

Brief Report

Preliminary Findings of Caregivers' Burden among Parents of Adolescents with Anorexia Nervosa: An Exploratory Study

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Abstract: Background: The multifactoriality of Anorexia Nervosa (AN) and the specificity of the treatment that provides for the compliance of parents (caregivers) is consolidated in the scientific literature. Caregivers' burden, in addition to negatively affecting parents' Quality of Life (QoL), can act as a maintenance factor for the disorder itself. Aim: Within a much broader research project, this work focuses on a preliminary analysis of the presence and level of burden in couples of parents of adolescents with Eating Disorders (EDs) and related variables. Methods: At a clinic dedicated to EDs, three couples of parents (mean age = 47.50; SD = 2.73) of three female patients with AN (mean age = 16; SD = 1.78), prior to taking charge, which includes protocol, psychoeducation, and family psychotherapy meetings. Caregivers completed a questionnaire consisting of standardized screening tests for assessing psychological assets: (a) Depression Anxiety Stress Scale-21 (DASS-21), (b) Family Strain Questionnaire—Short Form (FSQ-SF), (c) Resilience Scale (RS), and (d) semi-structured interview. Results: High levels of anxiety (18 ± 6.9), stress (13.33 ± 10.26), and depression (12 ± 6.9) are found in mother caregivers, while father caregivers are more resilient (57.33 ± 8.5). A high level of caregivers' burden was associated with being unemployed (3.33 ± 2.51), being a mother (4.33 ± 1.52), and with a highly pathological patient to care for (3 ± 4.24). Conclusions: Evaluating family caregivers of ED patients for risk factors of burden allows them to offer care and reduce the perceived stress of care.

Keywords: adolescents; eating disorders; emotional caregivers' burden; anorexia nervosa



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1. Background

Anorexia Nervosa (AN) is a chronic condition with a maximum incidence rate among adolescents [1]. Patients with Eating Disorders (EDs) are particularly vulnerable, with an ambivalent relationship regarding their desire for recovery, so it is very often complex to engage them in a therapeutic pathway [2]. Currently, Family-Based Therapy (FBT) shows important clinical evidence for the treatment of pediatric AN, and some studies have found faster recovery rates, a significant decrease in hospital readmissions, and associated treatment costs compared to individual psychotherapy [3,4]. Family functioning is defined as the balanced emotional, psychological, and physical interaction among the various members: in a review of the literature on this subject, Holtom-Viesel and Allan [5] documented serious difficulties in family functioning in families diagnosed with EDs compared with control samples.

The term primary caregiver refers to the parent who cares for their child on a daily basis. Several systematic reviews [6,7] have addressed the experience of carers of a person with EDs by investigating the so-called "burden". "Objective burden" is described by the time, in quantitative and qualitative terms, spent with the family member and the tasks performed by the carer, with particular attention paid to meal preparation and support of the ill family member during these times [8]. Carers with high levels of objective burden

have a high risk of developing accommodative behaviors, which are detrimental to the sick family member [9]. “Subjective burden”, on the other hand, refers to the level of psychological distress and is a “parameter” that correlates with the severity of EDs. Caring for a person diagnosed with EDs can contribute to the onset of stress, anxiety, depression, accommodation, and avoidance [10].

The present study, which is part of a much larger research project [11–13], aims to show preliminary results found in pairs of parents caring for their child with AN who were involved within a specialized protocol characterized by both the individual patient pathway and the family psychoeducation pathway. The study variables are perceived levels of anxiety, depression, and stress and the objective burden level and adaptive capacity detected through the resilience construct.

2. Methods

2.1. Participants

The participants included 3 couples (both mothers and fathers) of primary caregivers (mean age = 47.50; SD = 2.73) of 3 female patients with AN (mean age = 16; SD = 1.78) taken care of at the Clinic Unit for EDs of the ASL NAPOLI2 (Campania, Italy). Inclusion criteria for primary caregivers were: (a) having been included in the psychoeducation program on EDs; (b) having cared for their daughter for no less than one year.

The patients met the DSM-5 diagnostic criteria for AN [14]. Each patient has a disease duration of between 1 and 2 years and has had at least one hospital recovery.

