

EXTENDED SUMMARY:**UPDATE OF INTERVENTIONS AIMED AT THE FAMILY CONTEXT IN EATING DISORDERS: THE ROLE OF THE PARENTS****Ana Rosa Sepúlveda¹²³, Alba Moreno¹²⁴ y Lucía Beltrán¹²⁵**¹ Departamento de Psicología Biológica y de la salud,² Facultad de Psicología, Universidad Autónoma de Madrid. España³ ORCID: <https://orcid.org/0000-0002-6041-2889>⁴ ORCID: <https://orcid.org/0000-0002-6303-0915>.⁵ ORCID: <https://orcid.org/0000-0002-7254-9575>

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Abstract

Caregivers of relatives suffering from an Eating Disorder (ED) often have health problems and stress associated to the caregiving experience. Most caregivers are parents, due the illness onset is during adolescence. This study aims to review the involvement of family factors in the etiology of eating disorders, to study the impact on health and their needs. To revise the main interventions aimed at psycho-educational or skills-based interventions for parents. The results show there are aspects of the families that can influence on the maintenance of the pathology as expressed emotion or accommodating to the eating symptoms. The results show the importance of intervening in these maintaining factors associated to caregiver role, and that coping skill interventions directly on family members that have shown good results both in the well-being of family members and in the eating symptomatology of the patients.

Keywords: family, eating disorders, etiology, psycho-educational intervention, coping skill intervention.

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1. Eating disorders and their impact on the family

Eating Disorders (ED) are serious psychological problems, mainly beginning in adolescence, characterized by the alteration of eating behavior and body image (5.^a Ed.; DSM- V; American Psychiatric Association [APA], 2013; Toro, 2000). Their multifactorial etiology includes biological and genetic risk factors, as well as sociocultural and psychological ones, which interact facilitating the development of the pathology (Garner, David, & Garfinkel, 1980; Toro, 2004; Culbert, Racine, & Klump, 2015). Moreover, the accumulation of stressful events close to the onset of the disorder is a critical precipitating factor (Moreno - Encinas et al., 2020; Machado, Gonçalves, Martins, Hoek, & Machado, 2014).

The consequences of ED are significant at the personal, family, and social spheres (Harrison, Tchanturia, Naumann, & Treasure., 2012). The course of the illness is chronic for one-fifth of patients (Steinhausen, 2002; Steinhausen & Weber, 2009), and high resistance to treatment is common. Medical complications can emerge from malnutrition, severe weight loss or vomiting behavior (APA, 2013), which, together with suicide, reach high mortality rates (Arcelus, Mitchell, Wales, & Nielsen, 2011). At a socio-health context, eating disorders represent 23.1% of hospital admissions due to psychological disorders in women between 15-24 years in the Community of Madrid; and the average hospital stay is four times greater than all diagnoses (Oliva, Gandarillas, Sonego, Díez-Gañán, & Ordobás, 2012). The higher the psychiatric comorbidity, the higher the use of hospital admission, where more than half of the patients with ED meet the clinical criteria of another psychological problem, such as anxiety, depression, or obsessive-compulsive pathology (Arcelus et al., 2011).

In the family environment, living with a person with eating disorders is associated with higher levels of psychological distress (Sepúlveda , Kyriacou, & Treasure, 2012). Additionally, family members show high levels of stress, feelings of burden and physical fatigue, as well as communication, flexibility and family cohesion problems (Whitney, Haigh, Weinman, & Treasure, 2007; Sepulveda et al., 2009; Martín et al., 2011). Loss of control and failure of all attempts to help the person with an eating disorder causes frustration and hopelessness among family members. Primary caregivers (largest number of hours dedicated to caring) tend to have worse levels of psychological well-being (Sepúlveda et al., 2012). In this regard, there are gender differences: mothers tend to be primary caregivers (Berbel et al., 2010; Sepúlveda et al., 2012).

Concerning the impact of this disorder, ED families perceive the experience as caregivers, in terms of feelings of burden and distress, similar to families of patients with schizophrenia (Graap et al., 2008), but more negatively than families of adolescents with substance abuse or without pathology (Anastasiadou et al., 2016). Regarding the needs described by families, there is dissatisfaction with the information received by health professionals, suggesting the need to meet other families going through the same experience (Haigh & Treasure, 2003). The study

by Tierney (2005) showed caregivers felt the approach to the disorder was not adequate, it focused excessively on weight and not on other causes, and they were not informed about the progress of treatment. A recent systematic review by Johns, Taylor, John, and Tan (2019) reflects that families report the information collected on the internet, in self-help books or private health resources is more useful than the information received in primary care or schools settings.

