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Family perception of anorexia and bulimia: a systematic review

ABSTRACT

A systematic literature review published between 1990 and 2006 using a qualitative approach was conducted to explore family members' perception of anorexia and bulimia nervosa patients. Articles were critically reviewed and a meta-synthesis analysis was carried out based on a meta-ethnographic method to analyze and summarize data. Of a total of 3,415 studies, nine met the study inclusion and exclusion criteria. Reciprocal translation was used for data interpretation allowing to identifying two concepts: disease awareness and disease impacts. Feelings of impotence were often described in family reorganization. The study results point to distortions in the concept of disease associated with family involvement, resulting in changes in communication, attitudes, and behaviors in a context of impotence.

DESCRIPTORS: Anorexia Nervosa, psychology. Bulimia Nervosa, psychology. Family Relations. Health Knowledge, Attitudes, Practice. Qualitative Research. Review.

INTRODUCTION

Recently there have been an impressive growing number of studies linking family functioning to different medical conditions. Eisler et al¹⁰ have described the family as a health system for its members and provides an explanatory health-disease model. Family members act by a set of values, beliefs, knowledge, and practices for health promotion and disease prevention and treatment. This system comprises also a model of care, where the family supervises the health status of its members, makes decisions on the paths to be followed, and constantly follows up and evaluates their health and disease. According to the World Health Organization²³ (WHO), health systems are increasingly requiring that families play the role of caregiver.

However, the perception of the family of patients with eating disorders has not been much discussed in the literature. The few studies on that have found that the impact on the family's health would be comparable to that of caring for a psychotic patient.^{27,33}

Some qualitative studies have exposed family functioning from the perspective of patients with eating disorders. They identified characteristic patterns of family interactions apparently associated to the development and maintenance of eating disorders. It was observed an entanglement, i.e., family members become mixed together and personal limits are blurred, corresponding to the idea of inexistence of individual identity separated from the core family. These families are typically overprotective, controlling, and can hardly manage the separation and independence of its members. Also, continued importance given to physical appearance in the family seems to result in a distorted perception of the person with an eating condition. 1-4,20,27

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Received: 12/07/2007 Revised: 07/31/2008 Approved: 12/02/2008 Researches about the family's perspective are scarce and they are mostly epidemiological studies. 6,15,32 Qualitative investigations are rarely seen in the literature, 2,14 and they are commonly based on theoretical references such as the systemic one, where the disease is part of and have a role in the family structure; and the psychodynamic one, focused on understanding psychic dynamics. From a systemic perspective, Perkins et al²⁵ conducted semi-structured interviews addressing the experience of 20 family members of bulimic patients. Their comprehension of eating disorder largely involved a mixed perception and underestimation of disease and feelings of impotence, sadness, and guilt prevailed. Honey & Halse,14 based on a psychodynamic perspective, carried out in-depth interviews with 16 mothers and eight fathers of anorexic inpatients. Their coping strategies were predominantly self-distraction and optimism. These studies have indicated some distortions perceived by caregivers such as disease conception, treatment, coping strategies, among others.

The objective of the present study was to carry out a systematic review on how family members perceive anorexia and bulimia nervosa patients.

METHODS

The study consisted of three phases: 1- systematic literature review; 2- critical review of articles, and 3-meta-synthesis analysis.

A comprehensive electronic search of the databases PubMed, Lilacs, SciELO, ISI – Web of Science, PsycoInfo and EmbaseIt was conducted.

The following keywords were used for searching databases: one of the keywords of descriptors "eating disorder," "anorexia nervosa," and "bulimia nervosa" combined to at least one keyword "qualitative research," "qualitative study," "phenomenology," "perspective," "perception," "experiences," "family," and "caregivers" as well as their equivalents in other languages.

For the selection of articles, inclusion criteria were qualitative studies reporting the experiences of family members of patients with eating disorders published in Portuguese, English, Spanish or French between 1990 and 2006. The studies should clearly have the following design features: 1- original study including a sample of both male and female subjects; 2- methodological design and theoretical approach for data collection and analysis; 3- intentional samples with specific selection criterion and sample size defined by content saturation; 4- samples including both adolescents and adults; 5 – detailed description of data analysis such as procedures for data extraction, number of evaluators, category controls and use of triangulation.

There were excluded chapters of books, theses and Master's dissertations as well as studies whose main purpose was to investigate psychiatric disorders other than eating disorders or studies that did not explore the family's perspective.

