Soc Psychiatry Psychiatr Epidemiol (2013) 48:163–171
DOI 10.1007/s00127-012-0524-7

ORIGINAL PAPER

# A longitudinal examination of burden and psychological distress in carers of people with an eating disorder

**Kerri Coomber · Ross M. King**

Received: 8 September 2011 / Accepted: 17 May 2012 / Published online: 8 June 2012

## Abstract

*Purpose* Eating disorders are chronic conditions that require ongoing, high level care. Despite the chronic nature of eating disorders, to date, previous research examining eating disorder carer burden and psychological distress has been cross-sectional only. Therefore, the current study aimed to conduct a preliminary longitudinal examination of the predictors of carer burden and psychological distress for carers of those with an eating disorder.

*Methods* A self-report, quantitative questionnaire approach was utilised. Forty-two carers completed three self-report questionnaires over a period of 9 months (initial, 4½ and 9 months) assessing carer burden, psychological distress, carer needs, expressed emotion, coping strategies and social support.

*Results* Maladaptive coping, expressed emotion and carer needs were significant longitudinal predictors of carer burden. Carer psychological distress could not be predicted longitudinally.

*Conclusions* In order to reduce carer burden, interventions should test whether reducing maladaptive coping strategies, expressed emotion and addressing carer needs lead to lower carer burden and distress.

**Keywords** Eating disorders · Carers · Longitudinal · Carer burden · Psychological distress

K. Coomber · R. M. King (✉)
School of Psychology, Deakin University,
Locked Bag 20000, Geelong, VIC 3220, Australia
e-mail: ross.king@deakin.edu.au

## Introduction

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 % [1, 4, 5], and one-third to one-half of BN patients will still have an eating disorder of clinical severity at a 5- to 10-year follow-up [1]. Thus, while being of relatively low prevalence, eating disorders are chronic illnesses that require long-term care, usually from informal carers such as family members or friends.

Cross-sectional research has shown that caring for someone with an eating disorder is associated with a high level of burden [6, 7] and psychological distress [8]. While carer burden lacks a common definition, an underlying theme in most definitions relates to an adverse impact of the patient on the family and the family's health, and difficulties experienced by family members due to the patient's illness [9]. Qualitative (e.g. [10]) and quantitative (e.g. [11, 12]) research has identified a number of constructs related to carer burden and psychological distress, including, among others, carer needs, expressed emotion, coping strategies and social support.

Carers of patients with an eating disorder have a high level of unmet needs in terms of both physical and mental health and well-being [10, 13]. Further, these unmet needs are similar to those for carers of people with schizophrenia [14]. Carers of people with an eating disorder often identify a need for more general information about eating disorders, practical advice on the development of how to cope with the illness, and sources of informal and professional support [8, 10, 13]. The single quantitative study examining carer needs found that a higher need for support from people or organisations significantly predicted a negative appraisal of their caregiving situation [15].

Expressed emotion is a measure of family interaction and consists of the attitudes and behaviours that a family member communicates towards the ill member of the family [16, 17]. Expressed emotion refers to the tone, pitch and speed of negative and positive comments, in addition to the comments themselves. Five central areas to expressed emotion have been identified: critical comments, hostility, emotional overinvolvement, warmth and positive remarks [18]. With regard to expressed emotion in carers of those with an eating disorder, Zabala et al. [19] reviewed 20 studies; the majority of studies found that carers displayed high levels of expressed emotion, particularly in relation to critical comments and emotional overinvolvement. Further, this level of expressed emotion is similar to that seen in carers of people with depression. Lastly, high expressed emotion, as reported by the patient, predicts carer ill health and burden cross-sectionally [6], and self-reported carer expressed emotion predicts psychological distress and carer burden cross-sectionally [20].

Due to the emotional pressures experienced throughout the caregiving process [21], carers of individuals with an eating disorder may feel that they will be unable to cope with the prospect of long-term caregiving [22]. Qualitative research indicates that carers utilise both adaptive and maladaptive coping mechanisms. Adaptive coping strategies identified include humour, positive thinking, acceptance of the eating disorder [22], conceptualising the eating disorder as separate from their child [23] and an active enquiry into the illness [22]. In contrast, maladaptive coping responses include self-blame, blaming the patient for their problem, a sense of helplessness, or an overprotective or over-anxious response to the child's illness [23]. In a cross-sectional quantitative study, maladaptive coping strategies significantly predicted both carer burden and psychological distress [20].

Additionally, social support can be seen as a resource for coping [24], whereby an individual seeks social support as a means to cope with a stressful situation [25]. Limited qualitative research shows that support and understanding from others is seen as essential for carers of individuals with eating disorders [10]. This support can be gained from partners, friends, other parents of children with eating disorders and specialist services. Social support is also linked to coping; the presence of social support generally contributes to more adaptive coping strategies [26], while a lack of available social support is associated with maladaptive coping strategies [26]. Despite this, Dimitropoulos et al. [11] found that informal and professional support did not correlate with eating disorder carer burden or psychological distress. However, the lack of relationship between these variables could be due to Dimitropoulos et al. [11] using an overall measure of social support, rather than examining the separate components of support: that is, the number of available people in a social network and the perceived quality of the support received [24]. Past research indicates that it is the nature of social support, rather than the actual number of people in your support network that predicts burden (e.g. [27]).

