



Repositorio Institucional de la Universidad Autónoma de Madrid

<https://repositorio.uam.es>

Esta es la **versión de autor** del artículo publicado en:

This is an **author produced version** of a paper published in:

European Eating Disorders Review 24.4 (2016): 294–303

DOI: <http://dx.doi.org/10.1002/erv.2440>

Copyright: © 2016 John Wiley & Sons, Ltd and Eating Disorders Association

El acceso a la versión del editor puede requerir la suscripción del recurso
Access to the published version may require subscription

**Title: Family functioning and quality of life among families in eating disorders:
A comparison with substance-related disorders and healthy controls**

Dimitra Anastasiadou, PhD^{1*}, Ana R. Sepulveda, PhD¹, Julio César Sánchez, MsC²,
Melissa Parks, MsC¹, Tamara Álvarez, MsC¹, Montserrat Graell, MD PhD³

¹Department of Biological and Health Psychology, Faculty of Psychology,
Autonomous University of Madrid, Madrid, Spain.

²Proyecto Hombre – Programa Soporte, Madrid, Spain.

³ Eating Disorders Program, Child and Adolescence Psychiatry Department, Niño Jesus
University Hospital, CIBERSAM, Madrid, Spain.

**Correspondence* to: Dimitra Anastasiadou, Department of Biological and Health Psychology, Faculty of Psychology, Autonomous
University of Madrid, Madrid, Spain. E-mail: dimi.anastasiadou@gmail.com

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 to 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

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 et al., 1995), insulin-dependent diabetes mellitus (Sim et al., 2009) and healthy controls (Kyriacou et al., 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 et al., 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 of Drug Abuse). 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, & Graell, in press; Kyriacou et al., 2008a; Whitney et al., 2005). However, prior studies have not reported gender differences in levels of criticism (Anastasiadou et al., in press; van Furth et al., 1996).

On the basis of the empirical studies discussed above, 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 = 12-22) 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 = 12-18) 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. Sociodemographic 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 years 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 criteria and a Body Mass Index (BMI) of at least 17.5 kg/m²; 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 (2 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 (8 families refused to participate due to 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 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, 2 had problems with time and 4 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- 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 α 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 α of 0.92.

SF-36 Health Survey (SF-36) (Ware, Kosinski, & Keller, 1994). 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 α of 0.71-0.94). Also, reliability estimates for the two summary scores usually exceeded 0.90 (Ware et al., 1994).

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 MANCOVAs were carried out to assess the effect of carer group (ED, SRD, 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, 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 (η^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 Bulimia Nervosa 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 ($M = 51.78$, $SD = 10.33$ versus $M = 55.63$, $SD = 8.63$ and $M = 36.15$, $SD = 13.00$ versus $M = 41.89$, $SD = 13.86$, 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, 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-Mental Component. The last MANCOVA analysis 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-Mental Component. Results from the post-hoc analyses, performed separately for fathers and mothers, are summarized in Table 3 and Table 4, respectively.

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; Sim et al., 2009; 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/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 behaviour (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 of 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 above, 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., in press) and other clinical samples, such as dementia (Pinquart & Sorensen, 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 (Bedard et al., 2005; O'Rourke & Tuokko, 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 sociodemographic 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 female 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; National Institute for Clinical Excellence Clinical Guideline, 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

Dr. Sepulveda has a postdoctoral Ramon and Cajal scholarship from the Spanish Ministry of Science and Innovation (RYC-2009-05092) as well as a project funding from the same Ministry (PSI2011-23127). Dr. Anastasiadou was awarded with a Research Fellowship for students of PhD Programmes distinguished with Mention of Excellence. Mr. Graell is a member of the Spanish Psychiatric Research Network

(CIBERSAM). We express our gratitude to all the families who participated in this study, as well as to the headmasters and teachers from the Secondary Schools IES La Estrella, IES Las Musas and IES Alameda de Osuna that helped us with the study. Finally, we would like to express our thanks to our psychologist collaborators, L. Gonzalez and C. Bustos, who helped us with the sample recruitment.