Studies were critically reviewed based on the Critical Appraisal Skills Program⁸ (CASP), a checklist that sets out guidelines for the assessment of quality of qualitative studies. CASP consists of ten items that allow to categorizing articles based on their methodological structure. The studies were categorized into A and B.

Category A included studies with low risk of bias that met at least nine out of ten items proposed: 1- clear and rational objective; 2- adequate design to attain the objectives; 3- presentation and discussion of methods; 4- selection of an intentional sample; 5- description of data collection, instruments and saturation process; 6-relationship between investigator and subject; 7- ethical considerations; 8- dense sound analysis; 9- presentation and discussion of results focusing on reliability and use of triangulation; 10- description of contributions and implication of the knowledge produced in the study and its limitations as well.

Category B included studies that met at least five out of ten items and partially met the study criteria with a moderate risk of bias. Case studies were included in this category.

Noblit & Hare²² refer to meta-synthesis as a method of study based on the thorough analysis of theories, methods, and results found in qualitative studies. The objective of meta-synthesis is significantly different from that of meta-analysis as it implies interpretation rather than aggregation of numeric indexes.

At this step a meta-ethnographic approach was applied to analyze and synthesize data. Articles were categorized by two independent reviewers. All categories used in the review and meta-synthesis were obtained from consensus between the two reviewers. A meta-synthesis was conducted based on the following steps as proposed by Noblit & Hare:²²

- Definition of the area of interest and guiding question of the case studied perception of family members of anorexia and bulimia and search of studies using appropriate strategies.
- Selection of relevant studies to the sample according to inclusion and exclusion criteria.
- Rereading of studies and recording of information looking for keywords, subjects and main categories.
- Establishing a link between the studies, either by similarity or opposition.

- Comparison of studies between them.
- Synthesis of findings, seeking to associate them and prioritizing the most recurrent results.
- Documentation and dissemination of meta-synthesis results.

The final step of the study is a synthesis to clarify new meanings by primarily grouping subjects that are progressively refined, creating a new core consensus.

The selected studies were read and reviewed using a meta-ethnographic approach. It consists of induction and interpretation, and includes resignification (translation) of results between studies, allowing to understanding and transferring ideas, concepts, and metaphors among different studies. While resignifications enable to make comparisons between different studies, they preserve the structure of relations between concepts. Resignification is a two-step process as proposed by Noblit & Hare.²² The first step, known as second-order interpretation, is based entirely on original results and the synthesis per se is carried out. Relevant contexts and concepts of each study were recorded for better understanding interpretations.

Concepts can be related either by similarity, so-called reciprocal translation, or by opposition, when there are discrepancies. The second step, known as third-order interpretation, goes beyond the meaning of original results, and conceptually advances with rereading of originally synthesized categories. The categories used in the review and meta-synthesis were obtained from consensus between the authors. An article considered a gold-standard due its design was used as a reference to manage comparisons between different studies.³⁵

RESULTS

There were first identified 3,415 occurrences. After preselection based on the reading of titles and abstracts of all studies retrieved in the electronic search, there were selected 58 studies that met the pre-established criteria. They were read entirely and nine studies met the inclusion criteria. This set of articles was assessed for quality. Based on quality criteria, four studies were included into the category A and five into B. The studies selected are listed in the Table, and characterized by type of eating disorder, country, subjects, disease stage, and type of treatment, as well as method of data collection

Table. Studies with family members of people with eating disorders. (N=9)

Author/ year	Type of eating disorder	Country	Subjects	Disease stage/ modality of treatment	Methods/data collection	Level of quality of studies
Latzer et al (2002) ¹⁶	Anorexia nervosa	Israel	9 sisters of anorexic patients	Sisters of patients with acute disease. Treatment in a specialized center	Interviews	А
Chan & Ma (2000) ⁷	Anorexia nervosa	China	Patient, father, mother, sister and brother	Outpatient	Case study; family therapy sessions; videotapes	В
Tan et al (2003) ²⁹	Anorexia nervosa	England	10 female patients (aged 13–21); 8 mother; 1 father	7 outpatients and 3 inpatients	Interviews	В
Tan et al (2000) ³⁰	Anorexia nervosa	England	10 female patients (aged 13–21); 8 mothers; 1 father	7 outpatients and 3 inpatients	Interviews	В
Etxeberria et al (2002) ¹¹	Mixed eating disorders (anorexia and bulimia)	Spain	12 patients; about 12 family members (not specified)	Outpatients	7 focal groups (4 groups with patients; 2 groups with family members; and 1 group with providers)	Α
Perkins et al (2004) ²⁵	Bulimia	England	20 caregivers (14 mothers; 1 father; 5 partners)	Outpatients	Semi-structured interviews	В
Winn et al (2004) ³⁶	Bulimia	England	20 caregivers (14 mothers; 1 father; 5 partners)	Outpatients	Semi-structured interviews	В
Whitney et al (2005) ³⁵	Anorexia nervosa	England	20 mothers; 20 fathers	Inpatients	Letters	Α
Honey & Halsel (2006) ¹⁴	Anorexia nervosa	Australia	16 mothers;8 fathers	Inpatients	In-depth interviews	A

