Coping, family functioning and the experience of caring for an adolescent with an eating disorder:

A comparative study

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“And once the storm is over, you won’t remember how you made it through, how you managed to survive...But one thing is certain. When you come out of the storm, you won’t be the same person who walked in. That’s what this storm’s all about.”

~ Haruki Murakami

To all of the patients who have allowed me to accompany them through their storms

To those of you who have stood by me through mine
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Two roads diverged in a wood, and I—
I took the one less traveled by,
And that has made all the difference.

-Robert Frost

The first two lines of this excerpt from *The Road Not Taken*, sum up the decision I was faced with, and the path I ultimately chose, when I moved to Spain in 2009 and began grad school at the Universidad Autónoma de Madrid two years later. Anyone who has chosen to pursue their PhD knows that it is an experience fraught with reminders of why it is a road less traveled. However, as I now stand so near to completing this particular journey, I too can conclude that I am incredibly grateful for the choice I made, for everything I have learned along the way, and most of all for the many individuals who have helped make my dream of completing my PhD a reality: you have made all the difference.

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DEFINITION OF ACRONYMS

ADHD Attention Deficit Hyperactivity Disorder
AESED Accommodation and Enabling Scale for Eating Disorders
AESSA Accommodation and Enabling Scale for Substance Abuse
AN Anorexia Nervosa
AN-R Restrictive Anorexia Nervosa
BED Binge Eating Disorder
BMI Body Mass Index
BN Bulimia Nervosa
CC Critical Comments (component of expressed emotion)
CD Conduct Disorder
ECI Experience of Caregiving Inventory
ED Eating Disorder
EDNOS Eating Disorder Not Otherwise Specified
EE Expressed Emotion
EOI Emotional Over-involvement (component of expressed emotion)
FQ Family Questionnaire
HADS The Hospital Anxiety and Depression Scale
HC Healthy Controls
HRQoL Health Related Quality of Life
K-SADS-PL The Schedule for Affective Disorders and Schizophrenia for School-Age Children
OCD Obsessive-Compulsive Disorder
ODD Oppositional Defiant Disorder
SUD/SRD\(^1\) Substance Use Disorder
TCA Trastorno del Comportamiento Alimentario (ED in Spanish)
TCS Trastorno por Consumo de Sustancias (SUD in Spanish)

\(^1\)SUD is referred to as SRD in Chapter 5 (article 1). Following publication of this article, experts in the field of addictions recommended replacing the term \textit{substance-related disorder} with \textit{substance use disorder}.
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General Introduction
Once believed to be a leading cause in the development of their child’s ED, families of these patients are now seen as part of the solution, and important allies in their child’s treatment (NICE, 2004; Wilson & Shafran, 2005). This has in part been due to studies pointing to the effectiveness of family therapy and interventions aimed at caregivers (Fisher, Hetrick, & Rushford, 2010; Hibbs, Rhind, Leppanen, & Treasure, 2015), as well as research suggesting that impairment in family functioning may be a result of the disorder rather than difficulties that existed prior to the illness (Whitney & Eisler, 2005). Previous systematic reviews have demonstrated that those individuals caring for a family member with an ED experience mental health difficulties, a negative caregiving experience and exhibit patterns of behavior thought to serve as maintaining factors for the disorder, such as high expressed emotion (EE) and accommodation and enabling behaviors (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014; Zabala, Macdonald, & Treasure, 2009).

The empirical study upon which this thesis is based is the first study to examine ED family caregiving variables that employs both a comparison group of patients with a similar psychiatric disorder (SUD) and healthy controls. A recent systematic review of the literature on ED family caregiving concluded that future research studies would benefit from recruiting comparison and control groups (Anastasiadou et al., 2014). Such studies allow us to better understand if the experience of caring for an individual with an ED is unique to this patient group, or is shared by those caring for an individual with a similar psychiatric disorder. Furthermore, use of a control group allows us to determine if the experience of ED caregivers is distinct from that observed among family members of healthy individuals.

Despite the fact that the number of studies on ED family caregiving has increased during the past few decades, the vast majority have not used exclusively adolescent samples (Anastasiadou et al., 2014; Zabala et al., 2009). Research using adolescent samples are of particular importance for two reasons. First, EDs tend to develop during adolescence, a time
when most individuals are still living with their families (Lewinsohn, Striegel-Moore, & Seeley, 2000; Micali, Hagberg, Petersen, & Treasure, 2013) and increased hours of contact are believed to be associated with caregiver’s unhelpful responses to the illness (Goddard et al., 2013; Sepulveda et al., 2012). Second, research suggests that family therapy for EDs, particularly in the case of AN, is most effective among younger patients with a shorter duration of illness (Treasure & Russell, 2011). A better understanding of the experiences of family members of adolescent ED patients will allow us to clarify what variables may be useful to target in family and caregiver interventions and if they are distinct from those of adult patients.

Furthermore, this study is also unique in its recruitment of both mothers and fathers. Previous research has observed differences between ED mothers and fathers in terms of their caregiving experience and responses to the illness (Anastasiadou et al., 2014). However, many studies have failed to assess both parents and a particular strength of the present study is its assessment of differences between mothers and fathers of adolescent patients on a large number of family caregiving variables. An additional strength of this study is its assessment of not only caregiver variables, but patient variables as well, including the use of a semi-structured diagnostic interview to assess for the presence of comorbid psychiatric disorders. Finally, these results add to the growing body of research about the ED family caregiving experience in Spain.

The current thesis consists of the following eight chapters:

**Chapter 1** presents an introduction to EDs, including information on their prevalence, classification and comorbidity. Additionally, information about the prognosis of EDs is presented, arguing for the importance of interventions and research focused on adolescent patients with a short duration of illness.

A review of the role of the family in ED development, maintenance and treatment is provided in **Chapter 2**. The interpersonal maintenance model of eating disorders (Treasure &
Schmidt, 2013), which provided the theoretical underpinnings for the current study, is introduced, as well as a summary of current research findings on each variable assessed in the research articles, with special attention paid to studies using exclusively adolescent samples.

Chapter 3 includes a review of ED family caregiving studies which have employed comparison and/or control groups. Moreover, a comparison of the similarities between EDs and SUDs is provided in order to explain the rationale behind the use of this particular comparison group. Finally, a brief section is devoted to the experience of raising a healthy teen in reference to the use of a healthy control group.

Chapter 4 provides a brief overview of the study methods, beginning with an explanation of the study design, objectives and hypotheses. It continues with a description of the participants and procedure and concludes with a summary of the instruments and the statistical analyses that were carried out in each article.

The first published findings are presented in Chapter 5, entitled “Family functioning and quality of life among families in eating disorders: A comparison with substance-related disorders and healthy controls.” This article published in the European Eating Disorders Review (Quartile 1) aims to compare variables related to unhelpful responses to the illness (i.e. EE, accommodating and enabling behaviors), the caregiving experience and quality of life of parents of ED and SUD patients and parents of healthy adolescents. Furthermore, it assesses gender differences between mothers and fathers on each of these variables.

Limited quantitative results exist on the coping strategies used by ED caregivers. The article presented in Chapter 6 (currently under revision in Psychiatry Research, Quartile 1) entitled “Experience of caregiving and coping strategies in caregivers of adolescents with an eating disorder: A comparative study,” is the first study on ED caregiver coping in Spain. It presents differences between the coping strategies used by ED, SUD and healthy parents, as well as the clinical implications of these findings for caregiver interventions. Furthermore, this
article explores the relationship between patient and parent variables and the use of particular coping strategies and the association between the appraisal of the caregiving experience and coping.

Chapter 7 presents the article entitled "Psychiatric comorbidity and maternal distress among adolescent eating disorder patients: A comparison with substance use disorder patients." Published in Eating Behaviors (Quartile 2), this article presents rates of comorbid disorders among the two treatment seeking patient groups, as assessed by a semi-structured diagnostic interview. This article demonstrates that while the two patient groups present several similarities, they differ in their most frequent comorbid diagnoses. Furthermore, results reveal a relationship between maternal and adolescent psychological distress.

The Discussion section of this thesis (Chapter 8), provides a summary of the most important finding from the study. In addition, suggestions regarding the clinical implications, limitations and research questions that could be addressed in future studies, are provided. Following this chapter, the main conclusions to take away from this thesis are presented.
References


Resumen
Aunque anteriormente se pensaba que la familia era una causa principal en el desarrollo de los TCA, ahora los padres están vistos como una parte de la solución y una alianza importante en el tratamiento de su hijo (NICE, 2004; Wilson & Shafran, 2005). Este cambio ha sido gracias a los estudios mostrando la efectividad de la terapia familiar y las intervenciones con los cuidadores (Fisher, Hetrick, & Rushford, 2010; Hibbs, Rhind, Leppanen, & Treasure, 2015), y por los estudios que han mostrado que las dificultades en el funcionamiento familiar no necesariamente estaban presente antes de la enfermedad y podrían ser un resultado del trastorno (Whitney & Eisler, 2005). Revisiones sistemáticas anteriores han mostrado que las personas a cargo del cuidado de un familiar con TCA experimentan dificultades con su salud mental, una experiencia negativa como cuidador y respuestas a la enfermedad que podrían servir a mantenerla (la emoción expresada elevada y conductas de acomodación) (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014; Zabala, Macdonald, & Treasure, 2009).

Este estudio es el primero en examinar variables relacionadas con el cuidado de un familiar con TCA que utiliza un grupo comparativa de pacientes con un trastorno psiquiátrico parecido (TCS) y también un grupo de controles sanos. Una revisión sistemática reciente de la literatura sobre el cuidado de un familiar con TCA concluyó que se necesitan estudios adicionales con grupos de comparación (Anastasiadou et al., 2014). Este tipo de estudio nos permitirá a entender si la experiencia de cuidar a una persona con TCA es parecida a lo que experimentan los que cuidan a un familiar con otro trastorno psiquiátrico similar. Además, la recogida de un grupo control nos permitirá determinar si la experiencia de los cuidadores TCA es diferente que la de las familias de personas sanas.

A pesar de que el número de estudios sobre el cuidado de un familiar con TCA ha aumentado durante las últimas décadas, la mayoría no han recogido muestras compuestas de solamente pacientes adolescentes (Anastasiadou et al., 2014; Zabala et al., 2009). Estudios con...
muestras adolescentes son particularmente importantes por dos razones. Primero, los TCA suelen empezar durante la adolescencia cuando la mayoría de personas siguen viviendo con sus familias (Lewinsohn, Striegel-Moore, & Seeley, 2000; Micali, Hagberg, Petersen, & Treasure, 2013) y más horas de contacto entre los familiares y el paciente están asociadas con respuestas inútiles a la enfermedad por parte del cuidador (Goddard et al., 2013; Sepulveda et al., 2012). Segundo, los resultados de estudios anteriores sugieren que la terapia familiar para TCA, sobre todo en el caso de AN, es más eficaz en pacientes jóvenes con una enfermedad de corta duración (Treasure & Russell, 2011). Una mejor comprensión de la experiencia de los familiares de pacientes adolescentes con TCA nos permitirá a aclarar que variables deberíamos trabajar en intervenciones con la familia y los cuidadores y si son distintos a los de pacientes adultos.

Otro punto fuerte de este estudio es la recogida de tanto los padres como las madres. Estudios anteriores han observado una diferencia entre las madres y los padres TCA en cuanto a su experiencia como cuidador y su respuesta a la enfermedad (Anastasiadou et al., 2014). Sin embargo, muchos estudios no han evaluado la experiencia de los dos padres. El estudio presente analiza las diferencias entre las madres y los padres de pacientes adolescentes en una variedad de variables relacionados con la experiencia del cuidado familiar. Otra fortaleza de este estudio es su evaluación de las variables del paciente en adición a las variables de los cuidadores, por ejemplo la utilización de una entrevista diagnóstica para evaluar la presencia de trastornos psiquiátricos comórbidos. Finalmente, estos resultados contribuyen al cumulo de conocimiento sobre la experiencia de los cuidadores de familiares TCA en España.

Esta tesis está compuesta por los siguientes ocho capítulos:

Capítulo 1 presenta una introducción a los TCA, incluyendo información sobre su prevalencia, clasificación y comorbilidad. Adicionalmente, se presenta información sobre el
pronóstico de TCA y la importancia de las intervenciones y la investigación con pacientes adolescentes con una enfermedad de corta duración.

**Capítulo 2** presenta una revisión del papel de la familia en el desarrollo, mantenimiento y tratamiento de los TCA. También introduce el modelo de mantenimiento interpersonal de TCA (Treasure & Schmidt, 2013) que sirve como la base teórica para las variables que se evaluaron en esta tesis. Finalmente se presenta un resumen de los estudios llevados a cabo hasta la fecha que exploraban las variables evaluadas en esta tesis con un énfasis en los estudios que utilizaron muestras de solamente adolescentes.

**Capítulo 3** incluye una revisión de estudios que evaluaron el cuidado de un familiar con TCA que han recogido grupos de comparación y/o control. También presenta un resumen de las similitudes entre los TCA y TCS para explicar la razón por lo cual seleccionamos este grupo de comparación. Finalmente, una breve sección está dedicada a la experiencia de criar a un adolescente sano en referencia a la recogida de un grupo control sano.

**Capítulo 4** presenta el método del estudio, empezando con una explicación del diseño, los objetivos y los hipótesis. A continuación introduce una descripción de los participantes y el procedimiento, terminando con un resumen de los instrumentos y los análisis estadísticos que se llevaba a cabo en cada artículo.

Los primeros resultados publicados están presentados en el **Capítulo 5** con el título “Family functioning and quality of life among families in eating disorders: A comparison with substance-related disorders and healthy controls.” Este artículo que fue publicado en la revista, European Eating Disorders Review (Q1) pretende comparar las variables relacionadas con las respuestas inútiles a la enfermedad (EE y conductas de acomodación), la experiencia como cuidador y la calidad de vida de los padres de pacientes con TCA y TCS y los padres de adolescentes sanos. También evalúa las diferencias de género entre las madres y los padres por cada variable.
Hasta la fecha han publicado pocos estudios cuantitativos sobre las estrategias de afrontamiento utilizados por los cuidadores de los pacientes con TCA. El artículo presentado en el Capítulo 6 (actualmente bajo revisión en la revista Psychiatry Research, Q1) con el título "Experience of caregiving and coping strategies in caregivers of adolescents with an eating disorder: A comparative study," es el primer estudio de evaluar el afrontamiento de los cuidadores de pacientes con TCA en España. Se presenta las diferencias entre los tres grupos de padres en cuanto a su uso de varias estrategias de afrontamiento y también las implicaciones clínicas de estos hallazgos para las intervenciones con los cuidadores. Además, este artículo evalúa la relación entre las variables de los padres y los pacientes y el uso de diferentes estrategias de afrontamiento y también la asociación entre la evaluación de la experiencia como cuidador y el afrontamiento.

Capítulo 7 presenta el artículo con el título "Psychiatric comorbidity and maternal distress among adolescent eating disorder patients: A comparison with substance use disorder patients." Publicado en la revista Eating Behaviors (Q2), este artículo presenta las tasas de trastornos comórbidos, evaluado con una entrevista diagnostica, en los dos grupos de pacientes. Este artículo muestra que, a pesar de las similitudes entre los dos grupos de pacientes, se diferencian en los diagnósticos comórbidos que están más frecuentes en cada grupo. Además, los resultados muestran una relación entre la angustia psicológica de las madres y los pacientes.

La Discusión de esta tesis (Capítulo 8), presenta un resumen de los hallazgos más importantes del estudio. En adición, este capítulo incluye sugerencias sobre las implicaciones clínicas, las limitaciones y las líneas de investigación que podrían ser explorados en futuros estudios. Después de este capítulo, se presenta las conclusiones principales de la tesis.
Referencias


Chapter 1

An Introduction to Eating Disorders
CHAPTER 1: AN INTRODUCTION TO EATING DISORDERS

Introduction to the chapter

The present chapter provides a brief introduction to EDs, beginning with a summary of their prevalence and classification. Following this, information regarding the consequences of these illnesses, as well as the confounding role of psychiatric comorbidity in their treatment, is presented. The chapter concludes with information regarding the importance of early intervention in adolescent EDs.

The prevalence and classification of eating disorders

EDs are complex psychiatric disorders with a multifactorial etiology that involve a number of genetic and biological risk factors which interact with an individual’s environment in the development of the disorder (Culbert, Racine, & Klump, 2015; Stice, 2016). Once thought to affect only young women in Western countries, it is now known that EDs affect people of all ages and genders in countries around the world. They are among the most common psychiatric diagnoses found in adolescent females (Hoek, 2016) and may be on the rise among adolescents (Favaro, Caregaro, Tenconi, Bosello, & Santonastaso, 2009). The majority of studies regarding prevalence rates of EDs in Spain have been carried out among adolescents and young adults (Peláez Fernández, Raich Escursell, & Labrador Encinas, 2010) and present comparable rates to U.S. samples. Table 1 presents a summary of epidemiological studies from both the U.S. and Spain that used diagnostic interviews to ascertain the DSM-IV ED diagnoses of the sample.

In order to assess prevalence rates among Spanish female adolescents, Gandarillas, Zorrilla, Sepúlveda, and Muñoz (2003) applied the Eating Disorders Examination (EDE) (Fairburn, Cooper, & O’Connor, 2008), a diagnostic interview intended to assess criteria for ED diagnoses. Their rigorous two-phase epidemiological study of 1,534 Spanish female adolescents (age 15-18) revealed that 3.4% of the sample met criteria for an ED. An alarming finding from this study was that only 19% of those participants that met criteria for an ED were
receiving treatment. A similar study carried out by Peláez Fernández et al. (2007) amongst a sample of Spanish adolescents and young adults (age 12-21), which also included males, revealed that of these males, 0.2% met criteria for BN and 0.5% met criteria for EDNOS.

Although prevalence rates tend to be lower amongst males, researchers suspect that they are underestimated, possibly because males do not seek treatment, medical professionals may fail to recognize ED symptoms in males (Greenberg & Schoen, 2008) or because EDs manifest differently in males (Sepulveda et al., 2016).

The fourth version of the DSM (DSM-IV) (American Psychiatric Association, 2000) recognized two diagnostic categories for EDs (see Table 2). In addition to AN and BN, DSM-IV also included a residual category known as EDNOS. This category referred to eating disturbances that did not meet the full criteria for either AN or BN, such as individuals with BED, which is now recognized as its own diagnostic category in the DSM-5 (American Psychiatric Association, 2013) (see Table 3). Individuals in the EDNOS category still experienced marked functional impairment and levels of symptom severity and persistence.
Table 2. DSM-IV diagnostic criteria for anorexia nervosa and bulimia nervosa

### Anorexia nervosa

A. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g. weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).

B. Intense fear of gaining weight or becoming fat, even though underweight.

C. Disturbance in the way in which one’s body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.

D. In postmenarcheal females, amenorrhea, i.e. the absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g. estrogen, administration.)

#### Specify Type

- **Restricting Type:** During current episode of Anorexia Nervosa, the person has not regularly engaged in binge-eating or purging behavior.
- **Binge-Eating/Purging Type:** During the current episode of Anorexia Nervosa the person has regularly engaged in binge-eating or purging behavior.

### Bulimia nervosa

A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following: (1) eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances; (2) a sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating).

B. Recurrent inappropriate compensatory behavior in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, enemas, or other medications; fasting or excessive exercise.

C. The binge eating and inappropriate compensatory behaviors both occur, on average, at least twice a week for 3 months.

D. Self-evaluation is unduly influenced by body shape and weight.

E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

#### Specify Type

- **Purging type:** During the current episode, the person has regularly engaged in self-induced vomiting or the misuse of laxatives.
- **Non-purging type:** During the current episode of Bulimia Nervosa, the person has used other inappropriate compensatory behaviors, such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas.
Table 3. *DSM-5 diagnostic criteria for binge eating disorder*

<table>
<thead>
<tr>
<th>Binge eating disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following:</td>
</tr>
<tr>
<td>1. Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most people would eat in a similar period of time under similar circumstances.</td>
</tr>
<tr>
<td>2. A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating).</td>
</tr>
<tr>
<td>B. The binge-eating episodes are associated with three (or more) of the following:</td>
</tr>
<tr>
<td>1. Eating much more rapidly than normal.</td>
</tr>
<tr>
<td>2. Eating until feeling uncomfortably full.</td>
</tr>
<tr>
<td>3. Eating large amounts of food when not feeling physically hungry.</td>
</tr>
<tr>
<td>4. Eating alone because of feeling embarrassed by how much one is eating.</td>
</tr>
<tr>
<td>5. Feeling disgusted with oneself, depressed, or very guilty afterward.</td>
</tr>
<tr>
<td>C. Marked distress regarding binge eating is present.</td>
</tr>
<tr>
<td>D. The binge eating occurs, on average, at least once a week for 3 months.</td>
</tr>
<tr>
<td>E. The binge eating is not associated with the recurrent use of inappropriate compensatory behavior as in bulimia nervosa and does not occur exclusively during the course of bulimia nervosa or anorexia nervosa.</td>
</tr>
</tbody>
</table>

comparable to individuals with AN (Hay et al., 2010; Thomas, Vartanian, & Brownell, 2009).

Finally it is important to mention that a great deal of debate exists regarding the best way to classify EDs (Waller, 2008; Walsh & Sysko, 2009; Wonderlich, Joiner Jr, Keel, Williamson, & Crosby, 2007). Some authors have argued that instead of several ED diagnoses, a single diagnosis of “eating disorder” would be more appropriate (Fairburn, Cooper, & Shafran, 2003). This transdiagnostic approach, which emphasizes the “core psychopathology” shared by all individuals with an ED (e.g. overevaluation of weight and shape concerns), was developed in consideration of the fact that there is a great deal of crossover between the ED diagnoses. For example, patients may no longer meet criteria for a threshold eating disorder, but still could be diagnosed with EDNOS (Strober, Freeman, & Morrell, 1997). As the authors of this approach explain, “eating disorder diagnoses are snapshots in the course of an eating disorder” (Fairburn & Cooper, 2011).

**Physical and psychosocial correlates**
EDs bring with them a number of physical and psychological complications, some of them life-threatening (Banker et al., 2012). The malnutrition and severe weight loss inherent in AN and the purging behavior exhibited by individuals with varying ED diagnoses may result in complications in endocrine functioning, gastrointestinal disturbance, effects on bone mineral density, cardiovascular and pulmonary complications (e.g. increased risk for arrhythmias, discoloration of the extremities, and pneumomediastinum), kidney dysfunction, dehydration and electrolyte disturbance, among others (Mitchell & Crow, 2006). High mortality rates, often due to medical complications or suicide, are also present among individuals with all types of EDs, with the weighted annual mortality rates (i.e. deaths per 1,000 person-years) at 5.10, 1.74, and 3.31 for AN, BN and EDNOS, respectively (Arcelus, Mitchell, Wales, & Nielsen, 2011).

In addition to the physical complications of these disorders, they also present a number of consequences to the individual’s mental and psychosocial health. Impairments in HRQoL (Engel, Adair, Hayas, & Abraham, 2009), self-esteem (Noordenbos, Aliakbari, & Campbell, 2014), emotion regulation (Brockmeyer et al., 2014), family life (Hilge, Beale, & McMaster, 2006), and work and social functioning are all problems facing those individuals suffering from these disorders (Harrison, Mountford, & Tchanturia, 2014). In addition, more than half of individuals with an ED meet criteria for at least one DSM-IV Axis I disorder (Blinder, Cumella, & Sanathara, 2006; Hudson et al., 2007), with this number increasing to 97% among females receiving inpatient ED treatment (Blinder et al., 2006).

In AN in particular, worse long-term outcome and longer hospital stays have been associated with presenting psychiatric comorbidity (Herpertz-Dahlmann et al., 2001; Steinhausen, 2002; Strik Lievers et al., 2009). Studies suggest that rates of psychiatric comorbidity for treatment seeking adolescent patients with AN range between 47-73% (Bühren et al., 2014; Salbach-Andrae et al., 2008), with the most common diagnoses including mood disorders, anxiety disorders with OCD, OCD and substance use disorders. High rates of
suicidal ideation have also been found among adolescent patients with AN, particularly those that present depressive symptomatology (Bühren et al., 2014).

Although the profile of adolescent ED patients admitted to hospitals in Spain appears to be similar to other developed countries, a revision of hospital discharge data of adolescent ED patients in Spain suggested that following discharge only 18.2% of AN patients met criteria for another psychiatric disorder (Lopez de Andres et al., 2010). The authors noted that these lower rates of comorbid disorders were likely due to the fact that other studies have collected more detailed information. This would suggest a need for for future studies in Spain that use diagnostic interviews to assess for psychiatric comorbidity amongst treatment seeking ED patients. Although community based studies using semi-structured interviews have found similar rates of comorbidity among Spanish adolescents with an ED as those carried out in other countries (Rojo et al., 2003), it remains to be determined if the same is true for samples of treatment seeking ED patients.

The need for early intervention

Systematic reviews have suggested that less than half of patients with AN or BN fully recover from their disorder (45% in BN versus 46% AN). Of the remaining patients, around a third present considerable improvement with residual symptoms (27% in BN versus 33% in AN), while the rest show a protracted course for the illness (23% in BN versus 20% in AN) (Steinhausen, 2002; Steinhausen & Weber, 2009). Recovery from AN is much more likely if the illness is recognized and treated during adolescence (Steinhausen, 2002), soon after the development of the disorder (Zipfel, Giel, Bulik, Hay, & Schmidt, 2015).

Adolescence is a period marked by rapid physical, cognitive, emotional and social changes and is when many EDs first develop (American Psychiatric Association, 2013; Lewinsohn, Striegel-Moore, & Seeley, 2000). AN may begin with attempts at dieting or weight loss which, for vulnerable individuals (see Figure 1), may spin out of control and result in these
behaviors becoming rewarding in their own right (Walsh, 2013). As adolescence is a developmental period when the brain is already undergoing many changes, the malnutrition that comes along with AN, accompanied by the hormonal changes and stress of this life stage, may disrupt brain maturation and make it particularly difficult to recover from the disease (Treasure & Russell, 2011). The importance of intervening with early onset AN is further highlighted by the fact that a number of patients with AN will go on to develop a different ED. Of patients with a current BN diagnosis, 25% of patients have previously had AN (Agras, Walsh, Fairburn, Wilson, & Kraemer, 2000).

Figure 1. The multifactorial etiology of adolescent AN and illness prognosis (adapted from Kaye, Fudge, & Paulus, 2009).

Taken together, these findings point to the importance of intervening with adolescent patients with an ED. However, questions still remain regarding the factors that may serve to
maintain EDs during this particular developmental stage. One particular category of maintenance factors, that of family variables, will be explored more in depth in the following chapter.

Conclusions

We have seen through this chapter that EDs are complex, life threatening, psychiatric illnesses with high rates of comorbidity. Although EDs present poor rates of prognosis, treatment outcome is better when interventions are aimed at adolescents with a short illness duration. The following chapter will provide a rationale for assessing variables related to family caregiving among this particular population.
CHAPTER 1: AN INTRODUCTION TO EATING DISORDERS

References


Chapter 2

Eating Disorders and the Family
Introduction to the chapter

The current chapter begins with a summary of how the view of the family in the treatment of EDs has shifted from seeing them as part of the cause to part of the solution. The interpersonal maintenance model of EDs is then introduced as the theoretical model underlying the current study design. Finally, a summary of research among ED caregivers is presented for each of the variables in this model with an emphasis on studies that have used entirely adolescent samples.

The role of the family in eating disorders

Historically, families were seen as causal factors in the development of EDs and early treatment recommendations advocated for the separation of the patient from the family:

I would venture to say that the first physicians who attended the patients misunderstood the true significance of this obstinate refusal of food .... The hypochondriacal delirium, then, cannot be advantageously encountered so long as the subjects remain in the midst of their own family and their habitual circle .... It is therefore, indispensable to...change the habitation and surrounding circumstances, and to entrust the patients to the care of strangers (Marcé, 1860).

“I have remarked that these willful patients are often allowed to drift their own way into a state of extreme exhaustion, when it might have been prevented by placing them under different moral conditions. The patients should be fed at regular intervals, and surrounded by persons who would have moral control over them; relatives and friends being generally the worst attendants (Gull, 1874).

Separation from the family as part of a refeeding program was the treatment of choice for EDs up until the 1960’s (Dodge, 2012). However, with the development of Minuchin’s model of the “psychosomatic family” (Minuchin, Rosman, & Baker, 1978), a paradigm was formed on which to base family therapy for EDs. According to this theoretical model, the family was seen as the cause of the disorder in part due to their rigidity, over-involvement, enmeshment and avoidance of conflict. However, this model placed inappropriate blame on the family, considering that these observed patterns of behavior could just as easily be a consequence of the disorder, rather than a cause of it (Dare, Grange, Eisler, & Rutherford, 1994). Furthermore, researchers have argued that
evidence for this model is lacking and it is conceptually flawed (Eisler, 2005; Eisler, Simic, Russell, & Dare, 2007). Current guidelines do advocate for the involvement of family members in treatment (NICE, 2004; Wilson & Shafran, 2005). However, this is not because family members are seen as causing the disorder, but because they are seen as part of the solution and possibly the best resource for aiding in their child’s recovery (Eisler, 2005).

Along with this shift in the conceptualization of the role of the family has come the development of models that focus on factors which maintain the illness, rather than etiological models. This is because maintenance models may be more clinically relevant given that they offer information on variables that may be targeted in treatment (Eisler, 2005; Schmidt & Treasure, 2006). Two models that have received a great deal of attention in the literature are the conceptual model proposed by Eisler (2005) which has guided Family Based Therapy (FBT) for EDs and the interpersonal maintenance model of Schmidt and Treasure (2006), upon which a number of interventions aimed specifically at caregivers have been based (Goddard et al., 2011; Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008a; Treasure et al., 2008). Both of these models aim to steer away from blaming the family, focusing instead on how family members, in their efforts to help, may inadvertently become stuck in unhelpful forms of interaction, which may serve to maintain the illness and also lead them to lose sight of the resources and skills they have at their disposal (Whitney & Eisler, 2005).

According to Eisler (2005), the families of patients with an ED tend to reorganize themselves around the symptoms of the disorder and the ED quickly takes on a central role in family life. This reorganization is manifested through the following six processes based on clinical observations and supported with research findings summarized by Whitney and Eisler (2005):
1. The central role of the symptoms in family life. Family interactions become focused on food, weight and the eating disorder, which may lead family members to abandon their own well-being and engage in unhelpful responses to the illness.

2. Narrowing of time focus on the here-and-now. The consequence of the illness, as well as the high levels of emotional arousal it may cause among family members, leads to a sense of urgency. This may lead any difficulties at mealtimes to feel like a disaster.

3. Restriction of the available patterns of family interaction processes. In response to the illness, family members may feel stuck in terms of what they can do to help and may also find it difficult to modify their responses. This inflexibility may be manifested through providing comfort and reassurance without challenging ED behaviors (i.e. enabling and accommodating the illness).

4. The amplification of aspects of family functioning. Any pre-existing difficulties with family functioning may be amplified when adjusting to living with a relative with an illness, and may be seen as part of the problem.

5. Diminishing ability to meet family life-cycle needs. Particularly when the illness begins during adolescence, a time where children seek greater autonomy, it can be challenging for both parents and the sufferer themselves to have to rely once again on their parents.

6. The loss of a sense of agency (helplessness). The feeling that they are completely incapable of doing anything can help may affect the mental health of the family members.