While the above findings provide valuable insights into the experience of eating disorder carers' burden, some important limitations remain to be addressed. Currently, all the evidence for carer burden has come from cross-sectional studies (e.g. [8, 11, 23]), limiting conclusions regarding the predictors of long-term carer burden. Dimitropoulos et al. [11] specifically identified a need for longitudinal research to ascertain changes in the course of family functioning over time in order to determine the predictors of carer burden.

Therefore, the aim of the current study was to examine the longitudinal predictors of eating disorder carer burden and carer psychological distress. Given the chronic nature of eating disorders, the severe physical and psychological consequences, and frequent hospitalisations, it is hypothesised that longitudinally the level of carer burden, psychological distress, expressed emotion and carer unmet needs will remain consistently high. Secondly, based on prior cross-sectional carer research, it is hypothesised that burden and psychological distress will be longitudinally predicted by expressed emotion, coping strategies, social support and carer needs.

## Method

### Participants

A total of 56 carers (44 women and 12 men) were recruited: 42 were parents, 8 partners, 4 siblings and 2 friends. At baseline, the mean age of the participants was 45.79 (SD = 11.84) years. Carers had an average of 78.91 (SD = 63.83) h of contact with the person with an eating disorder per week, with 1 h (SD = 1.24) per week of direct treatment commitments. At Time Two, there were 45 carers (33 females and 12 males) consisting of 34 parents, 8 partners, 2 friends and 1 sibling. Forty-three carers (31 females and 12 males) remained at Time Three: 33 parents, 8 partners and 2 friends. Therefore, there was an overall retention rate of 76.78 % across all three time points.

There were 50 females and 6 males with an eating disorder. At baseline, the average age of the patients was 21.48 (SD = 8.67) years. Based on carer report at Time One, there were 38 patients diagnosed with AN, 7 with BN, 6 AN purging type and 1 participant with binge-eating disorder. The average duration of the illness was 5.09 years (SD = 5.03 years), with 45 (80.4 %) currently receiving treatment for their illness. The average BMI (excluding the patient with binge-eating disorder) of the sufferers, as reported by the carers, was 17.51 (SD = 2.22). At Time Two, BMI was 18.42 (SD = 5.56) and at Time Three 19.73 (SD = 6.39). Twenty-eight (50.8 %) patients had been hospitalised for their disorder at least once and 44 (78.5 %) were living at home with the carer.

## Materials

Participants completed the same self-report questionnaire at three time points. These questionnaires were completed over a 9-month period (initial, 4½ and 9 months). The sections of all three questionnaires are outlined below.

### *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 such as gender, age, current diagnosis and BMI regarding the person with the eating disorder was obtained.

### *Eating Disorders Symptom Impact Scale (EDSIS)*

The EDSIS is a 30-item measure examining specific burden for carers of individuals with an eating disorder and assesses the carers' perceptions of the emotional, psychological and tangible impact of caring for someone with an eating disorder [28]. Items are summed, with higher scores indicating more negative appraisals of specific aspects of caregiving. The EDSIS demonstrates acceptable reliability with Cronbach's alpha 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 $r = .60$). Further, the EDSIS has been demonstrated to be sensitive to changes in carers' experience of burden over time. The internal consistency for the total scale in the current study was high (Time One $\alpha = .82$; Time Two $\alpha = .89$; Time Three $\alpha = .92$).

### *Carers' Needs Assessment Measure (CaNAM)*

The CaNAM is a self-report questionnaire measuring the perceived needs of carers of individuals with an eating disorder [13]. The following domains from the CaNAM were used in the current study: need for information, need for professional support, need for support for self and information from GPs. These were summed to form a total scale. Higher scores indicate higher degrees of support and information obtained. The Cronbach's alphas for the total scale in the current study were high (Time One $\alpha = .93$; Time Two $\alpha = .93$; Time Three $\alpha = .94$).

### *General Health Questionnaire-12 (GHQ-12)*

The GHQ is the most widely used screening tool to detect psychological illness in community samples. The GHQ-12 is a 12-item self-report questionnaire measuring temporary deviations from normal functioning: that is, indications of possible psychological distress [29]. Items were scored 0–3 and summed to give a total score, with a higher score indicative of greater distress. The Cronbach's alphas for the current study were high (Time One $\alpha = .90$; Time Two $\alpha = .93$; Time Three $\alpha = .95$).

### *Brief COPE*

The Brief COPE provides a parsimonious method to assess various ways in which people cope with a specified situation [30]. The Brief COPE consists of 14 subscales, each with two items, as measured on a four-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-focused plus emotion-focused coping) [30]. The Brief COPE has been widely used and the subscales demonstrate acceptable reliability ranging from .50 to .90 [30]. For the current study, the Cronbach's alphas for maladaptive coping were acceptable (Time One $\alpha = .79$; Time Two $\alpha = .67$; Time Three $\alpha = .67$) and were high for adaptive coping (Time One $\alpha = .83$; Time Two $\alpha = .85$; Time Three $\alpha = .88$).

