



## Predictors of quality of life and caregiver burden among maternal and paternal caregivers of patients with eating disorders



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### ABSTRACT

This prospective study investigated quality of life and caregiver burden of 244 parent caregivers of 113 Spanish patients with Eating Disorders (ED). One hundred eleven mothers and 70 fathers fulfilled the inclusion criteria. ED patients completed the Hospital Anxiety and Depression Scale (HADS) and the Eating Attitudes Test-26. Caregivers completed the HADS, the Short Form-12 (SF-12), the Involvement Evaluation Questionnaire-EU version, and the Anorectic Behaviour Observation Scale. Descriptive statistics, ANOVA, Chi-square and Fisher's exact test were applied. Among mothers, anxiety and depression and patient age contributed to poorer quality of life. Caregiver variables that affected the burden for mothers were marital status, the mental subscale of the SF-12, and the mother's perception of the severity of her child's illness. Caregiver variables that affected the burden for fathers were the caregiver's anxiety and the physical domain of the SF-12. Among mothers but not fathers, being married was a protective factor of caregiver burden. Our findings suggest that mothers and fathers have different perceptions of their quality of life and caregiver burden, and that mothers of patients with ED may be in considerable need for extra psychosocial support.

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### 1. Introduction

Mental illness in a close relative can be stressful for family members, particularly those who are also the patient's caregiver (Schene, 1990; Szukler et al., 1996; Baronet, 1999; Hunt, 2003). Eating Disorders (EDs) pose special problems for families, as they tend to persist over long periods. For patients with EDs, parents are often the main caregivers and usually participate actively in the treatment process (Zipfel et al., 1998; Nielsen and Bará-Carril, 2003; Steinhausen, 2009).

Caregivers of patients with chronic conditions often feel burdened by the physical and mental stress of providing care and worries about their loved one's health status (Platt, 1985). Individuals caring for a patient with an ED are also exposed to other factors that may influence their mental or emotional health (Treasure, 2010). These include the unwillingness of many ED patients to accept their illness, the outward signs of malnutrition and resulting social stigmatisation, the daily struggles at meal

times, and the frequent alterations in behaviour and mood that often occur with EDs. Such stresses can affect a caregiver's Health-Related Quality of Life (HRQoL), defined as a person's subjective assessment of how a disease and its treatment affect his or her physical, psychological, and social functioning and well-being (Revicki et al., 2000). Caregiver burden refers to the problems, difficulties, and adverse events that affect the life of an individual who provides care to a patient (Platt, 1985). Family caregivers experience this burden on both a practical and an emotional level (Lowyck et al., 2004). Several studies have evaluated the impact on burden of caring for subjects with chronic disorders (Roick et al., 2006), including schizophrenia (van Wijngaarden et al., 2000; Foldemo et al., 2005; Gutiérrez-Maldonado et al., 2005), Alzheimer's disease (Bullock, 2004), obsessive-compulsive disorders (Stengler-Wenzke et al., 2006), depression (van Wijngaarden et al., 2004a), bipolar disorder (Reinares et al., 2006), multiple sclerosis (Buhse, 2008), Parkinson's disease (Spliethoff-Kamminga et al., 2003), cancer (Baider, 2003), stroke (Rigby et al., 2009) and dementia (Etters et al., 2008). Caregiver burden associated with EDs has also been evaluated (Graap et al., 2008a; Sepulveda et al., 2008; Coomber and King, 2011; Padierna et al., 2012). Indeed, some authors have found that family caregivers of ED patients have higher levels of anxiety, depression, and perceived caregiving

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burden than caregivers of patients with other psychiatric illnesses (Treasure et al., 2001; Graap et al., 2008b; Zabala et al., 2009).

