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Coping strategies and social support as predictors and mediators of eating disorder carer burden and psychological distress

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Abstract

Caring for someone with an eating disorder is associated with a high level of burden and psychological distress. While models for the prediction of carer burden have previously been investigated, these have typically neglected the role of coping strategies and social support. Thus, the current study will examine predictors of both carer burden and carer psychological distress in eating disorder carers. Further, the mediating roles of coping strategies and social support will be investigated. Methods Fifty-six carers completed a self-report questionnaire assessing burden, psychological distress, needs, expressed emotion, coping strategies and social support. Results Use of maladaptive coping strategies was a unique predictor of both burden and psychological distress. Further, maladaptive coping was a consistent mediator on the outcome of carer burden. Social support, however, did not significantly predict, or mediate, carer burden. Conclusions Interventions focusing on teaching appropriate coping strategies would benefit carers.

Keywords Eating disorders · Carer burden · Coping strategies · Social support

Introduction

Eating disorders are serious conditions that lead to high level of both psychological and physical consequences,

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R. M. King Deakin University, Geelong, Australia such as depression, anxiety, cardiovascular problems, and high mortality [1]. The estimated prevalence rate of anorexia nervosa (AN) is 0.7–1.0% [1, 2], with an average duration of 5 years [3]. Further, the lifetime prevalence rate of bulimia nervosa (BN) has been estimated to be 1–5% prevalence rate [1, 4, 5], with one-third to one-half of BN patients still having an eating disorder of clinical severity at a 5–10-year follow-up [1]. Thus, while being of relatively low prevalence, eating disorders are chronic, debilitating illnesses. As such, people with an eating disorder require long-term care, usually from informal carers, such as family members or friends.

Caring for someone with an eating disorder is associated with a high level of burden [6, 7] and psychological distress [8]. Qualitative [9] and quantitative [10, 11] studies identify several important factors related to the experience of carer burden and psychological distress, including carer needs, expressed emotion, coping strategies and social support.

Little prior research has been conducted on the needs of eating disorder carers; however, qualitative research suggests a high level of unmet needs in terms of both physical and mental health and well-being [12, 13]. Further, the problem areas identified by eating disorder carers have been found to be similar to that of schizophrenia carers [14]. Eating disorder carers often identify a need for more general information about eating disorders, practical advice on the development how to cope with the illness, and sources of informal and professional support [8, 9, 12]. Similarly, the one quantitative study examining eating disorder carer needs found that a higher need for support from people or organizations significantly predicted negative appraisal of the caregiving situation [15]. Given the preliminary indications of the importance of carers needs, more research is needed to understand the relationship of carer needs to burden and psychological distress.



In regards to expressed emotion in eating disorder carers, Zabala et al. [16] recently reviewed 20 studies that examined the level of expressed emotion in eating disorder carers. The majority of studies indicated that carers display high levels of expressed emotion, particularly critical comments and emotional overinvolvement, with similar levels to that seen in carers of people with depression. Further, Zabala et al. [16] found that expressed emotion is higher when the person had longer illness duration and were older in age. The presence of a high level of expressed emotion has been shown to be related to a poor outcome for sufferers [17] in that those undertaking family based therapy demonstrate poorer outcomes when there is high expressed emotion [18]. In addition, high expressed emotion is linked to higher levels of carer ill health and burden [7].

Due to the emotional pressures that are experienced throughout the caregiving process [19], carers of individuals with an eating disorder may feel as though they are unable to cope with the prospect of long-term caregiving [13]. However, qualitative research indicates that carers utilise both emotion and problem-focussed coping mechanisms. Emotion-focussed coping strategies; where an attempt is made to change the appraisal of a situation [20]; include humour, positive thinking, acceptance of the eating disorder [13], optimism regarding the outcome of their child's illness, and cognitive restructuring whereby the parents conceptualised their child's illness as separate from their child [11]. Conversely, problem-focussed coping; entailing deliberate attempts to alter the environment and situation [20]; include maintenance of own interests outside of the caregiver role and active enquiry into the illness [13]. Both emotion focussed coping and problem focussed coping strategies can be conceptualised as adaptive coping strategies [21]. However, some carers report more maladaptive coping responses that include self-blame, blaming the patient for their problem, a sense of helplessness, or an overprotective or overanxious response to the child's illness [22].