### *Social Support Questionnaire-Short Form (SSQ6)*

The SSQ6 is a six-item measure that assesses both the sources of social support and the respondents' satisfaction with the support received [31]. Separate scores are obtained for both number and satisfaction of social support. The SSQ6 demonstrates high internal consistency, with a Cronbach's alpha of .90 for number and .93 for satisfaction [31]. The Cronbach's alphas for the current study were acceptable: satisfaction subscale (Time One $\alpha = .89$; Time Two $\alpha = .94$; Time Three $\alpha = .95$) and quantity subscale (Time One $\alpha = .77$; Time Two $\alpha = .89$; Time Three $\alpha = .86$).

### *Family Questionnaire (FQ)*

The FQ is a self-report questionnaire based on the Camberwell Family Interview [CFI; 18] that measures the expressed emotion domains of critical comments and emotional overinvolvement [32]. 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 [32]. The FQ consists of 20 items as measured on a four-point Likert scale (1, never/very rarely, 4, very often). Items are then summed, with a score greater than 23 on the critical comments subscale and a score greater than 27 on the emotional overinvolvement subscale indicative of high levels of expressed emotion. With AN carers, the emotional overinvolvement and critical comments subscales have demonstrated good internal reliability of .76 and .88, respectively [33]. The Cronbach's alphas for the current study were high for critical comments (Time One $\alpha = .85$; Time Two $\alpha = .90$; Time Three $\alpha = .88$) and acceptable for emotional overinvolvement (Time One $\alpha = .57$; Time Two $\alpha = .79$; Time Three $\alpha = .80$).

### Procedure

The current study reports a subset 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 Web sites (e.g. b-eat, UK; EDFV, Australia), newspaper advertisements, radio interviews, distribution of flyers within carer support groups and carer workshops, questionnaire mail-outs via a hospital-based eating disorder service and questionnaire mail-outs via a not-for-profit eating disorder organisation. Interested participants were either mailed out a paper-based questionnaire package or were directed to the online version of the plain language statement and questionnaire. Carers completed the first questionnaire and provided contact details on a separate sheet for the paper-based version, or an email address for the online version. Paper-based questionnaires were then returned via reply-paid post. Paper-based questionnaires and contact sheets were coded with corresponding numbers to enable subsequent follow-up of participants (e.g. 001 or 002). Online questionnaires were matched on the basis of the provided email address.

## Results

All analyses were conducted using the Statistics Package for the Social Sciences (SPSS) Version 17. Less than 5 % of the data were missing; therefore, this random missing data were replaced using expectation maximisation. While latent growth curve modelling is the most appropriate statistical test to examine longitudinal prediction of carer burden and psychological distress, the sample size was insufficient to be able to conduct such analysis. As such, a series of multiple regression analyses and repeated-measures ANOVAs were conducted. It was hypothesised that the independent variables of satisfaction with social support (measured by the SSQ6), total expressed emotion (measured by the FQ), maladaptive coping (measured by the Brief COPE) and total needs (measured by the CaNAM) would predict the dependent variables of carer burden (measured by the EDSIS) and psychological distress (measured by the GHQ-12). Table 1 presents the means and standard deviations of the complete time point data, i.e. for the carers who completed all three questionnaires. As shown, carers reported consistent moderate psychological distress, moderate, high levels of critical comments and emotional overinvolvement, a moderate level of unmet needs, use of both maladaptive and adaptive coping strategies, and a low quantity of social support, but with high satisfaction.

**Table 1** Means and standard deviations for ANOVA analyses ($n = 42$)

| Variable | Time One | Time Two | Time Three | Scale range |
|---|---|---|---|---|
| GHQ-12 | 17.83 (6.44) | 14.79 (6.56)[a] | 16.48 (8.00) | 0–36 |
| Total EDSIS | 46.38 (14.93) | 41.93 (16.14) | 41.86 (17.96) | 0–96 |
| Critical comments | 26.50 (5.63) | 24.00 (6.04)[a] | 24.62 (6.21) | 10–40 |
| Emotional overinvolvement | 31.14 (3.52) | 28.76 (4.44)[a] | 28.05 (4.84)[b] | 10–40 |
| Total needs | 23.93 (13.36) | 30.60 (14.19)[a] | 30.14 (13.97)[b] | 0–56 |
| Adaptive coping | 42.93 (8.41) | 43.38 (8.38) | 39.02 (9.67)[b] | 16–64 |
| Maladaptive coping | 21.98 (5.36) | 20.48 (4.72) | 20.83 (4.76) | 12–48 |
| Quantity social support | 2.25 (1.35) | 2.32 (1.76) | 2.09 (1.21) | ≥0 |
| Satisfaction social support | 4.52 (1.18) | 4.80 (1.25) | 4.54 (1.35) | 1–6 |

[a] Significant difference from Time One to Time Two

[b] Significant difference from Time One to Time Three

The desired sample size for the current study was initially 100 participants. However, this aim was not met due to difficulty with recruitment of participants, both through the small number of potential participants requesting information and a low response rate. Therefore, due to the smaller than anticipated sample size, post hoc power analyses were conducted before each analysis to determine whether adequate power (.80) could be achieved. Post hoc power analyses are useful when non-significant results occur or are anticipated due to low participant numbers or power [34]. Post hoc power analyses for repeated-measures ANOVA indicated that the sample size was sufficient to achieve adequate power of .80 [35].

