

Understanding How Parents Cope with Living with Someone with Anorexia Nervosa: Modelling the Factors that are Associated with Carer Distress

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ABSTRACT

Objective: Caring for a person with anorexia nervosa (AN) has been associated with psychological distress and poor life quality of carers. Addressing carers' needs may impact on prognostic outcome. The aim was to explore and model factors associated with distress in parents of people with AN ($N = 151$).

Method: A cross-sectional design was used to assess caregiving strains (Pearlin Stress Scales) and psychological distress (Hospital Anxiety and Depression Scale).

Results: Over 70% of carers ($N = 107$) scored at or above the suggestive threshold (score ≥ 8) for anxiety, and 38% ($N = 54$) for depression. Over 50% of carers ($N = 78$) scored at or above the clinical

threshold (score ≥ 11) for anxiety, and 13% ($N = 20$) for depression. A model of carer distress after multiple regression analyses showed three significant associated variables. In order of significance, self-related strains, carer sex, and interpersonal strains accounted for 41% of the variance, ($F(3, 112) = 29.85, p < .001$).

Conclusion: Interventions aimed at improving outcome in AN may need to focus on reducing caregiving strains and carers' distress, particularly of mothers.
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Keywords: anorexia nervosa; carer distress; family factors

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Introduction

Carers of people with mental health problems experience high levels of distress, burden, and psychological morbidity, inconclusively related to demographic and illness-related characteristics.¹ Caring for a loved one with a mental disorder has been directly linked to the physical and mental health of the caregiver.² Most of the research on caregiving has been in schizophrenia³ and Alzheimer's disease.⁴ In the study of Alzheimer's disease, most of the caregiving strain has been attributed to the challenges and demands inherent in the illness.

In eating disorders (ED), the study of caregiving distress^a is an evolving area as the contributing factors remain unspecified. ED and especially anorexia nervosa (AN) entail many challenges to caregivers, including lack of information,^{5,6} stressful experiences in obtaining help through the health services, often marked by exclusion or even blame for the illness, psychological needs of carers themselves,^{7,8} and poor social support and understanding for carers.⁹

AN has an average illness duration of 6 years and in many cases the ego-syntonic nature of the illness delays the seeking of treatment and obstructs adherence to treatment.¹⁰ As yet little evidence exists that specifies what works in the treatment of AN.¹⁰ In addition to the ED symptomatology, AN typically presents comorbid clinical symptoms and difficult behaviors and personality traits.^{11,12} Any or all of these factors can lead to strained interpersonal relationships within families of individuals with AN.

Social support is a significant moderator of carer distress¹³ as well as a predictor of burden¹⁴ and a protective factor against the negative effects of caregiving.¹⁵ Carers of people with ED report that

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^aCarer distress, as used in the current study, will be conceptualized as an aggregate experience of psychological morbidity, indicated by combined, self-reported levels of anxiety and depression, as assessed by the Hospital Anxiety and Depression Scale.

most of their social support comes from family and friends, however, this support is limited, typically due to the high stigma and lack of understanding surrounding ED.⁹ Consequently, many carers feel isolated and alone.¹⁶ Carers' burden, isolation and frustration with the illness grow as people with chronic ED become increasingly reliant on their parents and spend more time with them.⁵ Other challenges include the strain of a developmental 'inappropriateness' involved in caring for dependent adult children.⁶ It is clear from several studies that carers of people with ED have high levels of distress, associated in some cases with depression and anxiety^{5,6,8,17–20} and that their needs often go unmet, resulting in an impaired quality of life.^{21,22} Mothers in particular have high levels of emotional distress.^{19,23}

Caregiver distress in ED has been compared with that of caregiving for someone with psychosis,¹⁸ while Treasure et al.⁶ found higher distress and difficulties reported by carers in AN. These AN carers have also been found to show high *subjective burden* (i.e., carers perceiving their experience as a heavy load) and *objective burden* (i.e., carers report tangible disruptions to carer's life as a result of the nature and demands of the sufferer's illness),²⁴ as well as high over-involvement with the patient. These negative experiences of caregivers were found to be most predictive of their distress.^{5,6,8} Negative appraisals of the illness have also been identified as a potent predictor of carer distress.¹⁷

