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ORIGINAL ARTICLE

Living with someone with an eating disorder: factors affecting the caregivers' burden

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Abstract
We focused on carers of subjects suffering from eating disorders (ED), and studied the characteristics that mostly expose them to high levels of stress, anxiety, depression and expressed emotion, favoring the accommodation of the family system to the cared person. We administered the accommodation and enabling scale for eating disorders (AESED) questionnaire, the family questionnaire (FQ) and the depression, anxiety and stress scale (DASS-21) questionnaire to 97 carers of 62 ED patients, and investigated the carer's characteristics associated with the scores in the three questionnaires. A personal history of ED, being the primary carer, and caring for a person with a diagnosis of anorexia nervosa are the characteristics that contribute most to aggravate the carers' burden in terms of stress, anxiety, depression, accommodation and enabling. Our findings may help doctors to provide effective support to caregivers and eventually improve the treatment of subjects with ED.

Keywords Caregiver burden · Eating disorder · Burden aggravating factors · Maintenance factors

Introduction

The international scientific community seems unanimous in proposing a bio-psycho-social model for the pathogenesis of eating disorders (ED), according to which there is no single cause, but a combination of risk factors—at individual, family, and socio-cultural level—that can variously interact with one another in promoting the emergence and perpetuation of the disease [1–3].

The role of the family has been very much emphasized in the past, especially with reference to the presence of a contentious relationship between the caregiver and the cared person. Current research has certified that there is a multiplicity of different family situations involving people suffering from ED, and that, therefore, there is no "typical family" which favors the onset of an ED. Rather, it is now considered that ED, and especially Anorexia Nervosa (AN), have a significant impact on family relationships. The impact of the ED on the family is greater when children and young adults are involved as they usually live with their parents. Other factors are associated with the long average duration of the disease (6–7 years) and the priority given to outpatient treatment, according to guideline recommendations [4, 5]. Family members of people suffering from ED often develop psychological problems, due to the stress and burden of care incumbent with their role as family carers [6]. These difficulties contribute to exacerbate the problems that may arise in the relationship between the caregiver and the ED patient, which in turn worsen the symptoms related to the ED [1–7].

In this perspective, Schmidt and Treasure have developed an interpersonal model of AN maintenance, according to which the quality of the caregiver-cared person relationship will affect the symptoms and duration of the disease of the latter [2, 3, 8, 9]. Based on the New Maudsley Model (NMM) proposed by these authors [10, 11], the emotional reactions of caregivers to the ED of a loved kin (characterized by high levels of stress, anxiety and depression) as well as their responses to dysfunctional disease (high expressed emotions—overprotection and hostility—and adaptive behaviors to the symptoms—accommodation and enabling)

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act as maintaining factors of the ED. Several assessment tools have been used to assess and quantify the impact of the ED on the family and develop treatment models more attentive to the carers' needs [12]. For example, questionnaires have been developed that assess, among interpersonal mechanisms that maintain the expressed emotions, also some factors that are specific of ED, such as accommodation and facilitation. The measures of the items that emerge from these tools can outline different family dysfunction profiles, which will help doctors provide more specific and effective treatments [13].

Here we aimed to identify the characteristics of carers that mostly expose them to high levels of stress, anxiety, depression, and expressed emotion, favoring the accommodation of the family system to the cared person's ED, and the maintenance of the illness itself. We hypothesized that any differences in the scores to the questionnaires that were administered [14–16] (i.e., any differences in the caregivers' burden) are related to factors like the patient diagnosis, the time spent together by the carer and the patient, the carer's previous history of ED, and whether the caregiver defines him- or herself as the primary or secondary carer.

Patients and methods

Study sample

We invited to participate to the study the carers of all patients suffering from an ED (any type) who were consecutively seen between May 2012 and June 2014 at the Children and Adolescents Psychiatry Unit of the Meyer Children's Hospital (Florence, Italy) and the Eating Disorder Unit of the Empoli Mental Health Service (Empoli, Italy), either in the outpatient or inpatient setting. All patients had been diagnosed according to the DSM 5 criteria. The battery of pretreatment assessment planned for training based on NMM was administered to these families.