Repeated-measures ANOVA were conducted to examine the first hypothesis that carer burden, psychological distress, expressed emotion and carer unmet needs would remain high over the three time points. There was no significant overall change in carer burden. However, psychological distress significantly changed over time ($F_{(2,\ 82)} = 3.04$, $p < 0.\ 05$, partial $\eta^2 = .07$) and simple contrasts (with Time One as the reference category) indicated that there was a significant reduction in psychological distress from Time One to Time Two ($F_{(1,\ 41)} = 7.77$, $p < .01$; partial $\eta^2 = .16$), but no significant difference between Time One and Time Three.

For expressed emotion, the repeated-measures ANOVA indicated a significant change in critical comments, $F_{(2,\ 82)} = 5.14$, $p < .01$. Simple contrasts (with Time One as the reference category) indicated that there was a significant reduction in critical comments from Time One to Time Two ($F_{(1,\ 41)} = 10.99$, $p < .01$; partial $\eta^2 = .22$), but no significant change from Time One to Time Three. Similarly, there was a significant change in emotional overinvolvement ($F_{(2,\ 76)} = 11.06$, $p < .001$; Huynh–Feldt correction), and simple contrasts (with Time One as the reference category) indicated that there was a significant reduction in emotional overinvolvement from Time One to Time Two ($F_{(1,\ 41)} = 11.38$, $p < .01$; partial $\eta^2 = .22$) and Time One to Time Three ($F_{(1,\ 40)} = 15.78$, $p < .001$; partial $\eta^2 = .28$).

There was also a significant change in total carer needs ($F_{(2,\ 73)} = 8.95$, $p < .01$; Huynh–Feldt correction), and simple contrasts (with Time one as the reference category) showed a significant reduction from Time One to Time Two ($F_{(1,\ 41)} = 12.88$, $p < .01$; partial $\eta^2 = .24$) and Time One to Time Three ($F_{(1,\ 41)} = 9.71$, $p < .01$; partial $\eta^2 = .19$). Further, there was a significant change in adaptive coping ($F_{(2,\ 82)} = 7.64$, $p < .01$) with simple contrasts (with Time One as the reference category) revealing a significant reduction in use of adaptive coping strategies from Time One to Time Three, ($F_{(1,\ 41)} = 7.56$, $p < .01$; partial $\eta^2 = .16$), but no change from Time One to Time Two. There was no significant difference in maladaptive coping strategies across the three time points. Lastly, in relation to social support, there were no significant changes in either quantity or satisfaction with social support.

## Longitudinal prediction of carer burden and psychological distress

A standard multiple regression analysis was conducted to test hypothesis two regarding the longitudinal prediction of carer burden and psychological distress. Due to the lower than expected sample size, post hoc power analyses were conducted to determine the maximum number of predictors to achieve a power of at least .80 [35]. Given the consistent relationship between the variables in the current study and carer burden, it was assumed that the regression models would achieve an $R^2$ of at least .30. Thus, .30 was chosen as the effect size. The alpha level was set at .05, and sample size taken from the $n$ at Time Three. Power calculations revealed that the maximum number of predictors to achieve acceptable power was four. The chosen predictors were: satisfaction with social support, total expressed emotion, maladaptive coping and total needs. Total expressed emotion, maladaptive coping and total needs were chosen due to their moderate to high correlation with carer burden and psychological distress within the current study. Satisfaction with social support was also chosen as a predictor due to prior research, indicating that satisfaction with, rather than quantity of, social support was the stronger

**Table 2** Correlations between longitudinal predictors and outcome measures

| | Satisfaction with social support (T1) | Expressed emotion (T1) | Maladaptive coping (T1) | Total needs (T1) |
|---|---|---|---|---|
| Carer burden (T2) | −.13 | .43** | .51*** | −.30* |
| Psychological distress (T2) | −.14 | .28 | .34* | .01 |
| Carer burden (T3) | −.10 | .27 | .41** | −.31* |
| Psychological distress (T3) | −.11 | .07 | .23 | .06 |

| | Satisfaction with social support (T2) | Expressed emotion (T2) | Maladaptive coping (T2) | Total needs (T2) |
|---|---|---|---|---|
| Carer burden (T3) | .00 | .36* | .41** | −.35* |
| Psychological distress (T3) | −.12 | .07 | .23 | −.08 |

* $p < .05$

** $p < .01$

*** $p < .001$

**Table 3** Standard multiple regression analyses for the longitudinal prediction of carer burden

| Predictor | Time One to Time Two | | | Time One to Time Three | | | Time Two to Time Three | | |
|---|---|---|---|---|---|---|---|---|---|
| | B | $\beta$ | sr$^2$ | B | $\beta$ | sr$^2$ | B | $\beta$ | sr$^2$ |
| Satisfaction with social support | .26 | .02 | .00 | 2.20 | .14 | .02 | .92 | .06 | .00 |
| Total expressed emotion | .73 | .36* | .10 | .34 | .14 | .02 | .23 | .13 | .01 |
| Maladaptive coping | .20 | .07 | .01 | 1.09 | .33* | .09 | 1.38 | .36* | .10 |
| Total needs | −.24 | −.21 | .04 | −.37 | −.27[a] | .07 | −.42 | −.34* | .10 |

[a] Approached significance

* $p < .05$

predictor of carer burden [36]. Table 2 presents Pearson's correlations for the chosen predictors and outcome measures.