References

- Abrahams, S., & Llewellyn-Jones, D. (2001). *Eating disorders (5th edition)*. New York: Oxford University Press.
- Albert, U., Salvi, V., Saracco, P., Bogetto, F., & Maina, G. (2007). Health-related quality of life among first-degree relatives of patients with obsessive-compulsive disorder in Italy. *Psychiatr Serv*, 58(7), 970-976. doi: 10.1176/appi.ps.58.7.970
- Alonso, J., Prieto, L., & Anto, J. M. (1995). [The Spanish version of the SF-36 Health Survey (the SF-36 health questionnaire): an instrument for measuring clinical results]. *Med Clin (Barc)*, 104(20), 771-776.

- American Psychiatric Association, APA. (2002). *Diagnostic and statistical manual of mental disorders (DSM-IV-TR)*. Washington, DC.
- Anastasiadou, D., Cuellar-Flores, I., Sepulveda, A. R., & Graell, M. (in press). The relationship between dysfunctional patterns of families' response to the illness and symptom severity in adolescent patients with anorexia nervosa at illness onset: A gender-specific approach. *Women & Health*.
- Anastasiadou, D., Medina-Pradas, C., Sepulveda, A. R., & Treasure, J. (2014). A systematic review of family caregiving in eating disorders. *Eat Behav*, 15(3), 464-477. doi: 10.1016/j.eatbeh.2014.06.001
- Becerra, J. A. (2009). Family expressed emotion and drug use among young people [Emocion expresada familiar y uso de drogas en juvenes]. *Salud y drogas*, 9(2), 209-221.
- Bedard, M., Kuzik, R., Chambers, L., Molloy, D. W., Dubois, S., & Lever, J. A. (2005). Understanding burden differences between men and women caregivers: the contribution of care-recipient problem behaviors. *Int Psychogeriatr*, 17(1), 99-118.
- Blair, C., Freeman, C., & Cull, A. (1995). The families of anorexia nervosa and cystic fibrosis patients. *Psychol Med*, 25(5), 985-993.
- Brady, K. T., & Randall, C. L. (1999). Gender differences in substance use disorders. *Psychiatr Clin North Am*, 22(2), 241-252.
- Copello, A. G., Velleman, R. D., & Templeton, L. J. (2005). Family interventions in the treatment of alcohol and drug problems. *Drug Alcohol Rev*, 24(4), 369-385. doi: 10.1080/09595230500302356
- Curran, L., Schmidt, U., Treasure, J., & Jick, H. (2005). Time trends in eating disorder incidence. *Br J Psychiatry*, 186, 132-135. doi: 10.1192/bjp.186.2.132
- De la Peña, F., Ulloa, R., Higuera, F., Ortiz, S., Arechavaleta, B., Foullux, C., . . . Dominguez, E. (2002). *Interrater reliability of the Spanish version of the K-SADS-PL*. Paper presented at the American Academy of Child and Adolescent Psychiatry Annual Meeting, San Francisco, CA.
- Dimitropoulos, G., Carter, J., Schachter, R., & Woodside, D. B. (2008). Predictors of family functioning in carers of individuals with anorexia nervosa. *Int J Eat Disord*, 41(8), 739-747. doi: 10.1002/eat.20562
- Eisler, I., Dare, C., Hodes, M., Russell, G., Dodge, E., & Le Grange, D. (2000). Family therapy for adolescent anorexia nervosa: the results of a controlled comparison of two family interventions. *J Child Psychol Psychiatry*, 41(6), 727-736.
- Ghodse, A. H., & Galea, S. (2005). Families of people with drug abuse In N. Satorius, J. Leff, J. Lopez-Ibor, M. Maj & A. Okasha (Eds.), *Families and mental disorders: From burden to empowerment*. Chichester, England: Wiley.
- Goddard, E., Macdonald, P., Sepulveda, A. R., Naumann, U., Landau, S., Schmidt, U., & Treasure, J. (2011). Cognitive interpersonal maintenance model of eating disorders: intervention for carers. *Br J Psychiatry*, 199(3), 225-231. doi: 10.1192/bjp.bp.110.088401
- Graap, H., Bleich, S., Herbst, F., Trostmann, Y., Wancata, J., & de Zwaan, M. (2008). The needs of carers of patients with anorexia and bulimia nervosa. *Eur Eat Disord Rev*, 16(1), 21-29. doi: 10.1002/erv.804