Data collection

All invited carers who consented to participate were required to fill a self-administered anamnestic questionnaire and provide information on their age, gender, marital status, level of education and employment status; degree of kinship with the patient; whether he/she lived with the patient and the overall number of people living in the household; and the average number of hours/week spent with the patient; and history of ED or psychiatric disorders. All participating carers were also requested to complete the following questionnaires:

- The accommodation and enabling scale for eating disorders (AESED) [14]: this is a 33-item questionnaire with a five-point Likert scale ("0": never, "1": rarely, "2": sometimes, "3": often, "4": nearly always), which measures the extent to which the caregiver tolerates or allows ED behaviors at home, and specifically: avoidance and modifying routines, reassurance seeking, meal ritual, family control, and "turning a blind eye." Higher scores indicate higher levels of accommodation to the ED symptoms by the family. The AESED questionnaire has shown good internal consistency and is able to discriminate in a satisfactory way between clinical variables [14].
- The family questionnaire (FQ) [15]: created as a more efficient self-report alternative to the CFI, it has shown good internal consistency of subscales (ranging from 0.78 to 0.80 for EOI and from 0.91 to 0.92 for CC). The questionnaire consists of 20 items, 10 for each subscale. Respondents are asked to rate the applicability of each item in describing their feelings and thoughts about the ED patient, such as ''I can't sleep because of him/her'' (EOI), and ''He/she does not appreciate what I do for him/her'' (CC). Responses range from ''never/very rarely'' with a score of 1, to ''very often'' with a score of 4. A higher total score indicates a higher expressed emotions (EE) status. The authors recommend cut-off points of 23 for CC and 27 for EOI.
- The depression, anxiety and stress scale (DASS-21) [16] consists of 21 items scored in a four-point Likert scale ("0": Did not apply to me at all, "1": applied to me to some degree, or some of the time, "2": applied to me to a considerable degree, or a good part of time, "3": applied to me very much, or most of the time). The DASS-21 measures depression, anxiety (psychological arousal) and stress (a cognitive, subjective symptom of anxiety) on three 7-item subscales equally distributed. Higher scores indicate higher levels of each domain. The Italian version of the DASS-21 has been described as a valid and internally consistent tool for use among both the community and clinical individuals [17].

Statistical analysis

We conducted a descriptive analysis of the study sample and used Student's *t* test to assess whether the scores to each subscale of the AESED questionnaire, the Family questionnaire and the DASS-21 questionnaire differed according to the carer's or cared person's characteristics.

All analyses were conducted using Stata software v14.0 (StataCorp, College Station, TX). All analyses were two-sided and a *p* value equal to 0.05 or less was considered as statistically significant.

Results

The study sample includes 97 carers (57.7% females and 42.3% males, mean age 48.8 years) (Table 1) of 62 different cared people (88.1% females, mean age 17.5 years, average duration of illness 2.8 years, no significant comorbidities reported, 52.6% outpatients and 47.4% inpatients). For 27 ED patients, only one carer agreed to participate: 25 defined themselves as the primary carer, and two as the secondary carer. For 35 ED patients, two carers participated to the study: for 18 patients, both carers defined him/herself as the primary carer, while for 17 patients, there was one primary and one secondary carer. Overall, therefore, 80 of 97 participating carers (80%) defined themselves as the primary carer of the ED patient. Most carers were parents living with the cared person (94.8%) and declared spending 21 or more h/week with the cared person (64.5%). An overall 29.7% of carers declared that she/he or another family member of the cared person had suffered from either a psychiatric disorder (5.5%), an ED (17.6%), or both (6.6%).

Table 1 Characteristics of carers (*n* = 97) of patients suffering from an eating disorder

Carer's characteristic	No.	%
Gender		
Male	41	42.3%
Female	56	57.7%
Marital status		
Married/living together	89	91.8%
Single/divorced/separated	8	8.2%
Highest education attained		
Secondary level	19	19.6%
Degree/diploma level	78	80.4%
Employment status		
Full/part time	73	75.3%
Unemployed	24	24.7%
Type of carer (self-defined)		
Primary	78	80.4%
Secondary	19	19.6%
Relationship with cared person		
Parent	92	94.8%
Spouse/partner	5	5.2%
Living with cared person		
No	5	5.2%
Yes	92	94.8%
Time spent with patient		
≤ 21 h/week	33	35.5%
> 21 h/week	60	64.5%
Whether the carer or another family member ever suffered from a psychiatric disorder and/or from an ED		
None	64	70.3%
Psychiatric disorder only	5	5.5%
ED only	16	17.6%
Both psychiatric and ED	6	6.6%

We report in Table 2 the carers' average score for each subscale of the AESED questionnaire, the Family questionnaire, and the DASS-21 questionnaire, overall and according to the selected carer's or cared person's characteristics.

Compared to carers of patients suffering from Bulimia Nervosa, those who cared for a person suffering from Anorexia Nervosa had higher scores in the "avoidance and modifying routine" (mean score 16.5 vs. 9.5, *p* value 0.02) and "reassurance seeking" (mean score 14.6 vs. 8.1, *p* value 0.05) subscales of the AESED questionnaire, and in the overall AESED score as well (mean score 47.0 vs. 29.4, *p* value 0.03). No differences emerged in the Family questionnaire and in the DASS-21 questionnaire according to the cared person's ED type.

