Salud Mental 2013;36:33-39
ISSN: 0185-3325
DOI: 10.17711/SM.0185-3325.2013.005

Anorexia nervosa: family experiences about the start of disorder, treatment, relapse and remission

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Original article

SUMMARY

Background

Anorexia nervosa is an eating behavior disorder in which family plays a relevant role, since a severe family dysfunction may be a risk factor and keep symptomatology. Family's participation in treatment increases the possibility of success.

The aim of this paper is to contribute with an analysis of the way in which the subjects suffering from anorexia nervosa and their parents, coexist with the suffering and share their story.

Materials and Methods

A qualitative research study and a narrative analysis by thematic axes with Kohler Riessman's model were conducted.

Informants were selected according to a theoretical non probabilistic sample and in-depth focused interviews were carried out. A family was selected for this report.

Results

The analyzed family was made up by three members: the mother, the father and the daughter suffering from anorexia nervosa, appearing excessively restrictive behaviors ranging between control and impulsivity.

The patient acts as the mother's confidante, while the father is strict and demanding. The treatment lasted approximately three years reaching an impasse since the patient did not show any evolution.

Discussion

In the four moments of the disorder evolution it was observed that each participant had different points of view. The bibliography of this research mentions the symbiotic relationship of mother and daughter as well as the peripheral relationship established with the father. The information obtained regarding this case confirms such structure.

Conclusions

These findings are an initial step to know the experiences of each of the family members during the start of the illness, the treatment, the relapse and the expectations towards the remission of the disorder.

Key words: Anorexia nervosa, treatment, relapse, remission.

RESUMEN

Antecedentes

La anorexia nervosa es un padecimiento de la conducta alimentaria en el que se ha observado que la familia desempeña un papel relevante, ya que una grave disfunción familiar puede ser un factor de riesgo y mantener la sintomatología. La participación de la familia en el tratamiento incrementa la posibilidad de éxito.

La presente investigación pretende contribuir con un análisis de la forma en la que los propios sujetos que padecen anorexia nervosa y sus padres, conviven con el padecimiento y narran su historia.

Material y métodos

Se llevó a cabo un estudio cualitativo y un análisis de narrativa por ejes temáticos de acuerdo al modelo de Kolher Riessman.

Los informantes se eligieron de acuerdo a un muestreo teórico no probabilístico y se realizaron entrevistas a profundidad focalizadas. Se eligió a una familia para este reporte.

Resultados

La familia analizada estuvo conformada por tres miembros: la madre, el padre y la hija con anorexia nervosa, presentándose conductas excesivamente rígidas que oscilan entre el control y la impulsividad.

La paciente funciona como confidente de la madre, en tanto que el padre se muestra rígido y exigente. El tratamiento duró tres años aproximadamente en *impasse* ya que la paciente no mostró ninguna evolución.

Discusión

En los cuatro momentos de la evolución del padecimiento se observó que cada uno de los participantes tenía diferentes puntos de vista. En la bibliografía se menciona la relación simbiótica de la hija con la madre y la relación periférica establecida con el padre, en la información obtenida en este caso se confirma esa estructura.

Conclusiones

Estos hallazgos son un primer paso para conocer las experiencias de cada uno de los integrantes de la familia durante el inicio de la enfermedad, el tratamiento, la recaída y las expectativas que se tienen en cuanto a la remisión del padecimiento.

Palabras clave: Anorexia nervosa, tratamiento, recaída, remisión.

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First version: June 5, 2012. Accepted: August 8, 2012.

Translation of the original version published in spanish in: Salud Mental 2013, Vol. 36 Issue No. 1

INTRODUCTION

A psychological and behavioral ailment related to the act of eating, anorexia nervosa is part of the eating disorders. Among its symptoms are deliberately having a body weight lower than the normal weight for the gender, height and age of the affected persons, besides developing amenorrhea and rejection to weight increase.[1,2] It starts in middle adolescence and involves considerable psychiatric and medical morbidity.[3] It affects approximately at 2% of young women and men ratio is 1:10.[4]

The first cases of anorexia nervosa were described since the Middle Ages as "anorexic saints".[5] It is the only psychiatric disorder that per se leads to death, and it is attributed to biological, psychological and social factors.

Probably Lasègue was the first 19th century physician who suggested that the rejection of food constituted an intrafamily conflict between the daughter and her parents.[6]

Apparently the perception of the disease from each family member plays an important role for the intervention and response to treatment.