Over-protective caregiving styles and high expressed emotion (EE) are common parental reactions, and these have been associated with carer distress and burnout.^{7,8} Kyriacou et al.¹⁹ have found that comorbid difficult behaviors and symptoms were significantly associated with carers' criticism (CC), while carers' anxiety was significantly associated with carers' emotional over-involvement (EOI). In the Maudsley model of maintenance of AN, high EE is a key component of the interpersonal domain that is thought to impact on outcome.¹²

In light of the severity of the illness and the impact on carers and families, it is becoming increasingly recognized that professionals need to address carer needs and provide families with the resources necessary to enable caregiving as well as help to create a familial environment which is conducive to adaptive changes in family functioning.^{25,26} Identifying and addressing carer needs carries unquestionable prognostic significance: providing support to carers and lowering their distress can empower carers, enabling the family to serve as an important resource in treatment, which in turn may help reduce relapse as well as convey

other benefits to sufferers.²⁷ The need for providing carers with information and support has also been recommended by the NICE^b ED guidelines for England and Wales.¹⁰ To develop interventions aimed at decreasing carer distress it is important to first identify modifiable factors entailed in the caregiving experience.

Pearlin et al. developed a model to understand the stress of carers of people with Alzheimer's disease^c.²⁸ In this study, we adapted and applied elements of this conceptualization within an exploratory model aimed at understanding carer distress in AN. The aim of this study was to investigate and model the factors associated with depression and anxiety in the carers of people with AN. Our hypothesis was that carer-related and illness-related characteristics would be associated with caregiving strains which in turn would be related to carer distress.

Method

Design

This was a cross-sectional study using self-report questionnaires to examine psychological distress in parents of people with AN. As the study was cross-sectional it precluded the examination of the exact mechanisms leading to the development of parental distress; such a 'mechanism hypothesis' would require a longitudinal design. Regression analyses as used in the study assess level of significance of association between the variables under exploration, hence our use of the term 'predictor' is meant to show this statistical association rather than to imply causality. Ethical approval of the study protocol was obtained from the Institute of Psychiatry (IoP) Research Ethics Committee (Ref. No. 317/03).

Participants

Parents on the Carers Volunteer Database maintained by the Eating Disorder Unit (EDU) of the IoP and Maudsley Hospital were offered the opportunity to participate in this project. The study was also advertised via the EDU website and newsletter. At the time of recruitment for

^bNational Institute for Health and Clinical Excellence.

^cThis model consists of four domains: the background and context of stress, encompassing demographics and characteristics of the carer and the illness; the stressors, entailing primary and secondary strains in terms of the consequences of caregiving first on the self ('self-related strains') and secondly on the interpersonal environment ('interpersonal-related strains') of the carer; the mediators of stress, namely coping and social support; and finally the outcome of caregiving stress in terms of physical and psychological manifestations. They created a collection of measures based on this model which assess aspects of the caregiving experience.

this project, the Carers Volunteer Database consisted of 197 carers^d. Parents who confirmed willingness to participate were sent the full set of questionnaires, along with an information and consent sheet and a prepaid return envelope. Participants were not offered any incentives for participation.

The inclusion criteria were that parents were currently caring for a child with AN (siblings and partners were excluded). One hundred and twenty-nine carers (a response rate of 65%) from the database and 36 parents from current EDU patients offered to participate giving a total of 165 carers. Fourteen carers were excluded because their responses were incomplete and/or the patient was currently well. The final sample consisted of 151 carers (91 mothers and 60 fathers).

Assessment Measures

Caregiving Stress Scale (CSS).²⁸ The scale consists of the following subscales: family conflict, expressive support, relational deprivation, overload, role captivity, loss of self, self-esteem, personal gain, coping, competence, and mastery. The items are phrased as statements rated with a Likert-type scale. When scored the items are given values of 1–4. Some items were reworded so as to be more relevant to ED^e. Cronbach's α tests showed that the reliability of the subscale remained high even with the addition/rewording of these items. Internal consistency for use with carers of individuals with AN was explored.

