Caring for individuals with an eating disorder

by

Ms Kerri Coomber, B. App. Sci. (Psych) (Hons)

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I certify that the thesis entitled: *Caring for individuals with an eating disorder* submitted for the degree of Doctor of Philosophy is the result of my own work and that where reference is made to the work of others, due acknowledgment is given.

I also certify that any material in the thesis which has been accepted for a degree or diploma by any university or institution is identified in the text.

Full Name.................................................................................................................
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Signed ......................................................................................................................

Date.............................................................................................................................
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ABSTRACT

Caring for someone with an eating disorder is associated with considerable burden and psychological distress. Factors identified as impacting on carer burden and distress include patient characteristics, expressed emotion, coping strategies, social support and carer needs. Lazarus and Folkman’s (1984) cognitive stress theory and Pearlin et al.’s (1990) stress process theory are commonly used as a basis for models of carer burden and psychological distress. While these theories state that coping strategies and social support are important mediators of carer burden and distress, there are no prior quantitative examinations of these mediators within eating disorder carers. Further, prior eating disorder research consists of cross-sectional studies only. Therefore, the current thesis examined the longitudinal experience of caring for someone with an eating disorder, in conjunction with testing the mediators of burden and distress. Study 1 comprised of a mixed quantitative and qualitative, longitudinal design. Forty-two carers completed three self-report questionnaires over a period of nine months. This questionnaire assessed carer burden and psychological distress, expressed emotion, carer needs, social support and coping strategies. Further, carers were asked to write about changes in the caring experience since completion of the previous questionnaire, and experiences with treatment services. Several key findings emerged. Firstly, carers reported moderate levels of burden and psychological distress, and this did not change over time. Secondly, carer needs, expressed emotion and maladaptive coping strategies were identified as important predictors of cross-sectional carer burden and psychological distress. Thirdly, carer burden was also predicted longitudinally by expressed emotion, maladaptive coping strategies and carer needs. However, psychological distress was not able to be longitudinally predicted. The last main finding showed that while maladaptive coping strategies is a mediator of carer burden and distress, social support did not act as a mediator. The qualitative findings from Study 1 reinforced the quantitative results; carers reported a number of difficulties in their situation, and with eating disorder treatment services. Further, these difficulties were ongoing due the chronic nature of eating disorders. Therefore, eating disorder carers experience a considerable level of ongoing
burden and psychological distress. As it is also unknown whether sufferers perceive that their carers are burdened, Study 2 of this thesis investigated the discrepancy between carer self-report of burden and sufferer perceptions of burden. Twenty matched pairs of carers and sufferers each completed a self-report questionnaire. Sufferers underestimated the burden of care experienced by their carer, particularly in relation to nutritional difficulties. While low participant numbers in both studies limited the analyses and conclusions, the findings allow for the development of targeted interventions and support for carers, therefore lowering the risk of serious health issues, such as depression and anxiety, as a consequence of their role. Lastly, the current findings also provide support for the use of collaborative care approaches and multi-family therapy in eating disorder treatments.
CHAPTER ONE

INTRODUCTION

Eating disorders are chronic, debilitating illnesses that have numerous severe psychological and physical effects. As such, patients with eating disorders often require ongoing informal care, typically from family members or friends. These carers have been shown to experience a considerable level of burden and psychological distress as a consequence of their role.

While a body of both quantitative and qualitative research on the experience of carers of those with an eating disorder exists, no longitudinal study has thus far examined carer burden in the context of eating disorders. This is despite eating disorders being chronic illnesses, with an average duration of approximately five years (Beumont, 2000; Fairburn & Harrison, 2003). Further, recommendations for longitudinal research examining the predictors of carer burden and psychological distress within eating disorder carers have been made (e.g., Dimitropoulos, Carter, Schachter, & Woodside, 2008).

Therefore, the current thesis will longitudinally investigate carer burden and psychological distress in relation to carers of those with an eating disorder. Such a study will achieve several aims. Firstly, it will allow for the investigation of change in carer burden, psychological distress and factors that influence these over time. Secondly, it will allow for the examination of the long-term predictors of burden and psychological distress. Thirdly, the separate cross-sectional data collection points will allow examination of potential mediators of carer burden and distress, identified within theoretical models, such as Lazarus and Folkman’s (1984) cognitive stress theory, and general mental illness carer models (e.g., Maurin & Boyd, 1990). As yet, there has not been a formal investigation of these mediators within eating disorder carer literature. Therefore, the current thesis will examine both coping strategies and social support as mediators of eating disorder carer burden and psychological distress. Lastly, while cross-sectional research indicates that eating disorder carers experience high levels of burden, there is currently no research investigating the sufferers’ perception of their carer’s burden. Therefore, discrepancies between carer self-report and sufferer perspectives of carer burden will be examined.
This chapter will provide a brief overview of the literature on the impact of eating disorders on carers. On the basis of this brief overview of the literature that will be comprehensively and critically reviewed in Chapters Two and Three, three key arguments will be proposed. Firstly, it will be argued that there is a need for longitudinal research using community based samples that uses questionnaires developed specifically for the eating disorder carer population. Secondly, it will be argued that coping strategies and social support should be investigated as potential mediators of eating disorder carer burden and distress. Thirdly, it will be argued that an examination of the discrepancy between carer self-report of burden and the level of carer burden perceived by the person with an eating disorder is warranted. Lastly, this chapter will present the aims of the thesis and an outline of the remaining chapters.

Overview of current literature

The Diagnostic and Statistical Manual of Mental Disorders 4th edition, Text Revision, (DSM-IV-TR; American Psychiatric Association; APA, 2000) identifies two key eating disorders; anorexia nervosa (AN) and bulimia nervosa (BN); as well as a further category for disordered eating that does not meet the criteria for these two disorders; eating disorders not otherwise specified (EDNOS). Included in the EDNOS category is a proposed third key eating disorder, binge eating disorder. While the prevalence rates for eating disorders is low, AN: 0.7% to 1.0%; BN: one percent to five percent (Fairburn & Harrison, 2003); EDNOS 2.4%. (Machado, Machado, Goncalves, & Hoek, 2007), they are serious and chronic illnesses (Beumont, 2000; Fairburn & Harrison, 2003). As such, those with an eating disorder often require informal care from family members or friends. Further details of these eating disorders will be provided in Chapter Two.

Within Australia, approximately 2.6 million people are classified as home-based carers of patients with an organic or mental illness, including eating disorders (Australian Bureau of Statistics; ABS, 2004). Eating disorders are the second leading cause of hospitalisation due to mental and behavioural disorders within females aged 12 to 24 years, and twelfth leading cause of hospitalisation due to mental health disorders within Australia across gender and all ages.
Further, BN and AN are the eighth and tenth leading causes of burden of disease and injury (as measured by disability-adjusted life years; DALYs), respectively for 15 to 24 year old females (AIHW, 2007). As such, eating disorders have a significant impact on the adolescent to young adult population. Further, due to the chronic and serious nature of eating disorders, a considerable number of patients with an eating disorder will require full-time informal care. In addition, the economic cost of treating someone with an eating disorder is substantial, with therapeutic costs for eating disorders being comparable or even higher than that of treating schizophrenia (Agras, 2001; Lock, Couturier, & Agras, 2008; Striegal-Moore, Leslie, Petrill, Garvin, & Rosenheck, 2000).

While there is substantial literature on the experience of caregiving for a variety of physical and mental illnesses, little attention has been given to the specific experience of carers of patients with eating disorders. A brief outline of the current literature regarding eating disorder carer burden will follow; a more comprehensive review of eating disorder caregiving will be provided in Chapter Three.

The burden of care and psychological distress associated with caring for someone with an eating disorder is high; carers of those with AN reported higher levels of psychological health problems and general difficulties, and a similar level of burden, as carers of patients with schizophrenia (Treasure et al., 2001). This finding is not unique; a recent review confirms caring for someone with an eating disorder leads to a high level of distress and burden (Zabala, MacDonald, & Treasure, 2009). However, while caring for someone with either BN or AN results in a high level of burden (e.g., Treasure et al., 2001; Winn et al., 2007), there are inconsistencies in the literature regarding whether caring for someone with AN has a greater, or equivalent, burden of care to caring for someone with BN.

Current cross-sectional models of carer burden show that there are various predictors of carer burden and psychological distress. These models are typically based on the cognitive stress theory (Lazarus & Folkman, 1984) or stress-process theory (Pearlin, Mullan, Semple, & Skaff, 1990). For instance, established predictors of carer burden for carers of patients with schizophrenia include expressed emotion, coping strategies and social support (Joyce et al., 2003;
Kuipers, Onwumere, & Bebbington, 2010; Schene, van Wijngaarden, & Koeter, 1998). For carers of patients with an eating disorder, predictors of carer burden and psychological distress include expressed emotion, interpersonal difficulties, support, sufferer symptom severity and carer needs (Dimitropoulos et al., 2008; Kyriacou, Treasure, & Schmidt, 2008b; Treasure, Whitaker, Whitney, & Schmidt, 2005; Winn et al., 2007).

Based upon the work of Lazarus and Folkman (1984) and Pearlin et al. (1990), and the existing models of carer burden (e.g., Dimitropoulos et al., 2008; Schene et al., 1998; Treasure, Whitaker, et al., 2005; Winn et al., 2007) reviewed in Chapter Three, a mediation model of carer burden will be proposed. This mediation model of eating disorder care burden consists of a number of predictor variables, including carer needs, patient characteristics, and interpersonal dynamics, specifically expressed emotion. The impact of these variables on carer burden and carer psychological distress are proposed to be mediated by coping strategies employed by the carer and the informal social support of carers which previous research has confirmed act as mediators of the relationship between a caregiving situation and a stressful outcome (e.g., Maurin & Boyd, 1990). It will be argued that the proposed mediation model improves upon previous models of eating disorder carer burden in that it acknowledges the mediating role of both coping skills and social support as outlined by Lazarus and Folkman (1984) and Pearlin et al. (1990), while also encompassing a number of established predictors of carer burden and psychological distress. A brief outline of each component within the mediation model will follow.

The current qualitative literature has identified a number of unmet needs in the eating disorder carer population. Firstly, carers identify a need for more information regarding eating disorders (Graap, Bleich, Herbst, Trostmann, et al., 2008; Haigh & Treasure, 2003; Winn, Perkins, Murray, Murphy, & Schmidt, 2004). Secondly, carers express a dominant need for practical advice on the development of coping strategies to help with cope with the illness, both in the current situation and in terms of prognosis and future plans (Haigh & Treasure, 2003; Winn et al., 2004). Thirdly, carers report a need for both professional and informal support (Graap, Bleich, Herbst, Trostmann, et al., 2008; Haigh & Treasure, 2003; Winn et al., 2004). Lastly, in regards to treatment, carers believed that treatment for the sufferer had not begun early enough and that they,
as carers, were not sufficiently informed as to the treatment process with an insufficient follow-up process after treatment cessation (Haigh & Treasure, 2003).

Research has also identified that there are often communication problems or conflict between carers and patients with an eating disorder (Graap, Bleich, Herbst, Trostmann, et al., 2008), with literature specifically examining expressed emotion typically focussing on the level of critical comments and emotional overinvolvement (Zabala et al., 2009). A recent review by Zabala et al. (2009) demonstrates that the level of expressed emotion within eating disorder families is high, particularly for those caring for older patients, or those with a longer length of illness. Further, this expressed emotion has been shown to be related to a poor outcome for sufferers (Butzlaff & Hooley, 1998); those undertaking family based therapy demonstrate poorer outcomes when there is high expressed emotion (Eisler et al., 2000). In addition, high expressed emotion is linked to higher levels of carer ill health and burden (Winn et al., 2007). Therefore, the presence of expressed emotion within a family will have a significant impact on both the carer and the sufferer.

In regards to the proposed mediator of coping strategies, current qualitative research examining the coping strategies used by eating disorder carers identifies a number of coping strategies. Adaptive coping strategies include humour and positive thinking, an active enquiry into the illness (Perkins, Winn, Murray, Murphy, & Schmidt, 2004), cognitive restructuring whereby the parents conceptualised their child’s illness as separate from their child (Whitney et al., 2005). Whereas, maladaptive coping responses include self-blame, blaming the patient for their problem, or a sense of helplessness (Whitney et al., 2005). While numerous coping strategies are utilised by eating disorder carers, in conjunction with the acknowledgement that coping strategies may mediate eating disorder carer outcomes (Treasure, Whitaker, et al., 2005), coping strategies have yet to be formally tested as a potential mediator.

Lastly, limited qualitative research shows that support and understanding from others is seen as essential for carers of patients with eating disorders. This support can be gained from partners, friends, other parents of children with eating disorders and specialist services. Theory suggests that rather than simply the number of people within your social network, it is the perceived quality of social support received that is important (Lazarus & Folkman, 1984). Further, mental
illness carer models (e.g., Maurin & Boyd, 1990) acknowledge social support as an important mediator on the outcome of carer burden and distress.

While it is known that eating disorder carers experience a considerable level of burden and psychological distress, it is unknown whether the sufferers perceive themselves to be a burden. For example, in a qualitative examination of anorexia, one sufferer remarked, “I gave very little thought to the people around me that I was affecting, my friends and my family…they became the enemy” (Shelley, 1997, p. 14). Further, Dow, Haralambous, Giummarra, & Vrantsidis (2004) identified a lack of research examining the care recipient perspectives as a gap in current carer literature. They argue that the carer relationship is reciprocal, not uni-dimensional, and that current carer research often fails to acknowledge this reciprocity. As such, the perceptions of sufferers will have an impact on how carers are able to cope with their role. One study examining the discrepancy between carer and sufferer perceptions of burden found that those with an affective disorder or psychotic disorder significantly underestimated the level of burden experienced by their carers (Cleary, Hunt, Walter, & Freeman, 2006). Therefore, an examination of the sufferer perspectives of carer burden is warranted.

The current research contained in this thesis extends the existing body of knowledge regarding the experience of eating disorder carers. While prior research on eating disorder carers has provided valuable insight into the experience of burden and distress, there are several significant limitations. Currently, only cross-sectional quantitative research has been conducted, meaning long-term predictors of eating disorder carer burden and psychological distress have yet to be investigated. Additionally, despite both theory (Lazarus & Folkman, 1984; Pearlin et al., 1990) and carer burden models (e.g., Maurin & Boyd, 1990) acknowledging the role of social support and coping strategies as mediators, there has yet to be a formal examination of these mediators of carer burden and psychological distress in eating disorder carers. Further, a large number of studies recruit participants from inpatient settings or volunteer databases, therefore the applicability of the current findings to a wider, community population may be questionable. Lastly, while it is known that caring for someone with an eating disorder is associated with considerable burden, no
prior research has investigated perceptions of this burden of care by the actual person with an eating disorder.

Thus, the current thesis will address these limitations in the research by conducting a longitudinal study examining the predictors of carer burden and psychological distress in carers of patients with an eating disorder. Secondly, an investigation of social support and coping strategies as mediators of carer burden and psychological distress will occur. Lastly, a second study will be conducted to investigate the differences in perceptions of burden, as reported by the carer and the person for whom they are caring. Thus, the current thesis will provide information on both the cross-sectional and longitudinal predictors of eating disorder carer burden and distress. Further, the mediators of carer burden and distress will be established. Knowledge of the longitudinal predictors will allow for early carer interventions and support that addresses the specific long-term predictors of burden and distress, as identified within the current thesis.

Providing carers with effective support and help will reduce their risk of significant psychological ill health, such as depression and anxiety, as a consequence of their role. Lastly, understanding sufferer perceptions of carer burden, and thus the reciprocity of carer burden, would provide support for the use of collaborative care approaches (e.g., Treasure, Sepulveda, Whitaker, & Todd, 2007) in eating disorder treatments.

Aims and outline of studies

The current thesis will aim to address a number of gaps in the current literature. Despite recognising the need for longitudinal research, no prior eating disorder carer burden study has utilised this type of design. Therefore, the first main aim is to quantitatively and qualitatively examine carer burden and psychological distress in eating disorder carers longitudinally. The second aim of this thesis is to examine both longitudinal and cross-sectional predictors of carer burden and psychological distress, and the role of social support and coping strategies as mediators. The third aim of the current thesis is to compare perceptions of carer burden from the perspective of the carer and the sufferer, so as to determine the nature and predictors of observed discrepancies in these perceptions.
These three aims will be achieved by conducting two studies. Study 1 is a longitudinal, self-report questionnaire design measuring carer burden, psychological distress, expressed emotion, coping strategies, social support, carer needs, and demographic information. Further, as many of the questionnaires used within prior cross-sectional eating disorder carer research are based upon scales developed for other carers of patients with other mental illnesses, such as schizophrenia, the current study will utilise specific measures developed for eating disorder carers. Participants will complete three questionnaires over a nine month period (initial, four and a half months, and nine months). The first two aims of the current thesis will be tested using multiple regression analyses to investigate the predictors of carer burden and psychological distress, both cross-sectionally and longitudinally. Secondly, the mediating roles of coping strategies and social support will be analysed using the Baron and Kenny (1986) method, the Sobel test, and bootstrapping. Lastly, repeated-measures ANOVAs will determine quantitative changes over time in regards to carer burden, psychological distress, coping strategies, social support, expressed emotion, and carer needs.

Further, as part of Study 1, qualitative information about carers’ experiences over time will be collected through written responses. The data from these questions will be used to provide a deeper understanding of the ongoing difficulties faced by eating disorder carers. In addition, carers’ views on treatment options and availability for patients with eating disorders are qualitatively assessed. Again, this information can be used to gain a better understanding of what carers experience while their loved one is receiving treatment for their illness.

Lastly, while there is strong cross-sectional evidence for a carer burden within eating disorder carers, no prior research has addressed carer burden from the perspective of sufferers. Therefore, Study 2 will address the third aim of this thesis and investigate the differences between carer-self report and sufferer perspectives of carer burden. Study 2 will consist of a cross-sectional, self-report questionnaire design. Both patients with an eating disorder, and their primary carer, will complete a questionnaire each. The carer questionnaire assesses demographics, carer burden, expressed emotion, psychological distress while the person with an eating disorder will provide information in relation to
demographics, their perceptions of the extent of carer burden experienced by their carer, their eating disorder symptom severity, and their stage of change. Paired-sample t-tests will be conducted to determine if there was a significant discrepancy between carer self-reports of burden, and sufferer perceptions of carer burden. Further, predictors of any discrepancy in perceptions of burden will be examined using multiple regression analyses.

Outline of the thesis

Chapter Two and Chapter Three of this thesis will provide a literature review of eating disorders and the experience of caring for someone with an eating disorder. Chapter Two will provide an overview of the key eating disorder diagnoses, including anorexia nervosa, bulimia nervosa, eating disorder not otherwise specified, and binge eating disorder. Prevalence, symptoms, medical complications, and prognosis of each disorder will be covered. This will provide the relevant background understanding of what eating disorders entail. As such, the seriousness of these disorders will be conveyed.

A discussion of the eating disorder carer literature will follow in Chapter Three. This chapter will outline established definitions of carer burden, followed by a discussion of the models of carer burden that have been applied to caring in general as well as those applied to caring for someone with an eating disorder. Based on established theory and carer models, a mediation model of eating disorder carer burden and psychological distress will be proposed. Lastly, a discussion of the individual components of the proposed mediation model will be critically analysed.

Chapter Four, Chapter Five and Chapter Six will describe the two studies conducted in relation to the current thesis. Chapter Four and Chapter Five will present both quantitative and qualitative data from Study 1; the longitudinal investigation of eating disorder carer burden. These chapters also address the first two main aims of the thesis. Chapter Four will provide the rationale and method for Study 1, while Chapter Five will present the results and discussion.

Chapter Six will describe the background, rationale, methodology and findings from Study 2, which examines the differential perspectives of carer burden from the point of view of the carer and the person with an eating disorder.
Therefore, Chapter Six will address the third aim of this thesis. Lastly, Chapter Seven will provide a generalised critical discussion of the two studies described within Chapters Four, Five and Six, including theoretical and clinical implications; including implications for eating disorder carer models, support and interventions for carers, and eating disorder treatment options; limitations of the current findings and research, suggested future research directions, and detailed conclusions in regards to the thesis.
CHAPTER TWO
LITERATURE REVIEW: EATING DISORDERS

This chapter will provide an overview of the eating disorder diagnoses, including anorexia nervosa, bulimia nervosa, eating disorder not otherwise specified, and binge eating disorder. This chapter will thus provide the context of the caring situation for eating disorder carers. Each section will describe the diagnostic criteria, prevalence rates, risk factors, medical complications, co-morbidities, and prognosis and outcomes. While the impact of these disorders on the carer will be touched upon in this chapter, detailed discussion of the carer experience will be covered in Chapter Three.

The DSM-IV-TR (APA, 2000) identifies two key eating disorders; anorexia nervosa (AN) and bulimia nervosa (BN); as well as a further category for disordered eating that does not meet the criteria for these two disorders; eating disorders not otherwise specified (EDNOS). Included in the EDNOS category is a proposed third key eating disorder, binge eating disorder. The diagnosis and clinical features of each of these disorders will now be described.

Anorexia Nervosa

Diagnosis and symptoms of Anorexia Nervosa

The diagnosis of anorexia nervosa requires meeting four criteria. Firstly, there must be a failure to maintain weight above 85% of the expected weight for height, or a body mass index (BMI; weight in kilograms per metre height squared) of 17.5 kg/m², or in children, a failure to make expected weight gains. This weight loss, or lack of weight gain, is self-induced, for example, through dietary restriction, laxative abuse or excessive exercise (Fairburn & Garner, 1988).

Secondly, there is an intense fear of gaining weight and fatness, despite being underweight, which consequently leads to an intense drive for thinness (Anderson, 2002; Fairburn & Garner, 1988). As such, often those with AN present with a phobia of weight gain, where a fear of attaining a mature body
weight and shape predominates (Crisp et al., 2006). Thirdly, AN is characterised by a distortion of body image, whereby the patients view themselves as larger than they are in reality, or minimise the seriousness of their weight loss (Garfinkel, 2002). Lastly, a disturbance in endocrine system function occurs, resulting in amenorrhea of at least three months in post-menarchal women (APA, 2000).

The DSM-IV-TR differentiates between two subtypes of AN: restricting and binge-eating/purging. The restricting subtype consists of a lack of engagement in purging behaviour or binge eating behaviour. Conversely, the binge-eating/purging subtype constitutes regular engagement in binging and/or purging behaviour. However, those with anorexia can often alternate between the two subtypes at different periods of their illness (APA, 2000). As a result of this significant cross-over, it is recommended that for the DSM-V, the subtype criteria include a three month time period (APA, 2010a).

The current diagnostic criteria for AN have been criticised as problematic, with a number of issues identified. It has been argued that AN can be better defined as an illness that is driven by weight loss, rather than the actual weight of the patient (Anderson, Bowers, & Watson, 2001). This recommendation has been given as the psychological impact of AN does not differ significantly for those with a weight below 85% of their healthy weight range, or those above this weight. Further, many patients from non-Western countries and cultures often deny a “true” weight concern (Lee & Lock, 2007; Lee, Ho, & Hsu, 1993; Murphy, Perkins, & Schmidt, 2005), explaining their weight loss as somatic symptoms, such as loss of appetite, or gastrointestinal symptoms. Thus, there are cultural limitations to the diagnostic criteria. Lastly, a further concern is the utilisation of amenorrhea as a diagnostic criterion; some patients continue to menstruate even at low weights, and in others loss of menstrual periods can occur before significant weight loss (Murphy et al., 2005). There are also complexities with respect to the applicability of this criteria to pre-menarche, menopause, or males (Abraham, Pettigrew, Boyd, Russell, & Taylor, 2005; Murphy et al., 2005). As such, some have concluded that there is insufficient evidence to support amenorrhea as a diagnostic criterion for AN (Abraham et al., 2005; Beumont, 2002), with removal of this criterion likely for the DSM-V (APA, 2010a).
Prevalence of Anorexia Nervosa

Despite the visibility of AN in the media and public consciousness as a result of it obvious symptoms (e.g., extremely low weight), it is actually quite rare. However, it is the tenth leading cause of burden of disease and injury (as measured by disability-adjusted life years; DALYs) for 15 to 24 year old females (AIHW, 2007).

The estimated prevalence rate for AN is 0.7% to 1.0% (Fairburn & Harrison, 2003; Hoek & van Hoeken, 2003), with approximately 90% to 95% of diagnosed patients being female (Fairburn & Harrison, 2003). Utilising information from the Australian twin registry of women aged between 28-39 years, a recent study found that the Australian lifetime prevalence rate of AN is 1.9% (Wade, Bergin, Tiggemann, Bulik, & Fairburn, 2006). Overall, the prevalence rate of AN has remained relatively stable since the 1970s (Currin, Schmidt, Treasure, & Jick, 2005; Fombonne, 1995; van Son, van Hoeken, Bartelds, van Furth, & Hoek, 2006). However, a Dutch study indicates that the incidence rate of AN for 15-19 year olds increased significantly by 94%; from 56.4 to 109.2 per 100,000 (van Son et al., 2006). Further, a recent Australian study shows that eating disorder behaviours, such as strict dieting and fasting, increased between 1995 and 2005 for both males and females (Hay, Mond, Buttner, & Darby, 2008). Lastly, young females aged between 15 to 24 years are most vulnerable to developing AN (le Grange, 1999; Levitt, 2001), with approximately 40% of all patients aged between 15 and 19 years (Hoek & van Hoeken, 2003). Similarly, male age of onset peaks at age 14 (Forman-Hoffman, Watson, & Anderson, 2008).

Behavioural, personality and cognitive correlates of Anorexia Nervosa

In addition to the key diagnostic criteria, there are a number of behavioural signs and personality traits associated with the diagnosis of anorexia nervosa. These relate to weight regulation and maintaining a sense of control over the environment. For example, use of exercise to maintain, or lose, weight,
or obsessive compulsive traits surrounding food, meals and weighing oneself. Prominent behavioural and personality correlates will be described below.

It has been stated that approximately 80% of patients with AN engage in excessive exercise as a form of weight control (Davis et al., 1997), though estimates vary from 33% to 100% (see Katz, 1996 for a review). The level of exercise undertaken defies what one may think an emaciated person is capable of enduring (Katz, 1996) but as indicated by Beumont, Beumont, and Touyz (1996), several retrospective case analyses reveal that this excessive exercise precedes the weight loss. Currently, excessive exercise is best defined as a situation whereby postponement of activity is met by extreme guilt, or when the exercise is undertaking for the sole purpose of losing weight (J.M. Mond, Hay, Rodgers, & Owen, 2006), thus elevating disordered eating behaviours (Ackard, Brehm, & Steffen, 2002; J.M. Mond, Hay, Rodgers, Owen, & Beumont, 2004). Further, those patients in the purging subtype tend to engage in excessive exercise to a greater extent than restricting subtypes (Shroff et al., 2006).

Patients with AN often use excessive exercise to regulate their affective state, especially for anxiety reduction, in conjunction with weight loss purposes (Penas-Lledo, Vaz Leal, & Waller, 2002). As a consequence, the propensity to undertake extreme levels of activity is associated with a longer time in inpatient treatment, as well as a shorter period of time before relapse (Shroff et al., 2006). Lastly, there are links between excessive exercise and obsessional and perfectionistic traits, higher scores on eating disorders measures, and lower minimum BMI (Davis & Kaptein, 2006; Shroff et al., 2006). Therefore, the presence of excessive exercise is associated with a poorer prognosis coinciding with elevated symptomatology.

Similarly, Bruch (1973) noted hyperactivity and engagement in activities, such as walking for long distances, refusing to sit down or even running around in circles. This hyperactivity is distinct from deliberate excessive exercise. There can be a broad restlessness, where the AN patient is unable to sit still for more than several minutes at a time (Katz, 1996). According to Bruch (1973) this excess activity is undertaken by the person with AN because of a fear of gaining weight or not burning off enough calorie. However, others have argued that hyperactivity and restlessness are biological in nature (Fichter & Pirke, 1995).
particular, low levels of leptin have been found to contribute to the increased level of activity (Casper, 1998).

In regards to personality traits associated with AN, perfectionism is a common trait that is present within sufferers. Perfectionism is consistently found to be elevated in those with AN as compared to normal controls, and also as compared with other psychiatric disorders (Bardone-Cone et al., 2007). This perfectionism appears not to be singly directed toward body image, but rather a more global self-presentation (Cockell et al., 2003). In this sense, perfectionism is a multidimensional construct whereby a fear of failure leads as concern over mistakes, doubting of actions taken, high personal standards, striving for high achievement, and perceptions of high expectations from others (Bardone-Cone et al., 2007; Sutandar-Pinnock, Woodside, Carter, Olmsted, & Kaplan, 2003). The presence of an increased level of perfectionism in the sufferer is related to a more negative prognosis (Sutandar-Pinnock et al., 2003) and poorer outcome up to five to 10 years later (Bizeul, Sadowsky, & Rigaud, 2001). Even after recovery, those with a prior AN diagnosis often retain perfectionistic traits and cognitive restraint (Bulik, Sullivan, Fear, & Pickering, 2000; Sullivan, Bulik, Fear, & Pickering, 1998).

Further, in regards to cognitive traits, those with AN tend to have difficulties with global processing (Lopez, Tchanturia, Stahl, & Treasure, 2008). As such, those with AN have more difficulty integrating information into a global whole, and have a high degree of attention for details (Garfinkel & Garner, 1982). This difficulty in processing global, versus detailed, information has been termed weak central coherence (Happe & Frith, 2006; Lopez et al., 2008). Weak central coherence is consistently replicated within research, with a review indicating a poorer performance level on tasks that involve a global problem-solving strategy, as compared to tasks that require a detail focussed strategy within those with an eating disorder (Lopez et al., 2008).

In addition, those with AN often exhibit rigidity, or inflexibility, in their thoughts. This is demonstrated in studies that employ set-shifting paradigms. Difficulties in set shifting are reflective of trouble moving back and forth between tasks, operations or sets (Holliday, Tchanturia, Landau, Collier, & Treasure, 2005; Miyake et al., 2000). The inability to quickly shift from one task or set to another is often present after weight restoration and long-term recovery.
(Tchanturia et al., 2004). Such cognitive rigidity may present further difficulties for carers in that the sufferer may insist plans be adhered to, with structure and routine needing to be adhered to. Further, it may be speculated that carers could have further difficulties due to sufferers having difficulties adapting to new situations and changing circumstances.

**Risk factors for the development of Anorexia Nervosa**

Anorexia nervosa has long been recognised as a complex, multidimensional disorder with biological, environmental, personality, and developmental risk factors (e.g., Garfinkel & Garner, 1982; Vitousek & Orimoto, 1993). Jacobi, Hayward, de Zwaan, Kraemer and Agras (2004) provide a comprehensive review of risk factors. The following section will provide a brief overview of the factors associated with the onset of AN.

At the most basic level of genetic factors, being female increases the risk for developing AN (Jacobi et al., 2004); approximately 90% to 95% of patients diagnosed with AN are female (Fairburn & Harrison, 2003). AN has a moderate genetic basis with a higher prevalence rate within the biological relatives of anorexic probands than in the general population; the risk of developing AN in female relatives of anorexic patients is 11.4 times higher than the risk of relatives from a normal population (Strober, Freeman, Lampert, Diamond, & Kaye, 2000). Further support for the genetic basis of AN comes from twin studies; several twin studies reveal a heritability index range of zero percent to 74% (Fairburn, Cowen, & Harrison, 1999; Klump, Miller, Keel, McGue, & Iacono, 2001; Kortegaard, Hoerder, Joergensen, Gillberg, & Kyvik, 2001; Wade, Bulik, Neale, & Kendler, 2000), with a concordance rate higher in monozygotic twins than dizygotic twins (Strober & Bulik, 2002; Treasure & Holland, 1995). The wide variation in heritability estimates can be accounted for through differing definitions of the disorders, diagnostic reliability and small sample sizes (Fairburn, Cowen, et al., 1999). However, the majority of studies suggest that genetic factors account for greater than 50% of the variance in AN (Klump & Gobrogge, 2005).

Further, susceptibility genes for AN have been investigated. A review of these studies shows that genes involved with serotonin, brain-derived neurotrophic factor and oestrogens production play a role in the development of
AN (Klump & Culbert, 2007). This may also explain the typical onset of AN during adolescence (Fairburn & Harrison, 2003); it has been speculated that the onset of AN at puberty may be linked to the increase in oestrogen, which then influences serotonin receptors. Further, genomic regions on chromosomes one and 10 have also been implicated in the development of AN (Klump & Gobrogge, 2005). These chromosomes, one and 10, have also been shown to have a link with social anxiety and perfectionism, both traits associated with AN.

Environmental factors are also significant in the development of AN and include a family history of eating disorders (Jacobi et al., 2004), familial communication of an ideal thin body shape (Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999) and exposure to dieting behaviour undertaken by other family members. A family history of an eating disorder poses both an environmental and genetic risk for AN in that eating disorder behaviour is being modelled (Thompson et al., 1999) and a genetic susceptibility is passed on (Jacobi et al., 2004). Familial communication of the thin-ideal can lead to a poor body image, and thus can pose a risk for the development of AN (Thompson et al., 1999).

However, despite sharing identical genes, family history and familial communication and modelling, an average of only 50% of identical twins with an AN proband show concordance. This suggests that other environmental factors are of importance. Personality factors and specific developmental experiences are two relevant factors.

With regards to personality factors associated with the development of AN, Jacobi et al.’s (2004) review suggests low self-esteem or a negative self-evaluation, inhibited emotionality and introversion all increase the risk. Lastly, in terms of thinking patterns, an inclination toward rigid, dichotomous thinking, and perfectionism are correlated with AN and these correlates are often perpetuated by the starvation of AN (Bardone-Cone et al., 2007; Fairburn & Harrison, 2003; Jacobi et al., 2004; Swift & Wonderlich, 1988).

Lastly a number of developmental factors, such as birth complications such as premature births, or severe birth trauma, and feeding difficulties during childhood have been identified as risk factors for the AN (Jacobi et al., 2004). For instance, problematic eating patterns, such as skipping breakfast during childhood and early adolescence, and consuming a high number of sugary snacks
before age 12, were related to later onset of an eating disorder (Fernandez-Aranda et al., 2007).

*Medical complications associated with AN*

Due to the extreme malnutrition associated with AN, it is a disorder that impacts on every body system. Therefore, sufferers are at risk for numerous complications, especially those associated with the cardiovascular, muscular-skeletal, and endocrine systems. In regards to the cardiovascular system, sufferers commonly experience bradycardia (slowed heart rate to less than 60 beats per minute), low blood pressure, and cardiac arrhythmias, occurring as a result of either hypokalemia (low potassium) or the frank loss of cardiac muscle due to malnutrition (Fairburn & Harrison, 2003; Hsu, 2004; Pomeroy & Mitchell, 2002; Sharp & Freeman, 1993). Musculoskeletal effects of AN include decreased muscle mass and strength and osteopenia or osteoporosis (Fairburn & Harrison, 2003). Osteoporosis occurs in up to 50% of patients with AN (Athey, 2003), most often within two years of onset (Sharp & Freeman, 1993). As a consequence, there is a seven-fold increase in fracture risk for the individual with AN compared to age-matched peers (Rigotti, Neer, Skates, Herzog, & Nussbaum, 1991). For young patients, lack of calcium can also lead to stunted growth (Fairburn & Harrison, 2003). This decrease in bone density remains at a lower level even after recovery from AN (Rigotti et al., 1991; Vestergaard et al., 2002).

Dermatological effects of starvation include loss of scalp hair, dry skin and brittle nails (Pomeroy & Mitchell, 2002). Moreover, approximately one-third of all patients develop fine, downy hair on their face and arms, known as lanugo (Pomeroy & Mitchell, 2002; Sharp & Freeman, 1993). AN also affects the gastrointestinal system, with sufferers often reporting symptoms such as constipation, bloating, and delayed stomach emptying (Fairburn & Harrison, 2003). Further, decreased fluid and food intake, and abuse of laxatives can lead to electrolyte disturbances, such as low sodium, potassium, magnesium and/or calcium levels (Pomeroy & Mitchell, 2002).

Neurological effects of starvation can lead to pseudo-atrophy of the brain, where there is enlargement of the ventricles and a decrease in grey and white
matter (Katzman et al., 1996); however, this is reversible with weight restoration (Golden et al., 1996). Further, patients with AN often have poor sleep patterns typified by early morning waking (Fairburn & Harrison, 2003; Sharp & Freeman, 1993).

Lastly, in regards to the endocrine system, sufferers often have hormonal disturbances which, for females, lead to amenorrhea (Fairburn & Harrison, 2003). Further, women with AN also have reduced fertility (Mehler & Krantz, 2003), coinciding with higher rates of miscarriage, obstetric complications, and postnatal depression (Pomeroy & Mitchell, 2002). In regards to males, endocrine system consequences include lower serum testosterone (Sharp & Freeman, 1993).

The medical complications associated with AN are often the cause of frequent hospitalisations of patients with AN. Research has shown that while the use of inpatient hospitalisation is an effective means of re-establishing weight (Olmsted et al., 2010), patients frequently drop-out of treatment and do not complete their stay. Given that the most severely ill patients are most likely to drop out of treatment (Olmsted et al., 2007), this poses a challenge to both professionals and family members of the person with the eating disorder. Further, for those who do successfully complete inpatient treatment, up to 42% of patients will relapse (Eckert, Halmi, Marchi, Grove, & Crosby, 1995), thus highlighting the need for further, ongoing treatment after cessation of inpatient treatment.

**Co-morbidities of Anorexia Nervosa**

Anxiety and affective disorders are often co-morbid with AN, and it can be speculated that such co-morbidities place further strain on both the sufferer and carer. The below section will briefly review the evidence in regards to co-morbidity of AN with anxiety disorders, including obsessive-compulsive disorder and depression.

Approximately 55% of patients with AN have been found to be diagnosed with at least one form of anxiety disorder (Kaye, Bulik, Thornton, Barbarich, & Masters, 2004). Kaye et al. (2004) found that the most common diagnoses were obsessive compulsive disorder (OCD; 35 percent) and social phobia (22 percent). Further research confirms the pattern of high co-morbidity of OCD with a
diagnosis of AN (Jacobi et al., 2004; Jordan et al., 2003). Interestingly, the onset of these anxiety disorders often precedes the onset of the eating disorder (Godart, Flament, & Jeammet, 2000; Kaye et al., 2004) with persistence of anxious traits even after weight restoration (Nilsson, Gillberg, Gillberg, & Rastam, 1999). Therefore, those with AN may display symptoms such as rigidity in thought and actions, neatness, high levels of conscientiousness, and a preoccupation with rules (Serpell & Troop, 2003). Lastly, the presence of obsessional and compulsive traits has been found to lead to poor psychosocial outcomes (Nilsson et al., 1999).

Depression is also often co-morbid with AN. In a 12 year longitudinal study, Fichter, Quadflieg and Hedlund (2006) found that the lifetime co-morbidity rate of AN with major depression was 54.5 percent. During recovery, weight gain has been found to both worsen (Fairburn & Harrison, 2003) and improve (Meehan, Loeb, Roberto, & Attia, 2006) reported depressive symptoms. These differential findings are argued (e.g., Fairburn & Harrison, 2003; Meehan et al., 2006) to be due to the weight of patients with AN. During recovery, some patients become despairing with weight gain, thus experiencing a worsening of depressive symptoms (Fairburn & Harrison, 2003), while in others, weight gain alleviates the depressive symptoms that are caused directly from the starvation state (Meehan et al., 2006).

Prognosis and outcome of Anorexia Nervosa

Anorexia nervosa is a chronic illness with an average duration of five years (Beumont, 2000). Approximately 45% of sufferers may have an illness duration greater than five years and 20% more than ten years (Whitney et al., 2005). The prognosis of someone with AN varies depending on age of onset, duration of eating disorder, and severity of symptoms. There is more favourable prognosis for those with an early onset and short history of the disorder (Neiderman, 2000). Conversely, those with a long history, severe weight loss, and who engage in binge-eating and vomiting have a more unfavourable prognosis (Fairburn & Harrison, 2003).

Approximately half of the patients diagnosed with AN will fully recover; within a clinical sample, at a 7.5 year follow-up, Herzog et al. (1999) found that
43% of patients with AN had fully recovered. Recovery was defined as an absence of symptoms for eight consecutive weeks. However, 40% of these patients relapsed after recovery during this follow-up period. The high rate of relapse may indicate that Herzog et al. (1999) did not utilise a robust measure of recovery. Fichter and Quadflieg (2007) found slightly higher recovery rates, with 54% fully recovered by a six year follow-up. As such, a large number of patients with AN do not recover from the illness, and therefore have chronic physical and psychological difficulties.

Lastly, AN has the highest mortality rate of all psychiatric disorders (Fichter, Quadflieg, & Hedlund, 2006; R. L. Palmer, 2003; Sullivan, 2002). The crude mortality rate of AN is 5.9% (Sullivan, 1995), with the mortality rate in AN patients of the binge-eating/purging subtype approximately twice as high as the restricting subtype (Zipfel, Lowe, & Herzog, 2003). At a 20 year follow up, approximately 10% to 20% of all anorexic patients will die (Crisp et al., 2006), meaning the mortality rate is three to five times that of the general population of comparable age (Beumont, 2000; Crisp et al., 2006). The majority of deaths in the AN population are a result from medical complications of malnutrition, or suicide (Crisp et al., 2006; Signorini et al., 2007; Sullivan, 2002). Between one-third and one-half of individual deaths are as a result of suicide (Goldner, Birmingham, & Smye, 1997; Theander, 1985), with the risk of successful suicide being approximately 20 (Sullivan, 1995) to 50 times (Keel et al., 2003) greater than that expected in the general population.