2.2. Procedure and Measures

Caregivers completed a questionnaire consisting of standardized screening tests for assessing psychological assets:

- (a) Depression Anxiety Stress Scale-21 (DASS-21) [15], composed of 21 items that evaluate general distress in three dimensions: anxiety (A), depression (D), and stress (S). The participants are asked to indicate how much the statement applies to them in relation to the previous week on a 4-point Likert scale (0 = Does not apply to me at all to 3 = Applies a great deal or most of the time to myself). Regarding the internal consistency, Cronbach’s alpha coefficient is: 0.87 for Depression, 0.80 for Anxiety, 0.89 for Stress, 0.93 for the total score.
- (b) Family Strain Questionnaire—Short Form (FSQ-SF) [16], consisting of 30 items with a dichotomous response (YES–NO), placed in order of severity and grouped in areas of increasing psychological risk to caregivers: OK area: the caregiver is reacting well to the situation; area R (Recommended): the caregiver is reacting well enough but with some inability to adapt; SR area (Strongly Recommended): the caregiver has an evident strain requires evaluation and psychological support; area U (Urgent): the caregiver has a significant strain and a high psychological risk. It is urgent that it be seen by a psychologist or a psychiatrist. It showed very good internal consistency (Cronbach’s alpha = 0.88).
- (c) The Resilience Scale (RS) [17] is one of the most widely used scales in the world to measure dispositional resilience in adults, defined as a personal trait that moderates the negative effects of stress and promotes adaptation. The RS uses a 7-step Likert scale from 1 “strongly disagree” to 7 “strongly agree” as its measurement mode. It showed excellent internal consistency with Cronbach’s alpha values ranging from 0.83 to 0.91.
- (d) The Eating Disorder Inventory—3 (EDI-3) [18] was administered to patients, an instrument for self-assessment of symptoms commonly associated with anorexia and bulimia; its goal is to measure psychological traits or key symptoms that are relevant to the development and maintenance of these disorders. The psychological profile generated by EDI-3 is a rich source of information and allows for the development of treatment plans and evaluation of their effects on the psychological aspects most relevant to EDs.

- (e) Exploratory in-depth semi-structured interviews were carried out (two questions on the difficulty of the care).

2.3. Data Analysis

Statistical analysis was performed with IBM-SPSS v.23 software. Descriptive type analysis (mean and standard deviation) was conducted for the scores obtained on the tests, comparison of percent averages, and correlation type analysis between the variables under study.

The interviews were transcribed verbatim and then analysed qualitatively with T-lab plus software.

3. Results

3.1. Quantitative Analysis

The global Psychological Maladjustment (GPM; EDI-3 test) index is severe, 127.67 (SD = 35.87). The cut-off index is >26.

Table 1 shows the mean scores obtained at DASS-21. Specifically, with regard to the clinical cut-off for stress (DASS-S > 15), anxiety (DASS-A > 8), and depression (DASS-D > 10), we note that mothers are found to be more distressed than fathers. In fact, the mean detected for stress is equal to 18 (SD = 6.92), for anxiety is 13.33 (SD = 10.26), and for depression is 12 (SD = 6.92).

Table 1. Mean differences in DASS Test scores.

		DASS-S	DASS-A	DASS-D
Mother	Mean	18	13.33	12
	SD	6.92	10.26	6.92
Father	Mean	11.33	6.67	7.33
	SD	6.11	1.15	6.11

Clinical cut-off for stress (DASS-S > 15); anxiety (DASS-A > 8); depression (DASS-D > 10).

Regarding the level of perceived strain detected by the FSQ, 27% of the sample fell into the OK Area, 24% into the R Area, 31% into the SR Area, and 18% into the U Area. In addition, response rates were made in relation to the parenting variable, and differences emerged between the rates obtained by fathers and mothers (see Table 2). Specifically, mothers fall 22% in Area OK, 27% in Area R, 31% in Area SR, and 20% in Area U. In contrast, Fathers are 50 percent in the OK Area, 29 percent in the R Area, 29 percent in the SR Area, and 7 percent in the U Area. It is evident from the percentages a perceived strain load more by mothers.

Table 2. Differences (%) in perceived strain load—FSQ.

	OK Area	R Area	SR Area	U Area
Mother	22%	27%	31%	20%
Father	50%	29%	29%	7%

OK area: the caregiver is reacting well to the situation; area R (Recommended): the caregiver is reacting well enough but with some inability to adapt; SR area (Strongly Recommended): the caregiver has an evident strain requires evaluation and psychological support; area U (Urgent): the caregiver has a significant strain and a high psychological risk.

A high level of caregivers' burden was associated with being unemployed (3.33 ± 2.51), being a mother (4.33 ± 1.52), and with a highly pathological patient to care for (3 ± 4.24).