Hospital Anxiety and Depression Scale (HADS).²⁹ The HADS is a reliable, self-report measure of anxiety and depression. The subscales have shown high internal consistency, with Cronbach's α of 0.80–0.93 for anxiety and 0.81–0.90 for depression. A score of 11 or higher for each

subscale is indicative of the corresponding mood disorder, and a score of 8–10 is suggestive.

Experience of Caregiving Inventory (ECI).³⁰ The ECI is a 66-item self-report questionnaire which assesses carers' perceptions of their experience of caregiving^f. The measure is comprised of 10 subscales, 8 of them being negative and 2 delving into positive aspects of caregiving, with the aim of assessing an overall, all-encompassing experience of caregiving. The scale can be used as a combined score of positive and negative caregiving, or assessed per individual subscale. The ECI has shown high internal reliability (Cronbach's α values ranging from 0.74 to 0.91) as well as strong construct validity. Internal consistency of the measure for carers of people with AN has been assessed in an earlier article and found to be satisfactory.¹⁹

Anorectic Behavior Observation Scale (ABOS).³¹ The ABOS was developed as a self-report questionnaire specifically aimed at parents' observations of their son/daughter's behaviors that may be symptomatic for AN or BN. The measure has been found to obtain reliable information from parents and to have specificity and sensitivity in capturing parents' observations of both behaviors and attitudes in their children that may be symptomatic of ED^g. The scale has a cut-off score of 19³¹ to indicate the presence of anorexic symptoms. The scale has demonstrated three separate factors: (1) eating behavior, concern with weight and food, denial of problems; (2) bulimic-like behavior; and (3) hyperactivity, with sufficient internal consistency (Cronbach's α values of 0.80, 0.69, and 0.69, respectively). The scale was used to yield a combined score indicative of AN symptomatology as reported by carers.

Selection of Variables and Model Building

Predictors were selected from the existing literature on caregiving stress. These included carer-related variables, (carer satisfaction with treatment and with professional support) and illness-related variables (sufferers' rejection of carers' help and rejection of having an illness, comorbidity, negative symptoms, difficult behaviors). From the

^dCarers in this database come from a variety of sources, such as Beat (*beat* is a national charity (Registered Charity No. 801343) based in the UK providing information, help and support for people affected by eating disorders and, in particular, anorexia and bulimia nervosa and their carers, families, etc). All of the 197 carers were eligible to participate, however, 68 did not respond to the study invitation. In addition, 36 carers came from current EDU inpatients. This sample was self-selected and we are unable to accurately comment on how many of the parents of inpatients were initially approached over the period of recruitment, how many refused to participate or what their exact reasons were for nonparticipation. This raises the issue of representativeness as the self-selected sample of carers may be skewed in terms of overrepresentation of actively involved and 'empowered' carers. We acknowledge this as a potential limitation.

^ee.g. Family Conflict: 'The seriousness of your relative's memory problem', re-phrased as 'eating disorder'. Management of Situation (one of the three subscales comprising Coping): 'Try to find ways to keep your relative busy', rephrased as 'calm'. Management of Meaning (2nd subscale comprising Coping): 'Remind yourself that it is something to expect as people get older', rephrased as 'adolescents and young adults'. Management of Distress (3rd scale comprising Coping): added items: 'Stay late at work'; 'Avoid mealtimes'.

^fItems ask carers to rate the frequency of experiences they have had over the past month, such as, 'How often in the past month have you thought about whether she/he will ever get well?', on a 5-point Likert scale ranging from 0, 'Never' to 4, 'Nearly always', with higher scores indicating greater frequency or severity.

^gThe complete scale consists of 30 items, asking parents to respond based on their observations of their child over the past month, answering yes, no, or unsure as to whether the behaviour occurred. The scale is scored as follows: 'yes' (2 points), '?' (1 point), and 'no' (0 points), with a higher score indicating higher frequency of symptomatic or pathological behaviour. Parents are instructed to rate an item, such as 'Patient shows obvious signs of tension at mealtimes', as 'unsure' if they did not have the opportunity to observe the behavior directly, if they were told it occurred, or if they can only suppose it did.