Therefore, the prognosis of someone with AN is poor. Further, in the absence of recovery, those with AN frequently crossover to a diagnosis of bulimia nervosa (BN; Sullivan, 2002; Sullivan et al., 1998). As such, 25% to 36% of patients with BN have had a past episode of AN (Agras, Walsh, Fairburn, Wilson, & Kraemer, 2000; Tozzi, Sullivan, Fear, McKenzie, & Bulik, 2003). Lastly, chronic patients of AN often develop a subthreshold eating disorder, termed eating disorder not otherwise specified (Fairburn & Walsh, 2002).

**Summary of Anorexia Nervosa**

AN is a rare, chronic and complex disorder. It is associated with perfectionism, obsessive compulsive behaviours, depression, anxiety and
cognitive rigidity. Further, only approximately 43% fully recover from the disorder, with a high incidence of relapse. There are also a number of medical complications due to AN, which involve all bodily systems. As such, repeated hospitalisations may be necessary. Further, AN has the highest mortality rate of all psychiatric disorders. Therefore, AN is a severe disorder with a poor prognosis. As a consequence patients with AN often require the involvement of informal carers, such as parents, family members and friends. This care is ongoing and difficult. A comprehensive discussion of the impact of caring for someone with AN will be covered in the following chapter.

Bulimia Nervosa

Diagnosis and symptoms of Bulimia Nervosa

Bulimia nervosa (BN) emerged as a diagnosable illness in the 1970s with four distinct features noted: periods of eating a larger than normal amount of food, followed by compensatory self-induced vomiting and purging behaviours; avoidance of fattening foods; and a morbid fear of becoming fat (Russell, 1979).

The current diagnostic criteria within the DSM-IV-TR incorporates the features listed by Russell (1979), however, now include five criteria. Firstly, there are recurrent episodes of binge-eating; the consumption of a larger than normal amount of food within a discrete time period, where food is consumed at a rapid pace (Beumont, 2002), coinciding with a sense of loss of control (Fairburn & Wilson, 1993; Walsh, 1993). These binge episodes are often triggered by factors such as low self-esteem, distress, the presence of attractive or fattening foods, or prior consumption of what is deemed a ‘forbidden’ food (Polivy & Herman, 1993).

Secondly, in response to the binge eating, there are recurrent inappropriate compensatory behaviours (purging), such as laxative abuse, vomiting or fasting, or non-purging compensatory behaviours such as excessive exercise or fasting (APA, 2000). Thirdly, the DSM-IV-TR specifies that the binging and compensatory behaviours both occur, on average, at least twice a week for three months. Frequencies less than this or occurring for less than three months are accorded a diagnosis of eating disorder not otherwise specified.
In regards to level of use of different compensatory behaviours Tobin, Johnson and Dennis (1992) report vomiting as the most common purging behaviour with approximately 82% engaging in vomiting behaviour at least once a week. Approximately 34% report fasting at least one day per week, 28% of patients use laxatives at least once per week, and 66% report exercising at least 30 minutes a day (Tobin et al., 1992).

Fourthly, as with AN, there is also an undue emphasis on body weight and shape, therefore, recognising the maladaptive attitudes that those with BN hold (Russell, 1979; Russell, 1988). However, the attempts to control weight via purging behaviours are perceived to be undermined by the frequent episodes of binge-eating, with the consequence that BN patients often describe themselves as ‘failed anorexics’ (Fairburn & Harrison, 2003). The bouts of uncontrolled eating mean that despite the use of compensatory behaviours, sufferers have a weight that generally remains within the normal range (Fairburn & Garner, 1988; Fairburn, Hay, & Welch, 1993; G. F. M. Russell, 1997; Vandereycken, 2002).

Lastly, the disturbance in eating patterns and body image does not occur exclusively during episodes of AN. Consistent with this criteria, an individual who engages in both binge eating and compensatory behaviour but who is markedly underweight is diagnosed as having anorexia nervosa, binge-purge subtype (APA, 2000).

There are two specified subtypes of BN within the DSM-IV-TR: purging subtype, where compensatory behaviours include self-induced vomiting and laxative abuse; and the non-purging subtype, where compensatory behaviours include measures such as fasting or excessive exercise. However, the validity of these subtypes is doubtful in both community (Mond, Hay, Rodgers, Owen, & Mitchell, 2006; Walters et al., 1993) and clinical samples (Tobin, Griffing, & Griffing, 1997), and the removal of these subtypes has been suggested for the DSM-V (APA, 2010b).

As with AN, the diagnostic criteria of BN are problematic. The major concern is associated with the definition of binge-eating and the time and frequency constraints. The current objective definition of a binge has been criticised as being arbitrary in nature (Garfinkel, 2002), with great variability in the size of individual binges (Rossiter & Agras, 1990) and no meaningful differences based upon these variations (Pratt, Niego, & Agras, 1998).
Specifically, Pratt et al. (1998) found no significant differences in other eating disorder symptom severity, BMI, self-esteem, current major depression, and other psychiatric symptoms. As such, most patients with bulimia describe binges that are not objectively large enough to fulfil the diagnostic criteria, despite having a clear psychological impact (Walsh, 1993). Further research confirms a lack of clinically significant differences between objective and subjective binge episodes, bringing into question the validity of the definition of a binge episode (Niego, Pratt, & Agras, 1997).

Further, the criterion of frequency of binge episodes has also come under scrutiny. The quantifiable differences between individual frequencies of binge-eating do not translate into meaningful qualitative differences (Franko, Wonderlich, Little, & Herzog, 2004; Kendler et al., 1991). As such, revisions in the DSM-V reduce the frequency of binge episodes required for a diagnosis to once a week (APA, 2010b). Lastly, the differential timeframes in which the binge takes place are not clinically meaningful (Franko et al., 2004). Therefore, with no difference in psychological outcome between differing subjective experiences of a binge episode, the definition of a binge becomes questionable (Niego et al., 1997). This has led to the argument that the experience of loss of control, rather than the frequency, size or timeframe of the binge episodes, is the more important predictor of psychological distress (Mond et al., 2006).

Prevalence of Bulimia Nervosa

The occurrence of BN is greater than that of AN, with an approximate one percent to five percent prevalence rate (Fairburn & Harrison, 2003; Fairburn et al., 1993; Murray, 2003). Within Australia, the lifetime prevalence rate within a community sample has recently been estimated to be 2.9% (Wade et al., 2006). Like AN, the rate of males diagnosed with BN is low, however it has been argued that prevalence estimates within this population are difficult to make (Cooper, Todd, & Wells, 2009). Nonetheless, some estimates place the prevalence of males with BN at close to one-tenth that of females (APA, 2000), with estimates of males accounting for 10% to 15% of bulimic patients in the community (Carlat & Camargo, 1991). Further, the features associated with males who have BN
differ to that of females. For instance, males have higher rate of premorbid obesity than females and higher rates of homosexuality (Carlat & Camargo, 1991; Carlat, Camargo, & Herzog, 1997)

The average age of onset of BN is slightly higher than that found in AN with the group most at risk for developing BN aged between 20 and 24 years old (Hoek & van Hoeken, 2003). However, females tend to have an earlier onset between 15 to 18 years, clustering around age 18 (Mitchell, 1990), with the age of onset for males between 18 and 26 years of age (Carlat & Camargo, 1991)

Lastly, the prevalence of BN was found to increase since the late 1980s, with a peak in the 1990s (Currin et al., 2005). However, since this peak in diagnoses during the 1990s, the prevalence rate now appears to be slowly falling (Currin et al., 2005).

Risk factors for the development of Bulimia Nervosa

Bulimia nervosa is a complex disorder that has a number of determining factors including genetic, environmental and personality risks. The main risk factors will be described in more detail below. A comprehensive review is found in Jacobi et al. (2004).

In regards to genetic factors, there is a possible hereditary component to the development of BN, with a vast heritability estimate range of zero percent to 83% (Bulik, Sullivan, & Kendler, 1998; Fairburn, Cowen, et al., 1999; Kendler et al., 1991), and a concordance rate greater for monozygotic twins than dizygotic twins (Kendler et al., 1991). Estimates of concordance rate for monozygotic female twins are 83.3 percent, with a lower rate for dizygotic female twins at 26.7% (Fichter & Noegel, 1990). As with AN, the variability in heritability estimates may be attributable to factors such as definitional differences, diagnostic inconsistency across studies, differing environments or small sample sizes (Fairburn, Cowen, et al., 1999). Further, having one relative with BN increases the risk of developing BN by 4.4 times greater than the general population (Strober et al., 2000). Lastly, being female also increases the risk of developing BN (Jacobi et al., 2004). However, recent data suggests that the ratio
of women to men may be decreasing, with recent estimates of 3:1 (Hudson, Hiripi, Pope, & Kessler, 2007).

Factors that have been identified as increasing the risk for developing BN are a combination of genetic and environmental factors, including: childhood obesity and parental obesity, and parental depression, use of alcohol and drugs (Jacobi et al., 2004). Approximately 40% of BN sufferers report a history of childhood obesity, as compared to 15% within healthy controls, and 44% report a history of parental obesity, as compared to 15% within healthy controls (Fairburn, Welch, Doll, Davies, & O'Connor, 1997). Further, within a sample of BN sufferers, approximately 24%, as compared to four percent within healthy controls, report parental alcoholism, and nine percent, compared to less than one percent within healthy controls, report parental drug abuse (Fairburn et al., 1997). Lastly, patients with BN have a higher incidence of parental depression (23% compared to five percent) than healthy controls (Fairburn et al., 1997).

In relation to environmental factors, repeated reinforcement within the family and peer group of a thin-ideal body shape is predictive of BN development (Thompson et al., 1999). Further, being exposed to dieting behaviour, or being on a diet, also increases the risk for BN (Fairburn et al., 1997; Jacobi et al., 2004). Similarly, those with BN are more likely to have parents who have a history of an eating disorder (Fairburn et al., 1997). As such, modelling of dieting or BN behaviours, particularly with an emphasis on weight and shape, puts young patients at risk of developing BN.

Lastly, there are a number of personality factors that increase the risk of developing BN. These include impulsivity (Fernandez-Aranda et al., 2006), a negative self-evaluation and low self-esteem, (Jacobi et al., 2004; Raffi, Rondini, Grandi, & Fava, 2000), shyness, and perfectionism (Fairburn et al., 1997). Raffi et al. (2000) report that 63% of patients with BN, as compared to three percent of controls have low self-esteem, indicating that it is a prodromal symptom of BN. Further, Fairburn and colleagues (1997) show that 40% of those with BN have a high level of shyness. Lastly, in relation to perfectionism, Fairburn et al. (1997) indicate that 42% of sufferers have a high degree of perfectionist tendencies. Further, a review by Franco-Paredes, Mancilla-Diaz, Vazquez-Arevalo, Lopez-Aguilar, and Alvarez-Rayon (2005) indicates a link between perfectionism and BN, however they do not provide correlation estimates. Further, they found that
perfectionism may predict onset of BN (Franco-Peredes, Mancilla-Diaz, Vazquez-Arevalo, Lopez-Aguilar, & Alvarez-Rayon, 2005).

There is a modest, but clinically significant correlation between BN and impulse control disorders (Fernandez-Aranda et al., 2006). The presence of general impulse problems, such as, alcohol abuse, self-harm, drug abuse, or sexual disinhibition (Lacey & Evans, 1986), in addition to binge eating behaviour, has led some authors to suggest a diagnosis of ‘multi-impulsive bulimia’ for a subset of patients. (Lacey & Evans, 1986; Lacey & Read, 1993). It has been suggested that where there is engagement in a history of at least three impulsive behaviours, patients display a differential personality profile, greater psychopathology and a poorer outcome than those with BN who are less impulsive (Fichter et al., 2006). However, while the distinction between less impulsive BN and multi-impulsive bulimia may be valid (Myers et al., 2006) these differences lie in general impulsive behaviours, patient history and related psychopathology, rather than within the bulimic behaviours themselves. As such, the categorisation of multi-impulsive bulimia has been argued to be questionable, and the suggestion that there is no underlying impulse control problem, with patterns of impulsive behaviour found within those with BN better explained through co-morbidity (Welch & Fairburn, 1996).

**Medical complication of Bulimia Nervosa**

The medical complications of BN are associated with the methods of self-induced purging. Three main modes of purging are utilised by those with BN, these are: self-induced vomiting, abuse of laxatives and misuse of diuretics (Mehler, Crews, & Weiner, 2004). Those who utilise self-induced vomiting often present with calluses and abrasions on the skin of their hand/s (also known as Russell’s sign) as a result of stimulating the gag reflex (Lasater & Mehler, 2001; Pomeroy, 2004). However, many bulimic patients reach the stage where they are able to reflexively vomit without manual stimulation of their gag reflex (Mehler et al., 2004). Repeated vomiting behaviour impacts upon the gastrointestinal system. After approximately six months of frequent vomiting, the acidic gastric contents begin to erode the dental enamel (Mehler et al., 2004). Further, vomiting
can also lead to more serious consequences, such as oesophageal ulcers, tears and ruptures (Lasater & Mehler, 2001; Mehler et al., 2004). Lastly, gastric dilation can often occur during binge eating, and rarely binge-eating may lead to rupturing (Pomeroy & Mitchell, 2002).

The main forms of purging also impact upon electrolyte balances in the body. These electrolyte abnormalities, such as low potassium and sodium levels (Halmi, 2002), occur as a direct result of regular vomiting and abuse of laxatives and diuretics (Mehler et al., 2004). These electrolyte imbalances can have an impact on both the gastrointestinal system and cardiovascular system. With sufferers consuming up to 50 laxatives a day, gastrointestinal problems occur (Mehler et al., 2004); with symptoms resembling irritable bowel syndrome, and future problems with laxative withdrawal (Lasater & Mehler, 2001). In terms of cardiovascular effects, electrolyte imbalances are a major risk factor for cardiac arrhythmias (Pomeroy & Mitchell, 2002).

Lastly, in relation to medical complications the binge-purge cycle often results in inadequate nutrition, which leads to hormonal dysfunction and menstrual irregularities, and lowered fertility (Mitchell, 1986; Resch, Szendei, & Haasz, 2004). Resch et al. (2004) found that all patients in their study (n = 14) had clinically reduced levels of Follicle Stimulating Hormone and Luteinising Hormone, which are hormones linked with fertility. However, while it is common for female sufferers to experience menstrual irregularities and reduced hormone levels throughout their illness, future fertility does not appear to be reduced (Crow, Thuras, Keel, & Mitchell, 2002; Mehler et al., 2004)

_Some of these complications are a result of the purging behaviors, such as vomiting, laxative abuse, and diuretic use, while others are a result of the binge-eating episodes._

Co-morbidities of Bulimia Nervosa

The most common co-morbidities with BN are affective disorders, substance use disorders, and borderline personality disorder. Again, as with AN, it can be speculated that the co-occurrence of such disorders with the eating disorder could place further strain on the carer. The section below will provide an overview of the evidence for the co-morbidity of these disorders within the BN population.
One study has reported a lifetime prevalence rate of 84% for any affective disorder within a clinical sample of patients with BN, and 44% within a community sample of patients with BN (Bushnell et al., 1994). Further, specific co-morbidity rates for BN and major depressive disorder have been estimated to be 60% to 70% within clinical samples (Godart et al., 2007), and 36% within a community BN sample (O’Brien & Vincent, 2003). Lastly, among adolescents, dysthymia is strongly related to BN at a rate believed to be greater than major depression (Perez, Joiner, & Lewinsohn, 2004; Zaider, Johnson, & Cockell, 2000). However, it has been suggested the presence of dysthymia may develop into major depression with illness progression and age. Therefore, the evidence suggests that depression is common among those with BN, with greater prevalence of depression among those with greater symptom severity, that is, within a clinical sample.

In relation to bipolar disorder, there appears to be a clear link between bipolar II and BN, sharing symptoms such as eating dysregulation, impulsivity, and craving for activity and/or exercise (McElroy, Kotwal, Keck, & Akiskal, 2005). Further, the odds ratio for BN and bipolar disorders has been reported to be 4.5 (Lunde, Fasmer, Akiskal, Akiskal, & Oedegaard, 2009). As such, patients with BN are four and a half times more likely to have a bipolar disorder than those with no eating disorder. When applying a broader definition of bipolar disorder, Lunde et al. (2009) found that the odds ratio for BN was 9.1 to 11.0, indicating a very high risk for bipolar symptoms within patients with BN. Due to the high co-morbidity of BN with bipolar disorder, care needs to be taken when administering pharmacological treatments to ensure that both disorders are adequately managed (McElroy, Kotwal, & Keck, 2006).

As stated, there is also moderate co-morbidity of substance use disorders with BN. The prevalence rates of substance use within BN range from nine percent to 55% (Polivy & Herman, 2002). In particular, there is a greater prevalence of alcohol use disorders among those with BN than in the general population, however these individuals are more similar to those who abuse alcohol (with no BN) than those who have BN with no alcohol dependence (Duncan et al., 2006). Nonetheless, co-morbidity with alcohol abuse is associated with a poorer outcome among those with BN (Duncan et al., 2006). Further, within a sample of adolescents with BN, the majority had used alcohol, and
approximately a third had used illegal drugs (Fisher & Le Grange, 2007). These patterns of adolescent substance use mirror adult BN behaviours, however, with a higher rate of use within adults.

Lastly, diagnosis of borderline personality disorder (BPD) is not uncommon (Serpell & Troop, 2003), with up to 28% of patients with BN having BPD (Sansone, Levitt, & Sansone, 2005). Consequently, self-harm behaviours, such as cutting or burning, and suicidal gestures may manifest (Wonderlich, Myers, Norton, & Crosby, 2002). The suicide attempts in those with co-morbid BN and BPD has been found to be up to 18 times that found in patients with BPD alone (Chen, Brown, Harned, & Linehan, 2009). However, a recent study has found that while, at pre-treatment, BN sufferers with BPD had higher purging rates and poorer general functioning, the rate and level of improvement over the course of three years did not differ to BN sufferers without borderline personality disorder (Rowe et al., 2008).

Prognosis and outcome of Bulimia Nervosa

On average, five years can pass before patients seek help for medical complications associated with BN (Lasater & Mehler, 2001) or BN itself (Fairburn & Harrison, 2003). A recent meta-analysis of the clinical course of BN indicates that approximately 45% of sufferers will fully recover from BN (Steinhausen & Weber, 2009). However, many individuals who do recover often display residual features of BN, such as an over-concern about weight and shape, a vulnerability to overeat (and subsequently purge) in response negative emotions, and low self-esteem (Sullivan, 2002). Further, at a five to 10 year follow-up, approximately one-third to one-half of BN patients will still have an eating disorder of clinical severity (Fairburn & Harrison, 2003).

As with AN, there is often a cross-over of diagnoses. One longitudinal study with 350 patients with BN found that 27% developed AN, binge-eating/purging subtype (Tozzi et al., 2003). Milos, Spindler, Schnyder and Fairburn (2005) report that, at a 30-month follow-up, 5.6% of those with BN will cross-over to a diagnosis of AN, and 26.9% will cross-over to a diagnosis of eating disorder not otherwise specified (EDNOS). More recently, Steinhausen
and Weber (2009) report that approximately 16% of BN sufferers will cross-over to a diagnosis of eating disorder not otherwise specified, which for most patients was subclinical BN, and approximately six percent developed AN.

Lastly, mortality rates in BN relatively low, due to the lack of the severe medical complications associated with acute malnutrition and starvation. Estimates of mortality rate range from one percent to 3.5% (Crow, Praus, & Thuras, 1999; Keel & Mitchell, 1997; Quadflieg & Fichter, 2003), which is not significantly different from the rate expected for age and sex matched general populations (Berkman, Lohr, & Bulik, 2007). A recent study estimated the crude mortality rate of BN at 3.9 percent, however, they do not provide an estimate of age and sex match mortality rate for a control population (Crow et al., 2009). While estimates of crude mortality are low, suicide rates for BN are significantly higher than suicide rates in AN and EDNOS (Crow et al., 2009), with a lifetime suicide attempt frequency estimated to be approximately 27% (Corcos et al., 2002; Fornaco et al., 2009)

**Summary of Bulimia Nervosa**

BN is a complex disorder that has a higher prevalence rate to AN. There are a number of medical complications, such as gastrointestinal problems, particularly related to purging behaviour and methods, such as tooth enamel erosion and electrolyte imbalances, attributable to the regular purging behaviour undertaken. Further, BN is often associated with borderline personality disorder, bipolar disorder, impulsivity problems and substance use disorders. Lastly, while the mortality rate of BN is low, the suicide rates are highest for all eating disorders.

With approximately 85% (Perkins, Winn, Murray, Murphy & Schmidt, 2004) to 87% (Winn et al., 2007) of carers living with the patients with BN, the potential for BN to adversely impact upon family members is apparent. The following chapter will provide a detailed discussion regarding the impact of caring for someone with BN.
Eating Disorders Not Otherwise Specified

Eating Disorders Not Otherwise Specified (EDNOS) is the most common diagnosis among all patients with eating disorders (Button, Benson, Nollett, & Palmer, 2005; Fairburn & Bohn, 2005; Machado et al., 2007). It is often described as a partial syndrome, where one criteria for AN or BN is not met (e.g. amenorrhea), or a subthreshold disorder, where diagnostic criteria are not sufficiently severe enough (Bisaga & Walsh, 2005). The DSM-IV-TR criteria incorporate these definitions, with an absence of an eating disorder symptom is necessary, or the symptoms are not as severe as a diagnosis for AN or BN (APA, 2000). Examples of diagnoses include: all criteria for AN are met, except there is regular menstruation; all criteria for BN are met, except there are less frequent binge-eating episodes; an individual engages in regular compensatory behaviour after eating a small amount of food, however they are still within the normal weight range (APA, 2000).

Often the distinction between EDNOS and the other eating disorders is not clear cut (Fairburn & Walsh, 2002). However, EDNOS has been criticized as being a ‘rag bag’ or ‘catch all’ diagnosis (le Grange et al., 2006; Sloan, Mizes, & Epstein, 2005). While patients with EDNOS do not fulfil all criteria for either AN or BN, their experience can be as severe and long lasting, requiring prompt clinical attention (National Institute for Clinical Excellence, 2004; Walsh & Garner, 1997).

Recently, Machado and colleagues (2007) found that the prevalence of EDNOS, within a community sample, was approximately 2.4%. A recent Australian study found that the lifetime prevalence rate of ‘partial AN’ (absence of amenorrhea) was 2.4%, and the prevalence rate for purging with no binge-eating behaviour was 5.3% (Wade et al., 2006). Of all eating disorders, EDNOS is estimated make up approximately 20% to 77% of patients (Button et al., 2005; Fairburn & Bohn, 2005; Franko et al., 2004; Machado et al., 2007). Further, a recent Australian survey indicates that the number of patients presenting with EDNOS has increased between 1995 and 2005 (Stark, 2007).
Criticisms of Eating Disorder Not Otherwise Specified

Given that EDNOS is such a large residual category, the validity and utility of the diagnostic criteria for AN and BN have become questionable (Palmer & Norring, 2005). As such, changes to the current classification system have been proposed. One response has been to re-examine the criteria currently in use for AN and BN diagnoses (Fairburn & Bohn, 2005). As discussed previously, there are problems associated with the DSM-IV-TR criteria for both AN and BN. The main concerns for AN are associated with amenorrhea (Abraham et al., 2005; Murphy et al., 2005) and over-evaluation of weight and shape (Lee & Lock, 2007; Lee et al., 1993; Murphy et al., 2005). Approximately 30% of women who meet all other AN criteria do not have amenorrhea (Abraham et al., 2005; Kruger, McVey, & Kennedy, 1998), however, they do not differ from those with diagnosable AN in the level of eating disorder psychopathology (Cachelin & Maher, 1998). For BN, the criterion that has received the most attention is in relation to binge-eating episodes (Franko et al., 2004; Niego et al., 1997). Again, there are no qualitative differences between the frequency of binges among those with subthreshold BN and full BN (Kendler et al., 1991; Niego et al., 1997). As such, subthreshold patients of AN and BN could be incorporated into the full diagnostic criteria. This would entail changes such as expanding the criteria of frequency of binge episodes and removing the criterion of amenorrhea for AN (Fairburn & Bohn, 2005).

An additional response proposed for the widespread nature of EDNOS within the current eating disorder classification system is a ‘transdiagnostic’ approach (Fairburn, Cooper, & Shafran, 2003). Fairburn and colleagues (2003) proposed that rather than having separate diagnoses, there be a transdiagnostic category that recognises common mechanisms in BN, AN and EDNOS. These include dietary restraint and restriction, binge eating, purging behaviours and over-evaluation of control over eating (Fairburn & Bohn, 2005). The argument is that eating disorders all share the same distinctive psychopathology. Evidence for this comes from the common pattern of patients moving between diagnostic states over time is cited (Fairburn et al., 2003), with this diagnostic crossover between AN and BN commonly occurring within the first five years of the illness (Tozzi et al., 2003). Further, chronic patients of AN and BN often develop into EDNOS.
(Fairburn & Walsh, 2002). Therefore, replacing diagnostic categories with one large group, based on the common disabling concern over food, body weight and body shape (Waller, 1993), with a focus on the similarities shared between eating disorders, rather than the differences, has been proposed (Fairburn & Bohn, 2005; Waller, 1993). However, the use of the transdiagnostic approach has come under scrutiny, with suggestions that eating disorders do not actually share similar pathologies (e.g., Beumont & Touyz, 2003; Birmingham, Touyz & Harbottle, 2008). For example, there are inconsistencies between AN and BN in relation to prevalence rates, age of onset, mortality rates and neurological outcomes (Birmingham et al., 2008).

**Binge Eating Disorder**

Of the EDNOS categories, a common diagnosis is that of Binge Eating Disorder (BED). The DSM-IV-TR identifies BED as a diagnosis provided for further study (APA, 2000). During the time since this recommendation, BED has emerged as a disorder warranting a full DSM-V entry (APA, American Psychiatric Association, 2010c; Dingemans, van Hanswijck de Jonge, & van Furth, 2005). BED is typified by recurrent binging over a number of days, with a sense of a loss of control and distress evident during the binge (Cooper & Fairburn, 2003; Franko et al., 2004). Unlike BN, those with BED do not engage in compensatory behaviours (Franko et al., 2004). Furthermore, patients with BED have a tendency to habitually overeat outside of binge episodes. Heightened negative affect has been cited as a precursor to a binge, followed by a further temporary increase in negative affect immediately post-binge (Stein & Woolley, 1996).

The prevalence of BED has been estimated to be approximately two percent to three percent within the general population, with higher figures from five percent to 10% for the obese population (Franko et al., 2004; Grilo, 2002). Indications are that BED is a chronic disorder (Pope et al., 2006). Factors associated with BED are similar to that of the other eating disorders, these include: self-criticism, low self-esteem, depressive symptoms, and an over-evaluation of the self in terms of weight and shape (Dunkley & Grilo, 2007). In addition, research indicates that those who develop BED experience a greater
number of life events, such as major changes in life circumstances or stress related to work, school or home environment, within the 12 months prior to onset (Pike et al., 2006). Therefore, a feeling of being overwhelmed by changes or stress leads to a reduced capacity to cope effectively, thus turning to binge eating.

Summary of chapter

Eating disorders have a low prevalence rate within the population, but are severe disorders. Eating disorders include anorexia nervosa, bulimia nervosa, eating disorder not otherwise specified and binge eating disorder. These disorders are often associated with other, significant diagnoses, such as depression, anxiety and personality disorders. Further, there are numerous medical complications associated with eating disorders, which can require frequent medical intervention and hospitalisation. Lastly, with an average duration of approximately five years, the prognosis and outcome of eating disorders is often poor.

The impact of eating disorders on the family and carers is significant. Patients may become the focus of attention within the family environment, with less time for friends and social activities (Nielson & Bara-Carril, 2003). There may be feelings of inadequacy and self-blame, with difficulties at meal times, sufferer self-harm behaviours, relationship difficulties between carer and sufferer, carer anxiety and depression (Monteleone, Treasure, Santonastaso, Favaro, & Brambilla, 2005). Therefore, there is a significant level of burden associated with caring for someone with an eating disorder, that can lead to carer exhaustion due to the protracted nature of the illness (Treasure, Schmidt, & Hugo, 2005). The following chapter will discuss the eating disorder carer burden literature in more detail.
CHAPTER THREE  
LITERATURE REVIEW: CARER BURDEN

Within Australia, approximately 2.6 million people are classified as home-based carers of patients with an organic or mental illness (ABS, 2004). A carer is defined as someone who provides informal assistance to a person who has a disability, mental illness, chronic condition, or is frail, on an ongoing basis for at least six months (ABS, 2004; Carers Australia, 2007). Caring for another person impacts on the physical and emotional health of the carer, for example, decreased energy, increased worrying, or a generalised decrease in wellbeing (ABS, 2004). This experience of carer burden has received much attention within research literature.

In terms of caring for someone with an organic illness, such as Alzheimer’s disease and dementia, carers report high levels of stress, carer burden, and depression (Mannion, 2008a; Mioshi, Bristow, Cook, & Hodges, 2009; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). Further, carers of patients with Alzheimer’s disease report the opportunity to take part in social activities were limited due to carer responsibilities (Mannion, 2008a, 2008b). Therefore, older carers often experience a number of psychological and social consequences due to their role. Similarly, caring for a child with a chronic illness, such as cystic fibrosis, can also lead to depression and relationship difficulties (Coyne, 1997). Coyne (1997) reports that carers will cope with this burden of care by sharing their burden with other family members or friends, incorporating their carer responsibilities into a daily schedule, and assigning greater meaning to the illness.

Similarly, caring for someone with a mental illness, such as schizophrenia, is associated with increased anxiety and depression (Fortune, Smith, & Garvey, 2005) and a strained relationship with the sufferer (Schene et al., 1998). Further, the way carers of patients with schizophrenia cope with the carer role has been found to impact upon their level of distress (Fortune et al., 2005). For example, Fortune et al. (2005) found that coping through emotional support, acceptance or positive reframing is associated with less distress, while coping through self-blame is associated with higher levels of distress. Similarly, carers of patients
with mood disorders report a high level of distress and burden (Highet, Thompson, & McNair, 2005; Scazufa, Menezes, & Almeida, 2002), and high levels of expressed emotion within the family for carers of those with bipolar disorder (Ogilvie, Morant, & Goodwin, 2005).

While there is substantial literature on the experience of care giving for a variety of physical and mental illnesses, limited attention has been given to the specific experience of carers of patients with eating disorders. The aim of this chapter is to review the current research examining caring for someone with an eating disorder. After a brief discussion of the definition of carer burden, an introduction to the burden of care associated with eating disorders will follow, with an analysis of the current models of care giving. Next, an in-depth review of the findings relating to carer burden in respect to eating disorders, covering interpersonal relationship difficulties, expressed emotion, the specific needs of carers, social support and coping strategies will occur. It will be concluded that there is a need for longitudinal study of carer burden and psychological distress, with the use of questionnaires developed specifically for eating disorder carers. A longitudinal design will allow for the examination of the long-term predictors of burden and distress. Secondly, an examination of the mediating role of social support and coping on carer burden and psychological distress is needed. Lastly, an investigation of carer burden from the perspective of the carer and the sufferer is required

Definitions in carer burden literature

The definition of caregiver burden is yet to receive universal agreement, with many studies failing to operationalise the term. The impact of caring has been described as caregiver strain, which encompasses excessive mental or physical exhaustion, and caregiver stress, involving a cognitive imbalance between the demands placed on the carer and the self-perceived capabilities of the carer (Hunt, 2003). The terms burden, strain and stress tend to be used interchangeably within the literature. However, despite a lack of a common definition, there is an underlying theme relating 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 (Kuipers & Bebbington, 2005).
In order to resolve the difficulties with the definition of carer burden, the differentiation between subjective and objective burden has been made (Hunt, 2003; Kuipers & Bebbington, 2005; Maurin & Boyd, 1990). Objective burden pertains to the observable, concrete, tangible costs to the carer (Hunt, 2003); including financial support, level of assistance required for daily activities, or time needed for attending appointments (Hillege, Beale, & McMaster, 2006). Maurin and Boyd (1990) suggest there are five dimensions of objective burden: patient behaviour, patient role performance, general adverse effects on the family, level of support given to the patient, and financial costs.

Conversely, subjective burden is the positive or negative feelings that are experienced throughout caregiving; in other words they are the personal appraisals of the illness and caring situation (Hunt, 2003; Maurin & Boyd, 1990). Examples of subjective burden include reactions such as worry and stress, depression, guilt about having been a cause of the illness, and fears for the patient’s health (Baronet, 1999; Maurin & Boyd, 1990). Therefore, subjective burden is closely related to concepts such as stress or distress (Kuipers & Bebbington, 2005).

While these concepts of objective and subjective burden have been utilised with some consistency within the carer burden literature (Maurin & Boyd, 1990), it has been argued that these definitions of the carer experience are biased towards a focus on the negative outcomes of caring (Pinquart & Sorensen, 2005). As such, positive aspects of the caregiving experience have been identified, including: increased self-esteem, a sense of self-satisfaction resulting from caring for another, finding a personal meaning from the experience, and strengthening the relationship between the carer and patient, have been identified (Gilbert, Shaw, & Notar, 2000; Hunt, 2003). Therefore, carer burden encompasses both a subjective and objective element, with potential negative consequences on the carers’ psychological and physical health. However, carers may also gain a positive outcome from the experience.

Lastly, the difference between carer burden and carer psychological distress, such as general worry, anxiety, and depression, need to be noted. Carer burden is a direct consequence to the specific roles of caregiving, whereas psychological distress is a more generalised response to a stressful situation.
For females aged 12 to 24 years, eating disorders are the second leading cause of hospitalisation due to mental and behavioural disorders (AIHW, 2006). Across gender and all ages eating disorders are the twelfth leading cause of hospitalisation due to mental health disorders within Australia (AIHW, 2006). Further, BN and AN are the eighth and tenth leading causes of burden of disease and injury (as measured by disability-adjusted life years; DALYs), respectively for 15 to 24 year old females (AIHW, 2007). In addition, the economic cost of treating someone with an eating disorder is substantial, with therapeutic costs for eating disorders being comparable or even higher than that of treating schizophrenia (Agras, 2001; Lock et al., 2008; Striegal-Moore et al., 2000). As such, there is often a need for informal carers to support those with an eating disorder.

While AN is characterised by mood and personality disturbance, medical complications and a high suicide rate, anorexic patients are often proud of their condition, seeing themselves as ‘superior’ to normal peers (Vandereycken, 2006b). Patients with anorexia commonly deny there is a problem and view their weight loss as an accomplishment, rather than an affliction (Vitousek, Watson, & Wilson, 1998). This egosyntonic nature often results in a reluctance to recover (Treasure & Schmidt, 2001), leaving to parents, partners or friends to compel sufferers to seek required treatment (Vitousek et al., 1998). Furthermore, of those who do recover from AN, core attitudes may remain (e.g., rigidity, perfectionism, and a drive for thinness) and their weight often remains in the low to low-normal range (Sullivan, 2002). As such, family members not only have to be able to care for the sufferer throughout the illness and recovery but also must be able to cope with their loved one maintaining some of these characteristics.

As with AN, BN is a complex, multidimensional disorder that has a significant impact on both the sufferer and their family. Those who have BN describe an illness that is isolating and secretive (Broussard, 2005; Orbanic, 2001). They are fearful of being judged, therefore often avoid other people, using lies and excuses to cover up their behaviour (Broussard, 2005). Patients with BN can often be ashamed of their binging and vomiting behaviours (Winn et al., 2007) and go to great lengths to covertly binge and purge in order to avoid the
Therefore, BN is a secretive illness that is commonly denied by the patient, leading to difficulties for family members in identifying the signs and symptoms of the illness (Perkins et al., 2004). Once family members do identify the problems, the BN is often at a severe level, leading to feelings of guilt and self-blame on the part of the carer.