and level of quality. Studies were classified based on three theoretical approaches: psychodynamic (n=4), systemic (n=3), and phenomenological (n=2).

More studies (six) addressed family members of anorexia than bulimia patients (three), of which two were exclusively on bulimia and one included bulimia and anorexia. They included a wide range of informants such as mothers, fathers, siblings, and husbands, totaling 118 family members. Mothers accounted for 62% of all informants (n=73).

Most studies conducted semi-structured interviews, one of them used a focus group¹¹ and another one was based on letter writing where emotions were reported as in a diary.³⁵ All articles were published from 2002, which indicates a very recent literature production. Most of them (five) were carried out in England.

The studies included in the sample showed the state of family members after the diagnosis of eating symptoms. Disease severity varied among the studies. Most involved as informants parents of outpatients (six) and inpatients (three). No studies were found with accounts of family members of male patients.

Acknowledgment of the disease

Acknowledgment of the disease was based on two themes. The first one (family comprehension about eating disorders) was based on the following categories: mixed perception of disease, chronicity, underestimation of the disease, and control strategy. The second one (perception of treatment) was based on satisfaction with treatment and dissatisfaction with treatment.

A. Family comprehension about eating disorders

The family comprehension about the disease, their emotional adjustment and how they manage this situation was one of the themes analyzed in the synthesis.

Mixed perception of the disease – the analysis of themes showed family members had difficulties understanding the eating disorder. Some did not have a clear perception of the disorder, its etiopathogenesis and prognosis. ^{25,35,36}

"I knew something was wrong, but I wasn't sure what it was." 25

Chronicity – parents perceived the disease as a chronic condition, expressing pessimism regarding their child's recovery and cure. This concern was only seen in studies including family members of anorexic patients, as shown in the discourse below: ^{14,30,35}

"I wanted our daughter back. And it took me quite a while to realize that this actually is not possible, that it will never happen. So you have to move forward, leave your old self behind and be happy with what you've got now."14

"It will take her years to readjust to normal life, maybe she will never make it." 35

Underestimation of the disease – underestimation was associated to the belief that their daughter's behavior changes were a typical and natural attitude of adolescents, as well as to the lack of knowledge on the disease and a mechanism of denial. ^{25,35}

"For quite a long time I really didn't realize it was an eating disorder. I thought it would never happen to me. I wasn't aware of that." ²⁵

Control strategy – the disease was perceived as a way for the patient to gain control over her own life and over other people's life. ^{7,30}

"(....) the only thing she can get control is over her own body because we went through hard times... it is the way she uses it (....)" ³⁰

B. Perception of treatment

This category illustrates how family members perceived treatment. It was divided into satisfaction and dissatisfaction with treatment.

Satisfaction with treatment – in some studies treatment was described as facilitator of family life. Most studies showed that either outpatient or inpatient treatment made the patient stable and facilitated living together in the family. ^{30,35,36}

"Since my daughter has been admitted to the hospital I see light at the end of the tunnel." 35

"The only time I can relax a little or have some kind of relief is now while she is at the eating disorder unit because she gets physically healthier with treatment."

Dissatisfaction with treatment – family members of patients revealed unaddressed needs such as information and practical guidance on how to manage the patient for they felt impotent and needed to share this experience with other people. ^{30,35-36}

"We need guidance on how to manage daily situations, this is my main problem now....if she has an eating binge, what should I do? Should I try and stop her? Should I try to talk to her? Or should I distract her... (....)" ³⁶

Disease impact

This theme was structured based on four blocs. The first bloc (feelings evoked by the disease in the family) was subcategorized as sadness, fear, impotence,

guilt, hopelessness, and ambiguity. The second one (changes to the patient) was subcategorized as personality changes and low school performance. The third (changes in the family after disease) was subcategorized as dysfunctional communication, role changes, and increased closeness. The fourth (coping strategies) was subcategorized as optimism and good mood, self-distraction, cognitive reconstruction, religiousness, search for information.