Table 3 presents the B-weights, $\beta$-weights and sr$^2$ for the longitudinal prediction of carer burden. Predictor variables were taken from Time One in order to predict Time Two and Time Three carer burden scores. For burden, the Time One to Time Two regression model was significant ($R^2 = .23$, $p < .05$; adjusted $R^2 = .16$), with total expressed emotion a significant unique predictor. The Time One to Time Three regression model was significant ($R^2 = .23$, $p < .05$; adjusted $R^2 = .15$), with maladaptive coping a significant unique predictor and total needs approaching significance a unique predictor ($p = .08$).

Similarly, predictor variables were also taken from Time Two to predict Time Three carer burden scores. The Time Two to Time Three regression model was significant ($R^2 = .31$, $p < .01$; adjusted $R^2 = .24$), with maladaptive coping and total needs significant unique predictors.

With respect to psychological distress, satisfaction with social support, total expressed emotion, maladaptive coping and total needs at Time One were also used to predict scores at Time Two and Time Three. However, both the Time One to Time Two, and Time One to Time Three regression models were not significant. Lastly, satisfaction with social support, total expressed emotion, maladaptive coping and total needs at Time Two were used to predict Time Three psychological distress score. Again, this regression model was not significant.

## Discussion

This is the first study to longitudinally examine eating disorder carer burden and psychological distress. The aim of the current study was twofold: firstly, to examine longitudinal changes in the level of expressed emotion, coping strategies, social support, carer needs, carer burden and psychological distress; secondly, to determine the longitudinal predictors of carer burden and psychological distress.

The first hypothesis was partially supported. Carers of people with an eating disorder experience long-term moderate to high levels of burden and psychological distress. The ongoing carer burden and psychological distress are not surprising given the chronic nature of eating disorders. Eating disorders have an average duration of 5 years, are often associated with psychiatric co-morbidities, such as depression or anxiety, and have a number of adverse physiological consequences [1]. As a result, carers are faced with ongoing difficulties related to the eating disorder and a lack of progress towards recovery. In addition, carers in the current study demonstrated long-term high levels of critical comments and emotional overinvolvement. Given the link between high levels of expressed emotion and outcomes for eating disorders [36, 37], the consistently high level of expressed emotion from carers could potentially contribute to the chronicity of the eating disorder and the ongoing high level of burden and distress. Lastly, while carers report an ongoing moderate level of unmet needs, there was a small, but significant, decrease in unmet needs over time.

This study was also the first to examine longitudinal changes in the use of coping strategies and social support over time. Carers continue to use moderate levels of maladaptive coping strategies and show a small, but significant, decrease in the use of adaptive coping strategies over time. The reduction in adaptive coping strategies is concerning, in that the use of adaptive coping strategies can help to decrease the level of distress in carers of people with a mental illness (e.g. [38]). Social support also demonstrated stability; across the time periods, carers reported that while they have only two to three people they can turn to for support, however, they are consistently satisfied with the quality of that support. Social support lessens the harmful effects of a stressful situation [24]; specifically, carers' satisfaction with social support, rather than simply size of a social network, is the stronger predictor of distress, positive affect and satisfaction with life [27, 39]. Therefore, the findings from the current study are positive; carer satisfaction with social support has the potential to be protective against burden and distress. In summary, carers of people with an eating disorder display chronic, moderate levels of burden, distress and use of maladaptive coping strategies.

A search for prior longitudinal carer literature revealed that there was a lack of longitudinal research examining carers of those with a mental illness. However, longitudinal research examining the impact of caring for someone with an organic illness indicates that there are ongoing difficulties, with little, or no, change in carer mental health or well-being over time [40–42]. Further, adverse health effects are more likely to be seen in those who provide 20 or more hours of care per week [43]. Therefore, the findings from the current study with regard to the chronicity of burden and distress, in conjunction with a high level of contact hours (approximately 79 h per week) and use of maladaptive coping strategies, suggest that carers of those with an eating disorder may be at risk of developing mental illnesses such as depressive or anxiety-related disorders.

The second hypothesis regarding the longitudinal prediction of carer burden and psychological distress was partially supported. While there was a low number of participants, the level of variance in carer burden explained was moderate to high (T1–T2: 23 %; T1–T3: 23 %; T2–T3: 31 %) [44]. Past models of eating disorder carer burden predict 18 % [6] to 38 % [11] of variance. However, other factors such as stigma or familial conflict may still be involved in determining the burden. More longitudinal research, using larger sample sizes, is needed to explore these factors.

Expressed emotion, maladaptive coping and carer needs were significant long-term predictors of carer burden. The limited prior research examining cross-sectional models supports the current finding that needs and expressed emotion predict carer burden. Whitney et al. [15] found that a need for support from people/organisations significantly predicted a negative appraisal of caregiving. Additionally, expressed emotion (as reported by the patient with an eating disorder) is predictive of a negative carer experience [6].