Relatives of individuals with a mental illness tend to judge their quality of life, especially their emotional well-being, significantly worse than the general population, and female relatives tend to find themselves more burdened when acting as a caregiver than male relatives (Fleischmann and Klupp, 2004). In a review of the association between gender and psychiatric morbidity, Yee and Schultz found that the majority of studies on depression and burden in caregiving found higher levels of both in female caregivers when compared to male caregivers (Yee and Schulz, 2000). Some studies have found that female caregivers report higher levels of caregiving burden than male caregivers (Bedard et al., 2000; Harwood et al., 2000). Other studies have shown that, in ED patients' families, mothers have higher levels of emotional distress than fathers (Whitney et al., 2005; Kyriacou, et al., 2008).

Identifying factors that may predict caregiver burden and quality of life among parental caregivers of ED patients could improve integrated health care strategies for this type of illness. A number of individual factors are known to determine carers' perceptions of quality of life and caregiver burden (Turró-Garriga et al., 2008). Specific factors that have been implicated include aspects of the patient's illness and the carer's physical and mental states (Baumgarten et al., 1992; Donaldson et al., 1998; Burns and Rabins, 2000). In relation to age, burden is modulated by the age. On the one hand, older caregivers show higher burden because they have coexisted during more time with the patient and the disorder (Caqueo-Urizar and Gutiérrez-Maldonado, 2006; Babarro et al., 2004). On the other hand, there are studies that have found an inverse relation of burden with age (Webb et al., 1998). In relation to educational level, this is a variable that can modulate the degree of burden experienced by the relatives (Phelan et al., 1998; Czuchta and McCay, 2001).

The aim of our study was to evaluate quality of life and caregiver burden among a sample of parents of patients with eating disorders. We asked: Are there any differences between mothers and fathers?, and What variables best predict quality of life and caregiver burden among mothers and fathers caring for a family member with an eating disorder?. The variables we included in our study are those belonging to categories proposed by Baronet (1999): demographic variables such as age or educational level, variables related to caregiver stress (psychological status, quality of life, and caregiver burden), and variables related to the disease, namely the caregiver's perception of the seriousness of the illness of his/her patient or the quality of life and psychological status of the patient (Baronet, 1999; O'Rourke and Tuokko, 2004; Turró-Garriga et al., 2008).

## 2. Methods

### 2.1. Study participants

We conducted a descriptive study of all patients diagnosed with, and treated for, an ED in the Eating Disorders Outpatient Clinic of the Psychiatric Services at one Hospital and one Mental Health Centre, both in Bizkaia, Spain. These institutions, which serve a population of 300,000 inhabitants, are part of the Basque Health Care Service, which provides free, unrestricted care to nearly 100% of the population. Outpatients diagnosed with anorexia nervosa or bulimia nervosa based on criteria established in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) (American Psychiatric Association, 1994), who were between the ages of 16 and 65 years, were eligible for the study. To be included, a patient's psychiatrist had to complete the clinical protocol and his or her caregiver had to complete four questionnaires. Patients were excluded if they had a malignant, severe organic disease, could not complete the questionnaires because of language barriers, or did not give written informed consent to participate in the study.

Caregivers were selected on the basis of being a family caregiver (mother or father) for an outpatient diagnosed with an ED. According to criteria established by

Perlick et al. (2005) a family caregiver is defined as an individual who fulfils at least 3 of the following 5 criteria: (1) is a parent, partner, child, sibling, or other relative; (2) maintains frequent contact with the patient; (3) provides significant financial support to the patient; (4) is often present during the patient's treatment and is aware of the severity of the patient's illness (i.e., accompanies the patient to consultation, participates in consultations and therapy, supervises eating behaviour at home, etc.); and (5) is the person whom the therapy team is asked to contact in the event of an emergency. In our centres, caregivers receive professional counseling from clinicians to help them cope with their relative's ED.