A. Feelings evoked by the disease in the family

The disease evoked in the family many feelings, sometimes contradictory ones. Guilt, sadness, and impotence were the most commonly perceived and expressed feelings by family. There was a prevailing feeling of impotence in the studies.

Sadness – feeling sadness was recurrently reported in several studies. ^{25,29,35}

"I would say that...while I'm talking to you, L. missed her childhood. I feel it very deeply, and now we don't have a happy 13-year-old girl, she is not a girl but someone who is taken by depression and negative feelings as if she were carrying the world upon her shoulders..(...)" ²⁹

Fear – family members were taken by a fear of losing their relative with the disease. Fear was evident in anorexia studies. ^{16,35}

Impotence – studies reported a subjective state of impotence, where the prevailing perception was that an appropriate action would not significantly affect the outcome. They felt lack of control over the situation. Many family members felt the disease had profoundly affected them, and they felt manipulated and controlled. 7.16.25.30.35

"There is nothing I can do that will make a difference." 35

Guilt – guilt is stressed in many studies. Parents felt somehow responsible for their daughters developing an eating disorder, and believed their own eating habits and attitudes could have influenced their daughter's behavior. 11,13,16,29 Feeling guilty is identified in the following discourses:

"How should a mother feel? A loser, helpless, awful, an idiot, guilty, guilty, guilty." ¹⁶

"I believe I actually did something, something that caused her this." ¹³

Hopelessness – several studies reported hopelessness especially regarding with the future. They saw no alternatives nor could not see any personal choices available and felt unable to channel their energies to their best interest. 11,13,16,18

Ambiguity – some studies reported a feeling of ambiguity among family members. Patients with eating disorders did not evoke only feelings of compassion and sympathy, but also anger, rejection and envy particularly among siblings.^{11,14,16} Etxeberria et al¹¹ study showed siblings sometimes acted as support and other times they were bothered by the attention given to their sick sister.

"If I envy her? They do much more for her than for me." 11

B. Changes to the patient

Family members talked about themselves and at the same time they mentioned the sick relative and their behavior changes. The most expressive behavior changes were personality changes and low school performance.

Personality changes – this change caused a negative impact on relationships. Some aspects mentioned were the fact that the patient was hiding things form others, that she was no longer authentic in her relationships. The patient became extremely meticulous and organized about her eating habits and other general activities. Aggressive behavior and mood fluctuations were also mentioned. 11,29,30

Low school performance – according to parents, the patients had a very good school performance before the disease and then some of them even dropped out of school.¹¹

C. Changes to the family after disease

New family arrangements were created and the old ones were changed; e.g., triangulation between the parents and the sick daughter or expelling of the sick one from the family structure. There were also role changes in the family. The disease became a new member of the family that would influence and have control over them all.

Dysfunctional communication – it is defined as a conflictive, incomplete and superficial form of communication. Family members reported that, because of the eating disorder, the patients would argue more, communicate less and lie more to cover up for their disease. The family relationship would improve as they recovered. ^{11,16,25}

"We tried to talk to her at home, but it would always end up in confrontation."²⁵

"Now that she's gained some weight, the relationship at home is better, we fight less (.....)" 11

Role changes – it is a switch of functions and roles a member can take on in the family in the event of a disease. Disease was described as a new member of the family. Former relationships were changed, and patients sometimes became estranged from their family.

Caregivers were overwhelmed as they had to conciliate care of the sick one and their work duties, in addition to other tasks. 16,25

Increased closeness between family members – coping with the disease made members come close to each other and strengthen family ties as seen in some discourses. The patient would demand a great deal of attention and external control, 14,25,29,30 as observed in the following discourse:

"J. and I were likely closer because of that, I know it may sound odd, but I believe that emotionally these things happen (.....)" ²⁵

D. Coping strategies

Coping strategies were either problem-centered or emotion-centered. In problem-centered coping the individual would make efforts to bring up the problem, work out solutions and make a choice of action. Emotion-centered coping involved an attempt to manage the emotional impact of stress using mainly defense psychic mechanisms.