2. Family maintenance factors in Eating Disorders

The most widespread etiologic model of eating disorders is the multifactorial model of Garner (1993). It describes three types of factors involved in the genesis and maintenance of this problem: predisposing, precipitating, and maintenance factors. Within the maintenance factors involved in prolonging or preventing the recovery of the person with an eating disorder, family factors are fundamental.

Initially, family factors were considered to cause the ED (Minuchin, Rosman, & Baker, 1978). Subsequently, they were re-conceptualized as a dysfunctional response to eating disorders (Dare, Grange, Eisler, & Rutherford, 1994), recognizing them as possible unintended maintainers of the problem (Whitney & Eisler, 2005). Thus, the change of these factors is the therapeutic focus of most of the interventions involving the family (Treasure & Schmidt, 2013). Systematic reviews in this regard have focused on the emotional distress of families, accommodation to symptoms, or the high levels of expressed emotion (Zabala, Macdonald, & Treasure, 2009).

Concerning **emotional distress**, current research shows that family members in ED experience high levels of anxiety or depression, high levels of burden, as well as patterns of dysfunctional family interaction (Anastasiadou et al., 2014; Whitney et al., 2007; Zabala et al., 2009). The use of maladaptive coping strategies facilitates feelings of inefficiency and psychological distress (Coomer & King, 2012). Likewise, the stigma of having a relative with a severe psychological disorder, the difficulty of understanding and the shame of the symptoms, as well as the lack of information about the treatment, can influence the emotional distress family members experience (Whitney et al., 2007). The caregivers' stress is associated with the duration of the disorder (Anastasiadou et al., 2014; Whitney et al., 2007).

Accommodation of symptoms refers to the normalization and accommodation towards inappropriate eating habits and rituals, as if it were a "lifestyle." Examples of these behaviors are the excessive purchase of low-calorie products, allowing the patient to excessively control family meals, or altering family plans (Perkins, Winn, Murray, Murphy, & Schmidt, 2004; Sepúlveda, Kyriacou, & Treasure, 2009). Family members accommodate to these symptoms to reduce emotional distress; however, organizing life around the illness may affect the negative impact of the caregiving experiences (Treasure, Gavan, Todd, & Schmidt, 2003). Higher accommodation to the symptoms has been associated with more severe psychosocial functioning deficits and anxiety symptoms among family members (Anderson, Smith, Nuñez, & Farrell, 2019).

Finally, the concept of **Expressed Emotion** (EE) refers to the attitudes and behaviors of family members towards a person with a mental disorder, which are characterized by emotional over-involvement, criticism, and hostility. Caring for people with ED can generate emotions such as guilt, shame, or anger, which are, in turn, associated with an increase in EE (Hooley, 2007). Prestigious systematic reviews have found high levels of EE in relatives of people with ED, associated with a negative impact on the caregiving experience and mood disorders in family members (Zabala et al., 2009; Anastasiadou et al., 2014). High rates of EE are related to a worse response to treatment, high relapse rates, and longer duration of the disorder (Peris & Miklowitz, 2015). The results of the latest research seem to indicate Expressed Emotion shows a reciprocal relationship between parents and children (Reinecke, Lebow, Lock, & Le Grange., 2017), with emotional over-involvement being more common in mothers and criticism in fathers (Kyriacou, Treasure, & Schmidt., 2008).

The interpersonal maintenance model (Treasure & Schmidt, 2013) proposes that family response to the Eating Disorder may create a vicious circle, therefore prolonging the recovery. Family members, who experience high levels of frustration and anxiety, would eventually accommodate to symptoms, and respond with higher levels of expressed emotion, which in turn would exacerbate the patient's ED psychopathology.

3. Update of interventions aimed at the family

The available clinical guidelines recommend the inclusion of the family in the treatment of eating disorders, being the first treatment option for children and adolescents (Gorrell, Loeb, & Le Grange, 2019; Hilbert, Hoek, & Schmidt, 2017). However, some authors recommend the inclusion of families of patients with AN regardless of the age of the patient (Treasure et al., 2005). Different psychoeducational interventions, family therapies or support groups have obtained satisfactory results (Schaumberg et al., 2017) and have increased the level of understanding of the pathology among family members (Highet, Thompson, & King, 2005).