- Grover, M., Williams, C., Eisler, I., Fairbairn, P., McCloskey, C., Smith, G., . . . Schmidt, U. (2011). An off-line pilot evaluation of a web-based systemic cognitive-behavioral intervention for carers of people with anorexia nervosa. *Int J Eat Disord*, 44(8), 708-715. doi: 10.1002/eat.20871
- Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C., . . . Glossop, R. (2004). Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *CMAJ*, 170(12), 1795-1801.
- Gutierrez-Maldonado, J., Caqueo-Urizar, A., & Kavanagh, D. J. (2005). Burden of care and general health in families of patients with schizophrenia. *Soc Psychiatry Psychiatr Epidemiol*, 40(11), 899-904. doi: 10.1007/s00127-005-0963-5
- Haigh, R., & Treasure, J. (2003). Investigating the needs of carers in the area of eating disorders: Development of the Carers' Needs Assessment Measure (CaNAM). *Eur Eat Disord Rev*, 11(2), 125-141.
- Hibbs, E. D., Hamburger, S. D., Kruesi, M. J., & Lenane, M. (1993). Factors affecting expressed emotion in parents of ill and normal children. *Am J Orthopsychiatry*, 63(1), 103-112.
- Holtom-Viesel, A., & Allan, S. (2014). A systematic review of the literature on family functioning across all eating disorder diagnoses in comparison to control families. *Clin Psychol Rev*, 34(1), 29-43. doi: 10.1016/j.cpr.2013.10.005
- Hoste, R. R., Labuschagne, Z., Lock, J., & Le Grange, D. (2012). Cultural variability in Expressed Emotion among families of adolescents with anorexia nervosa. *Int J Eat Disord*, 45(1), 142-145. doi: 10.1002/eat.20888
- Hoyle, D., Slater, J., Williams, C., Schmidt, U., & Wade, T. D. (2013). Evaluation of a web-based skills intervention for carers of people with anorexia nervosa: a randomized controlled trial. *Int J Eat Disord*, 46(6), 634-638. doi: 10.1002/eat.22144
- Kaufman, J., Birmaher, B., Brent, D., Rao, U., Flynn, C., Moreci, P., . . . Ryan, N. (1997). Schedule for Affective Disorders and Schizophrenia for School-Age Children-Present and Lifetime Version (K-SADS-PL): initial reliability and validity data. *J Am Acad Child Adolesc Psychiatry*, 36(7), 980-988. doi: 10.1097/00004583-199707000-00021
- Kessler, R. C., Angermeyer, M., Anthony, J. C., R. D. E. G., Demyttenaere, K., Gasquet, I., . . . Ustun, T. B. (2007). Lifetime prevalence and age-of-onset distributions of mental disorders in the World Health Organization's World Mental Health Survey Initiative. *World Psychiatry*, 6(3), 168-176.
- Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry*, 62(6), 593-602. doi: 10.1001/archpsyc.62.6.593
- Kloss, J. D., & Lisman, S. A. (2003). Clinician attributions and disease model perspectives of mentally ill, chemically addicted patients: a preliminary investigation. *Subst Use Misuse*, 38(14), 2097-2107.
- Klump, K. L., Bulik, C. M., Kaye, W. H., Treasure, J., & Tyson, E. (2009). Academy for eating disorders position paper: eating disorders are serious mental illnesses. *Int J Eat Disord*, 42(2), 97-103. doi: 10.1002/eat.20589
- Kyriacou, O., Treasure, J., & Schmidt, U. (2008a). Expressed emotion in eating disorders assessed via self-report: an examination of factors associated