Further, maladaptive coping was found to be a longitudinal predictor of burden. Past qualitative research [22, 23] indicates that carers use a number of different coping strategies, and a quantitative, cross-sectional study showed that maladaptive coping strategies predicts both burden and distress [20]. The current study, therefore, provides further support for the impact of maladaptive coping strategies, such as self-blame, denial and behavioural disengagement. Therefore, the long-term influence of expressed emotion, maladaptive coping and carer unmet needs on carer burden indicates that intervention and support programs for carers are required, specifically targeted at reducing expressed emotion, addressing long-term needs and teaching carers effective coping strategies to reduce their reliance on maladaptive strategies.

Interestingly, social support did not predict carer burden over time. No prior eating disorder model has examined informal social support as a predictor of carer burden or psychological distress. However, Dimitropoulos et al. [11] found that professional support outside the immediate family was the strongest predictor of family functioning. They concluded that those who lack social support outside the family may rely more heavily on immediate family members for aid, therefore, causing greater strain within the family unit. Due to the lack of a significant finding in the current study, it may be speculated that the impact of social support on burden and psychological distress is influenced by other aspects, such as family functioning.

Surprisingly, psychological distress was not able to be predicted longitudinally. This may indicate that distress is dependent more on the current situation, rather than past events. Therefore, carer psychological distress may result from a reactive process to current circumstances. Other cross-sectional research supports the difficulty in predicting psychological distress. Dimitropoulos et al. [11] found that burden and family conflict were not significant predictors of distress. However, other cross-sectional research indicates that psychological distress is predicted by negative experiences of caregiving [6], patient dependency and stigma [15], self-related strains, interpersonal strains and gender [45]. However, it is difficult to know whether these variables would predict psychological distress longitudinally. Future research needs to further examine the long-term predictors of distress.

Given the continued high levels of burden, distress, expressed emotion and maladaptive coping strategies, there is a need to provide ongoing support to carers of people with an eating disorder. Specifically, targeted intervention programs that aid carers in effectively coping with their role, reducing their level of expressed emotion and addressing carer needs are required. Such interventions have the potential to reduce the risk of serious psychological consequences of the ongoing carer burden, such as depression or anxiety. For instance, one existing workshop series for carers of patients with an eating disorder, targeted at reducing expressed emotion, has been successful in lowering the level of burden and psychological distress, as well as decreasing levels of expressed emotion [46, 47].

There are some limitations to consider for the current study. Firstly, it should be noted that the information regarding the patients' symptoms was obtained from carer reports and not collected directly from patients using standardised measures. In addition, it is possible that factors other than caring for a person with an eating disorder contribute to the level of psychological distress reported by the participants. For instance, work-related demands, needing to care for other family members or financial stress may impact upon the level of psychological distress reported by the carer.

The third set of limitations relates to the nature of the sample. Firstly, while the participants were a community sample, due to the self-selection into the study, it may be that the sample was not representative of more extreme cases. Carers whose situation was more extreme may not have the time to complete the study or may be too distressed by their situation to take part. Secondly, while carers of all eating disorder diagnoses and both genders were able to participate, the majority of the participants were female, AN carers. Thus, generalisability of the current findings may be limited. Lastly, the sample size was relatively small, thus limiting the analyses. The majority of previous research recruited participants from inpatient settings; therefore, it appears that there is greater difficulty in recruiting from a community population. Further, the low number of participants may limit the interpretability of the current findings.

The last main limitation relates to the measure of social support. The chosen measure did not predict burden or psychological distress. It may be speculated that the generalised nature of the social support measure used, as opposed to a specific, carer burden-focused measure of social support, did not adequately capture the construct. Further, the SSQ6 is a measure of emotional, rather than instrumental, support [31]. Instrumental support consists of behaviours that are intended to provide direct aid to another, such as doing a job or chore, in order to provide assistance with task-directed coping efforts [24, 48]. In contrast, emotional support encompasses support on an empathetic basis, such as being a confidant and providing reassurance, which communicates to an individual that he/she is cared for and loved [24, 48]. As such, while emotional support may not be a predictor of burden or distress, instrumental support may be important. Thus, future research needs to investigate the impact of instrumental support.

The current study shows that carers of people with an eating disorder experience an ongoing high level of burden and psychological distress. Further, carer burden is predicted longitudinally by maladaptive coping strategies, carer needs and expressed emotion. Additionally, the current research demonstrates the difficulty in predicting long-term psychological distress. Therefore, the outcome of distress may be influenced only by the current situation, rather than past difficulties. Lastly, the current research provides support for the implementation of carer interventions designed to reduce the level of expressed emotion and reliance on maladaptive coping strategies, in conjunction with addressing carer needs.