Table 3.1 presents a selective overview of empirical quantitative research that has examined caring for someone with an eating disorder. A literature search was conducted using the following terms: carers, carer burden, caregiving, eating disorder, anorexia nervosa, and bulimia nervosa. Only quantitative, peer-reviewed research articles from 2000 onwards were chosen for inclusion within Table 3.1. Table 3.2 presents a selective overview of empirical qualitative research investigating eating disorder carers. A literature search was conducted using the following terms: carers, carer burden, caregiving, qualitative, eating disorder, anorexia nervosa, and bulimia nervosa. A study was deemed qualitative if the methodology used was face-to-face interviews, focus groups or use of written responses. Only qualitative, peer-reviewed research articles from 2000 onwards were chosen for inclusion within Table 3.2. A discussion of specific findings from these studies will follow Table 3.1 and Table 3.2.
Table 3.1

*Quantitative research examining carer burden in eating disorder carers*

<table>
<thead>
<tr>
<th>Author</th>
<th>Location</th>
<th>Sample Type</th>
<th>Sample Size (Response rate)</th>
<th>Study Topic</th>
<th>Recruitment</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dimitropoulos, Carter, Schachter and Woodside (2008)</td>
<td>Toronto</td>
<td>AN</td>
<td>63</td>
<td>Determine influences on caregiver distress and family functioning</td>
<td>Inpatient program</td>
<td>BAS(^a), Family conflict scales, Devaluation of consumers and consumer families scales, SPS(^b), Professional support, FAD - GFS(^c), GHQ-12(^d)</td>
</tr>
<tr>
<td>Graap, Bleich, Herbst, Scherzinger et al. (2008)</td>
<td>Germany</td>
<td>AN, BN, Schizophrenia</td>
<td>ED – 32, SC – 30</td>
<td>Compare needs of ED and schizophrenia carers</td>
<td>Outpatient, inpatient and day services at hospital</td>
<td>PANSS(^e), EDE(^f), CNA(^g), GHQ-12, BI(^h)</td>
</tr>
<tr>
<td>Graap, Bleich, Herbst, Trostmann et al. (2008)</td>
<td>Germany</td>
<td>AN, BN</td>
<td>32</td>
<td>Examine needs of BN carers</td>
<td>Outpatient, inpatient and day services at hospital</td>
<td>EDE, CNA, GHQ-12, BI</td>
</tr>
<tr>
<td>Haigh and Treasure (2003)</td>
<td>London</td>
<td>AN</td>
<td>28</td>
<td>Development of carers needs measure</td>
<td>Convenience sample of carers attending a carers conference</td>
<td>CaNAM(^i), ECI(^j), GHQ-12</td>
</tr>
<tr>
<td>Hoste and Le Grange (2008)</td>
<td>Chicago</td>
<td>BN</td>
<td>80</td>
<td>Examine cultural differences in EE</td>
<td>Part of a treatment study</td>
<td>SCFI(^k), EDE</td>
</tr>
</tbody>
</table>

*Note.* \(^a\)Burden Assessment Scale; \(^b\)Social Provisions Scale; \(^c\)McMaster Family Assessment Device – General Functioning Subscale; \(^d\)General Health Questionnaire – 12; \(^e\)Positive and Negative Syndrome Scale; \(^f\)Eating Disorders Examination; \(^g\)Carer’s Needs Assessment; \(^h\)Burden Inventory; \(^i\)Carer’s Needs Assessment Measure; \(^j\)Experience of Caregiving Inventory; \(^k\)Standardised Clinical Family Interview.
Table 3.1 Continued

**Quantitative research examining carer burden in eating disorder carers**

<table>
<thead>
<tr>
<th>Author</th>
<th>Location</th>
<th>Sample Type</th>
<th>Sample Size (Response rate)</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Kyriacou, Treasure and Schmidt (2008a)</td>
<td>London</td>
<td>AN</td>
<td>151 (92%)</td>
<td>Examine EE in AN carers</td>
<td>Research database, Inpatient unit</td>
<td>FQ(^1), HADS(^m), ECI, ABOS(^n)</td>
</tr>
<tr>
<td>Kyriacou, Treasure and Schmidt (2008b)</td>
<td>London</td>
<td>AN</td>
<td>151 (92%)</td>
<td>Model factors associated with distress</td>
<td>Research database, Inpatient unit</td>
<td>CSS(^o), HADS, ECI, ABOS</td>
</tr>
<tr>
<td>Santonastaso, Saccon and Favaro (1997)</td>
<td>Italy</td>
<td>AN, BN</td>
<td>40</td>
<td>Explore the nature of burden</td>
<td>Outpatient unit</td>
<td>FPQ(^p)</td>
</tr>
<tr>
<td>Sepulveda, Lopez, Todd, Whitaker and Treasure (2008)</td>
<td>London</td>
<td>AN, BN</td>
<td>28</td>
<td>Examine impact of workshop series</td>
<td>Support group, hospital ED unit</td>
<td>GHQ-12, ECI, EDSIS(^q)</td>
</tr>
<tr>
<td>Sepulveda et al. (2010)</td>
<td>London</td>
<td>AN, BN</td>
<td>68 families</td>
<td>Examine association between EE and psychological distress and negative appraisals</td>
<td>b-eat, caregivers of referred patients</td>
<td>FMSS(^r), GHQ-12, ECI</td>
</tr>
<tr>
<td>Sepulveda, Whitney, Hankins and Treasure (2008)</td>
<td>London</td>
<td>AN, BN</td>
<td>196</td>
<td>Development of carer burden measure</td>
<td>ED service at hospital and volunteer database</td>
<td>GHQ-12, GAS(^s), ECI, EDSIS</td>
</tr>
</tbody>
</table>

*Note.* \(^1\)Family Questionnaire; \(^m\)Hamilton Anxiety and Depression Scale; \(^n\)Anorectic Behavior Observation Scale; \(^o\)Caregiving Stress Scale; \(^p\)Family Problems Questionnaire; \(^q\)Eating Disorder Symptom Impact Scale; \(^r\)Five Minutes Speech Sample; \(^s\)Global Assessment Scale.
Table 3.1 Continued

Quantitative research examining carer burden in eating disorder carers

<table>
<thead>
<tr>
<th>Author</th>
<th>Location</th>
<th>Sample Type</th>
<th>Sample Size (Response Rate)</th>
<th>Study Topic</th>
<th>Recruitment</th>
<th>Measures</th>
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<tbody>
<tr>
<td>Treasure et al. (2001)</td>
<td>London</td>
<td>AN, Schizophrenia</td>
<td>AN - 71; SC - 68</td>
<td>Compare experience of caregiving in AN and schizophrenia carers</td>
<td>AN - Inpatient; SC - prevalent cases part of another study</td>
<td>ECI, GHQ-28; Writing task</td>
</tr>
<tr>
<td>Whitney, Haigh, Weinman and Treasure (2007)</td>
<td>London</td>
<td>AN, BN</td>
<td>115 (67%)</td>
<td>Examine predictors of carer distress and appraisals</td>
<td>Research database</td>
<td>GHQ-12, ECI, IPQ-SCV(^t), CaNAM</td>
</tr>
<tr>
<td>Winn et al. (2007)</td>
<td>London</td>
<td>BN, EDNOS</td>
<td>112</td>
<td>Examine mental health problems and negative experiences, and what predicts these</td>
<td>Part of therapy trial study</td>
<td>ECI, GHQ-12, IIP(^u), LEE(^v), SFI(^v)</td>
</tr>
</tbody>
</table>

*Note.* \(^t\)Illness Perception Questionnaire – Schizophrenia Carers Version; \(^u\)Inventory of Interpersonal Problems; \(^v\)Level of Expressed Emotion Scale; \(^v\)Self-report Family Inventory.
<table>
<thead>
<tr>
<th>Author</th>
<th>Location</th>
<th>Sample Type</th>
<th>Sample Size</th>
<th>Study Topic</th>
<th>Recruitment</th>
<th>Domains reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cottee-Lane, Pistrang and</td>
<td>London</td>
<td>AN parents</td>
<td>11</td>
<td>General impact on parents</td>
<td>Child and ED clinic at teaching hospital</td>
<td>Understanding ED; Impact of ED; Managing ED and impact;</td>
</tr>
<tr>
<td>Bryant-Waugh (2004)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Sibling role within family; familial factors that influence and reinforce sibling role; consequences and benefits of ED to sibling; coping strategies of non-affected sibling; current and future intentions of caregiving; professional and informal support for siblings</td>
</tr>
<tr>
<td>Dimitropoulos, Klopfer, Lazar</td>
<td>Toronto</td>
<td>AN Siblings</td>
<td>12</td>
<td>General impact of ED on</td>
<td>Part of larger quantitative study (Dimitropoulos et al., 2008)</td>
<td></td>
</tr>
<tr>
<td>and Schachter (2009)</td>
<td></td>
<td></td>
<td></td>
<td>siblings</td>
<td></td>
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</tr>
<tr>
<td>Gilbert et al. (2000)</td>
<td>Ontario</td>
<td>ED Mothers</td>
<td>52</td>
<td>General impact of ED on</td>
<td>Clinic and hospital</td>
<td>Changes in relationship; Factors affecting relationship change;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>families</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Highet, Thompson and King</td>
<td>Melbourne</td>
<td>ED Carers</td>
<td>24</td>
<td>General impact of ED</td>
<td>Advertisement in newsletters, local newspapers, radio,</td>
<td>Progression of and ED; impact of experience of caring for person with ED; support for carers;</td>
</tr>
<tr>
<td>(2005)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>support groups, and local mental health professionals</td>
<td></td>
</tr>
<tr>
<td>Hillege et al. (2006)</td>
<td>Sydney</td>
<td>ED Parents</td>
<td>21</td>
<td>Impact on family life</td>
<td>Eating disorder support services</td>
<td>Family unification or disintegration; parent's inability to cope; inconsiderate comments from significant others; social isolation; financial impacts</td>
</tr>
<tr>
<td></td>
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<td></td>
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</table>
Table 3.2 Continued

**Qualitative research examining caring for someone with an eating disorder**

<table>
<thead>
<tr>
<th>Author and Year</th>
<th>Location</th>
<th>Sample Type</th>
<th>Sample Size</th>
<th>Study Topic</th>
<th>Recruitment</th>
<th>Domains reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Honey and Halse (2005)</td>
<td>Sydney</td>
<td>AN Parents</td>
<td>22</td>
<td>Parents response to AN</td>
<td>Through ED services</td>
<td>Daughter-directed activities; foundation activities; parallel activities; maintaining normality; compensating for changes in family life; providing additional support (to well siblings); protecting (well) siblings; managing the consequences</td>
</tr>
<tr>
<td>Honey and Halse (2006a)</td>
<td>Sydney</td>
<td>AN Parents and siblings</td>
<td>P - 24, S - 55</td>
<td>Impact on well siblings</td>
<td>Through ED services</td>
<td></td>
</tr>
<tr>
<td>Honey and Halse (2006b)</td>
<td>Sydney</td>
<td>AN Parents</td>
<td>24</td>
<td>How parents cope</td>
<td>Inpatient, outpatient, private paediatrics</td>
<td>Coping: explanatory work; thinking work; capacity work</td>
</tr>
<tr>
<td>Honey, Clarke, Halse, Kohn and Madden (2006)</td>
<td>Sydney</td>
<td>AN Parents and siblings</td>
<td>P - 24, S - 54</td>
<td>Impact on well siblings</td>
<td>Through ED services</td>
<td>Mechanisms of sibling influence; Contributing factors</td>
</tr>
<tr>
<td>Huke and Slade (2006)</td>
<td>Yorkshire</td>
<td>BN Partners</td>
<td>8</td>
<td>General impact on partners</td>
<td>Outpatient unit</td>
<td>Living with secrecy and deception; struggling to understand and find reasons; discovering your powerlessness; 'It's like growing to live with it'; experiencing strains and strengths in the relationships</td>
</tr>
<tr>
<td>Perkins, Winn, Murray, Murphy and Schmidt (2004)</td>
<td>London</td>
<td>BN Parents and partners</td>
<td>20</td>
<td>Emotional impact of caring</td>
<td>Via carers' conferences; volunteer database; outpatient unit</td>
<td>Detection of illness and impact of detection; Ongoing impact of caring - difficulties; Ongoing impact of caring - positive factors</td>
</tr>
<tr>
<td>Author</td>
<td>Location</td>
<td>Sample Type</td>
<td>Sample Size</td>
<td>Study Topic</td>
<td>Recruitment</td>
<td>Domains reported</td>
</tr>
<tr>
<td>-------------------------------------------------</td>
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</tr>
<tr>
<td>Whitney et al. (2005)</td>
<td>London</td>
<td>AN Parents</td>
<td>40</td>
<td>General impact of AN</td>
<td>Inpatient Unit</td>
<td>Carers' illness perceptions; impact of illness; emotional and cognitive processes; maladaptive beliefs and responses</td>
</tr>
<tr>
<td>Winn, Perkins, Murray, Murphy and Schmidt (2004)</td>
<td>London</td>
<td>BN Parents and partners</td>
<td>20</td>
<td>Needs of carers</td>
<td>Via carers' conferences; volunteer database; outpatient unit</td>
<td>Carer experiences of treatment; support received by carers; carer's needs</td>
</tr>
</tbody>
</table>

Table 3.2 Continued

Qualitative research examining caring for someone with an eating disorder
Overview of magnitude of carer burden and psychological distress

Caring for someone with an eating disorder is associated with considerable burden and psychological distress. Recently, Zabala, MacDonald and Treasure (2009) reviewed 20 studies that examined expressed emotion, caregiving burden and/or psychological distress in relation to eating disorder carers. Overall, the majority of studies found that carers experience a high level of distress and burden, and display high level of expressed emotion (Zabala et al., 2009). Further, caring for someone with AN was found to be of equivalent burden as caring for someone with psychosis (Graap, Bleich, Herbst, Scherzinger, et al., 2008; Treasure et al., 2001). Further, AN carers have higher levels of psychological health problems and general difficulties with the caregiving experience than the carers of patients with schizophrenia (Treasure et al., 2001).

While research indicates that caring for someone with either BN or AN results in a high level of burden (e.g., Treasure et al., 2001; Winn et al., 2007), there are inconsistencies in the literature regarding whether caring for someone with AN has a greater, or equivalent, burden of care to caring for someone with BN. Winn and colleagues (2007) found that caring for an individual with BN had comparable levels of distress and difficulties as that reported by Treasure et al. (2001) for AN and schizophrenia. However, Graap, Bleich, Herbst, Trostmann et al. (2008) reported a greater level of psychological distress, and reported moderate to serious problems, for AN carers as compared to BN carers. However, while Graap, Bleich, Herbst, Trostmann et al. (2008) reported a difference between AN and BN carers in the level of psychological distress, they found that there was no difference on level of experienced burden. Further, Graap, Bleich, Herbst, Scherzinger et al. (2008) found that as a result of the high level of problems related to caring for someone with an eating disorder and the number of unmet needs, 59% of carers stated that they felt depressed, burnt out or physically or mentally ill. Conversely, Santonastaso, Saccon and Favaro (1997) reported that the burden of care within relatives of patients with AN was significantly higher than relatives of patients with BN. These inconsistencies in findings may be attributable to the differences in measures used, the changing nature of eating disorders, and small sample sizes. Nonetheless, it is apparent that
caring for someone with an eating disorder results in considerable levels of burden and psychological distress for the carer.

While caring for someone with an eating disorder can have a negative impact upon the carer, it may be rewarding as well (Nielsen & Bara-Carril, 2003). Dealing with the eating disorder may bring the carer closer to the patient and strengthen the relationship (Gilbert et al., 2000; Perkins et al., 2004). Additionally, the carer may be able to use the illness as an opportunity to develop personally, by gaining personal strength, learning new skills, and developing a new understanding of others (Perkins et al., 2004). Further, successful coping with the eating disorder may be able to unite the family and build family support and bonds (Hillege et al., 2006; Perkins et al., 2004; Treasure et al., 2001).

Therefore while caring for someone with an eating disorder can lead to considerable burden and distress, it may also provide positive opportunities.

Lastly, while carers experience a high level of burden and distress, it is unknown whether the sufferers perceive their carers to be burdened. Cleary et al. (2006) examined the perceptions of burden in patients with schizophrenia, affective disorders, or other disorder (excluding eating disorders). Patients underestimated consequences of caregiving, especially the impact of strained atmosphere, global burden, worrying about their future and encouragement to undertake an activity. As such, carers of patients with a mental illness experience more burden than patients perceived. Thus, it would be speculated that those caring for patients with an eating disorder would experience a similar dissonance between carer and patient perceptions of need and burden.

As can be seen in Table 3.1, a strength of the current quantitative eating disorder research examining psychological distress in eating disorder carers is the consistent use of the General Health Questionnaire (GHQ) as a measure of distress. Similarly, the burden of care has been measured with Experience of Caregiving Inventory (ECI) for the majority of studies. As such, meaningful comparisons between findings can be made. However, the majority of current carer burden literature using the ECI or GHQ utilise samples from London (Zabala et al., 2009). While the samples are from different cohorts of carers (Zabala et al., 2009), such a sampling framework may restrict the generalisability of the findings. Further, for all quantitative studies the samples are predominantly drawn from a volunteer database or through inpatient programs. Such
convenience sampling techniques may provide biased results, in that those on a carer database may not be under as much stress as those who do not self-select to be on a database. Conversely, those recruited through inpatient programs may be carers who are over-burdened by their role due to the severity of the sufferer symptoms. However, despite these limitations, the evidence indicates that carers of patients with an eating disorder experience high levels of burden and psychological distress.

The following section will examine the models that have been developed in relation to carer burden, as well as carer burden models developed to explain eating disorder carer burden and distress. The end of this section will present a mediation model, combining the variables identified in the carer models with the qualitative and quantitative eating disorder carer burden will be proposed. Only one current eating disorder model incorporates coping as a mediator, but it is yet to be empirically tested. Further, the role of informal social support is yet to be examined. Therefore, coping strategies and social support require investigation in the context of eating disorder carers.

Models of carer burden

Several models of carer burden have been proposed to explain carer burden and distress. A number of these models draw from stress-coping theories such as cognitive stress theory (Lazarus & Folkman, 1984), or the stress-process theory (Pearlin et al., 1990). Consequently, the emphasis in these models for eating disorders is placed on varied sources of stress, such as family conflict, community attitudes, patient symptoms and interpersonal problems (Dimitropoulos et al., 2008; Kyriacou et al., 2008a; Winn et al., 2007). The cognitive stress theory proposes that an individual’s appraisal of a stressor (such as caregiving), which includes their ability to cope with the carer role, available social support, and available resources, mediates the relationship between the stressor, or caregiving situation, and the associated outcome of carer burden (Lazarus & Folkman, 1984). Coping strategies are proposed to mediate the effects of a stressful situation due to a transaction between the person and the
environment; that is, the particular coping strategy utilised is not present before the stressful situation occurs (Lazarus, 1999).

Pearlin et al.’s (1990) stress-process theory proposes that there are primary stressors, which are objective indicators of the caregiving situation, such as symptom severity, treatment commitments, and problematic behaviours. These primary stressors then influence secondary stressors that are a consequence of the caregiving situation, such as family conflict, job-caregiving conflict and other family commitments. These stressors then lead to psychological strains, which in turn leads to the outcomes of depression, anxiety or physical health problems. These predictors and outcomes are influenced by background and context, including socioeconomic status, family context and availability of treatment or support. Lastly, these factors are impacted by the mediators of coping and social support. Consequently, people who employ effective coping strategies and have adequate social support will have better outcomes than those who have less social support and use ineffective coping strategies.

Other carer models take into account patient, caregiver and relationship characteristics specific to caring for someone with a mental illness (e.g., Schene et al., 1998; Winn et al., 2007). Patient characteristics refer such factors as symptom severity, age of the sufferer, duration of the illness and changes over time. Caregiver characteristics take into account such aspects as education level, socioeconomic status, age of the carer, and contact with the sufferer’s health professionals. Lastly, relationship characteristics refer to number of contact hours, whether the sufferer lives at home, level of expressed emotion and general interpersonal difficulties.

The following section will firstly provide a discussion of a selection of current mental illness carer burden models and, secondly a discussion of eating disorder carer models of carer burden and psychological distress will follow. The mental illness carer models were chosen due to being based on either Lazarus and Folkman’s (1984) cognitive stress theory or Pearlin et al.’s (1990) stress process theory. Further, the mental illness models chosen also incorporate social support and coping strategies. Lastly, the eating disorder carer models encompass all current models within the literature.
Mental illness carer burden models

Maurin and Boyd (1990) provide a model of mental illness carer burden based on early review of literature examining the carer situation. This model is presented in Figure 3.1. As shown, the antecedent variables define the situation of mental illness, and include patient’s symptoms and functional status, the diagnosis of the patient, where the patient resides and the type of treatment they are receiving. These factors then contribute to objective burden, which is then perceived as varying levels of subjective burden. Lastly, the mediators between objective and subjective burden include social support, coping strategies, socioeconomic status, family member relationships and other life events.

Figure 3.1. A model of the relationship between mental illness in a family member and the experience of burden (Maurin & Boyd, 1990)
A further example of a general model of carer burden and depression was developed by Pinquart and Sorensen (2005) which incorporates both Lazarus and Folkman’s (1984) theory and Pearlin et al.’s (1990) stress-process model, as seen in Figure 3.2. This general model of caregiving hypothesises that background demographics influence amount of care provided, caregiver burden, and caregiver psychological and physical health. Further, the status of the care receiver (objective needs/symptoms) directly predicts the amount of care provided, which in turn predicts carer burden, which then directly impacts upon the psychological and physical health of the carer. Lastly, personal and social resources, such as social support and coping, have a reciprocal relationship with all the components of the model.

![Diagram](image)

**Figure 3.2.** A model of predictors of psychological and physical health of caregivers (Pinquart & Sorensen, 2005).

Specific mental illness carer burden models also, such as those predicting burden in schizophrenia carers also draw upon the elements presented in the models proposed by Maurin and Boyd (1990) and Pinquart and Sorensen (2005). Three models that predict schizophrenia carer outcomes will be presented below.
Based on the stress-coping model (Lazarus & Folkman, 1984), Joyce et al. (2003) examined a model of caregiving in schizophrenia carers over time. They found that, at a nine month follow-up, carer morbidity and distress was strongly, inversely related to effective coping, a negative appraisal of caregiving was predicted by the baseline report, and support from confidants was related to ineffective and effective coping, general support and caregiving difficulties. The follow-up model is shown in Figure 3.3. Thus, the authors showed that carer burden is a result of an interaction between the appraisals of the caregiver, carer coping abilities and social support.

![Figure 3.3](image)

**Figure 3.3.** Model of carer negative appraisals and caregiving difficulty (Joyce et al., 2003).

*Note. Solid line represents a positive relationship; dashed line represents a negative relationship; Negative appraisal predicted by baseline level*

Schene and others (1998) explored the relationship between patient, caregiver and relationship characteristics within a sample of carers of patients with schizophrenia. They found that patient characteristics (measured as current symptom severity), caregiver characteristics (including the ability to cope and a sense of mastery over the situation), and relationship characteristics (hours of personal contact with sufferer) predicted the carers’ experience (the tasks and problems associated with the carer role), which in turn directly predicted the level of carer distress/burden, as depicted in Figure 3.4. Further, caregiving tasks and...
problems was the strongest contributor to carer distress, and exerted the most influence on the relationship between relationship characteristics and distress. Therefore, the carer experience acted as a mediator between patient, carer and relationship characteristics and carer distress. Overall, the model by Schene et al. (1998) explained 42% of the variance in the overall carer experience, and 24% of the variance in the distress score.

![Figure 3.4. Model examining predictors of the carer experience and carer distress (Schene et al., 1998).](image)

Recently a cognitive model of caregiving in psychosis has been developed (Kuipers et al., 2010). This model proposes that carer attributions and appraisals of an illness impact on coping strategies and social support, and symptoms of depression and self-esteem. Further, the level of expressed emotion within a family influences the initial carer appraisal of the illness. Therefore, the outcome of carer burden depends on the pre-existing relationship between carer and sufferer. For example, if the relationship before the onset of psychosis was positive, carer is more likely to appraise the situation as not the fault of the sufferer and that the sufferer will need support. This positive appraisal in turn results in a stressful carer reaction, but confidence that as a carer the right decisions will be made. Further, there will be low expressed emotion present within the carer-sufferer relationship. Conversely, if the pre-existing relationship is critical and hostile, the carer will assign blame to the sufferer and react in a
stressful, angry and avoidant manner. Lastly, carers are more likely to be critical of the sufferer’s behaviour and be pessimistic about recovery.

Therefore, the mental illness carer models discussed above demonstrate the importance of a caregiver’s appraisal of their situation. Further, they highlight the influence of expressed emotion, social support, coping strategies and patient symptom severity on the outcome of carer burden and distress. The following section will examine current eating disorder carer models.

*Eating disorder carer burden models*

Recently, Winn and colleagues (2007) applied the model developed by Schene et al. (1998) to caring for adolescents with BN. The patient characteristic examined within their study was eating disorder symptom severity. The carer characteristic examined was level of education. Lastly, weekly contact hours, level of expressed emotion, and interpersonal difficulties were chosen as relationship characteristics. They found that only two of these variables – expressed emotion and weekly contact hours – were predictive of a negative carer experience. In turn, a negative carer experience significantly predicted carer distress or psychological health. Overall, the model predicted 18% of the variance in carer distress. The lack of relationship between carer characteristics and patient characteristics with carer experience, as well as the low predicted variance was attributed to the small sample size ($n = 112$) and exploratory nature of the research. It could also be speculated that the chosen characteristics were not adequate predictors. That is, level of carer education may not impact upon the carer experience, however, number of other children they need to care for, or the hours per week they are employed, may have an effect.

Using the stress-process model (Pearlin et al., 1990), Dimitropoulos et al. (2008) examined a similar model to that tested by Winn and colleagues (2007). They used a sample of carers of patients with AN. Predictors within this model were: the primary stressor of burden; secondary stressors, including, family conflict, attitudes and actions towards both the carer and the person with AN, and the experience of stigma toward the individual with AN and the family; and
resources, including social support. The model’s outcome variables were general family functioning and psychological distress of the carer, as seen in Figure 3.5.

Dimitropoulos et al. (2008) found that burden, family conflict, attitudes and actions, stigma and social support all significantly predicted family functioning, with burden and social support the strongest individual predictors. The model explained 38% of the variance in family functioning. Burden and family conflict were the only variables tested in the prediction of psychological distress, neither of these variables were significant predictors. This finding conflicts with that of Winn et al. (2007) who found that a negative carer experience (such as conflict) predicts carer distress. It could be speculated that the lack of a significant prediction to psychological distress within the study by Dimitropoulos et al. (2008) could be due to the choice of measure (Burden Assessment Scale) for carer burden not capturing the specific experience of eating disorder carers. Further, burden may not be a predictor of psychological distress; rather it may be an independent outcome of the caregiving situation.

Figure 3.5. Model of AN carer distress and family functioning (Dimitropoulos et al., 2008).
Similarly, using Pearlin et al.’s (1990) model of caregiving Kyriacou et al. (2008b) created a model of AN carer distress that incorporated sufferer symptoms, negative/difficult behaviours, and rejection of carer help, carer self-related/role strains and interpersonal strains, and carer gender (see Figure 3.6). The associations between these variables were tested using a series of multiple regressions. They found that AN symptoms predicted self-related carer strains, and negative/difficult behaviours and rejection of carer help predicted interpersonal strains. Lastly, self-related strains, interpersonal strains and carer gender significantly predicted carer distress. Therefore, carers who are female and/or have a number of self-related and interpersonal problems (such as difficult behaviours or rejections of help) have a higher level of psychological distress.

![Model of AN carer distress](image)

*Figure 3.6. Model of AN carer distress (Kyriacou et al., 2008b).*

Lastly, a model of eating disorder carer burden has been developed using qualitative data from families affected by eating disorders (Treasure, Whitaker, et al., 2005). As seen in Figure 3.7, this model proposes that the symptoms of the eating disorder are continuously impacting upon family relationships and family environment. These impacts from relationships and environment are exacerbated by the possible refusal, on the part of the individual with the eating disorder, to accept the impact the eating disorder is having. Further, carers may experience a number of different roles (e.g., employment, looking after their other children) which places extra demands on their resources. The way that the carer interacts
with the sufferer, whether the carer is overprotective, overly directive, ‘cut off’ from the sufferer, or displays too much emotion, is also taken into account. Lastly, the model proposes that carers have to cope with a high level of unmet needs and stigma surrounding the illness. These variables are then proposed to impact directly upon carers’ coping ability, which, in turn, predicts carer psychological distress. Thus, the coping strategies that the carer utilises mediate the relationship between the carer situation and carer burden. While this model is yet to be empirically tested, it is based upon existing eating disorder carer research and direct clinical findings from carers.

In summary, the existing models of eating disorder carer burden and psychological distress have a number of common elements. These include relationship components, such as interpersonal difficulties, expressed emotion, and contact hours; family components, such as conflict within the family unit and caring roles in relation to other siblings; patient components, including symptoms and resistance to treatment; and carer components, such as resources, coping, and needs. These elements are also common to other models of care giver burden for
mental illness carers (e.g., Joyce et al., 2003). The main difference between the current models relates to the outcome utilised, whether it be burden or psychological distress, and how this is conceptualised. As such, continuity between models in regards to the outcome measured is not achieved. Further, the measure of carer burden often changes between studies making direct comparisons difficult. Nonetheless, these models are important for the understanding of the eating disorder carer experience.

Based upon the work of Lazarus and Folkman (1984) and above reviewed models of carer burden (Dimitropoulos et al., 2008; Schene et al., 1998; Treasure, Whitaker, et al., 2005; Winn et al., 2007) a mediation model of carer burden is proposed (see Figure 3.8). This model of eating disorder carer burden has a number of predictor variables, including carer needs, patient characteristics, and interpersonal dynamics, which encompasses expressed emotion. The impact of these variables on carer burden and carer psychological distress are proposed to be mediated by coping strategies employed by the carer and the social support of carers. Social support and coping strategies have been found to mediate the relationship between a caregiving situation and a stressful outcome (Maurin & Boyd, 1990). This model improves upon previous models of eating disorder carer burden in that it acknowledges the mediating role of both coping skills and social support as outlined by Lazarus and Folkman (1984) and also encompasses a number of established predictors of carer burden and psychological distress.

Figure 3.8. A proposed mediation model of eating disorder carer burden.
The remainder of the chapter will focus on a detailed discussion of each of the components presented in the mediation model of eating disorder carer burden. As such, interpersonal dynamics of the carer with the sufferer and other family members will be discussed, followed by a discussion of expressed emotion. The needs of eating disorder carers will then be discussed. The mediating variables of coping skills and social support will also be examined. This chapter will conclude that a longitudinal investigation of eating disorder carer burden is needed.

Interpersonal difficulties

With parents often being the primary caregivers of patients who have an eating disorder (Honey & Halse, 2005), family relationships and interpersonal dynamics within the family unit may be negatively impacted by the eating disorder and the carer role. Qualitative research has been conducted examining the interpersonal difficulties experienced by carers and family unit. This qualitative research indicates that family conflict may arise as carers become frustrated, angry or even avoid the sufferer due to the eating disorder symptoms. Such conflict has been found to lead to problematic family interactions and a division between the carer and the person they are caring for (Hillege et al., 2006; Monteleone et al., 2005). Further, carers report that they may even become resentful toward the sufferer due to these inherent difficulties surrounding the illness (Gilbert et al., 2000). Particularly, patients with AN may become highly dependent on their carer/s, with the person dominating the carers’ time and making numerous demands regarding issues such as, what is to be eaten, what time meals are, or scheduling of exercise (Monteleone et al., 2005; Whitney et al., 2005). Carers often report giving into these demands in order to maintain the peace and a relationship with the sufferer (Honey & Halse, 2005).

The presence of a high level of conflict and dysfunction within the family environment often includes ineffective attempts on the carers’ part to logically argue with the sufferer (Monteleone et al., 2005). However, this strategy is often ineffective due to such characteristics as the inherent denial of the illness and egosyntonic nature of the symptoms, secretiveness or a need for
constant reassurance (Perkins et al., 2004; Vandereycken, 2006b). Thus, it may be speculated that such denial of the illness by the sufferer, and consequential conflict between carer and sufferer that may follow results in a higher degree of carer burden. Further, qualitative research examining the impact of AN on siblings shows that carers themselves may also deny, or minimise the extent of the illness (Dimitropoulos et al., 2009). Dimitropoulos et al. (2009) report that healthy siblings often state that their parents, as carers, ignore or minimise the symptoms of the eating disorder in the affected person. Such denial by the carer may be a means of coping with the illness, by possibly decreasing the emotional tension of the situation.

Parents are not the only family members that may be affected by the eating disorder. Again, qualitative research has been utilised to show that the relationship between siblings and those with eating disorders can also become strained. At times, siblings report becoming hypersensitive and uncertain as to how to act around the sufferer (Highet, Thompson, & King, 2005). However, siblings may also de-identify and withdraw from their sister or brother, becoming resentful or angry with the situation (Gilbert et al., 2000; Highet, Thompson, & King, 2005; Honey et al., 2006; Monteleone et al., 2005; Nielson & Bara-Carril, 2003). Conversely, siblings may respond to the situation and sufferer in a positive manner, becoming supportive and protective (Gilbert et al., 2000) and demonstrating a desire to help and support the sufferer in any way that they can (Honey et al., 2006). This desire to help can result in siblings taking on the role of mediator between their affected sibling and other members of the family (Dimitropoulos et al., 2009).

Lastly, qualitative research indicates that siblings may also be negatively impacted by the actions of their parents, who have a dual role of primary carer of the person with the eating disorder and parent. Healthy siblings may feel neglected by their parent and left out due to a disproportionate level parental attention given to the sufferer due to the illness (Treasure et al., 2001). However, other parents of a child with an eating disorder may make a conscious effort to look after the well sibling/s to maintain sense of normality and emotional support (Honey & Halse, 2006b).

Partners of patients with an eating disorder also report relationship difficulties. Partners often state feeling emotionally distant with an avoidance of
contact and intimacy (Hight, Thompson, & King, 2005). There is also a sense of insecurity within the relationship, frustration and a feeling of helplessness, with secrecy and deception placing strains on the relationship (Huke & Slade, 2006).

Lastly, social relationships outside of the immediate family environment may also be detrimentally affected by the eating disorder. There may be reduced social interaction, with particular avoidance of social activities involving food, in order to reduce the anxiety of the sufferer (Hight, Thompson, & King, 2005; Nielson & Bara-Carril, 2003). Further, others may exclude them from social situations due to the illness (Hildege et al., 2006). As such, carers often feel socially isolated from family and friends. The social isolation may also be due to a conscious choice on the part of the carer as they may feel they lack understanding from friends, or do not have the energy to maintain social relationships (Hildege et al., 2006).

Therefore, all family members are affected by the presence of an eating disorder. Additionally, extended social relationships outside of the family unit are also impacted by the disorder. One factors related to these interpersonal difficulties may be the presence high expressed emotion within the family.

Expressed emotion

Definition

Expressed emotion is a measure of family interaction, and consists of the attitudes and behaviours that a family member communicates toward the ill member of the family (Hodes & Le Grange, 1993; Rein et al., 2006). 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 (Vaughn & Leff, 1976). Critical comments refer to the frequency with which derogatory remarks are directed to the sufferer. Hostility is generalised criticism or rejection of an individual, or a combination of both. Emotional overinvolvement is a global level of high levels of emotional investment in the situation and patient or sufferer. Similarly, warmth refers to a global level of acceptance of the sufferer. Lastly, positive remarks refer to the
frequency with which praise, appreciation and approval are communicated to the person with the illness.

Utility of expressed emotion in mental illness research

The construct of expressed emotion has been widely studied within the context of mental illness. For instance, since the 1970s a large number of predictive studies have been conducted which confirm the link between high expressed emotion and relapse in patients with schizophrenia (Hashemi & Cochrane, 1999), with the risk of relapse twice as high when patients return to homes which have high levels of expressed emotion (Butzlaff & Hooley, 1998). Further, the effect of expressed emotion occurs over a range of locations, cultures and in both genders, with medication and family atmosphere having independent effects to that of expressed emotion (Bebbington & Kuipers, 2007). Lastly, relatives of patients with schizophrenia who were high on expressed emotion have higher scores on measures of burden as compared to low expressed emotion relatives (Scazufca & Kuipers, 1996).

Similarly, patients with depression who rate their relatives as more critical towards them have a higher rates of relapse than those with less critical relatives (Hooley & Teasdale, 1989). Additionally, rates of critical comments are significantly higher for youth with depression (Rosenbaum-Asarnow, Tompson, Woo, & Cantwell, 2001). Therefore, high expressed emotion may be a risk factor for the development of depression in adolescents. Further, patients with bipolar disorder who have caregivers high on expressed emotion experience more severe depression symptoms, but not mania (Kim & Miklowitz, 2004). Therefore, expressed emotion affects both sufferer and carer in a negative way.

Expressed emotion in eating disorder carer research

Research examining expressed emotion in carers of patients with an eating disorder has existed for around 25 years (e.g., Szmukler, Berkowitz, Eisler, Leff, & Dare, 1987; Szmukler, Eisler, Russell, & Dare, 1985). Recent research has identified that there are often communication problems or conflict between carers and patients with an eating disorder (Graap, Bleich, Herbst, Trostmann, et al., 2008), with literature specifically examining expressed emotion typically
focussing on the level of critical comments and emotional overinvolvement (Zabala et al., 2009). A recent review by Zabala et al. (2009), which reviewed 20 studies that examined expressed emotion and psychological distress in eating disorder carers, demonstrated that the level of expressed emotion within eating disorder families is high, particularly for those caring for older patients, or those with a longer length of illness. Further, eating disorder carers tend to display levels of expressed emotion at a similar level to carers of patients with depression. The following section will cover a selection of studies that have examined expressed emotion within eating disorder carers.

An early 1993 review examining expressed emotion found that the level of critical comments directed towards patients with an eating disorder to be relatively low (Hodes & Le Grange, 1993). However, they found that there is a higher level of critical comments are directed to patients with BN than directed toward patients with AN (Hodes & Le Grange, 1993). The authors speculated this could be explained by the antisocial nature of BN, the increased likelihood of alcohol abuse in those with BN, and that AN is typically rigid and predictable with obvious signs of frailty (Hodes & Le Grange, 1993). Thus, there is more likely to be a negative reaction to those with BN due to a higher prevalence of salient, difficult behaviours.

Blair, Freeman and Cull (1995) investigated the expressed emotion among carers of those with AN or cystic fibrosis (CF), as compared with control families, in order to determine the interpersonal dynamics of caring for someone with a chronic, life-threatening illness. They found that 42% and 34% of AN and CF households were living with high levels of expressed emotion, respectively. Specifically, mothers of those with AN or CF demonstrated higher emotional overinvolvement than the mothers in well control families. The authors speculated that this overinvolvement may be due to a natural reaction to on the part of the mother to their child experiencing a grave illness. Further, emotional overinvolvement was also found to be connected with the level of symptom severity, with higher scores of AN symptomatology associated with high emotional overinvolvement. Lastly, Blair and colleagues (1995) found no relationship between symptom severity and the frequency of critical comments, with a low overall level of critical comments within the AN and CF families and comparable to that seen within the well families. As such, the finding a low
overall level of critical comments is consistent with Hodes and Le Grange (1993) but inconsistent with more recent research (Zabala et al., 2009). This change in the level of critical comments may be due to the differences in the measures used to assess expressed emotion.

Winn et al. (2007), as part of a wider study, investigated expressed emotion within carers of patients with BN by surveying 112 carers and 60 adolescent patients. Parents reported relatively low levels of expressed emotion, while patients reported slightly higher levels. Furthermore, patient, as opposed to parent, report of expressed emotion predicted a negative caregiver experience. Winn et al. (2007) speculated that this may have been due to parents using a self-preserving bias, therefore rating their responses in a more socially desirable manner. As such, carer self-report measures may not adequately capture the extent of expressed emotion within a family unit, and the perspectives of the sufferer are also important.

More recently, Kyriacou, Treasure and Schmidt (2008) compared the level of expressed emotion within 151 parents of those with AN (carers group) and 93 parents of healthy control parents. They found that those in the carers group reported higher levels of both emotional overinvolvement and critical comments than those within the control group. Emotional overinvolvement was evident within 60% of the carer group as opposed to three percent in the control group. Further, consistent with Blair et al. (1995), mothers were more likely to demonstrate high levels of emotional overinvolvement than fathers. Similarly, 47% of the AN carers reported high levels of critical comments compared to 15% of those in the control group, a finding contrary to that of Blair and others (1995), Hodes and Le Grange (1993) and Winn et al. (2007), but in accordance with the review by Zabala et al. (2009). Again, these differences may be attributable to differences in sample size and measures utilised. Kyriacou and colleagues (2008) utilised a self-report measure of expressed emotion that was designed to reduce the impact of social desirability. As such, the low level of carer-reported expressed emotion in the study by Winn et al. (2007) could be attributable to the self-report measure they utilised.

Overall, while contradictions exist, the literature suggests that those carers of patients with an eating disorder may experience a high level of expressed emotion within the family, specifically emotional overinvolvement. Further, this
expressed emotion has been shown to be related to a poor outcome for sufferers (Butzlaff & Hooley, 1998); those undertaking family based therapy demonstrate poorer outcomes when there is high expressed emotion (Eisler et al., 2000). In addition, high levels of negative expressed emotion is linked to higher levels of carer ill health and burden (Winn et al., 2007). Therefore, the presence of negative expressed emotion within a family will have a significant impact on both the carer and the sufferer.

The needs of those caring for patients with an eating disorder

Currently, little research has been conducted on the needs of eating disorder carers, though preliminary indications from qualitative research show that there are a high level of unmet needs in terms of both physical and mental health and well-being (Haigh & Treasure, 2003; Winn et al., 2004). Further, the problem areas identified by eating disorder carers have been found to be similar to that of schizophrenia carers (Graap, Bleich, Herbst, Scherzinger, et al., 2008). Additionally, eating disorder and schizophrenia carers report that these needs often go unmet.

The current qualitative literature has identified a number of unmet needs in the eating disorder carer population. Firstly, carers identify a need for more information regarding eating disorders (Graap, Bleich, Herbst, Trostmann, et al., 2008; Haigh & Treasure, 2003; Winn et al., 2004) and that insufficient information is given to carers about eating disorders by health professionals (Haigh & Treasure, 2003; Winn et al., 2004). Specifically, more information about the nature of the disorder, reasons behind its development, and details regarding the differing treatment options available is desired (Winn et al., 2004). Further, carers report a lack of information regarding relapse prevention (Graap, Bleich, Herbst, Trostmann, et al., 2008). This information is best given early in the illness progression and on an individual basis in order to adequately prepare carers for their role (Graap, Bleich, Herbst, Trostmann, et al., 2008; Winn et al., 2004). Early provision of information can prevent the disappointment felt by carers due to the chronic nature of eating disorders, leading to concerns for the sufferers’ future (Graap, Bleich, Herbst, Trostmann, et al., 2008).
Secondly, carers express a dominant need for practical advice on the development of coping strategies to help cope with the illness, both in the current situation and in terms of prognosis and future plans (Haigh & Treasure, 2003; Winn et al., 2004). Further, this advice can provide reassurance to the carers that they are taking the best course of action regarding their role (Winn et al., 2004). However, while this need is identified little information and help is reported to be given in this regard (Haigh & Treasure, 2003).

Thirdly, carers report a need for both professional and informal support (Graap, Bleich, Herbst, Trostmann, et al., 2008; Haigh & Treasure, 2003; Winn et al., 2004). Carers wanted more availability and access to individual counselling and support as well as family counselling sessions (Graap, Bleich, Herbst, Trostmann, et al., 2008). However, carers are often disappointed with the support they receive from the health professionals with whom they have contact (Haigh & Treasure, 2003). Therefore, carers identify that it would be beneficial to meet other carers and share their own experiences and stories with them in a support group setting (Haigh & Treasure, 2003; Winn et al., 2004). The support group environment would enable carers to feel understood, as the carers could share information and experiences with others who had lived through a similar situation (Haigh & Treasure, 2003; Highet, Thompson, & King, 2005; Winn et al., 2004). Further, carers expressed a desire to meet patients who had recovered from an eating disorder; however, this did not often occur (Haigh & Treasure, 2003).

Lastly, in regards to treatment, carers believed that treatment for the sufferer had not begun early enough and that they, as carers, were not sufficiently informed as to the treatment process with an insufficient follow-up process after treatment cessation (Haigh & Treasure, 2003).

One quantitative study has examined the role of carer needs in predicting negative appraisals of caregiving (Whitney et al., 2007). Whitney et al. (2007) found that carers who received less information about eating disorders and treatment services available to them, in addition to receiving less support from health professionals/organisations, reported a more negative experience of caregiving. They concluded that carers, therefore, require both informal and professional social and comprehensive information about eating disorders and treatment.
Therefore, the current research findings indicate that carers of those with eating disorders consistently identify a high level of needs, which are often not met (Graap, Bleich, Herbst, Trostmann, et al., 2008; Haigh & Treasure, 2003; Winn et al., 2004). Carers’ dominant need is for practical advice, such as how to manage the sufferer and the illness and how to cope, and to receive more information from health professionals regarding the illness (Graap, Bleich, Herbst, Trostmann, et al., 2008; Haigh & Treasure, 2003; Poser, 2005; Winn et al., 2004).

While carers identify quite a large number of unmet needs and a high level the people they are caring for may not understand that their carers have these needs. Cleary et al. (2006) examined the convergence between patient and carer perceptions of need three diagnostic groups: schizophrenia, affective disorders, and a mix of other diagnoses. However, a limitation to their study was that a diagnosis of an eating disorder was an exclusion criterion, thus specific information on the convergence of patient and carer perspectives for an eating disorder is unknown. Nonetheless, Cleary et al. (2006) found that the level of agreement between patient and carer perceptions of need was low. As such, it may be speculated that a similar pattern of discrepancy between eating carers and patients may exist.