- with expressed emotion in carers of people with anorexia nervosa in comparison to control families. *Int J Eat Disord*, 41(1), 37-46. doi: 10.1002/eat.20469
- Kyriacou, O., Treasure, J., & Schmidt, U. (2008b). Understanding how parents cope with living with someone with anorexia nervosa: modelling the factors that are associated with carer distress. *Int J Eat Disord*, 41(3), 233-242. doi: 10.1002/eat.20488
- Lutzky, S. M., & Knight, B. G. (1994). Explaining gender differences in caregiver distress: the roles of emotional attentiveness and coping styles. *Psychol Aging*, 9(4), 513-519.
- Martin, J., Padierna, A., Aguirre, U., Quintana, J. M., Hayas, C. L., & Munoz, P. (2011). Quality of life among caregivers of patients with eating disorders. *Qual Life Res*, 20(9), 1359-1369. doi: 10.1007/s11136-011-9873-z
- National Institute for Clinical Excellence Clinical Guideline, NICE. (2004). Eating disorders. Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa, and related eating disorders. . from <https://http://www.nice.org.uk/guidance/cg9/resources/guidance-eating-disorders-pdf>
- National Institute of Drug Abuse, NIDA. The Science of Drug Abuse & Addiction. Health Effects. Retrieved 23/02/2015, from <http://www.drugabuse.gov/drugs-abuse/commonly-abused-drugs/health-effects>
- National Institute of Drug Abuse, NIDA. (2012). DrugFacts: Understanding Drug Abuse and Addiction. from <http://www.drugabuse.gov/publications/drugfacts/understanding-drug-abuse-addiction>
- O'Rourke, N., & Tuokko, H. A. (2004). Caregiver burden and depressive symptomatology: The association between constructs over time. *Clin Gerontol*, 27(4), 41-52.
- Oliva, A. (2006). Family relationships and adolescent development [Relaciones familiares y desarrollo adolescente]. *Anuario de Psicología*, 37(3), 209-223.
- Orford, J., Velleman, R., Copello, A. G., Templeton, L. J., & Ibanga, A. (2010). The experiences of affected family members: A summary of two decades of qualitative research. *Drugs: Education, prevention and policy*, 17(s1), 44-62.
- Padierna, A., Martín, J., Aguirre, U., González, N., Muñoz, P., & Quintana, J. M. (2013). Burden of caregiving amongst family caregivers of patients with eating disorders. *Soc Psychiatr Psychiatr Epidemiol*, 48, 151-161.
- Perkins, S., Winn, S., Murray, J., Murphy, R., & Schmidt, U. (2004). A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: The emotional impact of caring. *Int J Eat Disord*, 36(3), 256-268. doi: 10.1002/eat.20067
- Perlick, D., Clarkin, J. F., Sirey, J., Raue, P., Greenfield, S., Struening, E., & Rosenheck, R. (1999). Burden experienced by care-givers of persons with bipolar affective disorder. *Br J Psychiatry*, 175, 56-62.
- Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. *J Gerontol B Psychol Sci Soc Sci*, 61(1), P33-45.

- Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research & Practice*, 19(3), 276-288.
- Schene, A. H. (1990). Objective and subjective dimensions of family burden. *Soc Psychiatry Psychiatr Epidemiol*, 25(6), 8. doi: 10.1007/BF00782883
- Schmidt, U., & Treasure, J. (2006). Anorexia nervosa: valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *Br J Clin Psychol*, 45(Pt 3), 343-366.
- Sepulveda, A. R., Anastasiadou, D., Rodriguez, L., Almendros, C., Andres, P., Vaz, F., & Graell, M. (2014). Spanish validation of the Family Questionnaire (FQ) in families of patients with an eating disorder. *Psicothema*, 26(3), 321-327. doi: 10.7334/psicothema2013.310
- Sepulveda, A. R., Graell, M., Almendros, C., Berbel, E., Andres, P., & Carrobbles, J. A. (in preparation). Psychometric properties of the Spanish version of the Experience Caregiving Inventory (ECI) for carers of people with eating disorders.
- Sepulveda, A. R., Graell, M., Berbel, E., Anastasiadou, D., Botella, J., Carrobbles, J. A., & Morande, G. (2012). Factors associated with emotional well-being in primary and secondary caregivers of patients with eating disorders. *Eur Eat Disord Rev*, 20(1), e78-84. doi: 10.1002/erv.1118
- Sepulveda, A. R., Kyriacou, O., & Treasure, J. (2009). Development and validation of the accommodation and enabling scale for eating disorders (AESED) for caregivers in eating disorders. *BMC Health Serv Res*, 9, 171. doi: 10.1186/1472-6963-9-171
- Sepulveda, A. R., Todd, G., Whitaker, W., Grover, M., Stahl, D., & Treasure, J. (2010). Expressed emotion in relatives of patients with eating disorders following skills training program. *Int J Eat Disord*, 43(7), 603-610. doi: 10.1002/eat.20749
- Sim, L. A., Homme, J. H., Lteif, A. N., Vande Voort, J. L., Schak, K. M., & Ellingson, J. (2009). Family functioning and maternal distress in adolescent girls with anorexia nervosa. *Int J Eat Disord*, 42(6), 531-539. doi: 10.1002/eat.20654
- SPSS. (2006). *Statistical Package for the Social Sciences (SPSS) software version 15.0*. Chicago, USA.
- Szmukler, G. I., Burgess, P., Herrman, H., Benson, A., Colusa, S., & Bloch, S. (1996). Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory. *Soc Psychiatry Psychiatr Epidemiol*, 31(3-4), 137-148.
- Treasure, J., Murphy, T., Szmukler, G., Todd, G., Gavan, K., & Joyce, J. (2001). The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis. *Soc Psychiatry Psychiatr Epidemiol*, 36(7), 343-347.
- Treasure, J., & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: a summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *J Eat Disord*, 1, 13. doi: 10.1186/2050-2974-1-13
- Uehara, T., Kawashima, Y., Goto, M., Tasaki, S. I., & Someya, T. (2001). Psychoeducation for the families of patients with eating disorders and changes in expressed emotion: A preliminary study. *Compr Psychiatry*, 42(2), 132-138. doi: 10.1053/comp.2001.21215