While coping has been shown to mediate the relationship between a stressful situation and the outcome [20, 23], and specifically to mediate the relationship between a caring situation and carer burden [24], currently there is no quantitative research that has investigated coping strategies used by eating disorder carers. A quantitative examination of coping strategies would allow for the investigation of its predictive and mediating role on carer burden and psychological distress.

Social support has been found to generally contribute to more adaptive coping strategies within individuals, such as problem-focussed coping [25]. Conversely, the lack of available social support has been shown to be associated with maladaptive coping strategies [25]. Social support can be conceptualised to include both the structure of the social

ties and function of current relationships [26], and consists of emotional support, tangible support, and informational support [20, 27]. Emotional support encompasses support on an empathetic basis; such as being a confidant and providing reassurance; that communicates to an individual that they are cared for and loved [20, 27]. Tangible support consists of behaviours intended to provide direct aid to another, such as doing a job or chore [20, 27]. Last, informational support occurs when provision of information, advice or feedback about how a person is doing is given [20].

Limited qualitative research indicates that support and understanding from others is seen as essential for carers of individuals with eating disorders [9]. This support can be gained from partners, friends, other parents of children with eating disorders and specialist services. However, although carers may have the support from others, the presence of social support is not necessarily synonymous with understanding the nature of eating disorders or the caregiving role [28]. As such, while family and friends can offer support to the carer, there is recognition by the carers as to the limits of what family and friends can do to help [9]. Last, the presence of stigmatization and negative or unsympathetic reactions from others may result in carers being reluctant to seek out support [9, 29].

Currently, one quantitative study has examined social support in the context of caring for an individual with an eating disorder [10]. Dimitropoulos et al. [10] found neither informal nor professional support correlated with carer burden or psychological distress. However, the lack of a relationship between these variables may be due to Dimitropoulos et al. [10] using an overall measure of support, rather than examining the number of people available for social support, and the quality of this social support separately. Quality of social support, rather than the actual number of people in support networks, has been found to predict carer burden [30].

Like coping strategies, social support can also act as a mediator on the effects of caregiving [24, 31], with higher levels of social support related to higher life satisfaction and lower depression in carers [32]. However, this relationship has yet to be examined in eating disorder carers. Further, the separate aspects of quantity and satisfaction have yet to be examined in an eating disorder context.

Therefore, the aim of the current study is to determine the predictors of eating disorder carer burden and carer psychological distress, and determine the possible mediators of burden and psychological distress. It is hypothesised that carer burden and carer psychological distress would be predicted by social support, expressed emotion, maladaptive coping strategies, unmet needs, eating disorder symptom severity, and contact hours with the sufferer. In addition, the following mediation pathways were



hypothesised: the effect of expressed emotion on carer burden and carer psychological distress would be mediated by coping strategies and social support, and the impact of unmet needs on carer burden and carer psychological distress would be mediated by coping strategies and social support.

Methods

Participants

Participants were 56 carers (44 females and 12 males); 42 parents, 8 partners, 4 siblings, and 2 friends. The mean age for the participants was 45.79 (SD = 11.84). 50 carers resided in Australia, 4 from the UK, 1 from the USA and 1 from Canada. The average number of hours dedicated to caring for the individual with an eating disorder was reported to be 1 h per week for direct treatment commitments (SD = 1.24) and 78.91 (SD = 63.83) hours of general contact with the sufferer. In relation to the people with an eating disorder, there were 50 females and 6 males who were cared for by the participants. 38 were reported by the carer to have anorexia nervosa, 7 bulimia nervosa, and 6 a combination of both diagnoses. Four sufferers' diagnosis was unknown due to missing data. A further one was reported to have binge eating disorder. The average age for the patients was 21.48 (SD = 8.67) years. The mean illness duration was 5.09 (SD = 5.03) years, with 45 (80.4%) currently receiving treatment and 28 (50%) had been hospitalised at least once. Last, 44 (78.5%) of the sufferers were reported by carers as living at home with the carer.

Materials

The questionnaire consisted of two sections, a general information sheet and six scales assessing expressed emotion, coping strategies, social support, carer psychological health, carer burden, and needs as a carer.

