perception of anorexia nervosa and is not simply a question of reducing hunger or the body mass ratio. Worries about weight and food become a raison d’être.

In these studies [8, 11, 40], the patient’s self-image is precarious, providing fragile support for any feeling of personal identity. When these people become anorexic, they acquire a sense of structured identity. Anorexia ends up giving meaning to their experience. While disease is almost always a threat to the life of people, in anorexia the disorder assumes a different role, creating an identity and developing a protective meaning to the subject. Based on this understanding, abandoning symptoms means losing something that was structured into the lives of these people, that is, a constructed identity.

Systems of Control. Systems of control include mechanisms that maintain and perpetuate the clinical picture. Psychological and interpersonal factors participate in this system. This organization is kept active while the condition is able to produce comfort through success in weight control and relationships with others. As a result, anorexia nervosa relates to the question of power over the body as well as control over the self and the other. The results of this synthesis reveal that the theme of control is associated with a false idea of acquiring power.

Table 4 shows the third-order interpretation categories.

Discussion

Treatment for eating disorders often entails enormous difficulties. Helping these subjects is not likely to be successful if patient experience is not examined and understood. This is particularly true for those suffering from anorexia nervosa. Metasynthesis studies allow the integration of findings coming from small qualitative studies by broadening the data bank and diversity, yielding a contribution concerning collective experiences passed through by patients with anorexia nervosa.

In this analysis, people from different countries and regions of the world showed a relatively similar profile.
concerning experiences with anorexia nervosa. The synthesis was divided into two distinct stages. First, a second-order analysis resulted in two central concepts: symptom identification and disease interpretation. Symptom identification includes the representation of the disease, self-concept and the development of anorexia nervosa. Disease interpretation covers the positive and negative aspects of the problem, as well as areas affected in life.

Patient representation of anorexia nervosa takes on the aura of a lifestyle, in which the condition is not perceived as a disease but as a strategy for confronting the adversities of life or, even more frequently, as an entity that assumes the function of identity acting to structure the lives of these subjects. These multiple ways of interpreting the disorder have implications for the health professional in that patients and their families need to recognize some of these alterations in order to seek help.

Self-concept is highly negative in patients with anorexia. Various studies show low self-esteem, distorted body image and self-attribution for external problems. Self-attribution comes when patients take responsibility for the disease, self-concept and the development of anorexia nervosa. Disease interpretation covers the positive and negative aspects of the problem, as well as areas affected in life.

Distortions of body image confirm other research with anorexia nervosa [31]. In some studies, body image distortion is revealed as a nuclear symptom of eating disorders characterized by negative self-evaluation in the presence or absence of objective problems with weight and body shape. Bruch [15] comments that more disturbing than anorexia nervosa’s bad nutrition in and of itself is its association with body image distortion that, among other factors, comes out as an absence of worry about low weight, even when at an advanced stage. This situation creates a new challenge for professionals in that non-recognition of the disorder can delay the search for help. In addition, treating patients with anorexia nervosa who fight against recognizing the problem is particularly difficult for any health professional.

As regards the development of the clinical picture, our data show that patients identify various triggering factors. Stressful events, such as low grades on school work, peer criticism, problems in interpersonal relations, conflicts, family problems, or physical, verbal, or sexual abuse taken together with personality characteristics can contribute to a generalized state of disgust with life and with the patient himself or herself and serve to trigger the start of behavior leading to anorexia nervosa. These events’ association with development of the medical picture was not clarified in the work evaluated for this synthesis.

Inappropriate practices are rife in weight control, involving a gamut of behaviors that includes rigidity, self-induced vomiting, severe diets, excessive exercise, use of laxatives, and so on. The adoption of damaging as well as obsessive behaviors is done to build the perfect body, yielding a subject’s greater self-acceptance as well as improved acceptance by others [47].

Disease interpretation showed that the experience and meaning attributed to anorexia nervosa involve a certain ambiguity in that both positive and negative aspects are involved. The egosyntonic nature of some of the symptoms, that is, psychological aspects felt to be integral parts by the subject, interfere with the motivation to change.

The repercussions of anorexia nervosa in the family, emotional, social, and occupational spheres are related. Social compromise is relevant. There is the possibility of withdrawal from friends and family, increasing patient isolation. Comorbidity studies between eating disorders and mood disorders have shown an important association [48]. Their isolation can lead to feelings of sorrow and depression. Other possible factors that can set off depressive symptoms or depression are family friction and marital partners who suffer along with the affected person. Other aspects that can affect social life are connected with eating routines, exercise, and purgative practices that can take up a lot of patient time.

Anorexia nervosa’s influence on the construction of identity in patients was not altogether clear in each individual study. This situation became clearer with meta-synthesis. Another theme that stood out was control mechanisms.