At the end of the 19th century Charcot recommended —as a specific treatment for anorexia nervosa— the parentectomy,* limiting all kind of social influence.[5]

However, nowadays there are some studies on treatments made to patients with anorexia nervosa indicating that when the parents are involved in the treatment positive results have been attained.[7]

Other researches have underlined the importance of the family in the maintenance of eating disorders, thus the intervention with relatives has been an integral component of the treatment.[8,9] Likewise, the causes of anorexia nervosa have been searched, trying to find out why only some individuals are victims of this abnormality. These authors aim to the role played by the family in the development of anorexia nervosa.[3,10-12]

A Bruch's[13] study revealed the existence of hidden conflicts related to the parental attitude, particularly when describing the mothers as psychologically tormenting and torturing their daughters with comments about their body dimensions; attributing parents with extreme concern regarding the weight and figure of their own and their daughters.

Kalucy et al. analyzed 56 families who are victims of anorexia nervosa and found that in many cases the parents also had problems with their weight and eating habits.[10]

Similarly, Slade[14] mentions that two predisposing factors exist that may contribute to the development of the eating disorder: Dissatisfaction with life and low self-esteem due to adolescent conflicts and interpersonal issues, which seems to be more connected with the first life experiences and aspects related to the social area.

* Isolate the patient and separate her from the family.

Eisler et al.[15] state the very common difficulties in the bond established between mother and daughter, hence the family seems to play an important role, not as a causative agent specific of the disorder, but with an overprotective educative style that acts as keeping the symptom.

Some researches[11,13,15] establish descriptions of mothers and fathers of patients with eating disorders, where the mother is overinvolved and confused in the relationship with her daughter, whereas the father is described as cold and distant.

An eating disorder emergency on a daughter may undoubtedly affect the whole family dynamics.

The first initiative to include the family in the treatment of patients with anorexia nervosa was performed by Minuchin et al.,[11] who were based on the description of "psychosomatic" families and described alexithymic families* who avoid conflicts and emotional tensions. According to these authors the difficulties to express emotional experiences are because such experiences are blocked in order to avoid conflicts and keep the "myth of harmony". The somatic symptom would be the language of the whole family.

In turn, Selvini et al. openly mention the influence of family in the onset of the condition.[16]

In a review of the controlled studies about family relations concerning eating disorders, Espina et al.[17,18] conclude that, in general, the families of patients with anorexia nervosa are more hostile, disconnected and impulsive. The parents were not empathetic and had an upbringing deficit, failing to aid their children to understand the world of emotions.

From the point of view of systemic therapy, communication occurs through the eating behavior and it may be the necessary solution for families with a difficulty to connect themselves with the emotional world.[18]

The theoretical principles and the clinical application of the approach proposed by Minuchin et al. at the outset, have been used as the basis for the preparation of many controlled studies about family intervention conducted at the Maudsley Hospital in London,[19] which is a treatment model that currently supports the intervention to relatives, carried out in such institution specialized in eating disorders.

In Mexico there are no published in this regard, hence this investigation tries to contribute with an analysis in the way that the subjects themselves suffer the condition, and their parents coexist with the latter, narrate their story through experiences during the start of the disorder, the treatment, the relapse** and the remission*** of the symptomatology.

* Difficulty for processing emotions cognitively.
** Reappearance of illness without having reached the complete state of health, during the period of convalescence.
*** Reduction of the intensity of the symptoms.

MATERIAL AND METHODS

It is a qualitative study intended to understand the experiences of families within four specific moments: the start of the disorder, during the treatment, in the relapse,[20,22] and in the remission.[21]

In-depth focused interviews were used and the material was analyzed through a narrative analysis by thematic axes in accordance with Kohler Riessman's model.[23]

Informants

Informants were selected according to a theoretical non probabilistic sample. In the thesis project four family units were appointed, each made up by three subjects: mother, father and daughter with anorexia nervosa. For the purpose of this article only one family unit shall be analyzed.

Interviews were conducted individually. The daughter had to meet with at least three evolution years of anorexia nervosa in accordance with the DSM-IV-R criteria,[24] had suffered at least one relapse and that during this period had a close relationship with both parents who had attended to the therapeutic support group according to the Maudsley Hospital's model.[25,29] They were invited to participate through a prior informed consent in writing which clarified the objectives of the project, ensuring anonymity, confidentiality and that they could give up participation at any time.

Environment

This research and the interviews were conducted at a third-level Public Health Hospital with a department specialized in eating behavior disorders.