The updated interpersonal maintenance model (Treasure & Schmidt, 2013) complements the model outlined by Eisler (2005), but is strengthened in its identification of specific variables that may be at work in the family’s response to the illness. This model, which can be applied transdiagnostically, posits that the ED caregiver’s responses to the illness may inadvertently exacerbate ED symptoms and create a vicious cycle (Figure 2). It is hypothesized that both patient (e.g. duration of illness) and caregiver (e.g. contact hours) characteristics may influence the caregiver’s unhelpful response to the illness (e.g. EE, accommodating and enabling behavior), as well as their mental health (i.e. psychological distress and quality of life), which in turn impacts the patient’s own mental health and eating disorder symptoms (Goddard et al., 2013; Treasure et
al., 2008; Treasure, Smith, & Crane, 2007). The variables of caregiver coping and appraisal are also included in reference to the stress-coping model (Lazarus & Folkman, 1984) upon which the development of the Experience of Caregiving Inventory (ECI) (Szmukler et al., 1996) is based. Additional information regarding this can be found in the following section of this chapter.

Figure 2. The interpersonal maintenance model of eating disorders (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013), modified to include coping and appraisal (Szmukler et al., 1996).

The present thesis aims to identify if parents of adolescent ED patients present impairment on certain variables deemed as relevant to this model. The cross-sectional design of the study prohibits us from concluding whether these variables precede illness onset or are a result of the ED. However, in line with this model, the current study conceptualizes them to be a response to caring for a relative with a life threatening illness. The following six caregiver related variables
identified as playing a role in this model were analyzed in the present study: appraisal of the caregiving experience, caregiver coping, accommodation and enabling behaviors, EE, psychological distress, caregiver burden and health related quality of life. The subsequent sections will provide a definition of the concept, a rationale for the chosen assessment measure, a brief summary of the research findings among ED caregivers and a summary of the results of studies using exclusively adolescent samples.

**Appraisal of the caregiving experience**

Those caring for someone with an ED report a negative caregiving experience (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014) that persists over time (Coomber & King, 2013) and is equivalent to that of caring for someone with schizophrenia (Graap et al., 2008; Treasure et al., 2001). Within ED caregiver researcher a negative caregiving experience has often been synonymous with the term *burden*. However, there has been a great deal of debate in the literature regarding how to best operationalize and measure caregiver burden (Moller, Gudde, Folden, & Linaker, 2009). In response to these limitations, Szmukler et al. (1996) developed the ECI within a stress-coping paradigm (Folkman, Lazarus, Gruen, & DeLongis, 1986; Lazarus & Folkman, 1984). The authors intended the instrument to be used as a measure of appraisal of the caregiving experience, rather than a measure of burden (see Figure 3) and thus included positive, in addition to negative, aspects of the caregiving experience. However, a number of studies have continued to refer to the ECI negative scales as a measure of burden and indeed, this subscale of the ECI demonstrates good convergent validity with the Eating Disorders Symptom Impact Scale (EDSIS) (Sepulveda, Whitney, Hankins, & Treasure, 2008b), which an ED specific measure of burden. The current thesis has aimed to use the term “negative caregiving experience” when possible.
While a recent systematic review concluded that relatives caring for patients with a shorter duration of illness tend to report a less negative caregiving experience (Anastasiadou et al., 2014), it has also been suggested that a shorter illness duration is associated with a more negative caregiving experience (Whitney, Haigh, Weinman, & Treasure, 2007). The few studies assessing the caregiving experience amongst caregivers of adolescent patients have found that it was associated with patient ratings of EE, more weekly contact hours (Winn et al., 2007) and the presence of non-suicidal self-injury (Depestele et al., 2015). Furthermore, greater negative caregiving experience predicted mental health status among these caregivers (Winn et al., 2007).

There are mixed findings in the studies reporting on gender differences on the ECI among parents of adolescent ED patients. One study reported that mothers presented a more negative caregiving experience than fathers (Depestele et al., 2015), which is consistent with studies of adult and mixed populations (Anastasiadou et al., 2014), although a study of adolescent ED patients in a day hospital program found that fathers reported a more negative caregiving experience than mothers (Girz, Lafrance Robinson, Foroughe, Jasper, & Boachie, 2013). While psychoeducational interventions aimed at caregivers have been found to be effective at reducing reports of a negative caregiving experience (Hibbs, Rhind, Leppanen, & Treasure, 2015), an RCT
on the effects of a psychoeducational intervention of parents of adolescents did not reduce the negative caregiving experience (Spettigue et al., 2015). However, two other family therapy interventions for caregivers of adolescent ED patients were effective at reducing negative caregiving experience (Girz et al., 2013; Merwin, Zucker, & Timko, 2013).

Overall, few studies have explored the positive aspects of ED caregiving (Anastasiadou et al., 2014), despite the fact that it has been researched among those caring for patients with dementia (Cohen, Colantonio, & Vernich, 2002), cancer (Kim, Schulz, & Carver, 2007) and schizophrenia (Chen & Greenberg, 2004), among others. Managing the challenges of caring for a child with an ED may bring family members closer or provide them with a sense of satisfaction, and qualitative data suggests that caregivers recognize positive consequences of having a relative with an ED (Treasure et al., 2001). A previous study that aimed to identify predictors of a positive caregiving experience found that attributing the ED to their relative’s personality was the only significant variable significantly associated with the ECI-positive (Whitney et al., 2007). A review of studies using the ECI noted that illness duration did not appear to be related to a positive caregiving experience (Anastasiadou et al., 2014). Few studies have reported ECI-positive scores among adolescent samples (Anastasiadou et al., 2014; Zabala, Macdonald, & Treasure, 2009) and the majority of those that have (e.g. Depestele et al., 2015; Merwin et al., 2013; Winn et al., 2007) report similar scores as those assessing caregivers of adults. Finally, a recent study indicated that mothers report a greater positive caregiving experience than fathers (Depestele et al., 2015).

**Coping**

According to Lazarus and Folkman (1984), coping refers to “the cognitive and behavioral strategies that people use to manage specific demands they perceive as taxing or exceeding their personal resources.” Approach oriented strategies are seen as adaptive and tend to be associated
with lower levels of mental health concerns. Avoidance oriented strategies, on the other hand, are viewed as maladaptive and are often associated with greater levels of distress (Moos & Holahan, 2003). Only seven studies to date have quantitatively assessed coping among those caring for ED patients (Coomber & King, 2012, 2013; Fiorillo et al., 2016; Lantzouni, Cox, Salvador, & Crosby, 2015; Ohara et al., 2016; Pepin & King, 2013, 2016). Table 4 provides a brief overview of these studies, the samples used and the instrument employed to assess coping.

As can be observed in this table, three different questionnaires were used, the Brief COPE (Carver, 1997), the Coping Inventory for Stressful Situations (CISS) (Endler & Parker, 1990), and the Family Coping Questionnaire for Eating Disorders (FCQ-ED) (Fiorillo et al., 2015). The same research team based in Australia carried out the majority of these studies. Only one study employed an exclusively adolescent sample (Lantzouni et al., 2015), although they did not report on illness duration. The shortest illness duration of patients was observed in the study by Pepin and King (2016). None of the studies reported scores according to gender or type of caregiver. Finally, the studies had varying designs and objectives. For example, four of the studies assessed how often caregivers used distinct coping strategies (Coomber & King, 2012; Fiorillo et al., 2016; Lantzouni et al., 2015; Ohara et al., 2016), one assessed the progression of coping strategies over time (Coomber & King, 2013) and two examined how a caregiver intervention, based on the interpersonal maintenance model of EDs, affected caregiver’s coping strategies (Pepin & King, 2013, 2016).

Prior to the data collection phase of this study, none of these aforementioned studies on ED caregiver coping had been published and the questionnaire designed specifically for ED caregivers, the FCQ-ED (Fiorillo et al., 2015), had not yet been developed. The decision to use the COPE inventory (Carver, Scheier, & Weintraub, 1989) was based on the fact that it assesses a wide range
Table 4. Descriptive data of patients, caregivers and outcomes of studies assessing caregiver coping

<table>
<thead>
<tr>
<th>Reference and country</th>
<th>Study design; objectives</th>
<th>Patients</th>
<th>Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coomber and King (2012) (Australia)</td>
<td>Cross sectional; examine predictors of negative caregiving experience and psychological distress and the mediating role of coping strategies</td>
<td>56</td>
<td>56</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Age (M, SD)</td>
<td>Age (M, SD)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>21.48 (8.67)</td>
<td>45.79 (11.84)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Illness duration in years (M, SD)</td>
<td>Type of relative (%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5.09 (5.03)</td>
<td>Parent = 42</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Partner = 8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Sibling = 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Friends = 2</td>
</tr>
</tbody>
</table>
| | | | Gender (%)
| | | | F = 78.6 |
| | | | M = 21.4 |
| | | | Living with patient (%) |
| | | | 78.5 |
| | | | ≥ 21 Contact hours per week (%) |
| | | | 100 |
| | | Instrument used | Score (M, SD) |
| | | Brief COPE | T1 |
| | | | Adaptive = 42.45 |
| | | | Maladaptive = 21.89 (5.57) |
| Coomber and King (2013) (Australia) | Longitudinal; assess predictors of negative caregiving experience and psychological distress over 9 month period | -- | -- |
| | | | -- |
| | | | -- |
| | | | Instrument used | Brief COPE |
| | | | T2 |
| Fiorillo et al. (2016) (Italy) | Cross sectional; assess caregiver coping strategies used according to ED diagnosis, identify patient and caregiver variables associated with particular coping strategies | 72 | 127 |
| | | Age (M, SD) | Age (M, SD) |
| | | 24.9 (8.8) | 46.7 (13.2) |
| | | Illness duration in years (M, SD) | Type of relative (%) |
| | | 5.6 (5.5) | Mother = 40.2 |
| | | | Father = 33 |
| | | | Sibling = 15.8 |
| | | | Partner = 11 |
| | | | Gender (%)
| | | | F = 68 |
| | | | M = 32 |
| | | | Living with patient (%) |
| | | | NR |
| | | | ≥ 21 Contact hours per week (%) |
| | | | NR |
| | | Instrument used | FCQ-ED |
| | | | Collusion = 2.2 |
| | | | Seek information = 3.3 (0.8) |
| | | | Avoidance = 1.5 (0.6) |
| | | | Spiritual help = 3.6 (0.9) |
## Chapter 2: Eating Disorders and the Family

<table>
<thead>
<tr>
<th>Reference and country</th>
<th>Study design; objectives</th>
<th>Patients</th>
<th>Caregiver</th>
<th>Instrument used</th>
<th>Score (M, SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lantzouni et al. (2015) (USA)</td>
<td>Cross-sectional; evaluate if adolescent ED patients use similar coping styles as their mothers</td>
<td>29</td>
<td>15.9 (1.5)</td>
<td>NR</td>
<td>29</td>
</tr>
<tr>
<td>Ohara et al. (2016) (Japan)</td>
<td>Cross-sectional; Examine role of coping style and social support on caregiver mental health and burden.</td>
<td>79</td>
<td>26.6 (7.9)</td>
<td>8.8 (6.1)</td>
<td>79</td>
</tr>
<tr>
<td>Pepin and King (2013) (Australia)</td>
<td>Longitudinal, pilot study; Examine the influence of the Collaborative Care Skills Training workshops on caregiving variables, such as coping strategies</td>
<td>11</td>
<td>20.13 (3.04)</td>
<td>4.19 (3.46)</td>
<td>15</td>
</tr>
</tbody>
</table>
**Reference and country** | **Study design; objectives** | **Patients** | **Caregiver** | **Instrument used** | **Score (M, SD)**  
--- | --- | --- | --- | --- | ---  
Pepin and King (2016) (Australia) | Longitudinal; Examine the influence of the Collaborative Care Skills Training workshops on caregiving variables, such as coping strategies | 56 | 19.05 (4.13) | 1.88 (2.93) | 77 | 48.76 (7.08) | Mother = 64.9  
Father = 31.1  
Partner = 2.6  
Sister = 1.3 | NR | 79.0 | NR | Brief COPE | T1 Adaptive = 40.63 (7.63)  
Maladaptive = 20.86 (4.84)  
T2 Adaptive = 42.77 (7.31)  
Maladaptive = 19.76 (5.61)  
T3 Adaptive = 41.04 (8.01)  
Maladaptive = 19.47 (5.08)  
NR = not reported  
1 Information about the sample is not reported as it was the same sample used in the study by Coomber and King (2012)
of coping strategies, contains items that are relevant to the general population and is the most widely used coping scale to date, particularly among groups of caregivers (Kato, 2015; Litman, 2006).

**Accommodation and enabling behavior**

The Accommodation and Enabling Scale for Eating Disorders (AESED) (Sepulveda, Kyriacou, & Treasure, 2009) was developed in response to the observation that family members often reorganize their life around the symptoms of the patient (Eisler, 2005) and their efforts to reduce the patient’s or familial levels of stress in the short term may inadvertently allow symptoms to persist and hinder recovery. It is the only instrument which assesses these types of behaviors among caregivers of patients with an ED and was modeled after the Family Accommodation Scale for Obsessive-Compulsive Disorder (FAS) (Calvocoressi et al., 1995; Calvocoressi et al., 1999). Examples of accommodating and enabling behaviors include reassuring the patient that they are not fat, altering family plans (e.g. not going out to dinner), allowing the patient to exert high control over the family’s meals or cleaning up the bathroom after patient’s purging behavior. Caregivers who present high levels of EE, who spend more hours with the patient, or who have their own history of eating problems, may be more likely to engage in these behaviors. Furthermore, use of these behaviors are associated with psychological distress among patients (Goddard et al., 2013).

A systematic review carried by Anastasiadou et al. (2014) revealed that the majority of studies using this scale have been carried out in adult or mixed populations and that longer duration of illness is associated with greater use of these behaviors. However, a recent study assessing accommodating and enabling behaviors among caregivers of adolescent patients (Rhind et al., 2016) found that mothers of these patients exhibited higher scores than caregivers assessed in studies using adult or mixed patient populations (e.g. Goddard et al., 2011; Grover et al., 2011;
Sepulveda et al., 2009). A study examining the role of caregiving style on the outcome of these same patients found that for both mothers and fathers, accommodating and enabling behaviors were negatively associated with treatment outcome (Salerno et al., 2016a). Targeting these behaviors in treatment interventions aimed at parents of adolescent patients may be of particular importance given that they appear to mediate the relationship between objective burden and psychological distress (Rhind et al., 2016).

**Expressed emotion**

The concept of EE was originally developed in the context of research assessing the family relationships in patients with schizophrenia (Hooley, 2007). EE measures family member’s attitudes and behaviors towards their ill relative over five areas (i.e. emotional over-involvement (EOI), critical comments (CC), hostility, warmth and positive remarks) (Brown, Birley, & Wing, 1972). Families are considered to have high EE depending on how often they express EOI, CC and hostility. Although a study of adolescent ED patients revealed that parental warmth was related to good treatment outcome among adolescent patients (Le Grange, Hoste, Lock, & Bryson, 2011), a recent systematic review noted that in comparison to EOI, CC and hostility, the elements of warmth and positive remarks are not usually assessed in research on ED families. (Anastasiadou et al., 2014).

High EE been shown to be a predictive factor of relapse in both depression and schizophrenia and previous studies have shown that it impacts treatment outcome for EDs as well (Di Paola, Faravelli, & Ricca, 2010; Eisler et al., 2007; Le Grange et al., 2011; Rienecke, Accurso, Lock, & Le Grange, 2016; van Furth et al., 1996). Although the mechanisms through which EE operates to impact relapse and treatment outcome are not entirely understood (Duclos et al., 2014), it has been suggested that family members with high EE have higher expectations of patients and
thus EE is an expression of their frustration and attempt to control the situation when those expectations are not met (Hooley, 2007). Low EE families, on the contrary, may believe that the symptoms of the disorder are outside of the patient’s control and thus act with greater empathy towards the patient (Barrowclough & Hooley, 2003). More recently it has been posited that EE in the context of youth psychiatric disorders may be considered a form of “toxic family stress” in response to the illness (Peris & Miklowitz, 2015).

Two systematic reviews of studies assessing EE among ED caregivers (Anastasiadou et al., 2014; Zabala et al., 2009) found that this variable has been measured among ED family members and caregivers using both semi-structured interviews: the Camberwell Family Interview (CFI) (Vaughn & Leff, 1976), the Standardized Clinical Family Interview (SCFI) (Kinston & Loader, 1984), and the Five-Minute Speech Sample (FMSS) (Magaña et al., 1986) and self-report instruments: the Family Questionnaire (FQ) (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002) and Level of Expressed Emotion Scale (LEE) (Cole & Kazarian, 1988). While interviews are reliable measures of EE, they are time consuming and present coding difficulties as raters require previous training. As the FQ is a more cost-effective method and predicts CFI ratings better than any other short EE instrument (Wiedemann et al., 2002), it was chosen to assess EE in the current study.

Researchers have pointed to the importance of taking patient age into consideration when interpreting the results of studies assessing EE among ED families (Duclos, Vibert, Mattar, & Godart, 2012), due to the fact that parents of younger patients with shorter illness duration have demonstrated lower levels of EE (Le Grange et al., 2011). However, the majority of studies have not focused exclusively on caregivers of adolescents (Anastasiadou et al., 2014; Duclos et al., 2012; Zabala et al., 2009). An examination of studies that have recruited entirely adolescent
samples reveals that higher EE is associated with greater psychological distress and negative caregiving experience (Winn et al., 2007), which is similar to findings among adult samples (Coomber & King, 2012; Kyriacou, Treasure, & Schmidt, 2008). EE is also associated with symptom severity amongst adolescent patients and similar to studies of caregivers of adult and mixed ED patient samples (Anastasiadou et al., 2014), mothers of adolescent patients report higher levels of EE than fathers (Schwarte et al., 2017).

Parental EE levels appear to be an indicator of treatment outcomes among parents of adolescents (Eisler et al., 2007; Le Grange et al., 2011; Rienecke et al., 2016). Some studies have found that maternal criticism in particular is a predictor of poor treatment outcome among adolescent patients (Eisler et al., 2007; van Furth et al., 1996), while others have pointed to the importance of paternal criticism in predicting less improvement of ED psychopathology (Rienecke et al., 2016). Parental levels of EE may also help to guide clinicians in choosing the appropriate treatment interventions. One study suggested that adolescents whose mothers display hostility may benefit more from adolescent focused therapy than FBT (Rienecke, Lebow, Lock, & Le Grange, 2015), while another pointed to the benefits of using separated family therapy rather than FBT when family members present levels of high EE (Eisler et al., 2007). Finally, despite the fact that fewer parents of adolescents reach the cut-off for high EE when compared to adult caregivers (Duclos et al., 2012), it has been suggested that even low levels of CC may affect ED patients considering that they may be more sensitive to negative stimuli (Kaye, Fudge, & Paulus, 2009; Le Grange et al., 2011).

**Psychological distress**

Among ED caregivers, psychological distress has been conceptualized as psychiatric morbidity that may be expressed as anxiety, depression, worry, or stress (Kyriacou et al., 2008).
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The majority of studies have used the following self-report instruments: Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), the General Health Questionnaire (GHQ) (Goldberg & Williams, 1978), the Depression Anxiety Stress Scales (DASS) (Lovibond & Lovibond, 1993), the State-Trait Anxiety Inventory (STAI) (Spielberger, 1985), and the Symptom Checklist (SCL-90) (Derogatis, 1977). For the present study we chose to use the HADS as it is the most frequently used instrument to assess this variable among ED caregivers (Anastasiadou et al., 2014), thus allowing for us to compare our results with a number of other studies.

Caregivers of ED patients tend to present high levels of psychological distress, which are higher than those caring for a family member with psychosis (Treasure et al., 2001), and remain consistently high over time (Coomer & King, 2013). Mothers tend to present higher levels of distress than fathers and caregivers of patients with a longer duration of illness also appear to report greater distress (Anastasiadou et al., 2014). Cross-sectional research has suggested that predictors of psychological distress among this group of caregivers include maladaptive coping (Coomber & King, 2012), negative appraisal of the caregiving experience (Treasure et al., 2001), patient dependency and stigma, self-related strains, interpersonal strains and gender (Whitney et al., 2007). However, other cross-sectional (Dimitropoulos, Carter, Schachter, & Woodside, 2008) and longitudinal studies (Coomber & King, 2013) have been unsuccessful in identifying significant predictors of distress. It has also been suggested that maladaptive coping may mediate the effects of EE on psychological distress (Coomber & King, 2012).

Previous studies of caregivers of adolescent ED patients have revealed that when compared to community norms, both mothers and fathers reported greater levels of depression and anxiety (Ravi, Forsberg, Fitzpatrick, & Lock, 2008). Furthermore, mothers of adolescent ED patients were found to score higher on measures of depression than mothers of adolescent daughters with insulin-
dependent diabetes mellitus (Sim et al., 2009). Moreover, as compared to fathers, mothers demonstrated significantly higher levels of depression, anxiety and general psychopathological symptoms (Forsberg et al., 2015). Predictors of greater psychological distress among adolescent caregivers that have been identified in prior research include a negative caregiving experience (Winn et al., 2007) and symptom severity (Schwarte et al., 2017).

Both FBT and adolescent based therapy were found to reduce the level of psychological distress of adolescent caregivers, and these reductions were maintained at follow-up (Forsberg et al., 2015). Caregiver workshops (Sepulveda et al., 2008a) and DVDs (Goddard et al., 2011) based on the interpersonal maintenance model of EDs (Schmidt & Treasure, 2006) have been found to be effective at reducing psychological distress among caregivers of adult patients. Preliminary data on the effectiveness a similar intervention with caregivers of adolescent patients (Rhind et al., 2016) suggests that it may be able to interrupt the relationship observed between mother’s and patient’s psychological distress (Salerno et al., 2016b).

**Health related quality of life**

Several studies to date have found that HRQoL is affected among ED patients (Engel, Adair, Hayas, & Abraham, 2009). However, a recent systematic review of the studies measuring quality of life in ED patients and their family members revealed only four studies that had assessed HRQoL among caregivers of these patients (Ágh et al., 2016). Table 5 summarizes these studies, as well as two additional studies that were published since the systematic review was carried out (Las Hayas et al., 2014; Linacre, Heywood-Everett, Sharma, & Hill, 2015; Orive et al., 2013). The majority of these studies have been carried out by the same research group in Spain. HRQoL has
### Table 5. Descriptive data of patients, caregivers and outcomes of studies assessing caregiver HRQoL

<table>
<thead>
<tr>
<th>Reference and country</th>
<th>Patients</th>
<th>Caregiver</th>
<th>Instrument used</th>
<th>Score (M, SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$N$</td>
<td>Age (M, SD)</td>
<td>Illness duration (M, SD)</td>
<td>$N$</td>
</tr>
<tr>
<td>De La Rie, Van Furth, De Koning, Noordenbos, and Donker (2005) (Netherlands)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>246</td>
</tr>
<tr>
<td></td>
<td>145</td>
<td>25.56 (8.89)</td>
<td>NR</td>
<td>143</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>69</td>
</tr>
<tr>
<td>Las Hayas et al. (2014) (Spain)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>73</td>
</tr>
</tbody>
</table>

Note. PF = physical functioning subscale; PRF = physical role functioning subscale; BP = bodily pain subscale; GHP = general health perception subscale; V = vitality subscale; SF = social functioning subscale; ERF = emotional role functioning subscale; MH = mental health subscale; PCS = physical component summary; MCS = mental component summary; NR = not reported.

This study used the same sample as Martin et al. (2011), Padierna et al. (2013) and Orive et al. (2013) in a longitudinal study.
been measured among ED caregivers using the Short Form Health Survey-36 (SF-36) (Ware, Snow, Kosinski, & Gandek, 1993) or its reduced form, the Short Form Health Survey-12 (SF-12) (Ware, Kosinski, & Keller, 1996). The use of the SF-36 among caregivers of patients with mental health disorders was recently recommended in a review of HRQoL instruments (Harvey et al., 2008). It consists of 36 items describing 8 dimensions: Physical Functioning (PF), Social Functioning (SF), Physical Role Functioning (PRF), Emotional Role Functioning (REP), Mental Health (MH), Vitality (V), Bodily Pain (BP), and General Health (GH). A physical summary score (PCS) and mental summary score (MCS) can also be calculated.

Studies have shown that the HRQoL of ED caregivers is impaired in comparison to community norms (De La Rie et al., 2005; Linacre et al., 2015), particularly the mental health domain (Las Hayas et al., 2014; Martín et al., 2011). This is supported by the fact that worse scores on the mental health domain of HRQoL were associated with higher anxiety and depression (Martín et al., 2011). While a longitudinal study found that HRQoL (measured at baseline) was not a predictor of anxiety or depression at baseline or follow-up (Orive et al., 2013), greater psychological health at baseline has been found to be a predictor of improved HRQoL one year later (Las Hayas et al., 2014). A greater negative caregiving experience is reported among caregivers who demonstrate low levels of HRQoL (Padierna et al., 2013). However, Las Hayas et al. (2014) found that a reduction in negative caregiving experience, as well as improvements in the patient’s level of depression, both predicted improved HRQoL at one-year follow-up, leading authors to suggest that factors which reduce the negative caregiving experience may indirectly improve their HRQoL.

These studies have not found the physical domain of HRQoL to be impaired amongst this group of caregivers, possibly because the type of care provided by this group of caregivers does
not usually require them to exert physical energy, as in the case of caregivers of patients with dementia or a physical disability (Las Hayas et al., 2014; Martín et al., 2011). Previous studies have reported that mothers experience greater impairment on both mental and physical health domains of HRQoL than fathers (Martín et al., 2011). Finally, although no studies have been carried out in exclusively adolescent ED samples, duration of illness has not been found to be associated with HRQoL (Las Hayas et al., 2014; Linacre et al., 2015).

Conclusions

Over the past twenty years, the research on families and caregivers of patients with EDs has shed light on the family relationships and communication styles observed among ED families, shifting from blaming families to seeing them as a resource in their child’s path towards recovery. ED caregivers have been found to show heightened EE, accommodating behaviors, psychological distress, quality of life disturbances and a more negative caregiving experience, with mothers typically displaying greater deterioration than fathers. Finally, there is a lack of studies on both coping strategies and quality of life amongst this caregiver group and several of these variables have not been well studied among ED caregivers of entirely adolescent samples.
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References


Marcè, L. (1860). On a form of hypochondriacal delirium occurring consecutive to dyspepsia and characterized by refusal of food. *Psychological Medicine and Mental Pathology, 13*, 264–266.


Chapter 3

Comparing
Family Caregiving
**CHAPTER 3: COMPARING FAMILY CAREGIVING**

**Introduction to the chapter**

This chapter begins by providing a review of the studies that have been published to date on ED caregivers that have used clinical comparison and/or healthy control groups. An explanation for the selection of the comparison group for the current study, SUD patients, is then presented with a summary of the similarities between these two patient groups. The chapter concludes with what we know about the experience of caring for an adolescent in order to provide a vision of what may be considered a normative experience for those parents of the healthy control group.

**The use of comparison and control groups**

The use of healthy control groups in the study of families of ED patients originated in the 1980’s with the objective of exploring whether relatives of these patients presented higher rates of EDs and mental disorders (Halmi et al., 1991; Nilsson, Gillberg, & Råstam, 1998; Strober, Lampert, Morrell, Burroughs, & Jacobs, 1990; Strober, Morrell, Burroughs, Salkin, & Jacobs, 1985; Toro et al., 1995). A decade later, Blair, Freeman, and Cull (1995) expanded the scope of research to include variables related to family functioning and EE and in addition to a healthy control group recruited a clinical comparison group of patients with cystic fibrosis. Although difficulties in family functioning and impairment associated with the caregiving role are well-documented among other physical and psychiatric patient groups (e.g. Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010; Pai et al., 2007; Saunders, 2003; Schulze & Rössler, 2005), relatively few studies have utilized patient comparison groups in the study of these variables among ED families. A recent systematic review pointed to the need for additional studies using comparison groups in order to determine whether or not the factors associated with caring for an individual with an ED are unique to this patient population or are shared by those caring for someone with a mental and/or physical illness (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014). Prior to the data collection phase for the current
study, only four studies using clinical comparison or healthy control groups had been published (Blair et al., 1995; Kyriacou, Treasure, & Schmidt, 2008; Sim et al., 2009; Treasure et al., 2001). However, a revision of the literature since 2009 revealed an additional five studies that have been published which used clinical comparison or healthy control groups (Doba, Nandrino, Dodin, & Antoine, 2014; Goddard & Treasure, 2013; Martín et al., 2015; Rienecke, Sim, Lock, & Le Grange, 2016; Ruiz-Robledillo, Romero-Martínez, & Moya-Albiol, 2016).

Table 6 presents a summary of the existing studies that have assessed ED caregiving using clinical comparison and/or healthy control groups. The existing studies employing a clinical comparison group have found that ED families are more enmeshed, and present worse problem solving skills than families of patients with cystic fibrosis, although they present similar levels of over-involvement (Blair et al., 1995). These families also have a worse caregiving experience and present greater psychological distress than caregivers of patients with psychosis (Treasure et al., 2001), experience greater family conflict, less parental alliance and greater depression than mothers of daughters with insulin-dependent diabetes mellitus (Sim et al., 2009) and greater rates of worrying than caregivers of patients with schizophrenia and depression (Martín et al., 2015). A recent study examining differences in EE between caregivers of adolescent patients with AN, BN and major depressive disorder (MDD) found that fathers were more critical of the BN and MDD patients when compared to AN patients, whereas mothers presented higher levels of CC towards patients with BN (Rienecke et al., 2016).