General information sheet

The general information sheet obtained demographic information about the carer, such as age, gender, and time spent with the person with the eating disorder. In addition, demographic information regarding the person with the eating disorder was obtained, such as gender, age, current diagnosis, and BMI. Last, carers were asked about their perceptions of how important it is to the sufferer that they change and the sufferers' confidence that they can change. These two questions were rated on an 11-point Likert scale (0 = not important, 10 = very important) and were used to gauge perceived stage of change of the sufferer.

Eating Disorders Symptom Impact Scale (EDSIS)

The EDSIS is a 30-item measure examining the specific burden for carers of individuals with an eating disorder and carers' perceptions of the emotional, psychological and tangible impact of caring for someone with an eating disorder [33]. The EDSIS demonstrates acceptable reliability with Chronbach's alphas for the subscales ranging from .82 to .89, and a total scale reliability coefficient of .90. All subscales of the EDSIS show convergent validity with the Experience of Caregiving Inventory—negative subscale (range, r = .45 to r = .60). Only the total scale was used for the current study (Chronbach's $\alpha = .82$)

Carers' Needs Assessment Measure (CaNAM)

The CaNAM is a self-report questionnaire measuring the perceived needs of carers of individuals with an eating disorder across five domains [12]. In the current study, the following domains were used: need for information, need for professional support, need for support for self, and information from GPs. These were summed to form a total need score with higher scores indicating higher degrees of support and information obtained. The Chronbach's alpha for the total scale was high ($\alpha = .93$)

General Health Questionnaire-12 (GHQ-12)

The GHQ-12 is a self-report questionnaire measuring temporary deviations from normal functioning that may indicate psychological distress [34]. It is the most widely used screening tool to detect psychological illness in community samples. The GHQ-12 consists of 12 items that measure the participant's general health over the previous few weeks. Items were scored 0–3 and summed to give a total score, with a higher score indicative of greater distress. The Chronbach's alpha for the current study was high ($\alpha = .90$)

Brief COPE

The Brief COPE provides a parsimonious way to assesses various ways in which people cope with a specified situation [21]. The Brief COPE consists of 14 subscales, each with two items, as measured on a 4-point Likert scale (1 = Not at all, 4 = A lot). These 14 subscales are then divided into maladaptive coping (equivalent to dysfunctional coping) and adaptive coping (problem-focussed plus emotion-focussed coping) [21]. The Brief COPE has been widely used with the subscales demonstrating acceptable reliability ranging from .50 to .90 [21]. For the current study, the Chronbach's alpha for the two major subscales was acceptable (maladaptive subscale $\alpha = .79$; adaptive subscale $\alpha = .83$).



Social Support Questionnaire (SSQ6)

The SSQ6 is a six item measure that assesses separately both the quantity of social support and the respondents' satisfaction with the received support [35]. The SSQ6 demonstrates high internal consistency, with a Chronbach's alpha of .90 for number and .93 for satisfaction [35]. The Chronbach's alphas for the current study were acceptable, with $\alpha = .77$ and $\alpha = .89$ for quantity and satisfaction, respectively.

Family Questionnaire (FQ)

The FO is a self-report questionnaire based on the Camberwell Family Interview (CFI [36]) measuring the expressed emotion domains of critical comments and emotional overinvolvement [37]. It is the only self-report measure to date that closely corresponds to the critical comments (78% correct classification) and emotional overinvolvement (71% correct classification) subscales of the CFI [37]. The FQ consists of 20 items as measured on a 4-point Likert scale (1 = Never/Very rarely, 4 = Very often). Within AN carers, the emotional overinvolvement and critical comments subscales have demonstrated good internal reliability of .76 and .88, respectively [38]. Only the total scale score was used in the current study, with scores above 50 considered high on expressed emotion. For the current study, the total scale had a high internal consistency $(\alpha = .82).$

Procedure

The current study reports part of the findings from a larger longitudinal study examining caring for someone with an eating disorder. Approval for the study was obtained from the Deakin University Human Research Ethics Committee prior to commencing the study. A number of recruitment strategies were implemented: online advertisements on eating disorder organisation websites (e.g., b-eat, UK; The Butterfly Foundation, Australia), newspaper advertisements, radio interviews, distribution of flyers within carer support groups and carer workshops, and advertisement through the local hospital-based eating disorder service. Interested participants were either mailed out a paper-based questionnaire package or were directed to the online version of the questionnaire.