Relative to the resilience construct (*RS test*), there are differences within the "parenting" category. In fact, here again, there is a difference in the mean scores obtained: the mean for mothers is 50.67 (SD = 0.57), and for fathers, it is 57.33 (SD = 8.50). Again, mothers are found to be less resilient than fathers.

Significant correlations ($p = 0.05$) were also found between the variables age and parenting ($r = 0.867$) and of a negative type was found between the variable age and the areas of the FSQ, namely Area OK ($r = -0.911$), Area R ($r = -0.852$), Area SR ($r = -0.862$), and Area U ($r = -0.814$).

3.2. Qualitative Results

Table 3 shows the emotive and cognitive implications related to anxiety and depression risk for the role of the caregivers.

Table 3. Theme analysis of the transcript interviews.

Lemmas	Chi-Squared *
tone of the mood	13,650
conditions	13,650
physicist	9056
treatment	9056
path	7864

* Chi-squared value of the lemmas of the written transcript of the content of the interviews.

These are some stories narrated by the interview subjects:

"I sometimes have difficulties in understanding precisely how to behave, whether being too compliant or being too rigid". (Mother)

"Sometimes we get angry, sometimes we reassure her . . . my daughter has this mental block that leads her to make nutrition mistakes". (Father)

"I don't know how much we can help up . . . to a certain point". (Mother)

"When this situation started it was a nightmare . . . we didn't live anymore . . . but there is always the fear of going back to that situation". (Father)

4. Discussion and Conclusions

Despite the obvious limitations related to the large sample size, the present study nevertheless succeeded in its intent to offer data to provide an initial overview of the characteristics of the caregivers of patients with AN included in the psychoeducation programs covered by the protocol. The results of the Family Strain Questionnaire-Short Form confirmed the main hypothesis of the study: being a caregiver of a patient with AN generates stress, anxiety, and depression that, if not compensated with effective coping strategies, could lead to developing health problems related to excessive caregiving burden [19].

In fact, most of the family members interviewed fall into the risk areas of "SR" (strongly recommended): the caregiver has an obvious strain that requires psychological evaluation and support; and "R" (recommended): the caregiver is coping sufficiently well but with some inability to adapt. Psychological consultation is recommended if symptoms worsen.

The caregivers most affected by strain-related stress are female caregivers, in our case mothers. In other studies [20], findings also suggest gender differences, as mothers and fathers show different perceptions of both their quality of life and care burden; mothers of ED patients are found to have a considerable and greater need for psychosocial support.

From the results obtained, it emerges that there is a need to identify the caregiver that we could define as "fragile", and this could have important implications on home care and the risk of institutionalization of the patient. Therefore, the need for taking care of the frail caregiver, as well as the frail patient, would be configured [20].

In order to provide good care, one must always start with an objective assessment of the resources and limitations of the family unit and, from there, build a protective network not only toward the sick person but also in favor of his or her caregiver. The irreplaceable action of caregivers cannot be "spontaneous" and guided only by affection and common sense. Caregivers must be informed, educated, and supported to face, together with the sick person, the myriad difficulties of daily life. Competently supporting the caregiver

means alleviating his or her difficulties and raising the quality of care provided. A caregiver who receives more support will be in a position to increase the care he or she provides.

Being the caregiver of a patient with an ED creates a great responsibility, which leads to those who are not ready for this experience, a lower level of resilience, and mental and physical distress. So, it is necessary to supplement the protocols with coping skills training in order to remodel dysfunctional strategies and improve the Quality of Life of primary caregivers [21,22].

5. Limitations and Future Prospects

The present study, although exploratory in nature, has some limitations, including the small sample size of three pairs of parent respondents does not determine the possibility of being able to generalize the results to a much larger population. However, the preliminary results found are relevant to the findings of previous studies and encourage the line of research by expanding the sample size. It would be useful to include pre- and post-course monitoring of psychoeducation, to test the effectiveness of targeted treatments for caregivers.

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Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki and with the legislation of the Italian Code regarding the protection of personal data (Legislative Decree 196/2003); the participants were informed about the general purpose of the research, the anonymity of the answers, and the voluntary nature of participation and they signed an informed consent. There were no incentives given. This study was approved by the ethical commission of the “Asl Napoli 3” (Napoli, Italy).

Informed Consent Statement: Written informed consent was obtained from the subject(s) in order to publish this paper.

Data Availability Statement: The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Conflicts of Interest: The authors declare no conflict of interest.

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