A study of families of patients with AN-R and drug dependence disorder revealed that while mothers of these two groups were similar in terms of adaptability and cohesion, this was not true for fathers. Furthermore, mothers of patients with drug dependence reported higher CC than ED mothers (Doba et al., 2014). Studies employing a control group of caregivers of
### Table 6. A summary of studies on ED families employing comparison or control groups

<table>
<thead>
<tr>
<th>Reference and country</th>
<th>ED Patients</th>
<th>Caregiver</th>
<th>Comparison/Control Group</th>
<th>Caregiver</th>
<th>Family variables assessed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blair et al. (1995) (UK)</td>
<td>27</td>
<td>18.7 (3.2)</td>
<td>NR Parents NR 29 19.2 (2.7) - Patients with cystic fibrosis NR Parents NR</td>
<td>31 18.2 (2.6) - Healthy controls NR Parents NR</td>
<td>Family functioning (FAM, EFS) EE (CFI)</td>
</tr>
<tr>
<td>Treasure et al. (2001) (UK)</td>
<td>58</td>
<td>24.0 (2.0)</td>
<td>71 Parents, siblings, spouses, other NR 68 43 (17) Patients with psychosis 68 Parents, siblings, spouses, friends, children, other NR</td>
<td></td>
<td>Psychological distress (GHQ) Experience of Caregiving (ECI)</td>
</tr>
<tr>
<td>Kyriacou et al. (2008) (UK)</td>
<td>N.R. 23.3 (6.6)</td>
<td>151 Parents Female = 60.3% NR 17.3 (4.6) Healthy controls 93</td>
<td></td>
<td>Female = 43%</td>
<td>EE (FQ) Psychological distress (HADS) Experience of Caregiving (ECI)</td>
</tr>
<tr>
<td>Sim et al. (2009) (USA)</td>
<td>25</td>
<td>15.75 (1.7)</td>
<td>25 Mothers Female = 100% 24 15.67 (1.7) - Patients with insulin-dependent diabetes mellitus 24 Mothers Female = 100%</td>
<td>44 16 (1.7) - Healthy controls 44 Mothers Female = 100%</td>
<td>Family functioning (FES) Self-efficacy (PSOC) Parenting Alliance (PAI) Depression (BDI-SF) Worry (PSWQ)</td>
</tr>
</tbody>
</table>

NR = not reported; EE = Expressed Emotion; AN = Anorexia Nervosa; BN = Bulimia Nervosa; FAM = Family Assessment Measure; EFS = Edinburgh Family Scale; CFI = Camberwell Family Interview; GHQ = General Health Questionnaire; ECI = Experience of Caregiving Inventory; FQ = Family Questionnaire; HADS = Hospital Anxiety and Depression Scale; FES = Family Environment Scale; PSOC = Parenting Sense of Competence Scale; PAI = Parenting Alliance Inventory; BDI-SF = Beck Depression Inventory, Short Form; PSWQ = Penn State Worry Questionnaire;
### Chapter 3: Comparing Family Caregiving

<table>
<thead>
<tr>
<th>Reference and country</th>
<th>ED Patients</th>
<th>Caregiver</th>
<th>Comparison/Control Group</th>
<th>Caregiver</th>
<th>Family variables assessed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$N$</td>
<td>Age (M, SD)</td>
<td>Relationship</td>
<td>Gender</td>
<td>$N$</td>
</tr>
<tr>
<td>Goddard and Treasure (2013) (UK)</td>
<td>65</td>
<td>21.8 (5.5)</td>
<td>124</td>
<td>Parents</td>
<td>Female = 56.5%</td>
</tr>
<tr>
<td>Doba et al. (2014) (France)</td>
<td>25</td>
<td>20.6 (2.7)</td>
<td>NR</td>
<td>Parents</td>
<td>NR</td>
</tr>
<tr>
<td>Martin et al. (2015) (Spain, Netherlands, Denmark, UK)</td>
<td>146</td>
<td>25.85 (8.94)</td>
<td>251</td>
<td>Parents, spouses, siblings, children, friends</td>
<td>Female = 53.78%</td>
</tr>
<tr>
<td>Ruiz-Robledillo et al. (2016) (Spain)</td>
<td>30</td>
<td>22.16 (5.55)</td>
<td>30</td>
<td>Parents</td>
<td>Female = 60%</td>
</tr>
<tr>
<td>Rienecke et al. (2016) (USA)</td>
<td>175</td>
<td>AN = 14.42 (1.63)</td>
<td>BN = 15.94 (1.75)</td>
<td>Parents &amp; siblings</td>
<td>NR</td>
</tr>
</tbody>
</table>

NR = not reported; EDDS = Eating Disorder Diagnostic Scale; EAT-26 = Eating Attitudes Test; DASS = Depression Anxiety Stress Scales; STAI = State-Trait Anxiety Inventory; Liebowitz Social Anxiety Scale; IDI = Interpersonal Dependence Inventory; FACES-III = Family Adaptability and Cohesion Scale; IEQ-EU = Involvement Evaluation Questionnaire-European Version; ZBI = Zarit Burden Interview; SCFI = Structured Clinical Family Interview.

1 This study only required parents to not be caring for offspring with a physical and/or psychological illness and did not identify an index offspring.

2 A total of 72% of AN patients, 52% of BN patients and 22.5% of MDD patients had both parents participate in the interview. A total of 49% of AN patients, 28% of BN patients and 22.5% of MDD patients had siblings present during the interview.
CHAPTER 3: COMPARING FAMILY CAREGIVING

healthy individuals have found that ED caregivers present greater psychological distress, enmeshment, over-protective behaviors, EE, trait-anxiety, worry, depression, family conflict, insomnia, social dysfunction and less self-efficacy, satisfaction, problem solving skills and alliance with their partner than the caregivers of healthy controls (Blair et al., 1995; Goddard & Treasure, 2013; Kyriacou et al., 2008; Ruiz-Robledillo et al., 2016; Sim et al., 2009).

Not only is the number of studies employing comparison and/or control groups limited, but the studies published to date also present several shortcomings. First, only two studies recruited an exclusively adolescent sample of ED patients (Rienecke et al., 2016; Sim et al., 2009), the remainder presented mean ages ranging from 18.7 (Blair et al., 1995) to 25.9 (Martín et al., 2015). Only one of the studies with an entirely adolescent ED sample employed a control group of caregivers of healthy adolescents (Sim et al., 2009). The use of a healthy control group in an adolescent sample is of particular importance considering that it would provide an opportunity to determine whether the observed familial patterns are associated exclusively with caring for an adolescent with an ED or are universal to the experience of caring for a teenager. Furthermore, Sim et al. (2009) only recruited mothers and many of the studies in Table 6 did not report on the differences between mothers’ and fathers’ scores on the caregiver variables that were assessed.

Another shortcoming of the published studies is that many of the comparison groups were not selected in consideration of similarities between the two disorders. While the study by Doba et al. (2014) selected a comparison group of substance dependence disorder based on the similarities between the two groups, the sample sizes were small and they did not use adolescent samples, despite the fact that both of these disorders tend to begin during adolescence (American Psychiatric Association, 2013). Finally, several variables that have been explored in the context of ED family caregiving were not assessed in these studies, such as quality of life, accommodating behaviors or coping strategies. The remainder of this chapter
addresses the use of the particular comparison and control group used in the present thesis. First, the similarities between EDs and SUDs are presented. Second, a summary of findings related to parenting a teenager and how this relates to the use of an adolescent healthy control group is provided.

**Eating disorders and substance use disorders**

Individuals with a SUD engage in the recurrent use of alcohol and/or drugs resulting in clinically significant impairment or distress, which may include consequences to one’s health and safety and interference with work, school and/or home life. DSM-IV (American Psychiatric Association, 2000), differentiated between substance abuse and substance dependence, the criteria for which are outlined in Table 7. However, the DSM-5 no longer distinguishes between abuse and dependence (American Psychiatric Association, 2013).

Similar to findings from studies carried out in the U.S. (SAMHSA, 2014), the most common substances used by adolescents in Spain include alcohol and cannabis (Health Social Services and Equality Ministry, 2016). A recent survey of Spanish secondary students indicated that over the past thirty days, 32.2% had engaged in binge drinking (five or more alcoholic drinks in one occasion), 31.9% had engaged in risky alcohol consumption on the weekends (>49cc/day for males, >29cc/day for females) and 18.6% had consumed cannabis. Males were more likely than females to engage in binge drinking and consume cannabis (Health Social Services and Equality Ministry, 2016). Adolescent consumption of both alcohol and cannabis has been found to increase the risk for developing SUD or alcohol use disorder (AUD) in adulthood. Adults who first used cannabis at age 14 or younger had higher rates of SUD than those who first used cannabis after age 18. In regards to alcohol use, adults who had used alcohol at age 14 or younger were seven times more likely to develop AUD than individuals who consumed their first drink at age 21 or older (SAMHSA, 2012). In comparison to other illicit drugs, such as heroin and cocaine, cannabis use is less likely to lead to physical
dependence (Dennis & Pryor, 2014). However, the risk of dependence increases for those individuals who start using cannabis at an earlier age (Copeland, Swift, Roffman, & Stephens, 2001).

Table 7. *DSM-IV criteria for substance abuse and substance dependence*

<table>
<thead>
<tr>
<th>Substance Abuse</th>
<th>Substance Dependence</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>One (or more) in a 12-month period</em></td>
<td><em>Three (or more) in a 12-month period</em></td>
</tr>
<tr>
<td>• Recurrent use resulting in failure to fulfill major role obligation at work, home or school</td>
<td>• Tolerance (marked increase in amount OR marked decrease in effect)</td>
</tr>
<tr>
<td>• Recurrent use in physically hazardous situations</td>
<td>• Characteristic withdrawal symptoms OR substance taken to relieve withdrawal</td>
</tr>
<tr>
<td>• Recurrent substance-related legal problems</td>
<td>• Substance taken in larger amount and for longer period than intended</td>
</tr>
<tr>
<td>• Continued use despite persistent or recurrent social or interpersonal problems caused or exacerbated by effects of the substance</td>
<td>• A great deal of time spent to obtain, use and/or recover from the substance</td>
</tr>
<tr>
<td><em>The symptoms have never met criteria for Substance Dependence for this substance</em></td>
<td>• Important social, occupational, or recreational activities given up or reduced</td>
</tr>
<tr>
<td></td>
<td>• Use continues despite the knowledge of having adverse consequences (e.g., failure to fulfill role obligation, use when physically hazardous)</td>
</tr>
</tbody>
</table>

A number of studies in recent years have explored the similarities between SUDs and EDs (Dawe & Loxton, 2004; Gregorowski, Seedat, & Jordaan, 2013), which may in part be due to the high rates of comorbidity found between the two disorders (Dennis & Brewerton, 2014; Harrop & Marlatt, 2010). Research on clinical samples suggest that 14% of patients present with comorbid ED and SUD (Gilchrist, Gruer, & Atkinson, 2007), while this number increases to between 17 and 46% in studies carried out among community samples (Harrop & Marlatt, 2010). In fact, researchers have begun to explore whether EDs are not in fact
addictions themselves (Barbarich-Marsteller, Foltin, & Walsh, 2011; Davis & Claridge, 1998; Speranza et al., 2012). In recent years, the fields of psychiatry and psychology have broadened the definition of addiction to include behavioral or process addictions in addition to substances (Goodman, 2008; Petry et al., 2014; Smith, 2012), leading researchers to study EDs as possible “process addictions” (Brewerton, 2014). While much of the research on the association between EDs and SUDs has focused on patients with a binge-profile (Harrop & Marlatt, 2010), an “auto-addiction” model has been developed which considers restrictive EDs as possible addictions as well. This model posits that ED-related behaviors, such as prolonged starvation and excessive exercise, stimulate a release of β-endorphins, the body’s own endogenous opioids, which likely play a key role in the disorders’ onset and maintenance (Brewerton, 2014; Davis & Claridge, 1998).

It is common for both EDs and SUDs to begin during adolescence (American Psychiatric Association, 2000), a developmental stage in which individuals are particularly vulnerable to developing addictive behaviors (Barbarich-Marsteller et al., 2011). Chronic conditions with a multifactorial etiology (Dennis & Pryor, 2014), both disorders involve a number of mental and physical health consequences (Mitchell & Crow, 2006; National Institute on Drug Abuse, 2012) and are associated with the highest risk of mortality of all mental disorders (Harris & Barraclough, 1998). Particularly when they occur during adolescence, these disorders can effect important developmental and social transitions and interfere with normal brain maturation (Chui et al., 2008; National Institute on Drug Abuse, 2014b). Furthermore, both disorders present high rates of comorbidity with other mental disorders (Armstrong & Costello, 2002), which may influence treatment outcome (Grella, Hser, Joshi, & Rounds-Bryant, 2001; Herpertz-Dahlmann et al., 2001).

Another similarity found among EDs and SUDs is the important role of the family in terms of genetic and environmental influences, as well as the effect that these disorders have
on family relationships and the larger family structure. Family, twin and adoption studies reveal that SUD is largely influenced by genetic factors with children of alcoholics five to six times more likely to develop AUD (McGue, 1999) and adolescents of parents who abuse drugs 45-79% more likely to abuse drugs when compared to the general population (Agrawal & Lynskey, 2006; Tsuang, Bar, Harley, & Lyons, 2001). A large national survey carried out in the United States revealed that the maladaptive family functioning cluster (i.e. parental mental illness, parental SUD, criminality, family violence, physical abuse, sexual abuse and neglect) was strongly correlated with the onset and persistence of SUD (Green et al., 2010; McLaughlin et al., 2010). Research also indicates that parents influence their children’s alcohol and drug use through their parenting style, with an authoritative parenting style serving as the most protective against drug and alcohol use (Hoffmann & Bahr, 2014; Shakya, Christakis, & Fowler, 2012). Other family variables that have been found to increase the risk for subsequent drug or alcohol use include low family cohesion, low family communication and low parental monitoring (Velleman, Templeton, & Copello, 2005). Finally, high familial EE has been found to be an indicator for relapse among patients with SUD (Garcia, 2009).

High rates of relapse are observed in both ED and SUD (National Institute on Drug Abuse, 2014a; Steinhausen, 2009). As in the case of EDs, many individuals with SUD may delay or avoid seeking treatment, often because they are not ready to stop using (SAMHSA, 2014). Just as individuals with an ED may be reinforced for their ED behaviors (e.g. positive attention for changes to weight and shape, a sense of control or safety), those with an SUD are faced with the reinforcing properties of the substance they are using, as well as psychological and physical dependence, which may make it difficult for them to fully acknowledge the extent of their problem (Breda & Heflinger, 2004; Dennis & Pryor, 2014). For this reason, Motivational Interviewing (Miller & Rollnick, 2004), which focuses on exploring and resolving ambivalence about changing behaviors with the aim of increasing readiness for
change (Prochaska, DiClemente, & Norcross, 1992), has been found to have a positive effect on outcomes in both disorders (Barnett, Sussman, Smith, Rohrbach, & Spruijt-Metz, 2012; Macdonald, Hibbs, Corfield, & Treasure, 2012).

Similar to the case of EDs, the conceptualization of the family’s role in the development and treatment of SUDs has shifted in recent years, moving from blaming families for causing SUDs to seeing them as allies in the treatment process (Velleman et al., 2005). A review of the research on family therapy for SUDs concluded that this therapy modality is one of the most effective approaches for treating adult and adolescent SUD (Rowe, 2012), and a recent meta-analysis comparing outpatient treatment for adolescents with SUD found that family-based approaches demonstrated the strongest evidence for effectiveness (Tanner-Smith, Wilson, & Lipsey, 2013). Furthermore, research has also begun to focus on the impact of substance misuse on family members themselves (Copello, Velleman, & Templeton, 2005), revealing that relatives of SUD patients demonstrate deterioration in quality of life as well as physical and mental health problems (Hussaarts, Roozen, Meyers, van de Wetering, & McCrady, 2012). Similar to EDs, several interventions have been developed which are designed to help family members in their own right by improving coping skills and reducing the physical and psychological symptoms they experience (Copello, Templeton, Krishnan, Orford, & Velleman, 2000; Toumbourou, Blyth, Bamberg, & Forer, 2001). In short, the similarities between these two patient groups make SUD patients and their families an ideal comparison group for the study of ED family caregiving.

**Healthy controls: Caring for an adolescent**

Table 6 presents the five studies that have used a healthy control group in the assessment of ED family caregiving (Blair et al., 1995; Goddard & Treasure, 2013; Kyriacou et al., 2008; Ruiz-Robledillo et al., 2016; Sim et al., 2009). These authors have employed a healthy control group based on the fact that relatives of healthy controls are not faced with
many of the stressors experienced by family members of ED patients. For example, parents of healthy adolescents will not experience the same feelings of isolation or stigmatization as parents of an adolescent with an ED (Highet, Thompson, & King, 2005; Perkins, Winn, Murray, Murphy, & Schmidt, 2004), worry related to the fragile state of their child’s psychological and physical health (Cottee-Lane, Pistrang, & Bryant-Waugh, 2004) or the frustration associated with difficulties in accessing services (Winn, Perkins, Murray, Murphy, & Schmidt, 2004). However, certain aspects inherent to this developmental life stage and the resulting changes in parent-child relationships are important to consider as they may influence parents of healthy teens as well.

The term “adolescence” refers to children from age 10 through their early twenties and researchers have typically grouped this stage into three distinct periods which include early adolescence (age 10-13), middle adolescence (age 14-17) and late adolescence (age 18 to early twenties) (Smetana, Campione-Barr, & Metzger, 2006). This developmental stage is characterized by numerous physiological, social and contextual changes and transitions for both the child and their family (Steinberg, 2001). Although popular culture supports a vision of adolescence as a tumultuous period fraught with rebellion, moodiness and family conflict, the majority of research has failed to support the notion of adolescence being a time of “storm and stress.” Instead, results from decades of research have concluded that emotional turmoil as well as extreme conflict between an adolescent and their parents are experienced by only a small minority of families (Smetana et al., 2006). Bickering and disagreements over day to day concerns are a normative part of early adolescence and these conflicts tend to decline as children progress through adolescence (Peterson & Bush, 2015). In fact, those adolescents who experience moderate conflict with their parents tend to be better adjusted than those who experience no conflict or frequent conflict (Adams & Laursen, 2001) and this conflict is widely
seen as serving to help adolescents become more independent with greater autonomy (Smetana et al., 2006).

While adolescence is not necessarily marked by outright conflict, it is a time of notable transformations in the parent-child relationship and most parents state that it is the most difficult stage of parenting (Buchanan et al., 1990). Teenagers will likely demand greater autonomy and parents may struggle to accept the changes in the preexisting hierarchical relationship (Laursen & Collins, 2009). Furthermore, for many parents the job of raising an adolescent coincides with their entry into middle-age which may influence how they experience this task. Among middle-aged parents of adolescents, the transition to adolescence may affect the parent’s mental health more than that of their child’s (Steinberg & Steinberg, 1994). However, research on the psychological distress experienced by parents of adolescents is conflicting as some studies have reported that these parents experience greater psychological distress than parents without children, while others have found that they experience greater psychological well-being and growth (Wiley & Berman, 2012). Finally, a parent’s gender may also influence the relationship that they have with their child during adolescence. Regardless of their age, adolescents tend to have a closer relationship with their mother than father (Buhrmester & Furman, 1987) and are more likely to discuss private matters like dating and sexual attitudes with mothers than fathers (Noller & Callan, 1990). In short, caring for an adolescent is not without its own set of stressors. However, this present thesis is based on the assumption that the experience of caring for an adolescent will be distinct when the parent is faced with the challenge of caring for an adolescent with an ED, instead of a teen without a physical or psychological disorder.

**Conclusions**

While the number of studies on ED caregiving that have used comparison and/or control groups have increased in the past few years, those that do exist present a number of
shortcomings, which have been outlined in the present chapter. SUD patients are an ideal comparison group in the study of family caregiving among adolescent ED patients given the numerous similarities between these two disorders, primarily their age of onset, tendency for patients to deny the problem, physical and psychological consequences, disruptions to family relationships, and effects on the health of their caregivers. Finally, while caring for a healthy adolescent may involve certain stressors, overall adolescence is not destined to be a period marked by "stress-and strain," and the caregiving experience of these parents will likely be distinct from that of parents of a teen with a psychiatric disorder.
References


CHAPTER 3: COMPARING FAMILY CAREGIVING


SAMHSA. (2014). *Results from the 2013 national survey on drug use and health: Summary of national findings*. Rockville, MD: Substance Abuse and Mental Health Services Administration.


Chapter 4

Method
CHAPTER 4: METHOD

Introduction to the chapter

The present chapter aims to provide an overview of the study that the articles presented subsequent three chapters (Chapters 5 to 7) are based on. First, the study design, objectives and hypotheses are provided. Following this, the participants and procedure are described. The chapter concludes with a description of the instruments and statistical analyses that were carried out.

General and specific objectives

This cross-sectional study with a descriptive and comparative design recruited adolescent ED patients and their parents, along with a clinical comparison (SUD patients and parents) and healthy control group (healthy teens and their parents) in order to compare parents on a number of family caregiving variables that were identified to be relevant following a review of the ED family caregiving literature. The general aim of the study was to identify ways to improve clinical interventions with the parents of adolescent ED patients by 1) determining if ED parents differed from these two groups on the variables assessed, 2) assessing for gender differences between mothers and fathers, and 3) evaluating the relationship between parent and patient variables. The following specific objectives were developed for the present study:

- To determine what aspects of the experience of caring for an adolescent with an ED are unique and which may be shared by parents caring for an adolescent with a similar psychiatric illness by comparing ED and SUD parents on their levels of impairment on family caregiving variables (appraisal of the caregiving experience, EE, HRQoL, accommodation and enabling behavior) and frequency of using different coping strategies (Chapters 5 and 6).
CHAPTER 4: METHOD

• To assess whether parents of adolescent ED patients differ from parents of healthy teens on their levels of EE, HRQoL and frequency of using different coping strategies, by comparing the ED and HC groups on these variables (Chapters 5 and 6).

• To evaluate if mothers and fathers of ED patients presented gender differences in terms of their appraisal of the caregiving experience, EE, HRQoL, accommodation and enabling behavior and frequency of using different coping strategies (Chapters 5 and 6).

• To determine if there are certain parent and patient variables (socio-demographic and clinical) that are associated with the use of particular adaptive and maladaptive coping strategies among ED and SUD parents (Chapter 6).

• To evaluate if there is a relationship between appraisal of the caregiving experience and adaptive and maladaptive coping strategies among ED and SUD parents, in accordance with a stress-coping model (Chapter 6).

• To determine if, in spite of the similarities between the patient groups, they differed in terms of the frequency and type of comorbid psychiatric diagnoses, as assessed by a semi-structured diagnostic interview, and to determine if these findings are comparable to treatment seeking patients in other developed countries (Chapter 7).

• To evaluate if the interpersonal maintenance model of ED’s hypothesized relationship between maternal psychological distress and patient’s psychological distress and symptom severity is observed between the mothers and patients of the two patient groups (Chapter 7).

• To determine if parents of adolescent ED patients differ from caregivers evaluated in previous studies that have not used entirely adolescent patient samples on the various family caregiving variables that were assessed (discussed in Chapter 8).
In light of these specific objectives and the previously published research that was summarized in Chapters 1 to 3, the following hypotheses were developed for the study:

1. The ED and SUD parents will not present differences on the family caregiving variables.
2. The ED parents will present greater impairment than the HC parents and distinct coping strategies.
3. Parents will present gender differences on the family caregiving variables, with mothers reporting greater impairment than fathers.
4. In line with previous findings, parent’s age and the duration of illness will be associated with greater use of maladaptive coping strategies.
5. A positive appraisal of the caregiving experience will be associated with adaptive coping while a negative appraisal will be associated with maladaptive coping.
6. The two patient groups will present similar rates and types of psychiatric comorbidity as those found in previous studies in other developed countries.
7. Maternal distress will be positively associated with patient’s psychological distress and symptom severity.
8. The ED parents in the current study will present lower scores on family caregiving variables than those found in studies that have not used entirely adolescent samples.

**Participants and procedure**

The study sample consisted of 48 mothers and 45 fathers of patients diagnosed with an ED, 47 mothers and 37 fathers of patients diagnosed with a SUD and 66 mothers and 50 fathers of healthy adolescents. The ED patients were 49 females and 1 male ($M_{age} = 14.8; SD = 1.8$, Range: 12-18), the SUD patients were 8 females and 40 males ($M_{age} = 18.2; SD = 2.2$, Range: 13-23), and the healthy adolescents were 68 females ($M_{age} = 14.5; SD = 1.4$, Range: 12-18).
The inclusion criteria for patients were: 1) 12 to 23 years old; 2a) for the ED group: presence of an ED according to DSM-IV-TR diagnostic criteria, 2b) for the SUD group: presence of a SUD according to DSM-IV-TR diagnostic criteria, 2c) for the HC group: no history of a psychiatric disorder and a body mass index (BMI) of at least $17.5 \, \text{kg/m}^2$; 3) living with at least one parent. Patients were excluded if they had a diagnosis of psychosis, a learning disability, a neurologic disease or a disease affecting metabolic regulation (i.e. diabetes, hyperthyroidism) or comorbid ED and SUD. Data were collected from October 2011 to July 2014. The research was reviewed and approved by an Institutional Review Board (R-009/10), all participation was voluntary, participants provided informed written consent and no compensation was provided.

The families of patients with an ED were randomly recruited from the inpatient or outpatient services of an adolescent ED unit (Child and Adolescent Psychiatric Department, Niño Jesus University Hospital, Madrid, Spain). A description of the nature and objectives of the study was given to 53 families (“please help us to better understand your experience as a caregiver so that we are aware of how to better help you and your son/daughter”) during their visit to the mental health service. Two of the patients who were approached declined participation due to distrust regarding confidentiality of their personal information. Semi-structured clinical interviews were conducted and one patient was excluded because she presented psychotic symptoms.

The SUD families were randomly recruited from an adolescent outpatient program dedicated to treating substance abuse and dependence (‘Programa Soporte’ of Proyecto Hombre, Madrid, Spain). Forty-eight of the 55 families who were invited to participate provided informed consent and underwent a semi-structured clinical interview. Seven families declined participation due to lack of time and/or distrust regarding the confidentiality of their personal information. Two adolescents (one female and one male) had comorbid ED and were
not approached. All SUD patients that were interviewed met the selection criteria and were included in the study.

Healthy adolescents and their caregivers were recruited from public secondary schools in the region of Madrid. First, permission from the institutional board was obtained, as well as from their teachers. Then, a summary of the study was provided to students, asking them to inform their parents about it and offering them an optional psychological report after participation. Eighty-seven of the families that expressed interest in participating were approached and 73 agreed to participate in the study. Clinical interviews were carried out and five patients were excluded. Three of them presented ED symptoms, one presented symptoms of attention-deficit disorder and one had a BMI of less than 17.5 kg/m².

Following the interview, patients and their families were presented with a battery of self-report questionnaires.

Instruments

A list of the instruments that were used to assess each variable are provided in this section. Additional details regarding the instruments, including their psychometric properties, can be found in chapters 5 to 7 (articles 1 to 3).

For all participants

**Socio-demographic and clinical characteristics.** Parents provided information about their age, education level, family constitution, employment situation and time spent with the young participant. For all young participants, information about their age and gender was provided. Weight and height were also collected and BMI was calculated. For patients, subtype of diagnosis, illness duration and current treatment type was provided.

**Psychiatric diagnoses.** The Schedule for Affective Disorders and Schizophrenia for School-Age Children (K-SADS-PL) (De la Peña et al., 2002; Kaufman et al., 1997) was administered in the presence of the young participants and responses were confirmed with
parents when necessary.

**ED and SUD patients**

*Symptom severity.* The Eating Attitudes Test (EAT-26) (Castro, Toro, Salamero, & Guimerá, 1991; Garner, Olmsted, Bohr, & Garfinkel, 1982) was administered to ED patients and the Drug Abuse Screening Test (DAST-20) (Pérez Gálvez, García Fernández, de Vicente Manzanaro, Oliveras Valenzuela, & Lahoz Lafuente, 2010; Skinner & Goldberg, 1986) was administered to SUD patients.

*Psychological distress.* The Hospital Anxiety and Depression Scale (HADS) (Herrero et al., 2003; Zigmond & Snaith, 1983).

**Parents**

*Expressed emotion.* Family Questionnaire (FQ) (Sepulveda et al., 2014; Wiedemann, Rayki, Feinstein, & Hahlweg, 2002).

*Accommodating behaviour.* Accommodation and Enabling Scale for Eating Disorders (AESED) (Quiles Marcos, Quiles Sebastián, Pamies Aubalat, Sepúlveda García, & Treasure, 2016; Sepulveda, Kyriacou, & Treasure, 2009).

*Mental and physical HRQoL.* SF-36 Health Survey (SF-36) (Alonso, Prieto, & Anto, 1995; Ware, Snow, Kosinski, & Gandek, 1993).

*Appraisal of the caregiving experience.* Experience of Caregiving Inventory (ECI) (Sepulveda et al., in preparation; Szmukler et al., 1996).

*Coping strategies.* The COPE inventory (Carver, Scheier, & Weintraub, 1989; Crespo & Cruzado, 1997).

*Psychological distress.* The Hospital Anxiety and Depression Scale (HADS) (Herrero et al., 2003; Zigmond & Snaith, 1983).

**Statistical Analysis**

Data were analysed using the statistical software package SPSS and the criterion for
significance was set at $p < .05$.

**Chapter 5 (article 1)**

Continuous socio-demographic and clinical variables (age and BMI) in all groups were compared using one-way analysis of variance (ANOVA), followed by post hoc Tukey’s HSD tests. An independent-samples $t$-test was used to compare illness duration in the ED and SUD groups. Categorical socio-demographic variables of carers were entered after dichotomizing the data (educational level, family constitution, employment situation, hours of contact with the son/daughter) and were compared using chi-square tests, separately for mothers and fathers. Furthermore, gender differences in the various aspects of family functioning for each caregiver group (ED, SUD, HC) were analyzed using the Mann-Whitney $U$-test.

A series of one-way multiple analyses of covariance (MANCOVAs) were carried out to assess the effect of caregiver group (ED, SUD, and HC) on the various aspects of the caregiving experiences (EE, accommodating behavior, negative caregiving experience, HRQoL) while controlling for hours of face-to-face contact with the son/daughter and also for adolescents’ age. Analyses were performed separately for mothers and fathers. A series of one-way ANOVAs were carried out to further examine univariate main effects of each dependent variable and post-hoc comparisons were examined using Bonferroni correction.

**Chapter 6 (article 2)**

Patient and caregiver’s continuous socio-demographic variables were compared using one-way analyses of variance (ANOVAs) followed by post-hoc Tukey’s HSD tests. Caregiver’s categorical socio-demographic information was compared using chi-squared tests. Illness duration and hours of caregiver contact between patient groups was compared using independent $t$-tests.

To explore the effects of caregiver group (ED, SUD, and HC) on the frequency of using different coping strategies, one-way multiple analyses of variance (MANOVAs) were carried
out, for mothers and fathers separately. The subscales of the COPE were grouped into four factors which were used as dependent variables (socially supported, problem-focused, emotion-focused and avoidant coping) and caregiver group was used as the independent variable. A series of one-way ANOVAs were carried out to further examine univariate main effects of each dependent variable, and post hoc comparisons were carried out with a Bonferroni adjusted $\alpha$ level of .017. Mann Whitney $U$-tests were used to explore possible differences between mothers and fathers (separately for each group) on the frequency of using different coping strategies, and on the ECI positive and negative subscales for the two patient caregiver groups (ED, SUD). Finally, the associations between coping strategies, appraisal of the caregiving experience, and caregiver and patient demographic and clinical variables were assessed with Spearman correlations for the ED and SUD groups.

**Chapter 7 (article 3)**

The patients’ continuous socio-demographic and clinical data were compared using independent samples $t$-test. Patients’ categorical socio-demographic and clinical variables and mothers’ socio-demographic variables were described using contingency tables and compared using $\chi^2$ test or Fisher exact test, as appropriate. The relationship between the patients’ scores on psychological measures and mothers’ HADS scores was investigated using Pearson’s correlation coefficient, separately for each group of patients.

A series of logistic regression analyses were performed to identify which of the psychiatric comorbidities had a significant independent association with the likelihood that patients belonged to either the ED or SUD group. Mothers’ anxiety and depression were also each entered into a model as possible predictor variables and were categorized using HADS suggested cut-off points: absence of or low levels of anxiety/depression ($0 = \text{HADS-Anxiety/\text{HADS-Depression}} < \text{11}$) and probable presence of anxiety/depression ($1 = \text{HADS-Anxiety/\text{HADS-Depression}} \geq \text{11}$). Axis I disorders were grouped into three main categories
(unipolar mood disorders, anxiety disorders, ADHD). Disruptive behavior disorders (CD, ODD) were not included as a predictor variable due to the complete absence of this type of comorbidity in the ED group. All independent variables were categorical (0 = absence of psychiatric comorbidity; 1 = presence of psychiatric comorbidity).

Conclusions

This chapter has provided a summary of the methodology of the current study, including the design, objectives, hypotheses, participants, procedure, instruments and statistical analyses. The following three chapters will provide additional details regarding each of these aspects of the current study.
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References


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Caregiving Inventory. Social Psychiatry and Psychiatric Epidemiology, 31(3-4), 137-148.