- van Furth, E. F., van Strien, D. C., Martina, L. M., van Son, M. J., Hendrickx, J. J., & van Engeland, H. (1996). Expressed emotion and the prediction of outcome in adolescent eating disorders. *Int J Eat Disord*, 20(1), 19-31. doi: 10.1002/(SICI)1098-108X(199607)20:1<19::AID-EAT3>3.0.CO;2-7
- Vitousek, K., Watson, S., & Wilson, G. T. (1998). Enhancing motivation for change in treatment-resistant eating disorders. *Clin Psychol Rev*, 18(4), 391-420.
- Ware, J. E., Kosinski, M., & Keller, S. D. (1994). *SF-36 physical and mental health summary scales: A user's manual*. Boston, MA.
- Wendel, J. S., Miklowitz, D. J., Richards, J. A., & George, E. L. (2000). Expressed emotion and attributions in the relatives of bipolar patients: an analysis of problem-solving interactions. *J Abnorm Psychol*, 109(4), 792-796.
- Whitney, J., & Eisler, I. (2005). Theoretical and empirical models around caring for someone with an eating disorder: The reorganization of family life and inter-personal maintenance factors. *Journal of mental health*, 14(6), 575-585.
- Whitney, J., Haigh, R., Weinman, J., & Treasure, J. (2007). Caring for people with eating disorders: factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *Br J Clin Psychol*, 46(Pt 4), 413-428. doi: 10.1348/014466507X173781
- Whitney, J., Murphy, T., Landau, S., Gavan, K., Todd, G., Whitaker, W., & Treasure, J. (2012). A practical comparison of two types of family intervention: an exploratory RCT of family day workshops and individual family work as a supplement to inpatient care for adults with anorexia nervosa. *Eur Eat Disord Rev*, 20(2), 142-150. doi: 10.1002/erv.1076
- Whitney, J., Murray, J., Gavan, K., Todd, G., Whitaker, W., & Treasure, J. (2005). Experience of caring for someone with anorexia nervosa: qualitative study. *Br J Psychiatry*, 187, 444-449. doi: 10.1192/bjp.187.5.444
- Wiedemann, G., Rayki, O., Feinstein, E., & Hahlweg, K. (2002). The Family Questionnaire: development and validation of a new self-report scale for assessing expressed emotion. *Psychiatry Res*, 109(3), 265-279.
- Winn, S., Perkins, S., Murray, J., Murphy, R., & Schmidt, U. (2004). A qualitative study of the experience of caring for a person with bulimia nervosa. Part 2: Carers' needs and experiences of services and other support. *Int J Eat Disord*, 36(3), 269-279. doi: 10.1002/eat.20068
- Winn, S., Perkins, S., Walwyn, R., Schmidt, U., Eisler, I., Treasure, J., . . . Yi, I. (2007). Predictors of mental health problems and negative caregiving experiences in carers of adolescents with bulimia nervosa. *Int J Eat Disord*, 40(2), 171-178. doi: 10.1002/eat.20347
- Zabala, M. J., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: a systematic review. *Eur Eat Disord Rev*, 17(5), 338-349. doi: 10.1002/erv.925