Therefore, eating disorder carers have a need for more information, practical advice and support. However, these needs are often not met. Further, carers who have unmet needs report a more negative caregiving experience. Lastly, while carers report these needs, it may be speculated that the patients with the eating disorder do not necessarily perceive that their carer requires help.

_Coping mechanisms commonly utilised by carers_

Caring for someone with and eating disorder is a protracted and intense process that can impact upon the coping resources of the carer (Highet, Thompson, & King, 2005; Treasure, Whitaker, et al., 2005). Due to the emotional pressures that are experienced throughout the caregiving process (Hillege et al., 2006) carers may feel as though they are unable to cope with the prospect of long-term caregiving (Perkins et al., 2004). However, qualitative
research indicates that eating disorder carers utilise numerous coping mechanisms. The following section will provide a definition of coping, an outline of research examining coping strategies used by carers generally, and lastly a discussion of the research examining eating disorder carer coping.

**Definition**

Coping processes are cognitive and behavioural efforts utilised to manage specific external (environmental) and internal (individual) demands appraised as stressful for an individual (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984). As such, coping is a complex, multidimensional process influenced by both environmental demands and resources, and individual personality dispositions that affect appraisal of a situation (Folkman & Moskowitz, 2004). Further, coping has been shown to mediate the relationship between a stressful situation and the outcome (Lazarus, 1999; Lazarus & Folkman, 1984; Livneh & Martz, 2007), and specifically it is proposed to mediate the relationship between a caring situation and carer burden (e.g., Maurin & Boyd, 1990).

One categorisation of coping strategies commonly utilised is that of emotion-focused coping and problem-focused coping (Lazarus & Folkman, 1984). Emotion-focused coping is more likely to be used when a situation is deemed to be out of one’s own sense of personal control (Lazarus, 1999). This form of coping encompasses managing or regulating the emotions accompanying the stressful situation, thereby changing the way in which the situation is appraised without actually changing the situation itself (Lazarus, 2000; Parker & Endler, 1996). Conversely, problem-focused coping is more likely to occur when a situation is deemed to be within one’s own sense of personal control (Lazarus, 1999). Therefore, problem-focused coping may lead to changing environmental barriers or situational pressures, learning new skills, making cognitive changes, or developing new standards and values (Lazarus, 2000; Lazarus & Folkman, 1984; Parker & Endler, 1996). As such, carers are able to alter their current situation or manage their emotional response to the current situation of caregiving (Lazarus & Folkman, 1984). Recently, a third form of coping; meaning-focused coping; has been identified whereby people utilise
cognitive strategies to manage the meaning of the situation (Folkman & Moskowitz, 2004).

Coping with caring for someone with an organic or mental illness

In relation to coping with caring for an individual with an organic illness, Haley et al. (1996) found that high use of avoidance coping; generally a regarded as a maladaptive form of coping; and low use of approach coping (a tendency to cope by seeking information and closely monitoring the situation), was related to increased depression and lower life satisfaction among carers of patients with Alzheimer’s disease. Further, carers of patients with multiple sclerosis who use emotion-focussed coping show poorer adjustment, including higher levels of distress, depression and general impact of caregiving, than those who use problem focussed coping (Pakenham, 2001). Further, reliance on wishful thinking as a coping strategy is related to greater distress, acceptance of the situation is related to perceiving benefits from the carer role, and use of problem solving as a coping strategy is associated with higher levels of positive affect among young carers (Pakenham, Chui, Bursnall, & Cannon, 2007).

For carers of patients with a mental illness, it has been shown that carers of patients with schizophrenia who use effective coping strategies have lower levels of distress, while use of ineffective coping strategies increases distress (Joyce et al., 2003). Similarly, Fortune et al. (2005) found that, in schizophrenia carers, the coping strategies of self-blame, positive reappraisal and acceptance mediated the relationship between carer distress and their perceptions of the illness. Lastly, avoidance coping has been shown to be unhelpful for carers of patients with psychosis resulting in higher levels of expressed emotion (Raune, Kuipers & Bebbington, 2004).

Coping with caring for someone with an eating disorder

Existing research examining the coping strategies used by eating disorder carers has been qualitative in nature. Whitney and colleagues (2005) found that while mothers have a tendency to become more emotionally involved, therefore using more emotion-based coping strategies, fathers typically utilise a more
cognitive approach by distancing themselves from the issue (Whitney et al., 2005). While fathers use cognitive strategies to distance themselves from the situation, it could be argued that such a strategy is also emotion-focussed in that they seek to change their emotional reaction to the situation.

Specific emotion-focussed coping strategies that have been identified within BN carers include humour, positive thinking, acceptance of the eating disorder (Perkins et al., 2004). Additionally, parents of those with AN have been found to use emotion-focussed coping strategies such as hope, optimism regarding the outcome of their child’s illness, wishful thinking to reduce hopelessness and cynicism, or cognitive restructuring whereby the parents conceptualised their child’s illness as separate from their child (Whitney et al., 2005). Other forms of coping that appear to be more problem-focused have been identified within a sample of BN carers, including maintenance of their own interests outside of the caregiver role and active enquiry into the illness (Perkins et al., 2004). However, some AN carers report more maladaptive coping responses that 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 (Whitney et al., 2005).

Overall, there is limited research examining the coping strategies used by carers. Further, there is no current quantitative research that investigates coping strategies used by eating disorder carers, despite Treasure et al. (2005) acknowledging that it has an impact on the outcome of carer burden. As such, there is a need to quantitatively examine coping strategies, and determine whether they mediate burden and psychological distress in carer of patients with an eating disorder.

Social support for carers

Definition

Social support is broad concept that lacks a specific definition (Uchino, 2004). However, social support has generally been defined to include both the structure of the social ties and function of current relationships (Uchino, 2004). Social support has also been found to generally contribute to more adaptive
coping strategies within individuals, such as problem-focussed coping (Schreurs & de Ridder, 1997). Similarly, the lack of available social support has been shown to be associated with coping strategies that are less adaptive in the long run, such as avoidant coping (Schreurs & de Ridder, 1997). Additionally, social support can be seen as a resource for coping (Lazarus & Folkman, 1984), whereby an individual seeks social support as a means to cope with a stressful situation (Folkman & Moskowitz, 2004). In this case, the ability to cope is linked to the availability and satisfaction with one’s level of social support. Lastly, social support can be conceptualised as, a) a coping resource which precedes the coping process, b) a coping strategy that forms part of the coping process, c) dependent on coping in that it is a consequence of the way in which an individual is coping, or d) coping efforts of a social system such as “family coping” (Schreurs & de Ridder, 1997).

There are a number of different forms of social support that have been identified within the literature, these include: emotional support, instrumental, or tangible, support and informational support (Lazarus & Folkman, 1984; Pierce, Sarason, Sarason, Joseph, & Henderson, 1996). 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 (Lazarus & Folkman, 1984; Pierce et al., 1996). Instrumental, or tangible, 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 (Lazarus & Folkman, 1984; Pierce et al., 1996). Lastly, informational support occurs when provision of information, advice or feedback about how a person is doing is given (Lazarus & Folkman, 1984).

In terms of perceptions of social support, individuals tend to have a stable schematic representation of expected social support across both time and situation (Pierce et al., 1996). Therefore, in a situation such as the caregiver role each individual carer will seek out and utilise social support in an idiosyncratic manner.
Social support and caring for someone with an organic or mental illness

Social support has been shown to lessen or eliminate the harmful effects of a stressful situation by making the situation seem less consequential, or by providing resources for coping during the stressful time (Lazarus & Folkman, 1984). As such, social support has been theorised to moderate the effects of a stressful situation by acting as a buffer to ill health (Lazarus & Folkman, 1984). However, social support can also act as a mediator. The effects of caregiving have been found to be mediated by social support (Maurin & Boyd, 1990), with higher levels of social support related to higher life satisfaction and lower depression in carers of patients with Alzheimer’s disease (Haley et al., 1996).

Further, carers’ satisfaction with social support, rather than simply size of a social network, has been found to be a stronger predictor of distress, positive affect and satisfaction with life (Olshevski, Katz, & Knight, 1999; Pakenham et al., 2007). Specifically, greater satisfaction with social support is related to higher life satisfaction and positive affect, and lower global distress.

A review of the 2002 literature by Ohaeri (2003) indicated that informal social support consistently predicts carer burden and state of health in carers of patients with mental illness (not including eating disorders). In regards to caring for someone with schizophrenia, carers who lack social support utilise more ineffective coping strategies, which then results in greater caregiving difficulty and negative appraisals of caregiving (Joyce et al., 2003). Further, informal support from family members and support groups has been found to significantly predict caregiver gains, that is, the positive aspects of caregiving, in schizophrenia carers (Chen & Greenberg, 2004).

Social support and caring for someone with an eating disorder

Limited qualitative research shows that support and understanding from others is seen as essential for carers of patients with eating disorders. 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 (Cottee-Lane et
al., 2004). 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 (Winn et al., 2004). Therefore, carer support groups are often seen as more helpful in the process of caregiving, as there is a level of understanding that cannot be given by someone who has not lived through the same experience (Haigh & Treasure, 2003; Highet, Thompson, & King, 2005; Winn et al., 2004).

Currently, one quantitative study has examined social support in the context of caring for an individual with an eating disorder (Dimitropoulos et al., 2008). Dimitropoulos et al. (2008) examined both informal and professional social support. Interestingly, they found that both informal and professional support did not correlate with carer burden or psychological distress. The lack of relationship between these variables could be due to Dimitropoulos et al. (2008) using an overall measure of support, rather than examining social network, that is, the number of people available for social support (Lazarus & Folkman, 1984), and perceived social support, that is, the quality of the social support (Lazarus & Folkman, 1984) separately. Prior 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., Pakenham et al., 2007). Further, Dimitropoulos and colleagues (2008) did not examine the mediating role of social support in caring situations. As such, there is a need to examine the separate aspects of social support (social network and perceived support) and to investigate the mediating role of social support for eating disorder carers.

Summary

In summary, a number of factors have been found to impact upon carer burden and psychological distress in those who care for patients with an eating disorder. These include expressed emotion, coping strategies, interpersonal difficulties, appraisals of caregiving, social support and carer needs. Carers of patients with an eating disorder often have high levels of expressed emotion, particularly critical comments and emotional overinvolvement. Further, qualitative research indicates that eating disorder carers utilise both adaptive (problem-focused and emotion-focused coping) and maladaptive, unhelpful, coping strategies and have limited social support. Lastly, eating disorder carers
have a high level of unmet needs, which can lead to a more negative caregiving experience.

General models of carer burden and distress often draw upon Lazarus and Folkman’s (1984) stress coping model, which proposes that the way in which a person copes (including use of social support) with a situation mediates between the relationship stressful situation and the outcome. However, no current model of eating disorder carer burden and psychological distress incorporates both coping strategies and social support as mediators. Therefore, a quantitative examination of these factors as potential mediators is needed.

**Limitations of previous studies**

While all the previously discussed findings are important and provide valuable insight into the experience of carer burden for those who care for patients with an eating disorder, there are some limitations that need addressed. Currently, all the evidence for carer burden has come from cross-sectional studies (e.g., Dimitropoulos et al., 2008; Graap, Bleich, Herbst, Trostmann, et al., 2008; Highet, Thompson, & King, 2005; Whitney et al., 2005) which places limits on conclusions regarding the variables that predict the level of carer burden experienced over the long-term. Dimitropoulos et al. (2008) 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.

Secondly, the measures utilised within these studies have primarily been developed to assess carer burden for those who care for patients with schizophrenia, such as the Experience of Caregiving Inventory (Szmukler et al., 1996) or the Level of Expressed Emotion questionnaire (Cole & Kazarian, 1988). As such, research utilising more targeted measures such as the Eating Disorders Symptom Impact Scale (Sepulveda, Whitney, et al., 2008) and the Carers’ Needs Assessment Measure (Haigh & Treasure, 2003) is needed. Thirdly, many of the current studies use samples derived from inpatient settings (e.g., Dimitropoulos et al., 2008; Graap, Bleich, Herbst, Trostmann, et al., 2008) or volunteer databases, therefore the generalisation of these findings to the wider community may be limited. Fourthly, there has been no quantitative examination of the possible
mediators of coping strategies and social support, despite Lazarus and Folkman’s (1984) and Pearlin et al.’s (1990) theories stating that these variables act as mediators. Lastly, although it has been established that eating disorder carers experience a high degree of burden and psychological distress, it is unknown whether the sufferers perceive themselves to be a burden.

Therefore, undertaking longitudinal research, utilising eating disorder carer specific questionnaires, would allow for the examination of the dynamic nature of the caring role. Further, a longitudinal investigation would provide scope for analysis of the predictor variables, specifically, expressed emotion, social support, coping strategies, and the needs of carers, of carer burden and psychological distress. In addition, an examination of coping strategies and social support as mediators of carer burden and psychological distress is needed. Lastly, an investigation of sufferer perceptions of carer burden, and how this compares to carer self-report, is required. These investigations would allow for the development of appropriate interventions and support services for carer which can reduce the level of burden and distress experienced.
CHAPTER FOUR

STUDY 1: LONGITUDINAL EXAMINATION OF EATING DISORDER CARER BURDEN – RATIONALE AND METHOD

Rationale

As discussed in the previous chapter, eating disorder carers experience a high level of carer burden (Zabala et al., 2009) and a moderate to high level of psychological distress (e.g., Sepulveda, Lopez, Todd, et al., 2008; Winn et al., 2007). It was argued that understanding the factors that influence this burden and psychological distress will enable development of appropriate interventions and support services for carers which can reduce this burden and distress.

A number of models have been proposed to explain the experience of caregiving within eating disorder carers (e.g., Dimitropoulos et al., 2008; Treasure, Whitaker, et al., 2005). While these models explain a moderate degree of carer burden or psychological distress, they may not include all relevant variables. For example, these models typically do not consider the role of coping strategies and social support. However, there is a significant amount of both theoretical and empirical support to suggest that these may be potentially important mediating variables. For example, Lazarus and Folkman (1984) proposed the transactional theory of stress, which argues there is a person-environment bidirectional influence; and that the way people appraise a stressful situation, in conjunction with their available coping resources, impacts upon the outcome of burden or distress. Accordingly, the way in which a person copes with a stressful situation, such as the caregiver role, is influenced by the coping skills adopted. Lazarus and Folkman’s theory is not the only theory to recognise the importance of coping skills (and social support); Pearlin et al.’s (1990) stress-process theory also argues that coping skills and social support are important mediators of burden and psychological distress. There is strong empirical support for these two theories of stress and coping, with many carer burden and distress models using either Lazarus and Folkman’s (1984) or Pearlin et al.’s (1990) theory as a basis (e.g., Joyce et al., 2003; Kyriacou et al., 2008b; Pinquart & Sorensen, 2005).
Specific forms of coping skills that have been identified are problem-focused coping, emotion-focused coping, and social coping. Problem-focused coping occurs when people attempt to change the situation itself, for example, by seeking treatment or information (Lazarus, 1999). Conversely, emotion-focused coping strategies encompass managing the emotional reaction to a situation, such as being more hopeful (Lazarus, 1999; Parker & Endler, 1996). Lastly, social coping is when social support is sought and utilised as a means to cope with a situation (Lazarus & Folkman, 1984). These three forms of coping can be adaptive or maladaptive. For instance, use of emotion-focused strategies such as self-blame, or blaming the person with an eating disorder, are maladaptive forms of coping. In contrast problem-focused strategies, such as maintenance of one’s own interests outside of the caring role, can be classified as an adaptive form of coping. While there has yet to be an examination of impact of coping strategies on the outcome of carer burden or psychological distress within eating disorder carers, research with schizophrenia carers indicates that use of adaptive coping strategies lowers distress, while use of maladaptive coping strategies increases psychological distress (Joyce et al., 2003).

In regards to social support, there are a number of different forms that have been identified within the literature. These include emotional support, such as being a confidant or providing reassurance, instrumental support, such as doing a job or a chore, and informational support, such as providing practical advice and feedback (Lazarus & Folkman, 1984; Pierce et al., 1996). Further, social support can be broken down into two components: size of the social network, or quantity of people, and the level of satisfaction with the social support received. Research indicates that is the level of satisfaction with social support that is the stronger predictor of distress, positive affect and satisfaction with life (Olshevski et al., 1999; Pakenham et al., 2007).

Evidence for social support and coping skills as mediators of burden and distress can be found within mental illness carer literature. For example, the use of social support has been shown to lessen the extent of burden experienced by carers of patients with a mental illness (Ohaeri, 2003). Further, schizophrenia carers who lack social support have been shown to utilise more ineffective coping strategies (Joyce et al., 2003). As such, the inclusion of coping strategies and social support within an eating disorder caregiver model is warranted.
On the basis on this, a mediation model of eating disorder carer burden and psychological distress is proposed. This mediation model takes into account established factors that influence eating disorder carer burden, such as expressed emotion, needs, and patient characteristics, as well as incorporating Lazarus and Folkman’s (1984) transactional theory and Pearlin et al.’s (1990) stress-process theory. This mediation model proposes that the impact of carer expressed emotion, carer needs and patient characteristics on the outcomes of eating disorder carer burden and psychological distress is mediated by carer coping strategies and social support.

However, while it is argued that previous research on eating disorder carer burden has not considered all relevant variables, there are other inherent limitations that also need to be addressed in future research. Four key limitations can be identified. Firstly, all existing carer burden research has been cross-sectional (e.g., Dimitropoulos et al., 2008; Graap, Bleich, Herbst, Trostmann, et al., 2008; Highet, Thompson, & King, 2005; Whitney et al., 2005) which limits any conclusions regarding long-term predictors of the level of carer burden. Dimitropoulos et al. (2008) 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. Secondly, while there have been a small number of quantitative studies examining carer burden (e.g., Winn et al., 2004), there have been no quantitative evaluations of coping strategies or informal social support as mediators of carer burden or psychological distress. Thirdly, the measures utilised within these studies have primarily been developed to assess carer burden in those who care for patients with schizophrenia, such as the Experience of Caregiving Inventory (Szmukler et al., 1996). Therefore, it is argued that research utilising eating-disorder specific measures such as the Eating Disorders Symptom Impact Scale (Sepulveda, Whitney, et al., 2008) and the Carers’ Needs Assessment Measure (Haigh & Treasure, 2003) is needed. Lastly, the majority of previous research has utilised samples from inpatient settings or volunteer databases; therefore, the generalisability of prior findings to the wider carer population may be limited.

It is argued that a longitudinal research design, utilising eating disorder carer specific questionnaires, would allow for the examination of the dynamic nature of the caring role. Furthermore, the use of a community sample in a
longitudinal study will enable generalisability of findings. Such a design enables an analysis of the long-term predictor variables of carer burden, specifically, expressed emotion, social support, coping strategies, and the needs of carers, of carer burden. Lastly, the potential mediation role of social support and coping strategies can be assessed. Knowledge of both predictors and mediators of carer burden and psychological distress will allow for early, targeted, interventions to be developed for carers. Such interventions would reduce the long-term impact of caregiving, and therefore, reduce the risk for adverse health consequences of long-term caring, such as depression and anxiety.

In addition to a longitudinal, quantitative examination of carer burden and psychological distress, a qualitative investigation of how the carer situation changes over time is needed. Such qualitative information would provide more in-depth information about the meanings, impact and emotions carers experience than quantitative information is capable of providing. Further, previous qualitative literature indicates that there is a lack of treatment services, lack of understanding from health professionals, and delays in treatment initiation (Haigh & Treasure, 2003; Perkins et al., 2004; Winn et al., 2004). Therefore, longitudinal qualitative examination of the experiences of eating disorder carers would allow for a more meaningful understanding of the carer experience to be developed. In this way, the qualitative data will provide greater insight into the ongoing difficulties that carers may experience than quantitative data alone (Steckler, McLeroy, Goodmand, Bird, & McCormick, 1992).

Use of a mixed-method approach, which integrates both quantitative and qualitative data, can overcome the limitations of using a single method (Steckler et al., 1992). Quantitative and qualitative methods can be integrated in various ways. Four approaches to integration are described by Steckler et al. (1992). Firstly, qualitative methods can be used to aide development of quantitative measures and instruments. Secondly, qualitative methods can be used to explain current quantitative findings. Thirdly, quantitative methods are used to clarify qualitative findings. Lastly, both quantitative and qualitative are used in parallel within a single study to cross-validate the findings. The second approach will be used in the current study; the written qualitative responses will help to clarify and explain the quantitative findings.
Aims

The aim of the current study is to longitudinally examine of carer burden and psychological distress due to caring for someone with an eating disorder. Carers completed three surveys consisting of both questionnaires and qualitative sections over a time period of nine months (initial, four and a half months, and nine months). The specific aims of this study are:

1. To determine the predictors of carer burden and psychological distress both cross-sectionally and longitudinally for carers of patients with an eating disorder.

2. To determine patterns of change over time within carers of patients with an eating disorder in relation to: burden, psychological distress, social support, coping strategies, specific needs, and expressed emotion

3. To examine coping strategies and social support as cross-sectional mediators of carer burden and psychological distress

Further, the current study will examine qualitative data in relation to eating disorder carers’ perspectives of the treatment the person they are caring for receives. Lastly, an examination of carers’ written reports regarding general changes in the caregiving role over time will be conducted. These questions will enable a better understanding ongoing difficulties, problems, and positive aspects of caregiving. Thus, the specific aims in relation to the qualitative component are:

4. To gain a better understanding of carers’ experiences in relation to treatment initiation, degree of being informed of treatments the sufferer undergoes, and whether sufficient follow-up treatment is provided.

5. To examine patterns of change in relation to the carers’ situations, such as change to support networks or sufferer symptoms.
Hypotheses

The following section provides hypotheses for the quantitative component of the current study. As both previous qualitative (e.g., Perkins et al., 2004) and quantitative (e.g., Winn et al., 2007) studies consistently indicates that caring for someone with an eating disorder is associated with a high degree of burden, it is hypothesised that:

1. Carers will report at least a moderate level of carer burden, as measured by the EDSIS at all three time points.

   Further, previous research (e.g., Graap, Bleich, Herbst, Trostmann, et al., 2008; Kyriacou et al., 2008a; Winn et al., 2007) indicates that both critical comments and emotional overinvolvement are present at higher levels in families with eating disorders, as compared to healthy controls, it is hypothesised that:

2. At all three time points, carers will report a high level of expressed emotion, as determined by a score greater than 23 and 27 on the critical comments and emotional overinvolvement subscales of the Family Questionnaire, respectively.

   Similarly, past research (e.g., Dimitropoulos et al., 2008; Haigh & Treasure, 2003; Winn et al., 2007) examining the psychological health of eating disorder carers using the GHQ-12 demonstrates that carers experience at least a moderate level of distress. Therefore, it is hypothesised that:

3. Carers will report at least a moderate level of psychological distress, as determined by a score greater than 12 on the General Health Questionnaire-12 at all three time points.

4. There will be a high level of unmet needs, as measured by the Carers' Needs Assessment Measure.
Based upon the Treasure and colleagues’ (2005) model of eating disorder carer distress and burden, Lazarus and Folkman’s (1984) cognitive stress theory, Pearlin et al.’s (1990) stress-process theory, and the proposed mediation model of carer burden, the following correlations between variables are hypothesised.

5. There will be a significant negative correlation between carer burden, as measured by the EDSIS, and quantity of social support; satisfaction with social support; and use of adaptive coping strategies.

6. There will be a significant negative correlation between psychological distress, as measured by the GHQ-12, and quantity of social support; satisfaction with social support; and use of adaptive coping strategies.

7. There will be a significant positive correlation between carer burden, as measured by the EDSIS, and expressed emotion; maladaptive coping strategies; severity of symptoms; carer contact hours with the sufferer; and unmet needs.

8. There will be a significant positive correlation between carer burden, as measured by the EDSIS, and expressed emotion; maladaptive coping strategies; severity of symptoms; carer contact hours with the sufferer; and unmet needs.

Cross-sectional research examining the prediction of eating disorder carer burden and psychological distress indicates that familial conflict, support from others, carer needs, and sufferer symptoms all have an impact. However, longitudinal predictions of carer burden and carer psychological distress have yet to be examined in prior research, despite recognising the need for such longitudinal research (Dimitropoulos et al., 2008). Further, changes in the magnitude of these variables associated with carer burden over time are also yet to be measured. Therefore, hypotheses relating to the prediction of carer burden over time, and any changes in participants self-reports over time, will be
necessarily exploratory in nature. Based upon prior eating disorder carer models, the cognitive stress theory (Lazarus & Folkman, 1984), stress-process theory (Pearlin et al., 1990), and the proposed mediation model of carer burden and psychological distress, it is hypothesised that:

9. Carer burden as measured by the EDSIS will be predicted, both cross-sectionally and longitudinally, by: quantity, of, and level of satisfaction with, social support; expressed emotion as reflected by levels of critical comments and emotional overinvolvement on the Family Questionnaire; maladaptive coping strategies as measured by the Brief COPE; eating disorder symptom severity; contact hours with the sufferer; and, unmet needs as measured by the CaNAM

10. Psychological distress, as measured by the GHQ-12 will be predicted, both cross-sectionally and longitudinally, by: quantity, of, and level of satisfaction with, social support; expressed emotion as measured by critical comments and emotional overinvolvement on the Family Questionnaire; maladaptive coping strategies as measured by the Brief COPE; eating disorder symptom severity; contact hours with the sufferer; and, unmet needs as measured by the CaNAM

11. The following mediation pathways, at a cross-sectional level, are hypothesised:

   i. The effect of critical comments on carer burden will be mediated by coping strategies and social support

   ii. The effect of emotional overinvolvement on carer burden will be mediated by coping strategies and social support

   iii. The impact of critical comments on carer psychological distress will be mediated by coping strategies and social support

   iv. The impact of emotional overinvolvement on carer psychological distress will be mediated by coping strategies and social support
v. The impact of unmet needs on carer burden will be mediated by coping strategies and social support

vi. The effect of unmet needs on carer psychological distress will be mediated by coping strategies and social support

Method

Participants

Fifty-six carers (44 females and 12 males) were recruited; consisting of 42 parents, eight partners, four siblings, and two friends. At Time One, the mean age for the participants was 45.79 (SD = 11.84). At Time Two, there were 45 carers (33 females and 12 males); consisting of 34 parents, eight partners, two friends and one sibling. Forty-three carers (31 females and 12 males) remained at Time Three; 33 parents, 8 partners, and two friends. Therefore, the overall retention rate was 76.78% across the three time points. Lastly, from the 56 carers four pairs of parents each cared for one sufferer per parental unit. As such, eight carers report on only four sufferers.

In relation to the patients with an eating disorder being cared for, at baseline (Time One) there were 50 females and six males being cared for by the participants. The average age for these patients was 21.48 (SD = 8.67) years. Based on the carers’ report, 38 were diagnosed with AN, seven with BN, six with a combination of AN and BN, and one with binge eating disorder.

Forty-four (78.5%) of patients were reported by carers as living at home with the carer. The average number of hours dedicated to their caring role was reported to be one hour per week for direct treatment commitments (SD = 1.24) and 78.91 (SD = 63.83) hours of general contact with the sufferer.

Materials

The selection of scales for the carer questionnaire was determined on the need to balance the capacity to collect comprehensive data regarding the carers’
experience and participants’ time commitment to complete the questionnaires. As such, short but psychometrically sound scales were selected for the current study. Further, the measures were chosen to maintain consistency with prior research and on the basis that they were eating disorder carer specific. The questionnaire consisted of two sections, a general information sheet, and six measures assessing the variables of expressed emotion, coping strategies, social support, carer psychological health, carer burden, and needs as a carer. These scales are described in the proceeding paragraphs.

General information sheet

The general information sheet was used to obtain information regarding both the carer and the person affected by the eating disorder. The following demographic information was obtained regarding the carer: gender; age; relationship to the person they were caring for; how many children they had in total; their average hours of employment during a one week period; and all treatment commitments they had due to their carer role. In addition, the carer was asked to rate their perception of the importance that the person they were caring for changed their eating behaviour (rated on an 11-point Likert scale, 0 = not important, 10 = very important) as well as their confidence that the person they are caring for would be able to change (as rated on an 11-point Likert scale, 0 = not confident, 10 = very confident).

With regards to the individual with the eating disorder, the carer was asked to provide the following information: gender; age; their current diagnosis; and their BMI. Carers were also asked to indicate whether the person displayed specific eating disorder-related symptoms; for example, “Do they describe their body as being fat despite evidence or being told otherwise?”, on a corresponding 5-point, or 6-point, Likert scale (1 = absence of symptom; 5/6 = high level of symptom). In addition, carers were asked to indicate the number of hours of contact they had with the sufferer. Lastly, carers were asked to rate their perception of how important change was to the individual with the eating disorder (as rated on an 11-point Likert scale, 0 = not important, 10 = very important), and how much confidence the person they are caring for had that they can change (as rated on an 11-point Likert scale, 0 = not confident, 10 = very confident). While
based on the carers’ perception, these last two questions were included to obtain an indication of the discrepancy between the carer and the sufferer’s perception of readiness and confidence for change with respect to the eating disorder behaviour.

**Questionnaires**

*Eating Disorders Symptom Impact Scale (EDSIS)*

The EDSIS measures the specific burden for carers of patients with AN or BN and by assessing carers’ perceptions of the emotional, psychological and tangible impact of caring for someone with an eating disorder (Sepulveda, Whitney, et al., 2008). A total of 30 items assess different aspects of caring for someone with an eating disorder, as measured on a 5-point Likert scale (0 = *Never*, 4 = *Nearly Always*). An example item is “During the past month, how often have you thought about: Feeling that there could have been something I should have done.” Items are summed with higher scores indicating higher perceived burden. The EDSIS is comprised of four subscales: nutrition, dysregulated behaviour, guilt and social isolation. The EDSIS demonstrates acceptable reliability with Cronbach’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 \( r = .60 \)). Further, the EDSIS has been demonstrated to be sensitive to changes in carers’ experience of burden over time.

In the current study, the Chronbach’s alphas were high for each of the subscales; nutrition (Time One \( \alpha = .83 \); Time Two \( \alpha = .82 \); Time Three \( \alpha = .88 \)), guilt (Time One \( \alpha = .85 \); Time Two \( \alpha = .88 \); Time Three \( \alpha = .91 \)), dysregulated behaviour (Time One \( \alpha = .78 \); Time Two \( \alpha = .80 \); Time Three \( \alpha = .85 \)), and social isolation (Time One \( \alpha = .88 \); Time Two \( \alpha = .80 \); Time Three \( \alpha = .89 \)).

*Carers’ Needs Assessment Measure (CaNAM)*

The CaNAM is a self-report questionnaire measuring the perceived needs of carers of patients with an eating disorder (Haigh & Treasure, 2003). The CaNAM consists of a combination of quantitative and qualitative items covering
the following domains: information about eating disorders, passing on
information to carers, support from other people/organisations, support for self,
treatment received by the person with an eating disorder, information general
practitioners provide carers about eating disorders, and training general
practitioners receive. The current study utilised a shortened version of the
CaNAM and removed many of the qualitative items due to measurement overlap
with other scales. Only the section measuring treatment remained as in the
original, with the qualitative items intact.

The quantitative items are measured on a 3-point Likert scale with anchors
reflecting the specific content of the question (e.g., 0 = No, but I’d like to receive
more support, 1 = No, but I don’t mind, 2 = Yes, I have received enough support),
while other items are answered binomially as “Yes” or “No”. An example item is
“Do you think that your GP has given you enough information about the
following areas?” Items for each subscale are summed to provide a total score for
each domain. Higher scores indicate higher degrees of support and information.

Three qualitative questions on the CaNAM ask about treatment: “Did the
treatment for the person you are caring for start early enough?”, “Have you been
kept sufficiently informed of the person you are caring for’s treatment?”, and
“Do you think that there is sufficient follow-up treatment (e.g., visits from social
workers, day patient units) for people with an eating disorder?” Participants who
responded “no” were asked to write about their experiences. Participants were
asked all three treatment questions at Time One, with only the latter two being
asked at Time Two and Time Three.

The CaNAM has been shown to provide adequate information regarding
the needs of carers of patients with eating disorders, with the quantitative
subscales demonstrating adequate internal consistency. Chronbach’s alphas for a
bimodal scoring method range from .61 to .91 (Whitney et al., 2007). For the
current study, the Chronbach’s alpha for the need for information subscale were
high (Time One α = .94; Time Two α = .91; Time Three α = .90). The need for
support from organisations also had adequate internal consistency (Time One α =
.63; Time Two α = .80; Time Three α = .75). However, the need for support for
self subscale displayed a low internal consistency (Time One α = .55; Time Two
α = .58; Time Three α = .76); removal of an item did not improve the
Chronbach’s alphas for this subscale. The need for information from GPs
subscale had a high internal consistency across all three time points (Time One $\alpha = .95$; Time Two $\alpha = .93$; Time Three $\alpha = .95$). Lastly, the training GPs receive in relation to eating disorders subscale demonstrated a high internal consistency (Time One $\alpha = .95$; Time Two $\alpha = .92$; Time Three $\alpha = .96$).

*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 self-report questionnaire measuring temporary deviations from normal functioning; that is, indications of possible psychological ill health (Goldberg & Williams, 1988). This 12 item measure assesses the participant’s general health over the previous few weeks, as measured on a 4-point Likert scale with anchors reflecting the specific content of the question (e.g., 0 = *Not at all*, 3 = *Much more than usual*). An example item is, “Have you recently felt constantly under strain?” Items can be scored in two ways. Firstly, scoring can be bimodal, with responses of zero and one receiving a score of zero, and a response of three or four receiving a score of one. Secondly, items can be scored as 0-3 and summed to give a total score. A higher score on the GHQ is indicative of greater ill health. The second method of scoring was utilised in the current study in order to maintain consistency with previous research involving eating disorder carers (Zabala et al., 2009).

The GHQ-12 has been shown to discriminate well between normal and psychological ill health with a sensitivity rating of 89% and specificity rating of 80% (Goldberg & Williams, 1988). Lastly, the GHQ-12 demonstrates good internal consistency with Cronbach’s alphas ranging from .82 to .90 across varied samples (Doi & Minowa, 2003; French & Tait, 2004; Goldberg & Williams, 1988; Picardi, Abeni, & Pasquini, 2001). The Chronbach’s alpha for the current study was high across all three time points (Time One $\alpha = .90$; Time Two $\alpha = .93$; Time Three $\alpha = .95$).

*Brief COPE*

The Brief COPE is based upon the larger COPE inventory (Carver, Scheier, & Weintraub, 1989) and assesses various ways in which people cope
with a specified situation (Carver, 1997). The COPE is applicable to the general community (Folkman & Moskowitz, 2004), with the Brief COPE providing a parsimonious way in which to assess an individual’s current coping mechanisms. 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 subscales measure the following forms of coping: active coping, planning, positive reframing, acceptance, humour, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement, and self-blame. An example item is “I’ve been accepting the reality of the fact that it has happened.” The subscales of the Brief COPE can be combined to form three factors: emotion focussed coping, problem focussed coping and dysfunctional coping (Carver et al., 1989; Coolidge, Segal, Hook, & Stewart, 2000). Further, the Brief COPE can be divided into maladaptive coping (equivalent to dysfunctional coping) and adaptive coping, which combines problem focussed and emotion focussed coping (Carver, 1997). For the current study, both factor structures have been used.

The Brief COPE has been widely used and the subscales demonstrate acceptable reliability ranging from .50 to .90 (Carver, 1997). While some of the subscales reliability coefficients are below the common acceptable standard of .70 or above (Nunnally & Bernstein, 1994), this usual standard is not necessarily appropriate for coping scales as use of one coping strategy alone may in itself be sufficient to lessen stress (Folkman & Moskowitz, 2004). Thus, there may not be consistent use of coping strategies within a particular subscale. Further, due to the concise nature of the questionnaire, there are only two items per subscale leading to difficulties in conducting meaningful reliability analyses (Nunnally & Bernstein, 1994). The COPE scale has been previously utilised in research involving carers of stroke patients (McClenahan & Weinman, 1998), and the Brief COPE has been utilised in research with carers of those with schizophrenia (Fortune et al., 2005).

For the current study, the Chronbach’s alpha for the problem-focussed subscale were acceptable (Time One $\alpha = .87$; Time Two $\alpha = .89$; Time Three $\alpha = .92$). Similarly, the emotion-focussed subscale had acceptable Chronbach’s alphas (Time One $\alpha = .74$; Time Two $\alpha = .79$; Time Three $\alpha = .79$). Lastly, the maladaptive/dysfunctional subscale was acceptable at all three time points (Time
One $\alpha = .79$; Time Two $\alpha = .67$; Time Three $\alpha = .67$), and the adaptive subscale was high (Time One $\alpha = .83$; Time Two $\alpha = .85$; Time Three $\alpha = .88$).

**Social Support Questionnaire – Short Form (SSQ-6)**

The SSQ-6 is based upon the more extensive Social Support Questionnaire (SSQ; Sarason, Levine, Basham, & Sarason, 1983), and assesses the both the sources of social support and the respondents’ satisfaction with the support received (Sarason, Sarason, Shearin, & Pierce, 1987). The SSQ-6 provides a parsimonious manner in which to assess social support. The SSQ-6 consists of six items asking the participants how many people provide support within a particular social support domain and how satisfied the participants are with regard to the specified area. An example question is “Whom can you really count on to help you feel more relaxed when you are under pressure or tense?” Separate scores are obtained for both number and satisfaction of social support.

The original SSQ is related to the experience of anxiety, depression and hostility (Sarason et al., 1983), with the SSQ-6 having a significant negative correlation with anxiety, depression and loneliness scales (Sarason et al., 1987). The SSQ-6 is comparable with the SSQ on both number and satisfaction of social support, with intercorrelations ranging from .95 to .96 for number and .37 to .55 for satisfaction (Sarason et al., 1987). The SSQ-6 demonstrates high internal consistency, with a Chronbach’s alpha of .90 for number and .93 for satisfaction (Sarason et al., 1987). Lastly, the SSQ-6 has been used successfully in carers of those with Alzheimer’s disease (Goode, Haley, Roth, & Ford, 1998; Haley et al., 1996) and young carers aged 10-25 years old (Pakenham et al., 2007).

The Chronbach’s alphas for the current study at Time One were acceptable ($\alpha = .77$ and $\alpha = .89$ for quantity and satisfaction, respectively). At Time Two, the Chronbach’s alphas were .89 and .94 for quantity and satisfaction, respectively. At Time Three, the Chronbach’s alphas were high ($\alpha = .86$ and $\alpha = .95$ for quantity and satisfaction, respectively).

**Family Questionnaire (FQ)**

The FQ is a self-report questionnaire based on the Camberwell Family Interview (CFI; (Vaughn & Leff, 1976) that measures the expressed emotion
domains of critical comments and emotional overinvolvement (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002). 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 (Wiedemann et al., 2002). Overall, the FQ demonstrates 74% concordance with the CFI for overall expressed emotion ratings; a similar level of accuracy for the Five Minute Speech Sample (Wiedemann et al., 2002). Additionally, each item on the FQ was designed to reduce social desirability, in that the items were formulated to reconceptualise negative responses from a fault of the carer to necessary outcomes due to the stressful situation. The FQ consists of 20 items, with 10 items per subscale, as measured on a 4-point Likert scale (1 = Never/Very rarely, 4 = Very often). An example item is “I keep thinking about the reasons for his/her illness.” 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.

The FQ demonstrates acceptable reliability, with a Chronbach’s alpha of .90 to .92 for the Critical Comments and .79 to .82 for the Emotional Overinvolvement subscales, respectively (Wiedemann et al., 2002). Within carers of patients with AN, the EOI and CC subscales demonstrates an internal reliability of .76 and .88, respectively (Kyriacou et al., 2008a). Further, the FQ is sensitive to both EOI and CC with carers of patients with eating disorders, with possibly more sensitivity than the CFI (Kyriacou et al., 2008a). Therefore, while the psychometric evidence for the FQ is preliminary, this evidence is promising (McNab, Haslam, & Burnett, 2007).

At all three time points the Chronbach’s alphas for the critical comments subscale were high (Time One α = .85; Time Two α = .90; Time Three α = .88). The emotional overinvolvement subscale also demonstrated acceptable internal consistency (Time One α = .57; Time Two α = .79; Time Three α = .80).

**Qualitative changes over time**

Lastly, for the questionnaires completed at Time Two and Time Three participants were asked to write about what had changed for them during the previous four and a half months. This was a broad question that allowed carers to
report on any aspect of change that they perceived as important. This question was included in order to gain a deeper understanding about how their situation had changed in relation to aspects such as support, treatment programs, sufferer symptoms or family situations, since their completion of the previous questionnaire. Further, this question provided more insight into the ongoing difficulties experienced by eating disorder carers.

Procedure

Approval for the study was obtained from the Deakin University Human Research Ethics Committee prior to commencing the study (Appendix A). A number of recruitment strategies were implemented. Online advertisements (see Appendix B for an example) on eating disorder organisation websites (e.g., b-eat, UK; EDFV, Australia), newspaper advertisements in Australian national newspapers (see Appendix C for an example), one newspaper article in a local newspaper, two radio interviews at local Geelong radio stations, distribution of flyers within carer support groups and carer workshops, questionnaire mail-outs via the Geelong, Victoria hospital-based eating disorder service, and questionnaire mail-outs to carers listed with The Butterfly Foundation (an Australian not-for-profit organisation that supports patients affected by eating disorders). As such, a community sample was recruited.