Chapter 5

Family Functioning and Quality of Life Among Families in Eating Disorders: A Comparison with Substance-Related Disorders and Healthy Controls

Abstract

The aim of this study was to compare the family functioning of Spanish parents of patients with an eating disorder (ED) with that of carers of patients with substance-related disorders (SRDs) and families of healthy controls (HC). This cross-sectional study included 48 mothers and 45 fathers of 48 adolescent patients with an ED, 47 mothers and 37 fathers of 47 patients with an SRD and 66 mothers and 50 fathers of 68 HCs. Families of ED patients reported lower levels of criticism, symptom accommodation and negative caregiving experience than families of SRD patients. However, relatives of both ED and SRD patients reported similar levels of quality of life related to their mental health. Furthermore, families of HCs generally exhibited better scores on all scales assessing their caregiving experiences. Regarding gender differences, there was a tendency in mothers, primarily those from the ED group, to report more adverse experiences as caregivers compared with fathers. Symptoms characteristic to each disorder may be associated with differential patterns of family functioning and may require specifically tailored family interventions. Early family intervention in adolescence is crucial, as relatives' quality of life does not seem to have been badly affected at this point in the course of the illness.

**Keywords:** eating disorders; substance-related disorders; family functioning; quality of life; gender
**CHAPTER 5: FAMILIES, EATING DISORDERS AND SUBSTANCE ABUSE**

**Introduction**

The experience of caring for a person suffering from an eating disorder (ED) is stressful and demanding. Given that the onset of the illness is usually in adolescence, the responsibility for providing care and spending time with the patient tends to fall on family caregivers (Haigh & Treasure, 2003; Whitney & Eisler, 2005). As a result, families often find themselves trapped in unhelpful patterns of response to the illness which, in turn, may lead to a more burdensome caregiving experience, thereby serving as maintenance factors associated with a slower rate of recovery in patients with anorexia nervosa (AN) (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013), and in other ED diagnoses, such as bulimia nervosa (BN) and ED not otherwise specified (EDNOS) (Holtom-Viesel & Allan, 2014; Winn et al., 2007). Studies on family reactions as maintaining factors have identified expressed emotion (EE) as a core factor associated with a negative response from patients to treatment (Eisler et al., 2000) and have shown that accommodating and enabling behaviours may also negatively influence the patients’ outcome (Sepulveda, Kyriacou, & Treasure, 2009).

Likewise, other studies on ED have suggested that a negative caregiving experience, defined as an appraisal of carers’ demands within a stress-coping context (Szmukler et al., 1996), is commonly associated with mental health problems and distress among carers (Whitney, Haigh, Weinman, & Treasure, 2007; Winn et al., 2007). In turn, a negative caregiving experience can be associated with health-related quality of life, defined as a person’s perception of how an illness and its treatment may affect his/her physical, psychological and social functioning. However, caregiver’s quality of life does not seem to affect his/her perception of burden (Martin et al., 2011).

Recent systematic reviews (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014; Zabala, Macdonald, & Treasure, 2009) have attempted to synthesize findings related to the experiences of caregivers in EDs. They concluded that further research in this area was
required, particularly studies that include control or comparison groups, in order to identify factors that are specific to the experience of caring for a loved one with an ED which can influence the outcome of the illness. To date only five studies have compared the family functioning of caregivers of patients with an ED with family functioning in other groups of caregivers. The studies concluded that the experience of caring for a person with an ED appears to be more negative, in terms of deterioration in physical health, distress, burden and EE, than that of families of patients with psychosis (Treasure et al., 2001), cystic fibrosis (Blair, Freeman, & Cull, 1995), insulin-dependent diabetes mellitus (Sim et al., 2009), and healthy controls (Kyriacou, Treasure, & Schmidt, 2008a), although there were some similarities in the experiences of caregivers of patients with AN and schizophrenia (Graap et al., 2008). However, these studies present several limitations. First of all, the comparison groups were randomly selected. That is, selection was not based on common or differentiating factors with respect to the caregiving experience or the nature of the illness. Furthermore, they were also limited in terms of sample size and representativeness, and only one of them included an adolescent sample of patients.

In light of the current state of research, the aim of this study was to examine the family functioning of Spanish mothers and fathers of patients with an ED and to compare it with the family functioning of families caring for patients with substance-related disorders (SRDs) and the families of healthy controls (HC). More specifically, we planned to compare levels of EE, symptom accommodation, caregiving experience and quality of life separately for mothers and fathers in the three groups.

The decision to include SRD families was based on the fact that both EDs and SRDs are life-threatening chronic mental illnesses with adolescent onset and a lengthy recovery process. Furthermore, the trans-theoretical model of change which was initially developed and used for treatment of addictions (Prochaska & DiClemente, 1982) was later adapted for
treatment of EDs (Vitousek, Watson, & Wilson, 1998). This was mainly due to functional similarities between restrictive type EDs and SRDs, given that both patients often deny their symptoms and are resistant to help. It is potentially relevant to family functioning due to the fact that in both conditions, parents are exclusively involved in the caregiving of their sick child, requiring them to spend many hours each day in contact with him or her (Kyriacou, Treasure, & Schmidt, 2008b), as well as to cope with the serious impact that either illness has on their child’s health (Abrahams & Llewellyn-Jones, 2001; National Institute on Drug Abuse, 2016). As a consequence, the literature suggests that there are similarities in family reactions to the two problems, ranging from complete assumption of responsibility and over-protectiveness to complete disengagement and rejection and criticism of the patient (Becerra, 2009; Kyriacou et al., 2008a). Economic problems, problems in setting limits and assigning roles and responsibilities, lack of understanding of the causes of the problem and the stigma associated with having a child with a psychiatric condition have also been described in both conditions (Dimitropoulos, Carter, Schachter, & Woodside, 2008; Ghodse & Galea, 2005; Orford, Velleman, Copello, Templeton, & Ibanga, 2010; Perkins, Winn, Murray, Murphy, & Schmidt, 2004; Winn, Perkins, Murray, Murphy, & Schmidt, 2004).

Gender differences in family functioning have been reported in the families of patients with AN, with mothers reporting higher levels of anxiety, emotional over-involvement and a more negative perception of caregiving than fathers (Anastasiadou, Cuellar-Flores, Sepulveda, Parks, & Graell, 2016; Kyriacou et al., 2008a; Whitney & Eisler, 2005). However, prior studies have not reported gender differences in levels of criticism (van Furth et al., 1996).

On the basis of the empirical studies discussed previously, we developed the following hypotheses: First, we predicted that parents of patients with an ED or SRD would have higher levels of EE and symptom accommodation, a worse experience of caregiving and lower quality of life than parents of HCs. Second, we predicted that there would be no differences between
the ED and SRD groups on the above variables. Finally, we predicted that there would be gender difference in family functioning in the comparison clinical groups, with mothers reporting poorer family functioning and lower quality of life than fathers.

Methods

Participants

Forty-eight girls (Mean age = 14.8; SD = 1.7, Range = 12-18) diagnosed with either AN restrictive type, BN non-purging type or an EDNOS restrictive type formed the ED patient group. The SRD patient group consisted of 47 adolescent girls and boys (Mean age = 18.2; SD = 2.1; Range = 12-22) diagnosed with SRD and the HC group included 68 female healthy controls (Mean age = 14.5; SD = 1.4; Range = 12-18). Forty-eight mothers (Mean age = 44.9, SD = 4.5) and 45 fathers (Mean age = 47.5, SD = 4.1) of the ED patient group were compared with 47 mothers (Mean age = 49.6, SD = 4.9) and 37 fathers (Mean age = 51.5, SD = 5.7) of the SRD patient group and with 66 mothers (Mean age = 47.5, SD = 4.0) and 50 fathers (Mean age = 50.0, SD = 4.1) of the HC patient group. Table 1 presents the patients’ demographic and clinical characteristics and the differences between groups. Socio-demographic characteristics of carers can be seen in Table 2, separately for mothers and fathers.

Procedure

We conducted a cross-sectional study with a descriptive and comparative design. Patients, along with their mothers and fathers, were recruited over a 3-year period (October 2011 to July 2014). The inclusion criteria for the patients and their healthy peers were as follows: 1) 12 to 22 years old; 2a) for the ED group: presence of a restrictive or non-purging ED according to DSM-IV-TR diagnostic criteria (American Psychiatric Association, 2002), 2b) for the SRD group: presence of a SRD according to DSM-IV-TR diagnostic criteria, 2c) for the HC group: no history of psychiatric disorder according to DSM-IV-TR diagnostic
Table 1
Sociodemographic and clinical characteristics of patients

<table>
<thead>
<tr>
<th></th>
<th>ED patients (N=48)</th>
<th>SRD patients (N=47)</th>
<th>HC (N=68)</th>
<th>Group</th>
<th>Post hoc</th>
<th>For t; p</th>
<th>Post hoc comparisons</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td>14.67 (1.72)</td>
<td>18.15 (2.12)</td>
<td>14.38 (1.40)</td>
<td></td>
<td>74.53; 0.001</td>
<td>ED &lt; SRD = HC</td>
<td></td>
</tr>
<tr>
<td><strong>Body Mass Index (kg/m²)</strong></td>
<td>18.16 (1.84)</td>
<td>21.65 (2.13)</td>
<td>21.49 (3.34)</td>
<td></td>
<td>26.45; 0.001</td>
<td>SRD &gt; ED = HC</td>
<td></td>
</tr>
<tr>
<td><strong>Illness Duration (months)</strong></td>
<td>12.48 (12.3)</td>
<td>24.22 (16.5)</td>
<td>-</td>
<td></td>
<td>-3.87; 0.001</td>
<td>n.a.</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td>Female 48 (100%)</td>
<td>7 (14.9%)</td>
<td>68 (100%)</td>
<td>123.218; 0.001</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Male 0</td>
<td>40 (85.10%)</td>
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</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td>AN-R 37 (78%)</td>
<td></td>
<td>-</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td>BN-NP 3 (6%)</td>
<td></td>
<td>-</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>EDNOS-R 8 (16%)</td>
<td></td>
<td>-</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Alcohol abuse 6 (12.2%)</td>
<td></td>
<td>-</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Cannabis abuse 45 (95.9%)</td>
<td></td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cannabis dependence 29 (61.2%)</td>
<td></td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Treatment type</strong></td>
<td>Ambulatory care 10 (20.8%)</td>
<td>0</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Home hospitalization 18 (37.5%)</td>
<td>47 (100%)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Day hospital 3 (6.3%)</td>
<td>0</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Inpatient 17 (35.4%)</td>
<td>0</td>
<td>-</td>
<td></td>
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</tr>
<tr>
<td><strong>Family constitution</strong></td>
<td>Intact (married/living together) 40 (83.3%)</td>
<td>37 (78.72%)</td>
<td>60 (88.2%)</td>
<td>1.760; 0.415</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Divorced (single/divorced/widowed) 8 (16.67%)</td>
<td>10 (21.28%)</td>
<td>8 (11.8%)</td>
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</tbody>
</table>

AN-R: anorexia nervosa restrictive type; BN-NP: bulimia nervosa non-purging type; EDNOS-R: eating disorder not otherwise specified restrictive type
criteria and a Body Mass Index (BMI) of at least 17.5 kg/m$^2$; 3) living with at least one parent. Adolescents were excluded if they were acutely suicidal or if they had a diagnosis of psychosis, learning disability, neurologic diseases or diseases affecting metabolic regulation (i.e. diabetes, hyperthyroidism). In order to obtain a more homogeneous ED sample, patients with an impulsive/bulimic profile, presenting objective binges and purging behaviours (vomiting, laxative and/or diuretic use) were excluded from the study. Participants with comorbid ED and SRD were also excluded. The research was reviewed and approved by an Institutional Review Board (R-009/10), all participation was voluntary and participants provided informed consent.

ED patients and their parents were randomly recruited from consecutive admissions to inpatient or outpatient services at the Eating Disorders Unit of the Child and Adolescent Psychiatric Department of the Niño Jesus University Hospital in Madrid, Spain. A description of the nature and objectives of the study was given to 51 families (“please help us to better understand your experience as a caregiver so that we are aware of how to better help you and your son/daughter”) during their visit to the mental health service and 49 of them decided to participate in the study (two of them refused to participate expressing distrust regarding confidentiality of their personal information). Clinical semi-structured interviews (K-SADS-PL and EDE.12) were then carried out by two of the authors (D.A. and M.G.). Following the interview, one patient was excluded because she exhibited psychotic symptoms.

SRD patients and their parents were randomly recruited from an adolescent outpatient clinic for treatment for substance abuse or dependence, which was part of the “Programa Soporte” of Proyecto Hombre. After inviting them to participate and providing them with a short description of the study, 47 out of 55 families provided their informed consent and proceeded to the subsequent phases of the study (eight families refused to participate because of lack of time and/or expressed distrust regarding confidentiality of their personal information). Clinical interviews (K-SADS-PL) were carried out by D.A., under the
Table 2

Socio-demographic data of carers for mothers and fathers separately

<table>
<thead>
<tr>
<th></th>
<th>Mothers ED group N=48</th>
<th>Mothers SRD group N=47</th>
<th>Mothers HC group N=66</th>
<th>( \chi^2 ); p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>School/Secondary level</td>
<td>23 (47.9)</td>
<td>16 (34)</td>
<td>17 (26.2)</td>
<td>5.775; 0.056</td>
</tr>
<tr>
<td>Degree/Diploma</td>
<td>25 (52.1)</td>
<td>31 (66)</td>
<td>48 (73.8)</td>
<td></td>
</tr>
<tr>
<td><strong>Employment situation</strong></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Full time/Part time</td>
<td>34 (72.3)</td>
<td>37 (78.7)</td>
<td>50 (92.6)</td>
<td>7.335; 0.026</td>
</tr>
<tr>
<td>Unemployed/Retired</td>
<td>3 (6.5)</td>
<td>10 (21.3)</td>
<td>4 (7.4)</td>
<td></td>
</tr>
<tr>
<td><strong>Hours of Contact</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 21h/week</td>
<td>7 (14.6)</td>
<td>22 (46.8)</td>
<td>4 (8)</td>
<td>23.485;</td>
</tr>
<tr>
<td>≥ 21h/week</td>
<td>41 (85.4)</td>
<td>25 (53.2)</td>
<td>46 (92)</td>
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<td></td>
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<tr>
<td>Fathers ED group N=45</td>
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<td></td>
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<tr>
<td><strong>Educational level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School/Secondary level</td>
<td>24 (53.3)</td>
<td>12 (33.3)</td>
<td>13 (26)</td>
<td>7.909; 0.019</td>
</tr>
<tr>
<td>Degree/Diploma</td>
<td>21 (46.7)</td>
<td>24 (66.7)</td>
<td>37 (74)</td>
<td></td>
</tr>
<tr>
<td><strong>Employment situation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time/Part time</td>
<td>38 (86.4)</td>
<td>30 (88.2)</td>
<td>38 (82.6)</td>
<td>0.541; 0.763</td>
</tr>
<tr>
<td>Unemployed/Retired</td>
<td>6 (13.6)</td>
<td>4 (11.8)</td>
<td>8 (16.4)</td>
<td></td>
</tr>
<tr>
<td><strong>Hours of Contact</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 21h/week</td>
<td>14 (31.1)</td>
<td>23 (62.2)</td>
<td>3 (7.1)</td>
<td>27.292;</td>
</tr>
<tr>
<td>≥ 21h/week</td>
<td>31 (68.9)</td>
<td>14 (37.8)</td>
<td>39 (92.9)</td>
<td>0.001</td>
</tr>
</tbody>
</table>
supervision of C. S. All SRD patients met the selection criteria and were included in the study.

Finally, the HC group consisted of families recruited from public secondary schools in Madrid and were matched for age and gender with ED patients, given that they were part of the sample used in another study by the same authors (Risk factors study-ANOBAS, PSI2011-23127). First, permission from the institutional board was obtained, as well as from their teachers. Then, a summary of the study was provided to students, asking them to inform their parents about it and offering them an optional psychological report after participation. Eighty-seven of the families that expressed interest in participating were approached and 73 agreed to participate in the study (8 refused because the study included blood tests, two had problems with time and four adolescents did not want participate). Clinical interviews (K-SADS-PL) were carried out by authors A.R.S., D.A. and T.A. Five patients were excluded. Three of them presented ED symptoms, one presented symptoms of attention-deficit disorder and one had a BMI of less than 17.5 kg/m². Weight and height data for all patients, as well as their healthy peers were collected prior to the clinical interviews.

Following clinical interviews, patients and their families were presented with a battery of questionnaires.

**Instruments**

**For all participants**

*The Schedule for Affective Disorders and Schizophrenia for School-Age Children (K-SADS-PL)* (De la Peña et al., 2002; Kaufman et al., 1997) is a semi-structured diagnostic interview designed to assess current and lifetime psychopathology in children and adolescents and their parents.

*Sociodemographic and clinical characteristics.* Parents provided information about their age, education level, family constitution, employment situation and time spent with the patient. For all young participants, information about their age and gender was provided.
Weight and height were also collected and BMI was calculated. For patients, subtype of diagnosis, illness duration and current treatment type was provided.

For parents

*Family Questionnaire* (FQ) (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002). This is a brief self-report questionnaire, composed of 20 items that evaluate family members’ levels of EE. Responses to items are given using a Likert scale ranging from 1 (*never*) to 4 (*frequently*). The FQ is made up of two subscales: Criticism (CC) and Emotional Over-involvement (EOI) and total scores on the subscales range from 10 to 40 with higher scores indicating higher EE. Acceptable reliability coefficients have been reported for the original version, with Cronbach’s α of 0.92 and 0.80 for the CC and EOI subscales respectively, and similar reliability coefficients were found in the Spanish version (Sepulveda et al., 2014). In this current study, Cronbach’s α was 0.81 for the CC scale and 0.80 for the EOI scale.

*Accommodation and Enabling Scale for Eating Disorders (AESED)* (Sepulveda et al., 2009). This is a 33-item self-report scale, which is used to evaluate the degree to which familial caregivers for ED patients accommodate and enable their illness. Responses are given on a five-point Likert scale ranging from 0 (*never*) to 4 (*every day*). Total score ranges from 0 to 132, with higher scores indicating greater familial tolerance of ED-related behaviours. This scale is made up of five subscales, which have Cronbach’s α values between 0.77 and 0.90. In this study, only the AESED total score was used, which had a Cronbach’s α of 0.90. The scale was also adapted to SRD-related behaviours by D.A., and was referred to as the *Accommodation and Enabling Scale for Substance Abuse (AESSA)*. Only a slight variation in the wording of the questions of the original AESED was made. Higher scores suggest a greater degree of familial accommodation to ED-related or SRD-related behaviours.

*Experience of Caregiving Inventory (ECI)* (Szmukler et al., 1996). This is a self-report questionnaire made up of 66 items; responses are given on a five-point Likert scale ranging from
0 (never) to 4 (almost always). It is used to evaluate the experience of a person caring for someone with a mental illness. It is made up of ten subscales. Eight measure negative aspects of caregiving and higher scores on these subscales indicate that the individual has more negative experiences related to caregiving (total ECI-negative score range: 0 to 208). Two positive scales assess positive caregiving experiences (total ECI-positive score range: 0 to 56). All of the subscales have been shown to have acceptable internal consistency, with Cronbach’s $\alpha$ between 0.74 and 0.91. The validation of the Spanish version in caregivers for ED patients also reported acceptable reliability coefficients, ranging 0.67 to 0.90 (Sepulveda et al., in preparation). In this study, the total ECI-negative dimension was used, obtaining a Cronbach’s $\alpha$ of 0.92.

SF-36 Health Survey (SF-36) (Ware, Snow, Kosinski, & Gandek, 1993). This is a self-report questionnaire consisting of 36 items assessing physical and mental health status. The scale is made up of eight subscales and two summary scales that aggregate the scores of the other 8 scales, the Physical Component Summary and the Mental Component Summary. In this study, these two component summaries were used in the analyses, with higher scores indicating better health. The Spanish version (Alonso, Prieto, & Anto, 1995) was shown to have acceptable internal consistency (Cronbach’s $\alpha$ of 0.71-0.94). Also, reliability estimates for the two summary scores usually exceeded 0.90 (Ware et al., 1993).

Statistical analysis

Data were analysed using the statistical software package SPSS 15.0 for Windows (2006) and the criterion for significance was set at $p < .05$. Continuous sociodemographic and clinical variables (age and BMI) in all groups were compared using one-way analysis of variance (ANOVA), followed by post hoc Tukey’s HSD tests. An independent-samples $t$-test was used to compare illness duration in the ED and SRD groups. Categorical sociodemographic variables of carers were entered after dichotomizing the data (educational level, family constitution, employment situation, hours of contact with the son/daughter) and were compared
using chi-square tests, separately for mothers and fathers. Furthermore, gender differences in the various aspects of family functioning for each carer group (ED, SRD, HC) were analyzed using the Mann-Whitney $U$-test.

A series of one-way multiple analyses of covariance (MANCOVAs) were carried out to assess the effect of carer group (ED, SRD and HC) on the various aspects of the caregiving experiences while controlling for hours of face-to-face contact with the son/daughter and also for adolescents’ age. First, we included the following three subscales, which reflected family reactions to the illness: FQ-CC, FQ-EOI and AESED/AESSA, as the dependent variables. Next, variables associated with negative caregiving experience and quality of life, the ECI-negative dimension, SF-36 Physical Component and SF-36 Mental Component, were identified as the dependent variables. Analyses were performed separately for mothers and fathers. Preliminary checks were previously conducted to ensure that there was no violation of the assumptions of normality, linearity, homogeneity of variances, homogeneity of regression slopes and reliable measurement of the covariate. Pillai’s $F$-test was used to evaluate multivariate significance because homogeneity of covariance matrix assumption was violated, as indicated by significant Box’s $M$ test, and partial eta-squared ($\eta^2$) provided the estimate of effect size. A series of one-way ANOVAs were carried out to further examine univariate main effects of each dependent variable and post-hoc comparisons were examined using Bonferroni correction.

**Results**

**Clinical characteristics of patients**

Regarding the ED group, the majority of the patients presented a diagnosis of AN-R (78%), followed by 16% with a diagnosis of EDNOS-restrictive type and 6% with BN non-purging type. Regarding the SRD group, 95.9% of the patients presented a diagnosis of
cannabis abuse, 61.2% a diagnosis of cannabis dependence and 12.2% a diagnosis of alcohol abuse.

**Gender differences in family functioning**

Gender differences for the carers of the ED group yielded statistically significant results for the FQ-EOI subscale ($z = -2.325; p = .020$), with a mean of 27.10 ($SD = 5.07$) for mothers and 24.90 ($SD = 4.25$) for fathers, as well as for the ECI-negative dimension ($z = -2.267; p = .023$) with a mean of 78.67 ($SD = 27.85$) for mothers and 66.91 ($SD = 23.72$) for fathers. Also, the SF-36 Physical Component ($z = -1.945; p = .050$) and the SF-36 Mental Component proved to be statistically significant ($z = -2.276; p = .023$), with mothers showing poorer physical and mental health than fathers ($M = 51.78$, $SD = 10.33$ vs. $M = 55.63$, $SD = 8.63$ and $M = 36.15$, $SD = 13.00$ vs. $M = 41.89$, $SD = 13.86$, respectively). Regarding the SRD group, gender differences were observed for the FQ-EOI subscale ($z = -1.984; p = .047$), with mothers scoring higher ($M = 28.26$, $SD = 4.94$) than fathers ($M = 26.46$, $SD = 3.51$). Finally, with regards to the HC group, gender differences were observed for the SF-36 Physical Component summary ($z = -1.965; p = .049$), with HC mothers showing poorer physical health ($M = 52.42$, $SD = 6.42$) than fathers ($M = 54.36$, $SD = 5.06$).

**Family reactions to illness between carer groups**

The first MANCOVA analysis, with hours of contact and adolescents’ age as covariates and family reactions to the illness (FQ-CC, FQ-EOI, AESED/AESSA) as dependent variables, was carried out among the sample of fathers, revealing a significant main effect of carer group [Pillai’s trace = .458, $F (2, 95) = 9.215$, $p = .001$, $\eta^2 = .229$]. However, there was no main effect for hours of contact [Pillai’s trace = .022, $F (1, 95) = 0.686$, $p = .563$, $\eta^2 = .022$] or for adolescents’ age [Pillai’s trace = .006, $F (1, 95) = 0.175$, $p = .913$, $\eta^2 = .006$]. Univariate tests confirmed that there were statistically significant differences for the three groups of carers on CC, on EOI and on AESED scores. Results from the post-hoc analysis are presented in Table
3. The second MANCOVA using the previously listed variables, carried out among the sample of mothers, revealed a significant main effect of carer group [Pillai’s trace = .458, $F (2, 95) = 9.196, p = .001, \eta^2 = .229$] but no main effect for hours of contact [Pillai’s trace = .063, $F (1, 95) = 2.060, p = .111, \eta^2 = .063$] or for adolescents’ age [Pillai’s trace = .035, $F (1, 95) = 1.101, p = .353, \eta^2 = .035$]. Simple main effects analyses showed significant differences for the three comparison groups on CC, on EOI and on AESED subscale. Results from the post-hoc analysis are shown in Table 4.

**Negative Caregiving Experience and Quality of Life between carer groups**

The third MANCOVA analysis for the sample of fathers, with burden of caregiving (ECI-negative dimension) and quality of life (SF-36 Physical Component and SF-36 Mental Component) as dependent variables, adjusting for hours of contact and adolescents’ age, revealed a significant main effect of carer group [Pillai’s trace = .346, $F (2, 113) = 7.741, p = .001, \eta^2 = .173$] but no main effect for hours of contact [Pillai’s trace = .001, $F (1, 113) = 0.007, p = .999, \eta^2 = .001$] or for adolescents’ age [Pillai’s trace = .037, $F (1, 113) = 1.390, p = .250, \eta^2 = .037$]. Univariate tests confirmed that there were statistically significant differences for the three comparison groups on ECI-negative and on SF-36 Mental Component. The last MANCOVA for the mothers’ sample showed a significant main effect of carer group [Pillai’s trace = .643, $F (2, 113) = 20.705, p = .001, \eta^2 = .322$] but no main effect for hours of contact [Pillai’s trace = .047, $F (1, 113) = 2.124, p = .100, \eta^2 = .047$] or adolescents’ age [Pillai’s trace = .001, $F (1, 113) = 0.010, p = .999, \eta^2 = .001$]. Simple main effects analyses showed significant differences for the three groups on ECI-negative and on SF-36 Mental Component. Results from the post-hoc analyses, performed separately for fathers and mothers, are summarized in Table 3 and Table 4, respectively.
Table 3

*Between-Subjects Effects of MANCOVA comparing fathers’ group (ED, SRD, HC) on various aspects of caregiving experiences, after adjusting for hours of contact and for adolescents’ age*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean (SD)</th>
<th>F-value</th>
<th>p</th>
<th>Partial η²</th>
<th>ED vs. SRD</th>
<th>ED vs. HC</th>
<th>SRD vs. HC</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family reactions to illness</strong></td>
<td></td>
<td></td>
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<tr>
<td>FQ-EOI</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>ED</td>
<td>25.21 (0.63)</td>
<td>18.667</td>
<td>0.001</td>
<td>0.282</td>
<td>-</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>SRD</td>
<td>26.67 (0.69)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>HC</td>
<td>20.07 (0.83)</td>
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<tr>
<td>FQ-CC</td>
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<tr>
<td>ED</td>
<td>21.32 (0.75)</td>
<td>21.834</td>
<td>0.001</td>
<td>0.315</td>
<td>*</td>
<td>-</td>
<td>*</td>
</tr>
<tr>
<td>SRD</td>
<td>27.06 (0.82)</td>
<td></td>
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<tr>
<td>HC</td>
<td>18.68 (1.00)</td>
<td></td>
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<tr>
<td>AESED/AESSA Total</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>ED</td>
<td>37.72 (2.83)</td>
<td>21.741</td>
<td>0.001</td>
<td>0.314</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>SRD</td>
<td>50.00 (3.09)</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>HC</td>
<td>16.69 (3.75)</td>
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<tr>
<td><strong>Negative Caregiving and quality of life</strong></td>
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<td></td>
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<tr>
<td>ECI-Negative Dimension</td>
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<tr>
<td>ED</td>
<td>66.92 (3.68)</td>
<td>36.657</td>
<td>0.001</td>
<td>0.39</td>
<td>*</td>
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<tr>
<td>SRD</td>
<td>83.25 (4.42)</td>
<td></td>
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<tr>
<td>HC</td>
<td>29.54 (4.34)</td>
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<tr>
<td>SF 36-Physical Component</td>
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<tr>
<td>ED</td>
<td>55.64 (0.98)</td>
<td>0.534</td>
<td>0.587</td>
<td>0.01</td>
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<tr>
<td>SRD</td>
<td>55.02 (1.18)</td>
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<tr>
<td>HC</td>
<td>54.08 (1.16)</td>
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<tr>
<td>SF 36-Mental Component</td>
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<tr>
<td>ED</td>
<td>41.87 (1.73)</td>
<td>8.490</td>
<td>0.001</td>
<td>0.13</td>
<td>-</td>
<td>*</td>
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<tr>
<td>SRD</td>
<td>42.92 (2.08)</td>
<td></td>
<td></td>
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<tr>
<td>HC</td>
<td>52.46 (2.04)</td>
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</tbody>
</table>

MANCOVA, multiple analyses of covariance; ED, eating disorder; SRD, substance-related disorder; HC, healthy controls; FQ-EOI, Family Questionnaire Emotional Over-involvement; FQ-CC, Family Questionnaire Criticism; AESED, Accommodation and Enabling Scale for Eating Disorders; AESSA, Accommodation and Enabling Scale for Substance Abuse; ECI, Experience of Caregiving Inventory; SF-36, SF-36 Health Survey.

* Differences between groups after Bonferroni correction at p < 0.05.

Bold values indicate statistically significant differences between ED, SRD and HC group of fathers.
Table 4

Between-Subjects Effects of MANCOVA comparing mothers’ group (ED, SRD, HC) on various aspects of caregiving experiences, after adjusting for hours of contact and for adolescents’ age

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean (SD)</th>
<th>F-value</th>
<th>p</th>
<th>Partial η²</th>
<th>ED vs. SRD</th>
<th>ED vs. HC</th>
<th>SRD vs. HC</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family reactions to illness</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>FQ- EOI</td>
<td>ED 27.14 (0.72)</td>
<td>31.853</td>
<td><strong>0.001</strong></td>
<td>0.299</td>
<td>-</td>
<td>*</td>
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<tr>
<td></td>
<td>SRD 28.69 (0.73)</td>
<td></td>
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<tr>
<td></td>
<td>HC 18.50 (1.06)</td>
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</tr>
<tr>
<td>FQ- CC</td>
<td>ED 22.84 (0.71)</td>
<td>12.199</td>
<td><strong>0.001</strong></td>
<td>0.204</td>
<td>*</td>
<td>-</td>
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<tr>
<td></td>
<td>SRD 26.75 (0.72)</td>
<td></td>
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<tr>
<td></td>
<td>HC 20.76 (1.04)</td>
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<tr>
<td>AESED/AESSA Total</td>
<td>ED 43.44 (2.81)</td>
<td>20.266</td>
<td><strong>0.001</strong></td>
<td>0.401</td>
<td>-</td>
<td>*</td>
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<tr>
<td></td>
<td>SRD 47.03 (2.85)</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>HC 15.82 (4.13)</td>
<td></td>
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</tr>
<tr>
<td><strong>Negative caregiving and quality of life</strong></td>
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<tr>
<td>ECI Negative</td>
<td>ED 78.44 (3.47)</td>
<td>101.31</td>
<td><strong>0.001</strong></td>
<td>0.604</td>
<td>-</td>
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<tr>
<td></td>
<td>SRD 85.46 (3.63)</td>
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<tr>
<td></td>
<td>HC 19.48 (3.56)</td>
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<tr>
<td>SF 36 Physical Component</td>
<td>ED 51.57 (1.20)</td>
<td>1.086</td>
<td>0.340</td>
<td>0.02</td>
<td></td>
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<tr>
<td></td>
<td>SRD 54.17 (1.26)</td>
<td></td>
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<tr>
<td></td>
<td>HC 52.57 (1.23)</td>
<td></td>
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<tr>
<td>SF 36 Mental Component</td>
<td>ED 35.89 (1.60)</td>
<td>26.635</td>
<td><strong>0.001</strong></td>
<td>0.286</td>
<td>-</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td>SRD 40.64 (1.68)</td>
<td></td>
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<tr>
<td></td>
<td>HC 52.15 (1.65)</td>
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</tbody>
</table>

MANCOVA, multiple analyses of covariance; ED, eating disorder; SRD, substance-related disorder; HC, healthy controls; FQ-EOI, Family Questionnaire Emotional Over- involvement; FQ-CC, Family Questionnaire Criticism; AESED, Accommodation and Enabling Scale for Eating Disorders; AESSA, Accommodation and Enabling Scale for Substance Abuse; ECI, Experience of Caregiving Inventory; SF-36, SF-36 Health Survey.