The average scores for each subscale of the three questionnaires did not differ according to the time spent by the carer with the cared person nor between inpatients and outpatients.

Carers who had ever suffered from an ED had higher scores (compared to those who did not) to all subscales of the three questionnaires. The difference was statistically significant for the subscales "reassurance seeking" of the AESED questionnaire (mean score 17.0 vs. 12.2, *p* value 0.03) and the overall AESED score (mean score 52.2 vs. 41.6, *p* value 0.05); the "criticism" subscale of the family questionnaire (mean score 21.7 vs. 19.0, *p* value 0.04); and the "stress" subscale of the DASS-21 questionnaire (mean score 16.3 vs. 12.6, *p* value 0.05).

Finally, primary carers had higher scores, compared to secondary carers, for the "avoidance and modifying routine" (mean score 16.3 vs. 12.0, *p* value 0.05) and the "reassurance seeking" (mean score 14.2 vs. 9.6, *p* value 0.05) subscale of the AESED questionnaire. The difference in the overall AESED score significantly deviated from the null value as well (mean score 46.7 vs. 33.6, *p* value 0.02). Instead, there were no significant differences between primary and secondary carers in any subscale of either the family questionnaire or the DASS-21 questionnaire.

Discussion

We investigated how some characteristics of carers of ED family members may affect their levels of anxiety, depression and stress and how these could result in a higher level of accommodation and enabling of ED symptoms. Very few reports have been published to date on these important aspects of the caregiver-cared person interaction; however, the findings from our and similar studies may be of great

Table 2 Mean score (standard deviation) to the AESED questionnaire, the family questionnaire and the DASS-21 questionnaire, overall and by selected carer's or cared person's characteristics

	Total sample	Cared person's ED			Time spent with cared person			Ever suffered from an ED			Type of carer		
		Anorexia nervosa	Bulimia nervosa	*p* value	< 21 h/week	≥ 21 h/week	*p* value	Ever	Never	*p* value	Primary	Secondary	*p* value
	(*n* = 97)	(*n* = 62)	(*n* = 10)		(*n* = 33)	(*n* = 60)		(*n* = 23)	(*n* = 74)		(*n* = 78)	(*n* = 19)	
AESED													
Avoidance and modifying routine	15.5 (8.7)	16.5 (8.0)	9.5 (4.7)	0.02*	14.2 (8.6)	15.9 (8.7)	0.34	16.9 (7.2)	15.0 (9.2)	0.38	16.3 (8.6)	12.0 (8.8)	0.05*
Reassure seeking	13.3 (9.3)	14.6 (9.8)	8.1 (7.5)	0.05*	13.6 (7.6)	13.2 (10.4)	0.83	17.0 (7.7)	12.2 (9.5)	0.03*	14.2 (9.6)	9.6 (6.9)	0.05*
Meal ritual	4.9 (5.2)	5.3 (2.8)	1.8 (2.8)	0.07*	4.3 (3.9)	5.1 (6.0)	0.46	5.6 (4.3)	4.6 (5.5)	0.44	5.3 (5.6)	3.1 (2.8)	0.09
Control of family	8.2 (4.7)	8.5 (4.6)	7.1 (4.6)	0.40	7.2 (4.6)	8.5 (4.7)	0.22	9.8 (4.3)	7.7 (4.7)	0.06	8.6 (4.7)	6.7 (4.5)	0.13
Turning a blind eye	2.2 (2.8)	2.2 (3.0)	2.9 (2.4)	0.48	2.8 (2.7)	1.9 (2.9)	0.16	2.9 (3.1)	2.0 (2.7)	0.21	2.2 (2.8)	2.2 (2.8)	0.92
Overall AESED score	44.1 (23.0)	47.0 (24.3)	29.4 (18.1)	0.03*	42.1 (19.9)	44.7 (24.8)	0.61	52.2 (19.3)	41.6 (23.6)	0.05*	46.7 (23.5)	33.6 (23.0)	0.02*
Family questionnaire													
Criticism	19.6 (6.0)	19.9 (6.5)	18.9 (4.2)	0.66	20.1 (5.1)	19.3 (6.6)	0.53	21.7 (5.2)	19.0 (6.1)	0.04*	19.7 (5.5)	19.2 (8.0)	0.71
Emotional over-involvement	24.6 (5.9)	25.2 (5.7)	22.6 (4.4)	0.17	24.5 (4.7)	24.5 (6.6)	0.94	25.3 (4.8)	24.4 (6.3)	0.48	25.1 (5.4)	22.5 (7.5)	0.09
DASS-21													
Stress	13.5 (7.8)	13.3 (7.4)	13.2 (7.7)	0.97	13.5 (7.3)	13.8 (8.3)	0.86	16.3 (8.0)	12.6 (7.6)	0.05*	13.7 (7.7)	12.7 (8.4)	0.63
Anxiety	5.0 (5.1)	4.7 (5.1)	5.8 (4.5)	0.54	5.6 (5.9)	4.8 (4.7)	0.46	5.4 (3.8)	4.8 (5.5)	0.65	4.9 (5.4)	5.2 (3.7)	0.86
Depression	9.2 (7.4)	9.5 (7.8)	9.2 (7.8)	0.91	10.0 (8.2)	8.7 (7.1)	0.43	11.2 (7.8)	8.6 (7.2)	0.13	9.0 (7.2)	10.0 (8.1)	0.60