Instruments

A semi-structured focused interview was applied to the participants. Each interview was recorded and then literally transcribed. The purpose of the qualitative interviews was reaching a deeper insight in learning important aspects about the mind of informants: their meanings, perspectives and definitions; the way they see and experience the world.[30]

1. *Focused Interview:* also known as focus interview. This type of interview was developed by Fisk and Kendall and implies a combination of the depth and flexibility of non-structured interviews with the direction and meaning of structured interviews.[31]
2. *Interview Guidelines:* The interview guidelines is a support used for ensuring to avoid the omission of exploring key topics with the interviewees.[30] The guidelines designed for this research were semi-structured, seeking to remove the subjectivity of the interviewer while also allowing, as needed, any topic to be developed more fully. The guidelines contained the following sections: socio-demographic aspects, perception of the constitution and dynamics of family, perception and experiences on anorexia nervosa, the treatment, the relapse and the expectations of recovery.

Procedure

This article shows the results of the interviews conducted in depth to one of the four family units investigated with a daughter suffering from anorexia nervosa (mother, father and daughter) regarding the start of the illness, the experiences on the treatment, the experiences on the relapse period and the experiences during the remission of the symptomatology.

The interviews were conducted individually, without circular questions. That is to say, during the interview there was no interaction among them. And the questions were later transcribed and analyzed by the researcher (LGM). The interview with each interviewee lasted approximately one hour.

Data analysis

The data analysis was made through a narrative analysis in thematic axes, which emphasizes the contents of the text. It focuses on "what" the participants say rather than "how" they say it. Its purpose is to monitor how the respondents put the flow of experience in order. This methodological approach assess the story told and analyzed how the language and cultural resources are integrated.[23,32]

RESULTS

The analyzed family is made up by three members, the mother (A), the father (M) and the daughter (D) that, as mentioned, meets the criteria of anorexia nervosa.24 It is presented with a body mass index (BMI) of 13 kgm^2, which is within malnutrition levels, since she weighted 36 kg. and she lost 15 kilograms in three months limiting all kinds of food, being weighted three times a day and making calorie consumption calculations, having insomnia and anxiety with panic attacks. During the treatment she attained to elevate her BMI to 18 kgm^2., weighting 48 kg, although still had a very low weight, which lasted almost three years. Furthermore, she had strict behaviors, ranging between control and impulsivity.

D had a problematic relationship with both parents; the mother turned her into her confidante, while the father was too strict and demanding. The treatment lasted approximately three years reaching an impasse until the parents were involved, participating in a therapeutic support group.33 The patient did not show any evolution.

Translation of the original version published in spanish in:
Salud Mental 2013, Vol. 36 Issue No. 1

The thematic axes put forward for the narrative analysis were: the start of the disorder, during the treatment, the moment of the relapse and during the remission of the symptom.

Analysis of the thematic axes

Beginning of the disorder

During the beginning of the disorder, a very specific family structure is shown: the mother (A) is the extramarital relationship of the father (M) and she has a great fusion with the daughter (D) and with her daughter's partner, besides an emotional distance very noticeable regarding the father, who is totally distanced and dissociated from the mother and the daughter, keeping a totally peripheral functioning.[34] The mother attributes the start of the disorder to the fact that the father begins a new relationship with another woman, and he stops giving them money, therefore, the daughter is not able to continue studying and the mother has to find a job.

> (A) "*…I think it happened because my daughter had to drop out of college… he summoned us overnight and told us that he would not be able to pay university tuition fees. I think that that was the moment everything started… she felt really bad… so I believe that problem triggered the illness off*"

The father put forward another argument and blames himself for having triggered his daughter's illness when he persuaded her to go with him and visit a physician so that both of them could lose weight.

> (M) "*I partly blame myself for her illness… I started going to the damned ear acupuncture and I did lose weight… I knew that my daughter was fatty… I detected that, suddenly, she started to get away from boys or her friends, precisely because her slight obesity… I took her there and we started to lose weight; I stopped but she kept on…*"

The patient attributes the beginning of the illness to both circumstances. She feels as too aggressive the fact that her father took her with a physician to lose weight and that she really began to watch what she ate and to stop eating well, because she dropped out of college and she did not have anything to do; she only remembered she spent endless hours reading food labels.