4. Psychoeducational programs

Programs focused on psychoeducation have shown good results by reducing family members' distress (Gutiérrez, Sepúlveda, Anastasiadou, & Medina-Pradas, 2014; Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008). Both the acquisition of new skills and the increase of knowledge improve the care experience (Sepúlveda et al., 2012). Likewise, belonging to a support group help to reduce emotions such as shame or guilt (Pasold, Boateng, & Portilla, 2010). Some of these programmes are:

- a) **The parent support group of the Arkansas Children's Hospital** (1994). It emerged as a space for family members to have a confidential space to share their concerns and fears. A psychologist and a doctor coordinate the group, who carry out psychoeducation and discussion sessions. The

results, lately replicated, are positive, with increased knowledge of family members (Pasold et al., 2010).

- b) **The Aachen Program** (Holtkamp, Herpertz-Dahlmann, Vloet, & Hagenah, 2005). Aimed at increasing the knowledge of caregivers on ED, it is carried out by a nutritionist, a psychiatrist, and an occupational therapist. It consists of five sessions of 90 minutes. The results of the program were assessed as positive by family members.
- c) **The Family Psychoeducation Program for Eating Disorders** (Gutiérrez et al., 2014). The program consists of six biweekly sessions of two hours. The content is based on Fairburn model (2008) and follows the structure of the intervention model of the Maudsley Hospital (Treasure et al., 2007). The results were positive and maintained at three months, with a decrease in psychological distress and a reduction in expressed emotion (Gutiérrez et al., 2014).
- d) **Family Intervention Calgary Model** (Wright & Leahey, 2009). The program, developed by nurses, consisted of four weekly sessions, which addresses four stages: commitment, evaluation, intervention, and discussion. Parents reported the program was useful and valuable for their families (Gísladóttir & Svavarsdóttir, 2011).

5. Skills-based interventions

Family-centered interventions had a significant development on the treatment of eating disorders (National Institute for Clinical Excellence, 2017). Mainly in AN, several studies have shown better results than individual intervention (Eisler, Simic, Russell, & Dare, 2007). The team that has developed these interventions the most belongs to the Maudsley Hospital in London. Some of the most influential interventions they have proposed are:

- a) **Family-Based Treatment or the Maudsley Approach**. It trains family members to exercise control over the feeding of their children. It involves 15 to 20 sessions for one year. It works in three phases: 1) family members take control over their children's eating patterns, 2) food control is gradually placed back to the children, 3) maintenance of healthy identity. The NICE Guide (National Institute for Clinical Excellence, 2017) recommends this treatment in adolescents with a duration of the illness for less than three years, as well as for bulimia nervosa (Dodge, Hodes, Eisler, & Dare, 1995) in teenagers, with some specifications.
- b) **The Maudsley Collaborative Care Program**. The program consists of six sessions with a duration of two hours each. It aims to improve communication skills and increase willingness to change using the Motivational Interview (Miller & Rollnick, 2015) and the change model proposed by Prochaska and DiClemente (1984); it uses animal metaphors for this purpose. This intervention has shown to reduce the levels of burden in

caregivers (Sepulveda et al., 2008).

- c) **The Maudsley Collaborative Care Program, digital version** (Sepulveda, Lopez, Macdonald, & Treasure, 2008). It aims to teach parents positive communication and coping skills through DVD viewing. It consists of 5 DVDs aimed at family members who could not attend the face-to-face intervention. The DVDs used the same metaphors and proved useful for families.

6. Conclusions

Once the evidence-based paradigm shift has taken place, the family is considered an active agent of change in the process of recovery. Currently, the intervention focus on family factors that inadvertently maintain the disorder, and scientific evidence provides a solid basis on the effectiveness of interventions that include these factors. The psychoeducational stress management groups, the change in family communication styles, and the training of caregivers in the management of eating symptoms show promising results in the treatment of eating disorders, mainly during childhood and adolescence. Future research could focus on those conditions that make each of these treatments more effective (Gorrell, Loeb, & Le Grange, 2019), as well as the inclusion of the family in long-standing adult patients treatment.