Optimism and good humor – emotion-centered coping strategies helped in some situations to adjust or minimize the disease impact, but could also indicate distortions and defense mechanisms. 14,25,35

"I'm always trying to be optimistic (...) you have to think about it positively." ²⁵

Self-distraction – it can involve professional activities, physical exercises, manual work and leisure activities. This is an emotion-centered coping strategy. 14,25,35

"I get immersed in my work and other projects but then she comes to my mind." 35

Cognitive reconstruction – strategies of cognitive reconstruction consist of efforts by family members to find positive aspects in the disease experience and seize it as an opportunity for personal growth by giving it a less threatening and painful meaning. ^{14,25,35}

"It has changed my life, my opinions and the way I see things, it has been positive in this sense....(....)." ²⁵

"Everyday I try to find something positive." 14

Religiousness – comprises accounts of religiousness to cope with the disease based on faith in recovery or spirituality to find a meaning to the illness. ^{26,37}

Search for more information – it was noted in some accounts a search for information about the disease and treatment. Parents sought to get information in textbooks and on the internet and by talking to health providers. Information about the disease helps alleviating the feeling of impotence and answering questions, making them feel more confident and reassured. ^{14,25,36}

"I have been doing that and it has been very helpful, especially for things I used to find difficult to do." ¹⁴

Third-order interpretation

In the meta-synthesis, themes of each individual study comprised metacategories that allowed an overall analysis. The new metacategory "family restructuring" was related to two second-order groupings: acknowledgment of the disease and disease impact. This metacategory, which was not individually found in specific studies, included different information found from the studies.

Eating disorders lead to overall family restructuring, changing its dynamics, and requiring emotional, cognitive, and material adjustments. Family life would revolve around the affected member, leading to changes in the interactions between other family members. A notable estrangement from other children could be seen. Negative feelings such as hopelessness and impotence emerged. Adaptative mechanisms such as self-distraction, optimistic thinking, good humor and religiousness were also seen. It can also be noted social withdrawal since the disease causes a burden that disrupts the existing routine.

Eating disorder is an experience that calls for adaptative challenges of different degrees. Family restructuring does not necessarily mean resolution, i.e, fully understanding and accepting the disease, but rather is an organization of less conflictive ways of coping with it.

DISCUSSION

Family members have diverse comprehensions as well as a wide variety of viewpoints on anorexia and bulimia. Studies reported mixed perception of the disease, underestimation of the problem, understanding of the disease as a chronic condition and as a strategy of control over one's own life and the life of others.

The first contact with the disease makes parents anxious and fearful. They quite often express their disbelief regarding the diagnosis. Parents go through different phases, the so-called first reactions (shock, disbelief, confusion, fear, anger, conflict, stress) that can have varying duration, and then a long denial phase, that affect the whole family, hindering an appropriate adjustment.³⁸

Some of these situations may be determinant for making the decision whether to seek or not professional help.

Failure to acknowledge the disease may delay treatment start and aggravate the condition by making it more chronic and increasing the risk of death in severe cases.³⁴

The most recurrent themes found in the studies were impotence, sadness, fear, and guilt. Feelings of impotence and guilt were recurrent and caused family suffering. Pichon-Rivière, 26 while studying family relationships, found that parents tend to believe they are able to determine what is right and what is wrong to their children. Failure to do so, indicated by their child's eating disorder, makes them experience a profusion of feelings such as discomfort, distress, and impotence. They feel helpless and believe they are bad parents and that they are unable to help.

Family support groups help easing these feelings of guilt, sadness, helplessness and to express their heavy emotional burden.

The sick person suffers as well as their entire family. Before disease onset, the family environment is described as "normal" and the affected person as healthy. Conflicts were either inexistent (harmonic family pattern) or they did exist but were not perceived by the family. Even though when they are perceived in family interactions, it is hard to associate conflicts to the manifestation or persistence of an eating disorder. 6,21,25

Bruch² have investigated family functioning before symptom onset and stressed that there is inadequate interpersonal relationships, characterized by apparent harmony that covers up severe latent conflicts. Lawrence¹⁷ and other authors have corroborated these findings, pointing out the role of psychological conflicts in family relationships of patients with eating disorders.