*Differences between groups after Bonferroni correction at p < 0.05.

Bold values indicate statistically significant differences between ED, SRD and HC group of mothers.
Discussion

This aim of this study was to explore the way in which families of adolescent patients with an ED react to their child’s illness, as well as their experience as caregivers and their quality of life, by comparing them with the families of adolescents with a SRD and the families of healthy controls. As we outlined previously, previous studies have identified a need for comparative research on EDs (Zabala et al., 2009). Such research should improve the understanding of factors that differentiate ED from other similar conditions. It could be used to develop intervention programs that target the specific needs of each clinical group in order to improve prognosis and caregiving experiences and maximise quality of life for both families and patients. This study was the first research on EDs to use adolescents with a SRD as a comparison group. It showed that families of ED patients reported lower levels of criticism, symptom accommodation and negative caregiving experience than families of SRD patients. However, relatives of both ED patients and SRD patients reported similar levels of quality of life related to their mental health. Furthermore, families of HCs generally exhibited better scores on all scales assessing their family functioning. Regarding gender differences, there was a tendency in mothers, primarily from the ED group, to report more adverse experiences as caregivers compared to fathers.

One of the strengths of this study is the selection of an adolescent sample. It has been argued that ED research should focus on this developmental stage as it has not been studied thoroughly, despite being noted as stage in which there are important changes in family relationships and functioning (Hoste, Labuschagne, Lock, & Le Grange, 2012; Sim et al., 2009). Given that adolescent patients tend to be living with their parents (Haigh & Treasure, 2003; Whitney & Eisler, 2005), difficulties in the parent-child relationship can emerge during this period and the quality of parent-child interactions play an especially important role in adolescent development and well-being (Oliva, 2006).
Family functioning and quality of life: Clinical groups versus healthy controls

The results provided support for our first hypothesis; the families of both ED and SRD patients reported higher levels of EOI and more accommodation to illness-related behaviours than the families of the healthy adolescents. Similar results were found with respect to negative caregiving experience and quality of life. However, the levels of criticism among mothers and fathers of the ED group did not differ from those expressed by HC carers, confirming the findings of the study by Blair et al. (1995) in which no differences in CC were found between patients with an ED and a control group. In general, our findings are similar to those reported in previous studies comparing EE and caregiving in the families of adult ED patients and healthy controls or patients with other physical or psychological illnesses (Blair et al., 1995; Kyriacou et al., 2008a; Treasure et al., 2001). As only a limited number of studies in this area have been published, it is recommended that further research continue along these lines.

Family functioning and quality of life: ED versus SRD group

Although this is the first study to compare family functioning and quality of life in relatives of patients with an ED with those of patients with a SRD, we expected that relatives would show similar outcomes on these variables. This is due to the fact that previous studies have shown that families respond in similar ways to these two illnesses (Becerra, 2009; Kyriacou et al., 2008a). However, rather than displaying similar levels of family functioning, the families of SRD patients, specifically for the sample of fathers, actually reported more criticism and symptom accommodation than families of ED patients, as well as a more negative caregiving experience. Regarding the sample of mothers, higher levels of criticism were also observed in the SRD group compared to the ED group. The fact that neither hours of contact with the patient, or age of the adolescent, when included in the analyses as covariates, had a significant effect on these variables, would suggest that differences in the family functioning may be explained by the illness-specific characteristics that distinguish SRDs from EDs.
First, a child’s use of illegal substances is often associated with more negative social effects than ED-related behaviours and as a result, a more burdensome caregiving environment. More specifically, criminal activity, stealing money, domestic violence and declining academic performance, which have all been associated with SRDs, may have a devastating effect on the family of a child with a SRD and result in increased societal stigma. Stigmatisation may make it more difficult for the family of a person with SRD to resolve interpersonal conflicts and share relevant experiences with loved ones and experts and this could in turn give rise to inappropriate family responses to the illness, including high levels of EE and symptom accommodation (Ghodse & Galea, 2005). Second, patients with a SRD appear to embrace their reputation for being particularly unmotivated and resistant to change to an even greater extent than patients with EDs; this attitude may make substance abuse a more difficult disorder for families to cope with (Vitousek et al., 1998).

It is also possible that the differences between the two groups could be explained by the family’s attribution of the causes of the illnesses. Greater levels of EE have been associated with relatives attributing the patient’s behaviour to internal factors, controllable by the patient, rather than external ones (Wendel, Miklowitz, Richards, & George, 2000) and studies of other mental illnesses (Perlick et al., 1999; Whitney et al., 2007) have found that when caregivers feel that the patient is responsible for his or her illness, as opposed to external factors, the caregivers tend to report a more negative caregiving experience. In the case of ED, despite citing the patient’s characteristics as the main cause of the illness, relatives have also been found to endorse the belief that other external factors, including family problems, play a role in the illness (Whitney et al., 2007). However, in regards to SRD, there is still question, even among health professionals, whether or not substance abuse is a chosen behavior (Kloss & Lisman, 2003). This is in spite of the fact that research has helped to support the disease model of substance abuse, which recognizes the psychological, biological and behavioural...
components of the illness (National Institute on Drug Abuse, 2012) and points to the possibility that the parents of the SRD patients may not fully understand the complexity of the causes contributing to their child’s illness.

In comparison with previous research on the quality of life of parents of patients with a variety of illnesses, we found that the quality of life of parents of the two clinical groups used in the present study (ED and SRD) was less affected than that of families of patients with OCD (Albert, Salvi, Saracco, Bogetto, & Maina, 2007), families of patients with advanced breast cancer (Grunfeld et al., 2004) and families of patients with schizophrenia (Gutierrez-Maldonado, Caqueo-Urizar, & Kavanagh, 2005). This may be because the patients in our study were younger and had been ill for a shorter period of time. Taking into account the current findings from the perspective of the Maudsley model, which was previously described (Schmidt & Treasure, 2006), it may be suggested that the quality of life of the ED and SRD carer groups in the current study was less affected by the patient’s illness than that of the families of the clinical groups mentioned previously, despite the evidence that the child’s illness had already had a negative impact on other family maintenance factors, such as EE, symptom accommodation and caregiver burden, which are thought to precede deterioration of health and quality of life in caregivers (Sepulveda et al., 2012).

**Family functioning and quality of life: Gender differences**

The results also provided some support for our third hypothesis, which was that mothers of patients would have lower quality of life and report worse family functioning than fathers. Mothers from both patient groups seemed to be more emotionally over-involved than fathers. Furthermore, mothers of ED patients reported more negative caregiving experiences and lower quality of life related to both mental and physical health, compared to fathers. These results only partially support our hypothesis, as there were no gender differences in symptom accommodation, CC, caregiving experience and quality of life in the SRD and HC groups.
These results are consistent with previous studies, using ED samples (Anastasiadou et al., 2016) and other clinical samples, such as dementia (Pinquart & Sörensen, 2006), OCD (Albert et al., 2007) and schizophrenia (Gutierrez-Maldonado et al., 2005), in which female caregivers reported worse quality of life and mental health and a greater caregiving burden than male caregivers. One possible hypothesis behind these gender differences may include the fact that mothers tend to be the primary caregivers, spending more hours of contact with the patient than their fathers. Additional contact hours may imply more responsibility and therefore greater stress on the primary caregiver and more opportunities for negative interactions with the patient. In the case of EDs, a prior study comparing primary and secondary caregiver well-being found that primary caregivers were more responsible for the nutritional aspects of caring for their ED patient, leading them to experience greater levels of anxiety and depression (Sepulveda et al, 2012). An alternate explanation that has been proposed by prior research could be that women use less effective coping styles, such as emotion-focused coping rather than problem-solving strategies, in the face of distress, thereby leading their mental health and quality of life to suffer more than men (Lutzky & Knight, 1994). Overall, these findings also raise some interesting questions about how gender roles influence perceptions of family functioning and health status (Bédard et al., 2005; O'Rourke, 2004).

Limitations

This study has several limitations. First, evaluations were carried out using self-report questionnaires and the results may therefore have been biased by socially desirable responding. In addition, a more careful interpretation of outcomes from self-report questionnaires should be made, given that the psychometric properties of some of them have only been tested among adult samples (i.e. FQ). Another potential limitation is that the evaluation was carried out at a specific moment in time and therefore does not provide information about changes in the variables investigated over the course of an illness; future longitudinal research would provide
useful evidence on how many years of unremitting illness impact family functioning. Furthermore, a bias regarding HC families should be taken into account: Maybe those families willing to participate in the study were the ones who were worried about their daughters’ health status? It is also worth noting that the study used strict exclusion criteria, which may limit the ability to generalize the findings to other patient groups, such as non-restrictive ED patients or patients with comorbid ED and SRD. Furthermore, differences between the samples of carers in regards to their socio-demographic characteristics were at times significant (contact hours, educational level, family constitution, occupational level), which raises questions about the generalizability of the findings. Lastly, it is important to note that the ED group and SRD group differed both in terms of gender and age, that is, the ED group was primarily women and presented an earlier age of onset than the SRD group. This being said, we also feel it necessary to point out that these same differences in clinical characteristics for each group have been widely reported in previous epidemiological studies (Brady & Randall, 1999; Currin, Schmidt, Treasure, & Jick, 2005; Kessler et al., 2007; Kessler et al., 2005).

Implications

More comparative research on ED, using both healthy and clinical control groups, is needed to corroborate the findings reported here. Furthermore, there is a need to assess other factors specific to particular illnesses, which were not taken into account in this study. For example, the social costs of illness may contribute to inappropriate patterns of family interaction and emotional distress, especially in the case of families of patients with SRD. Nevertheless, we feel that our results have implications for family interventions with both ED and SRD patients. The appearance of an ED or SRD has a substantial impact on the relatives of patients, and may result in physical, mental or emotional overload (Orford et al., 2010; Padierna et al., 2013). Our results appear to reinforce the idea that each clinical group is heterogeneous, and we would therefore emphasise that a multidimensional approach should be
used to treat both illnesses. Interventions should be related to the characteristics and interpersonal maintenance factors, which are specific to the illness, and the family should be involved in the treatment process (Copello, Velleman, & Templeton, 2005; NICE, 2004).

Second, our results showed that mothers and fathers of adolescents with an ED or a SRD react negatively to their child’s illness, reporting higher levels of EE and symptom accommodation, a more negative caregiving experience and poorer mental health than the families of healthy adolescents. However, in this study the quality of life of these parents was not as negatively affected by the illness compared to other clinical groups in the literature. This suggests that it may be crucial to intervene in these families in the early stages of the illness in order to reduce EE and symptom accommodation and improve their caregiving experience in the hope of preserving their quality of life and thus preventing complications related to the patient’s illness and treatment.

Acknowledgements

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References


CHAPTER 5: FAMILIES, EATING DISORDERS AND SUBSTANCE ABUSE


SPSS. (2006). *Statistical Package for the Social Sciences (SPSS) software version 15.0*. Chicago, USA.


Chapter 6

Experience of Caregiving and Coping Strategies in Caregivers of Adolescents with an Eating Disorder: A Comparative Study

Parks, M., Anastasiadou, D., Sepulveda, A. R., Sánchez, J. C., & Graell, M.

Submitted for publication to Psychiatry Research on November 21, 2016
Abstract

Caring for a relative with an eating disorder (ED) is associated with heightened psychological distress, which, according to a stress-coping model, may be influenced by coping and appraisal. However, limited quantitative studies have assessed coping in ED caregivers. This cross-sectional study aims to examine the differences in coping between caregivers of adolescent patients with an ED, caregivers of patients with a substance use disorder (SUD) and healthy adolescents (HC) and assess what patient and caregiver variables are associated with coping and appraisal of the caregiving experience. A one-way MANOVA was significant for caregiver group for mothers, but not fathers. ED and SUD mothers used more self-sufficient problem focused coping than HC mothers. Patient caregivers did not significantly differ from HCs in their use of maladaptive strategies. Mothers used more social support strategies than fathers. A positive experience of caregiving was significantly associated with the use of adaptive coping in ED caregivers and a negative experience of caregiving was significantly associated with maladaptive coping in ED mothers. Older ED caregivers were less likely to use maladaptive coping. Future interventions could help ED caregivers to recognize their coping preferences and how to appropriately use these strategies when faced with illness-related stressors.

Keywords: caregiver; carer; eating disorders; substance use disorders; adolescent
CHAPTER 6: EXPERIENCE OF CAREGIVING AND COPING STRATEGIES

Introduction

The past twenty years has seen an increase in the number of studies exploring the experience of caregivers of patients with an eating disorder (ED), revealing that caregivers tend to present heightened levels of psychological distress, caregiver burden and expressed emotion (EE) (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014; Zabala, Macdonald, & Treasure, 2009). This is of particular interest considering that caregiver distress and dysfunctional responses to the illness, such as high EE, may lead to worsening symptoms among patients (Goddard et al., 2013; Treasure & Schmidt, 2013). According to Lazarus and Folkman’s stress-coping model (Folkman, Lazarus, Gruen, & DeLongis, 1986; Lazarus & Folkman, 1984), a caregiver’s coping and appraisal of the caregiving experience play an important role in whether or not caring for an ill relative will have consequences on the caregiver’s psychological health (Szmukler et al., 1996).

Coping refers to both behavioral and cognitive techniques that individuals employ in order to manage (i.e. master, tolerate, or minimize) stress. Several ways of categorizing coping have been proposed (Skinner, Edge, Altman, & Sherwood, 2003). Traditionally, coping research has distinguished between emotion-focused (i.e. doing something to regulate feelings related to the stressor) and problem-focused (i.e. doing something to alter the source of the stress) coping. Nevertheless, other researchers have argued that it is more appropriate to categorize coping in terms of adaptive (engaged) vs maladaptive (avoidant) strategies (Carver & Connor-Smith, 2010; Coomber & King, 2012; Dijkstra & Homan, 2016; Litman, 2006). Using the latter classification, researchers have found that among ED caregivers, greater psychological distress and burden were associated with the use of maladaptive coping (Coomber & King, 2012; Ohara et al., 2016), and that the use of maladaptive coping predicted caregiver burden over time (Coomber & King, 2013).
However, there is a dearth of quantitative research on ED caregiver coping and it remains unclear what factors are associated with the use of different types of coping strategies in this population. A recent study addressing this question found that certain adaptive strategies (i.e. seeking information and positive communication) were correlated with a higher level of education among relatives, while maladaptive (avoidant) strategies were more common among those whose relative had a longer duration of illness (Fiorillo et al., 2016). However, one drawback of this study is that it employed a recently developed instrument designed to assess coping specifically among family caregivers of patients with an ED (Fiorillo et al., 2015), whereas the other six quantitative studies published to date on ED caregiver coping (Coomer & King, 2012, 2013; Lantzouni, Cox, Salvator, & Crosby, 2015; Ohara et al., 2016; Pepin & King, 2013, 2016) have employed two of the most frequently used instruments to assess coping (Kato, 2015), the brief COPE (Carver, 1997) and the Coping Inventory for Stressful Situations (CISS) (Endler & Parker, 1990). Unlike an illness specific instrument, these generic instruments allow researchers to compare results between different groups, which a recent review expressed was needed in future studies on ED caregivers (Anastasiadou et al., 2014). Finally, no studies on ED caregiver coping have assessed how these strategies relate to the caregiver’s appraisal of the caregiving experience, despite the fact that the stress-coping model suggests these two variables are interrelated (Szmukler et al., 1996).

Previous research on coping has revealed gender differences, with men tending to use more problem-focused strategies, whereas women prefer emotion-focused or social-support strategies, even when faced with the same stressor (Ptacek, Smith, & Dodge, 1994). Much of this research has assumed that problem-focused strategies were more adaptive, leading to the conclusion that women employ less effective coping strategies (Lutzky & Knight, 1994). However, the authors of a meta-analysis exploring gender differences in coping found limited
differences between men and women in terms of the types of coping strategies employed, with the exception of social support coping, which women used more frequently (Tamres, Janicki, & Helgeson, 2002).

Only one quantitative study to date exploring ED caregiver coping has used an entirely adolescent sample of patients, but it did not include fathers (Lantzouni et al., 2015). A better understanding of adolescent caregivers is of particular importance considering that Anorexia Nervosa (AN) tends to have an onset in adolescence and a Cochrane review of the effectiveness of family therapy in this patient group suggested that this treatment modality is more effective among younger patients with a shorter duration of illness (Fisher, Hetrick, & Rushford, 2010). Furthermore, previous longitudinal research has shown that ED caregiver’s use of adaptive coping strategies decreases over time, further underlining the importance of assessing caregivers of patients with a shorter illness duration (Coomber & King, 2013). Employing a comparison group of parents of healthy controls (HC) will allow us to assess whether the coping strategies used among ED caregivers are specific to caring for a child with an ED or are related to caring for an adolescent in general. Furthermore, by employing a second comparison group (i.e. caregivers of patients with a substance use disorder, SUD), we will be able to assess whether the use of particular coping strategies, and the factors associated with their use, are unique to caregivers of patients with an ED or may be shared by caregivers of a child with a mental illness with adolescent onset (American Psychiatric Association, 2013).

The present cross-sectional study aims to: 1) evaluate how caregivers of adolescent patients with an ED differ from caregivers of SUD patients and HCs in the frequency of coping strategies used; 2) assess gender differences in the use of coping strategies among these three groups; and 3) explore the association between caregiver and patient variables and
the use of different coping strategies and the appraisal of the caregiving experience in the two patient groups (ED and SUD).

Method

Participants and procedure

The study sample consisted of 48 mothers and 44 fathers of patients diagnosed with an ED, 46 mothers and 36 fathers of patients diagnosed with a SUD and 63 mothers and 50 fathers of healthy adolescents. Families were recruited from October 2011 to July 2014. The inclusion criteria for the patients and healthy adolescents were: 1) 12 to 22 years of age; 2a) for the ED group: presence of an ED according to DSM-IV-TR diagnostic criteria (American Psychiatric Association, 2000) 2b) for the SUD group: presence of an SUD according to DSM-IV-TR diagnostic criteria; 2c) for the HC group: no history of a psychiatric disorder and a body mass index (BMI) of at least 17.5 kg/m². All of the young participants needed to be living with at least one parent and were excluded if they were acutely suicidal. Furthermore, to ensure more homogenous patient samples, patients with comorbid ED and SUD were excluded.

The families of patients with an ED were randomly recruited from the inpatient or outpatient services of an adolescent ED unit (Child and Adolescent Psychiatric Department, Niño Jesus University Hospital, Madrid, Spain). The SUD families were randomly recruited from an adolescent outpatient program dedicated to treating substance abuse and dependence (‘Programa Soporte’ of Proyecto Hombre, Madrid, Spain). Healthy adolescents and their caregivers were recruited from public secondary schools in the region of Madrid. The research was reviewed and approved by an Institutional Review Board (R-009/10). Participation was voluntary, all participants provided written consent and no compensation was provided.

Measures
Demographic variables. Caregivers reported on their age, gender, highest level of education, and current employment status. Their children provided information on their age and gender. Researchers measured weight and height in order to calculate BMI. For the two patient groups, the hours of contact between the caregiver and the patient and the illness duration was also collected.

Diagnostic interview. The adolescents underwent a semi-structured diagnostic interview, The Schedule for Affective Disorders and Schizophrenia for School-Age Children (K-SADS-PL) (Kaufman et al., 1997; Ulloa et al., 2006), in order to ascertain the patient’s current diagnosis, or potential diagnosis in the HCs.

Caregiver coping strategies. The COPE inventory (Carver, Scheier, & Weintraub, 1989), the most frequently used coping scale to date, particularly among caregivers (Kato, 2015), assesses 15 styles of coping and has been translated into Spanish by Crespo and Cruzado (1997). The COPE includes 60 items which are answered on a 4-point Likert scale (from 1 = “usually do not do this at all” to 4 = “usually do this a lot.”). The 15 coping styles can be grouped into four categories as in previous research (Litman, 2006). These are: 1) self-sufficient emotion focused coping (restraint, positive reinterpretation, acceptance, humor, religion); 2) self-sufficient problem focused coping (planning, active coping, suppression of competing activities); 3) socially-supported coping (emotional social support, instrumental social support, venting) and 4) avoidant coping (behavioral disengagement, mental disengagement, denial, substance use). The first three factors are considered “adaptive” strategies while the fourth one is “maladaptive.” Higher scores indicate greater use of the particular strategy. Cronbach’s alphas for the current sample were .87 for self-problem, .79 for self-emotion, .88 for social, and .69 for avoidant coping.

Appraisal of the caregiving experience. The Experience of Caregiving Inventory (ECI) (Szmukler et al., 1996) was completed by ED and SUD caregivers. The ECI is composed of
66-items and is designed to measure how a person caring for someone with a serious mental illness appraises the experience. The ten subscales can be grouped into the ECI-negative (difficult behaviors; negative symptoms; stigma; problems with services; effects on family; need to backup; dependency; and loss) and ECI-positive (rewarding personal experiences; good aspects of relationship with the patient). Responses are on a 5-point Likert scale (ranging from 0 = “never” to 4 = “nearly always”). Higher scores indicate a more positive or negative appraisal of the caregiving experience. The ten scales have been found to have satisfactory reliability with Cronbach’s $\alpha$ ranging from .74 to .91 or the original version and .67 to .90 for the Spanish version (Sepulveda et al., in preparation). The internal reliability coefficients of the current sample were .81 for the ECI-positive and .92 for the ECI-negative.

**Statistical Analyses**

Data were analyzed using the statistical software package SPSS version 20 for Mac and the criterion for significance was set at a $p$ value of .05. Patient and caregiver’s continuous sociodemographic variables were compared using one-way analyses of variance (ANOVAs) followed by post-hoc Tukey’s HSD tests. Caregiver’s categorical sociodemographic information was compared using chi-squared tests. Illness duration and hours of caregiver contact between patient groups was compared using independent $t$-tests.

To explore the effects of caregiver group (ED; SUD; HC) on the frequency of using different coping strategies, one-way multiple analyses of variance (MANOVAs) were carried out, for mothers and fathers separately. The subscales of the COPE were grouped into four factors which were used as dependent variables (socially supported, problem-focused, emotion-focused and avoidant coping) and caregiver group was used as the independent variable. Preliminary checks revealed that there was a violation of the assumption of normality, but given the fact that this was not due to extreme outliers, the choice was made to proceed with the analyses. Pillai’s Trace was used to evaluate multivariate significance
because the homogeneity of covariance matrix assumption was violated, as indicated by significant Box’s M test, and partial eta-squared ($\eta^2$) provided the estimate of effect size. A series of one-way ANOVAs were carried out to further examine univariate main effects of each dependent variable, and post hoc comparisons were carried out with a Bonferroni adjusted $\alpha$ level of .017.

Mann Whitney U-tests were used to explore possible differences between mothers and fathers (separately for each group) on the frequency of using different coping strategies, and on the ECI positive and negative subscales for the two patient caregiver groups (ED; SUD). Finally, the associations between coping strategies, appraisal of the caregiving experience, and caregiver and patient demographic and clinical variables were assessed with Spearman correlations for the two patient caregiver groups.

**Results**

**Clinical and sociodemographic characteristics**

Information concerning the caregiver and patient variables are provided in Table 1. ED caregivers were significantly younger for both mothers [$F (2, 148) = 15.43, p < .001$] and fathers [$F (2, 123) = 6.07, p = .002$]. In regards to average hours of contact per week, both ED mothers [$t (90) = 4.54, p < .001$] and fathers [$t (77) = 3.31, p < .001$] spent significantly more hours of contact with their children. The SUD patients were significantly older than the other two groups [$F (2, 159) = 73.68, p < .001$]. The majority of the patients ($n = 39$) in the ED group warranted a diagnosis of AN-restrictive subtype and the majority of patients with SUD met criteria for multiple substance-related diagnoses.

**Differences in frequency of coping strategies between caregiver group**

The first MANOVA for mothers revealed that the differences between caregiver groups on the combined dependent variables was statistically significant, $F(8, 304) = 2.52, p = .012$; Pillai’s trace = .124, partial $\eta^2 = .06$. Follow-up univariate ANOVAs (Table 2)
### Table 1

**Caregiver and patient variables**

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<tr>
<th></th>
<th>Mothers ED group</th>
<th>Mothers SUD group</th>
<th>Mothers HC group</th>
<th>F or $\chi^2$, p-value</th>
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<td><strong>Age</strong> $M (SD)$</td>
<td>44.88$_a$ (4.61)</td>
<td>49.95$_a$ (4.54)</td>
<td>47.56$_a$ (3.91)</td>
<td>15.43; $p &lt; .001$</td>
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<td>7.96; .019</td>
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<td>Full-time</td>
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<td></td>
<td></td>
<td>6.17; .187</td>
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<td><strong>Fathers ED group</strong></td>
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<td></td>
<td>6.70; .002</td>
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<td><strong>Age</strong> $M (SD)$</td>
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<td>Full-time</td>
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<td>Degree/Technical school</td>
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<tr>
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<td><strong>ED patients</strong></td>
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<td>18.3$_{ab}$ (2.14)</td>
<td>14.39$_b$ (1.41)</td>
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<td>BMI</td>
<td>18.14$_{ab}$ (1.86)</td>
<td>21.34$_a$ (2.12)</td>
<td>21.65$_b$ (2.97)</td>
<td>31.69; $p &lt; .001$</td>
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<td>Duration of Illness$^2$</td>
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<td>24.22 (16.3)</td>
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<td>-4.16; $p &lt; .001$</td>
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<td>BN</td>
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<td>EDNOS</td>
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<td>Substance Dependence</td>
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<td>30 (65.2)</td>
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*Note:* $^1$ Also includes retired, unemployed, and medical leave. $^2$ Refers to months since detection of the illness.

Means in a row sharing subscripts are significantly different from each other. ED = eating disorder, SUD = substance use disorder; HC = healthy controls; BMI = Body Mass Index; AN = Anorexia Nervosa; BN = Bulimia Nervosa; EDNOS = Eating Disorder Not Otherwise Specified.
Table 2
Follow-up univariate analyses of variance (ANOVA) of the coping strategies for the three caregiver groups

<table>
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<th>SUD</th>
<th>HC</th>
<th>F</th>
<th>p</th>
<th>partial η²</th>
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<tr>
<td>Self-sufficient problem focused</td>
<td>31.56 (5.14)</td>
<td>31.95 (5.04)</td>
<td>28.33ab (6.32)</td>
<td>7.05</td>
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<td>.08</td>
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<td>Self-sufficient emotion focused</td>
<td>39.90 (7.18)</td>
<td>39.83 (5.84)</td>
<td>39.52 (6.59)</td>
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<td>.950</td>
<td>.001</td>
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<td>Social support</td>
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<td>31.24a (6.54)</td>
<td>27.02a (5.83)</td>
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<td>.003</td>
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<td>Avoidant</td>
<td>20.46 (3.37)</td>
<td>21.30 (3.15)</td>
<td>20.65 (3.64)</td>
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<tr>
<td>Self-sufficient problem focused</td>
<td>29.27 (7.19)</td>
<td>30.50 (5.85)</td>
<td>29.62 (5.11)</td>
<td>0.42</td>
<td>.658</td>
<td>.01</td>
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<td>Self-sufficient emotion focused</td>
<td>39.45 (7.99)</td>
<td>41.33 (6.97)</td>
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<td>Social support</td>
<td>24.43 (5.93)</td>
<td>26.42 (4.79)</td>
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<tr>
<td>Avoidant</td>
<td>21.52 (3.51)</td>
<td>22.67 (4.93)</td>
<td>21.12 (4.12)</td>
<td>1.49</td>
<td>.230</td>
<td>.02</td>
</tr>
</tbody>
</table>

Note. ED = eating disorder group; SUD = substance use disorder group; HC = healthy controls. Means in a row sharing subscripts are significantly different from each other.

showed that both self-sufficient, problem-focused coping \( F(2, 154) = 7.05, p = .001 \); partial \( η^2 = .08 \) and social support coping \( F(2, 154) = 6.03, p = .003 \); partial \( η^2 = .07 \) were statistically different between the mothers from different groups. Tukey post-hoc tests revealed that for self-sufficient problem-focused coping, the mothers of the ED and SUD groups had statistically higher scores than the mothers of the HC participants \( p = .009; p = .003 \), respectively), but there were no statistically significant differences between the mothers of the ED and SUD group \( p = .938 \). In regards to social support coping, the mothers of the SUD group had statistically higher scores than the HC group \( p = .002 \). However, there were no statistically significant differences between the ED and SUD mothers \( p = .405 \) or the ED and HC mothers \( p = .101 \). Finally, in regards to the groups of fathers, the MANOVA did
not detect any statistically significant differences between caregiver groups on the combined dependent variables, $F(8, 250) = 1.49, p = .162$; Pillai’s trace = .091, partial $\eta^2 = .05$.

**Gender differences in coping styles and caregiver appraisal**

A series of Mann-Whitney U tests were carried out to assess the differences between mothers and fathers on their use of different coping strategies for the three groups (ED, SUD, HC) and caregiver appraisal for the two patient groups (ED, SUD). Mothers and fathers differed significantly in their frequency of using social support coping strategies for the ED ($U = 619.5, z = -3.42, p = .001$), SUD ($U = 460.5, z = -3.44, p = .001$), and HC ($U = 1004, z = -3.31, p = .001$) groups, with mothers using these strategies more than fathers. No other statistically significant difference was found between mothers and fathers in regards to coping strategies for the three groups. Mothers scored significantly higher than fathers on the ECI-positive scale in the ED ($U = 753.5, z = -2.09, p = .037$) and SUD ($U = 520, z = -2.72, p = .007$) groups. Moreover, ED mothers scored significantly higher than fathers on the ECI-negative ($U = 743.5, z = -2.17, p = .03$). No statistically significant differences were found between SUD mothers and fathers on the ECI-negative subscale ($U = 775.5, z = -.28, p = .778$).

**The relationship between coping strategies, caregiver appraisal and caregiver and patient variables**

Table 3 summarizes the correlations between the different variables, separated by patient group (ED or SUD), and mothers and fathers. Avoidant strategies were negatively associated with parent age for the ED mothers ($r_s = -.43$) and ED fathers ($r_s = -.33$) and positively associated with duration of illness for the SUD mothers ($r_s = .35$). A significant negative association was found between self-sufficient emotion focused coping and parent age for SUD fathers ($r_s = -.35$). No other significant associations were found between coping strategies and patient or caregiver variables. However, a significant positive association was
Table 3
Correlations between frequency of coping strategies, ECI scores and sociodemographic/clinical variables for patient caregiver groups (ED and SUD)

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<td>.36*</td>
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### CHAPTER 6: EXPERIENCE OF CAREGIVING AND COPING STRATEGIES

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**Note:** COPE = COPE inventory; ECI = Experience of caregiving inventory. Correlations for caregivers of ED patients are presented below the diagonal, correlations for caregivers of SUD patients are presented above the diagonal.