Questionnaires were available in both paper-based and online formats. Participants completed three questionnaires: initial, four and a half months, and nine months. Intervals of four and a half months were chosen to allow sufficient time to capture any significant changes that may have occurred between data collection points. The total time frame of nine months was chosen to provide sufficient time to capture the chronicity of eating disorders with balancing participant commitment. Those requesting a paper-based questionnaire were mailed out a questionnaire package consisting of the questionnaire (Appendix D and E), plain language statement (Appendix F) and consent form (Appendix F) 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 email address for the online version. Paper-based questionnaires were then returned via reply-paid
post. These questionnaires and contact sheets were coded with corresponding numbers to enable subsequent follow-up of participants (e.g., 001 or 002). Contact details were kept in a separate, secure cabinet from the questionnaires to maintain anonymity.

Questionnaires that were completed online were matched on the basis of the provided email address. Participants were sent follow-up emails at the time when the next questionnaire was due to be completed. Reminders were sent for those not responding within one month.
CHAPTER FIVE

STUDY 1: LONGITUDINAL EXAMINATION OF EATING DISORDER CARER BURDEN – RESULTS AND DISCUSSION

Results

Participants were assessed in relation to level of carer burden, psychological distress, expressed emotion, carer needs, coping strategies, and social support. This data will be used to evaluate the predictors of carer burden and psychological distress. Further, the mediational roles of coping strategies and social support will be assessed.

The analysis and findings for the current investigation will be presented in eight sections: data screening; demographic information; general descriptive statistics; Pearson’s correlations; repeated measures Analysis of Variance (ANOVA) examining change across time in the measured variables; multiple regressions examining predictors of carer burden and psychological distress; and mediation analysis examining the mediational role of coping strategies and social support. Lastly, results from the qualitative component of the current study will be presented. All quantitative analyses were conducted using Statistical Package for the Social Sciences (SPSS) version 17.

Data Screening

Accuracy of data entry, missing values and compliance with assumptions of univariate and multivariate analyses were determined. Random missing data was replaced using mean replacement. At Time One and Time two, univariate outliers on the variable measuring the importance to carers that the person they care for change were detected through examination of z-scores ($z > \pm 3.29$) and changed to one unit larger than the next most extreme case (Tabachnick & Fidell, 2001). There were no multivariate outliers detected using Mahalabonis distance (critical value at <.001 of 39.25) at Time One, Time Two, or Time Three.

For Time One, examination of histograms, normal q-q plots and skew statistics revealed no violations of normality, linearity or homoscedasticity. At
Time Two, the quantity of social support subscale of the SSQ-6 was positively skewed (3.49) and the satisfaction with social support subscale of the SSQ-6 was negatively skewed (-4.40). The skew for both variables was removed utilising a square root transformation. Normality, linearity and homoscedasticity assumptions were met at Time Two. There were no violations of normality, linearity or homoscedasticity at Time Three. Multicollinearity was not an issue for the data at any of the three time points.

The desired sample size for the current study was initially 100 participants. However, this aim was not met. 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 (Onwuegbuzie & Leech, 2004). These power analyses were conducted using the G*Power program (Faul, Erdfelder, Lang, & Buchner, 2007). Within this program, power for a given statistical test is determined via a provided effect size, alpha level, total sample size, and number of predictors. These power analyses will be reported throughout the following sections where applicable.

**Demographic information**

The baseline (Time One) demographics are provided in the following section. A total of 56 carers were recruited at Time One. Demographic data of the carers are included in Table 5.1. Due to a number of carers reporting 24 hours a day, seven days a week as contact hours, the average hours of contact the carer had with their child was an elevated 78.91 ($SD = 63.83$). Only a small amount of time was directly involved with treatment commitments, with an average of one hour per week ($SD = 1.24$) dedicated to taking the sufferer to health professionals.
Table 5.1

Demographic variables of carers completing the questionnaires at Time One

<table>
<thead>
<tr>
<th>Time One characteristics of carers</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>56</td>
<td>Mean = 45.79 (SD = 11.84)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12</td>
<td>21.4</td>
</tr>
<tr>
<td>Female</td>
<td>44</td>
<td>78.6</td>
</tr>
<tr>
<td>Relationship to sufferer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>36</td>
<td>64.3</td>
</tr>
<tr>
<td>Father</td>
<td>6</td>
<td>10.7</td>
</tr>
<tr>
<td>Sibling</td>
<td>4</td>
<td>7.1</td>
</tr>
<tr>
<td>Partner</td>
<td>8</td>
<td>14.3</td>
</tr>
<tr>
<td>Friend</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>Country of residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>50</td>
<td>89.3</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>4</td>
<td>7.1</td>
</tr>
<tr>
<td>United States</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Canada</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Employment status(^a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>23</td>
<td>41.8</td>
</tr>
<tr>
<td>Part time</td>
<td>25</td>
<td>45.5</td>
</tr>
<tr>
<td>Not currently employed</td>
<td>7</td>
<td>12.7</td>
</tr>
<tr>
<td>Living with sufferer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>44</td>
<td>78.6</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>21.4</td>
</tr>
<tr>
<td>Number of daughters/sons(^b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>2</td>
<td>4.3</td>
</tr>
<tr>
<td>Two</td>
<td>16</td>
<td>34.8</td>
</tr>
<tr>
<td>Three or more</td>
<td>26</td>
<td>56.5</td>
</tr>
</tbody>
</table>

Note. \(^a\)The N for employment status is 55 due to missing data for one participant
\(^b\)The N for number of daughters/sons is 44 due to this question only being relevant for parents.
Table 5.2 presents the demographic and eating disorder-related information in regards to the person with an eating disorder, as reported by the carer. 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 19.73 ($SD = 6.39$) at Time Three. At Time One, 45.0% of sufferers binged, with 46.4% of patients engaging in purging behaviour. At Time Two, 42.2% of patients binged, with 44.4% of patients engaging in purging behaviour. At Time Three, 48.8% of patients binged, with 39.5% of patients engaging in purging behaviour. The most common methods of purging utilized were vomiting and laxative abuse. The patients undertook an average of 2.65 hours ($SD = 6.15$) of exercise per day at Time One. At Time Two the average hours of exercise per day decreased to 1.24 ($SD = 1.23$), and an average of 1.39 ($SD = 2.16$) at Time Three. Further, 67.9% of female sufferers had amenorrhea at Time One.

The carers’ perceptions of sufferer symptoms were also assessed. Fear of fatness and weight gain was measured on a 5-point Likert scale ($1 = no \text{ fear or distress}, 5 = severe \text{ fear and distress}$), with a mean of 4.14 ($SD = .82$) at Time One, mean of 3.56 ($SD = 1.01$) at Time Two, and 3.42 ($SD = 1.20$) at Time Three. Similarly, whether the patient described themselves as fat, despite conflicting evidence, was measured on a 5-point Likert scale ($1 = never, 5 = always$), with a mean of 3.68 ($SD = 1.32$) at Time One, 3.20 ($SD = 1.31$) at Time Two, and 3.30 ($SD = 1.30$) at Time Three. As such, carers reported that the person they cared for displayed a moderate to high degree of fear of fatness and a moderate degree of perceptual disturbance in relation to their body size.
Table 5.2

Demographic variables of the sufferers with an eating disorder at Time One

<table>
<thead>
<tr>
<th>Time One characteristics of patients</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>56</td>
<td>Mean = 21.48 (SD = 8.67)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
<td>10.7</td>
</tr>
<tr>
<td>Female</td>
<td>50</td>
<td>89.3</td>
</tr>
<tr>
<td>Eating disorder diagnosis(^a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anorexia Nervosa</td>
<td>38</td>
<td>73.1</td>
</tr>
<tr>
<td>Bulimia Nervosa</td>
<td>7</td>
<td>13.5</td>
</tr>
<tr>
<td>Both AN and BN</td>
<td>6</td>
<td>11.5</td>
</tr>
<tr>
<td>Binge Eating Disorder</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>Total admissions to hospital(^b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>27</td>
<td>49.1</td>
</tr>
<tr>
<td>One</td>
<td>10</td>
<td>18.2</td>
</tr>
<tr>
<td>Two</td>
<td>5</td>
<td>9.1</td>
</tr>
<tr>
<td>Three or more</td>
<td>13</td>
<td>23.5</td>
</tr>
<tr>
<td>Duration of patient’s illness (years)</td>
<td>55</td>
<td>Mean = 5.09 (SD = 5.03)</td>
</tr>
<tr>
<td>Currently receiving treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>45</td>
<td>80.4</td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>19.6</td>
</tr>
</tbody>
</table>

Note. \(^a\)Eating disorder diagnosis N is 52 due to missing data for five participants
\(^b\)Total admissions to hospital N is 55 due to missing data for one participants.

Lastly, carers were asked to rate on an 11-point scale how important it was to them that the person they care for change and how confident they were they could help the person they care for change. Also, they were asked to rate their perceptions of how important the sufferer felt that they change their own behaviour, and how confident the sufferer was in regards to implementing change. As seen in Table 5.3, carers had a high level of importance that the person they care for change but were not very confident they could help the person change.
Further, carers believed that the person they cared for placed a moderate level of importance on change and had low confidence in their ability to change.

Table 5.3

Means and standard deviations of ratings of importance and confidence to change

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time One (n = 56)</th>
<th>Time Two (n = 45)</th>
<th>Time Three (n = 43)</th>
<th>Scale Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer important change</td>
<td>9.91 (.29)</td>
<td>9.73 (.65)</td>
<td>9.30 (2.05)</td>
<td>0-10</td>
</tr>
<tr>
<td>Carer confident can help change</td>
<td>5.25 (2.64)</td>
<td>5.58 (2.90)</td>
<td>5.19 (3.03)</td>
<td>0-10</td>
</tr>
<tr>
<td>Important to patient they change</td>
<td>6.18 (3.24)</td>
<td>7.49 (2.75)</td>
<td>6.65 (3.34)</td>
<td>0-10</td>
</tr>
<tr>
<td>Patient confidence they can change</td>
<td>3.55 (2.76)</td>
<td>5.11 (2.95)</td>
<td>4.63 (3.34)</td>
<td>0-10</td>
</tr>
</tbody>
</table>

Descriptive statistics

In order to test the first four hypotheses relating to carer scores for expressed emotion, burden, psychological distress and needs, descriptive statistics were calculated and are provided in Table 5.4, Table 5.5 and Table 5.6. As this is the first longitudinal study of carers, for comparison purposes, results for the same measures in previous cross-sectional studies of eating disorder carers will also be presented.

Expressed emotion

The hypothesis that, at all three time points, the mean score for the critical comments and emotional overinvolvement subscale of the FQ would be above the cut-off points was partially supported. At Time One, the mean score for both subscales was above the cut-off (23 for critical comments and 27 for emotional overinvolvement); however, at Time Two only the emotional overinvolvement subscale mean was above the cut-off point. However, by Time Three both critical
comments and emotional overinvolvement were above the cut-off points. The one previous study has utilised the FQ within a sample of carers of patients with AN (Kyriacou et al., 2008a) reported a mean score of 22.5 \( (SD = 6.1) \) for critical comments and 27.9 \( (SD = 4.5) \) for emotional overinvolvement. For the current study, the mean scores at Time One were higher than those reported by Kyriacou et al. (2008). However, at Time Two and Time Three the mean scores for the FQ subscales were more comparable to Kyriacou et al. (2008a).

The level of expressed emotion was examined utilising the cut-off point of 23 for critical comments, and 27 for emotional overinvolvement (Wiedemann et al., 2002). At Time One, 89.3% of carers displayed a high level of emotional overinvolvement and 73.2% of carers reported high levels of critical comments. At Time Two, 60% of carers were high on emotional overinvolvement, and 46.7% of carers reported high levels of critical comments. At Time Three, 65.1% carers reported high levels of emotional overinvolvement and 60.5% of carers were high on critical comments.

Table 5.4

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time One ( (n = 56) )</th>
<th>Time Two ( (n = 45) )</th>
<th>Time Three ( (n = 43) )</th>
<th>Scale range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Critical Comments</td>
<td>25.77 (5.79)</td>
<td>23.33 (6.38)</td>
<td>24.88 (6.38)</td>
<td>10-40</td>
</tr>
<tr>
<td>Emotional Overinvolvement</td>
<td>31.12 (3.40)</td>
<td>28.31 (4.63)</td>
<td>28.23 (4.93)</td>
<td>10-40</td>
</tr>
<tr>
<td>GHQ-12</td>
<td>17.84 (6.54)</td>
<td>14.24 (6.74)</td>
<td>16.60 (8.95)</td>
<td>0-36</td>
</tr>
</tbody>
</table>

Psychological distress

The hypothesis that, at all three time points, carers would report at least a moderate level of psychological distress was supported. As seen in Table 5.4, the carers in the current study consistently reported a moderate level of psychological distress across all the time points, based on the cut-off points provided by
Goldberg and Williams (1988). These cut-off point specify that scores less than 12 are classified as low distress, scores 13 to 24 as moderate, and scores higher than 24 as severe. At Time One, the level of psychological distress as reported by carers was moderate for 62.5% of carers and severe for 17.9% of carers. At Time Two, 40% of carers reported moderate distress and 11.1% severe psychological distress. At Time Three, 48.8% and 16.3% of carers reported moderate and severe levels of psychological distress, respectively. For comparison, GHQ-12 scores from previous studies examining carers of patients with eating disorders are presented in Table 5.5. As shown, the majority of studies report a lower mean score than Time One in the current study. At Time Two and Time Three, the mean scores on the GHQ-12 were more comparable to previous studies. Only one study (Dimitropoulos et al., 2008) reports a higher mean than the current study across all three time points.

Table 5.5

GHQ-12 means and standard deviations for previous studies examining eating disorder carers

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>GHQ-12 mean and standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Winn et al., 2007)</td>
<td>BN</td>
<td>15 (6.2)</td>
</tr>
<tr>
<td>(Haigh &amp; Treasure, 2003)</td>
<td>AN</td>
<td>17.2 (7.9)</td>
</tr>
<tr>
<td>(Whitney et al., 2007)</td>
<td>AN</td>
<td>16.9 (7.1)</td>
</tr>
<tr>
<td>(Graap, Bleich, Herbst, Trostmann, et al., 2008)</td>
<td>AN</td>
<td>5.4a (4.1)</td>
</tr>
<tr>
<td></td>
<td>BN</td>
<td>1.9a (2.36)</td>
</tr>
<tr>
<td>(Sepulveda, Whitney, et al., 2008)</td>
<td>Mixed</td>
<td>14.3 (7.5)</td>
</tr>
<tr>
<td>(Sepulveda, Lopez, Todd, et al., 2008)</td>
<td>Mixed</td>
<td>17.7 (13.3)</td>
</tr>
<tr>
<td>(Dimitropoulos et al., 2008)</td>
<td>AN</td>
<td>20.10 (4.61)</td>
</tr>
</tbody>
</table>

Note: aBimodal scoring method used.
Carer burden

The hypothesis that, at all three time points, carers would report at least a moderate level of carer burden was partially supported. In regards to the level of carer burden reported by participants, as seen in Table 5.6 carers reported a moderate level of nutrition difficulties, a low level of guilt, a low level of disruption due to dysregulated behaviour, and a low to moderate level of social isolation. Further, the overall burden total is moderate. The total burden score from the current study at Time One is higher than that reported by Sepulveda, Lopez, Todd et al. (2008), who reported a mean total of 39.1 ($SD = 13.3$). However, by Time Three it is more comparable. Further, the obtained mean for total burden at Time One is higher than that seen in a study with AN carers (Sepulveda, Whitney, et al., 2008), which reported a mean of 41 ($SD = 12.6$). However, it is more comparable to BN carers within the study by Sepulveda, Whitney et al. (2008), where BN carers were reported to have a mean of 47.2 ($SD = 14.0$). Due to the low number of BN carers in the current study, it was not feasible to determine a separate mean for this subset of carers.

Table 5.6
Means and standard deviations for carer burden subscales as measured by the EDSIS

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Time One ($n = 56$)</th>
<th>Time Two ($n = 45$)</th>
<th>Time Three ($n = 43$)</th>
<th>Scale range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition</td>
<td>19.36 (6.41)</td>
<td>17.22 (6.57)</td>
<td>17.79 (7.66)</td>
<td>0-32</td>
</tr>
<tr>
<td>Guilt</td>
<td>9.32 (4.77)</td>
<td>7.69 (5.07)</td>
<td>8.35 (5.46)</td>
<td>0-20</td>
</tr>
<tr>
<td>Dysregulated Behaviour</td>
<td>10.14 (6.12)</td>
<td>9.62 (6.60)</td>
<td>10.09 (6.72)</td>
<td>0-28</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>7.21 (4.24)</td>
<td>6.40 (3.77)</td>
<td>6.35 (4.11)</td>
<td>0-16</td>
</tr>
<tr>
<td>Total EDSIS</td>
<td>46.04 (15.80)</td>
<td>40.93 (16.12)</td>
<td>42.58 (18.37)</td>
<td>0-96</td>
</tr>
</tbody>
</table>
Carer needs

Lastly, the hypothesis that, at all three time points, carers would report a high level of unmet needs was supported. When examining the data relating to carer needs, as seen in Table 5.7 the reported means for all domains of needs at Time One are relatively low. This indicates that carers’ needs, particularly in relation to information from GPs and training requirements of GPs, are not being met. Whitney et al. (2007) also utilised the CaNAM to assess carer needs, however, they use a bimodal ‘yes/no’ scoring method. They provided data for the information subscale, organisational support subscale, and support for self subscale with the highest identified need for relating to information.

Table 5.7
Means and standard deviations for needs as measured by the CaNAM

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Time One (n = 56)</th>
<th>Time Two (n = 45)</th>
<th>Time Three (n = 43)</th>
<th>Scale range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for information</td>
<td>11.36 (9.14)</td>
<td>16.53 (8.22)</td>
<td>15.74 (7.83)</td>
<td>0-28</td>
</tr>
<tr>
<td>Need for support from organisations</td>
<td>3.32 (2.24)</td>
<td>4.09 (2.59)</td>
<td>4.23 (2.41)</td>
<td>0-8</td>
</tr>
<tr>
<td>Need for support for self</td>
<td>4.77 (2.57)</td>
<td>5.80 (2.36)</td>
<td>5.19 (2.93)</td>
<td>0-10</td>
</tr>
<tr>
<td>Information from GPs</td>
<td>3.77 (3.51)</td>
<td>4.60 (3.31)</td>
<td>4.47 (3.60)</td>
<td>0-10</td>
</tr>
<tr>
<td>Training of GPs</td>
<td>2.75 (3.40)</td>
<td>3.49 (3.52)</td>
<td>3.70 (5.58)</td>
<td>0-8</td>
</tr>
</tbody>
</table>

Additionally, Table 5.8 presents the percentage of carers who found a variety of sources of information as useful. As shown, at Time One carers reported support groups, conferences, helplines, leaflets and newsletters, the internet and lectures to be useful sources of information. However, GPs were not found to be a useful source of information about eating disorders at Time One. A similar pattern was found for Time Two and Time Three.
Table 5.8  
*Percentage of carers indicating sources of information as useful at all three time points*

<table>
<thead>
<tr>
<th>Information Source</th>
<th>Percentage Time One ((n = 56))</th>
<th>Percentage Time Two ((n = 45))</th>
<th>Percentage Time Three ((n = 43))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers’ support groups</td>
<td>89.3</td>
<td>93.3</td>
<td>93.0</td>
</tr>
<tr>
<td>‘Buddy’ support/peer support</td>
<td>80.4</td>
<td>71.1</td>
<td>74.4</td>
</tr>
<tr>
<td>Carers’ conferences</td>
<td>76.8</td>
<td>73.3</td>
<td>79.1</td>
</tr>
<tr>
<td>Helplines</td>
<td>87.5</td>
<td>84.4</td>
<td>79.1</td>
</tr>
<tr>
<td>Leaflets</td>
<td>82.1</td>
<td>71.1</td>
<td>67.4</td>
</tr>
<tr>
<td>Newsletters</td>
<td>83.9</td>
<td>80.0</td>
<td>79.1</td>
</tr>
<tr>
<td>Lectures</td>
<td>81.5</td>
<td>80.0</td>
<td>79.1</td>
</tr>
<tr>
<td>Internet</td>
<td>83.3</td>
<td>84.4</td>
<td>83.7</td>
</tr>
<tr>
<td>GP</td>
<td>55.6</td>
<td>57.8</td>
<td>51.2</td>
</tr>
</tbody>
</table>

**Coping strategies and social support**

As seen in Table 5.9, the level of adaptive coping used by carers is moderate. In terms of problem focussed and emotion focussed coping (two subscales that when combined form adaptive coping), use of emotion focussed coping was very high while use of problem focussed coping was low. Carers also used maladaptive coping strategies to a moderate degree. As can also be seen in Table 4.9, carers reported a low quantity of social support; with immediate family members the most commonly reported sources of support. Lastly, although the number of people perceived to be sources of support was low, participants were moderately to highly satisfied with this support.
Table 5.9
*Means and standard deviations of coping strategy subscales as measured by the Brief COPE and social support subscales as measured by the SSQ-6*

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Time One</th>
<th>Time Two</th>
<th>Time Three</th>
<th>Scale range</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$(n = 56)$</td>
<td>$(n = 45)$</td>
<td>$(n = 43)$</td>
<td></td>
</tr>
<tr>
<td>Adaptive Coping</td>
<td>42.45 (7.89)</td>
<td>43.69 (8.44)</td>
<td>38.86 (9.60)</td>
<td>16-64</td>
</tr>
<tr>
<td>Problem Focused Coping</td>
<td>18.57 (4.17)</td>
<td>18.09 (4.39)</td>
<td>15.88 (4.86)</td>
<td>10-40</td>
</tr>
<tr>
<td>Emotion Focused Coping</td>
<td>23.87 (5.25)</td>
<td>25.60 (5.65)</td>
<td>22.98 (6.05)</td>
<td>6-24</td>
</tr>
<tr>
<td>Maladaptive Coping</td>
<td>21.89 (5.57)</td>
<td>20.36 (4.63)</td>
<td>21.00 (4.83)</td>
<td>12-48</td>
</tr>
<tr>
<td>Quantity Social Support</td>
<td>2.28 (1.36)</td>
<td>2.34 (1.70)</td>
<td>2.04 (1.23)</td>
<td>$\geq 0$</td>
</tr>
<tr>
<td>Satisfaction Social Support</td>
<td>4.53 (1.23)</td>
<td>4.87 (1.24)</td>
<td>4.46 (1.43)</td>
<td>1-6</td>
</tr>
</tbody>
</table>

**ANOVA analyses for changes over time**

In order to explore potential changes over time in the experience of caring, a series of repeated-measures ANOVAs were conducted. Specifically, the ANOVAs examined changes over time in the GHQ-12, EDSIS subscales and total EDSIS scale, FQ subscales, total carer needs (the sum of the CaNAM subscales: information needs, support from organisation needs, support for self needs and GP needs), Brief COPE adaptive coping and maladaptive coping subscales, and the SSQ-6 number and satisfaction subscales.

Forty-two carers completed the questionnaire set at all three time points. Table 5.10 presents the means and standards deviations of the complete time point data; that is, for the carers who completed all three questionnaire sets. Post-hoc power analyses for repeated measures ANOVA indicated that the sample size was sufficient to achieve adequate power of .80 (Faul et al., 2007).
Table 5.10

Means and standard deviations for included variables in ANOVAs (n = 42)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time One</th>
<th>Time Two</th>
<th>Time Three</th>
</tr>
</thead>
<tbody>
<tr>
<td>GHQ-12</td>
<td>17.83 (6.44)</td>
<td>14.79 (6.56)</td>
<td>16.48 (8.00)</td>
</tr>
<tr>
<td>Nutrition</td>
<td>18.90 (6.21)</td>
<td>17.29 (6.59)</td>
<td>17.60 (7.64)</td>
</tr>
<tr>
<td>Guilt</td>
<td>9.05 (4.37)</td>
<td>7.88 (5.08)</td>
<td>8.12 (5.31)</td>
</tr>
<tr>
<td>Dysregulated Behaviour</td>
<td>11.00 (5.81)</td>
<td>10.12 (6.55)</td>
<td>9.88 (6.65)</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>7.43 (4.30)</td>
<td>6.64 (3.74)</td>
<td>6.26 (4.12)</td>
</tr>
<tr>
<td>Total EDSIS</td>
<td>46.38 (14.93)</td>
<td>41.93 (16.14)</td>
<td>41.86 (17.96)</td>
</tr>
<tr>
<td>Critical Comments</td>
<td>26.50 (5.63)</td>
<td>24.00 (6.04) *</td>
<td>24.62 (6.21) †</td>
</tr>
<tr>
<td>Emotional Overinvolvement</td>
<td>31.14 (3.52)</td>
<td>28.76 (4.44) *</td>
<td>28.05 (4.84) †</td>
</tr>
<tr>
<td>Total Needs</td>
<td>23.93 (13.36)</td>
<td>30.60 (14.19) *</td>
<td>30.14 (13.97) †</td>
</tr>
<tr>
<td>Adaptive Coping</td>
<td>42.93 (8.41)</td>
<td>43.38 (8.38)</td>
<td>39.02 (9.67) †</td>
</tr>
<tr>
<td>Maladaptive Coping</td>
<td>21.98 (5.36)</td>
<td>20.48 (4.72)</td>
<td>20.83 (4.76)</td>
</tr>
<tr>
<td>Quantity Social Support</td>
<td>2.25 (1.35)</td>
<td>2.32 (1.76)</td>
<td>2.09 (1.21)</td>
</tr>
<tr>
<td>Satisfaction Social Support</td>
<td>4.52 (1.18)</td>
<td>4.80 (1.25)</td>
<td>4.54 (1.35)</td>
</tr>
</tbody>
</table>

Note. *significant difference from Time One to Time Two; †significant difference from Time One to Time Three.

Carer burden and psychological distress

In terms of psychological distress, a repeated measures ANOVA approached significance, $F(2, 82) = 3.04, p = .053, \eta^2 = .07$. 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 ($F(1, 41) = 7.77, p < .05, \eta^2 = .16$). There were no significant changes in the carer burden subscales; however, social isolation approached significance for a decrease between Time One and Time Three ($F(1, 41) = 3.95, p = .054$). Lastly, there were no significant
differences in the total carer burden scale; however, the decrease from Time One to Time Two approached significance \((F_{(1, 41)} = 3.82, p = .057)\).

**Expressed emotion**

For expressed emotion, the repeated measures ANOVA indicated a significant change in critical comments \((F_{(2, 82)} = 5.14, p < .01, \eta^2 = .11)\). 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 \((F_{(1, 41)} = 10.99, p < .01, \eta^2 = .22)\) and Time One to Time Three \((F_{(1, 41)} = 4.14, p < .05)\). Similarly, a repeated measures ANOVA showed a significant change in emotional overinvolvement \((F_{(2, 82)} = 11.06, p < .001, \eta^2 = .22)\). 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 \((F_{(1, 41)} = 11.38, p < .01, \eta^2 = .22)\) and Time One to Time Three \((F_{(1, 40)} = 15.78, p < .001, \eta^2 = .28)\).

**Carer needs, coping strategies and social support**

A repeated measures ANOVA (Huynh-Feldt correction) revealed a significant change in total carer needs \((F_{(2, 73)} = 8.95, p < .01, \eta^2 = .18)\). Simple contrasts (with Time One as the reference category) showed a significant reduction from Time One to Time Two \((F_{(1, 41)} = 12.88, p < .01, \eta^2 = .24)\) and Time One to Time Three \((F_{(1, 41)} = 9.71, p < .01, \eta^2 = .19)\). In relation to coping strategies, a repeated measures ANOVA indicated a significant change in adaptive coping \((F_{(2, 82)} = 7.64, p < .01, \eta^2 = .16)\). Simple contrasts (with Time One as the reference category) revealed a significant reduction in use of adaptive coping strategies from Time One to Time Three \((F_{(1, 41)} = 7.56, p < .01, \eta^2 = .16)\). 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.
**Pearson’s correlations**

In order to test hypothesis five and six regarding the exploration of variables negatively correlated with carer burden and carer psychological distress, Pearson’s correlations were conducted. However, these correlations must be interpreted with caution, as the sample size was insufficient to achieve minimum acceptable power of .80 (Faul et al., 2007).

**Negative correlations with carer burden and psychological distress**

As seen in Table 5.11, there were no significant negative correlations between carer burden and quantity of social support, satisfaction with social support or use of adaptive coping strategies at Time One. Similarly, at Time One, there were no significant correlations between psychological distress and quantity of social support, satisfaction with social support or use of adaptive coping strategies. At Time Two, there was a significant negative correlation between the quantity of social support and psychological distress, indicating that the more people carers have in their support network the less distress they report. There were no significant correlations between psychological distress and satisfaction with social support or adaptive coping. Similarly, at Time Two there were no significant correlations between carer burden and quantity of social support, satisfaction with social support or use of adaptive coping strategies. Lastly, at Time Three, quantity of social support was significantly, negatively correlated with both carer burden and carer psychological distress, indicating that the more people in the carers’ social network, the less burden and distress experienced.
Table 5.11  
*Pearson’s correlations between carer burden and psychological distress and social support and adaptive coping at all three time points*

<table>
<thead>
<tr>
<th></th>
<th>Time One (n = 56)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Quantity of social support</td>
<td>Satisfaction with social support</td>
<td>Adaptive coping</td>
</tr>
<tr>
<td>Carer burden</td>
<td>-.10</td>
<td>-.22</td>
<td>-.14</td>
</tr>
<tr>
<td>Psychological distress</td>
<td>-.02</td>
<td>-.18</td>
<td>.07</td>
</tr>
<tr>
<td></td>
<td>Time Two (n = 45)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quantity of social support</td>
<td>Satisfaction with social support</td>
<td>Adaptive coping</td>
</tr>
<tr>
<td>Carer burden</td>
<td>-.16</td>
<td>-.00</td>
<td>-.09</td>
</tr>
<tr>
<td>Psychological distress</td>
<td>-.30*</td>
<td>-.24</td>
<td>-.24</td>
</tr>
<tr>
<td></td>
<td>Time Three (n = 42)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quantity of social support</td>
<td>Satisfaction with social support</td>
<td>Adaptive coping</td>
</tr>
<tr>
<td>Carer burden</td>
<td>-.33*</td>
<td>-.21</td>
<td>-.01</td>
</tr>
<tr>
<td>Psychological distress</td>
<td>-.56**</td>
<td>-.19</td>
<td>-.15</td>
</tr>
</tbody>
</table>

*p < .05; **p < .01; ***p < .001.

Positive correlations with carer burden and psychological distress

Pearson’s correlations were also conducted to test hypothesis seven and eight, which concerned exploring variables positively correlated with carer burden and carer psychological distress. As seen in Table 5.12, at Time One there were significant positive correlations between carer burden and critical comments, emotional overinvolvement, maladaptive coping strategies, and sufferer purging behaviour. There was also a significant negative correlation between carer burden and carer needs. As such, carers who have a high level of expressed emotion, use more maladaptive coping strategies and have a high level of unmet needs report a greater level of burden. Further, at Time One carers who report high levels of emotional overinvolvement and higher use of maladaptive coping strategies report higher levels of psychological distress.
At Time Two, there were significant positive correlations between carer burden and critical comments, emotional overinvolvement, maladaptive coping strategies, and patient symptoms (including fear of fatness, binge eating, and purging behaviour). Further, there was a significant negative correlation between carer burden and total needs. These results indicate that carers who have higher expressed emotion, use more maladaptive coping strategies, care for someone with greater symptom severity, and have unmet needs report a greater level of carer burden. In regards to psychological distress, at Time Two there were significant positive correlations between psychological distress and critical comments, emotional overinvolvement, and maladaptive coping.

At Time Three, carer burden was significantly, positively correlated with critical comments, emotional overinvolvement, maladaptive coping, binging behaviour, and purging behaviour, and perceived fear of fatness in the patient. Further, there was a significant negative correlation between carer burden and total needs. Thus, at Time Three, carers who are high on expressed emotion, use maladaptive coping strategies, report a higher level of fear of fatness, binging and purging in the patient, and have unmet needs report a greater extent of carer burden. Lastly, at Time Three, psychological distress was significantly, positively correlated with emotional overinvolvement, maladaptive coping strategies and whether the patient described themselves as fat.
Table 5.12

Pearson’s correlations between carer burden and psychological distress and predictor and outcome variables at all three time points

<table>
<thead>
<tr>
<th></th>
<th>Time One (n = 56)</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CC</td>
<td>EOI</td>
<td>Maladaptive coping</td>
<td>Fear of fatness</td>
<td>Describe as fat</td>
<td>Binge</td>
<td>Purge</td>
<td>Contact Hours</td>
<td>Total needs</td>
</tr>
<tr>
<td>Carer burden</td>
<td>.44**</td>
<td>.36**</td>
<td>.42**</td>
<td>.22</td>
<td>.13</td>
<td>.26</td>
<td>.39*</td>
<td>.13</td>
<td>-.53**</td>
</tr>
<tr>
<td>Psychological distress</td>
<td>.26</td>
<td>.46**</td>
<td>.46**</td>
<td>.10</td>
<td>.19</td>
<td>-.06</td>
<td>.05</td>
<td>.28</td>
<td>-.17</td>
</tr>
</tbody>
</table>

|                  | Time Two (n = 45) |          |          |          |          |          |          |          |          |
|                  | CC                | EOI      | Maladaptive coping | Fear of fatness | Describe as fat | Binge | Purge | Contact Hours | Total needs |
| Carer burden     | .53***            | .61***   | .51***   | .36*     | .29      | .43**    | .40**    | -.04     | -.34*     |
| Psychological distress | .33*             | .62***   | .34*     | .15      | .20      | .15      | .12      | .02      | -.17      |

|                  | Time Three (n = 43) |          |          |          |          |          |          |          |          |
|                  | CC                | EOI      | Maladaptive coping | Fear of fatness | Describe as fat | Binge | Purge | Contact Hours | Information needs |
| Carer burden     | .48**             | .72**    | .49**    | .45*     | .19      | .41**    | .47**    | .15      | -.45**    |
| Psychological distress | .24             | .45**    | .40**    | .29      | .33*     | .10      | -.05     | .07      | -.23      |

*p < .05; **p < .01; ***p < .001.
Multiple regression analyses

The next set of analyses was conducted in order to test the cross-sectional and longitudinal prediction of carer burden and psychological distress. While path analysis is the most appropriate statistical test for testing hypotheses nine and 10 (Yager, 2007), the sample size was insufficient to be able to conduct such analysis. As such, a series of multiple regression analyses were conducted to test hypothesis nine and 10. Both cross-sectional and longitudinal analyses were conducted in order to determine the predictors of carer burden and psychological distress. Due to the small sample size, post-hoc power analyses were conducted to determine the maximum number of predictors to achieve a power of at least .80 (Faul et al., 2007). 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 sizes taken from the $n$ at Time One, Time Two, and Time Three.

For Time One, the maximum number of cross-sectional predictors that resulted in a minimum acceptable power was seven. For Time Two and Time Three, the maximum number of cross-sectional predictors resulting in adequate power was four. The chosen predictors for Time One were: 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. Total expressed emotion, maladaptive coping, and total needs were chosen due to having a 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, rather than quantity, of social support being the stronger predictor of carer burden (Olshevski et al., 1999). Lastly, perceptions of sufferer confidence and importance to change, and contact hours, were chosen as an indicator of symptom severity. The chosen predictors for Time Two and Time Three were: satisfaction with social support, total expressed emotion, maladaptive coping, and total needs. As with Time One, the predictor
variables were chosen on the basis of magnitude of correlation with burden and psychological distress in the current study, as well as prior theory and research. Standard multiple regression analyses were conducted for Time One, Time Two and Time Three.

Cross-sectional prediction of carer burden

Table 5.13 presents the B-weights, β-weights, and sr² for the cross-sectional prediction of carer burden at Time One, Time Two and Time Three. At Time One, the regression model was significant ($R^2 = .48$, $p < .001$; Adjusted $R^2 = .39$). Both total expressed emotion and total needs were significant unique predictors. At Time Two, the regression model was significant ($R^2 = .50$, $p < .001$; Adjusted $R^2 = .45$), with maladaptive coping and expressed emotion significant unique predictors. At Time Two, total needs also approached significance as a unique predictor ($p = .06$). At Time Three, the regression model was significant ($R^2 = .58$, $p < .001$; Adjusted $R^2 = .53$), with maladaptive coping, expressed emotion and total needs all significant unique predictors.
Table 5.13

*Standard multiple regression analysis for the cross-sectional prediction of carer burden*

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Time One (n = 56)</th>
<th>Time Two (n = 45)</th>
<th>Time Three (n = 43)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>β</td>
<td>sr²</td>
</tr>
<tr>
<td>Satisfaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>with social support</td>
<td>1.01</td>
<td>.08</td>
<td>.01</td>
</tr>
<tr>
<td>Total expressed emotion</td>
<td>.67</td>
<td>.34*</td>
<td>.08</td>
</tr>
<tr>
<td>Maladaptive coping</td>
<td>.57</td>
<td>-.19</td>
<td>.03</td>
</tr>
<tr>
<td>Total needs</td>
<td>-.47</td>
<td>-.42**</td>
<td>.14</td>
</tr>
<tr>
<td>Important to change</td>
<td>1.23</td>
<td>.25</td>
<td>.04</td>
</tr>
<tr>
<td>Confidence can change</td>
<td>-.63</td>
<td>-.11</td>
<td>.04</td>
</tr>
<tr>
<td>Contact hours</td>
<td>.03</td>
<td>.12</td>
<td>.02</td>
</tr>
</tbody>
</table>

*p < .05, ** p < .01, † approached significance.

Cross-sectional prediction of psychological distress

Table 5.14 presents the B-weights, β-weights, and sr² for the cross-sectional prediction of psychological distress at Time One, Time Two and Time Three. At Time One, the regression model was significant ($R^2 = .32, p < .05$; *Adjusted $R^2 = .20$*). At Time One, only maladaptive coping was a significant unique predictor. At
Time Two, the regression model was significant ($R^2 = .27, p < .05$; Adjusted $R^2 = .19$), with only total expressed emotion approaching significance as a unique predictor ($p = .06$). At Time Three, the regression model was significant ($R^2 = .23, p < .05$; Adjusted $R^2 = .15$), with maladaptive coping approaching significance as a unique predictor ($p = .054$).

Table 5.14

*Standard multiple regression analysis for the cross-sectional prediction of psychological distress*

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Time One ($n = 56$)</th>
<th>Time Two ($n = 45$)</th>
<th>Time Three ($n = 43$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>$\beta$</td>
<td>$sr^2$</td>
</tr>
<tr>
<td>Satisfaction with social support</td>
<td>-.03</td>
<td>-.01</td>
<td>.00</td>
</tr>
<tr>
<td>Total expressed emotion</td>
<td>.17</td>
<td>.21</td>
<td>.03</td>
</tr>
<tr>
<td>Maladaptive coping</td>
<td>.43</td>
<td>-.37*</td>
<td>.10</td>
</tr>
<tr>
<td>Total needs</td>
<td>.01</td>
<td>.03</td>
<td>.00</td>
</tr>
<tr>
<td>Important to change</td>
<td>.01</td>
<td>.01</td>
<td>.00</td>
</tr>
<tr>
<td>Confidence can change</td>
<td>-.32</td>
<td>-.06</td>
<td>.00</td>
</tr>
<tr>
<td>Contact hours</td>
<td>.02</td>
<td>.23</td>
<td>.05</td>
</tr>
</tbody>
</table>

*$p < .05$, † approached significance.
Longitudinal prediction of carer burden and psychological distress

For the longitudinal regression analyses, power calculations revealed that the maximum number of predictors to achieve acceptable power was four due to the sample size at Time Two being 45 participants, and at Time Three 43 participants. The chosen predictors were: satisfaction with social support, total expressed emotion, maladaptive coping, and total needs. These predictors were chosen in order to maintain consistency with the cross-sectional multiple regression analyses.

Longitudinal prediction of carer burden

Table 5.15 presents the B-weights, β-weights, and sr² 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. 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 also significant ($R^2 = .23$, $p < .05$; Adjusted $R^2 = .15$), with maladaptive coping a significant unique predictor and total needs approaching significance as unique predictor ($p = .08$). Similarly, predictor variables were taken from Time Two in order 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.
Table 5.15

*Standard multiple regression analysis for the longitudinal prediction of carer burden*

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Time One to Time Two</th>
<th>Time One to Time Three</th>
<th>Time Two to Time Three</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>β</td>
<td>sr²</td>
</tr>
<tr>
<td>Satisfaction with social support</td>
<td>.26</td>
<td>.02</td>
<td>.00</td>
</tr>
<tr>
<td>Total expressed emotion</td>
<td>.73</td>
<td>.36*</td>
<td>.10</td>
</tr>
<tr>
<td>Maladaptive coping</td>
<td>.20</td>
<td>.07</td>
<td>.01</td>
</tr>
<tr>
<td>Total needs</td>
<td>-.24</td>
<td>-.21</td>
<td>.04</td>
</tr>
</tbody>
</table>

*p < .05, † approached significance.