Caregiving Stress Scale (CSS) two aggregate scales were derived, comprising interpersonal and self-related strains^h. For the multivariate analyses used to create a carer stress model in this study, the *HADS* was used as a combined score, aggregating anxiety and depression into a total score indicative of distress. This was considered appropriate in order to minimize multiple testing and, as the aims of the study were exploratory, it was advisable from a statistical point of view to test a model with a single predicted outcomeⁱ. The combined version of the scale has been used in eating disorder research by our unit.³² Only two of the negative scales of the *ECI* were used: Difficult behaviors (e.g., him/her being unpredictable) and negative symptoms (e.g., him/her being withdrawn) were used as a combined score, again, in order to minimize number of predictors.

Analyses

Parametric tests were first carried out in order to check the homogeneity of the variance and normal distribution of the data. Data were entered and checked for normality in SPSS 13³³ and were then transferred to STATA 9³⁴ using STAT TRANSFER,³⁵ in which all analyses were performed. There was clustering within families as 120 of the 151 carers were from the same families and caring for the same individual with AN (i.e., 60 pairs of parents (60 mothers, and 60 fathers). This violates the first assumption required for analysis of variance, that is, independence of observations. *Robust cluster regression* controls for minor deviations from normal distributions and heterogeneity in the data, as well as allows for analyses to be conducted using a sample that may contain 'intra-class' correlations within observations. *Huber-white sandwich estimators of variance*^{36,37} using the robust cluster option in STATA were thus used^l. Gender comparisons included only parents from the same families. A series of univariate regressions were first carried out to identify the association between demographic and patient/illness/carer-

related characteristics and self-related and interpersonal strains, as well as with the outcome of distress (combined anxiety and depression scores). Variables reaching significance of $p < .001$ were then explored for degree of predictive power via multivariate regressions using forward selection procedures; variables were added to the model in order of ascending p value. R^2 partitioning of variance was then conducted to ascertain the unique variance that could be attributed to each of the variables by fitting a series of models.

Results

Psychometric Properties of Instruments

The internal consistency of the self-related strains and interpersonal strains subscales of the *CSS* were assessed using Cronbach's α . Both subscales showed adequate internal consistency ($\alpha = 0.89$ and 0.91 , respectively).

Demographic and Clinical Information

Demographic and caregiving information is presented in **Table 1**. Mean age of carers was 54.3 years ($SD = 7.2$). Women with AN had an average age of 23.3 ($SD = 6.6$). Average duration of illness was 7.8 years ($SD = 5.5$).

Caregiving Strains

Gender comparisons were conducted on carers' scores on the self-related strains and interpersonal strains subscales and identified differences in terms of higher scores for mothers on both subscales. Specifically, mothers scored significantly higher on three of the self-related strains scales, namely, *overload*, *role captivity*, and *loss of self*. Mothers' and fathers' endorsement of both the combined and individual subscales is shown in **Table 2**.

Psychological Distress

Mothers (m) also had higher levels of depression and anxiety (individual and combined subscales) than fathers. Over 70% of carers ($n = 107$, $m = 77$) scored at or above the suggestive threshold (score ≥ 8) on the anxiety subscale, and 38% ($n = 54$, $m = 42$) scored at or above the suggestive threshold on the depression subscale. Over 50% of carers ($n = 78$, $m = 60$) scored at or above the clinical threshold (score ≥ 11) for anxiety, and 13% ($n = 20$, $m = 15$) scored at or above the clinical threshold for depression. Both mothers and fathers had similar (high) scores on the *ABOS* scale.

^hThe aggregate measures were: family conflict, expressive support, relational deprivation, (combined as interpersonal strains); overload, role captivity, self-esteem, loss of self, personal gain, coping, competence, mastery (combined as self-related strains). For subscales measuring positive concepts the scores were reversed in order to yield a combined score indicative of carer strains.

ⁱFurthermore, due to the high correlation between anxiety and depression, it may not be feasible or indeed useful to attempt to conceptually distinguish between the two constructs (Landau, 2006, personal communication). In our sample of participants inter-correlation of subscales was highly significant at $.68$ ($p < .01$).