On the other hand, our literature review showed that patients with anorexia nervosa recognize various positive aspects of the disease including security, protection, power, control, and a feeling of being different and a special person. Some references show the disease to be a ‘guardian’. These findings indicate the presence of powerful factors that justify the presence and maintenance of the disease for the individual. These components can frustrate treatment. As a result, programs caring for this population should consider the need not only for a careful clinical evaluation but also for an examination of the condition’s role in the psychological organization of the patient [49].
Third-order interpretation reveals the disease as identity and control systems as meta-categories. The synthesis shows anorexia nervosa as identity and not simply as a disease or syndrome. Worries about weight and food become existence itself. As a result, there is a need for psychological work to modify the old identity supported by the disease and favoring a space for re-creation, for developing a new identity. Difficulties in this field are enhanced by the frequent association of anorexia nervosa with personality disorders. Prevalence studies show that the rates of association are high and range between 27 and 94% [50–52]. Patients presenting with anorexia nervosa tend to have higher rates of type C personality disorders, such as the traits of perfectionism, obsessive-compulsiveness, and histrionics when compared with bulimic patients [53]. The co-occurrence of borderline personality disorder is associated with greater severity of the eating symptoms, higher rates of hospitalization, risky conduct, and suicide attempts [51, 54]. Not only the comorbidity with the personality disorders, but also family organization [55], genetics [56], temperament [57], and other dimensions of the personality [54] tend to contribute to the notion of the disease, formation of self-image, and prognostics of the disease. This occurs due to the intricate relationships the personality disorder establishes with anorexia nervosa and which frequently present as a chronic feature. Generally, the cases of eating disorders appear at very early ages. These patients build their personality, identity, and character in the light shed by the eating disorder. Towards the end of adolescence and beginning of adulthood, the same individual can display a form of thinking, feeling, and relating to others which is very different from that of the population that does not present with these disorders. This way of functioning can perpetuate even in the absence of the eating disorder, thus leaving a limitation in the functionality of the patient [58].

The synthesis process revealed the role of anorexia nervosa in organizing identity and not simply as a disorder. Worries about weight and food become existence itself. Based on this understanding, leaving the disease behind means a threat to identity, to something used to structure these people’s lives. The simple elimination of symptoms represents a break in their modus vivendi, that is, taking away what keeps the subject alive. A meta-ethnography of the experience of women with breast cancer has shown that these people go through various phases of suffering [59]. By way of contrast, a negative finding that deserves mention is the lack of reference to suffering connected with the disease. This may come due to the structuring role the disease has for the subject’s identity. Suffering can be necessary for transformation. A study of breast cancer patients showed that suffering can stimulate the examination of the disease [60].

Control systems contain the mechanisms maintaining and perpetuating the clinical picture, often in search of a feeling of self-control. The need for control over one’s body, feelings, and the world is highlighted in the articles. Santos et al. [47] argue that anorexia nervosa patients feel their bodies to be imperfect or have a poor body image, generating a need to control their lives. Body control is a perfect candidate, in that it is independent of other people. Through diets and fasts, patients try to attain total control over themselves and thus transfer all of their anxieties and psychological problems to eating and weight control. Williams [49] considers anorexia nervosa and bulimia as manifestations of psychological suffering. They are structured around extremely powerful defensive organizations that confine the mind in an ‘incarcerated body’. This investigation seeks to elucidate the psychodynamics of anorexia nervosa and other eating disorders in a context involving the development of relationships of dependence.

Like in other psychiatric diseases, the presence of defensive mechanisms in anorexia nervosa seems to be more a rule than an exception [51, 61]. Nevertheless, the nature of mechanisms is heterogeneous when compared with other disorders. Gothelf et al. [62] compared ego defense mechanisms in adolescents with anorexia nervosa and other major psychiatric disorders to defenses in healthy adolescents. Results showed that anorectic adolescents use in large scale relatively more mature defenses than do psychiatrically ill patients, and they also use in large scale immature defenses when compared with healthy adolescents. This combination of mature and immature defenses may be related to the uniquely heterogeneous ego functioning seen in anorectic patients, and it may provide insight into the nature of the psychopathology of anorexia nervosa. It also could have important psychotherapeutic and prognostic value.

The analysis of these 24 articles about the recognition and representation of anorexia nervosa reveals that this condition should not be seen simply from the reductionistic perspective experienced by these patients. Anorexia nervosa can be seen as forming identity and involving many positive aspects such as protection, security, and power. The perspective of losing their identity as well as their defense mechanisms can trigger behaviors of withdrawal and lack of interest in the treatment [63, 64]. In accordance, Skårderud [17] showed understanding and
empathy in relation to patients’ feelings, especially regarding their terror of losing control over their weight and their difficulty in letting go of aspects of their identity, which are relevant to the management and follow-up of these patients. Future studies can investigate these issues more deeply as well as include them in clinical research to screen patient groups with anorexia nervosa in whom the syndrome is a source of identity and protection.

Some study limitations should be mentioned. Only published works were considered in that the authors did not have access to transcripts and field notes. The authors of the original studies were not consulted about the applicability of the second- and third-order interpretations. Most of the results come from B-grade studies that used qualitative methodology, implying the need for caution in data interpretation. Also, study populations were almost exclusively female, thus revealing the phenomenon only as it manifests among girls and women. Moreover, no comparison was attempted concerning the severity of the condition between studies. Finally, information on anorexia nervosa was self-reported, and no proxy information was collected.

In addition, scientific production is concentrated in a few developed countries, thus requiring care concerning cultural bias. There are few studies involving social influences, especially touching on media impact, although these aspects are prominent in the literature of the area. New studies should take into account (1) more refined methodology, (2) investigations in developing countries and different cultures, and (3) investigations on other ethnic and racial groups.

Acknowledgement

This study was supported by FAPESP – Fundação de Amparo à Pesquisa do Estado de São Paulo (The State of São Paulo Research Foundation), Grant 07/50739-1.

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