**Longitudinal prediction of psychological distress**

Additionally, satisfaction with social support, total expressed emotion, maladaptive coping, and total needs at Time One were used to predict Time Two and Time Three psychological distress scores. 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. This regression model was not significant.

**Cross-sectional mediation analyses**

The last set of quantitative analyses concerned the examination of maladaptive coping strategies and social support as mediators of both carer burden and psychological distress. A full test of the mediation model proposed in Chapter
three, using path analysis, was not possible due to the small sample size. Therefore, a series of mediation analyses were conducted using the Baron and Kenny (1986) method for testing mediation in order to examine hypothesis 11. This method stipulates that four criteria be met for mediation:

1. The independent variable (IV) must be significantly related to the mediator (path a)
2. The IV must be significantly related to the dependent variable (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’)

These pathways are depicted in Figure 5.1. 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. The Baron and Kenny (1986) method of mediation is tested using a series of regression analyses.

![Figure 5.1. Baron and Kenny (1986) method for evaluating potential mediators.](image)

Given the limitations of the Baron and Kenny (1986) method of testing mediation, such as low power, high Type I error rate and inability to determine if the indirect effect is significantly different from zero, the Sobel test and bootstrapping were also used. The Sobel test determines the significance of an indirect effect by using the product of the IV to mediator path and the mediator to DV path (Preacher
& Hayes, 2004; Sobel, 1982), and addresses the limitations with the Baron and Kenny (1986) method. The significance of the indirect is determined by a critical ratio for the Sobel test, calculated with the product of the two paths and standard error, and compared an alpha level of .05. However, the Sobel test is very conservative (MacKinnon, Warsi, & Dwyer, 1995).

Bootstrapping is a technique that does not require the assumption of normality to be met, and can be applied to small samples of less than 20 (Preacher & Hayes, 2004). Bootstrapping is a process whereby a very large number of replications are conducted, with samples drawn with replacement from a given data set (Tabachnick & Fidell, 2001). Bootstrapping provides an estimate for a 95% confidence interval (CI) for an indirect effect size (Preacher & Hayes, 2004). If the CI is found to include zero, then it is interpreted as a non-significant indirect effect. A more robust result is calculated when a larger number of replications are conducted, as greater power is achieved (Davidson & MacKinnon, 2000). Therefore, the number of replications chosen for the following analyses is 5000. Both the Sobel statistic and bootstrapping were conducted using the Sobel macro for SPSS developed by Preacher and Hayes (2004).

Maladaptive coping as a mediator between expressed emotion and carer burden

The first mediation analysis conducted examined the relationship between expressed emotion and carer burden as mediated by maladaptive coping at Time One. Maladaptive coping, rather than adaptive coping, was chosen as maladaptive coping was consistently significantly correlated with carer burden at all three time points. Figure 5.2 presents β-weights for the 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. Lastly, bootstrapping provided 95% confidence intervals ($CI = .00$ to $.52$), approached significance for an indirect effect.
These analyses were repeated for Time Two and Time Three. Partial mediation was found at Time Two using the Baron and Kenny (1986) method (see Figure 5.3). The Sobel test approached significance for an indirect effect ($z = 1.83; SE = .11, p = .06$) and bootstrapping approached significance for an indirect effect ($CI = .01$ to $.47$). At Time Three, partial mediation was apparent using the Baron and Kenny (1986) method (see Figure 5.4). The Sobel test indicated a non-significant indirect effect ($z = 1.68; SE = .12, p = .09$) and bootstrapping approached significance for an indirect effect ($CI = -.05$ to $.64$).

**Figure 5.2.** Model showing partial mediation using the Baron and Kenny (1986) method by maladaptive coping on the relationship between expressed emotion and burden at Time One.

* $p < .05$, ** $p < .01$, *** $p < .001$.

**Figure 5.3.** Model showing partial mediation using the Baron and Kenny (1986) method by maladaptive coping on the relationship between expressed emotion and burden at Time Two.

* $p < .05$, ** $p < .01$, *** $p < .001$. 
Figure 5.4. Model showing partial mediation using the Baron and Kenny (1986) method by maladaptive coping on the relationship between expressed emotion and burden at Time Three.

* $p < .05$, ** $p < .01$, *** $p < .001$.

Maladaptive coping as a mediator between expressed emotion and psychological distress

The second set of mediation analyses examined the mediating role of maladaptive coping on the relationship between expressed emotion and carer psychological distress. At Time One, this relationship was found to be fully mediated by maladaptive coping using the Baron and Kenny (1986) method (see Figure 5.5). The Sobel test indicated a significant indirect effect ($z = 2.05; SE = .09, p < .05$), and bootstrapping approached significance for an indirect effect ($CI = .02$ to .23). At Time Two, maladaptive coping did not significantly contribute to the model (with expressed emotion included), therefore mediation analyses were unable to be conducted. At Time Three, Baron and Kenny (1986) analyses revealed full mediation (see Figure 5.6). However, the Sobel test ($z = 1.51; SE = .06, p > .05$) and bootstrapping ($CI = -.06$ to .35) method for an indirect effect were both non-significant.
Social support as a mediator between expressed emotion and both carer burden and psychological distress

The third 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. As satisfaction with social support did not significantly contribute
to the model at Time One, Time Two or Time Three, mediation analyses were unable to be conducted. The fourth set of mediation analyses to be conducted examined the mediating role of satisfaction with social support on the relationship between expressed emotion and psychological distress. Again, as satisfaction with social support did not significantly contribute to the model at Time One, Time Two or Time Three, mediation analyses were unable to be conducted.

**Maladaptive coping as a mediator between carer needs and carer burden**

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 Baron and Kenny (1986) method, a partial mediation model was found at Time One (see Figure 5.7). However, both the Sobel test ($z = -1.62, p > .05$) and bootstrapping ($CI = -.26$ to $.00$) indicated non-significant indirect effects. At Time Two and Time Three, total needs did not significantly predict maladaptive coping, therefore, mediation analyses were unable to be conducted.

* $p < .05$, ** $p < .01$, *** $p < .001$. 

**Figure 5.7.** Model showing partial mediation using the Baron and Kenny (1986) method by maladaptive coping on the relationship between total needs and psychological distress at Time One.
Maladaptive coping as a mediator between carer needs and psychological distress

The sixth set of mediation analyses examined the mediating role of maladaptive coping on the relationship between total carer needs and psychological distress. At Time One, Time Two, and Time Three total needs did not significantly predict psychological distress, therefore, mediation analyses were unable to be conducted.

Social support as a mediator between carer needs and both carer burden and psychological distress

The seventh set of mediation analyses examined the mediating role of satisfaction with social support on the relationship between total carer needs and carer burden. At Time One and Time Two, total needs did not significantly predict satisfaction with social support, and satisfaction with social support did not significantly contribute to mediation model, therefore, analyses were unable to be conducted. At Time Three, satisfaction with social support did not significantly predict total carer burden, therefore, analyses were unable to be conducted.

The final set of mediation analyses examined the mediating role of satisfaction with social support on the relationship between total carer needs and psychological distress. At Time One and Time Two, total needs did not significantly predict satisfaction with social support, and satisfaction with social support did not significantly contribute to mediation model, therefore, analyses were unable to be conducted. At Time Three, satisfaction with social support did not significantly predict total carer psychological distress; therefore, analyses were unable to be conducted.

Qualitative results

In conjunction to the quantitative scales, participants provided written qualitative information about their experiences as carers of someone with an eating
disorder. This information was collected in order to allow for a more in-depth understanding of the ongoing difficulties experienced by eating disorder carers. However, the use of written responses does not provide the opportunity to follow up on responses or ask for further clarification which focus groups or face-to-face interviews allow. Participants’ written responses for the questions regarding changes over time were analysed using a template analysis design (King, 1998). For the changes over time, templates were developed to reflect a priori themes of whether the changes in carers’ situations worsened, improved or did not change. Further, responses were also examined with a priori themes in relation to whether the carer indicated change in themselves only, the sufferer only, or both themselves and the person they care for. The questions regarding experiences with treatment services were explored for common themes. The qualitative analysis was checked by another researcher who was independent of the current study. The independent researcher confirmed the themes chosen. Further, the independent coding of the qualitative responses correlated highly with the original coding.

**Experiences with treatment services**

Approximately two-thirds of carers indicated that treatment for the eating disorder did not begin early enough or that there was insufficient follow-up treatment. This late initiation of treatment was attributed to a number of issues including a) denial, or a lack of insight into the illness from both sufferer and carer, b) an absence of available services, c) barriers to treatment access, such as prohibitive costs, and d) health professionals having a lack of knowledge about eating disorders.

Carers reported that the person they were caring for often hid their symptoms or refused to have treatment, thus delaying the onset of help. Of note, all BN carers reported that treatment was delayed; however, the reasons for late initiation of treatment were similar to that of AN carers. The patients with an eating disorder also often denied that they had any problems in conjunction with refusal of treatment. This denial led to feelings of frustration and anxiety about the situation. Carers wanted to provide any help they could, however, were unable to due to the refusal on the part of the sufferers. In addition, a number of carers also indicated that they
themselves missed the signs of the eating disorder. As such, there was slow recognition as to the seriousness of the illness. They felt that they should have noticed it earlier and, therefore, would have been able to start treatment earlier. The lack of recognition on the part of the carers may also have occurred due to the sufferers hiding their symptoms. Carers’ perceptions that they could have done something were accompanied by feelings of guilt.

“Once we identified the problem, it took us at least another 9 months to convince our daughter to accept/let us get help for her. She still resists now – believes she doesn’t need it” (Participant 010)

“...Son found many reasons why all treatments didn’t apply to him.” (Participant 039)

“...we should have taken action sooner in hindsight, rather than wait until it took the school to ring us and say they were worried.” (Participant 013)

“I think that we (her parents) could have sought treatment earlier, but we were in denial...” (Participant 006)

While the initiation of treatment may have been delayed due to both the sufferers and carers not recognising the symptoms for what they were, carers also reported difficulty accessing treatment due to the expensive nature of the treatment options or simply nothing being available for the person they care for within their local area. Particularly, rural areas tended to have problems in regards to treatment services, with a lack of understanding and knowledge about eating disorders. A level of cynicism and mistrust could be seen in the responses. In addition, the lack of follow up treatment was also attributed to the absence of available treatment options. This absence of treatment services resulted in the need to travel long distances to access health professionals; this added to the feelings of burden for the carers due to
the time invested in taking their loved one to the appropriate health professionals and
treatment services. Again, this led to feelings of frustration and helplessness.
Further, carers felt ignored and isolated due to the lack of services available in their area.

“...If you don’t have private health care and make a big noise, you
WILL be overlooked” (Participant 024)

“Live too far away for treatments to be offered, daughter travels 1400km round
trip each fortnight to visit psychiatrist.” (Time Three, Participant 037)

In addition, the length of waiting lists for treatment services left carers
exasperated and impatient. There were often long delays in treatment; sometimes up
to a year; before carers could get them help they desperately wanted for their loved
one. Further compounding the problem of long waiting lists, carers identified
problems with the both the public and private health systems in relation to providing
treatment and support. There was a high degree of disappointment in these services,
leaving carers feeling let down and cynical about the health systems. These
difficulties were felt more for carers of boys with an eating disorder. There did not
appear to be treatment options that were suitable for males with an eating disorder; as
a consequence, carers felt helpless and lost. In relation to the public health system,
there was often simply no option available for patients with an eating disorder.
Further, due to the high cost of private health services, such services were frequently
not a viable alternative. Lastly, despite expectations due to the high costs that private
health care would provide superior treatment options, there was no guarantee that
private services would be able to provide better help than public health options. This
lack of efficacy added to the feelings of disappointment expressed by carers.

“Due to insufficient funding of certain public health outpatient
facilities...there are no outpatient programs...she [my daughter] was offered
no outpatient care and totally relapsed due to a total lack of support” (Time
Two, Participant 055)
“...have had to follow-up with private consultations for eating disorder...Public health system totally useless” (Time Three, Participant 004)

“...Seemed to be no available help for boys. Ended up in an expensive, unsuccessful private program after program.” (Participant 040)

“NOTHING available in Bendigo [rural Victoria, Australia] at all...we are getting assistance from CAMHS [Child and Adolescent Mental Health Service], but they are not knowledgeable re. eating disorders” (Time One, Participant 004)

“In rural Victoria [Australia] resources are stretched and the quality is not as high a standard as in the city” (Time Two, Participant 051)

Adding to the problems with the health systems in general, a number of carers indicated that the first professional they sought help from did not recognise the symptoms presented by the person they are caring for were eating disorder related. Therefore, they felt that professionals such as GPs or nurses did not understand the eating disorders comprehensively enough. There was a sense of frustration and helplessness from the carers; they felt that there was no-one to turn to, including professionals from who support and understanding was expected. Carers felt there was a high level of ignorance when they approached medical professionals about their loved ones’ eating problems. As such, carers felt let down by health professionals, and reported a degree of anger towards them. Further, carer concerns about their loved one were downplayed and this added to their feelings of frustration.

“Medical professionals I approached in the 1st instance (GP) said there was ‘nothing’ I could do...2nd GP didn’t understand enough!...We lost valuable time...” (Participant 014)
“She was ignored by the nurse initially when I took her along to see her about her fear of weight gain – the nurse told her to ‘pull her socks up and eat sensibly’...it took 2 years to be referred to these idiots” (Participant 049)

“...we saw so many people who had little idea about anorexia. i.e. doctors, psychologists, etc.” (Participant 033)

Lastly, carers were asked if they were being sufficiently informed regarding the treatment of the person they care for at all three time points. Over the three time points, the number of carers indicating they were not being sufficiently informed about treatment options decreased. The patterns found were similar across differing diagnoses and carer relationship to sufferer. Therefore, over time carers felt that they were being more informed of the treatment that their loved one was undergoing. This increased sense of being informed about treatment may be due to carer becoming more assertive and making sure that they found out what was going on. This information may be coming from the health professionals or the sufferer themselves.

The common theme in all three time points was a lack of information due to the person they were caring for being over the age of 18. This resulted in carers feeling like they were not involved enough in the treatment that their loved one was undertaking. Further, carers recognised that their loved ones did not have the ability to cope and, therefore, were surprised that they were left uninformed. As such, there were feelings of disappointment due to the lack of information they, as carers, received.

“We are told that she is over 18, so is independent and we don’t get told a lot, even though she can’t cope on her own” (Time One, Participant 054)

“Daughter is 20 and treated as an adult, though I am full time carer I am rarely informed of changes...” (Time Two, Participant 008)
“Due to privacy issues, I was unable to find out how my daughter was doing and what treatment she was getting” (Time One, Participant 031)

Carer perceptions of change over time

Carers were asked to provide information about how their situation had changed since the completion of their previous questionnaire. These responses were examined for improvements, worsening, or no change in their situation. Further, the carer responses were divided into those who focussed on the changes in the sufferer only, change in themselves only, or focussed on both themselves and the sufferer. Table 5.16 provides the number and percentage of carers in each of these categories. As shown, the majority of carer focussed on the sufferer only, with most saying that their situation had worsened or not changed. Further, these patterns were similar across diagnosis and carer relationship to sufferer.

Table 5.16

Number (and percentage) of types of change reported by carers

<table>
<thead>
<tr>
<th>Time Point</th>
<th>Change in situation</th>
<th>Change in whom</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Situation improved</td>
<td>No change</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Situation worse</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Focus on self</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Focus on sufferer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Focus on both</td>
</tr>
<tr>
<td>Time Two (n = 45)</td>
<td>21 (47)</td>
<td>11 (24)</td>
</tr>
<tr>
<td></td>
<td>13 (29)</td>
<td>8 (18)</td>
</tr>
<tr>
<td></td>
<td>26 (58)</td>
<td>11 (24)</td>
</tr>
<tr>
<td>Time Three (n = 42)</td>
<td>16 (38)</td>
<td>12 (29)</td>
</tr>
<tr>
<td></td>
<td>14 (33)</td>
<td>6 (14)</td>
</tr>
<tr>
<td></td>
<td>26 (62)</td>
<td>10 (24)</td>
</tr>
</tbody>
</table>

Carers who perceived an improvement in the sufferers’ situation tended to report progress in treatment, weight gain or sufferer independence. As such, the focus for the carers was on tangible aspects of the disorder. There was an emphasis on concrete behavioural or somatic improvements in the sufferer, rather than any cognitive changes. Carers were happy when their loved one found some
independence and self-motivation as it lessened the burden on them. Such changes in
the person with an eating disorder impressed carers, and they felt more confident that
their loved one would fully recover. The positive attitudes expressed by the sufferer
helped to bolster the carer, and enabled the carer to cope better with the situation and
their role.

“My daughter has forged ahead in a self-motivated way, has taken charge of
her recovery and has made constant and steady progress.” (Time Two,
Participant 055)

“Daughter improving, gaining weight, behavioural improvements” (Time
Two, Participant 002)

“My sister has made a lot of progress in her recovery; has been able to
maintain a healthy weight…” (Time Two, Participant 032)

Those carers who perceived changes for the worse wrote about changes in the
eating disorder behaviours or treatments. Additionally, the diagnosis of the person
they cared for sometimes changed. A change in diagnosis, such from AN to BN, was
confusing for the carers; they found it difficult to understand why and how such
changes could occur. Further, finding out that the person they were caring for had a
co-morbid diagnosis, such as depression or bipolar, made the situation worse for
carers. They perceived themselves as now having to cope with a new set of problems
and difficulties related to the additional diagnosis. Carers also reported difficulties
finding enough support for themselves, and consequently felt isolated and alone.

“Anorexia changed to bulimia (very confusing)....hasn’t been
hospitalised....but harder at home...” (Time Three, Participant 007)

“Daughter has been hospitalised for the last 14 weeks, and she had been
additionally diagnosed with bipolar disorder” (Time Two, Participant 037)
“Our daughter’s condition has deteriorated. She has lost weight...she continues to exercise excessively...she refuses all attempts to encourage her to seek treatment” (Time Three, Participant 016)

Carers who wrote about changes within themselves were both positive and negative. As time went on, some carers some became more settled in their role and had a better understanding of what they could do, including the limits of the help they could provide. Other carers sought help from eating disorder carer support groups or workshops. As such, they searched beyond the health professionals for advice and to learn more about what they can do to help their loved one and also to how to help themselves. Also, by finding others in the same situation as themselves they were able to lean on these other carers for support and help, knowing that they fully understand what it is like to care for someone with an eating disorder. In this way, there was a shared understanding and empathy among people in these support groups and workshops. Lastly, by attending support groups and workshops they were able to learn how to cope with their role.

“We have started a support group...and a new person is coming each fortnight which is excellent” (Time Three, Participant 026)

“Attending...training days...Use online forum for support...” (Time Three, Participant 046)

“Aware of my role in the recovery and feeling more settled with that” (Time Two, Participant 052)

However, some carers reported worsening circumstances for themselves. They felt isolated and alone, with little direction as to what they could do. There were feelings of depression and helplessness due to their perceived futile attempts to help both their loved one and themselves. Carers felt anxious about these negative feelings, and were lost as to what they could do to help themselves. Further, they felt pushed away by the person they were caring for, with a degree of resentfulness
directed at them from the sufferer. Further, the chronicity of the eating disorder was exhausting and draining for them due to the ongoing struggles and difficulties associated with the eating disorder.

“Feel depressed and out of control – this person I try to care for...distances herself from me (and everyone) more than ever.” (Time Two, Participant 044)

“I have had less support from as those people closest to me...I have found it harder to be positive and have at times felt quite empty and down.” (Time Three, Participant 008)

Discussion

The aims of the current study were three-fold. The first aim was to determine the predictors of carer burden and psychological distress both cross-sectionally and longitudinally for carers of patients with an eating disorder. Secondly, to determine patterns of change over time within carers of patients with an eating disorder in relation to: burden, psychological distress, social support, coping strategies, specific needs, and expressed emotion. Thirdly, to investigate the role of coping strategies and social support as cross-sectional mediators of carer burden and psychological distress. Lastly, to investigate qualitatively ongoing difficulties that may be experienced by carers. These aims were achieved by using a mixed quantitative and qualitative longitudinal study design. To achieve these aims, carers completed three questionnaires over a period of nine months, providing information regarding demographics, expressed emotion, coping strategies, social support, needs, psychological distress, level of burden and changes that occurred since the previous questionnaire.

The discussion section will evaluate the current findings in relation to both the proposed hypotheses and existing research and theoretical literature presented within Chapter Three. Firstly, a comparison of the current participant demographics to that of past research will be made to evaluate the representativeness of the sample. Secondly, an evaluation of the first four hypotheses relating the changes in the level
of carer burden, expressed emotion, psychological distress and needs over time will be addressed. Thirdly, the relationships between both carer burden and carer psychological distress and coping strategies, expressed emotion, social support, needs and symptom severity, as covered in hypotheses five to nine, will be discussed. Next, an evaluation of hypotheses nine and 10, regarding the cross-sectional and longitudinal prediction of carer burden and psychological distress will occur. Following this, the mediation pathways indicated in hypothesis 11 will be evaluated. Lastly, an discussion regarding the qualitative changes over time will occur.

Sample characteristics

The current research aimed to address the limitations identified with samples within previous research. Past research investigating carer burden has predominately utilised convenience samples; for example, from inpatient settings or volunteer databases. To address this limitation, the current research recruited participants from the community in order to obtain a more representative sample. However, this aim was only partly achieved. The majority of carers in the current study were female, were parents, and living with the sufferer. Further, the majority of the patients being cared for had a diagnosis of AN. Therefore, while a strength of the current sample is that it is community-based, it may not be representative of all eating disorder carer situations due to the lack of variability in diagnoses of the sufferer and carer gender.

Level of carer burden, psychological distress, and predictors

The first four hypotheses relating to the reported level of carer reported burden, psychological distress, expressed emotion and carer needs were supported. At all three time points, carers indicated a moderate level of burden associated with caring for someone with an eating disorder. In particular, carers reported more difficulties in regards to nutritional areas and social isolation as a consequence of their carer role, and lower levels of guilt and disruption due to sufferer dysregulated behaviour. Further, the magnitude of burden in the EDSIS subscales did not change
over the three time points. The level of burden found within the current study is consistent with prior cross-sectional eating disorder carer research (Treasure et al., 2001; Winn et al., 2007; Zabala et al., 2009). However, direct comparisons of level of burden can only be made with two previous studies that have utilised the EDSIS (Sepulveda, Lopez, Todd, et al., 2008; Sepulveda, Whitney, et al., 2008). These two studies reported comparable burden levels to the current study. Therefore, the current study confirms previous research that eating disorder carers experience a high level of burden. Further, the current study shows that this burden is ongoing and does not decrease over time.

Given the inconsistency with past research in regards to level of burden within AN as compared to BN carers (e.g., Graap, Bleich, Herbst, Trostmann, et al., 2008; Santonastaso et al., 1997), it would have been beneficial to examine these diagnosis differences in the current study. This was particularly so, given that Sepulveda, Whitney et al. (2008) found a higher level of burden in BN carers, as compared to AN, using the EDSIS, the burden measure used in the current study. However, as there was a substantially lower number of carer of patients with BN in the sample; therefore, comparative burden analyses between diagnoses were not able to be conducted.

**Psychological distress**

In relation to psychological distress, at all three time points carers reported a moderate level of distress, with no significant change over time. The current study’s findings are consistent with previous research that indicates carers of patients with either AN and BN report moderate levels of psychological distress (e.g., (Sepulveda, Lopez, Todd, et al., 2008; Whitney et al., 2007; Winn et al., 2007). In relation to differential distress experienced by BN and AN carers, examination of GHQ-12 scores across prior eating disorder carer research shows that caring for someone with BN results in lower distress (Graap, Bleich, Herbst, Trostmann, et al., 2008; Winn et al., 2007) than caring for AN (Dimitropoulos et al., 2008; Haigh & Treasure, 2003;
Whitney et al., 2007). However, as with carer burden, due to the low numbers of BN carers in the current study, a comparison between diagnoses could not be made.

**Expressed emotion**

Similarly, expressed emotion was consistently high across all time points. Both critical comments and emotional overinvolvement were above the high cut-off point at all three time points. This level of expressed emotion is consistent with that found by Kyriacou et al. (2008) who also used the Family Questionnaire. It is also consistent with the review by Zabala et al. (2009) who reported a consistent high level of critical comments and emotional overinvolvement for carers of patients with an eating disorder. While, Zabala et al. (2009) indicated that mothers tend to have a higher level of emotional overinvolvement than fathers, there were very few fathers (six) as opposed to mothers (36) in the current study, so a meaningful comparison could not be made. Further, while prior research has indicated that the level of critical comments in carers of patients with AN is relatively low (Hodes & Le Grange, 1993), an exploratory analysis for the current study, with the removal of carers for patients other than AN, did not reduce critical comments and emotional overinvolvement to below the cut off. Therefore, AN carers in the current study report a high level of both critical comments and emotional overinvolvement. However, this difference in findings may be attributable to the different measures used in the research reviewed by Hodes and Le Grange (1993) and the current study.

While there are some issues related to self-report problems with expressed emotion, in that carers may exhibit a social desirability bias (e.g., Winn et al., 2007), the current research aimed to overcome this by utilising a measure that is specifically designed to limit social desirability bias. Given that carers consistently reported levels of critical comments and emotional overinvolvement above the cut-off for high expressed emotion, it can be assumed that they did not exhibit a social desirability bias.
Carer needs

Lastly, carers reported a number of unmet needs, specifically in relation to information about the disorder, treatments and options for professional help. Further, carers’ need for information from GPs was largely unmet, and there was a belief that GPs required more training in relation to eating disorders. In terms of sources of information and support, carers indicated that the most useful sources of help included carer support groups and peer support from others in the same situation. This finding is consistent with prior qualitative research that suggests carers do not necessarily receive adequate support from family members or friends (Cottee-Lane et al., 2004; Winn et al., 2004). That is, while carers recognise that family and friends may offer support, they feel that they do not necessarily fully understand what the carer is experiencing.

The least useful source of information and support was their GP. Given that GPs are generally the first point of contact when getting help with an eating disorder, it is apparent that carers perceive they and the sufferers are not receiving the best advice or care. These quantitative findings were supported by the qualitative items asking carers about their experiences with treatment services. Carers wrote about their frustrations when approaching GPs for help, in that GPs lacked awareness and knowledge about eating disorders. The current findings are also consistent with prior qualitative research showing eating disorder carers want more information in relation to eating disorders, treatment options and prognosis (Graap, Bleich, Herbst, Trostmann, et al., 2008; Haigh & Treasure, 2003; Winn et al., 2004) and practical advice as to what they can do themselves to help and where to access professional and informal support (Whitney et al., 2007).

The perceived need to begin treatment earlier was also clear in the qualitative data. Carers were aware that in many cases it was their inexperience in recognising the signs and symptoms of the eating disorder that contributed to the delayed intervention. However, they were also aware that the lack of knowledge about the disorder on the part of health professionals was also a contributing factor. This contrasted with their expectation that health professionals would possess this
expertise. Previous qualitative research has also reported a slow pattern of discovery by carers of the disorder, and late treatment initiation attributed to a lack of knowledge from medical professionals and GPs (Highet, Thompson, & King, 2005; Perkins et al., 2004; Winn et al., 2004).

Additionally, carers stated that the person they cared for contributed to delays in initiating treatment due to their abject refusal or denial of the seriousness of their situation. The degree to which sufferers hid their symptoms may have also contributed to the slow recognition of the eating disorder on the part of the carers. Previous literature reports denial as a common aspect of eating disorders, with patients often delaying treatment as a result (e.g., Vandereycken, 2006a, 2006b; Yager, 2007). Thus, the current findings reinforce previous findings of denial characteristically exhibited by the sufferers, which subsequently impacts on their carers.

Carers also reported that the cost of treatment was beyond their means, therefore, delaying onset. This prohibitive cost lead to feelings of frustration, disappointment and cynicism towards the health care system. Carers felt that while their loved one desperately needed help, it was unable to be accessed unless they were prepared, and able, to pay substantial amounts of money.

In relation to follow-up treatment, over half of the carers in the current study consistently reported a lack of follow-up options available. The lack of follow up was due to expense of treatments and private medical options only being available in conjunction with no public services. Carers also reported disappointment in the fact that while private health options were costly, there was no guarantee that they would provide superior help to public services. Further, living in a rural or regional area also made it difficult to access appropriate follow-up treatment. This lack of options in rural areas is consistent with Winn et al. (2004) who found a similar lack of eating disorder specialists in rural areas. This lack of support in their local area left carers feeling isolated and helpless. Possible options for carers in rural areas may be to use telephone counselling or online support; these options could provide comprehensive information about treatment options, services in carers’ local area and professional support. Delivery of carer skills-based training via DVD and telephone coaching has
been shown to reduce psychological distress in eating disorder carers (Sepulveda, Lopez, MacDonald, & Treasure, 2008). Therefore, it is feasible that targeted telephone or online support could be beneficial to carers.

Over the course of the nine month data collection period, total carer needs significantly decreased over the three time points in the current study. Carers required less information and support as time went on. As the average length of the sufferer’s diagnosis in the current study was five years, the decrease in needs is interesting. It may be speculated that the carer needs would be highest at during the initial diagnosis phase, with a drop over time as the carer adjusts to their situation. Further, it may be that in completing the questionnaire, carers are self-reflecting on their situation on completion of the first questionnaire and realising that they are in need of more information and support, thus seek it out. The decrease in needs may also be attributed to carers becoming more adjusted to their situation; that is, it is becomes ‘normalised’. Lastly, it may be that carers have a high level of needs in the initial stages of the illness due to a belief that there is a straight forward solution. Over time they may become more realistic, or more resigned, about the chronicity and seriousness of the eating disorder. As such, it is unclear as to why there is a decrease in the level of carer needs. Future research could aim to address this limitation.

The current qualitative responses on questions about carers’ needs and experiences regarding treatment services for eating disorders reflect the quantitative findings. Over the three time points, the number of carers reporting that they were not sufficiently informed of treatment dropped substantially. Therefore, it appears that the carers in the current study are receiving adequate information about their loved one’s treatment, either from the medical professionals or the sufferer themselves. However, it is unlikely that the health system has become more ‘carer friendly’. Rather, it may be that the carers were becoming more assertive in relation to finding out how their loved one was progressing. As such, carers may have started becoming more proactive, and actively seeking information for themselves. Again, it is unclear as to why there is an increase in carers being informed about their loved one’s treatment; future research could aim to explore this further.
However, those who indicated that they did not receive enough information about the treatment of person consistently mentioned privacy and confidentiality issues. For instance, carers of people over the age of 18, even if the sufferer lived at home with them, were not informed of the sufferer’s treatment or progress due to privacy laws. Being excluded from the treatment process left carers feeling frustrated and isolated. They felt that it was their right, as the primary carer, to be told how their loved one was progressing during treatment. As such, it was difficult to reconcile the fact that while the person they were caring for lived at home and were dependent on their care for help, the sufferers’ age meant they, as carers, were not told vital information about treatment progression. This finding is consistent with Winn et al. (2004) who also found that carers were often not informed of the treatment status of their loved one, even if the sufferer lived at home with them.

Coping strategies

While no specific quantitative hypotheses were made, an exploration of coping strategies indicated that carers consistently utilised a high level of emotion-focussed coping, and a relatively low level of problem-focussed coping. This is not surprising as past research indicates that people who are in a stressful situation that they perceive as uncontrollable will use emotion-focussed coping to a greater degree (Lazarus, 1999). Thus, the carers in the current study use strategies that change the way they perceive the situation, rather than change the situation itself. In relation to the adaptiveness of the coping strategies used by carers, both adaptive and maladaptive coping strategies were utilised to a moderate degree. While carers do use adaptive coping strategies (which encompass both problem-focussed and emotion-focussed strategies), they also rely on more maladaptive strategies, such as self-blame, venting and behavioural disengagement. Further, there was a small, but significant, reduction in the use of adaptive coping strategies over the three time points, but no change in the level of maladaptive coping. Therefore, it may be speculated that over time carers become more reliant on maladaptive coping strategies in the face of a lack of progress in the sufferer.
Prior qualitative research indicates that eating disorder carers use both adaptive, such as humour, seeking information or distraction, and maladaptive coping strategies, such as self-blame, however, the magnitude of use has not previously been examined (Perkins et al., 2004; Whitney et al., 2005). Therefore, a strength of the current research is that it shows an equal use of both maladaptive coping and adaptive coping, particularly the emotion focussed aspect of adaptive coping.

Social support

Lastly, an exploration of the level of number of people in carers’ social network and satisfaction with social support was conducted. The current study found that while carers have only two to three people; mainly family members and close friends; they use for informal support, they are moderately satisfied with the support they receive. These findings are consistent with prior qualitative research (Winn et al., 2004). However, while Winn et al. (2004) indicated that family and friends may be able to provide only limited help, the current study found that carers were satisfied with the social support they received. This difference may be due to the general nature of the social support questionnaire used in the current study; if carers had been asked to rate their satisfaction on direct support for their caring role, it may be that they would have reported lower levels of satisfaction.

Variables associated with eating disorder carer burden and psychological distress

Hypothesis five and six regarding anticipated correlations between measured variables were partially supported. In relation to the predicted negative correlations with carer burden and psychological distress, only quantity of social support was significantly related to psychological distress at Time Two and burden and psychological distress at Time Three. The lack of correlation between satisfaction with social support and burden and psychological distress is surprising due to past research indicating that satisfaction is the stronger predictor of outcome (e.g., Pakenham et al., 2007). This lack of relationship with satisfaction with social
support may be due to the measure utilised not adequately capturing social support specific to the carer situation. The SSQ-6 may more effectively capture emotional support (Pierce et al., 1996), and it may be speculated that instrumental support (Pierce et al., 1996) would be a more appropriate aspect of social support to assess.

However, the current findings are consistent with Dimitropoulos et al. (2008) who also reported a lack of relationship between both informal and professional social support and psychological distress. However, Dimitropoulos et al. (2008) found that social support outside of the immediate family environment was the strongest predictor of family functioning. Therefore, Dimitropoulos et al. (2008) concluded that those with a lack of social support outside of the family may rely heavily on immediate family members for aid, therefore, causing greater strain within the family unit. As such, while the current study did not find a relationship between satisfaction with social support and burden and psychological distress, it may be that social support is linked to aspects not measured in the current study such as family functioning.

Lastly, the lack of relationship between adaptive coping and burden and psychological distress is also surprising. Past research (Joyce et al., 2003; Pakenham et al., 2007) shows that those who use adaptive coping strategies while caring for someone have a more positive outcome with less burden. Specifically, the use of effective coping leads to lower levels of distress in schizophrenia carers (Joyce et al., 2003). Further, the stress-coping model proposed by Lazarus and Folkman (1984) supports the relationship between adaptive coping and a more positive outcome in stressful situation. A post hoc exploration of the components of adaptive coping (emotion-focused coping and problem-focused coping) showed there was no relationship between these components and burden or psychological distress. Therefore, it may be concluded that the use of adaptive coping strategies as an overall measure of problem-focused and emotion-focused coping is not masking any differential effects of these constructs.

Hypothesis seven and eight, regarding positive correlations between measured variables was also partially supported. Maladaptive coping was consistently positively related to both burden and psychological distress at all three time points.
This indicates that carers who utilise less helpful coping strategies more at risk for psychological ill health and burden. Past research examining caring for someone with an organic illness (Haley et al., 1996) and schizophrenia (Fortune et al., 2005; Joyce et al., 2003) also supports this finding. The significant relationship of maladaptive coping, but not adaptive coping, with burden and psychological distress, highlights that use of maladaptive coping (even if utilised in conjunction with adaptive coping strategies) has the potential to negatively affect eating disorder carers. Therefore, interventions to reduce burden and psychological distress in eating disorder carers do not necessarily require a focus on teaching carers adaptive coping strategies. Rather, interventions could focus on educating carers about the maladaptive coping strategies they may be using and how to reduce their reliance on these types of strategies.

Similarly, there was a consistent positive relationship of carer burden and psychological distress with emotional overinvolvement. However, critical comments was only consistently related to burden at all three time points, and correlated with psychological distress at Time Two only. Prior eating disorder carer research supports this pattern of findings. Sepulveda et al. (2010) found that carers high on expressed emotion had significantly higher negative experiences of caregiving, but no significant difference in relation to psychological distress. Further, Winn et al. (2007) report that expressed emotion is linked to higher levels of carer burden. As such, it appears that expressed emotion is more closely linked to carer burden than general psychological distress. However, there may be a reciprocal relationship between burden and expressed emotion. As such, it is difficult to discern whether higher expressed emotion leads to higher burden, or a higher level of carer burden results in a higher level of expressed emotion due to carer frustration with the sufferer.

Carer needs were also consistently correlated with burden at all three time points; when carers’ needs were unmet, the burden they experienced significantly increased. However, there was no relationship between carer needs and psychological distress. This finding is interesting considering the moderate correlation between burden and psychological distress at all three time points. Therefore, the specificity
of the needs in relation to the information, treatment and prognosis in regard to eating disorder may explain the significant relationship with the specific measure of eating disorder carer burden. One quantitative eating disorder carer study that examined carer needs found that a need for support from people and organisations was significantly related to negative appraisals of caregiving (Whitney et al., 2007). However, Whitney et al. (2007) did not examine the relationship of carer needs to psychological distress. Further, Graap, Bleich, Herbst, Trostmann et al. (2008) reported a significant correlation between a need for interventions and burden and psychological distress. Further, using the CaNAM, Haigh and Treasure (2003) reported no correlation between information about eating disorders needs and burden or psychological distress. However, they reported significant correlations with a need for support from people and organisations and the following aspects of carer burden: negative symptoms, problems with services, and effect on the family. No significant correlation between need for professional support and psychological distress was found. Thirdly, Haigh and Treasure (2003) reported no significant correlation between a need for support for self and burden or psychological distress.

The current study examined the relationship between a composite measure of needs (need for information, need for professional support, need for support for self and need for information from GPs) and burden. Therefore, the consistent correlations in the current study, as opposed to the inconsistent findings of Haigh and Treasure (2003), could be attributable to the use of this composite measure. Further, the measure of burden differed between the current study (EDSIS) and Haigh and Treasure (2003; ECI). As such, the lack of correlations found in Haigh and Treasure (2003) could be attributable to their choice of measure for burden.

Lastly, there were mixed results in relation to symptoms of the sufferer and contact hours with the sufferer. Contact hours with the sufferer was not significantly related to burden or psychological distress at all three time points. However, past eating disorder carer research shows that contact hours is predictive of a negative carer experience (Winn et al., 2007). It could be speculated that, in the current study, the diagnosis of an eating disorder is sufficient to cause burden and distress in the carers, rather than actual time spent with the sufferer. Further, the impact of contact
hours with the sufferer on burden and psychological distress may be mediated by another factor, such as expressed emotion. In regard to symptom severity, binging and purging behaviour was consistently related to burden and psychological distress at all three time points. However, describing themselves as fat was not associated with either burden or psychological distress, and a fear of fatness was only related to burden at Time Two and Time Three. Past research eating disorder research confirms this finding in that symptom severity was not related to a negative caregiver experience (Winn et al., 2007). Therefore, it seems that the overt physical behaviours, rather than cognitive manifestations of eating disorders, are more problematic for carers.

Cross-sectional and longitudinal prediction of carer burden and psychological distress

Hypothesis nine, the cross-sectional and longitudinal prediction of burden, and hypothesis 10, the cross-sectional and longitudinal prediction of psychological distress, were partially supported. These hypotheses were based on the proposed mediation model of eating disorder carer burden and distress (see Chapter Three). Due to the smaller than anticipated sample size, path analysis testing the mediation model could not be conducted. As such, a series of standard multiple regression analyses were done. The cross-sectional regression models predicted 48%, 50% and 58% of the variance in burden and Time One, Time Two and Time Three, respectively. Cross-sectionally, expressed emotion, maladaptive coping and needs were consistent predictors for burden at all three time points. This is consistent with the correlations found in the current study. However, the regression models for psychological distress only predicted 32% (Time One), 27% (Time Two) and 23% (Time Three) of the variance, with maladaptive coping at Time One the only significant unique predictor. Taken together, these cross-sectional findings provide partial support for the proposed mediation model. While there was support for coping strategies, carer needs and expressed emotion as predictors of carer burden and distress, social support and symptom severity were not predictors.
Prior cross-sectional models have shown that psychological distress in eating disorder carers is predicted by self-related strains, interpersonal strains and carer gender (Kyriacou et al., 2008b), carer burden (Winn et al., 2007) and dependency and stigma (Whitney et al., 2007). One model examining predictors of negative appraisals of caregiving found that illness duration, need for support from people and organisations, and consequences on the patient (i.e., symptom impact) were significant predictors (Whitney et al., 2007). Further, expressed emotion (as reported by the sufferer) has been found to predict a negative carer experience (Winn et al., 2007). Currently, no eating disorder model takes into account informal social support or coping as predictors of carer burden or psychological distress.

Previous research has found that satisfaction with social support significantly predicts distress, positive affect and satisfaction with life in young carers (Pakenham et al., 2007). Further, a review of predictors of mental illness carer outcomes indicates that informal social support is a consistent predictor of carer burden and state of health (Ohaeri, 2003). Surprisingly, in the current study satisfaction with social support did not predict burden or psychological distress at all three time points. This may be due to the measure of social support utilised in the current study.