^lThe robust cluster option in STATA does not provide standardized beta coefficients, therefore the regression coefficients presented in this study are unstandardized. Furthermore, when measuring the effect of an independent variable on an outcome, it is suggested that *unstandardized* regression coefficients are superior and preferable over correlation coefficients.³⁸

TABLE 1. Clinical and demographic Information

	N Total	Frequencies	N/Mean (s.d.)	%
Demographic Characteristics (Possible score range)				
Parental sex ^a	151	Female	91	60
		Male	60	40
Amount of contact with daughter per week	144	<21 h	89	62
		>21 h	55	38
Parental age in years	145		54.3 (7.2)	
Daughter age in years	142		23.3 (6.6)	
Parental Marital Status	151	Single	1	1
		Married or Living together	133	88
		Divorced, Separated or Widowed	17	11
Parental education level	143	Up to A level	87	61
		University/equivalent	56	39
Parental employment status	145	Full-time	58	40
		Not full time	87	60
Residing with daughter	151	Yes	93	61.5
		No	58	38.5
Patient/illness-related characteristics				
Anorexic behaviors observation scale (ABOS) (0–60) ^{a,b,c}	149		27.5 (10.6)	
Duration of illness in years	140		7.8 (5.5)	
Acceptance/rejection of eating disorder by sufferer ^a	149	Denies/Ambivalent	33	22
		Acceptance of ED	116	78
Rejection of carers' help by sufferer ^{a,b,c}	151	Yes	102	67
		No	49	32
Additional diagnosis/comorbidity of daughter	150	Yes	87	58
		No	63	42
Sufferer's average number of hospital admissions	110		2.9 (2.7)	
Sufferer currently in treatment	149	Yes	112	75
		No	37	25
Age of diagnosis	137		16.7 (4.4)	
Age of onset	140		15.2 (4.7)	
Parent-related characteristics				
Hospital anxiety and depression scale (HADS)				
Total of Combined Anxiety and Depression Scales (0–42)	150		16.6 (7.9)	39.5
Anxiety Scale (0/21)	150		10.4 (4.9)	49.5
Depression Scale (0–21)	150		6.2 (3.7)	29.5
Experience of Caregiving Inventory (ECI)				
Total of combined difficult behaviors and negative symptoms scales (0–56) ^{a,b,c}	150		24.9 (12.3)	44
Caregiving stress scale (CSS)				
Total of combined interpersonal strains scales (26–104) ^s	147		51.2 (12.9)	49
Total of combined self-related strains scales (57–228) ^a	145		126.1 (17.5)	55

Notes: Percentage out of total score enables quick comparisons between subscales. This transforms the ratio of mean value to maximum total value into a percentage value for each individual subscale, showing level of subscale endorsement.

Regressions results for Carers Group:

^a Univariate association with distress (anxiety and depression combined) significant at $p < .001$.

^b Univariate association with interpersonal strains significant at $p < .001$.

^c Univariate association with self-related strains significant at $p < .001$.

Regression Analyses of Variables Interpersonal Strains

Of the illness- and carer-related variables, negative/difficult behaviours (ECI), rejection of carer's help, and AN symptoms were all significantly associated with interpersonal strains ($p < .001$) and were simultaneously entered into a forward multiple regression model. The model accounted for 28.5% of the variance of interpersonal strains. The most significant variable was *negative/difficult behaviors*, which accounted for 19% of the variance at the first step of R^2 partitioning ($p < .001$). At the second and final step, *rejection of carer's help* accounted for an additional 3% of the variance. The

results of these multivariate regressions are shown in **Table 3**.

Regression Analyses of Variables Associated with Self-Related Strains

Negative/difficult behaviours (ECI), rejection of carer's help, and AN symptoms were significantly associated with self-related strains ($p < .001$), assessed via simple regressions, and were simultaneously entered in a multiple regression model. The only significant associated variable was *AN symptoms*, accounting for 10.5% of the outcome variance. Results are also shown in **Table 3**.