* $p < .05$

** $p < .01$
found between adaptive strategies and the ECI-positive among ED parents \( (r_s = .35-.59 \text{ for mothers, } r_s = .35-.43 \text{ for fathers}) \), but among SUD parents only some of the adaptive strategies (self-sufficient emotion focused coping for mothers and social support for fathers) were significantly positively associated with the ECI-positive scores \( (r_s = .42 \text{ for mothers; } r_s = .38 \text{ for fathers}) \). Finally, the ED mother’s use of avoidant coping strategies was positively associated with higher ECI-negative scores \( (r_s = .51) \), however, this was not found among ED fathers or SUD parents.

**Discussion**

The first objective of the present study was to explore whether caregivers of ED patients differed from two other groups of caregivers in their use of coping strategies. Both ED and SUD mothers used self-sufficient, problem-focused coping more than HC mothers. This category of coping comprises planning, active coping and suppression of competing activities. In general, these strategies tend to be considered “adaptive” since the person is doing something to deal with the stressor rather than to withdraw (i.e. avoidant coping) (Litman, 2006). However, it is important to consider how this type of coping may be problematic when the “stressor” that needs to be coped with is having an adolescent with a mental illness. In the case of ED caregivers in particular, many report they do not possess enough information about EDs (Haigh & Treasure, 2003), which is a prerequisite for planning. Furthermore, an example of active coping is “I take additional action to try to get rid of the problem,” which could lead parents to engage in unhelpful responses to their adolescent’s illness such as criticism, hostility and overinvolvement, which are reflected in the high levels of EE reported among ED caregivers (Anastasiadou et al., 2014; Sepulveda et al., 2010), and may serve to worsen ED symptoms (Anastasiadou et al., 2016b; Treasure & Schmidt, 2013). Finally, suppression of competing activities could lead caregivers to ignore
the importance of taking time out from their caregiving responsibilities to focus on their own self-care (Treasure, Whitaker, Whitney, & Schmidt, 2005).

The awareness that caregivers of patients with a mental illness may use this class of strategies more frequently could serve to guide caregiver interventions. The ability of the Maudsley Collaborative Care Skills Training Workshop (Goddard et al., 2011; Pepin & King, 2013; Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008) and related interventions (Hibbs et al., 2015) to improve caregiver and patient outcomes (Gutiérrez, Sepulveda, Anastasiadou, & Medina-Pradas, 2014; Treasure & Nazar, 2016) may be in part due to their ability to use ED caregiver’s natural tendency towards problem-focused coping in a way that allows them to more effectively employ these strategies. The Maudsley workshops in particular provide caregivers with additional information about the problem they are faced with (i.e. psychoeducation, communication skills), to demonstrate how taking a step back may actually lead to symptom reduction, and helps them to focus on their own well-being (Sepulveda et al., 2008; Treasure, Smith, & Crane, 2007). Two studies have found that this intervention decreases maladaptive coping (Pepin & King, 2013, 2016), but due to the way that coping strategies were categorized, we were unable to ascertain how problem-focused coping was affected.

The only other significant difference for mothers was in regards to social support coping, with SUD mothers employing this type of strategy more frequently than HC mothers. This finding was not replicated between the ED and HC mothers. Previous research has suggested that social support serves as a buffer against the harmful effects of stress (Joyce et al., 2003; Litman & Lunsford, 2009). Research on this aspect of the caregiving experience in EDs is limited, but suggests that ED caregivers view support and understanding from others as essential (Winn, Perkins, Murray, Murphy, & Schmidt, 2004) and has highlighted the importance of distinguishing between the quantity and quality (i.e. level of satisfaction) of
social support (Coomber & King, 2013). The finding that SUD caregivers employ social strategies more than HCs is particularly interesting considering that previous research suggests that the support networks of patient caregivers may diminish as the patient’s illness progresses (Anderson, Hogarty, Bayer, & Needleman, 1984). One possible explanation could be that parents who participate in their adolescent’s treatment receive encouragement to seek social support (Selbekk, Sagvaag, & Fauske, 2015).

Regarding the father groups, no statistically significant differences were found. That is, fathers of ED patients did not use adaptive or maladaptive coping strategies more or less frequently than SUD or HC fathers. Furthermore, no differences were found between the ED mothers and SUD mothers in regards to their use of different coping strategies, nor did they differ from the mothers of healthy adolescents in terms of their use of self-sufficient emotion focused, socially supported or avoidant coping strategies. One explanation for the similarities between the patient and HC caregivers may be that although caring for a healthy adolescent is in many ways distinct from caring for a child with a mental illness, it may still be considered a stressor by a number of parents. Adolescence is a period associated with numerous physical, cognitive, emotional and social changes for the child, as well as changes to the child-parent relationship, which may affect parents (Steinberg, 2001). Although not all parents experience an increase in outright parent-child conflict when their child is an adolescent (Laursen, Coy, & Collins, 1998), some do experience the rejection of values and rules that comes with this developmental stage as a rejection of their own parenting (Steinberg, 2001). These considerations are important to take into account for future research employing healthy controls.

The second aim of the study was to examine gender differences in coping strategies. The results of the present study demonstrated that mothers of all groups used social support coping significantly more than fathers. This replicates the results of a meta-analysis exploring
sex differences in coping behavior (Tamres et al., 2002), which the authors hypothesize could be a result of both gender socialization and biological differences between the sexes. Furthermore, gender differences were also found on the ECI subscales with ED mothers scoring higher than fathers on both scales. That is, these mothers detected more negative aspects, as well as positive aspects, of the caregiving experience than fathers. These findings add support to previous research which has argued for the inclusion of fathers in research and the consideration of possible gender differences in clinical interventions (Anastasiadou, Cuellar-Flores, Sepulveda, Parks, & Graell, 2016a).

Finally, the present study aimed to identify patient and caregiver variables that may be associated with the use of particular coping strategies and the appraisal of the caregiving experience in the patient caregiver groups. In regards to demographic and clinical variables, the only one which was associated with coping strategies in the ED caregiver group was that of parent’s age and avoidant coping with the use of avoidant strategies decreasing as parent’s age increased. One tentative explanation for this could be that experience has taught older parents that avoidant coping strategies are not effective (Aldwin, 1991). An interesting association emerged in terms of the relationship between appraisal of the caregiving experience and type of coping strategies used. The ED mother’s use of avoidant coping strategies was associated with higher ECI-negative scores, although this was not found among the group of fathers. This may be related to the fact that women tend to use avoidant strategies more frequently than men when the stressor is interpreted as more severe (Tamres et al., 2002). No previous studies have explored the relationship between a positive caregiving experience and coping strategies in ED caregivers. According to the present findings, in the case of both mothers and fathers of this patient group, greater use of adaptive coping strategies was associated with the identification of more positive aspects of the caregiving experience. Items from the ECI-positive scales, such as "I have discovered
CHAPTER 6: EXPERIENCE OF CAREGIVING AND COPING STRATEGIES

strengths in myself,” tap into an underexplored concept in ED caregiver research (Anastasiadou et al., 2014), but which has gained considerable attention in the fields of positive psychology (Seligman & Csikszentmihalyi, 2000) and clinical psychology (Hayes, Beevers, Feldman, Laurenceau, & Perlman, 2005). Future longitudinal studies are needed to clarify whether the ECI-positive is measuring an outcome of the coping process or another type of coping strategy (Park, 2010).

The present study is not without its limitations. First, the cross sectional nature of the study does not allow us to draw conclusions about the stability of coping strategies and appraisal of the caregiving experience over time. An additional limitation of the present study is that coping was measured via self-report questionnaires, which may be influenced by social desirability and therefore may not be an accurate indicator of how caregivers actually respond when faced with a stressor. Finally, it may be that parents who employ problem-focused coping strategies are more likely to help their adolescent seek treatment, to be engaged in their child’s treatment, or to participate in a research study. Future studies employing larger community based samples could explore this possibility.

To our knowledge, this was the first study to use a widely utilized instrument, the COPE inventory, to assess coping strategies among caregivers of patients with an ED and compare them with caregivers of healthy adolescents and those caring for a child with another mental illness. The use of an exclusively adolescent sample of patients with an ED, as well as the recruitment of both mothers and fathers, adds to the strength of the present study. The current study suggests that ED caregivers do not notably differ from caregivers of healthy adolescents, although they do favor strategies which could be counterproductive if they are not partnered with information about EDs and caregiver self-care. Considering that many ED caregivers report that they feel incapable of helping with the illness, it is possible that treatment interventions may benefit from informing caregivers of the coping strategies
they already have in their possession and discussing ways in which these may help them in the face of their child’s illness.

**Acknowledgements**

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References


CHAPTER 6: EXPERIENCE OF CAREGIVING AND COPING STRATEGIES


Chapter 7

Psychiatric Comorbidity and Maternal Distress Among Adolescent Eating Disorder Patients: A Comparison with Substance Use Disorder Patients


CHAPTER 7: COMORBIDITY IN ADOLESCENT EATING DISORDER PATIENTS

Abstract

High rates of comorbidity are found among eating disorder (ED) patients, which may negatively affect treatment outcome and prognosis. However, there is a shortage of studies in Spain using clinician administered interviews to assess rates of comorbidity among these patients, particularly in adolescents. This study aimed to evaluate Axis I psychiatric diagnoses in adolescent patients with an ED and to compare them with patients with a distinct disorder with adolescent onset, substance use disorder (SUD) patients. Considering that maternal psychological distress is another factor involved in ED prognosis, a secondary aim was to examine the relationship between patient's psychological variables and maternal distress (depression and anxiety). The cross-sectional study included 50 ED patients, 48 SUD patients, and their mothers. More than half of the patients received a diagnosis for a comorbid disorder. Internalizing problems were more common among EDs and externalizing disorders were the most common comorbidities among SUDs, similar to findings from other countries. Maternal distress was associated with higher levels of depression and symptom severity in patients. No differences in distress were found between mothers of patients with a comorbid diagnosis and those without. Elevated anxiety or depression in mothers did not increase the likelihood of patients having a particular primary diagnosis. In short, while both ED and SUD patients presented high rates of comorbidity, the types of comorbid diagnoses were specific to each group. Assessing for the presence of comorbid disorders and targeting maternal psychological distress may guide treatment interventions and improve patient prognosis.

Keywords: Eating disorders; Substance use disorders; Comorbidity; Caregivers; Diagnostic interview; Adolescents
CHAPTER 7: COMORBIDITY IN ADOLESCENT EATING DISORDER PATIENTS

Introduction

Eating disorders (EDs) are chronic mental illnesses, with a typical onset during adolescence or early adulthood (American Psychiatric Association, 2013), and significantly elevated mortality rates, particularly in the case of Anorexia Nervosa (AN) (Arcelus, Mitchell, Wales, & Nielsen, 2011). Another group of chronic, life threatening mental illnesses with a similar age of onset are substance use disorders (SUDs) (Oyefeso, Ghodse, Clancy, Corkery, & Goldfinch, 1999; Smink, van Hoeken, & Hoek, 2012). Both present a long recovery process (American Academy of Pediatrics, 2011) and high risk of poor prognosis (American Academy of Pediatrics, 2011; Steinhausen, 2002). Furthermore, they share a multifactorial etiology, involving a combination of genetic, biological and personality vulnerabilities that interact with environmental factors (Davis & Claridge, 1998; Emmelkamp & Vedel, 2012; Fairburn & Harrison, 2003; Klump, Bulik, Kaye, Treasure, & Tyson, 2009).

Both EDs and SUDs present high rates of comorbidity, with 40 to 98% of AN patients in particular (Blinder, Cumella, & Sanathara, 2006; Bühren et al., 2014; Salbach-Andrae et al., 2008), and 40 to 90% of SUD patients (Armstrong & Costello, 2002; Chan, Dennis, & Funk, 2008; Langenbach et al., 2010; Shrier, Harris, Kurland, & Knight, 2003) reporting a comorbid Axis I diagnosis. The most frequent comorbid diagnoses among ED patients are mood disorders, followed by anxiety disorders and obsessive-compulsive disorder (OCD) (Blinder et al., 2006; Bühren et al., 2014; Jordan et al., 2008; Salbach-Andrae et al., 2008). In SUD patients, conduct disorder (CD) and oppositional defiant disorder (ODD) are the most frequent comorbid diagnoses, although a strong association has been found with depression (Armstrong & Costello, 2002; Chan et al., 2008; Couwenbergh et al., 2006), a weaker one with anxiety (Armstrong & Costello, 2002; Chan et al., 2008), and an ascending trend of comorbidity rates have been found with attention-deficit/hyperactivity disorder (ADHD) as well (Couwenbergh et al., 2006).
A recent study highlighted the need for additional research on comorbidity rates among adolescents ED patients, particularly those with AN, as the majority of research to date has involved adult samples despite the fact that ED onset typically takes place during adolescence (Bühren et al., 2014). Psychiatric comorbidity appears to be associated with worse long term prognosis for both SUD (Grella, Hser, Joshi, & Rounds-Bryant, 2001) and ED (Herpertz-Dahlmann et al., 2001). While information regarding rates of comorbidity and common comorbid diagnoses may aid mental health professionals working with these patients, in Spain in particular, very few studies have assessed rates of psychiatric comorbidity in either patient sample (Couwenbergh et al., 2006; Godart, Flament, Perdereau, & Jeammet, 2002; Godart et al., 2007). Furthermore, the use of diagnostic interviews to assess prevalence rates of EDs is relatively recent in Spain (Peláez Fernández, Raich Escursell, & Labrador Encinas, 2010) in spite of the fact that semi-structured diagnostic interviews have long been considered the “gold-standard” for assessing the presence of psychiatric disorders as they are more reliable than other forms of assessment (Jewell, Handwerk, Almquist, & Lucas, 2004; Peterson, Ranson, & Hodgins, 2014).

Research on both EDs and SUDs have seen a shift in recent years, taking into consideration not only the patient, but the family as well (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014; Templeton, Velleman, & Russell, 2010), revealing that family members report increased levels of stress and strain (Orford, Velleman, Copello, Templeton, & Ibanga, 2010; Treasure et al., 2001). Within the field of ED research, this distress is one component of the interpersonal maintenance model of AN (Treasure & Schmidt, 2013), which provides a theoretical framework for understanding the relationship between patient and family variables. This model posits that the high levels of distress reported by family members may be risk factors preceding illness onset, as well as maintenance factors which influence prognosis (Anastasiadou, Cuellar-Flores, Sepulveda, Parks, & Graell, 2016; Treasure et al.,
2008). To date, studies assessing the distress experienced by ED family members have not used exclusively adolescent samples and most do not include a comparison group, which makes it difficult to know if the relationship between patient and family variables are unique to ED or are generalizable to family members of patients with other chronic mental illnesses (Anastasiadou et al., 2014). There is reason to believe that the latter may be true considering that the broader literature on child and adolescent psychopathology suggests that there is an association between mother’s mental health and their children’s behavioral problems and emotional functioning (Goodman et al., 2011).

The primary objective of this study was to use semi-structured diagnostic interviews to assess rates of psychiatric Axis I comorbidities in treatment-seeking adolescent ED and SUD patients and to compare these two groups on the type and frequency of psychiatric diagnoses, and other sociodemographic variables. A secondary objective was to assess the relationship between patients’ psychological variables and mothers’ levels of distress.

In regards to our hypotheses, we predicted that the rates of comorbidity and types of comorbidity for both groups would be similar to those found in prior studies carried out in other Western countries with treatment seeking adolescents (i.e. more internalizing problems in the ED group and more externalizing problems in the SUD group). We also expected to find an association between mother and patient variables in both groups, independent of the patient’s primary diagnosis.

**Method**

**Participants**

Forty-nine females and 1 male (Mean age = 14.8; SD = 1.8, Range: 12-18) diagnosed with an ED were compared with 8 females and 40 males (Mean age = 18.2; SD = 2.2, Range: 13-23) diagnosed with a SUD. The patients’ mothers were also enrolled in this study.
CHAPTER 7: COMORBIDITY IN ADOLESCENT EATING DISORDER PATIENTS

Procedure

A cross-sectional study with a descriptive and comparative design was carried out. The inclusion criteria for patients were: 1) 12 to 23 years old; 2a) for the ED group: presence of an ED according to DSM-IV-TR diagnostic criteria, 2b) for the SUD group: presence of a SUD according to DSM-IV-TR diagnostic criteria, 3) living with at least one parent. Patients were excluded if they had a diagnosis of psychosis, a learning disability, a neurologic disease or a disease affecting metabolic regulation (i.e. diabetes, hyperthyroidism) or comorbid ED and SUD. Data were collected from October 2011 to July 2014. The research was reviewed and approved by an institutional review board (R-009/10), all participation was voluntary and participants provided informed consent.

ED patients and their mothers were randomly recruited from consecutive admissions to inpatient and outpatient services at the Eating Disorders Unit of the Child and Adolescent Psychiatric Department of the Niño Jesus University Hospital, Madrid, Spain. A total of 53 patients were approached for the study, one female and one male patient with comorbid SUD were not approached. Two of the patients who were approached declined participation due to distrust regarding confidentiality of their personal information. Then, three of the authors (D.A., M.P. & M.G.) carried out semi-structured clinical interviews and one patient was excluded because she presented psychotic symptoms.

SUD patients and their mothers were randomly recruited from the adolescent outpatient clinic of “Programa Soporte” (Support Program), which is part of Proyecto Hombre, an association based in Madrid which provides treatment to adolescents and young adults with substance abuse and dependence related problems, as well as their families. Forty-eight of the 55 families who were invited to participate provided informed consent and underwent the semi-structured clinical interview carried out by D.A. Seven families declined participation due to lack of time and/or distrust regarding the confidentiality of their personal information. Two
adolescents (one female and one male) had comorbid ED and were not approached. All SUD patients that were interviewed met the selection criteria and were included in the study. Following the interview, patients and their mothers completed a set of self-report instruments detailed below.

**Instruments**

**Patients and Mothers**

Demographic and clinical characteristics were collected using a clinical interview designed for the specific purposes of the study. Mothers provided their age, education level, marital status, employment situation and history of psychiatric illness. Age, gender and illness duration was collected from all patients. The researcher conducting the interview measured the weight and height of the patient in order to calculate BMI.

The Schedule for Affective Disorders and Schizophrenia for School-Age Children (K-SADS-PL) (Kaufman et al., 1997) is a semi-structured diagnostic interview capable of generating 32 DSM-IV Axis I child psychiatric diagnoses. It consists of an introductory interview, diagnostic interview and supplementary diagnostic interview questions, which are administered when deemed relevant. The interview was carried out in the presence of the patient and responses were confirmed with mothers if the interviewer had doubts. The interview has been validated for use in Spain (De la Peña et al., 2002; Ulloa et al., 2006) and a pilot study proposed the extension of the K-SADS to young adults aged 18-25 years, although results have not yet been published (National Institute of Mental Health, 2016). For the current study we only considered current episodes of mental disorders.

**ED patients**

The Eating Attitudes Test (EAT-26) (Garner, Olmsted, Bohr, & Garfinkel, 1982) is a 26-item questionnaire with a six-point Likert-type scale (range 0–5) used to assess disordered eating behaviors. Scores of 20 or more indicate ED pathology although these scores alone
cannot yield a specific ED diagnosis. The questionnaire is highly reliable and valid (Garner et al., 1982) and its Spanish version has demonstrated satisfactory psychometric properties (Castro, Toro, Salamero, & Guimerá, 1991).

**SUD patients**

The *Drug Abuse Screening Test* (DAST-20) (Skinner & Goldberg, 1986) consists of 20 items scored on a two-point Likert scale (1 = yes, 0 = no). It measures problematic drug use and associated consequences and a total score of six or above suggests possible drug abuse (Skinner & Goldberg, 1986). The questionnaire has shown good internal consistency (Saltstone, Halliwell, & Hayslip, 1994; Skinner, 1982) with Cronbach’s alpha of .84 and .78 for men and women, respectively. The instrument has been validated in Spain in an adult population (Pérez Gálvez, García Fernández, de Vicente Manzanaro, Oliveras Valenzuela, & Lahoz Lafuente, 2010) and is considered valid and reliable.

**For both patients and their mothers**

The *Hospital Anxiety and Depression Scale* (HADS) (Zigmond & Snaith, 1983), is designed to detect the presence and severity of anxiety and depression in both adults and adolescents (White, Leach, Sims, Atkinson, & Cottrell, 1999). It is comprised of 14 items, scored on a four-point Likert-type scale. While the factor structure has been debated, several studies exploring the psychometric properties of the Spanish version of the instrument have confirmed a two-factor structure (Terol-Cantero, Cabrera-Perona, & Martín-Aragón, 2015). The items are equally distributed in two subscales: anxiety (7 items) and depression (7 items). Scores of 11 or more on each subscale indicate probable anxiety or depression. The original version of the instrument obtained satisfactory reliability, with Cronbach’s alpha of .86 for each subscale. The Spanish version has shown satisfactory internal consistency of .86 for the anxiety subscale and .87 for the depression subscale (Herrero et al., 2003).
Statistical analysis

Data were analyzed using SPSS 20.0 (SPSS, 2011) for Windows and the criterion for significance was set at $p$ value of 0.05. Kolmogorov–Smirnov tests confirmed that the data followed a normal distribution and parametric tests were used. The patients’ continuous sociodemographic and clinical data were compared using independent samples $t$-test. Patients’ categorical sociodemographic and clinical variables and mothers’ sociodemographic variables were described using contingency tables and compared using $\chi^2$ test or Fisher exact test, as appropriate. When comorbidity with a specific DSM-IV Axis I disorder was absent in one of the two groups, no $\chi^2$ test or Fisher exact test was performed. The relationship between the patients’ scores on psychological measures and mothers’ HADS scores was investigated using Pearson’s correlation coefficient, separately for each group of patients. The relationship between mother’s HADS scores and having a child with a comorbid disorder was explored using independent sample $t$-tests.

A series of logistic regression analyses were performed to identify which of the psychiatric comorbidities had a significant independent association with the likelihood that patients belonged to either the ED or SUD group. Mothers’ anxiety and depression were also each entered into a model as possible predictor variables and were categorized using HADS suggested cut-off points: absence of or low levels of anxiety/depression ($0 = \text{HADS-Anxiety/HADS-Depression} < 11$) and probable presence of anxiety/depression ($1 = \text{HADS-Anxiety/HADS-Depression} \geq 11$). Axis I disorders were grouped into three main categories (unipolar mood disorders, anxiety disorders, ADHD). Disruptive behavior disorders (CD, ODD) were not included as a predictor variable due to the complete absence of this type of comorbidity in the ED group. All independent variables were categorical ($0 = \text{absence of psychiatric comorbidity}; 1 = \text{presence of psychiatric comorbidity}$).
Results

Demographic and clinical data

Detailed demographic and clinical data for the patients is provided in Table 1. In regards to the mother’s sociodemographic data, ED mothers had a mean age of 44.9 (SD = 4.6), the majority (52.1%) had completed higher education, 83.3% were married or living with their partner and 72.3% had a full- or part-time job. SUD mothers had a mean age of 49.6 (SD = 4.9), the majority (66%) had completed higher education, 78.7% were married or living with their partner and 78.7% had a full- or part-time job. All of the mothers were living with their son/daughter. Finally, 25% of the ED mothers and 21.3% of the SUD mothers reported having a psychiatric history ($\chi^2 (1) = 0.19, p = .667$).

Psychiatric comorbidity

Table 2 shows the DSM-IV Axis I comorbidities in the ED and SUD groups. A total of 66% of the ED patients and 68.8% of the SUD patients received a diagnosis of a comorbid disorder. The most common diagnosis among the ED group was major depressive disorder (66%), which was significantly higher than in the SUD group ($\chi^2 = 7.20, p = .007$). Anxiety disorders were present in 32% of ED patients and in 4.2% of SUD, with no statistically significant differences between groups. Similarly, both groups reported the same rates of simple phobia, but the type of phobia differed, with 1 case of nyctophobia in the ED group and 1 case of claustrophobia in the SUD group. Externalizing disorders (ADHD, CD and ODD) were the most common comorbidities among the SUD group (73%). ADHD was the only one of these disorders seen in the ED group (6%), and its prevalence was significantly lower than in the SUD group ($\chi^2 = 11.71; p = .001$). All ED patients with a comorbid diagnosis were female. In the SUD group, 7 females presented a comorbid diagnosis of either depression (n = 4), ADHD (n = 1), CD (n = 1) or ODD (n = 1).
## Table 1

**Sociodemographic and clinical data of young participants**

<table>
<thead>
<tr>
<th></th>
<th>ED group (N = 50)</th>
<th>SUD group (N = 48)</th>
<th>All (N = 98)</th>
<th>t-test or χ² test</th>
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<tr>
<td><strong>Mean (SD)</strong></td>
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<tr>
<td>Age (years)</td>
<td>14.78 (1.79)</td>
<td>18.19 (2.17)</td>
<td>16.45 (2.61)</td>
<td>t = -8.5, p &lt; .001</td>
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<td>Illness duration (months from detection)</td>
<td>15.22 (11.79)</td>
<td>33.96 (21.01)</td>
<td>24.40 (19.31)</td>
<td>t = -5.47, p &lt; .001</td>
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<td>Treatment duration (weeks)</td>
<td>19.73 (39.91)</td>
<td>27.32 (26.63)</td>
<td>23.45 (34.10)</td>
<td>t = -1.09, p = .278</td>
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<td>Body Mass Index (kg/m²)</td>
<td>18.14 (1.82)</td>
<td>21.34 (2.12)</td>
<td>19.39 (2.50)</td>
<td>t = -7.29, p &lt; .001</td>
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<tr>
<td><strong>N (%)</strong></td>
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<tr>
<td>Sex</td>
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<tr>
<td>Female</td>
<td>49 (98.0%)</td>
<td>8 (16.7%)</td>
<td>57 (58.2%)</td>
<td>χ² = 66.58, p &lt; .001</td>
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<td>Male</td>
<td>1 (2.0%)</td>
<td>40 (83.3%)</td>
<td>41 (41.8%)</td>
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<td>Anorexia Nervosa Restrictive type</td>
<td>39 (78.0%)</td>
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</tr>
<tr>
<td>Bulimia Nervosa Non Purging type</td>
<td>3 (6.0%)</td>
<td>0</td>
<td>3 (3.1%)</td>
<td></td>
</tr>
<tr>
<td>Eating Disorder Not Otherwise Specified (Restrictive type)</td>
<td>0</td>
<td>6 (12.5%)</td>
<td>6 (6.1%)</td>
<td></td>
</tr>
<tr>
<td>Alcohol Abuse</td>
<td>0</td>
<td>47 (97.9%)</td>
<td>47 (48%)</td>
<td></td>
</tr>
<tr>
<td>Substance (Cannabis) Abuse</td>
<td>0</td>
<td>30 (62.5%)</td>
<td>30 (30.1%)</td>
<td></td>
</tr>
<tr>
<td>Substance (Cannabis) Dependence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Mothers’ distress and patients’ variables

In both groups, significant correlations were found between mother’s HADS scores (anxiety and depression subscales) and nearly all patient psychological variables (Table 3). The exception was patient’s anxiety scores, which were not significantly associated with mothers’ HADS scores. Mothers of children with a comorbid disorder and those with only a primary diagnosis of ED or SUD did not differ in their HADS anxiety ($t(91) = -.41, p = .686$) or depression scores ($t(91) = -.85, p = .396$).

Table 2

<table>
<thead>
<tr>
<th>Comorbid DSM-IV Axis I diagnoses (K-SADS) for each patient group</th>
<th>ED group N = 50</th>
<th>SUD group N = 48</th>
<th>All patients N = 98</th>
<th>$\chi^2$-test or Fisher Exact test</th>
<th>$p$-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any Axis I diagnosis</td>
<td>33 (66.0%)</td>
<td>33 (68.8%)</td>
<td>66 (67.3%)</td>
<td>$\chi^2 = 0.84, p = .772$</td>
<td></td>
</tr>
<tr>
<td>Major depressive disorder</td>
<td>28 (56.0%)</td>
<td>14 (29.2%)</td>
<td>42 (42.9%)</td>
<td>$\chi^2 = 7.20, p = .007$</td>
<td></td>
</tr>
<tr>
<td>Dysthymic disorder</td>
<td>1 (2.0%)</td>
<td>0</td>
<td>1 (1.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Panic disorder without agoraphobia</td>
<td>7 (14.0%)</td>
<td>0</td>
<td>7 (7.1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Panic disorder with agoraphobia</td>
<td>1 (2.0%)</td>
<td>0</td>
<td>1 (1.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simple phobia</td>
<td>1 (2.0%)</td>
<td>1 (2.1%)</td>
<td>2 (2.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social phobia</td>
<td>2 (4.0%)</td>
<td>0</td>
<td>2 (2.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generalized anxiety disorder</td>
<td>2 (4.0%)</td>
<td>1 (2.1%)</td>
<td>3 (3.1%)</td>
<td>$p = .999$</td>
<td></td>
</tr>
<tr>
<td>Separation anxiety disorder</td>
<td>3 (6.0%)</td>
<td>0</td>
<td>3 (3.1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obsessive-compulsive disorder</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attention-deficit/hyperactivity disorder</td>
<td>3 (6.0%)</td>
<td>16 (33.3%)</td>
<td>19 (19.4%)</td>
<td>$\chi^2 = 11.71, p = .001$</td>
<td></td>
</tr>
<tr>
<td>Conduct disorder</td>
<td>0</td>
<td>9 (18.8%)</td>
<td>9 (9.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oppositional defiant disorder</td>
<td>0</td>
<td>10 (20.8%)</td>
<td>10 (10.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-harm/Suicidal ideation</td>
<td>20 (40.0%)</td>
<td>14 (29.8%)</td>
<td>34 (34.7%)</td>
<td>$\chi^2 = 1.27, p = .260$</td>
<td></td>
</tr>
<tr>
<td>Self-harm/Suicidal intention</td>
<td>7 (14.0%)</td>
<td>4 (8.3%)</td>
<td>11 (11.2%)</td>
<td>$\chi^2 = 0.79, p = .374$</td>
<td></td>
</tr>
<tr>
<td>Self-harm/Suicide attempts</td>
<td>8 (16.0%)</td>
<td>8 (16.7%)</td>
<td>16 (16.3%)</td>
<td>$\chi^2 = 0.01, p = .929$</td>
<td></td>
</tr>
</tbody>
</table>
Table 3

Pearson correlations between mothers’ HADS scores and patients’ scores on psychological measures

<table>
<thead>
<tr>
<th>Measures</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EDs (N=48)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(1) HADS-Depression/child</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) HADS-Anxiety/child</td>
<td></td>
<td>.75***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3) EAT-26/child</td>
<td></td>
<td>.62***</td>
<td>.66***</td>
<td></td>
</tr>
<tr>
<td>(4) HADS-Depression/mothers</td>
<td>.30*</td>
<td>.20</td>
<td>.38**</td>
<td></td>
</tr>
<tr>
<td>(5) HADS-Anxiety/mothers</td>
<td>.29*</td>
<td>.27</td>
<td>.49***</td>
<td>.73***</td>
</tr>
<tr>
<td><strong>SUDs (N=38)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(1) HADS-Depression/child</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) HADS-Anxiety/child</td>
<td></td>
<td>.67***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3) DAST-20/child</td>
<td></td>
<td>.48**</td>
<td>.55***</td>
<td></td>
</tr>
<tr>
<td>(4) HADS-Depression/mothers</td>
<td>.52***</td>
<td>.26</td>
<td>.34*</td>
<td></td>
</tr>
<tr>
<td>(5) HADS-Anxiety/mothers</td>
<td>.46**</td>
<td>.19</td>
<td>.31*</td>
<td>.75***</td>
</tr>
</tbody>
</table>

*Note.* HADS-Depression/child=Hospital Anxiety and Depression Scale-Depression subscale for group of adolescents listed in heading (ED or SUD); HADS-Anxiety/child=Hospital Anxiety and Depression Scale-Anxiety subscale/child; EAT-26/child=Eating Attitudes Test for group of adolescents listed; HADS-Depression/mothers=Hospital Anxiety and Depression Scale-Depression subscale/group of mothers; HADS-Anxiety/mothers=Hospital Anxiety and Depression Scale-Anxiety subscale/group of mothers; DAST-20/child=Drug Abuse Screening Test for SUD patients.

