Anorexia nervosa in children: ethics of treatment

Anorexia nervosa in età evolutiva: etica del trattamento

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Anorexia nervosa (AN) is a serious psychiatric illness with onset mainly in adolescence, characterized by an important food restriction, fear for weight gain and a serious body image alteration. Often, the severity of the disease, denied by the patient, can lead to serious medical consequences, including death. Medical therapeutic goals are easy to define: weight regain and physical condition recovery, nutritional re-education and building a strong motivation to care. However, the way to reach these goals often collides with the difficulty in managing the anorexic patient, and raises ethical problems regarding pharmacological and psychological care, as well as the involvement of the family in the care process. It seems therefore clear that it is necessary to understand the mechanism underlying psychopathology of AN to address the heavy sense of helplessness and frustration of the clinician to avoid enforcement actions that may aggravate the course of the disease.

Key words: Anorexia nervosa, ethics, treatment, adolescence

L’anoressia nervosa (AN) è una grave patologia psichiatrica con esordio prevalentemente in età adolescenziale, caratterizzata da una importante restrizione alimentare, paura ad aumentare di peso e una grave alterazione dell’immagine corporea. Spesso la gravità della malattia, negata dalla paziente, può portare a gravi conseguenze mediche, tra cui la morte. Gli obiettivi terapeutici da raggiungere sul piano medico sono facilmente definibili: recupero del peso e delle condizioni fisiche, rieducazione alimentare e costruzione di una solida motivazione alle cure. Tuttavia, la modalità con cui realizzarli spesso si scontra con la difficoltà di gestione della paziente anoressica e incontra problemi etici sia nella cura farmacologica e psicologica della paziente, che nel coinvolgimento nel percorso di cura dei suoi familiari. Appare quindi chiaro comprendere il meccanismo psicopatologico alla base dell’AN per affrontare il gravoso senso di impotenza e di frustrazione del clinico per evitare interventi coercitivi che potrebbero aggravare l’andamento terapeutico.

Parole chiave: Anorexia nervosa, etica, trattamento, adolescenza
Anorexia nervosa (AN) has been identified as a specific nosographic identity since the 17th century, when Richard Morton described it as an atrophic and consumption state, characterized by excessive weight loss, due to prolonged poor nutrition, primary and secondary amenorrhea, weakness, motor hyperactivity without rise in temperature, cough and/or dyspnea.

In the late 1800s, Lasange and Gull better specified the etiology of this condition, stressing the presence of an intellectual perversion, due to a hidden or confessed strong emotion or even to psychic anomaly. AN has been definitely classified as a psychic disease in the first ‘900s.

By a clinical point of view, the most striking AN symptom is weight loss after progressive restriction in food intake. According to the Diagnostic and Statistical Manual of mental disorders (DSM-5, APA, 2013), in order to diagnose AN, the following criteria have to be satisfied:

- restriction in energy intake, lower than requirements, that determines significant lower weight than what expected for age, gender, developmental trend and physical health;
- intense fear of weight gain and obsessive behavior to maintain low weight, even if significantly underweight;
- altered weight and body perception, overrated self-esteem or underrating the gravity of excessively low weight.

This pathology shows in variable ways during the developmental age: as temporary forms, due to specific critical developmental phases, or as more severe forms, that negatively affect physical and psychological children’s development, with a chance of death of 1.8% (10-15% in adulthood; Steinhausen, 2009). In the general population, however, the risk of death for a person diagnosed with AN is 5-10 times higher than that of healthy subjects of the same age and sex. Suicide accounts for about 20% of all causes of death, while the medical complications of acute and chronic forms (especially infections, depletion of protein and electrolyte abnormalities) are the most frequent causes of death (Ministry of Health, 2013).

Onset is about the age of 15-19 years, but recently early onset, even at age 9, is becoming more frequent (Nicholls, Bryan-Waugh, 2008; Spettigue et al., 2008). AN generally affects principally females with a ratio male-female of 1:9 (Hoek, 2006), even though most recently males are being more consistently involved. In studies of clinical populations, males account for between 5% and 10% of cases of AN nervosa (Ministry of Health, 2013). Considering only the end of adolescence, the lifetime prevalence for AN in this age group is estimated at 0.3% (Swanson et al., 2011).

At the onset of AN, patients show a normal, compliant and obliging behavior, but later on, with symptoms strengthening, they become emotionally cold and detached, with a decrease of social interactions. Food rejection goes along with a high physical and intellectual activity, supported by a feeling of omnipotence and the firm belief to withstand to fatigue, even without food or rest. Another typical characteristic with which these patients live their illness is the egosyn-tonic dimension with which they perceive their symptoms, which consequently cannot be criticized.