Results

Table 1 presents descriptive statistics for the measured variables. As shown, carers displayed a moderate level of burden and psychological distress. Further, they reported a



Variable	Mean (SD)	Scale range 0–96	
Burden (EDSIS)	46.04 (15.80)		
Psychological distress (GHQ-12)	17.84 (6.54)	0-36	
Carer needs (CaNAM)	23.21 (14.07)	0-56	
Expressed emotion (FQ)	56.89 (7.86)	20-80	
Adaptive coping (Brief COPE)	42.45 (7.89)	16-64	
Maladaptive coping (Brief COPE)	21.89 (5.57)	12-48	
Quantity social support (SSQ6)	2.28 (1.36)	≥0	
Satisfaction social support (SSQ6)	4.53 (1.23)	1–6	

Table 2 Standard multiple regression analysis for the prediction of carer burden and carer psychological distress

Predictor	lictor Burden			Psychological distress		
	\overline{B}	β	sr^2	В	β	sr^2
Satisfaction with social support	1.01	.08	.01	03	01	.00
Total expressed emotion	.67	.34*	.08	.17	.21	.03
Maladaptive coping	.57	19	.03	.43	37*	.10
Total needs	47	42**	.14	.01	.03	.00
Important to change	1.23	.25	.04	.01	.01	.00
Confidence can change	63	11	.04	32	06	.00
Contact hours	.03	.12	.02	.02	.23	.05

^{*} p < .05, ** p < .01

high level unmet needs, high expressed emotion, a moderate level of maladaptive and adaptive coping strategies and moderate level of satisfaction with social support.

While path analysis is the most appropriate statistical test for the hypotheses, the sample size was insufficient to conduct such an analysis. Therefore, a series of multiple regression analyses and mediation analyses were conducted. Further, due to the small sample size, post hoc power analyses were conducted to determine the maximum number of predictors to achieve a minimum acceptable power of .80 [39].

Prediction of carer burden and psychological distress

For the multiple regression analyses the maximum number of predictors that resulted in a minimum acceptable power was seven, with the chosen predictors being: satisfaction with social support, total expressed emotion, maladaptive coping, total needs, carers' perceptions of how important it was to the sufferer that they change, carers' perception of the sufferers' confidence that they could change, and the number of hours carers spent with the sufferer.

Table 2 presents the *B*-weights, β -weights, and sr^2 for the prediction of carer burden and carer psychological



distress. For burden (as measured by the EDSIS) the regression model was significant ($R^2 = .48$, p < .001; $Adjusted R^2 = .39$), with total expressed emotion and total needs the significant unique predictors. For psychological distress (as measured by the GHQ-12) the regression model was significant ($R^2 = .32$, p < .05; Adjusted $R^2 = .20$), with maladaptive coping the only significant unique predictor.

Mediation of carer burden and psychological distress

To test the mediation relationships, the Baron and Kenny [40] method for testing mediation was utilised; which stipulates that four criteria must be met for mediation.

- 1. The IV must be significantly related to the mediator (path a).
- 2. The IV must be significantly related to the DV (path c).
- 3. The Mediator must be significantly related to the DV (path b).
- 4. The relationship between the IV and DV is reduced in significance while controlling for the mediator (path c').

Two types of mediation can occur. Full mediation occurs when the addition of the mediator reduces the final path (path c') to non-significance. Partial mediation occurs when the final path (path c') is only reduced in significance.

Given the limitations of the Baron and Kenny [40] method of testing mediation, such as low power, high Type I error rate and not addressing whether the indirect effect is significantly different from zero, the Sobel test and bootstrapping were also used to address these limitations. Both the Sobel statistic and bootstrapping were conducted using the Sobel macro for SPSS developed by Preacher and Hayes [41].