* p < .05

** p < .01

*** p < .001

Prediction of patient group based on mothers’ HADS scores and Axis I comorbidities

Table 4 presents results of the two logistic regressions with ED as a reference category. The first model was carried out to ascertain the effects of mothers’ depression and the presence of one of the three most prevalent Axis I comorbidities (mood disorders, anxiety disorders, and ADHD) on the likelihood that patients belonged to the ED or SUD group. The logistic regression model was statistically significant, \( \chi^2 (4) = 25.36, p < .001 \). It explained 34% (Nagelkerke \( R^2 \)) of the variance in the ED group and correctly classified 71.3% of cases. Anxiety disorders were 6.1 times more likely and mood disorders were 2.9 times more likely to co-occur with an ED. However, ADHD was associated with a reduction in the likelihood of
belonging to the ED group (5 times less likely). When SUD was used as a reference category, as expected, ADHD was 6.4 times more likely to co-occur with SUD, and mood and anxiety disorders were associated with a reduction in the likelihood of belonging to the SUD group (2.9 and 6.2 times, respectively). Similarly, when mothers’ anxiety was entered in a new logistic regression model to replace mothers’ depression, the model proved to be statistically significant, \( \chi^2 (4) = 25.18, p < .001 \). It explained 32% (Nagelkerke \( R^2 \)) of the variance and correctly classified 67.7% of the cases. Mother’s anxiety and depression were not significant predictors in the models.

Table 4

<table>
<thead>
<tr>
<th>Predictors</th>
<th>OR</th>
<th>95% CI</th>
<th>Overall test of effect</th>
<th>B</th>
<th>S.E.</th>
<th>Wald ( \chi^2 )</th>
<th>df</th>
<th>( p )-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Model 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mothers’ HADS-Depression</td>
<td>2.3</td>
<td>0.5-10.8</td>
<td>1.2</td>
<td>0.84</td>
<td>0.78</td>
<td></td>
<td>1</td>
<td>.282</td>
</tr>
<tr>
<td><strong>Axis I comorbidities</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood disorders</td>
<td>2.9</td>
<td>1.1-8.0</td>
<td>0.51</td>
<td>1.07</td>
<td>0.51</td>
<td>4.3</td>
<td>1</td>
<td>.037</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>6.1</td>
<td>1.1-33.4</td>
<td>0.87</td>
<td>1.80</td>
<td>0.87</td>
<td>4.3</td>
<td>1</td>
<td>.039</td>
</tr>
<tr>
<td>Attention-deficit/hyperactivity disorder</td>
<td>0.2</td>
<td>0.04-0.7</td>
<td>-1.85</td>
<td>0.73</td>
<td>0.73</td>
<td>6.5</td>
<td>1</td>
<td>.011</td>
</tr>
<tr>
<td><strong>Model 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mothers’ HADS-Anxiety</td>
<td>1.8</td>
<td>0.7-4.8</td>
<td>0.49</td>
<td>0.59</td>
<td>0.49</td>
<td>1.4</td>
<td>1</td>
<td>.230</td>
</tr>
<tr>
<td><strong>Axis I comorbidities</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mood disorders</td>
<td>2.5</td>
<td>1.0-6.5</td>
<td>0.48</td>
<td>0.93</td>
<td>0.48</td>
<td>3.7</td>
<td>1</td>
<td>.054</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>7.9</td>
<td>1.4-43.7</td>
<td>0.87</td>
<td>2.07</td>
<td>0.87</td>
<td>5.6</td>
<td>1</td>
<td>.018</td>
</tr>
<tr>
<td>Attention-deficit/hyperactivity disorder</td>
<td>0.2</td>
<td>0.04-0.7</td>
<td>-1.74</td>
<td>0.70</td>
<td>0.70</td>
<td>6.1</td>
<td>1</td>
<td>.013</td>
</tr>
</tbody>
</table>

Note. CI = Confidence interval for odds ratio (OR)

Discussion

This study revealed that comorbid psychiatric disorders were present in over half of the patients (66% for the ED group and 68.8% for the SUD group). Despite the fact that EDs and SUDs share a complex interaction of genetic, biological and personality vulnerabilities,
environmental and familial factors (Dennis & Brewerton, 2014), findings suggest that the type of psychiatric comorbidities may be specific to each illness. The most frequent clinical manifestations for the ED group were internalizing disorders (i.e. mood and anxiety disorders) whereas for the SUD group externalizing disorders (i.e. ADHD, CD and ODD) were most common, which was further supported by results of the logistic regression. These findings are similar to those found in prior studies employing standardized diagnostic interviews to assess rates of Axis I disorders among treatment seeking adolescent patients with ED (Bühren et al., 2014; Salbach-Andrae et al., 2008) and SUD (Chan et al., 2008), as well as Spanish adolescent community samples in Spain with ED (Rojo et al., 2003). The one exception was the complete absence of OCD among the ED group, which is contrary to findings from prior studies (Swinbourne & Touyz, 2007). One possible explanation is that patients with OCD could have been seen in other units of the psychiatric department. According to Toro and Vilardell (1987), in AN patients with comorbid OCD, symptoms of AN can remit following successful treatment for OCD.

A discussion of these findings also requires consideration of the differences in gender composition between the two groups. The primarily male SUD group and primarily female ED group raise the question of whether these comorbidities are not specific to the patient group, but rather a result of gender. Externalizing disorders tend to be more frequent in male adolescents males, while internalizing disorders are more frequent in females (Scaramella, Conger, & Simons, 1999). While we cannot definitively conclude whether it is the primary diagnosis or the gender that is associated with the particular comorbid diagnoses, these results do confirm that the gender composition and Axis I comorbidities of each patient group were similar to those found in previous studies employing adolescent treatment seeking ED and SUD samples from other countries (Couwenbergh et al., 2006; Herpertz-Dahlmann et al., 2001; Schmidt et al., 2008). Therefore, these findings may be generalizable to treatment settings both
inside and outside of Spain. Results point to the importance of assessing for comorbid symptoms in treatment seeking ED and SUD patients, and are suggestive of the most common comorbid diagnoses which clinicians may encounter, which may help to guide and improve treatment interventions (Askey, 2007; Milos, Spindler, Buddeberg, & Crameri, 2003).

Furthermore, these findings provide a foundation upon which to address future research questions regarding treatment seeking adolescent patients with ED or SUD. Previous research demonstrates that many individuals with these disorders have never received treatment (Bijl & Ravelli, 2000; Compton, Thomas, Stinson, & Grant, 2007), and future studies could explore the possibility of unmet care needs among Spanish adolescents with ED or SUD. A recent survey carried out in Spain showed that 14.4 to 47.6% of adolescents, depending on their age, presented risky alcohol consumption, with greater rates among females than males (Health Social Services and Equality Ministry, 2016). However, only a small percentage of our SUD sample (12.5%) presented a diagnosis of alcohol abuse and only 16.7% were female. Future studies could investigate the role of gender, cultural norms regarding drugs and alcohol, and the presence of externalizing disorders (and their associated interpersonal, familial and legal consequences) in seeking treatment for SUD in Spain. The role of gender in seeking or receiving ED treatment for adolescent males could also be explored. While research on body dissatisfaction and EDs in males has advanced in recent years (Raevuori, Keski-Rahkonen, & Hoek, 2014), they continue to be seen as a “women’s illness.” This may lead males to delay seeking treatment (Räisänen & Hunt, 2014), to present EDs in ways that require less intensive treatment, or professionals themselves may fail to recognize ED symptoms in males (Greenberg & Schoen, 2008).

It is common for both EDs and substance abuse to begin during adolescence, a developmental stage in which individuals are particularly vulnerable to developing addictive behaviors (Barbarich-Marsteller, Foltin, & Walsh, 2011). Adolescents are exposed to a number
of pressures, such as acceptance by their peers, experimentation with “adult” behaviors, and overwhelming feelings of distress and painful self-awareness. While all adolescents may experience these pressures to a greater or lesser degree, seen from the perspective of the developmental psychopathology principle of multifinality (Cicchetti & Rogosch, 1996), not all of them will present the same outcome (e.g. type of psychopathology). While these groups of patients differed in terms of the manifestation of their symptoms (both the primary and comorbid diagnoses), they may be representations of underlying levels of distress intolerance (Daughters et al., 2009).

In terms of the second aim of the study, our hypotheses were partially supported. Anxiety and depression in both groups of mothers were associated with patients’ levels of depression and symptom severity, but not with patients’ anxiety. This is similar to recent cross-sectional studies exploring the relationship between parental and adolescent psychopathology in which maternal mental health has been shown to be associated with both internalizing and externalizing disorders (Ranøyen, Klöckner, Wallander, & Jozefiak, 2015; Van Loon, Van de Ven, Van Doesum, Witteman, & Hosman, 2014). According to the interpersonal maintenance model of AN (Treasure & Schmidt, 2013), these correlations may be indicative of the vicious cycle of maintenance in which parental psychological distress may increase in the face of ED symptoms, thereby leading to unhelpful responses to the illness, which then serve to worsen the prognosis (Treasure & Schmidt, 2013). While initial empirical support suggests that parental distress leads to worse distress and symptoms in ED patients (Goddard et al., 2013), future longitudinal studies would allow us to elucidate if maternal distress serves as a risk or maintenance factor for ED, as well as SUD and the common comorbid mental illnesses identified in this study (Anastasiadou et al., 2016). A recent meta-analysis found that interventions targeted specifically at those caring for someone with an ED are effective at
reducing caregiver distress (Hibbs, Rhind, Leppanen, & Treasure, 2015). Future studies could explore the effectiveness of similar interventions in SUD parents and caregivers.

In addition to those already noted, certain study limitations must be considered. First, the cross-sectional design does not permit us to draw causal relationships between the primary psychiatric disorders and their comorbidities. Longitudinal studies would allow us to discover if adolescents with higher rates of internalizing behaviors are more likely to engage in ED-related behaviors than to experiment with drugs, and if those with externalizing behaviors are more inclined to do the opposite. Furthermore, it would allow researchers to observe the development and trajectory of EDs and their associated comorbidities. Future studies may also benefit from recruiting larger samples in order to assess for differences in comorbidity or maternal mental health between patients in early, middle and late adolescence.

Another limitation involves the differences between the two patient groups in terms of gender, age and illness duration. While this was expected given the specific characteristics of each condition (Brady & Randall, 1999; Currin, Schmidt, Treasure, & Jick, 2005; Kessler et al., 2007; Kessler et al., 2005), it remains relevant to note that these differences may have had an indirect effect, which could not be examined due to the design of the present study. The strict exclusion criteria established for this study added a further limitation. The decision to exclude patients with comorbid SUD and ED prohibited us from detecting the frequency of the co-occurrence of ED and SUD, which is a finding that has been reported in previous studies (Couwenbergh et al., 2006; Salbach-Andrae et al., 2008).

The findings of the present study, which employed a semi-structured diagnostic interview, reveal a high frequency of psychiatric comorbidities in adolescent patients seeking treatment for their ED or SUD in Spain. Furthermore, the most common comorbid mental illnesses were distinct in each group. While these groups differed in terms of certain demographic and clinical variables, their representativeness increases the generalizability of
the findings. Clinicians must take care to not only treat the symptomatology associated with the patient’s primary diagnosis, but also assess for the highly likely occurrence of comorbid symptomatology, as psychiatric comorbidity is associated with worse prognosis in both patient groups (Grella et al., 2001; Herpertz-Dahlmann et al., 2001). In recent years, both SUD and ED treatment and research have seen a shift from seeing parents as part of the problem to part of the solution (Orford et al., 2010; Treasure, Schmidt, & Macdonald, 2009). The current findings suggest that maternal distress may be an appropriate treatment target in interventions directed at parents and caregivers.

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CHAPTER 7: COMORBIDITY IN ADOLESCENT EATING DISORDER PATIENTS

References


Treasure, J., Murphy, T., Szmukler, T., Todd, G., Gavan, K., & Joyce, J. (2001). The experience of caregiving for severe mental illness: A comparison between anorexia
nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology, 36*(7), 343-347.


Chapter 8

Discussion


**DISCUSSION**

**General discussion**

EDs are complex (Stice, 2016), life threatening (Arcelus, Mitchell, Wales, & Nielsen, 2011) and enduring psychiatric illnesses (Steinhausen, 2002; Steinhausen & Weber, 2009) and caring for patients with these disorders has been associated with psychological distress (Kyriacou, Treasure, & Schmidt, 2008b) and impairment in quality of life (De La Rie, Van Furth, De Koning, Noordenbos, & Donker, 2005). The current thesis has aimed to provide a picture of the caregiving experience of mothers and fathers of adolescent patients with an ED as compared to that of parents of patients with SUD and parents of healthy adolescents.

The first three chapters of the current thesis comprised a review of the relevant literature on EDs, family caregiving and the use of comparison groups in order to highlight gaps in the current research and explain the rationale for the current study objectives and design. Chapter 4 presented a summary of the study methods and chapters 5 to 7 consisted of three research articles which present the empirical results of the cross-sectional study upon which this thesis is based. Together, these results present a picture of how the experience of ED family caregivers in Spain compares to that of parents of SUD patients and healthy teens on a number of variables (i.e. quality of life, unhelpful responses to the illness, coping strategies, appraisal of the caregiving experience, and parental mental health). The objective of the current chapter is to summarize the findings of this study, as well as to present possible limitations and implications for clinical practice and future research.

**Representativeness of the current sample of ED patients**

The patients and their families that are reported on in the three articles were part of the same sample, although the participants that were included in each article varied slightly according to the specific aims of the article. A review of studies assessing ED prevalence rates among Spanish adolescents found that they are comparable to those of other developed countries (Peláez Fernández, Raich Escursell, & Labrador Encinas, 2010) and the current
findings add support to the idea that adolescent ED patients in Spain are similar to those in other countries. The current sample included a total of 50 ED patients that were recruited from a specialized child and adolescent ED unit and they were similar to prior studies of adolescent ED patients in that the majority were female (98%), all were living with at least one parent and they presented a short duration of illness (in months, $M = 12.48$, $SD = 12.3$) (e.g. Le Grange, Hoste, Lock, & Bryson, 2011; Ravi, Forsberg, Fitzpatrick, & Lock, 2008; Salerno et al., 2016a; Schwarte et al., 2017; Sim et al., 2009). The BMI of our sample ($M = 18.16$, $SD = 1.84$) was higher than that reported in many of the previous studies of adolescent patients with AN (e.g. Bühren et al., 2014; Sim et al., 2009). However, this may be due to the fact that the majority of our patients were not receiving inpatient treatment. Furthermore, our patients had already undergone an average of five months of therapy and current international (NICE, 2004), as well as Spanish (Catalan Agency for Health Technology Assessment and Research, 2009), guidelines place weight restoration as a central goal in the treatment of patients with AN.

Although previous studies have included adolescent ED patients with varying diagnoses (e.g. Eisler, Simic, Russell, & Dare, 2007; Girz, Lafrance Robinson, Foroughe, Jasper, & Boachie, 2013), our sample was comprised of patients with a restrictive ED and the majority met criteria for AN-R (78%). This was largely an artifact of the recruitment design as it is the patient profile primarily seen in consecutive admissions at the specialized child and adolescent ED unit at the hospital participating in the study. Finally, in regards to comorbidity our results revealed that 66% of ED patients presented an Axis-I comorbid diagnosis, which was similar to treatment seeking adolescent ED patients in Germany (Bühren et al., 2014; Salbach-Andrae et al., 2008), as well as adolescent ED community samples in both the U.S. (Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011) and Spain (Rojo et al., 2003). The finding that the most frequent comorbid disorders were mood and anxiety disorders was also similar to previous studies (Salbach-Andrae et al., 2008), as were the high rates (40%) of
self-harm/suicidal ideation (Fennig & Hadas, 2010; Ruuska, Kaltiala-Heino, Rantanen, & Koivisto, 2005).

**Similarities and differences between ED and SUD patients**

The selection of SUD patients as a comparison group was done so based on the fact that the two disorders share a complex interaction of genetic, biological and personality vulnerabilities, environmental and familial factors (Dennis & Brewerton, 2014). A total of 48 SUD patients were recruited from a specialized outpatient center. The results presented in Chapter 7, assessed via a semi-structured diagnostic interview (K-SADS-PL) (Kaufman et al., 1997), revealed that both ED and SUD patients presented high rates of comorbid psychiatric diagnoses (66% and 68.8%, respectively). However, the most common comorbid disorders were distinct for each patient group. While the ED group presented higher rates of mood and anxiety disorders, the SUD patients were more likely to present ADHD or conduct disorders. In addition, differences in age were found between the ED and SUD groups ($M = 14.78$, $SD = 1.78$; $M = 18.19$, $SD = 2.17$, respectively), although the results from Chapter 5 suggest that this did not have an impact on the findings regarding family caregiving variables.

Prior to sample recruitment, no articles had been published comparing ED and SUD families. However, since this time, Doba, Nandrino, Dodin, and Antoine (2014) published an article in which they compared French parents of patients with AN-R with parents of patients with drug dependence disorder. While these authors were able to match patients according to age and illness duration, this may be due to the fact that their ED patients were older ($M = 20.6$) and had a longer duration of illness ($M = 3.63$ years). By recruiting an older ED patient sample, we may have obtained more comparable groups. However, in consideration of the fact that one of our main objectives was to explore the caregiving experience of parents of an exclusively adolescent ED sample, this would not have been possible. Finally, it is worth mentioning that despite these differences between the two groups, their gender composition
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and the common comorbidities of each patient group are similar to those found in prior studies of adolescent treatment seeking ED and SUD patients outside of Spain (Couwenbergh et al., 2006; Herpertz-Dahlmann et al., 2001; Schmidt et al., 2008).

Similarities and differences between ED patients and healthy adolescents

A total of 68 healthy adolescents and their families (50 fathers and 63 mothers) that were recruited from secondary schools in the region of Madrid agreed to participate in the current study. The ED patients and HCs in the current sample did not present statistically significant differences in terms of their age \((M = 14.78, SD = 1.78; M = 14.39, SD = 1.41,\) respectively). This was the first study of ED caregiving that recruited HCs which used a semi-structured diagnostic interview to assess for a current ED diagnosis (as well as additional psychiatric disorders) among HCs. The previous studies have used self-report questionnaires to assess for ED psychopathology (Goddard & Treasure, 2013; Sim et al., 2009) or have not specified if or how they assessed for a current ED among HCs (Blair, Freeman, & Cull, 1995; Kyriacou, Treasure, & Schmidt, 2008a; Ruiz-Robledillo, Romero-Martinez, & Moya-Albiol, 2016). Another strength of the current study is that we recruited both mothers and fathers, whereas the previous study of caregiving among adolescent ED patients that used a control group had only recruited mothers (Sim et al., 2009).

Certain differences were observed between the parents of the two groups which must be taken into consideration. For example, more HC than ED mothers had full-time employment (78.8 versus 52.1, respectively). In addition, more HC mothers (47.5%), as well as fathers (55.1%), had completed university or graduate studies, as compared to ED mothers and fathers (31.3% and 34.1%, respectively). It may be that HC parents with higher levels of education were more willing to participate in a research study. There were no statistically significant differences between the ED and HC groups regarding family constitution. Previous studies that used mixed age samples of ED patients and HCs found that ED parents had more hours of
contact with their child than HCs (Goddard & Treasure, 2013; Kyriacou et al., 2008a). In contrast, our results suggest that parents of adolescent ED patients actually spend less hours with their adolescent child than parents of healthy adolescents. This finding highlights the fact that studies of ED caregiving that use entirely adolescent samples are distinct from those using mixed age samples. Unlike offspring that live away from their parents, or those who live at home, but are older and thus more autonomous, healthy adolescents may have more opportunities to interact with their parents through family meals, transportation or assistance with their homework.

**Family caregiving: ED versus SUD parents**

In this thesis, several variables have been grouped together under the term “family caregiving,” which includes EE, accommodating and enabling behaviors, psychological distress, quality of life, appraisal of the caregiving experience and coping strategies. Previous studies have assessed ED caregiving using comparison groups composed of patients with psychosis (Treasure et al., 2001), cystic fibrosis (Blair et al., 1995), insulin-dependent diabetes mellitus (Sim et al., 2009), major depressive disorder (Rienecke, Sim, Lock, & Le Grange, 2016b), and schizophrenia and depression (Martín et al., 2015). A recent study also used a comparison group of patients with drug dependence, but the sample sizes were smaller than those of the current study and the patient samples were not exclusively adolescents (Doba et al., 2014).

To our knowledge the only other study that has used the ECI to compare the caregiving experience of ED caregivers with another group of patient caregivers was Treasure et al. (2001) who found that caregivers of ED patients had a higher ECI negative score when compared to caregivers of patients with psychosis. In the present study we found that SUD fathers reported a greater negative caregiving experience than ED fathers, but there were no differences between mothers of the two patient groups. Previous research has suggested that a negative
caregiving experience among ED caregivers is predicted by greater unmet needs, such as information and support (Coomber & King, 2012). While this variable was not measured in the current study, it may indicate a possible direction for future research. Previous research has indicated that drug use is associated with paternal distancing, which would suggest that fathers may have less of an opportunity to address any unmet needs (Andersson & Eisemann, 2003). We are not aware of any previous studies that have compared ED caregiver coping to another patient group. However, our results suggest that ED and SUD caregivers do not differ in their frequency of using particular coping strategies.

Similar to studies using comparison groups with major depressive disorder (Rienecke et al., 2016b) and drug dependence (Doba et al., 2014), we did not find any differences between ED and SUD parents on EOI, which is not surprising given that researchers have suggested that greater EOI may be a common reaction to a serious illness of a loved one (Koutra et al., 2016; Kyriacou et al., 2008a). In regards to CC, SUD parents presented higher scores than the ED group, which was similar to the findings by Doba et al. (2014) who found that mothers of patients with drug dependence were more critical than ED mothers. However, in contrast to the present study, these authors did not find any differences between their groups of fathers. This may be related to the fact that while the mean CC of our ED fathers and those of Doba et al. (2014) were similar, the mean CC of our SUD fathers was higher. One explanation for the increased levels of CC among our SUD fathers could be related to the high rates of externalizing disorders that were found among our SUD group, which was a variable that was not reported by Doba et al. (2014). A previous studies of ED caregivers found that negative and difficult behaviors were a significant predictor of CC and it is possible that the same is true for SUD parents (Kyriacou et al., 2008a).

No differences were found between the two patient caregiver groups in terms of mental or physical HRQoL. Previous studies have found that ED caregivers report greater mental
health difficulties than those caring for patients with psychosis (Treasure et al., 2001) and insulin-dependent diabetes mellitus (Sim et al., 2009), however the current results would suggest that ED and SUD parents present comparable impairments to mental health. In regards to accommodating behaviors, SUD fathers scored higher than ED fathers, although no differences were found between mothers. Interestingly, although greater levels of accommodating behaviors have been found to be associated with increased hours of contact with the patient (Goddard et al., 2013), the SUD fathers reported spending less time with patients than ED fathers. However, it could be related to the high scores among SUD fathers on CC, considering that increased use of accommodating behaviors has also been found to be associated with higher EE (Goddard et al., 2013). Future studies could explore the role of self-blame among SUD fathers, as it has recently been found to be predictive of increased accommodating behaviors among ED parents (Stillar et al., 2016).

In general, these results suggest that SUD parents, particularly fathers, tend to have a worse caregiving experience and present more unhelpful responses to the illness in the form of accommodating behaviors and critical comments. As was hypothesized in the Discussion section of Chapter 5, this may be related to the fact that having a child with substance use problems could be associated with more negative social consequences and stigma. Another reason for the differences may be found in the parent’s assumptions regarding the causes of the illness, which could be further explored in future studies of caregivers of adolescent patients (Whitney, Haigh, Weinman, & Treasure, 2007).

Family caregiving: ED versus HC parents

Only one previous study has used a healthy control group to compare ED caregivers on the ECI (Szmukler et al., 1996), and similar to the present study, they found that ED parents presented a more negative caregiving experience (Kyriacou et al., 2008a). One particular strength of the current study was that it was the first to compare ED parents and parents of
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healthy adolescent on their use of coping strategies. While no differences were found between the father groups, the ED mothers displayed greater use of self-sufficient problem solving strategies than HC mothers.

In terms of EE, our results on the EOI component of EE were similar to previous studies using a mixed healthy control group (i.e. adults and adolescents) in that ED parents presented greater EOI than HC parents (Blair et al., 1995; Kyriacou et al., 2008a). For CC, our results mirrored those of Blair et al. (1995) as our ED parents did not differ from HC parents. However, this was in contrast to the results of Kyriacou et al. (2008a) who found that ED parents displayed greater CC than HCs. This finding is surprising given the fact that we employed the same instrument as this study. However, one possible hypothesis for this discrepancy could lie in the differences in age and illness duration. Whereas the patient group in the study by Kyriacou et al. (2008a) had a mean duration of illness of 7.8 years, the duration of illness for our sample was a little over one year. Prior studies suggest that parents of younger patients with a shorter illness duration demonstrate lower CC (Le Grange et al., 2011). While we did not find alterations in CC levels, as compared to HCs, it has been suggested that patients with AN may be highly sensitive to negative stimuli and thus, even low levels of CC may affect them (Kaye, Fudge, & Paulus, 2009; Le Grange et al., 2011). This would suggest that CC, in addition to EOI, is an important variable to assess when working with adolescent ED caregivers.

In terms of HRQoL, the ED parents presented impairment in the mental health domain, but not the physical health domain, of the SF-36. This is in line with prior studies which have most consistently found disruptions in mental health among ED caregivers when comparing them to healthy control groups (Goddard & Treasure, 2013; Kyriacou et al., 2008a; Ruiz-Robledillo et al., 2016; Sim et al., 2009) and community norms (Las Hayas et al., 2014; Martín et al., 2011). Authors have suggested that physical functioning is often not impaired in this
group of caregivers due to the fact that while the type of care they provide requires them to exert mental and emotional energy (e.g. supervising mealtimes, encouraging socializing), it does not require the physical effort that is involved in caring for patients with dementia or a physical disability (Las Hayas et al., 2014; Martín et al., 2011).

**Gender differences between ED mothers and fathers**

The systematic reviews of family caregiving carried out by Anastasiadou, Medina-Pradas, Sepulveda, and Treasure (2014) and Zabala, Macdonald, and Treasure (2009) suggested that ED mothers tended to demonstrate worse scores on a number of variables than ED fathers. Similar to previous studies (Anastasiadou et al., 2014; Depestele et al., 2015), ED mothers in the current study reported higher scores than fathers on both the ECI positive scale and ECI negative scale. An explanation for these findings may be found in the fact that ED mothers reported more hours of contact than fathers. More hours of contact have been shown to be associated with a greater negative caregiving experience (Whitney et al., 2007). However, it may also be that spending more time with their child allowed these mothers to foster a greater sense of empathy towards them or to observe the positive ways in which their relationship had grown since the start of the illness.

Results regarding EE replicated the findings of some of the previous studies assessing parental EE among adolescent ED patients (Hoste, Labuschagne, Lock, & Le Grange, 2012; Rhind et al., 2016) in that mothers and fathers presented comparable CC scores, but that mothers reported higher EOI than fathers. However, other studies using adolescent samples (Rienecke, Accurso, Lock, & Le Grange, 2016a; Rienecke, Lebow, Lock, & Le Grange, 2015; Schwarte et al., 2017) have found that fathers exhibit greater CC. It has been suggested that greater paternal CC could be due to a lack of understanding about the causes of the illness (Anastasiadou et al., 2014), but the father’s willingness to participate in the current study may indicate that they were already involved in their child’s treatment. As part of the treatment
protocol of the hospital in which patients were receiving treatment, parents receive psychoeducation about the causes of ED, which may have resulted in lowering father’s levels of CC.

In regards to HRQoL, mothers presented worse mental and physical health than fathers, which is similar to studies assessing those caring for patients with ED (Martín et al., 2011), as well as OCD (Albert, Salvi, Saracco, Bogetto, & Maina, 2007) and schizophrenia (Gutierrez-Maldonado, Caqueo-Urizar, & Kavanagh, 2005). Research on ED caregivers has consistently found that mothers report greater psychological distress than fathers (Goddard & Treasure, 2013; Jacobs et al., 2009; Kyriacou et al., 2008b; Raenker et al., 2013; Whitney et al., 2007). Regarding research on accommodating behaviors, a recent study of adolescent ED patients found that mothers presented less of these behaviors than fathers (Rhind et al., 2016). However, we did not find a difference between parents. Addressing accommodating behaviors in both mothers and fathers may be important given that it has been found to be negatively associated with treatment outcome (Salerno et al., 2016a).

Overall, we observed differences between mothers and fathers on a number of caregiving variables and, with the exception of the ECI positive scale, mothers presented greater impairment than fathers. This mirrors gender discrepancies found in the larger body of caregiver research (Yee & Schulz, 2000) and may be due to the fact that mothers tend to be much more involved in the care of their child than fathers (Connell & Goodman, 2002) or because they may feel a greater obligation to fulfill the caregiving role (Bédard et al., 2005). Taken together, these results highlight the importance of assessing the experience of both parents, as well as their hours of face-to-face contact with the patient, and reporting the scores for mothers and fathers separately, which has not been done in many of the prior studies of ED caregiving (Anastasiadou et al., 2014).

**Relationship between patient characteristics and family caregiving**
According to the results presented in Chapter 7, having a child with a comorbid ED did not influence the degree of psychological distress reported by mothers, which mirrors previous findings (Schwarte et al., 2017). However, a significant association was found between ED mother’s anxiety and depression and patient’s level of depression. This is in line with both the broader literature on adolescent psychopathology (Goodman et al., 2011), as well as studies of ED populations (Goddard et al., 2013), which suggest that there is an association between maternal mental health and children’s emotional functioning. Our finding that mother’s psychological distress was associated with patient symptom severity is also similar to that of a recent study in Germany which found that the psychological distress of parents of an adolescent with an ED was associated with lower BMI and worse patient ED psychopathology (Schwarte et al., 2017). Using structural equational modeling in a group of caregivers of primarily adult ED patients, Goddard et al. (2013) found that caregiver’s psychological distress affects ED symptoms through its influence on patient’s psychological distress. Future studies could reveal if this holds true for adolescent populations as well, or if the model is distinct from that of caregivers of adult patients.