> (D) "*…I started diets because I was overweight, until I really enjoyed how I was losing weight, but there was a moment in which I lost control… my father forced me to visit a physician… because I didn't really want to go; I conceived it as a very aggressive thing…*"

The treatment

The treatment followed through at the Institution is the first treatment that the patient undergoes. In the beginning she is invited to take part and involve in her treatment. However, due to the egosyntony with the illness and to the ambivalence to stop the symptom[32] it is very difficult that the patient follows medical directions and does something to modify her behavior. Likewise, due to the results, it was necessary to include the parents in the treatment.

Family dynamics was modified from the moment in which the joint treatment starts: bonds between the mother and the daughter become stronger, but the mother continues using her daughter as her confidante, speaking negatively about the father. The daughter's partner persists in the fusion with the mother-daughter dyad who, in spite of being angry with the father, it achieves to involve the father in the treatment. Notwithstanding, the father-daughter relationship becomes even more distant.

D is who asks for help. She is desperate because of the way in which the disorder has got out of control.

The mother realizes this but takes no part in the illness, only through her daughter's friends she involves in the disorder.

> (A) "*…actually I had to find a job… I think she started to have problems because her friends said that she had cried… it seems that she was going to faint, but I had to keep working, since in that time he didn't give us any money,… she bought a scale and start saying that she was very fat; she bought small clothing and thus I began to realize,… and when D started to say that she needed help…*"

Although the father still plays a peripheral role, he can observe his daughter's restrictive behavior:

> (M) "*…I realized that she was losing weight, but I never took it seriously until it was evident and D told us that she wanted to speak with us; she said she had lost control, that she had already found this hospital and that she felt she could die…*"

D. is desperate, trapped in the inactivity and the food exhaustive control.

> (D) "*…emotionally I felt bad,… the first thing was realizing I was using the disorder to hide many other things; I was sad and angry; mostly because I had many problems with my parents, that is to say, despite that apparently there were no problems… I always tried to smile; I think that I was using the anorexia so that I could do that…*"

The relapse

The relapse is the occurrence of those behaviors in which a progress had already made and which falling back causes a reduction of what has been achieved; therefore, the patient could return to the initial stage of his/her pathology. In eating disorders the most likely time of relapse is the first year after the discharge. Within the five following years relapse is also frequent in situations of severe stress and radical vital changes.[21]

During relapse the patient goes back to behaviors such as weighting herself three times a day and to the calorie calculation she was used to make. Again, she had a weight within malnutrition levels, with a body mass index (BMI) of 16 kgm^2. weighting 43 kg. The mother stops insisting the father to be involved in the treatment and, paradoxically, the latter starts approaching the daughter, and controlling her, until attaining a more suitable approach which improves their relationship. At the same time he is able to come closer to the mother and then both are involved as a couple to help

their daughter and make the treatment and the required care easier.

The mother attributes the relapse to the father's level of demand, who is a controlling father since he does not let her go out with friends, the constant criticism regarding her clothing, her body and her activities:

> (A) "*…he's quite authoritarian; what he says must be made when he wants; I believe this is why they don't get on at all… and all this is related to D's illness*"

> (A) "*…the psychologist told me that I should protect my daughter and not vice versa; then, I realized that it was true that I made many mistakes and took refugee in my daughter…*"

The father attributes the relapse to his bad bond with the mother and to the fact that he was indulgent towards his daughter:

> (M) "*…she took advantage of us… because I still was buying her what she wanted… and supposedly I wanted to please her thus I used to buy her a box of yogurt, a box of low-calorie water bottles, and many other boxes; I really felt good for it… now I know that it was a terrible mistake…*"

> (M) "*…the situation of our marital relationship was the main problem… we were very divided… hence everything was utterly triangulated…*"

The daughter detected her parents' difficulties to reach an agreement as well as the lack of control in their relation, the explosive way in which they get on and that both parents put pressure on her in excess, demanding more than she can give:

> (D) "*…with the disorder I handle my emotions well, everything under control; when I say what I think I have problems with my father, I prefer to have everything under control… so the fact that I didn't eat was something I did to be ok with them*".