TABLE 2. Gender differences on combined and individual caregiving stress scales

Caregiving Stress Scales (Possible score range)	Total Mean (s.d.)	% Out of Total Score	M, N	Mothers Mean (s.d.)	% Out of Total Score	Fathers Mean (s.d.)	F, N	% Out of Total Score
Total of Combined Interpersonal Strains Scales (26–104)*	51.2 (12.9)	49	59	53.1 (12.8)	51	48.3 (12.7)	57	46%
Family conflict (12–48)	23 (8.4)	48	60	23.8 (8.4)	49.5	21.8 (8.5)	58	45
Expressive support (8–32)	25.4 (4.7)	79	59	25.1 (5.1)	78	26 (4.2)	58	81
Relational deprivation (6–24)*	13.6 (4)	57	60	14.3 (3.9)	56	12.5 (3.8)	57	52
Total of Combined Self-related Strains Scales (57–228)*	126.1 (17.5)	55	59	128.7 (17.6)	56	121.9 (16.7)	55	53
Overload (4–16)**	9.9 (2.8)	62	60	10.5 (2.8)	66	8.9 (2.6)	58	56
Role captivity (3–12)**	7.3 (2.7)	61	59	8.1 (2.5)	67.5	6.1 (2.5)	58	51
Loss of self (2–8)**	4.1 (1.8)	51	59	4.4 (1.6)	55	3.5 (1.8)	58	44
Self-esteem (10–40)	17.5 (3.3)	44	59	17.1 (2.9)	43	18.1 (3.6)	58	46
Personal gain (4–16)	10.2 (3.2)	64	59	10.5 (3.3)	67	9.7 (3)	58	61
Coping (23–92)*	47.4 (6.5)	52	59	46.6 (6.6)	51	48.9 (6.2)	55	53
Competence (4–16)	11.2 (2.5)	70	59	11.3 (2.5)	71	11 (2.5)	58	69
Mastery (7–28)*	18.5 (3.9)	66	59	17.8 (3.6)	63.5	19.5 (4.2)	58	70

Notes: (M = Mothers; F = Fathers) Gender differences by simple regressions.

*significant ($p < .05$).

**significant ($p < .001$).

TABLE 3. Results of multivariate regression analyses

Forward Selection Model	Reg. coef.	Rob. Stand. Error	t-Test Statistic (DF)	p-value	R ²
Interpersonal Strains					
Step 1					
Negative/difficult behaviors	.46	.08	5.68 (1, 113)	<.001	.194
Step 1					
Negative/difficult behaviors	.34	.09	3.80	<.001	.223
Rejection of carer's help	5.59	2.16	2.59	<.001	
At final step			$F(2, 113) = 18.42, p < .001$		
Self-Related Strains					
Step 1					
Illness symptoms (ABOS)	.54	.14	3.77	<.001	.105
At final step			$F(1, 111) = 14.24, p < .001$		
Distress					
Step 1					
Self-related strains	2.48	.03	6.98 (1, 112)	<.001	.312
Step 2					
Self-related strains	.23	.03	6.43	<.001	.375
Carer sex	.14	.03	5.09 (2, 112)	<.001	
Step 3					
Self-related strains	.19	.03	5.71	<.001	.411
Carer sex	-3.61	1.22	-2.95	.004	
Interpersonal strains	.12	.05	2.69	.008	
At final step			$F(3, 112) = 29.85, p < .001$		

Notes: Degrees of Freedom given for clusters, not individual cases.

Reference groups as follows: patient accepts carer's help; female (mothers). All remaining variables are continuous.