*Results which were statistically significant at 0.05 value importance to inform interventions aiming to promote caregivers' coping and eventually improve the long-term outcome of the disordered patients.

In terms of ED diagnosis, our results show that when the cared person suffers from anorexia nervosa, carers score significantly higher in the areas of avoidance and modifying routine, reassurance seeking and AESED total score, compared to caregivers of patients suffering from bulimia nervosa. Thus, in our sample, typical accommodation signs are more frequently observed among carers of people with AN, while no significant differences are observed in terms of EE (FQ), anxiety, depression and stress (DASS-21). This is in accordance with the many studies which have examined these aspects among carers of patients suffering from anorexia nervosa, most of which observed high levels of psychological distress, burden and EE [18]. When looking at time spent between carers and ED patients, there are no significant differences in the investigated dimensions. We had initially hypothesized that the more time spent with the ED patient, the greater the burden for the caregiver; however, our results did not confirm this hypothesis. This may have been influenced by the young age of our sample or by the choice of the cut-off (21 h/week), which may be unsuitable to highlight existing differences. In fact, some studies report a greater number of hours [19] as having the most influential impact on the carers' burden.

In families where a parent had ever suffered from an ED, the "reassurance seeking" and "control of family" dimensions of the AESED questionnaire and the total AESED score, the "criticism" factor in the Family Questionnaire, and the "stress" dimension in the DASS-21 questionnaire, was significantly higher compared to families without a history of ED. Therefore, it appears that carers with a personal history of ED suffer from a relatively higher levels of stress, expressed emotion, accommodation and enabling of the ED, which was in line with our expectations.

Family members who define themselves as the primary carer of the person with the ED had significantly higher scores in the dimensions of avoidance and modifying routine, reassurance seeking and AESED total score, compared to secondary carers, while no significant differences were observed in terms of EE (FQ), anxiety, depression and stress (DASS-21). The primary carer is by definition the person who is most invested in the management and care of the patient; therefore, it is not surprising that his/her emotional burden be higher than for secondary caregivers. An excessive emotional burden of the primary caregiver might even contribute to maintain the illness, given his/her unique role in the treatment of a person suffering from an ED. However, both parents defined themselves as the primary carer for a not negligible number of ED patients in our study, so these findings warrant confirmation in future studies.

The main strengths of our study are its straightforward design and its focusing on many different factors that have the potential to worsen the caregivers' burden, some of which (like being a primary or secondary carer, and the type of ED diagnosis of the cared person) have been relatively neglected in previous reports. Our study has a number of limitations as well, the most important of which is its small sample size. This prevented from fitting multiple regression models, also because the unbalanced distribution of some factors. Nonetheless, it is important to highlight that our study succeeded in revealing important determinants of caregivers' emotional burden, which may have implications for health professionals. Follow-up studies able to include more patients (for instance, by extending the study period, or involving more centres) may help overcome these limitations and examine more in detail the hypotheses that emerged from our study. Also, the study would have benefited of the availability (or of a better quantification) of variables like individual body mass index, duration of illness, ED subtype, age, and time spent by the carer with the cared person. Further discussions could explore other contact time ranges, and possible profiles of carers who are more exposed to the ED "check mate".

In conclusion, we found that a personal history of ED, being the primary carer and caring for a person with a diagnosis of anorexia nervosa, are the features which contribute most to aggravate the carers' burden in terms of stress, anxiety, depression, accommodation and enabling. This, in turn, may represent a maintenance factor for the cared person's ED, thus constituting a vicious cycle that further increases the carers' burden. As already mentioned, the family is a crucial resource for the treatment of a person suffering from ED, however, the carers frequently need to receive full support to carry out their role in the most efficient way, while "a carer with an excessive burden is not a good carer" [20]. In this perspective, identifying the factors that describe certain types of carers at increased risk can help doctors to provide effective support to caregivers and eventually improve the treatment of subjects with ED [21, 22].

Compliance with ethical standards

Conflict of interest All Authors declare they have no conflicts of interest to disclose.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in this study.

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