The remission

As for the remission as a reduction of the intensity of the symptom,[20-22] the patient gradually stops weighing herself and she considerably reduces the food restriction, achieving a healthy weight (BMI of 22.1kgm^2 weighing 58 kg.) and maintaining it. Alliances between mother and daughter start blurring and the daughter is less pressured so that she can involve more deeply in the father's relationship. Then, the mother attains that the patient's partner again takes care of her. So, she can give up work and feel more supported and not alone, which allows her to free her daughter and allow her to have a better relation with her partner. The daughter decides to live with her partner, hence attaining to separate herself from the mother-daughter symbiotic bond.[34]

The mother attributes the remission to the fact that they have freed their daughter letting her be herself and be responsible of her things:

> (A) "*…she had answered very well; I think that she became a very responsible person… I was aware of everything she ate, and what she didn't eat… I decided not to ask her anymore; she could decide whether eating or not; I couldn't be taking care of her all day…*"

The father attributes the remission to the fact that he stopped controlling his daughter and being so aware of her. He is still concerned about her behavior of eating or smoking, but he neither criticizes her nor demands her to do what he wants, as before:

> (M) "*…because again talking about the start of the illness… I blame myself… due to the damned ear acupuncture… I caused her anorexia… well… that's what I felt before, now I don't feel it…*"

The daughter confesses to be less pressed and demanded by both parents. Also, she says that they do not control her anymore. Apparently, from the moment she stopped being her mother's confidante she has been able to focus on her partner and her daughter:

> (D) "*…I think that when I left my parents I had other thinks in my mind… I was gradually leaving behind everything that affected me, that is to say, I'm sad that my mother is like that, but now I have many things to deal with… little by little my mother gives me some space as well as her problems; of course, her problems affect me but not to the extent that I have to stop eating; I really feel much more calm and relaxed*".

DISCUSSION

The four moments of the illness evolution have several points of view according to each informant. The bibliography of this article mentions the symbiotic relationship of mother and daughter as well as the peripheral relationship established with the father.[13,34,35] The information obtained regarding this case confirms such structure, therefore, the fact of achieving a change in family alliances[11,28] facilitates the mobilization of bonds. Also, Minuchin and Selvini's initial hypothesis is thus confirmed: the daughter becomes ill to "get her parents together". It is known that the first experiences with food start at home, and that the family is the most important influence on the style of feeding; and that the environment surrounding food affects, in turn, such response.[36]

In accordance with this research, apparently rigidity and control by any of the parents and the loss of family hierarchies are central elements in the appearance and development of the illness.[11,26,29,36] Likewise, it can be deducted that the start of strict diets can trigger anorexia nervosa.[11,29,37]

The parents are overinvolved with the daughter but are unable to detect the real symptoms of the condition and its needs.[36] The information obtained is consistent with Bruch's ideas about the mother-daughter relationship and the father's concern for his daughters' weight.[35,36]

The relapse works differently for each of the family members and, in this case, plays an essential role in the symptomatic remission since it is possible to observe the peripheral relationship established with the father and the symbiotic relationship with the mother. In the relapse, the father involves in the treatment and saves his daughter from the symbiotic bond with the mother, achieving to modify the family dynamics and restore hierarchies.[11,26,33]

Translation of the original version published in spanish in:
Salud Mental 2013, Vol. 36 Issue No. 1

In the remission independence is achieved and roles are again established, in such a way that it is possible to observe the disease's evolution and the disappearance of the anorexic symptom.

In conclusion, in this research it was observed how the perception of the disease for each family member plays an essential role in the intervention and in the response to the treatment. Also, these findings are a first step for knowing the experiences of each family member during treatment as well as the expectations regarding the remission of the illness, which provide information that could be useful to assess future interventions.

However, it is necessary to examine more deeply the role that the family plays towards eating disorders, since it can be observed that this contributes both in the appearance of the disorder and in the maintenance of the symptom. In a propitious atmosphere comments about the weight and figure will explain the illness. Thus, appropriate family relations and parental roles are of vital importance.

Finally, the expectations of knowledge about how the condition develops within a Mexican family provide us guidelines to carry out better treatment proposals, focused on more specific necessities.

Parents of patients with anorexia nervosa may want to find the way to help their daughters; therefore, it is critical that they are involved in the relevant health care to aid them with the proper support at home.

Translation of the original version published in spanish in: Salud Mental 2013, Vol. 36 Issue No. 1

ACKNOWLEDGEMENTS

To physicians Samuel Jurado, Ma. Emily Ito, Shoshana Berenzon, Ma. Elena Medina-Mora, Marcela Blum, Víctor Ruíz Velasco and Beatriz Camarena for their support and comments, and to the Comité de Ciencia y Tecnología CONACYT (Internship 223213).

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Declaration of conflict of interests: None

Translation of the original version published in spanish in:
Salud Mental 2013, Vol. 36 Issue No. 1