After its onset, disease manifests as a unit in which family members are affected showing varying degrees of symptoms. The family's response has also an effect on the patient. In general, the entire family structure needs restructuring to cope with and to adjust to the new circumstances of disease and treatment. The contact with medical procedures (consultations, testing, and several therapies) and sometimes with hospital settings lead to changes in the daily home routine, disorganization, and distress. Any intervention should take into account the family environment. Gabbard¹³ (1992) proposes family therapy and counseling to parents as strategies for treating adolescent patients as they are a source of support and can provide information on the condition. This author believes that addressing the family allows to address relationship problems that perpetuate the symptom. Likewise, Eisler et al¹⁰ have conducted a randomized clinical trial to assess the efficacy of two different family interventions compared to a control. One intervention was applied to the patient, and the other one was a support to the patient and involved family counseling. The results showed significant symptomatic and psychological improvement of individual and family functions in both approaches. Dare et al,⁹ in a randomized clinical trial with adult patients, reported the results of a comparison among two psychodynamic treatments (focal psychodynamic psychotherapy and cognitive-analytic therapy), family therapy, and control. No statistical difference was observed between the different psychotherapy approaches, but focal psychotherapy and family therapy proved to be more effective for gaining weight when compared to the control treatment.

Studies on coping mechanisms for eating disorders show that family members use more emotion-centered strategies to protect themselves and keep a certain level of stability in family life. But these strategies may make family members neglect the patient's actual health status.

Folkman et al¹² propose that the term coping should be used to express skills that help manage and adjust to stress situations. According to Carver & Scheier,⁵ coping is a response to stress to reduce its adverse effects. These strategies address specific demands arising from crisis and are a burden to one's personal resources. They can be learned, but people should be advised and trained to better cope with stress situations.

Lazarus & Folkman¹⁸ claim that when people make use of optimism to face adversity they are prevented from thinking and acting to solve the problem because the purpose is only to modify the accompanying emotional content and facilitate the adaptative process.

Pargament²⁴ described the relevance of religiousspiritual coping when people turn to religion to alleviate their problems. Tarakeshwar & Pargament³¹ described the five main goals of religion: search of meaning, control, spiritual comfort, closeness to God and to other social members, life transformation, and search for physical, psychological, and emotional well-being.

Another coping strategy is to search for information about the disease. It helps family to recover a sense of self-help and control over the situation and open up a possibility of helping the family member with an eating disorder. These mechanisms attenuate suffering by lessening the feeling of impotence. However, Wiserman³⁷ says that, in addition to searching for and acquiring information, it is paramount to use this information to help the member's recovery by changing behaviors and restructuring their daily life.

The intensity and continuity of care can provide more knowledge on the disease and reduce anxiety created by earlier lack of knowledge when the family was not able to help the patient as intended.

Eating disorders evoke strong feelings that are sometimes contradictory. Physical and social aspects of family life are also affected by physical burnout and daily commitment, precipitating crisis and disrupting the family dynamics. The disease potentiates already existing conflicts and creates new ones, wearing out attachments and inflicting psychic pain. In this scenario of changes and deadlocks, the family structure has to be restructured so its members can face the new reality and adjust to life conditions produced by disease and treatment.

The family is a major component of treatment. Family dynamics can play a role in disease manifestation or its persistence. Conflictive family relationships, mostly marked by no limit setting, produce intense suffering. Overprotection, high expectations, and values centered on success and external appearance are also part of this family dynamics. ^{19,21,28} The body of the sick member concentrates these limitations, needs and difficulties, and the symptom is an important form of expression and denunciation.

There should be noted some limitations of the present study: 1 – constraints of the search (16-year period, inclusion of studies in English, Spanish, French and Portuguese only), leaving out other studies; 2- exclusion of non-indexed studies (theses and chapters

of books) may have resulted in few studies; 3- the majority of studies had design flaws (sampling strategies and analysis techniques) that compromised their quality; 4- varied levels of relationship of informants in the studies; 5- varying disease severity found in the different studies.

In conclusion, besides parents, family members showed similar views about the disease affecting another member of the family. Care provided to patients should include the opportunity of examining and consulting family members at diagnosis and interventions. These interventions can meet demands for clarifications and general information about patient care (advice of psychoeducational nature is recommended) and situations involving pathological functioning of patients and their family (complex interventions for restructuring of personality and family dynamics are recommended). Support networks with staff trained to diagnose and provide interventions should be strongly considered and low-cost procedures may have positive effects on patient management such as meeting with families experiencing similar situations or self-help networks.

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