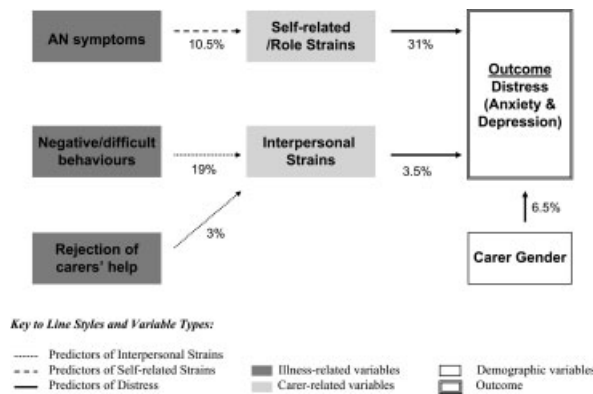
Regression Analyses of Variables Associated with Distress

Carers' sex was the only demographic variable significantly associated with carer distress, with mothers showing higher levels of distress than fathers. Negative/difficult behaviors, rejection of carers' help, rejection of having an ED, AN symptoms, as well as self-related and interpersonal strains were also significantly associated with distress ($p < .001$). All of these variables were entered into a forward selection model. Three variables remained highly significant in the final model, which accounted for 41% of the outcome variance:

Self-related strains, carers' sex, and interpersonal strains. Unique variance attributable to each variable following R^2 partitioning was 31% for self-related strains, 6.5% for carers' sex, and 3.5% for interpersonal strains. These results are also shown in **Table 3**.

The final model following multiple regression analyses is presented in **Figure 1**. Only predictive relationships of significance of $p < .01$ or lower are shown. Different styles of lines, as explained below the model, are used to denote the relationship between all proposed predictors and each of the three outcome variables (self-related strains, inter-

FIGURE 1. A model of carer distress following multiple regression analyses.



personal strains, and distress) as identified through multiple regression analyses. The individual R^2 value of each predictor is given to show the significance or strength of the predictor (i.e. the portion of the variance that the variable has been found to explain).

Conclusion

The aim of this study was to investigate and model the factors associated with depression and anxiety in carers of people with ED. Over 50% of carers scored at or above the clinical threshold (score ≥ 11) for anxiety, and 13% scored at or above the clinical threshold for depression. Three variables remained highly significant in the final model of factors contributing to carer distress: *Self-related strains*, *carer sex*, and *interpersonal strains*. Results appear congruent with the interpersonal component of the Maudsley model of maintenance in AN, while the gender differences in self-related strains and overall distress are consistent with previous findings that suggest that female carers are more anxious and more emotionally involved in caregiving.^{19,23}

Mothers had higher levels of depression and anxiety, and scored higher on both the self-related and interpersonal strains scales. These findings suggest that for mothers, the demands of caring for a child with AN may take a greater toll, especially as their caregiving role appears to be all-encompassing and internalised in terms of self-related stress and strains. Furthermore, the higher maternal psychological distress identified in the current study corroborates the overall gender discrepancy reported in a review of the research on caregiving in other areas.³⁹ As the majority of the current sample of

mothers were not in full-time employment, it is possible that employment status may act as a protective factor against carer strains and distress, allowing for respite and providing an alternate role in which carers have mastery. These findings suggest that mothers of individuals with AN may be in considerable need for psychosocial support and that their own psychological wellbeing is likely to be compromised by demands of the caregiving role.

Weekly contact time was not found to be a predictor of carer stress and coping in the current study, in contrast to findings of distress in carers of people with BN²⁰ and with schizophrenia.⁴⁰ It may be that the predictive significance of amount of contact as found in other studies is confounded by other variables, such as interpersonal interactions. It is possible that with greater contact, interpersonal friction and family conflict are intensified, thereby affecting the dysphoria experienced by carers. Negative/difficult behaviours, rejection of carer's help, and degree of AN symptomatology were all implicated as factors contributing to caregiving strains. These results add evidence in support of the significant and aversive impact of caregiving for individuals with ED and highlight the strong association between negative symptoms and difficult behaviours in patients and high levels of carer distress.^{5,6,8,17-20}

In terms of comparability of psychological distress of the current carer sample to carers in other areas of mental health, it appears that these AN carers experience significant psychological morbidity, and particularly anxiety, similar to or even greater than in other areas. In comparison to HADS scores of carers in Alzheimer's disease, for example,⁴¹ our carers show higher psychological morbidity. This difference is consistent with evidence reported by Treasure et al.⁶ who compared caregivers' mental wellbeing in psychosis and AN and found that AN carers had significantly higher psychological morbidity. Our findings offer additional evidence of the considerable psychological morbidity experienced by carers in ED.