## References

1. Fairburn CG, Harrison PJ (2003) Eating disorders. Lancet 361:407–416. doi:10.1016/S0140-6736(03)12378-1
2. Hoek HW, van Hoeken D (2003) Review of the prevalence and incidence of eating disorders. Int J Eat Disord 34:383–396. doi:10.1002/eat.10222
3. Beumont P (2000) Anorexia nervosa as a mental and physical illness: the medical perspective. In: Gaskill D, Sanders F (eds) The encultured body: policy implications for healthy body image and disordered eating behaviours. Queensland University of Technology, Brisbane, pp 80–94
4. Fairburn CG, Hay PJ, Welch SL (1993) Binge eating and bulimia nervosa: distribution and determinants. In: Fairburn CG, Wilson GT (eds) Binge eating: nature, assessment, and treatment. The Guilford Press, New York, pp 123–143
5. Murray T (2003) Wait not, want not: factors contributing to the development of anorexia nervosa and bulimia nervosa. The Fam J Couns Therapy Couples Fam 11:276–280. doi:10.1177/1066480703252470
6. Winn S, Perkins S, Walwyn R, Schmidt U, Eisler I, Treasure J, Berelowitz M, Dodge L, Frost S, Jenkins M, Johnson-Sabine E, Keville S, Murphy R, Robinson P, Yi I (2007) Predictors of mental health problems and negative caregiving experiences in carers of adolescents with bulimia nervosa. Int J Eat Disord 40:171–178. doi:10.1002/eat.20347
7. Treasure J, Murphy R, Szmukler G, Todd G, Gavan K, Joyce J (2001) The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis. Soc Psychiatry Psychiatric Epidemiol 36:343–347. doi:10.1007/s001270170039
8. Graap H, Bleich S, Herbst F, Trostmann Y, Wancata J, de Zwaan M (2008) The needs of carers of patients with anorexia and bulimia nervosa. Eur Eat Disord Rev 16:21–29. doi:10.1002/erv.804
9. Kuipers E, Bebbington PE (2005) Research on burden and coping strategies in families of people with mental disorders: Problems and perspectives. In: Sartorius N, Leff J, Lopez-Ibor JJ, Maj M, Okasha A (eds) Families and mental disorders: from burden to empowerment. John Wiley and Sons, New Jersey
10. Winn S, Perkins S, Murray J, Murphy R, Schmidt U (2004) A qualitative study of the experience of caring for a person with bulimia nervosa. Part 2: carers' needs and experiences of services and other support. Int J Eat Disord 36:269–279. doi:10.1002/eat.20068
11. Dimitropoulos G, Carter J, Schachter R, Woodside DB (2008) Predictors of family functioning in carers of individuals with anorexia nervosa. Int J Eat Disord 41:739–747. doi:10.1002/eat.20562
12. Whitney J, Eisler I (2005) Theoretical and empirical models around caring for someone with an eating disorder: the reorganization of family life and inter-personal maintenance factors. J Ment Health 14:575–585. doi:10.1080/09638230500347889
13. Haigh R, Treasure J (2003) Investigating the needs of carers in the area of eating disorders: development of the Carers' Needs Assessment Measure (CaNAM). Eur Eat Disord Rev 11:125–141. doi:10.1002/erv.487
14. Graap H, Bleich S, Herbst F, Scherzinger C, Trostmann Y, Wancata J, de Zwaan M (2008) The needs of carers: a comparison between eating disorders and schizophrenia. Soc Psychiatry Psychiatric Epidemiol 43:800–807. doi:10.1007/s00127-008-0364-7
15. Whitney J, Haigh R, Weinman J, Treasure J (2007) Caring for people with eating disorders: factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. Br J Clin Psychol 46:413–428. doi:10.1348/014466507X173781
16. Hodes M, Le Grange D (1993) Expressed emotion in the investigation of eating disorders: a review. Int J Eat Disord 13:279–288. doi:10.1002/1098-108X(199304)13:3<279:AID-EAT2260130306>3.0.CO;2-2
17. Rein Z, Perdereau F, Curt F, Jeammet P, Fermanian J, Godart N (2006) Expressed emotion and anorexia nervosa: the validation of the five-minute speech sample in reference to the Camberwell