Data collection started in 2007; 1 year follow-ups were conducted through 2008. Psychiatrists collaborating in the study informed their patients about the objectives of the study and requested the participation of their primary caregivers. Those who agreed to take part in the study received the questionnaires and the informed consent form by mail. They were asked to return these by mail using an enclosed, pre-stamped envelope. Caregivers who did not return the information within 20 days were sent a reminder letter.

The same documents were mailed to participants 1 year after the first round of information gathering. As before, those who did not return the information within 20 days were sent a reminder letter.

Family caregivers were included in the study if they provided written informed consent and the patient for whom they were caring also agreed to participate. Exclusion criteria for the caregivers were the same as for the patients.

### 2.2. Measures

The ED patients sociodemographic information was recorded from their medical records.

All ED patients completed the Eating Attitudes Test (EAT-26) (Garner et al., 1982), which assesses the behavioural and cognitive characteristics of ED patients. It consists of 26 items and provides a total score between 0 and 76. Scores above 20 indicate the presence of behaviours or thoughts characteristic of ED individuals. It has been validated in the Spanish population (Castro et al., 1991).

They also completed the Hospital Anxiety and Depression Scale (HADS). This 14-item instrument is used to screen for anxiety and depression in a nonpsychiatric setting (Zigmond and Snaith, 1983). It includes 7 questions on anxiety and 7 on depression, all scored on a 0–3 scale. A score of 0–7 on any subscale indicates the absence of symptoms of anxiety or depression, a score of 8–10 indicates a borderline level of symptoms of anxiety or depression, and scores of 11 or above indicate the presence of symptoms of anxiety or depression. The validity and reliability of the HADS have been confirmed (Quintana et al., 2003), and the scale has been adapted and validated in a Spanish population (Herrmann, 1997).

In addition, each patient's psychiatrist recorded the severity of the patient's ED by completing the Clinical Global Index Scale (CGI) (Guy, 1976).

Caregivers provided self-reported sociodemographic data, including age, gender, marital status, level of education, and relationship to the patient. They also completed four instruments to assess their quality of life, perception of caregiving, mental health, and perception of the patient's illness. As did the patients, caregivers completed the HADS. The three other instruments were:

The Involvement Evaluation Questionnaire EU Version (IEQ-EU). This self-rated questionnaire assesses the consequences or burden of being a caregiver. A 27-item total score can be computed, and items are scored on a 5-point Likert scale. The IEQ-EU has been translated into, and validated in, Spanish (van Wijngaarden et al., 2000) and shows good internal consistency and adequate test-retest reliability. It has been used previously in studies of caregivers of patients with ED, schizophrenia, and depression (van Wijngaarden et al., 2000; van Wijngaarden et al., 2004b; Martín et al., 2011).

The Short-Form 12 (SF-12). This 12-item instrument is widely used to assess Health-Related Quality of Life (HRQoL) (Ware et al., 1996). The SF-12 generates two subscores regarding the individual's perceived health: the Mental Component Summary Scale (MCSS-12) and the Physical Component Summary Scale (PCSS-12). A score above 50 in a summary scale indicates a positive perception of health, a score below 50 indicates a negative perception. We used a version of the SF-12 that has been validated in Spanish (Gandek et al., 1998).

The Anorectic Behaviour Observation Scale (ABOS) (Vandereycken, 1992). This questionnaire is used to evaluate a patient's eating behaviour based on information provided by his or her caregiver. The ABOS consists of 30 items, each with three response options (scored as 0–2). The total score can range from 0 to 60, and is divided into three domains: concern about diet, bulimic behaviour, and hyperactivity. The higher the total score, the greater the patient's pathology. The ABOS has been translated into Spanish (Instituto Nacional de la Salud, 1995).

### 2.3. Data analysis

An exploratory descriptive analysis of the sample was performed using mean and standard deviations for continuous variables (age and scores of the caregivers) and frequencies and percentages for qualitative data. To determine differences between categorical caregivers' sociodemographic characteristics and the type of caregiver (mother/father), we used the Chi Square or Fisher's Exact Test. For the

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