Table 1

Sociodemographic and clinical characteristics of patients

	ED patients (N=48)	SRD patients (N=47)	HC (N=68)	Group statistics <i>F or t; p</i>	<i>Post hoc</i> comparisons
	M (SD)	M (SD)	M (SD)		
Age (years)	14.67 (1.72)	18.15 (2.12)	14.38 (1.40)	74.53; 0.001	SRD > ED = HC
Body Mass Index (kg/m²)	18.16 (1.84)	21.65 (2.13)	21.49 (3.34)	26.45; 0.001	ED < SRD = HC
Illness Duration (months)	12.48 (12.3)	24.22 (16.5)	-	-3.87; 0.001	n.a.
	N (%)			<i>χ²; p-value</i>	
Sex					
Female	48 (100%)	7 (14.9%)	68 (100%)	123.218; 0.001	
Male	0	40 (85.10%)			
Diagnosis					
AN-R	37 (78%)		-		
BN-NP	3 (6%)		-		
EDNOS-R	8 (16%)		-		
Alcohol Abuse		6 (12.2%)	-		
Cannabis Abuse		45 (95.9%)	-		
Cannabis Depend.		29 (61.2%)	-		
Treatment type					
Ambulatory care	10 (20.8%)	0	-		
Home hospitalization	18 (37.5%)	47 (100%)	-		
Day hospital	3 (6.3%)	0	-		
Inpatient	17 (35.4%)	0	-		
Family constitution					
Intact (<i>married/living together</i>)	40 (83.3%)	37 (78.72%)	60 (88.2%)	1.760; 0.415	
Divorced (<i>single/divorced/widowed</i>)	8 (16.67%)	10 (21.28%)	8 (11.8%)		

AN-R: Anorexia Nervosa Restrictive type; BN-NP= Bulimia Nervosa Non-Purging type; EDNOS-R: Eating Disorder Not

Otherwise Specified Restrictive type

Table 2

Sociodemographic data of carers for mothers and fathers separately

	Mothers ED	Mothers SRD	Mothers HC group	
	group N=48	group	N=66	
		N=47		
	N (%)	N (%)	N (%)	χ^2 ; <i>p-value</i>
Educational level				
School/Secondary level	23 (47.9)	16 (34)	17 (26.2)	5.775; 0.056
Degree/Diploma	25 (52.1)	31 (66)	48 (73.8)	
Employment situation				
Full time/Part time	34 (72.3)	37 (78.7)	50 (92.6)	7.335; 0.026
Unemployed/Retired	13 (27.7)	10 (21.3)	4 (7.4)	
Hours of Contact				
< 21h/week	7 (14.6)	22 (46.8)	4 (8)	23.485; 0.001
≥ 21h/week	41 (85.4)	25 (53.2)	46 (92)	
	Fathers ED group	Fathers SRD group	Fathers HC group	
	N=45	N=37	N=50	
	N (%)	N (%)	N (%)	χ^2 ; <i>p-value</i>
Educational level				
School/Secondary level	24 (53.3)	12 (33.3)	13 (26)	7.909; 0.019
Degree/Diploma	21 (46.7)	24 (66.7)	37 (74)	
Employment situation				
Full time/Part time	38 (86.4)	30 (88.2)	38 (82.6)	0.541; 0.763
Unemployed/Retired	6 (13.6)	4 (11.8)	8 (16.4)	
Hours of Contact				
< 21h/week	14 (31.1)	23 (62.2)	3 (7.1)	27.292; 0.001
≥ 21h/week	31 (68.9)	14 (37.8)	39 (92.9)	

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*

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

Asterisk (*) indicates significant differences between groups after Bonferroni correction at $P < 0.05$

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*

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

Asterisk (*) indicates significant differences between groups after Bonferroni correction at $P < 0.05$.