The first mediation analysis conducted examined the relationship between expressed emotion and carer burden as mediated by maladaptive coping. Maladaptive coping, rather than adaptive coping, was chosen due to the higher correlation with carer burden (r = .42, compared to r = -.14, respectively). Figure 1 presents β -weights for the

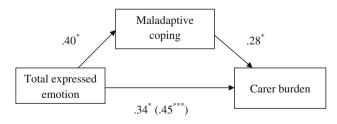


Fig. 1 Model showing partial mediation using the Baron and Kenny (1986) method by maladaptive coping on the relationship between expressed emotion and burden. Note: *p < .05, **p < .01, ***p < .001

mediation analysis, with the figure in the parenthesis the co-efficient for the IV when the mediator has not been entered into the equation. As the β -weight for the total expressed emotion reduces in significance once maladaptive coping is entered, partial mediation is apparent. A Sobel test was also conducted (z=1.75; SE = 0.12, p=.08), indicating a non-significant indirect effect. Last, bootstrapping (with 5,000 samples) provided 95 percent confidence intervals (CI = .00 to .52), which approached significance for an indirect effect.

The second set of mediation analyses examined the mediating role of maladaptive coping on the relationship between expressed emotion and carer psychological distress. This relationship was found to be fully mediated by maladaptive coping using the Baron and Kenny [40] method (Fig. 2). The Sobel test indicated a significant indirect effect (z = 2.05; SE = .09, p < .05), and bootstrapping set at 5,000 samples was also significant for an indirect effect (CI = .02 to .23).

The third and fourth set of mediation analyses to be conducted examined the mediating role of satisfaction with social support on the relationship between expressed emotion and carer burden and psychological distress. However, as satisfaction with social support did not significantly contribute to the model, for either burden or psychological distress, mediation analyses were unable to be completed.

The fifth set of mediation analyses examined the mediating role of maladaptive coping on the relationship between total carer needs and carer burden. Using the

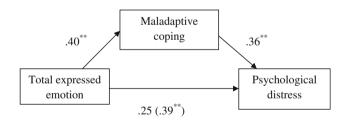


Fig. 2 Model showing full mediation using the Baron and Kenny (1986) method by maladaptive coping on the relationship between expressed emotion and psychological distress. Note: *p < .05, **p < .01

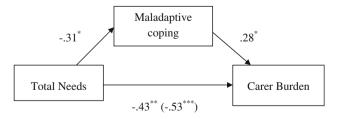


Fig. 3 Model showing partial mediation using the Baron and Kenny (1986) method by maladaptive coping on the relationship between total needs and psychological distress. Note: *p < .05, **p < .01, ***p < .001



Baron and Kenny [40] method, a partial mediation model was found (see Fig. 3). However, both the Sobel test (z = -1.62, p > .05) and bootstrapping set at 5,000 samples (CI = -.26 to .00) indicated non-significant indirect effects.

The final series of mediation analyses, examining the mediation of carer needs and burden by social, and the mediation of carer needs and psychological distress, were not conducted due to a lack of relationship between carer needs and psychological distress and carer needs and satisfaction with social support.

Discussion

The aim of the current study was twofold; to determine the predictors of carer burden and psychological distress within eating disorder carers; and to determine the mediators of burden and psychological distress within eating disorder. With respect to the second aim, this is the first study to examine the mediational role of social support and maladaptive coping on the outcome of eating disorder carer burden and psychological distress.

The regression models developed to predict carer burden and psychological distress were both moderately successful. The regression model for carer burden predicted 48 percent of the variance in burden with expressed emotion and carer needs being significant unique predictors. For psychological distress, however, the regression model only predicted 32 percent of the variance, with maladaptive coping the only unique predictor. Interestingly, satisfaction with social support was not a unique predictor for either carer burden or psychological distress.

This impact of unmet carer needs and levels of expressed emotion on carer burden is consistent with the limited prior research examining cross-sectional models. Sufferer's report of familial expressed emotion predicted a negative caregiving experience, but carer reports of expressed emotion did not predict a negative experience, possibly due to a social desirability bias [7]. The significant predictor role of carer reported expressed emotion in the current study may be due to the use of a measure that is specifically designed to reduce such biases.