In relation to the longitudinal prediction of carer burden, the models tested significantly predicted burden. However, the longitudinal regression models for psychological distress were not significant. For burden from Time One to Time Two, the model explained 23% of the variance in burden at Time Two, with expressed emotion a significant unique predictor. Further, for the Time One prediction to Time Three of burden, the entire model explained 23% of the variance in burden and Time Two, with maladaptive coping and needs approaching significance as unique predictors. Similarly, the Time Two to Time Three prediction of burden explained 30% of the variance in burden, with maladaptive coping and needs approaching significance as unique predictors. However, while the longitudinal prediction of carer burden is low, the unique predictors were consistent with the cross-sectional predictions.

The difficulty predicting carer burden and psychological distress longitudinally may be reflective of the carer situation and the nature of eating
disorders. It may be that carers’ situations and the sufferers’ illness is highly changeable, therefore, long-term prediction of caregiving outcomes, particularly psychological distress, is difficult. Further, carers may be reacting to the current situation only, not taking into account past experiences or possible future changes. Therefore, caring for someone with an eating disorder may be very much a ‘here and now’ condition. However, while it is difficult to predict future levels of carer burden, maladaptive coping strategies, carer needs and expressed emotion appear to have some long-term impact on the level of carer burden. Such a finding reinforces the need for targeted interventions aimed at these aspects of caring for someone with an eating disorder.

Mediation of carer burden and psychological distress

Hypothesis 11, regarding the mediational relationships of expressed emotion and carer needs on burden and psychological distress, was partially supported. These hypotheses were based upon the proposed mediation model of eating disorder carer burden and prior theory (e.g., Lazarus & Folkman’s (1984) cognitive stress theory) There was a consistent partial mediation of expressed emotion by maladaptive coping on carer burden at all three time points. While the Sobel tests were not significant, given the small sample size, the Sobel test results need to be interpreted with caution. Lastly, bootstrapping approached significance for all tests of an indirect effect. Thus, it can be interpreted that the impact of expressed emotion of carer burden is dependent on maladaptive coping mechanisms.

Further, the relationship of expressed emotion to psychological distress was fully mediated by maladaptive coping at Time One and Time Three. Additionally, bootstrapping approached significance for an indirect effect. Therefore, it appears that expressed emotion and maladaptive coping are strongly linked. This finding can be linked to both Lazarus and Folkman’s (1984) cognitive stress theory and Pearlin et al.’s (1990) stress process theory. It could be speculated that expressed emotion is a stressor, as in the cognitive stress theory, and that it forms part of the primary or secondary stressors, as in the stress process theory. Therefore, according to these two
theories, the way in which a person copes will mediate the relationship of expressed emotion on the outcomes of burden and psychological distress. Specifically, it appears that carers who are high on expressed emotion may also use a higher level of maladaptive coping strategies, which in turn increases the level of burden and distress.

In relation to the mediating role of satisfaction with social support, no significant mediation was found. This finding is consistent with the lack of correlations and cross-sectional and longitudinal prediction of carer burden and psychological distress in the current study. The lack of significant mediation is most likely due to the measure used, in that it was a generalised social support measure, rather than a targeted social support for their carer role. Further, the SSQ-6 is a measure of emotional support (Sarason et al., 1987). It may be speculated that satisfaction with other forms of social support, such as instrumental support, is more influential. As such, there is a need to further investigate social support using a more situation specific social support scale, as well as other forms of social support.

The relationship between carer needs and burden was partially mediated by maladaptive coping at Time One, but not at Time Two or Time Three. However, this finding can provide some further support for the role maladaptive coping strategies play in the level of burden experienced by carers of patients with an eating disorder. Again, these findings can be linked to the cognitive stress theory (Lazarus & Folkman, 1984) and stress process theory (Pearlin et al., 1990). Lastly, as there was no relationship between carer needs and social support, mediation analyses could not be conducted to investigate the mediating role of social support on the relationship between needs and burden and psychological distress.

Taken together, these findings provide partial support for the proposed mediation model of eating disorder carer burden and psychological distress. The mediation analyses show that maladaptive coping strategies are an important mediator of carer burden and psychological distress, as proposed in the model. However, there was no support for social support as a mediator, as proposed in the model. Future research needs to examine the role of adaptive coping strategies and
other forms of social support as mediators of eating disorder carer burden and psychological distress.

Qualitative changes over time

At Time Two and Time Three, carers completed an open-ended written section about changes in their situation since the completion of the previous questionnaire. The responses from this section reflect the findings from the quantitative component of the current study in that carers experience a considerable degree of ongoing difficulties and problems. Further, these responses provided a greater level of insight into carers’ experience and how they cope than could be discerned from quantitative data alone.

The majority of responses were in relation to the sufferer, rather than the carers themselves. This may indicate the high level of focus on the person with an eating disorder, and the precedence they take over the carers. Further, this finding can be linked in with the high levels of emotional overinvolvement reported by carers in the quantitative component of this study. However, while the question about changes over time was open-ended and non-specific, it may be that the question was interpreted in such a way that carers believed it was asking about changes in the sufferer only. As such, this may have biased the responses given by carers.

When carers perceived that the person they were caring for worsened, they became pessimistic about recovery and felt that the situation would never improve. Further, changes in diagnosis, such as AN to BN, were confusing to the carers and meant that carers needed to learn about and cope with new signs and symptoms. Lastly, a co-morbid diagnosis, for example of depression, in the sufferer added to the level of burden felt by the carers as they struggled to cope with the different symptoms and behaviours.

While a sizable percentage of carers reported improvements in their situation, there was only one report of a full recovery. This lack of full recovery is not surprising given the chronic nature of eating disorders. However, when carers noted that their loved one had improved, they tended to focus on the observable,
behavioural changes rather than any cognitive changes. This could be due to the sufferer having difficulty changing the way they think, or a greater difficulty in carers noticing such changes compared to overt behaviours. Nonetheless, when carers did perceive improvements in the sufferer, they became more optimistic and positive about the future and their ability to cope with the caring role.

The carers responses about changes in themselves were evenly split between improvements and declines in their situation and themselves. Of those who mentioned improvements, most wrote about attending support groups or workshops for eating disorder carers. These support groups have the potential to provide an empathic atmosphere where carers can share their stories and provide a level of understanding that can only come from those in the same situation (Enright, Butterfield, & Berkowitz, 1985; Rice & Faulkner, 1992). Carers also have the opportunity to learn new ways to cope and apply these skills to their own lives (Enright et al., 1985; Rice & Faulkner, 1992). In this way, carers are being self-protective and ensuring that their own health does not decline while in the caregiver role.

Conversely, some carers reported deterioration over time; they felt increasingly depressed and anxious about both the sufferer and themselves. They had difficulties coping with the chronic nature of the eating disorder and the ongoing struggles associated with it. They experienced difficulty dealing with the fact that their loved one was not improving and the associated problems and difficulties were not abating. As a consequence, it was hard for them to maintain a sense of hope about the situation. Lastly, carers were worried about being depressed and anxious themselves, further impacting upon their psychological well-being.

Therefore, carers have ongoing chronic difficulties in their caregiver role. Both how the person with the eating disorder is progressing and how the carer copes with their role have a significant impact on how carers assess their situation. The qualitative responses from the current study highlight the fact that while carers of patients with an eating disorder may feel depressed and anxious as a result of their situation, with adequate support carers are able to cope much better with their role.
Summary and conclusions

The current study is the first to longitudinally examine carer burden and psychological distress in carers of patients with an eating disorder. Using the proposed mediation model of carer burden and psychological distress (see Chapter Three) various predictors and mediators of carer burden and psychological distress were investigated. Lastly, an investigation of the qualitative changes over time was conducted. The study showed that carers have consistently high levels of burden and psychological distress over time. Further, carers also have consistently high levels of expressed emotion, maladaptive coping strategies and unmet needs. Expressed emotion, maladaptive coping and carer needs were consistent cross-sectional predictors of burden and psychological distress, thus providing support for the mediation model of carer burden and psychological distress. Additionally, maladaptive coping, expressed emotion and needs were longitudinal predictors of burden and psychological distress. Lastly, maladaptive coping was a consistent mediator of burden and psychological distress, providing partial support for the proposed mediation model of carer burden and distress. As such, there was partial support for the proposed mediation model of eating disorder carer burden and psychological distress. Therefore, interventions need to be focussed on reducing carers’ use of maladaptive coping strategies, and decreasing their level of expressed emotion. However, a main limitation of the current study was a low sample size. The low participant numbers limited power, and therefore the ability to conduct detailed analyses. Further, the use of interviews, instead of a questionnaire approach may have increased the sample size. The theoretical and clinical implications, limitations of the current research, and future research directions will be discussed in further detail within Chapter Seven of this thesis.
CHAPTER SIX

STUDY 3: CROSS-SECTIONAL EXAMINATION OF THE DISCREPANCY BETWEEN EATING DISORDER CARER AND SUFFERER REPORTS OF BURDEN

Rationale

The previous study (see Chapter Four and Chapter Five) showed that carers of patients with an eating disorder experience a considerable and ongoing level of burden. However, no existing research has examined whether those with an eating disorder are aware of the level of burden of care their carers experience. For instance, qualitative responses from Study 1 show that sufferers may distance themselves from their carer (“…she distances herself from me (and everyone) more than ever”); “She's incredibly secretive about everything”) and may not want their carer to be involved in their recovery (“…[she] doesn't like my involvement”). Therefore, it may be speculated that patients with an eating disorder do not believe themselves to be burden.

An extensive search of the literature failed to locate any prior research specifically investigating eating disorder sufferer perceptions of the carers’ experience of care-giving. However, while those with an eating disorder recognise that it is their carer that often compels them to seek treatment, thus acknowledging that the carers perceive there is a problem, sufferers may not fully grasp the extent of the impact of the eating disorder on their carers (Jones & Crawford, 1995; Shelley, 1997). For example, in a qualitative examination of anorexia, one sufferer remarked, “I gave very little thought to the people around me that I was affecting, my friends and my family…they became the enemy” (Shelley, 1997, p. 14). However, while at the time those with an eating disorder may not realise the level of burden experienced by their carers, later they may show awareness; “I am sure that my parents went through hell” (Shelley, 1997, p. 89). Lastly, as those with an eating disorder often deny (Vandereycken, 2006a, 2006b) and hide their illness (Broussard, 2005; Orbanic,
2001), it is speculated that this may also lead to an underestimation of the impact of the illness on their carer. If sufferers do lack insight into how their carers are affected by the eating disorder, then this may negatively impact on the carers.

This gap in the literature regarding sufferer perceptions of burden is not specific to eating disorders; others have suggested that research is required to understand whether patients with a mental illness perceive themselves to be a burden or not (Maurin & Boyd, 1990). Similarly, Dow, Haralambous, Giummarra, & Vrantsidis (2004) identified a lack of research examining the care recipient perspectives as a gap in current carer literature. They argue that the carer relationship is reciprocal, not uni-dimensional, and that current carer research often fails to acknowledge this reciprocity. Therefore, there is a need to investigate whether those with an eating disorder are aware of what their carer experiences, and how this then impacts upon the carers themselves.

Early research examining the care recipient response to being helped indicates that recipients who perceive that too much, or unneeded, help is being provided are more likely to have a negative reaction to care (Depaulo, Brittingham, & Kaiser, 1983). Further, care recipients who have a greater sense of control are at a greater risk for negative reactions to caregiving (Newsom & Schulz, 1998). Therefore, given that eating disorders are typically associated with denial of the illness (Vandereycken, 2006a, 2006b), thus perhaps perceiving help as unneeded, in conjunction with a high need for control (Fairburn, Shafran, & Cooper, 1999), it may be speculated that eating disorder sufferers would have a negative reaction to caregiving attempts. As such, those with an eating disorder may underestimate the level of burden for their carer.

Previous research examining patients with a mental illness’ perspectives of carer burden has found those in an inpatient setting who have been diagnosed with either an affective disorder (unipolar or bipolar depression) or a psychotic disorder significantly underestimate the burden experienced by their carers (Cleary et al., 2006). Cleary et al. (2006) measured four domains of carer burden: tension, supervision, worrying and urging. Patients particularly underestimated the impact on the carer of a strained atmosphere, the global burden experienced by the carer, the
level to which carers worried about the future, and the extent to which carer tried to encourage patients to undertake activities. However, of relevance to the current research, Cleary et al.’s study specifically excluded patients with an eating disorder diagnosis. In addition, they did not examine the predictors of the sufferer-carer difference in perceptions of burden.

Therefore, given the preliminary findings by Cleary et al. (2006) and the lack of research investigating the convergence between eating disorder sufferer and carer views of burden, the current study will seek to examine this issue. Further, the current study will measure possible predictors for a discrepancy between sufferer and carer perspectives of burden. Understanding the determinants of discrepancies between perceptions of burden may increase the scope for collaborative treatment with both carer and sufferer. In this way, identified predictors of carer burden perception discrepancies could become a focus in family-based interventions in order to help reduce the extent of carer burden experienced. For example, Treasure, Whitaker et al. (2005) identify that a specific aim of working with eating disorder families is to help carers cope with their role. However, while they identify that it is important for carers to modify their behaviour towards the sufferer, they do not address the possibility of increasing the sufferers’ awareness of how they may be affecting their carer. As such, understanding the differences in perceptions of carer burden, and what contributes to these differences, may provide a starting point for more reciprocity in family-based interventions.

The predictor variables chosen for potential differences in perceptions of carer burden consisted of both carer and sufferer-related factors: carer level of psychological distress and expressed emotion, and symptom severity of the sufferer, and the sufferer’s stage of change. Carer psychological distress and level of expressed emotion were chosen due to their high correlations with carer burden found in Study 1. Patient symptom severity was thought to be warranted as it is often been identified as a contributor to the level of carer burden (e.g., Kyriacou et al., 2008b; Maurin & Boyd, 1990; Treasure, Whitaker, et al., 2005). Further, the qualitative responses from Study 1 show that when a loved one showed improvement in their symptoms, carers were often less worried and anxious. Conversely, Study 1
indicated that a worsening in symptoms consequently lead to carers feeling more helpless and depressed about their situation.

Lastly, the sufferer’s readiness to change and motivation for recovery was thought to be a potentially relevant predictor. A lack of motivation to recover is a predictor of both treatment response (Amettler, Castro, Serrano, Martinez, & Toro, 2004; Rieger et al., 2000; Treasure et al., 1999) and the outcome of eating disorders (D. E. Herzog, Keller, & Lavori, 1988). Further, this lack of motivation commonly seen within those with an eating disorder has been linked to the egosyntonic nature of the symptoms (Orimoto & Vitousek, 1992). Given the pervasive lack of motivation to recover, often after lengthy and intensive inpatient treatment (Rieger & Touyz, 2006), it could be speculated that sufferers may underestimate the level of burden their carers experience.

The most researched theoretical model of motivation for change with respect to health behaviours is the stages of change or transtheoretical model (Prochaska & DiClemente, 1982; Prochaska, DiClemente, & Norcross, 1992; Prochaska & Velicer, 1997). According to this model a person can be assigned a stage, or category, motivation or readiness to change. There are five distinct stages: pre-contemplation, contemplation, preparation, action and maintenance. A person within the pre-contemplation stage does not consider that they have a problem, such as an eating disorder, and therefore do not take any means to recover. The contemplation stage is when a person acknowledges that they have a problem, but are not taking any steps to change. Preparation and action are when a person prepares for change and engages in change, respectively. Lastly, the maintenance stage occurs when a person is recovered from an illness, such as an eating disorder, and is working to prevent relapse. Sufferers in the earlier stages of change (i.e., pre-contemplation and contemplation) have been shown to have a less adaptive relationship with their parents than those in later stages of change (Zaitsoff & Taylor, 2009). Therefore, it may be speculated that those with an eating disorder who are in the pre-contemplation or contemplation stages may also underestimate the burden imposed by their disorder on their carers.
Therefore, it is argued that an examination of the degree of difference in perceptions of carer burden associated with eating disorders on the part of the sufferer and the carer themselves is required. Further, understanding the predictors of any such discrepancies would allow for the development of interventions aimed at increasing sufferer awareness of the impact of the eating disorder on the carer. Thus there are implications for collaborative care approaches to treatment of eating disorders (Treasure et al., 2007) and multi-family therapy (Scholz, Rix, Scholz, Gantchev, & Thomke, 2005). Lastly, while it is expected that eating disorder sufferers will underestimate carer burden, any areas of agreement could have the potential to reduce conflict and increase treatment co-operation in the context of family-based interventions (Cleary et al., 2006).

Aim and hypotheses

The aims of this study are two fold. Firstly, to examine the degree of discrepancy between carer self-report of burden and sufferer perceptions of carer burden. Secondly, to examine the predictors of discrepancies between carer self-report, and sufferer perceptions of, carer burden.

Based upon findings of Cleary et al. (2006) that patients with an affective disorder or psychotic disorder significantly underestimated the degree of carer burden experienced by their primary carer, it is hypothesised that:

1. Those with an eating disorder will perceive a significantly lower carer burden than that reported by the carers themselves.

2. Symptom severity will be negatively correlated with sufferer perceptions of carer burden and positively correlated with the discrepancy between carer self-report and sufferer perceptions of burden

Lastly those in pre-contemplation and contemplation stages of change are more likely to deny their illness, while those in preparation, action or maintenance stages of change are more likely to be aware of their symptoms (Prochaska &
Velicer, 1997). For example, those in the pre-contemplation or contemplation stages are more likely to choose treatment options that focus on simply receiving support or an exploration into their illness (Levy, 1997). Whereas, sufferers in the action stage are more likely to choose treatments that focus on actual symptom change and skill building (Levy, 1997). Therefore, it is hypothesised that:

3. Stage of change will be positively correlated with sufferer perceptions of carer burden and discrepancy between carer self-report and sufferer perceptions of burden

The last hypothesis concerns the predictors of carer-suffer discrepancy in perceived carer burden. Carers who experience high levels of expressed emotion and psychological distress are more likely to report higher levels of carer burden (see Study 1). Further, there is a proposed correlation between stage of change and symptom severity and discrepancies in perceived burden. As such, it is hypothesised that:

4. Carer expressed emotion and psychological distress, sufferer stage of change and symptom severity will predict sufferer and carer discrepancies in perception of carer burden

Method

Participants

Participants consisted of 20 matched pairs of patients diagnosed with an eating disorder (19 females, 1 male) and their carer (14 females, 6 males). There were 18 sufferers diagnosed with AN and two diagnosed with BN. Their average age was 24.10 years ($SD = 7.89$), and they had an average BMI of 18.71 ($SD = 2.03$). Carers had an average age of 43.45 ($SD = 11.42$). Sufferers reported an average of 56.17 ($SD = 44.60$) hours of contact with their carer per week while carer reported slightly higher contact of 61.76 ($SD = 42.56$) hours per week.
Materials

Two short questionnaires were utilised for this study: one for the person with the eating disorder, and one for the carer. The scales were chosen due to their strong psychometric properties and specificity for eating disorders. The questionnaires were designed to obtain comprehensive information, while balancing participant commitment. These questionnaires are described below.

Sufferer Questionnaire

Participants completed a questionnaire package consisting of a general information sheet and scales assessing the participants’ perceptions of the level of burden experienced by their carer, their eating disorder symptom severity, and readiness to change their eating disorder behaviours (i.e., stage of change).

General Information Sheet

The general information sheet obtained the following information: gender, age, weight and height, the relationship of the carer to them, their eating disorder diagnosis, contact hours with their carer per week, duration of their illness, if they were currently receiving treatment, and how many time they had been admitted to hospital for their eating disorder. In addition, the participants are asked to rate on an 11-point Likert scale how important it is to them that they change (0 = not important, 10 = very important) and how confident they are that they can change (0 = not confident, 10 = very confident). These last two items were included to provide a representation of sufferer stage of change and self-efficacy regarding change, respectively.
Eating Disorder Symptom Impact Scale – Sufferer Form (EDSIS-SF)

The EDSIS measures the specific burden for carers of patients with AN or BN and assess the carers’ perceptions of the emotional, psychological and tangible impact of caring for someone with an eating disorder (Sepulveda, Whitney, et al., 2008). The EDSIS-SF is a modified version that rewords the questions to reflect carer burden from the sufferers’ perspective. That is, the questions ask the sufferer about their perception of their carer’s experience as a carer. The EDSIS-SF is comprised of four subscales: nutrition, dysregulated behaviour, guilt and social isolation. Thus, a total of 30 items assess different aspects of caring for someone with an eating disorder, as measured on a 5-point Likert scale (0 = Never, 4 = Nearly Always). An example item is “During the past month how often do you think the person who cares for you has thought about: Feeling that there could have been something they should have done.” The reliability and validity information in the EDSIS has been described in the method section for study one. The internal consistencies for the subscales of EDSIS-SF in the current study were acceptable (Nutrition α = .85; Guilt α = .93; Dysregulated behaviour α = .72; Social isolation α = .86) and high for the total scale (α = .89).

Anorexia Nervosa Stages of Change Questionnaire (ANSOCQ)

The ANSOCQ (Rieger et al., 2000) is a 20-item measure based on Prochaska and DiClemente’s (1982) stages of change model. The ANSOCQ assesses aspects of weight and body shape, eating behaviours, methods of weight control, and emotional and relational issues. For each item, participants are required to select one of five statements that correspond to pre-contemplation, contemplation, preparation, action and maintenance stages of change. The items are scored in a Likert-scale fashion, from 1 (pre-contemplation) to 5 (maintenance), with a high score indicating a high motivation to change and recover. The ANSOCQ has high internal consistency (Chronbach’s α = .90) and one-week test-retest reliability (Chronbach’s α = .89) (Rieger et al., 2000). Further, the scale demonstrates good construct validity (Rieger,
The ANSOCQ demonstrated a high internal consistency for the current study (Chronbach’s $\alpha = .93$)

_Bulimia Nervosa Stages of Change Questionnaire (BNSOCQ)_

The BNSOCQ is designed to measure the readiness to recover in patients with bulimia nervosa (Martinez et al., 2007) and is based upon the ANSOCQ (Rieger et al., 2000). The BNSOCQ contains 20 items assessing a number of eating disorder symptoms, including: aspects of weight and body shape, methods of weight control, eating behaviours, emotional and relational issues, and binge eating and purging behaviours characteristic of patients with bulimia. For each item, participants are required to select one of five statements that correspond to pre-contemplation, contemplation, preparation, action and maintenance stages of change. The items are scored in a Likert-scale fashion, from 1 (pre-contemplation) to 5 (maintenance). A high total score indicates a high motivation to change and recover. The BNSOCQ demonstrates good internal consistency (Chronbach’s $\alpha = .94$) and one-week test-retest reliability ($r = .93$) (Martinez et al., 2007). Further, the BNSOCQ correlates highly with a number of EDI-2 subscales (range, $r = -.51$ to $r = -.84$) and the BDI ($r = -.71$; Martinez et al., 2007). The Chronbach’s alpha was unable to be conducted for the current study due to only two participants being diagnosed with BN.

_Eating Disorder Examination – Questionnaire (EDE-Q 6.0)_

The EDE-Q is a 28-item self-report measure assessing participant’s eating disorder symptoms (Fairburn & Beglin, 2008). As such, the EDE-Q provides information in regards to the frequency of eating disorder related behaviours and also the severity of aspects of the psychopathology of eating disorders. It has four subscales: restraint, eating concern, shape concern and weight concern. The subscale score is obtained by summing the relevant items in that subscale and dividing the total by the number of items in the subscale. Similarly, a global score is obtained by summing the subscale scores and dividing by four (i.e., the number of subscales).
Higher scores on subscales indicate greater severity. The EDE-Q has been normed for adolescent girls (Carter, Stewart, & Fairburn, 2001), young adult women (Luce, Crowther, & Pole, 2008; J. M. Mond, P. J. Hay, B. Rodgers, & C. Owen, 2006) and young adult men (Lavender, De Young, & Anderson, 2010). Earlier versions of the EDE-Q demonstrate good internal consistency, with subscale Chronbach’s alphas ranging from .70-.93, and acceptable test-rest reliability (range, $r = .81$ to $r = -.94$) (Luce & Crowther, 1999; Peterson et al., 2007). Further, the EDE-Q has good concurrent validity with the interview version of the EDE, and acceptable criterion validity (J. M. Mond, Hay, Rodgers, Owen, & Beumont, 2004). The internal consistencies for the subscales in the current study were moderate (Restraint $\alpha = .76$; Eating concern $\alpha = .59$; Shape concern $\alpha = .73$; Weight concern $\alpha = .56$) and high for the total scale ($\alpha = .68$). Removal of items did not improve low Cronbach’s alphas.

**Carer Questionnaire**

Participants completed a questionnaire package consisting of a general information sheet and three scales assessing the participants’ experiences of carer burden, their level of expressed emotion, and their psychological health.

**General information sheet**

The general information sheet obtained the following demographic information: gender, age, their relationship to the person they were caring for, how many children they had, their average hours of paid employment, the treatment commitments they had in relation to the person they care for, and how many hours per week contact they had with the person they were caring for. In addition, the participants were asked to rate on an 11-point Likert scale how important it was to them that the person they care for change (0 = not important, 10 = very important) and how confident they were that they could help the person they care for change (0 = not confident, 10 = very confident).
Eating Disorder Symptom Impact Scale (EDSIS)

The EDSIS measures the specific burden for carers of patients with AN or BN and assesses the carers’ perceptions of the emotional, psychological and tangible impact of caring for someone with an eating disorder (Sepulveda, Whitney, et al., 2008). Details of this scale are provided in the method section for Study 1, Chapter Four. The Cronbach’s alpha for the subscales in the current study were high for each of the subscales (Nutrition \( \alpha = .86 \); Guilt \( \alpha = .90 \); Dysregulated behaviour \( \alpha = .80 \); Social isolation \( \alpha = .91 \)) and for the total scale (\( \alpha = .89 \)).

Family Questionnaire (FQ)

The FQ is a self-report questionnaire based on the Camberwell Family Interview (CFI; Vaughn & Leff, 1976) that measures the expressed emotion domains of critical comments and emotional overinvolvement (Wiedemann et al., 2002). Details of the FQ are provided in the method section for Study 1. The internal consistency for the current study was acceptable for both subscales (Emotional overinvolvement \( \alpha = .75 \); Critical comments \( \alpha = .90 \)) and high for the total scale (\( \alpha = .88 \)).

General Health Questionnaire-12 (GHQ-12)

The GHQ-12 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 ill health (Goldberg & Williams, 1988). The GHQ-12 is described in full in the method section of Study 1. The Chronbach’s alpha for the current study was high (\( \alpha = .91 \)).
Procedure

Approval for the study was obtained from the Deakin University Human Research Ethics Committee prior to commencing the study (Appendix G). Participants were recruited in a number of ways; distribution of flyers in support group for carers and/or sufferers, distribution of questionnaires in treatment centres, online advertising (Appendix H) on eating disorder organisation websites (e.g., b-eat, UK; Butterfly Foundation, Australia; Eating Disorder Hope, USA), distribution of information via email lists (Australia and New Zealand Academy for Eating Disorders), and by contacting the participants in the main longitudinal study.

Participants were either directed to the online questionnaire or mailed paper-based questionnaires (Appendix I, J and K). Participants were provided with a plain language statement, consent form (Appendix L and M) and questionnaire. Those sufferers who were under the age of 18 were required to provide parental/guardian consent to take part. Online questionnaires were completed independently, with a code used to match responses (the three initials of the carer’s name, followed by the three initials of the sufferer’s name). Carers and sufferers independently completed the questionnaires, which were returned via reply paid post. Upon, receipt, each paper-based questionnaire pair was coded with corresponding numbers to enable matching of data (e.g., 001 or 002). Consent forms were kept in a separate, secure cabinet from the questionnaires to maintain anonymity. The response rate for the paper-based questionnaires in the current study was low, totalling only 17%. While this is a low response rate, the use of ‘cold-calling’, in conjunction with distribution to interested participants, may have artificially lowered the response rate. The response rate for the online questionnaire is unknown. Lastly, due to the majority of responses being online, and no participants from the longitudinal study completing paper-based questionnaires, it is unknown how many from the longitudinal study took part in the current research.
Results

Carers participating in the current study were assessed in relation to level of carer burden, psychological distress, and expressed emotion. Patients with an eating disorder participating in the current research provided information on their perceptions of carer burden, their stage of change, and symptom severity. These data was used to evaluate the discrepancy between carers’ self-report of carer burden and sufferers’ perceptions of carer burden. Further, predictors of such discrepancy were assessed. The analysis and findings for the current investigation will be presented in six sections: data cleaning, demographic information, descriptive statistics, comparison between sufferer and carer reports of burden, correlations with the discrepancy between sufferer perspective and carer self-report of burden, and prediction of the discrepancy in reported burden. All analyses were conducted using SPSS version 17.

Data cleaning

Accuracy of data entry, missing values and compliance with assumptions of univariate and multivariate analyses were determined. Random missing data was replaced using mean replacement. No univariate outliers were detected through examination of z-scores using the criterion of $z > \pm 3.29$ (Tabachnick & Fidell, 2001). There were no multivariate outliers detected using Mahalanobis distance (critical value at <.001 of 20.52).

Examination of histograms, normal q-q plots and skew statistics revealed no violations of skewness or kurtosis. Multicollinearity was not an issue. Scatterplots revealed no violations of normality, linearity, and homoscedasticity.

Demographics

Table 6.1 presents the demographic information regarding the carers in the current study. As shown, the majority of the carers were female and mothers. Further, most had more than one child and were employed.
Table 6.2 presents the demographic information regarding the sufferers in the current study. As shown, the majority of sufferers were females with a diagnosis of AN. Further, most of the participants were currently seeking treatment, with the majority having been hospitalised at least once during their illness.

Table 6.1

*Demographic variables of carers*

<table>
<thead>
<tr>
<th>Time One characteristics of carers</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>20</td>
<td>Mean = 43.45 (SD = 11.42)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
<td>30.0</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>70.0</td>
</tr>
<tr>
<td>Relationship to sufferer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>12</td>
<td>60.0</td>
</tr>
<tr>
<td>Sibling</td>
<td>1</td>
<td>5.0</td>
</tr>
<tr>
<td>Partner</td>
<td>7</td>
<td>35.0</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>10</td>
<td>30.0</td>
</tr>
<tr>
<td>Part time</td>
<td>5</td>
<td>25.0</td>
</tr>
<tr>
<td>Not currently employed</td>
<td>5</td>
<td>25.0</td>
</tr>
<tr>
<td>Number of daughters/sons&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>2</td>
<td>10.0</td>
</tr>
<tr>
<td>Two</td>
<td>7</td>
<td>35.0</td>
</tr>
<tr>
<td>Three or more</td>
<td>5</td>
<td>25.0</td>
</tr>
</tbody>
</table>

*Note.*<sup>a</sup>N for number of daughters/sons is 14 due respondent not having children or missing data.
Table 6.2

Demographic variables of the sufferers

<table>
<thead>
<tr>
<th>Time One characteristics of patients</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>20</td>
<td>Mean = 24.10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(SD = 7.89)</td>
</tr>
<tr>
<td>BMI&lt;sup&gt;a&lt;/sup&gt;</td>
<td>19</td>
<td>Mean = 18.71</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(SD = 2.03)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>5.0</td>
</tr>
<tr>
<td>Female</td>
<td>19</td>
<td>95.0</td>
</tr>
<tr>
<td>Eating disorder diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anorexia Nervosa</td>
<td>18</td>
<td>90.0</td>
</tr>
<tr>
<td>Bulimia Nervosa</td>
<td>2</td>
<td>10.0</td>
</tr>
<tr>
<td>Total admissions to hospital&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td>20.0</td>
</tr>
<tr>
<td>One</td>
<td>5</td>
<td>25.0</td>
</tr>
<tr>
<td>Two</td>
<td>3</td>
<td>15.0</td>
</tr>
<tr>
<td>Three or more</td>
<td>6</td>
<td>30.0</td>
</tr>
<tr>
<td>Duration of patient’s illness (years)</td>
<td></td>
<td>Mean = 7.15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(SD = 7.68)</td>
</tr>
<tr>
<td>Currently receiving treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14</td>
<td>70.0</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>30.0</td>
</tr>
</tbody>
</table>

*Note.* <sup>a</sup>N for BMI is 19 due to missing data for one participant  <sup>b</sup>N for total admissions to hospital is 18 due to missing data.

Descriptive statistics

Table 6.3 presents the means and standard deviations for both sufferer and carers for the each of the scales. As shown, carers reported a moderate level of
nutritional difficulties, guilt, and dysregulated behaviour and a low level of social isolation. Sufferers reported a similar pattern on their version of the EDSIS.

The carers also reported a high degree of critical comments, with 50.0% above the cut-off point. Further, 60.0% of carers were high on the emotional overinvolvement subscale. Lastly, using the cut-off scores for the GHQ-12 provided by Goldberg and Williams (1988), 40.0% of carers reported moderate distress, while 20.0% reported severe levels of psychological distress. The mean for the GHQ-12 in this study is consistent with Study 1 of this thesis and prior research (e.g., Haigh & Treasure, 2003; Sepulveda, Lopez, Todd, et al., 2008).
Table 6.3

*Means and standard deviations for sufferer and carer data*

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (SD)</th>
<th>Scale Range</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sufferer</td>
<td>Carer</td>
</tr>
<tr>
<td>EDSIS– Nutrition</td>
<td>14.45 (7.35)</td>
<td>18.05 (7.58)</td>
</tr>
<tr>
<td>EDSIS – Guilt</td>
<td>9.75 (6.58)</td>
<td>11.70 (4.93)</td>
</tr>
<tr>
<td>EDSIS – Social isolation</td>
<td>6.20 (3.89)</td>
<td>6.50 (4.03)</td>
</tr>
<tr>
<td>EDSIS – Dysregulated behaviour</td>
<td>8.35 (4.84)</td>
<td>8.00 (5.61)</td>
</tr>
<tr>
<td>EDSIS – Total</td>
<td>33.95 (19.05)</td>
<td>44.25 (15.81)</td>
</tr>
<tr>
<td>Importance to change</td>
<td>7.45 (2.54)</td>
<td>9.60 (1.19)</td>
</tr>
<tr>
<td>Confidence to change</td>
<td>4.40 (2.78)</td>
<td>6.25 (2.59)</td>
</tr>
<tr>
<td>ANSOCQ</td>
<td>45.50 (16.07)</td>
<td>--</td>
</tr>
<tr>
<td>BNSOCQ</td>
<td>53.00 (1.41)</td>
<td>--</td>
</tr>
<tr>
<td>FQ – Critical comments</td>
<td>--</td>
<td>22.05 (6.52)</td>
</tr>
<tr>
<td>FQ – Emotional overinvolvement</td>
<td>--</td>
<td>28.25 (4.39)</td>
</tr>
<tr>
<td>GHQ-12</td>
<td>--</td>
<td>16.75 (6.79)</td>
</tr>
</tbody>
</table>

As shown in Table 6.4, sufferers were in the 95th to 99th percentile for community samples for EDE-Q scores on each subscale and total scale (Lavender et al., 2010; Luce et al., 2008; J. M. Mond et al., 2006). Therefore, they were reporting a high level of severity of symptoms on each subscale.
Table 6.4

*Means and standard deviation of the symptom severity of the sufferer as measured by the EDE-Q*

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Mean (SD)</th>
<th>Scale Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restraint</td>
<td>4.39 (1.23)</td>
<td>0-6</td>
</tr>
<tr>
<td>Eating concern</td>
<td>4.00 (1.13)</td>
<td>0-6</td>
</tr>
<tr>
<td>Shape concern</td>
<td>5.24 (0.81)</td>
<td>0-6</td>
</tr>
<tr>
<td>Weight concern</td>
<td>5.09 (0.81)</td>
<td>0-6</td>
</tr>
<tr>
<td>Global score</td>
<td>4.68 (0.76)</td>
<td>0-6</td>
</tr>
</tbody>
</table>

Total scale scores for the ANSOCQ and BNSOCQ were averaged in order to classify sufferers into stages of readiness to recover. Average scores could range from 1 (pre-contemplation stage) to 5 (maintenance stage). As shown in Table 6.5, on the basis of these average scores, the majority of participants were in the lower stages of change, that is, most were in contemplation or preparation.

Table 6.5

*Sufferer stages of change on the ANSOCQ and BNSOCQ*

<table>
<thead>
<tr>
<th>Stage of Change</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-contemplation</td>
<td>2 (10.0)</td>
</tr>
<tr>
<td>Contemplation</td>
<td>9 (45.0)</td>
</tr>
<tr>
<td>Preparation</td>
<td>6 (30.0)</td>
</tr>
<tr>
<td>Action</td>
<td>3 (15.0)</td>
</tr>
<tr>
<td>Maintenance</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>
Comparison of carer self-report and sufferer perceptions of burden

In order to test hypothesis one, that patients with an eating disorder will significantly underestimate the burden of care experienced by their carers, a paired-sample t-test was conducted on each of the EDSIS subscales and EDSIS total. In addition, Table 6.6 presents the Cohen’s Kappa (Cohen, 1960) coefficient for the 24 items on the EDSIS. The Kappa statistic represents the level of agreement between carers and sufferers on their ratings of the item and provides a result between -1.00 and 1.00. For the Kappa coefficient analysis, items were dichotomised to 0 (‘never’, ‘rarely’, sometimes’) and 1 (‘regularly’, ‘often/always’). This categorisation is consistent with that used by Cleary et al. (2006). The Kappa coefficient was interpreted using the guidelines proposed by Landis and Koch (1977). As shown, there was a higher level of agreement on behavioural items, and less agreement on items related to conflict.

Paired-sample t-tests revealed a significant difference between total carer EDSIS and sufferer EDSIS ($t_{(18)} = -2.67, p < .05; \text{Cohen’s } d = .82$), with sufferers perceptions of total burden lower than carer self-report (see Table 6.3). Examination of the subscales indicated that only the nutrition subscale was significantly different ($t_{(18)} = -2.46, p < .05; \text{Cohen’s } d = .48$), with sufferers’ reports of nutritional difficulties lower than carer self-report.
Table 6.6
Kappa coefficient for the level of agreement between EDSIS items

<table>
<thead>
<tr>
<th>Subscale and item</th>
<th>Sufferer view</th>
<th>Carer view</th>
<th>Kappa coefficient and interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>EDSIS = 0</td>
<td>EDSIS = 1</td>
<td>EDSIS = 0</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Social isolation subscale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends/relatives stopped visiting</td>
<td>17 (85)</td>
<td>3 (15)</td>
<td>15 (75)</td>
</tr>
<tr>
<td>Losing friends</td>
<td>16 (80)</td>
<td>4 (20)</td>
<td>16 (80)</td>
</tr>
<tr>
<td>Feeling unable to go out for evenings, weekends or on holiday</td>
<td>13 (65)</td>
<td>7 (35)</td>
<td>13 (65)</td>
</tr>
<tr>
<td>Cancelling or refusing plans to see friends or relatives</td>
<td>15 (75)</td>
<td>5 (25)</td>
<td>16 (80)</td>
</tr>
<tr>
<td><strong>Guilt subscale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling should have noticed it before it became so bad</td>
<td>11 (55)</td>
<td>9 (45)</td>
<td>10 (50)</td>
</tr>
<tr>
<td>Feeling have let her/him down</td>
<td>13 (65)</td>
<td>7 (35)</td>
<td>9 (45)</td>
</tr>
<tr>
<td>Feeling that there could have been something should have done</td>
<td>15 (75)</td>
<td>5 (25)</td>
<td>7 (35)</td>
</tr>
</tbody>
</table>

*p < .05, **p < .01.
Table 6.6 Continued

Kappa coefficient for the level of agreement between EDSIS items

<table>
<thead>
<tr>
<th>Subscale and item</th>
<th>Sufferer view</th>
<th>Carer view</th>
<th>Kappa coefficient and interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>EDSIS = 0</td>
<td>EDSIS = 1</td>
<td>EDSIS = 0</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Guilt subscale continued</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thinking that perhaps wasn’t strict enough</td>
<td>14 (70)</td>
<td>6 (30)</td>
<td>14 (70)</td>
</tr>
<tr>
<td>Thinking about where went wrong</td>
<td>12 (60)</td>
<td>8 (40)</td>
<td>9 (45)</td>
</tr>
<tr>
<td><strong>Dysregulated behaviour subscale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physically and/or verbally aggressive</td>
<td>15 (75)</td>
<td>5 (25)</td>
<td>14 (70)</td>
</tr>
<tr>
<td>Having an out of control temper</td>
<td>15 (75)</td>
<td>5 (25)</td>
<td>17 (85)</td>
</tr>
<tr>
<td>Being controlling or manipulative</td>
<td>14 (70)</td>
<td>6 (30)</td>
<td>13 (65)</td>
</tr>
<tr>
<td>Lying or stealing</td>
<td>16 (80)</td>
<td>4 (20)</td>
<td>19 (95)</td>
</tr>
<tr>
<td>Food disappear from the cupboards</td>
<td>18 (90)</td>
<td>2 (10)</td>
<td>16 (80)</td>
</tr>
<tr>
<td>Difficulties with blocked drains, plumbing</td>
<td>20 (100)</td>
<td>0 (0)</td>
<td>19 (95)</td>
</tr>
<tr>
<td>Bad smells and poor hygiene in the bathroom</td>
<td>19 (95)</td>
<td>1 (5)</td>
<td>19 (95)</td>
</tr>
</tbody>
</table>

\( p < .05, \quad ** p < .01, \quad *** p < .001, \quad -- \) analysis could not be conducted.
Table 6.6 Continued

*Kappa coefficient for the level of agreement between EDSIS items*

<table>
<thead>
<tr>
<th>Subscale and item</th>
<th>Sufferer view</th>
<th>Carer view</th>
<th>Kappa coefficient and interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>EDSIS = 0</td>
<td>EDSIS = 1</td>
<td>EDSIS = 0</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Nutrition subscale</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experience difficulties preparing meals</td>
<td>11 (55)</td>
<td>9 (45)</td>
<td>12 (60)</td>
</tr>
<tr>
<td>Arguments with other family members about how to handle mealtimes</td>
<td>15 (75)</td>
<td>5 (25)</td>
<td>14 (70)</td>
</tr>
<tr>
<td>Arguments or tension during mealtimes</td>
<td>15 (75)</td>
<td>5 (25)</td>
<td>10 (50)</td>
</tr>
<tr>
<td>Long periods of time shopping for food</td>
<td>17 (85)</td>
<td>3 (15)</td>
<td>12 (60)</td>
</tr>
<tr>
<td>Turn up the heat due to her/his feeling cold</td>
<td>16 (80)</td>
<td>4 (20)</td>
<td>13 (65)</td>
</tr>
<tr>
<td>Check on her/him to ensure was okay</td>
<td>11 (55)</td>
<td>9 (45)</td>
<td>7 (35)</td>
</tr>
<tr>
<td>Notice or think about how the illness was affecting her/him physically</td>
<td>13 (65)</td>
<td>7 (35)</td>
<td>10 (50)</td>
</tr>
<tr>
<td>Notice or think about how the illness was affecting her/him mentally</td>
<td>12 (60)</td>
<td>8 (40)</td>
<td>2 (10)</td>
</tr>
</tbody>
</table>

*p < .05, **p < .01.*
Correlation with discrepancies in perceived burden

Pearson’s correlations were conducted in order to test hypothesis three, that eating disorder participants with greater symptom severity will perceive a lower level of burden, and hypothesis four, that stage of change will be positively correlated with sufferer perceptions of burden. These correlations were conducted on both the sufferer perceptions of burden and the discrepancy between carer self-report and sufferer reports of burden. The discrepancy between reports of burden was calculated by subtracting sufferer perceptions of burden score from carer self-report burden score. The means and standard deviations for these differences are presented in Table 6.7. As shown, there is a large discrepancy between carer self-report and sufferer perceptions on the nutrition subscale, a small difference on the guilt subscale and no difference on the social isolation or dysregulated behaviour subscale.