Family Interview. Int J Eat Disord 39:217–223. doi:10.1002/eat.20245
18. Vaughn C, Leff J (1976) The measurement of expressed emotion in the families of psychiatric patients. Br J Soc Clin Psychol 15:157–165
19. Zabala MJ, MacDonald P, Treasure J (2009) Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: a systematic review. Eur Eat Disord Rev 17:338–349. doi:10.1002/erv.925
20. Coomber K, King RM (2011) Coping strategies and social support as predictors and mediators of eating disorder carer burden and psychological distress. Soc Psychiatry Psychiatric Epidemiol. doi:10.1007/s00127-011-0384-6
21. Hillege S, Beale B, McMaster R (2006) Impact of eating disorders on family life: individual parents' stories. J Clin Nurs 15:1016–1022. doi:10.1111/j.1365-2702.2006.01367.x
22. Perkins S, Winn S, Murray J, Murphy R, Schmidt U (2004) A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: the emotional impact of caring. Int J Eat Disord 36:256–268. doi:10.1002/eat.20067
23. Whitney J, Murray J, Gavan K, Todd G, Whitaker W, Treasure J (2005) Experience of caring for someone with anorexia nervosa: qualitative study. Br J Psychiatry 187:444–449. doi:10.1192/bjp.187.5.444
24. Lazarus RS, Folkman S (1984) Stress, appraisal, and coping. Springer Publishing Company, New York
25. Folkman S, Moskowitz JT (2004) Coping: pitfalls and promise. Annu Rev Psychol 55:745–774. doi:10.1146/annurev.psych.55.090902.141456
26. Schreurs KMG, de Ridder DTD (1997) Integration of coping and social support perspectives: implications for the study of adaptation to chronic diseases. Clin Psychol Rev 17:89–112. doi:10.1016/S0272-7358(96)00050-5
27. Pakenham KI, Chui J, Bursnall S, Cannon T (2007) Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. J Health Psychol 12:89–102. doi:10.1177/1359105307071743
28. Sepulveda AR, Whitney J, Hankis M, Treasure J (2008) Development and validation of an Eating Disorders Symptom Impact Scale (EDSIS) for carers of people with eating disorders. Health Qual Life Outcomes 6:28. doi:10.1186/1477-7525-6-28
29. Goldberg D, Williams P (1988) A user's guide to the general health questionnaire. NFER-NELSON, Windsor
30. Carver CS (1997) You want to measure coping but your protocol's too long: consider the Brief COPE. Int J Behav Med 4:92–100. doi:10.1207/s15327558ijbm0401_6
31. Sarason IG, Sarason BR, Shearin EN, Pierce GR (1987) A brief measure of social support: practical and theoretical implications. J Soc Pers Relat 4:497–510. doi:10.1177/0265407587044007
32. Wiedemann G, Rayki O, Feinstein E, Hahlweg K (2002) The Family Questionnaire: development and validation of a new self-report scale for assessing expressed emotion. Psychiatry Res 109:265–279. doi:10.1016/S0165-1781(02)00023-9
33. Kyriacou O, Treasure J, Schmidt U (2008) Expressed emotion in eating disorders assessed via self-report: an examination of factors associated with expressed emotion in carers of people with anorexia nervosa in comparison to control families. Int J Eat Disord 41:37–46. doi:10.1002/eat.20469
34. Onwuegbuzie AJ, Leech NL (2004) Post hoc power: a concept whose time has come. Underst Statistics 3:201–230. doi:10.1207/s15328031us0304_1
35. Faul F, Erdfelder E, Lang AG, Buchner A (2007) G*Power: a flexible statistical power analysis program for the social, behavioural, and biomedical sciences. Behav Res Methods 39:175–191. doi:10.3758/BF03193146
36. Olshevski JL, Katz AD, Knight BG (1999) Stress reduction for caregivers. Taylor and Francis, Philadelphia
37. Butzlaff RL, Hooley JM (1998) Expressed emotion and psychiatric relapse. Arch Gen Psychiatry 55:547–552. doi:10.1001/archpsyc.55.6.547
38. Eisler I, Dare C, Hodes M, Russell G, Dodge E, le Grange D (2000) Family therapy for adolescent anorexia nervosa: the results of a controlled comparison of two family interventions. J Child Psychol Psychiatry 41:727–736. doi:10.1111/1469-7610.00660
39. Joyce J, Leese M, Kuipers E, Szmuckler G, Harris T, Staples E (2003) Evaluating a model of caregiving for people with psychosis. Soc Psychiatry Psychiatric Epidemiol 38:189–195. doi:10.1007/s00127-003-0618-3
40. Gaugler JE (2010) The longitudinal ramifications of stroke caregiving: a systematic review. Rehabil Res 55:108–125. doi:10.1037/a0019023
41. Goode KT, Haley WE, Roth DL, Ford GR (1998) Predicting longitudinal changes in caregiver physical and mental health: a stress process model. Health Psychol 17:190–198. doi:10.1037/0278-6133.17.2.190
42. Svavarsdottir EK (2005) Caring for a child with cancer: a longitudinal perspective. J Adv Nurs 50:153–161. doi:10.1111/j.1365-2648.2005.03374.x
43. Hirst M (2005) Caregiver distress: a prospective, population-based study. Soc Sci Med 61:697–708. doi:10.1016/j.socscimed.2005.01.001
44. Cohen J (1992) A power primer. Quant Methods Psychol 112:155–159. doi:10.1037/0033-2909.112.1.15
45. Kyriacou O, Treasure J, Schmidt U (2008) Understanding how parents cope with living with someone with anorexia nervosa: modelling the factors that are associated with carer distress. Int J Eat Disord 41:233–242. doi:10.1002/eat.20488
46. Sepulveda AR, Todd G, Whitaker W, Grover M, Stahl D, Treasure J (2010) Expressed emotion in relatives of patients with eating disorders following skills training program. Int J Eat Disord 43:603–610. doi:10.1002/eat.20749
47. Sepulveda AR, Lopez C, Todd G, Whitaker W, Treasure J (2008) An examination of the impact of "the Maudsley Eating Disorder Collaborative Care Workshops" on the well-being of family members: a pilot study. Soc Psychiatry Psychiatric Epidemiol 43:584–591. doi:10.1007/s00127-008-0336-y
48. Pierce GR, Sarason BR, Sarason IG, Joseph HJ, Henderson CA (1996) Conceptualizing and assessing social support in the context of the family. In: Pierce GR, Sarason BR, Sarason IG (eds) Handbook of social support and the family. Plenum Press, New York, pp 3–25