In regards to needs, Whitney et al. [15] found unmet needs for professional support from people/organisations significantly predicted negative appraisals of caregiving. Currently, no eating disorder model takes into account informal social support (such as friends and family members) as a predictor of burden or distress. However, research examining schizophrenia carers has shown that informal social support predicts a positive caregiving experience [42] and those who lack social support use more ineffective coping strategies and have a more negative

appraisal of the caring situation [43]. Further, satisfaction with social support significantly predicts distress, positive affect and satisfaction with life in young carers [30]. Given the established link between informal social support and carer burden for schizophrenia carers, the lack of prediction by social support in the current study is surprising. This is may be due to the measure used, in that it typically measures emotional support [35]. It may be that eating disorder carers find instrumental, or tangible, support, more useful. Therefore, an exploration of the impact of other forms of social support on eating disorder carer burden and distress is needed. Further, the lack of relationship may be due to the generalised nature of the social support measure, rather than using a targeted social support measure for the carer role. As such, the use of a more situation-specific social support scale is warranted in future research.

Coping as a predictor of carer burden or psychological distress has not previously been examined in eating disorder carer research. However, higher levels of distress in carers of people with schizophrenia has been found to be associated with self-blame and less use of adaptive coping strategies, such as active-coping and positive reframing [44]. Further, carers of people with multiple sclerosis, like eating disorders a chronic illness, have poorer outcomes when using emotion-focussed coping [45]. Therefore, the current study supports the findings in schizophrenia research that the use of maladaptive coping strategies predicts burden and distress in eating disorder carers.

The second hypothesis regarding the meditation relationships of expressed emotion and carer needs on burden and psychological distress was partially supported. There was a partial and full mediation of expressed emotion by maladaptive coping on carer burden and psychological distress, respectively. The relationship between carer needs and burden was partially mediated by maladaptive coping. Last, social support did not significantly contribute to the mediation models; therefore, mediation analyses were not conducted. Again, this lack of a significant relationship in regards to social support may be attributable to an inappropriate measure.

Taken together, the mediation results indicate that impact of expressed emotion and carer needs is influenced by maladaptive coping mechanisms used by carers. This finding support prior theory on stress, such as Lazarus and Folkman's [20] cognitive stress theory and Pearlin et al.'s [45] stress process model. Further, prior mental illness carer models has argued that social support and coping skills are significant mediators of carer burden [24, 31] and stressful outcomes [46, 47]. However, neither prior research has examined the specific mediating role of these variables on the impact of expressed emotion and carer needs, nor has there been an examination of coping and social support of mediators for eating disorder carer burden. Therefore, the current study provides important preliminary findings in this area.



Limitations

Several limitations should be noted for the current study. The first set of these limitations relates to the nature of the sample. First, while the participants were a community sample, self-selection of participants may mean the sample was not representative of more extreme cases. It may be speculated that those carers whose situation was more extreme would not have the time to complete the study or may be too distressed by their situation to take part. Second, while all carers of all forms of eating disorders were eligible to be included, the majority of the participants cared for someone with AN. Similarly, while both genders were included, the majority of the carers were female. Thus, generalisability of the current findings may be limited.

Last, the sample size was relatively small, limiting the analyses that could be conducted. Much of the previous research has recruited participants from inpatient settings; therefore, it may be more difficult to recruit carers from a community population.

The second main limitation relates to the measure of social support. The chosen measure did not predict burden or psychological distress, limiting any conclusions regarding the role of social support. As indicated earlier it may be speculated that due to the generalised nature of the social support measure used, as opposed to a specific, carer burden focussed measure of social support, it did not adequately capture the construct. Further, the items in the SSQ-6 are very general and affective in nature, with no questions on instrumental, or tangible, support. As such, instrumental support may be the more important predictor of carer burden and distress. These aspects require further investigation.

Conclusions

The current study has highlighted the importance of expressed emotion, maladaptive coping strategies and carer needs on the outcomes of carer burden and psychological distress. In order to decrease the level of burden experienced by eating disorder carers, interventions aimed at increasing adaptive coping strategies, coinciding with a decrease in maladaptive coping strategies, and decreasing expressed emotion are needed. Further, it is imperative that carers be given comprehensive information and guidance in relation to eating disorders and what they can do to help their loved on during recovery. Carer-directed interventions such as the collaborative skills workshops developed by Treasure and associates [48] which specifically targets these aspects are, therefore, warranted.

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