Psychic balance of AN patients exacerbates if the onset occurs during sexual maturation critical age: these young girls, facing adult onerous obligations, refuse to grow up, with a resulting interruption of their psychophysical development. Continuous negation of own physical needs and instincts may cause eating dyscontrol episodes, such as actual bulimic crises.

Etiology of AN is multifactorial: according to the biopsychosocial or multidimensional model, biological, psychological and sociocultural factors concur to AN (Garfinkel, Garner, 1982; Hudson et al., 2007).

As regards biological factors, genetic susceptibility seems to be one of the causes. Familiarity studies revealed that having a first grade relative with AN or BN, higher psychopathological level as Anxiety Disorder (Obsessive Compulsive Disorder in particular) and Mood Disorders are correlated with higher chances to develop Eating Disorders (EA; Lilienfeld et al., 1998; Bellodi et al., 2001). Twins studies also reported inheritance high levels (Bulik et al., 2006).

As far as risk factors are concerned, retrospective studies show that some personality traits of adolescents and adults with ED, as obsessiveness, rigidity, perfectionism, tend to occur early in their life story. Some authors in fact consider their presence in childhood as a risk factor for ED (Herpertz-Dahlmann et al., 2011; Lingiardi et al., 2013). Other features in high risk ED children are dysphoric mood, altered self-awareness, in addition to neuro-cognitive deficits regarding global information processing and reduced cognitive flexibility (Steinglass et al., 2006; Friederich, Herzog, 2011).

Socio-cultural factors include, in addition to the general thinness idealization of Western societies, even family environment dynamics that may hinder the separation and autonomy process (Favaro et al., 2003).

Finally, some factors can anticipate and precipitate the onset of the disease, such as loss, grief, shock, illnesses, separations, altered family balance, or any other event perceived as traumatic.

Therapy

Treatment of AN differs depending on severity, going from commitment for more serious cases, to day hospital or institutionalization in specialized centers for more severe forms. Weight regain and physical recovery are the main goals in emergencies, concurrently to nutrition re-education and stronger motivation to change. Individual or family psychotherapy and drug therapy can integrate the therapeutic intervention and are foundations for long-term treatment (Donini, Cuzzolaro, Spera et al., 2010).

Both the National Institute for Health and Clinical Excellence (NICE, 2004), and the American Psychiatric Asso-
cation (APA, 2006) agree with the need of an integrated and multidisciplinary approach, involving several professional figures (Psychiatrists, Psychologists, Nutritionists, Internists and Nurses) and developing on different levels (from general medicine, outpatient setting, and day-hospital, to rehabilitation and hospitalization).

Even if medical goals are easy to define, often their actual fulfillment collides with the difficulty of managing an AN patient: in fact AN patients or their families tend to underestimate the seriousness of the disease and sometimes refuse appropriate psychiatric and medical therapy.

It is known that AN patients are not collaborative, refuse nutrition and adopt several strategies to boycott treatment (food hiding, or vomiting for instance).

Facing this resistance by patients, therapists do not know how to achieve therapeutic goals, especially when attempts to convince patients to feed fail, and clinical options, such as parenteral or tube feeding collide with the patient’s right to self-determination.

So which is the right and ethical way to approach a patient who refuses care?

Is it fair to adopt therapeutic strategies that may be perceived as extreme and coercive (such as parenteral or enteral feeding)?

For adults, the Italian legislation recognizes AN as a psychiatric illness in which it is allowed to apply Mandatory Medical Treatment, as provided by law 833/78 art. 34.

Such conditions include the presence of “mental changes which require urgent therapeutic intervention”, the inability to “take timely and appropriate health measures outside hospitals”, “the denial of consent to treatment by the patient” (Santonastaso, 2009).

In developmental age, these the presence of these conditions is not necessary, because parental approval is sufficient to start treatment judged necessary, such as hospitalization and artificial feeding. However, even if the management of anorexic patients’ treatment may seem simple in this age, a reflection is necessary on how the use of these aids remains a gory intervention, involving extreme suffering of the patient. The Patients’ positive response to therapy can be determined more by the fear of losing control over their symptoms, than by the actual cure of the disease.

To this end, the involvement of family members in the treatment of AN, as indicated by the main guidelines, is an important resource that facilitates the construction of an alternative access, and promotes compliance to treatment by patients, rather than the use of more invasive measures.

Several studies point out the effectiveness of familiar treatment in eating disorders in childhood and adolescence (Eisler, 2005; Le Grange & Lock, 2007; Mitchell & Carr, 2000; Wilson & Fairburn, 2007), but if initially the family was given the primary responsibility of the disease, current research emphasizes the importance of the family’s involvement as a potential resource for treatment.