Limitations

The current sample of carers was self-selected as participants from an existing database were sought, which raises the question of representativeness of the respondents. Although, some of the carers on this database are parents of the unit's inpatients (36 parents in the current sample), they may also come from a variety of sources such as beat, and may differ in terms of experience of care-

giving and familiarity with services and resources to carers, which may impact on physical and psychological wellbeing. It could be argued, furthermore, that these carers are more empowered and actively involved in seeking treatment and support for themselves and their loved ones, which could lead to a skewed sample. We therefore acknowledge a limitation as regards the representativeness of the database sample.

These carers may also be caring for patients with more severe ED (a high proportion of the patients had comorbidity and needed inpatient treatment). Nevertheless, comorbidity, illness duration and number of inpatient admissions were not significantly predictive of carer distress. It will be important to test these models in consecutive studies, and at different stages of treatment and recovery, as well as include carers of people with BN. Furthermore, the diagnosis of the sufferers was reported by carers but was not verified. Parents have been found to report accurately on offspring's illness symptoms and behaviors,⁴² and the consistency between mothers and fathers in the current sample as assessed by the ABOS scale further suggests that parents are reliable informants of symptomatology.

Also, we did not examine for a broad range of psychopathology (such as ED) in the carers' history. Assessment of carer distress should, furthermore, attempt to distinguish between state and trait-dependent anxiety and depression, which are likely to confound results. It is increasingly appreciated that carers and family members of individuals with ED experience psychiatric disorders at rates greater than in those in the general population. The role of possible shared genetic traits contributing to such psychiatric symptoms in affected families must also be acknowledged when addressing carer needs; such shared traits are likely to exacerbate the interpersonal friction within affected families, as well as compound the burden of care for family members, increasingly depleting their own physical and mental resources and therefore curtailing their ability to offer care, which has obvious implications for the sufferer's rehabilitation and risk for relapse. It is possible, for example, that depressed or anxious parents experience greater caregiving strains, however, this association may be bidirectional in that increased caregiving strains contribute to carers' anxiety and depression. Longitudinal studies are needed to resolve the issue of bidirectionality.

In addition, we must acknowledge the possible limitation due to multicollinearity of variables; for example, the individual outcome variance that self-

related and interpersonal strains appear to account for may be inflated by carer- and illness-related characteristics. For instance, we have previously found higher maternal EOI in carers of individuals with AN,¹⁹ which raises the possibility that the predictive significance of gender in the model we present in this study is confounded by EE.

As the current study was cross-sectional in design, these results suggest the predictive value of factors contributing to carer distress, however, no causal links can be identified. A longitudinal study of carer distress and EE from the early stages over the course of an ED and exploring the mechanisms contributing to both carer distress and EE would be needed to elucidate the exact process leading to the development of these constructs. Given the comparatively small sample size of the current study, a path analysis was unfeasible. Replication using more sophisticated methods of analysis, such as structural equation modeling, as well as larger samples of carers and controls is therefore recommended. Comparisons with other carer populations, as well as the use of related measures of psychological morbidity, and replication of the Pearlin scales for carers in ED, are also suggested.

Clinical Implications

In this study, AN symptoms, comorbid difficult behaviours and rejection of carers' help were implicated as contributing factors to caregiving strains, which in turn were associated with carer psychological distress. These findings add support to our clinical model of carer stress which emphasises how illness-related problems in combination with role strain and interpersonal friction can overwhelm carers' coping resources and contribute to anxiety, depression, and stress, which can be unhelpful both for carers and individuals with ED.⁷ Interventions aimed at ameliorating outcome and adherence to treatment, reducing relapse, as well as improving family functioning may need to focus on strategies for providing skills and support to decrease caregiving strains, and for improving the mood and quality of life for carers. Mothers of individuals with AN may be in particular need for support. Educational and/or skills-based interventions for carers of people with ED can reduce parental distress, burden and EE.^{21,27,43-46} Whether such interventions can ameliorate adherence to and outcome of treatment requires further investigation.

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