Chapter 6 was unable to identify any patient characteristics (i.e. age, duration of illness) that were associated with the use of particular coping strategies or appraisal of the caregiving experience. This is in contrast to the study by Fiorillo et al. (2016) who found that patient’s age and duration of illness were associated with greater use of avoidance. However, this study used a different assessment of coping strategies and the mean age and duration of illness of the patients was higher than our sample. Finally, while a recent systematic review of ED family caregiving (Anastasiadou et al., 2014) suggested that illness duration may be related to a higher score on the ECI negative scale, our current results did not support this. This may be related to the fact that all of our patients had a relatively short illness duration.

**Relationship between parent characteristics and family caregiving**
In addition to the role of gender, other parent variables (i.e. age, socioeconomic status, education level, employment status and face-to-face contact hours with the patient) and their relationship to coping strategies and appraisal of the caregiving experience were explored in Chapter 6. Although a prior study found that the use of adaptive ED caregiving strategies (i.e. seeking information, positive communication) were positively associated with the caregiver’s level of education, we did not replicate this finding. The only significant relationship between parent characteristics and coping was that older parents were less likely to use avoidant strategies. Unlike Winn et al. (2007), we did not find that more face-to-face contact hours were associated with a greater negative caregiving experience. This may have been due to the fact that although these authors used an exclusively adolescent sample, it was composed of patients with BN and EDNOS, whereas our sample was comprised of patients with a restrictive ED, primarily AN-R.

**Strengths and limitations**

The current study presents several strengths. First, it included several family caregiving variables that had previously not been studied, or rarely studied, amongst caregivers of adolescent ED patients. A comparison of our parents’ scores with the scores reported in the systematic reviews of Anastasiadou et al. (2014) and Zabala et al. (2009) of studies that had used samples of adult and/or mixed age patients revealed that our parents scored lower on EE, a negative caregiving experience, mental HRQoL and accommodating behaviors, thus underscoring the importance of separating caregivers of adolescent and adult patients when carrying out research on ED family caregiving. Additional strengths include a homogenous ED patient sample in terms of age, illness duration and diagnosis and the use of a semi-structured diagnostic interview (K-SADS-PL). Furthermore, the recruitment of both a healthy control group, as well as a clinical comparison group selected according to the similarities between
ILLN, and the assessment of both mothers and fathers, add to the novelty of this study. Finally, these results add to the growing body of literature assessing ED caregivers in Spain.

Despite these strengths, a discussion of the results would not be complete without taking into account some of the study’s shortcomings. First, the majority of the variables were assessed via self-report questionnaires and thus, they are subject to the limitations inherent to this method, such as socially desirable responding. In the case of EE, the FQ self-report instrument was chosen instead of an interview as it is more cost-effective and overcomes some of the coding difficulties associated with interviews, yet still presents convergent validity with interviews. However, the lack of a structured clinical interview to assess EE meant that we were unable to assess the positive aspects of this construct (i.e. warmth and positive remarks), which have been underreported in the literature amongst this caregiver group (Anastasiadou et al., 2014). A previous study using the SCFI to assess the EE of parents of adolescents with AN revealed that warmth and positive remarks were common amongst both mothers and fathers (Rienecke et al., 2016a), whereas another study using this same instrument found that baseline levels of warmth were predictive of treatment outcome (Le Grange et al., 2011).

Another limitation of this study is that the parents who participated may not be representative of all ED and SUD caregivers as their willingness to participate in this research may indicate that they were more involved in their child’s treatment. This also raises the question of whether or not HC parents who participated in the study did so because they were concerned about their child’s, or their own, well-being. The results regarding accommodating and enabling behaviors in SUD patients must be interpreted with caution as this is the first study to use the AESSA. However, the fact that SUD parents reported high scores on this measure is in line with prior studies that have found that these parents tend to be over-permissive towards their children (Velleman, Templeton, & Copello, 2005), and suggests that future studies could explore its psychometric properties in this patient group.
Another limitation is in reference to the differences between the patient groups in regards to patient and caregiver characteristics. Although some of these differences were expected given the characteristics of each condition (Brady & Randall, 1999; Currin, Schmidt, Treasure, & Jick, 2005; Kessler et al., 2007; Kessler et al., 2005), it is important to keep in mind that these differences may have had an indirect effect on the variables assessed. Furthermore, our study did not include patients with BN or BED, and previous studies have found differences in EE between different ED diagnoses (Anastasiadou et al., 2014; Rienecke et al., 2016b). Finally, the selection of variables to be assessed in the current study were largely based on the interpersonal maintenance model of EDs (Treasure & Schmidt, 2013). However, the cross-sectional nature of the study did not allow for determining the causal relationships between these variables, nor can we conclude with certainty that results on particular variables (e.g. EE, mental health difficulties, use of coping strategies) were a direct cause of having a child with a mental illness. Future longitudinal studies would allow for us to better understand the development of these variables over time, as well as to draw stronger conclusions regarding the direct impact of the illness on caregiver well-being.

**Clinical implications**

More than half of ED patients were found to have a comorbid diagnosis, which is associated with poor prognosis (Herpertz-Dahlmann et al., 2001) and thus, clinicians need to ensure they assesses for comorbid psychopathology when treating these patients. In regards to ED parents, they reported high levels of EE and the presence of accommodating and enabling behaviors, which have both been found to be predictors of poor treatment outcome among adolescent ED patients (Rienecke et al., 2016a; Salerno et al., 2016a), and are therefore important behaviors to target. The fact that our caregivers reported a lower negative caregiving experience and less unhelpful responses to the illness as compared to studies of adult samples reinforces the importance of intervening with parents soon after illness onset as maintenance
factors may not yet be in place and parents may not be as affected by the illness. However, we did observe that parents reported greater mental health difficulties when compared to HCs and prior studies. Furthermore, maternal psychological distress was associated with worse depression and ED symptoms among patients. This suggests that addressing parent’s mental health, particularly mother’s, may be of particular importance for clinicians working with these families.

Taken together these findings add strength to current international guidelines recommending the involvement of the family in the treatment of adolescent EDs (Catalan Agency for Health Technology Assessment and Research, 2009; NICE, 2004). One way for families to be involved in treatment is through family therapy, which, according to a Cochrane review (Fisher, Hetrick, & Rushford, 2010), is the most effective intervention for adolescent patients with a short illness duration. Another way to involve families is through interventions aimed directly at caregivers, which a recent meta-analysis found to be effective at reducing negative caregiving experience, distress and EE among caregivers (Hibbs, Rhind, Leppanen, & Treasure, 2015b).

One such example is the New Maudsley Collaborative Care approach workshops (Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008) and DVDs (Goddard et al., 2011a) aimed at increasing caregiver’s communication skills and improving their ability to manage difficult behaviors (Treasure & Nazar, 2016). This intervention in particular has been shown to be effective at reducing caregiver distress (Sepulveda et al., 2008), accommodating and enabling behaviors (Goddard et al., 2011a), and EE (Sepulveda et al., 2010). Patients have also reported positive effects following this intervention, and a reduction in ED psychopathology has been observed (Goddard, Macdonald, & Treasure, 2011b; Hibbs et al., 2015a). While the majority of these interventions have been carried out with caregivers of adult patients, a recent RCT (Rhind et al., 2016) assessed its effectiveness among caregivers of adolescents with AN.
Preliminary results found that it was effective in breaking part of the vicious cycle of maintenance proposed by the interpersonal maintenance model of EDs in regards to the relationship between mother’s and patient’s distress (Salerno et al., 2016b). Such an intervention could also prove to be effective when intervening with parents of adolescents with EDs in Spain and any intervention that is carried out should include both parents.

Although several differences were observed between ED and SUD patients and their families, the fact that SUD parents also demonstrated unhelpful responses to the illness, mental health difficulties, and a negative caregiving experience may have implications for practitioners working with this patient group. For example, certain aspects of the interpersonal maintenance model for EDs may be true for those caring for a patient with SUD as well. As in the case of EDs, EE and accommodating behaviors may inadvertently cause an increase in the symptoms of SUD patients, thereby leading to greater impairments in parent’s mental health as the illness continues. Thus, the interventions for caregivers that are based on this model, such as the New Maudsley Collaborative Care approach, which was previously outlined, may also be effective at assisting these parents in learning more helpful responses to the illness and help them to focus on their own well-being. Another possibility could be to develop a combined intervention for ED and SUD parents. Non-disease specific caregiver interventions which have combined caregivers of patients with varying psychiatric illnesses have also been effective in lowering caregiver distress (Gatta et al., 2011). An intervention that included both caregiver groups could impart aspects of the Maudsley approach that are not specific to the illness, such as focusing on caregiver’s mental health and teaching motivational interviewing, which has been found to help both patient groups increase their readiness to change (Barnett, Sussman, Smith, Rohrbach, & Spruijt-Metz, 2012; Macdonald, Hibbs, Corfield, & Treasure, 2012; Sepulveda, Wise, Zabala, Todd, & Treasure, 2013)

**Directions for future research**
DISCUSSION

There are a number of opportunities for future research in the field of ED family caregiving. First, as previously mentioned, future studies could explore the progression of these caregiving variables through a longitudinal study. A recent study carried out among caregivers of German adolescents with AN (Schwarte et al., 2017) found that although parent’s levels of EE and psychological distress decreased following treatment, at follow-up 2.5 years later their levels of CC had increased. A similar study could be carried out in Spain assessing the wide range of variables reported on in the current study. Furthermore, a longitudinal study would allow for us to determine if parent’s scores on the caregiving variables at the start of the illness predicted patient’s outcome in the future, thus providing empirical support for the interpersonal maintenance model of EDs (Salerno et al., 2016a). Such a study would benefit from utilizing a general measure of ED psychopathology to assess outcome as other indicators of improvement (i.e. weight, binge-purge behavior, diagnostic criteria, etc.) may not be applicable to all ED diagnoses (Dingemans et al., 2016).

Another method for obtaining support for this model could be through the application of structural equational modeling as it would allow for testing the hypothesized relationships between variables. Using this statistical technique, Goddard et al. (2013) confirmed that primary caregiver distress predicted ED behaviors through its relationship with patient’s distress. Future studies could expand upon these findings to include additional variables, and to see if the model differed between primary and secondary caregivers or with the use of an entirely adolescent sample. Another route could be to assess relational changes through use of the Actor-Partner Interdependence Model (Kenny, 1996), which analyzes the caregiver and patient as a unit, such as the recent study by Salerno et al. (2016b).

There are additional variables related to family caregiving that could be explored in future studies, particularly among caregivers of Spanish adolescents with an ED. Treasure and Nazar (2016) provided a review of ED specific instruments that assess caregiver needs and the
caregiving experience, some of which are not yet validated and translated into Spanish. For example, the Caregiver Skills scale (CASK) (Hibbs et al., 2015c), which was recently developed to assess aspects of caregiver behavior that can be modified and that may improve patient outcome (e.g. self-care, frustration tolerance). A study of parents of adolescents with AN found that low paternal CASK scores had less of an effect on the course of illness if the mother had good skills (Salerno et al., 2016a), and future studies could explore if this holds true amongst Spanish caregivers. Another instrument that could be utilized among parents of adolescent ED patients in Spain is the Parent Versus Anorexia Nervosa (PvAN) scale, which measures parental self-efficacy. Previous studies have found that parental self-efficacy has a positive effect on a number of patient outcomes among adolescents with AN (Byrne, Accurso, Arnow, Lock, & Le Grange, 2015; Robinson, Strahan, Girz, Wilson, & Boachie, 2013). While generic measures have shown that the Maudsley caregiver interventions increase caregiver’s self-efficacy (Goddard et al., 2011a), this disease specific instrument may be more appropriate for measuring the ability of this intervention to increase self-efficacy in parents of adolescents with AN.

Future studies would also benefit from assessing the patient’s perspective on family functioning. Patient’s reports on the family climate have been found to be associated with recovery (Nilsson, Engstrom, & Hagglof, 2012) and it has been suggested that patient reports of EE may be more accurate and important than their parents (Nelemans, Hale, Branje, Hawk, & Meeus, 2014; Winn et al., 2007). Patients with a long illness duration have underestimated the extent of the negative caregiving experience reported by their caregivers (Coomber & King, 2013) and future studies could determine if the same was true for patients with a short illness duration. Furthermore, exploring the experience of siblings may also be important as previous research suggests that siblings are also affected by the illness (Dimitropoulos, Klopfer, Lazar,
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& Schacter, 2009), and non-ill siblings may differ from the patient in their observations regarding family functioning (Dimitropoulos, Freeman, Bellai, & Olmsted, 2013).

As this was the first study to examine ED caregiver coping strategies in Spain and the second to use an entirely adolescent sample to assess ED caregiver coping, there are a number of future research questions that could be addressed in relation to this variable. An ED-specific measure to assess caregiver coping was recently developed (Fiorillo et al., 2015) and future studies could apply this instrument along with another widely used generic instrument, such as that used in the present study, to determine the convergent validity as well as any possible differences for predictors of the distinct coping strategies. It would also be interesting to replicate the analyses carried out by Coomber and King (2012) to determine if maladaptive coping predicts a negative caregiving experience and distress among parents of adolescent ED patients. Finally, future longitudinal studies could clarify the relationship that was observed in the current study between appraisal of the caregiving experience and type of coping in order to determine if there is a causal relationship between these two variables.
References


Conclusions
• In general, ED parents, particularly fathers, showed less impairment on family caregiving variables than SUD parents, which may be due to greater stigma surrounding SUD or less understanding about its causes. However, the fact that parents of both patient groups expressed greater EOI and mental health difficulties than HC parents suggests that these may be shared experiences among parents caring for an adolescent child with a psychiatric illness.

• Results suggest that caring for an adolescent with an ED differs from caring for a healthy teen in that these parents present a more negative caregiving experience, higher EE, and more mental health difficulties. These findings present several parallels with previous studies employing healthy control groups in the assessment of ED family caregiving and underscore the importance of targeting parental EE and mental health in treatment interventions.

• Fathers have previously been underrepresented in ED family caregiving research and therapy. The present results highlight the importance of including both parents due to the fact that they both present impairments and unhelpful responses to the illness. However, as mothers often spend more hours with the patient, they may be more affected by the illness in terms of mental and physical health difficulties and a negative caregiving experience, which should be taken into consideration in caregiver interventions.

• Compared to ED caregiving studies that have not used an exclusively adolescent sample, our parents scored lower on EE, accommodating behaviors, psychological distress and a negative caregiving experience. This may mean that the unhelpful responses to the ED, which the interpersonal maintenance model of EDs proposes serve to maintain the illness, are not yet be in place. Furthermore, caregiver’s mental health may not yet be as affected, thus making it an ideal moment for intervention.
• Maladaptive coping strategies have been found to predict a negative caregiving experience and psychological distress among ED caregivers. However, our results indicate that ED parents do not use maladaptive coping more frequently than parents of healthy teens. Additional studies are needed to continue exploring the role of coping strategies among ED caregivers.

• This study was the first to assess the relationship between appraisal of the caregiving experience and coping strategies. Results revealed that among ED parents, a positive appraisal was significantly associated with adaptive coping, while among mothers, a negative appraisal was associated with maladaptive coping. This relationship could be further explored in longitudinal studies and with other samples of ED caregivers.

• Although more than half of the patients from both groups met criteria for a comorbid Axis I disorder, the results revealed that they differed from one another in regards to the most common types of psychiatric comorbidity. While comorbid internalizing disorders were most common among ED patients, SUD patients were more likely to present a comorbid diagnosis of an externalizing disorder.

• The observed relationship between maternal distress and patient’s depression and ED severity is of particular concern. According to the interpersonal maintenance model of EDs, this could be a sign of a vicious feedback cycle between mother’s and patient’s psychological distress. That is, the adolescent’s psychological distress and ED severity may lead mothers to experience increased distress which then worsens their child’s distress and ED symptoms.

• The present study addressed several gaps in the existing research on ED family caregiving. In particular, it was novel in its measurement of a number of caregiving variables among both parents of adolescent patients with early onset ED, as well as its recruitment of two
CONCLUSIONS

comparison groups: parents caring for a patient with a similar psychiatric disorder (SUD) and parents of healthy adolescents whose age was similar to that of the ED patients.

• This cross-sectional study allowed for us to get a picture of the experience of adolescent patients with an ED and the parents caring for them. However, future longitudinal studies are needed in order to observe the progression of the illness and the caregiver variables, as well as to assess relationships between patient and caregiver variables over time. These studies would also provide us with empirical evidence regarding the usefulness of the interpersonal maintenance model of EDs in caregivers of adolescent patients.

• Finally, although interventions with ED caregivers have tended to focus on areas in which they are impaired and what needs to be improved (e.g. EE, accommodating behavior, etc.), the current results suggest that these caregivers may also bring with them particular strengths. For example, they use certain adaptive coping strategies more than parents of healthy teens and their acknowledgement of positive aspects of the caregiving experience is associated with greater use of adaptive coping. Future interventions may benefit from incorporating these findings in order to help parents effectively use the resources that they already have at their disposal when caring for their child with an ED.
• En general, los padres TCA, sobre todo los varones, mostraron menos problemas en las variables del cuidado familiar. Este resultado podría ser debido a que hay más estigma asociada con los TCS o porque hay menos comprensión sobre sus causas. Sin embargo, el hecho de que, en comparación a los padres sanos, los padres de los dos grupos de pacientes mostraron más sobreimplicación emocional y dificultades con su estado de salud mental sugiere que podrían ser aspectos compartidos entre los padres que están cuidando a un hijo adolescente con una enfermedad mental.

• Los resultados sugieren que la experiencia de cuidar a un adolescente con un TCA es distinta a la de cuidar a un adolescente sano dado que estos padres muestran una experiencia como cuidador más negativa, niveles de EE más alta, y más dificultades con su salud mental. Estos hallazgos son parecidos a los encontrado por estudios anteriores que han utilizado una muestra sana en la evaluación del cuidado familiar TCA y subrayan la importancia de intervenir en la EE y la salud mental de los padres.

• Los padres han sido infrarrepresentados en la terapia familiar y en las investigaciones sobre el cuidado familiar de los pacientes TCA. Los resultados actuales subrayan la importancia de incluir los dos padres dado que ambos presentan dificultades y respuestas inútiles a la enfermedad. Sin embargo, como las madres suelen pasar más horas con el paciente, su salud física y mental puede estar más afectada por la enfermedad y hay que tenerlo en cuenta en las intervenciones dirigidas a los cuidadores.

• En comparación a los estudios sobre el cuidado de los pacientes TCA que no utilizaron una muestra de pacientes adolescentes, nuestros padres presentaban puntuaciones más bajas en EE, conductas de acomodación, angustia psicológica y la experiencia negativa como cuidador. Esto podría significar que los factores que el modelo de mantenimiento interpersonal de TCA propone que sirven a mantener la enfermedad todavía no están
CONCLUSIONES

establecidos, la salud mental del cuidador aún no está afectado y podría ser un momento ideal para intervenir con los cuidadores.

• Estudios anteriores han encontrado que las estrategias de afrontamiento no adaptativas predicen una experiencia negativa como cuidador y la angustia psicológica en los cuidadores TCA. Sin embargo, nuestros resultados sugieren que los padres TCA no utilizan este tipo de estrategias con más frecuencia que los padres de adolescentes sanos. Sería necesario llevar a cabo estudios adicionales para seguir explorando el papel de las estrategias de afrontamiento en los cuidadores TCA.

• El estudio actual era el primero en evaluar la relación entre la experiencia como cuidador y las estrategias de afrontamiento. Los resultados muestran que para los padres TCA, la evaluación positiva estaba asociada significativamente con el afrontamiento adaptativa mientras que para las madres TCA, la evaluación negativa estaba asociada con el afrontamiento no adaptativa. Esta relación podría ser explorado más al fondo con estudios longitudinales y utilizando otras muestras de cuidadores TCA.

• Aunque más que la mitad de los pacientes TCA y TCS cumplieron los criterios para un trastorno psiquiátrico comórbido, los resultados muestran que los dos grupos se diferencian en cuanto a los tipos de trastornos comórbidos más comunes. Mientras que los trastornos por internalización fueron los más comunes en los pacientes TCA, los trastornos por externalización fueron más frecuentes en los pacientes TCS.

• La relación observada entre la angustia maternal y la depresión y la severidad de la enfermedad de los pacientes con TCA es especialmente preocupante. Según el modelo de mantenimiento interpersonal de TCA esta relación podría ser indicativa de un ciclo vicioso de retroalimentación entre la salud mental de la madre y el paciente. La angustia psicológica y la severidad del TCA del adolescente podría llevar a su madre a experimentar más
CONCLUSIONES

angustia psicológica, con lo cual llevaría a los adolescentes a mostrar aún más angustia psicológica y empeoramiento de los síntomas de su enfermedad.

- El estudio actual abordó varias lagunas en el campo de investigación sobre la experiencia de los familiares de los pacientes con TCA. En particular, fue novedoso en su evaluación de varias variables en una muestra de padres de pacientes adolescentes con un TCA de inicio temprano y la recogida de dos grupos comparativos: padres que estaban cuidando a un paciente con un trastorno psiquiátrico parecido (TCS) y padres de adolescentes sanos con una edad parecida a los pacientes TCA.

- Este estudio transversal nos permitió tener una idea de la experiencia de los pacientes adolescentes con un TCA y los padres quienes les estaban cuidando. Sin embargo, hace falta llevar a cabo estudios en el futuro con un diseño longitudinal para poder observar la progresión tanto de la enfermedad como las variables de los cuidadores y la relación entre las variables de los pacientes y los cuidadores. Este tipo de estudio también podría proveer evidencia empírica sobre la utilidad del modelo de mantenimiento interpersonal de TCA en los cuidadores de pacientes adolescentes.

- Por último, hasta ahora las intervenciones con los cuidadores TCA han estado enfocadas en las áreas en que los cuidadores presentan deficiencias y podrían mejorar (EE, conductas de acomodación, etc.). Sin embargo, los resultados actuales sugieren que estos cuidadores también presentan algunas fortalezas. Por ejemplo, tienden a utilizar ciertas estrategias adaptativas de afrontamiento más que los padres sanos y su reconocimiento de aspectos positivos del cuidar al paciente está asociado con más uso de estrategias adaptativas. Intervenciones futuras con los cuidadores TCA podrían incluir estos aspectos para ayudar los padres a utilizar, de una forma eficaz, los recursos que ya tienen a su disposición.
CURRICULUM VITAE

PERSONAL INFORMATION

Name: Melissa Christina Parks
Date of Birth: September 1st, 1984
Telephone: +34 633 57 75 27
E-mail: miss.melissa.parks@gmail.com

EDUCATION

May 2013-present
PhD student in Clinical and Health Psychology
Universidad Autónoma de Madrid, Spain
Doctoral Thesis: Coping, family functioning and the experience of caring for an adolescent with an eating disorder: A comparative study

September 2013-August 2014
Undergraduate Degree Recognition-Spain (Homologación del Titulo)
Universidad Autónoma de Madrid/Spanish Minstry of Education
One year of additional coursework and exams in order to have my undergraduate degree recognized in Spain and be eligible for licensure (Colegio Oficial de Psicólogos)

September 2011-June 2013
Master’s Degree in Clinical and Health Psychology
Universidad Autónoma de Madrid, Spain
Master’s Thesis: The uniqueness of male body image: Validation of an instrument to measure body dissatisfaction among Spanish adolescent males.

September 2002-June 2006
Bachelor’s Degree in Psychology, Minor in Sociology
Seattle Pacific University, Seattle, Washington, USA
Merits: Summa cum laude, Alpha Kappa Sigma honor society, Psi Chi, Dean’s List, Faculty of the Year Award, and Young Alumni Award for making a difference in the community.

PROFESSIONAL EXPERIENCE

September 2011-Present
Universidad Autónoma de Madrid (Madrid, Spain)
Graduate Research Assistant
Assisting with a grant funded multi-study project entitled “Biological, Psychological and Familiar Markers Present for Optimizing Diagnosis, Prognosis and Treatment of Eating Disorders and Children Obesity: ANOBAS study.” (Economy and Competitiveness Ministry Grant, Madrid, Spain). Aided in the development of the study protocol, administration of diagnostic interviews (Schedule for Affective Disorders and Schizophrenia for School-Age Children--Present and Lifetime Version, K-SADS and Eating Disorders Examination, EDE) and relevant questionnaires, creation and management of SPSS databases, training of new research assistants, development of patient reports, literature reviews, preparation of manuscripts and conference presentations and translation of relevant research materials (scientific articles and questionnaires).

September 2014-present
Private Practice
Mental Health Therapist
In-person and online therapy for individuals around the world. Clients include expats with a variety of different mental health concerns (mood and anxiety disorders, the grieving process, relationship concerns, emotion regulation difficulties, etc.) and individuals with eating disorders and body image concerns. Facilitated a support group for expat women from September 2014 to August 2016
June 2016-December 2017  
**GGZ Rivierduinen Eating Disorders Center Ursula / Leiden University Medical Center (Leiden, Netherlands)**  
*Visiting Researcher (Erasmus + Internship)*  
Collaboration with the center’s research team on a variety of projects at the oldest and largest specialized treatment program for individuals with eating disorders in the Netherlands. Gained additional knowledge regarding statistical analyses, study design and the latest developments in the field of eating disorders through serving as a co-reviewer for articles submitted to the International Journal of Eating Disorders, Eating and Weight Disorders and Eating Behaviors.

September 2014-September 2016  
**SINEWS Multilingual Therapy Institute (Madrid, Spain)**  
*Mental Health Therapist*  
Individual, couples and family therapy (in-person and online) for study abroad students, expats, and multicultural couples in both English and Spanish. The designated body image and eating disorders specialist of the team, I also saw patients who present with anxiety and mood disorders, personality disorders, ADHD and difficulties in cultural adaptation. All hours from March 2014-September 2015 were jointly supervised by a licensed mental health therapist and psychiatrist.

September 2012-June 2014  
**Usara Mental Health Center (Madrid, Spain)**  
*Clinical Research Assistant*  
Assisted with a study comparing the effectiveness of Maudsley based family treatment support groups versus a psychoeducation group for parents of adolescent and adult patients with a current eating disorder. Responsibilities included preparation and facilitation of groups, administration of questionnaires, management of research material and SPSS databases, training of new research assistants and data analysis.

September 2012-June 2013  
**Body Image and Eating Disorder Consulting Center, Center for Applied Psychology, Universidad Autónoma de Madrid (Madrid, Spain)**  
*Individual and Family Therapist (Master’s Degree Practicum)*  
Three hundred supervised clinical hours working with patients diagnosed with an eating disorder. Responsible for intake interviews, correction of patient questionnaires, development of treatment plans and providing therapy to patients and their family members.

September 2012-June 2013  
**Usara Mental Health Center (Madrid, Spain)**  
*Individual, Family and Group Therapist (Master’s Degree Practicum)*  
Two hundred supervised clinical hours with patients diagnosed with an eating disorder and their families. Tasks included intake assessments and interviews, development and implementation of treatment plans and assisting with family support groups.

February 2010-August 2011  
**Universidad Autónoma de Madrid (Madrid, Spain)**  
*Volunteer Clinical Research Assistant*  
Assisted the body image and eating disorders research team with various studies, including the validation of instruments to measure male body image in Spain. Responsible for executing literature reviews, administration of study questionnaires, management of SPSS databases, assistance with preparation of manuscripts and conference presentations, and presenting psychoeducational workshops on eating disorder prevention to study participants.
March-June 2009  
**Seattle Pacific University (Seattle, Washington, USA)**  
*Study Abroad Teaching Assistant*  
Led class discussions regarding European language, culture, literature and other relevant topics for a group of fifteen study abroad university students during a twelve week trip throughout Western Europe. Responsible for the planning and organization of extracurricular activities designed to facilitate greater understanding of the language, history and culture of the host countries. Provided emotional support to students through individual mentoring and team building activities.

February 2007-March 2009  
**Seattle Children’s Hospital (Seattle, Washington, USA)**  
*Pediatric Mental Health Specialist on the Inpatient Psychiatric Unit*  
Responsible for managing the milieu through implementation of skill building group curriculums (including DBT groups) according to the developmental age level of participants (ages 3-21). Other tasks included the utilization of verbal de-escalation and effective communication skills in order to execute individual behavior management plans, as well as employing emotion coaching, functional analysis and problem solving skills for patients with a variety of different psychiatric diagnoses and coaching their parents to implement these skills as well. Duties also included the evaluation of the effectiveness of treatment interventions through observation and documentation of patient behavior.

October 2004-March 2009  
**National Eating Disorder Association (Seattle, Washington, USA)**  
*Helpline Volunteer, Intern and Interim Supervisor*  
In a variety of different roles, my duties included the provision of psychoeducational resources, referrals and support to callers from around the country, development and implementation of training materials for new Helpline volunteers, the management of NEDA’s Nationwide Support Group Database and “Ask an Expert” resources, creation of educational handouts distributed on NEDA’s website, assistance with the coordination of the National Awareness Week (NEDAW), and coordination and facilitation of training for new Helpline volunteers.

September 2004-March 2008  
**Seattle Children’s Hospital (Seattle, Washington, USA)**  
*Lead Clinical Research Assistant*  
Volunteered for a study entitled “Randomized Control Trial of Individualized Yoga for the Treatment of Eating Disorders,” administration and coding of the Eating Disorder Examination (EDE), supervision and training of new research assistants, creation of consent and assent forms, and management and entry of study related data, administration of participant questionnaires, charting for individual participants and literature reviews.

July 2004-February 2005  
**Ruth Dykeman Children’s Center (Burien, Washington, USA)**  
*Residential Counsellor for Children and Adolescents (Undergraduate Internship)*  
Provision of direct care and supervision of children with emotional and behavioral problems, collaborating with fellow staff members to creatively develop and implement treatment plans, and utilizing de-escalation techniques to intervene in crises.

**PUBLICATIONS IN PEER-REVIEWED JOURNALS**


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**MANUSCRIPTS IN PREPARATION**


Blanco, M., Sepulveda A.R., La Cruz, T., Parks, M., Real, B., & Martin, Y. (under review). Examining maternal psychopathology, family functioning and coping skills in childhood obesity: Case-control ANOBAS study. *European Eating Disorders Review*

**BOOK CHAPTERS**


[1] Book published by the AEPC comprised of presentations at the VI International and XI National Congress of Clinical Psychology

[2] Book published by the AEPC comprised of presentations at the V International and X National Congress of Clinical Psychology
PROFESSIONAL PRESENTATIONS


POSTER PRESENTATIONS


WORKSHOP PRESENTATIONS

• **Introduction to Mindfulness Course.** Creation and implementation of the curriculum for a four week (8.0 hours total) course designed to introduce participants to the practice of Mindfulness and the possible benefits it can have on their daily lives. Madrid, Spain, 2015 –present

• **Eating Disorders Prevention Workshop** Assisted with the creation of a program curriculum designed to raise awareness of balanced eating, exercise and body image amongst college women. Facilitated program presentations on a college campus and trained new program facilitators. Seattle Pacific University, Seattle, Washington, United States, 2005 –2009.

PROFESSIONAL ASSOCIATIONS

• Academy of Eating Disorders
• Spanish Association for the Study of Eating Disorders (Asociacion Española para el Estudio de los Trastornos de la Conducta Alimentaria)
• National Eating Disorders Association
• Madrid Psychological Association (Colegio Oficial de Psicologos de Madrid, #M-29447)

GRANTS AND AWARDS

• **Research Excellence Travel Fellowship.** Clinical & Health Psychology PhD Program, Autonomous University of Madrid, Spain.

• **Erasmus + Internship Grant.** Office of International Relations, Autonomous University of Madrid, Spain.

SKILLS AND ABILITIES

• **Languages:** English: native speaker; Spanish: working proficiency
• **Software:** Proficient in SPSS, MS Office, Endnote