Family Based Therapy (FBT) of Mausdley Hospital (Lock et al., 2001; Lock, 2007) is the most studied family intervention. This family based model involves parents in the treatment: in a first step, parents are involved in the management of the child’s food problem, in order to restore their parental competence, distressed by the severity of symptoms. In later stages, the family therapist works on patients to first restore their autonomy on own nutrition and later to help them deal with personal problems and relationships, also working on the dysfunctional family dynamics that do not facilitate the release of the patient from his/her family.

However, when is the family not a resource? What can be done when parents, crushed by helplessness and emotionally subdued by fear, implement behaviors that collude with the severity of eating disorder behaviors or, at the opposite, trigger coercive and violent control on their children’s feeding?

The Italian legislation (Article 9.1 L. 184/83, Art. 331, 357, 358, 361, 362, 365, 591, 593 cod. Pen., art. 403 cod. Civ.) provides for the obligation for health professionals, who are aware of such problems, to report parental negligence to Social Services, or directly to the Juvenile Court. Following this report, the legal protection and subsequent monitoring of treatment of the patient can be transferred, with a request by the Judicial Authority, directly to Social Services.

However, are we certain that this measure, surely protective for patients, always represents a positive response to the complexity of the child’s psychopathological picture and to the already compromised parenting?

Often the activation of the social services is perceived by parents, and sometimes used by doctors, as a punitive and judgmental tool oriented to implementing an immediate solution of the actual problem. Conversely, the family monitoring by social services should represent a valuable tool to protect the child, if it is integrated with a psychological and/or psychoeducational work on parents. In this way, parents may acquire awareness of their difficulties, even emotional, in managing the disease, and initiate a process of durable transformation.

Work with family

Although the current empirical research does not support the thesis that there is a specific functioning pattern of families with a member suffering from AN, actually in clinical practice some structures and relational characteristics seem to be recurring.

For example, the tendency to focus all the attention on the “identified patient”, denying a discomfort within the family context is frequently found. In these circumstances, the family’s commitment to care is difficult to obtain, because the implicit request is that therapy is exclusively focused on the patient.

It seems therefore necessary to immediately create an
atmosphere of trust with parents, in order to prevent that the care setting is seen as a source of judgment, but instead creating and consolidating a working alliance that, recognizing to parents their skills, allows them to gradually recognize themselves in the issue.

Family tendency to collude with the symptoms without understanding the actual gravity of the problem may be frequent too. This attitude often reflects a tendency of the family to deny the discomfort and idealize family relationships, as well as the parents’ fear of disappointing expectations of their children, who promise to be able to find a solution by themselves.

In both cases, the tendency to cover emotions and maintain an ideal unattainable harmony, negatively predisposes these families to conflicts and often involves a late reporting of the disease, when physical conditions of the patient have already deteriorated.

The family coming to therapy has developed dysfunctional relational modalities to front the problem, and is often unable to try other ways. The dietary symptoms have exalted dysfunctional aspects of relationship dynamics and have reduced the family’s adaptability and problem-solving skills.

The operating characteristics of families fall into “maintenance factors” of anorexic symptoms and it is therefore essential to understand these characteristics and their evolution. The most important experience that the family can do is to recognize the psychological discomfort, explain the conflicts, and try out new strategies to deal with, discovering skills hitherto unknown to them.

**Drug treatment**

As a last point of reflection it is important to dwell on the ethical problem arising from the possible use of drugs in AN treatment. In fact, as regards drug therapy, most of the drugs studied and used in clinical practice are not recognized for treatment of this disease, but only for the correction of psychopathological conditions present as comorbidities. Their clinical use is at present mostly off-label, and there is no evidence of their effectiveness. However, the quality, often delusional, of anorexic thoughts, body image misperception (Hoffman & Halmi, 1993) and the lack of insight into the disease exhibited by patients, often make the use of these drugs necessary. Scientific studies are still very limited and mainly based on empirical data, rather than on strong scientific evidence, and up to now no drug is considered as a first choice intervention, but only as an additional option to the various psychological therapies (NICE, 2004).

**Conclusions**

In light of the above, it is clear that a close relationship with AN patients and their families is essential to understand the mechanism behind AN. In fact, strong relational closure characterizing the clinical encounter with these patients, the lack of access on an emotional level and the continuous failure to change eating behaviors not compatible with a concept of healthy nutrition and good health, exponentially increase the sense of helplessness and frustration of the clinician involved in the therapeutic process. Carrying out enforcement actions may be seen as an answer, which, although conceived as a strategy for unlocking the severe symptoms related to food, may unknowingly respond to the therapist’s need to limit the heavy sense of impotence he or she feels. Such measures are likely, if not managed consciously, to trigger a “duress relationship” with the patient, who, in less fortunate cases, may respond with a stronger compulsion and even more severe food restriction.

**References**