Table 6.7
Mean and standard deviation for the difference between carer and sufferer scores on the EDSIS

<table>
<thead>
<tr>
<th>EDSIS subscale</th>
<th>Mean difference (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition</td>
<td>3.60 (6.56)</td>
</tr>
<tr>
<td>Guilt</td>
<td>1.95 (5.96)</td>
</tr>
<tr>
<td>Social isolation</td>
<td>0.30 (3.46)</td>
</tr>
<tr>
<td>Dysregulated behaviour</td>
<td>-0.35 (4.80)</td>
</tr>
<tr>
<td>Total burden</td>
<td>10.30 (17.24)</td>
</tr>
</tbody>
</table>

As shown in Table 6.8, there were no significant correlations between stage of change and symptoms and reports of burden. However, there was a trend towards greater symptom severity being related to sufferers perceiving a higher level of carer burden, and a lower discrepancy between reports. Also, there is a trend towards higher stage of change being associated with a lower discrepancy. However, due to the low number of participants there was a lack of statistical power. Therefore, these results must be interpreted with caution.
Table 6.8

Correlation of stage of change and symptom severity with reports of carer burden

<table>
<thead>
<tr>
<th></th>
<th>Stage of change</th>
<th>Symptom severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sufferer perception of burden</td>
<td>.10</td>
<td>.32</td>
</tr>
<tr>
<td>Discrepancy between perceptions of burden</td>
<td>-.22</td>
<td>-.27</td>
</tr>
</tbody>
</table>

Prediction of discrepancies in perceptions of carer burden

In order to test hypothesis four, a standard multiple regression analysis was conducted (see Table 6.9). The discrepancy between carer self-report and sufferer perceptions of total burden was used as the dependent variable. The regression model was not significant. However, symptom severity was a significant unique predictor, and stage of change approached significance ($p = .08$) as a unique predictor. However, due to the low number of participants there was a lack of statistical power. As such, these results must be interpreted with caution.

Table 6.9

Standard multiple regression analysis for the prediction of discrepancy in total carer burden

<table>
<thead>
<tr>
<th>Predictor</th>
<th>B</th>
<th>$\beta$</th>
<th>$sr^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sufferer symptoms</td>
<td>-12.81</td>
<td>-.56*</td>
<td>.22</td>
</tr>
<tr>
<td>Sufferer stage of change</td>
<td>-9.38</td>
<td>-.48</td>
<td>.17</td>
</tr>
<tr>
<td>Carer psychological distress</td>
<td>.35</td>
<td>.14</td>
<td>.02</td>
</tr>
<tr>
<td>Carer Expressed emotion</td>
<td>.13</td>
<td>.07</td>
<td>.00</td>
</tr>
</tbody>
</table>

*$p < .05$. 
Discussion

There were two main aims for the current study. The first aim was to determine level of discrepancy between carer self-report of carer burden and sufferer perceptions of carer burden. The second aim was to examine the predictors of the discrepancy between carer and sufferer perceptions of carer burden. These aims were achieved by using a quantitative, cross-sectional study design. Matched pairs of carers and sufferers completed a short questionnaire each. The carers provided information about demographics, carer burden, expressed emotion and psychological distress. The sufferers provided information regarding demographics, perceptions of carer burden, symptom severity and stage of change.

The discussion section will evaluate the current findings in relation to the proposed hypotheses and literature presented within the rationale. The discussion section will systematically examine the four hypotheses of the current study before critically analysing the findings in relation to prior research and theory.

Hypothesis one, that patients with an eating disorder will significantly underestimate the level of burden that carers experience was supported. Eating disorder sufferers’ reports of overall burden was significantly lower than carer self-report. Further, the mean score for sufferers on the nutritional difficulties subscale of the EDSIS was lower than that of carer’s self-report. These findings support Cleary et al. (2006) who found that patients with schizophrenia or affective disorders underestimated the level of burden experienced by their primary carer. However, a previous investigation of the differences in perceptions of carer burden in a population with amyotrophic lateral sclerosis (ALS), a form of motor neurone disease, found that patients had a good objective perception of their impact on caregivers (Chio, Gauthier, Calvo, Ghiglione, & Mutani, 2005). These differential findings may be due to differences between organic and mental illnesses. It may be speculated that those with a mental illness, such as schizophrenia, affective disorders or an eating disorder, have less insight in to their disorder and their situation and, therefore, their carer’s experience. Alternatively, though less likely, the difference may be due to the age of the participants in these studies. The patient sample within Chio et al.’s (2005) study had an average age of 60.9 ($SD = 9.6$) years, compared to the current
study’s patient sample’s average age of 24.16 (SD = 8.09) years and Cleary et al. (2006) sample of 37.0 (SD = 0.8) years. As such, a greater degree of maturity may lead to a better understanding and empathy towards their carer.

Qualitative research examining the process of recovery for patients with a mental illness may also help understand the differences in perceived carer burden. Research has shown that carers and sufferers often focus on different aspects of the illness and the recovery process (Noiseux et al., 2010). For instance, carers may underestimate the level of active participation of the sufferer in their own recovery and, instead, attribute recovery to external factors, such as treatment or medications. Further, while patients recovering from an eating disorder identify family and friends as important in the recovery process (Frederici & Kaplan, 2008; Keski-Rahkonen & Tozzi, 2005; K. Nilsson & Hagglof, 2006), it is acknowledged that family and friends can, at times, be unhelpful in this process (Keski-Rahkonen & Tozzi, 2005). This identified discrepancy between sufferer and carer perceptions of recovery, and the finding that family and friends may not always provide adequate help, may help to explain the differential perspectives of carer burden in the current study.

When examining the specific items on the EDSIS for extent of agreement between carers and sufferers in the current study, the lowest level of agreement was for items related to conflict (e.g., lying/stealing, arguments and tension at mealtimes). This finding is consistent with Cleary et al. (2006) who found that patients with an affective or psychotic disorder underestimated the level of strained atmosphere, as compared to what their carer reported. The current findings in relation to the patients with an eating disorder may be attributable to sufferers exhibiting a social desirability bias and not wanting to present themselves as ‘difficult’. Further, it may also be attributable to the sufferer’s believing that the conflict is due to the carers pushing them to eat (e.g., Honey & Halse, 2005), rather than due to themselves. Lastly, it may be speculated that sufferers attribute conflict to their own anxiety about eating and weight gain, as such do not attribute it to anger. The highest level of agreement was for items related to more concrete, behavioural aspects (e.g., food disappearing, bad hygiene in the bathroom). It could be speculated that sufferers are more willing to accept, and perhaps work on, more concrete, behavioural aspects of the eating disorder.
The finding that patients appear to be more willing to acknowledge difficulties in behavioural aspects of their eating disorder, rather than cognitive aspects of their illness may be linked to stage of change. Previous research has indicated that stage of change cannot be applied globally to eating disorder symptoms. That is, patients with an eating disorder will show varying levels of motivation to change for the different aspects of the eating disorder (Hasler, Delsignore, Milos, Buddleberg, & Schnyder, 2004). For instance, a patient may be willing to work on, and change, their excessive exercise behaviour, but may not be willing to stop strict dietary restriction. Post-hoc examination of the three factors (Rieger & Touyz, 2006) for the ANSOCQ in the current study indicated that AN sufferers were willing to change their eating, weight and shape concerns ($M = 2.48; SD = .88$) and ego-alien ($M = 2.42; SD = .89$), or subjectively distressing aspects, of their illness. However, they were less willing to change their weight gain rate ($M = 1.94; SD = .95$). Therefore, the participants from the current study are more likely to work on their concerns about their illness, rather than increase their weight. Interestingly, post-hoc correlations revealed that there was a trend towards sufferers who are more willing to work on weight gain and ego-alien aspects of their illness perceiving greater problems with dysregulated behaviour ($r = -.43; r = -.45$, respectively) as measured by the EDSIS-SF. As such, those who want to increase their weight and work on distressing aspects of their illness have a greater insight into the potential behavioural problems that may occur as a result of their illness. Similarly, post-hoc correlations showed that a later stage of change in regards to eating, shape or weight concerns was associated with a lower discrepancy on the nutritional difficulties subscale ($r = -.47, p < .05$). Therefore, the current study shows that stage of change is an important influence on the level of awareness the sufferer may have about the impact of the eating disorder on their carer.

From a treatment perspective, the domains where carers and sufferers had a high level of agreement may useful in facilitating collaborative involvement between sufferers and carers in treatment. Cleary et al. (2006) suggests that agreement between areas has the potential to lead to greater collaboration, understanding and openness between carers and patients. As such, there is the potential to reduce the level of conflict between carers and sufferers that may arise from the treatment process. The collaborative care approach for patients
affected by eating disorder, such as that developed by Treasure and colleagues (e.g., Treasure et al., 2007; Treasure, Whitaker, et al., 2005), is one such program that could be used. Further, multi-family therapy, which includes aims such as allowing carers to have a central role in recovery, reducing familial conflict and addressing carer psychological problems and burden (Scholz et al., 2005) could also be useful.

Hypothesis two and hypothesis three regarding the correlations of stage of change and symptom severity with sufferer perceptions of burden and reported burden discrepancy were not supported. While no significant correlations were found, there was a trend in the hypothesised direction with respect to stage of change. There was a low negative correlation between stage of change and burden discrepancy. This trend is not unexpected as those with an eating disorder who are in a higher stage of change, such as preparation or action, have a more positive relationship with their parents (Zaitsoff & Taylor, 2009). As such, it may be speculated that they would have more insight into the impact of the eating disorder on their carer. In support of this, prior research has indicated that those with BN who are in the action or maintenance stage of change are more likely to choose a treatment option that provides skills to change behaviour, whereas those in the pre-contemplation or contemplation stage of change are more likely to choose treatment options that simply provide support for, and exploration of, their relationship with food (Levy, 1997). Therefore, it appears that those in a higher stage of change may have a greater insight into their illness. As such, it may be speculated that this higher level of insight into their own illness may lead to higher insight into their carer’s experiences.

There was also a trend for sufferers with greater symptom severity to perceive a higher level of burden for their carers, and a lower discrepancy of burden reports. Interestingly, stage of change has been shown to be related to symptom severity, with a greater motivation change having less severe eating disorder symptoms (Zaitsoff & Taylor, 2009), with such a correlation found in the current study. Therefore, it could be anticipated that lower symptom severity would be related to a lower discrepancy of burden; however the opposite trend was found in the current study. Given a typical characteristic of those with an eating disorder is denial (Vandereycken, 2006a, 2006b); it is interesting that those with greater symptom severity perceive a higher level of burden for their carers.
As such, it may be speculated that although there may be a degree of denial in relation to their symptoms, the sufferers may still be aware of the impact on their family and friends. This pattern may be due to the self-selection of participants; that is those who choose to take part may be more aware of the impact that their illness has on their carers.

Lastly, hypothesis four, that stage of change, sufferer symptom severity, carer expressed emotion, and carer psychological distress would predict discrepancy in burden was not supported. While the overall model was not significant, sufferer symptom severity was a significance unique predictor, with greater symptom severity predicting a lower discrepancy between perceptions. Again, this is a surprising finding given the characteristic denial associated with eating disorders (Vandereycken, 2006a, 2006b). Further, sufferer stage of change also approached significance as a unique predictor, with later stages of change, such as preparation or action, predicting a lower discrepancy between perceptions of carer burden. Therefore, the degree of symptom severity and sufferer stage of change are important in determining sufferer perceptions of burden.

Lastly, given that carer report of expressed emotion did not contribute to the model, it may be speculated that sufferer level of expressed emotion could be a better predictor of burden discrepancy. However, due to the very low participant numbers it is difficult to draw accurate conclusions regarding the lack of prediction by expressed emotion.

**Summary and conclusions**

The current study demonstrates that patients with an eating disorder underestimate the level of burden experienced by their carer. Further, those with a greater symptom severity perceive a higher level of carer burden, thus resulting in a lower level of discrepancy. Further, carers and sufferers have a greater degree of agreement on behavioural aspects of the eating disorder. While the current study provides important preliminary findings, the low number of participants limits the interpretability of the results. Therefore, the ability to conduct detailed analysis was limited. As such, there is a need for further research, with larger samples sizes, examining the discrepancies between perceptions of carer burden. Further, qualitative research that examines the
reasons behind any discrepancies would be valuable. The limitation of low participant numbers, and suggestions for future research, will be discussed in more detail in the following chapter.

Nonetheless the current study provides support for the use of collaborative care approaches to treatment. For instance, where there is a higher level of agreement between carers and sufferers perceptions of burden, this may provide an opportunity for more understanding and provide possible opportunities for collaborative involvement in therapy (Cleary et al., 2006). As such, these findings provide support for the use of collaborate treatment programs developed for eating disorders (e.g., Treasure et al., 2007) or multi-family therapy (e.g., Scholz et al., 2005). Lastly, it can be seen that burden is an interactive process between sufferer and carer (Maurin & Boyd, 1990), with both sufferer and carer influencing the outcome of carer burden. The implications, limitations and future directions drawn from this study will be discussed in the following chapter.
CHAPTER SEVEN
SUMMARY AND CONCLUSIONS

Informal carers of patients with an eating disorder, such as family members or friends, often experience a high level of burden and psychological distress as a consequence of their role. While there is considerable existing cross-sectional qualitative and quantitative research examining this burden and distress, no study has explored the nature and extent of changes over time. In addition, while research indicates that a number of variables such as expressed emotion and unmet needs are associated with burden and psychological distress, the role of these have also yet to be examined longitudinally. Further, although social support and coping have been identified as important mediators in the relationship between the carer’s situation and burden (e.g., Lazarus & Folkman, 1984; Maurin & Boyd, 1990), to date this relationship has not been examined within eating disorder carers. Lastly, while carers of patients with an eating disorder report considerable burden, it is currently unknown whether the sufferers perceive their carer is burdened to a similar degree. Therefore, the current research was undertaken in order to explore the longitudinal changes in, and predictors, of carer burden and psychological distress, as well as the role of social support and coping strategies as mediators of this burden and distress. This research also examined the possible discrepancy between carer self-report of burden and sufferer perspectives of carer burden.

This chapter summarises the findings from the current thesis. Firstly, the results of the longitudinal eating disorder carer burden studies (Study 1) and the cross-sectional sufferer perspectives on burden study (Study 2) are briefly discussed. Secondly, the methodological implications of the current research, including limitations, will be examined. Thirdly, the theoretical and clinical implications of the research are presented. Lastly, suggestions for further research investigating eating disorder carer burden are provided.
Summary of thesis

Following a literature review of eating disorders and the burden of care associated with caring for someone with an eating disorder, a mediation model of eating disorder carer burden was proposed. This model hypothesised that the influence of sufferer symptoms, carer expressed emotion and carer needs on carer burden and psychological distress is mediated by social support and coping strategies. This model was based on two existing theories; Folkman and Lazarus’ (1984) cognitive stress theory and Pearlin et al.’s (1990) stress-process theory; as well as existing eating carer burden models and empirical literature.

Further, based on a review of the existing empirical literature, the current thesis aimed to address a number of identified gaps in the current eating disorder literature. To date, there has been no longitudinal examination of eating disorder carer burden and psychological distress. Secondly, coping strategies and social support have not been tested as potential mediators of carer burden and distress. Lastly, there has yet to be an examination of the perspectives of eating disorder sufferers in regards to burden of care. As such, there were three main aims for the current thesis. Firstly, to quantitatively and qualitatively examine carer burden and psychological distress in eating disorder carers longitudinally. Secondly, to examine both longitudinal and cross-sectional predictors of carer burden and psychological distress, including the potential mediatory role social support and coping strategies. Lastly, to investigate perceptions of carer burden from the perspective of the carer and the sufferer, in order to examine the nature and predictors of any discrepancies. Two studies were conducted in order to achieve these aims.

Study 1 was a longitudinal quantitative study which addressed the first two aims of this thesis. This study drew upon the mediation model of eating disorder carer burden and psychological distress proposed in Chapter Three. This mediation model hypothesises that coping strategies and social support mediate the relationship between symptom severity, expressed emotion and carer needs on the outcome of eating disorder carer burden and psychological distress. Fifty-six carers of patients with an eating disorder participated in the study, completing a set of questionnaires three times over a nine month period. Firstly, this study investigated changes over time in relation to carer burden, psychological distress,
expressed emotion, carer needs, coping strategies, and social support. Secondly, this study examined both longitudinal and cross-sectional predictors of carer burden and psychological distress. Thirdly, the hypothesised cross-sectional mediators (coping strategies and social support) of carer burden and psychological distress were tested. While path analysis testing the mediation model of carer burden and psychological distress was initially planned for Study 1, due to an insufficient sample size multiple regression and mediation analyses were conducted.

Study 1 confirmed the presence of high burden, psychological distress, expressed emotion and unmet needs in carers. Expressed emotion, carer needs and maladaptive coping strategies were consistent cross-sectional predictors of carer burden and psychological distress. In terms of the longitudinal prediction of burden and psychological distress, expressed emotion, needs and maladaptive coping were again the strongest predictors. Interestingly, psychological distress could not be predicted longitudinally. Lastly, the study showed that maladaptive coping strategies, but not social support, was a mediator of carer burden and distress.

Study 1 also collected qualitative data in order to investigate carers’ perceptions of changes in the carer role over time and of the sufferer’s treatment. This qualitative component of Study 1 indicated that carers have ongoing difficulties with their role. They reported late initiation of treatment primarily due to the sufferer hiding the true extent of their problem, the carers themselves not recognising the signs and symptoms, or health professionals and treatment services not providing the help needed. These difficulties with treatment were also related to a lack of available services within their local areas and non-public sector treatments often being prohibitively expensive. These issues resulted in feelings of frustration, helplessness and worry being experienced by the carers. Further, carers often felt isolated and cut-off from the treatment services and health professionals due to a lack of provided help.

In relation to changes since the completion of the previous questionnaire, the majority of carers wrote about the sufferer, rather than themselves. When carers perceived improvements in the sufferer’s condition, they became more hopeful and optimistic about their situation and the future. Conversely, when there was no change, or a decline, in the sufferer’s condition, carers became
increasingly worried about their loved one and pessimistic about the future. Therefore, the chronic nature of eating disorders can be draining on the carer, with a feeling of hopelessness when the sufferer does not show improvement.

In regards to qualitative carer responses about themselves, when there were improvements carers indicated that this was due to attending carer support groups or carer workshops. These groups allowed for the sharing of stories, a reciprocal understanding and positive learning experience. As such, carers felt more able to cope effectively with the situation and their role. However, not all carers reported an improvement in themselves. Some carers wrote about their feelings of depression and anxiety due to the situation. They felt that they were unable to cope with their role and as a consequence were highly stressed and worried.

Study 2 addressed the third aim of the current thesis and used a sample of 20 pairs of carers and sufferers to examine the cross-sectional discrepancy between carer self-report of burden and sufferer perspectives of burden. This study indicated that patients with an eating disorder significantly underestimate the level of burden experienced by their carer, particularly in relation to nutritional difficulties. Further, there was a positive trend towards an association between symptom severity and sufferer perceptions of burden, and a negative trend with discrepancy of burden. This suggests symptom severity may be an important contributor to eating disorder sufferers’ perceptions of burden of care. Lastly, post-hoc analyses examining the factor scores for the ANSOCQ (Rieger & Touyz, 2006) in relation to sufferer stage of change revealed a trend towards sufferers who were willing to work on weight gain and ego-alien aspects of their illness perceiving greater problems with dysregulated behaviour. Similarly, post-hoc correlations showed that a later stage of change in regards to eating, shape or weight concerns was associated with a lower discrepancy on the nutritional difficulties subscale.

Confirmation of previous findings

The current thesis confirms previous findings that carers of patients with an eating disorder experience considerable burden and psychological distress
(e.g., Dimitropoulos et al., 2008; Treasure et al., 2001; Whitney et al., 2007). Further, the current study shows that carers report a high level of expressed emotion, specifically critical comments and emotional overinvolvement, and unmet needs, specifically in regard to information, treatment options and sources of professional support. These findings are consistent with prior eating disorder research examining expressed emotion (Zabala et al., 2009) and carer needs (Graap, Bleich, Herbst, Trostmann, et al., 2008; Haigh & Treasure, 2003; Winn et al., 2004). Therefore, carers of patients with an eating disorder experience a high level of difficulties associated with their role.

The current study also supports prior models of carer burden and psychological distress. Specifically, the current findings are consistent with prior research that carer burden and distress is predicted by maladaptive coping (Joyce et al., 2003; Pinquart & Sorensen, 2005), carer needs (Treasure, Whitaker, et al., 2005) and expressed emotion (Kuipers et al., 2010). Further, the findings that maladaptive coping is a mediator of eating disorder carer burden and psychological distress supports both prior theory (Lazarus & Folkman, 1984; Pearlin et al., 1990) and carer models (Maurin & Boyd, 1990).

The current qualitative research reaffirms the difficulties carers, and patients with an eating disorder, have in terms of eating disorder treatment services. It was often reported that GPs and other health professionals lack knowledge and expertise in eating disorders. Further, there is frequently an absence of accessibility to eating disorder services, particularly in regional or rural areas. Carers also reported that they were often not told about the treatment, progress or prognosis of the sufferer due to privacy and confidentiality regulations. Lastly, carers reported a shortage of follow-up services and options. These finding are consistent with previous qualitative research (Haigh & Treasure, 2003; Hight, Thompson, & King, 2005; Perkins et al., 2004; Winn et al., 2004) which shows that carers of patients with an eating disorder lack information about the illness and treatments, feel that there is an absence of appropriate treatments, and that health professionals often lack understanding about eating disorders.
New research findings

The current research is the first to longitudinally examine carer burden and psychological distress, and the variables associated with these outcomes, in eating disorder carers. The longitudinal examination conducted in Study 1 indicated that the level of carer burden and psychological distress was moderate at all three time points, with no change over time. The magnitude of psychological distress is comparable to that found in previous cross-sectional eating disorder carer research using the GHQ-12 (e.g., Sepulveda, Lopez, Todd, et al., 2008; Whitney et al., 2007; Winn et al., 2007). The level of burden found in the current study is also comparable to prior cross-sectional eating disorder carer literature using the EDSIS (Sepulveda, Lopez, Todd, et al., 2008; Sepulveda, Whitney, et al., 2008). In terms of expressed emotion, while the reported level of critical comments and emotional overinvolvement had a small, but significant decrease, the levels remained above the cut-off point for high expressed emotion. Again, these levels of expressed emotion are consistent to prior cross-sectional eating disorder carer research utilising the FQ (Kyriacou et al., 2008a). Further, there was a small decrease in carer needs over the three time points. Therefore, eating disorder carers experience considerable and ongoing difficulties with their role. A search for prior longitudinal carer literature revealed that there is a lack of general longitudinal mental illness carer research. However, longitudinal research examining the impact of caring for someone with an organic illness, such as Alzheimer’s or stroke indicates that there are ongoing difficulties, with little, or no, change in carer mental health over time (Gaugler, 2010; Goode et al., 1998). Similarly, longitudinal research examining caring for a child with cancer indicates no changes in carer well-being over time, in conjunction with ongoing carer demands (Svavarsdottir, 2005).

Further, the current research is also the first to quantitatively examine the use of coping strategies and informal social support in eating disorder carers. In regards to coping strategies, carers consistently used both maladaptive and adaptive coping strategies to a moderate level. At all three time points, carers reported having two to three people (typically family members or close friends) as sources of support, and that they were moderately satisfied with this support.
Therefore, carers utilise a number of coping strategies, and are happy with the informal support they receive from others.

Additionally, this thesis is the first to examine the role of coping strategies and social support as mediators on the outcome of carer burden and psychological distress for eating disorder carers. While path analysis examining the proposed mediation model of eating disorder carer burden and distress was not able to be conducted, mediation analyses indicated that maladaptive coping strategies is a significant mediator on the relationship between carer expressed emotion and needs and the outcomes of burden and distress. However, social support was not found to be significantly related to these constructs, therefore, mediation was not explored. However, as discussed below, this lack of relationship may be due to the measure of social support selected. Thus, there is partial support for the proposed mediation model of carer burden and psychological distress.

In terms of the cross-sectional prediction of carer burden and psychological distress, maladaptive coping strategies, carer expressed emotion and carer needs were consistent predictors. Overall, the cross-sectional models predicted 48%, 50%, and 58% of the variance in carer burden at Time One, Time Two and Time Three, respectively. The cross-sectional models predicted a lower amount of variance in psychological distress, with 32%, 27%, and 23% of the variance explained at Time One, Time Two and Time Three, respectively. To date, there has no literature that quantitatively tests the longitudinal predictors of carer burden in eating disorder carers. However, previous cross-sectional models of eating disorder carer psychological distress have explained 53% (Whitney et al., 2007) and 41% (Kyriacou et al., 2008b) of variance. The difference in the predictor variables chosen may explain why the models in the current study predicted a lower amount of variance. The prior research used dependency and stigma (Whitney et al., 2007) and self-related strains, carer sex and interpersonal strains (Kyriacou et al., 2008b) as predictors. Therefore, the predictors, or the chosen measures, in the current study, are not as strong predictors of psychological distress.

Similarly, maladaptive coping strategies, expressed emotion and carer needs were longitudinal predictors of carer burden. The longitudinal models of carer burden explained 23%, 23%, and 31% of variance for Time One to Time Two, Time One to Time Three, and Time Two to Time Three models,
respectively. Due to the low to moderate amount of variance predicted, further longitudinal eating disorder carer research is needed to investigate other potential long-term predictors. However, it can be concluded that maladaptive coping, expressed emotion and carer needs have a significant impact on the experiences of eating disorder carers. Psychological distress, however, could not be predicted longitudinally. This may be speculated to be attributable to high variability during the course of an eating disorder, and therefore, the carer situation being quite changeable. If so, it can be speculated that carers are focused on the ‘here-and-now’ and the past situation does not have an influence on current levels of psychological distress.

From a qualitative perspective, new research findings from the current thesis relate to the changes in eating disorder carers’ situation over time. The majority of carers reported changes in the sufferer rather than themselves, perhaps reflecting a greater focus on helping the sufferer rather than on themselves as carers. Further, this sufferer focus may be linked to the high level of emotional overinvolvement reported by carers in Study 1.

In relation to the qualitative component of Study 1, the responses reflected that found with the quantitative component. Carers reported ongoing difficulties, both within themselves (for example, depression and anxiety) or within the person they were caring for (such as co-morbidities or worsening eating disorder symptoms). These difficulties subsequently resulted in an ongoing struggle that led to a reduction in the ability to cope and the development of pessimism about the future. Further, carers reported consistently encountering problems with treatment services and health professionals; help was often not available, or prohibitively expensive. Further, when help was available, there was no guarantee that there would be sufficient understanding or expertise to enable effective treatment.

Lastly, Study 2 demonstrated that patients with an eating disorder underestimate the level of burden experienced by their carer, particularly in relation to nutritional difficulties. This discrepancy may then result in greater difficulties for the carer due to the lack of insight on the part of the sufferer. Further, it appears that sufferer symptom severity may have a role in the patient’s perceptions of burden. Specifically, those with greater symptom severity report a higher level of burden for their carers, and thus, a lower discrepancy between
carer self-report and sufferer perceptions of burden. Lastly, post-hoc analyses using the factors scores for the ANSOCQ (Rieger & Touyz, 2006) showed that stage of change in relation to weight gain and ego-alien aspects of their illness was negatively correlated with dysregulated behaviour and stage of change in regards to eating, shape or weight concerns was associated with a lower discrepancy on perceptions of nutritional difficulties. These findings indicate that while stage of change is an important determinant of sufferer insight into the degree of burden experienced by their carer, due to the differential pattern of correlations between different aspects of stage of change and perceptions of burden, there is a need to assess stage of change in a multidimensional way (Hasler et al., 2004; Rieger & Touyz, 2006).

Methodological implications

The main methodological strength of the current research was the use of a longitudinal design, in conjunction with utilising questionnaires specifically designed for the eating disorder carer population. Further, the current research, where possible, used measures consistent with prior research, such as the GHQ-12, to allow for more direct comparability. Thirdly, the use of a community based sample improves upon past eating disorder carer burden research that typically has recruited from inpatient or database sources to improve the generalisability of the findings. Lastly, the current research is also the first to examine the differences between carer self-report and sufferer perspectives of carer burden.

Limitations

When interpreting the current thesis’ findings, a number of methodological and design limitations need to be considered. The current thesis has the usual inherent limitations relating to self-report biases, such as the possibility of reports being influenced by a social desirability bias. Further, in regards to both Study 1 and Study 2, the first set of specific limitations relates to the nature of the samples. Firstly, while the participants were drawn from community samples, due to the self-selection in to the study, it may be that the samples were not representative of more extreme patients. It may be speculated
that the more extreme patients (both carers and sufferers) would not have the time to complete the study or may be too distressed or depleted by their situation to take part. Further, it may be that the patients who participated had more insight into their situation, and thus wanted to share their story. Secondly, while all eating disorder diagnoses were intended to be included in the samples, the majority of the participants cared for, or were, someone with AN. However, given that carers reported on the diagnosis of the sufferer, rather than patient self-report, it may be that the information provided was not accurate. For instance, due to sufferers concealing their symptoms from their carers, it may be that carers are not accurately assessing the level of restriction, binging or purging behaviour. Similarly, while both genders were included, the majority of the carers and sufferers were female for all three studies. However, this is characteristic of eating disorder carer samples in previous quantitative research (e.g., Graap, Bleich, Herbst, Trostmann et al., 2008; Dimitropoulos et al., 2008; Winn et al., 2007). Therefore, comparisons between sufferer diagnosis or carer and sufferer gender could not be made, meaning generalisability of the current findings may be limited. These limitations could be addressed in future research by ensuring that the sample has an equal representation of gender and diagnosis.

Lastly, and most importantly, the sample sizes in both Study 1 and Study 2 were small (42 completed all three time points in Study 1, and 20 pairs participated in Study 2), thus limiting the analyses that could be conducted. Further, it may be speculated that there is greater difficulty in recruiting from a community population, as in the current thesis. Participant recruitment for Study 1 and Study 2 took place over a period of approximately 12 months and 10 months, respectively. Numerous approaches were used such as online advertisements on eating disorder organisation websites, newspaper advertisements in Australian national and local newspapers, two radio interviews at local radio stations, distribution of flyers within carer support groups and carer workshops, questionnaire mail-outs via a hospital-based, and privately operated, eating disorder services, and questionnaire mail to carers listed with The Butterfly Foundation. Despite the variety of approaches, in conjunction with providing participants with the option to complete the study online or with paper-based questionnaires, the sample sizes did not reach expectations, with the response rates for the paper-based questionnaires in both studies very low (28% for Study 1
and 17% for Study 2). The low response rates may be directly attributable to the use of questionnaires in that response rates of questionnaire methods are typically 30% or below (Goyder, 1985). The low response rate may also be attributable to the length of the questionnaire and sensitive nature of the questions (Edwards et al., 2002). Use of an interview methodology may have increased the response rate of participants. For instance, use of interviews for schizophrenia research has shown to have a 55% (Kuipers et al., 2007) to 75% (Grice et al., 2009) response rate. While interviews may have lead to a higher response rate, a self-report questionnaire methodology was chosen in order to maintain consistency with prior research and obtain a wide ranging, community sample from a large geographic area. Attempts to increase the response rate, such as follow-ups, within Study 2 could not be made due to the anonymous nature of the study.

Further, while the post hoc power analyses conducted for Study 1 were of benefit, it has been argued that these analyses may overestimate the power within a particular test (Gillett, 1994). Therefore, power for Study 1 may be reduced, thus limiting the interpretability of the current findings. Similarly, reduced power is also an issue for Study 2 due to an insufficient sample size. While the current thesis argued that recruiting from inpatient settings or volunteer databases was a limitation of previous research, it may be that this is a more feasible way to recruit participants, thus ensuring an adequate sample size. As such, future research could recruit from both the general community in conjunction with inpatient settings and volunteer databases in order to ensure that the sample is of adequate size as well as being representative of the general population.

For Study 1, the second main limitation relates to the measure of social support. The chosen social support measure did not correlate with the other variables, nor did it predict burden or psychological distress. 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 social support in relation to the carer role. Further, the SSQ-6 only measures emotional support, rather than other forms of social support (Sarason et al., 1987). Therefore, it may be speculated that eating disorder carers require more instrumental, or tangible, social support from others. As such, it may be that the full version of the SSQ, which measures both emotional and tangible support, is a more appropriate measure of social support for eating
disorder carers (Sarason et al., 1983; Sarason et al., 1987). However, prior research using the SSQ-6 as a measure of social support indicates that quantity and satisfaction with social support predicts burden of care for carers of patients with Alzheimer’s disease (Kerherve, Gay, & Vrignaud, 2008), and is correlated with psychological distress in young carers (Pakenham et al., 2007). As such, there is evidence of the utility of the SSQ-6 as a measure of social support. This limitation could be addressed in future research by utilising the full version of the SSQ.

The final limitation for Study 1 relates to the evaluation of carer needs. While valuable information was ascertained in relation to a reduction in overall need for information about treatment, as well as an overall reduction in carer needs, there was no way to ascertain why this might be the case. As such, interpretative conclusions regarding the processes that lead to a reduction in carer needs over time are limited. Future research could incorporate a qualitative assessment of why carers may require less information about their loved one’s treatment, as well as having less needs in general. Understanding what contributes to the reduction in carer needs would provide scope for the development of targeted help in relation to carer needs.

Theoretical and clinical implications

The current research has a number of theoretical implications that will be discussed before considering the clinical implications. A major aim of the current thesis was to test a proposed a mediation model of carer burden. Figure 7.1 presents the pathways and variables that were supported within the current thesis. While this model was unable to be tested in full in Study 1 due to insufficient participant numbers, regression and mediation analyses were conducted in order to test components of this model. Cross-sectional and longitudinal regression analyses showed that maladaptive coping strategies, carer needs and expressed emotion are important predictors of carer burden and psychological distress. Further, maladaptive coping strategies were found to mediate the following relationships: expressed emotion and carer burden, carer needs and carer burden, expressed emotion and psychological distress, and carer needs and psychological distress.
distress. Thus, Study 1 provided partial support for the mediation model of eating disorder carer burden and distress. As such, the predictive capacity of coping strategies, expressed emotion and carer needs on burden and psychological distress needs to be taken into account. Therefore, future models of eating disorder carer burden need to incorporate these variables. Secondly, the mediatroy role of maladaptive coping strategies on the relationship of expressed emotion and needs with burden and psychological distress needs to be considered more fully.

![Mediating variable diagram]

**Figure 7.1.** A proposed mediation model of eating disorder carer burden

Additionally, the current finding of maladaptive coping as a mediator of carer burden and psychological distress provides further support for the cognitive stress theory (Lazarus & Folkman, 1984) and stress-process theory (Pearlin et al., 1990), in conjunction with general caregiving models (Maurin & Boyd, 1990; Pinquart & Sorensen, 2005). Further, the current research reflects the prior models of schizophrenia carers (Joyce et al., 2003; Kuipers et al., 2010), in that expressed emotion and maladaptive coping strategies were found to be consistent predictors of burden and psychological distress. Lastly, prior eating disorder carer models have shown that expressed emotion (Winn et al., 2007), carer needs (Treasure, Whitaker, et al., 2005) and coping strategies (Treasure, Whitaker, et al., 2005) contribute to eating disorder carer outcomes. Thus, the findings from Study 1 provide further support for these models.

Clinical implications include interventions that could be developed to teach carers how to effectively cope with their situation, reduce their level of
expressed emotion and to ensure that their needs, as carers, be met. Prior research has indicated that a workshop series aimed at reducing expressed emotion successfully reduced both critical comments and emotional overinvolvement (Sepulveda et al., 2010). Further, these workshops have been shown to reduce burden and psychological distress (Sepulveda, Lopez, Todd, et al., 2008; Sepulveda et al., 2010). In addition, the qualitative findings from Study 1 indicate that those in rural or regional areas do not have access to adequate support or treatment. Therefore, there is scope for delivery of support by telephone or online. For instance, delivery of carer skills-based training via DVD and telephone coaching has been shown to reduce psychological distress in eating disorder carers (Sepulveda, Lopez, MacDonald, et al., 2008).

In addition, both carer and sufferers need to be included in the treatment process, with carers requiring individual support and help. The findings from Study 2 provide support for the argument that carer burden is an interactive process between sufferer and carer (Maurin & Boyd, 1990), with both sufferer and carer influencing the outcome of carer burden. Therefore, the use of collaborative treatments and multi-family therapy may be useful. For instance, multi-family therapy, allows carers to have a central role in recovery and addresses carer psychological problems and burden, in conjunction with helping the sufferer with recovery (Scholz et al., 2005). Further, the collaborative care approach developed by Treasure and colleagues (e.g., Treasure et al., 2007; Treasure, Whitaker, et al., 2005) would also be of benefit. The collaborative care approach can be implemented by way of carer workshops or training sessions to help eating disorder carers cope with their role. For instance, a series of workshops has been developed that provides carers with skills improve their ability to cope with their role as well as to help their loved one more effectively (Treasure, Sepulveda, Whitaker, Todd, & Lopez, 2010). In this way, the situation for both the carer and sufferer has the potential for improvement.

Lastly, prior research examining treatment of patients with schizophrenia indicates that early intervention reduces the acute psychotic symptoms and improves long-term outcomes (McGlashan, 1999). Further, early interventions reduce the incidence of relapse for patients with schizophrenia (Gumley et al., 2003). Similarly, treatment of eating disorder is more effective when implemented early, with early recognition associated with lower mortality and
morbidity in adolescents with an eating disorder (Rome et al., 2003). As such, early prevention and intervention is important in improving outcomes for those with an eating disorder. As the carers in the current study reported that they did not feel informed about the nature and treatment of eating disorders, an important opportunity for parents to implement early preventative procedures may have been missed. Therefore, greater education about eating disorders, particularly in relation to signs and symptoms, treatment options, and how parents can help, may improve outcomes for both carers and sufferers.

Future research directions

Future research should continue to utilise a longitudinal design to focus on the long-term experience of carers. Continued use of eating disorder specific measures, such as the CaNAM and EDSIS is required in order to ensure that the measures are valid for the population. Additionally, the use of a better social support measure is needed in order to adequately capture its influence on burden and psychological distress.

Future studies with larger, more diverse sample sizes would also be beneficial. Use of a large sample size would allow for the use of more powerful statistical techniques such as latent growth curve analysis to test the proposed mediation model of carer burden and psychological distress over time. A more diverse sample, with equal representation of gender, age and diagnosis would allow for comparative analyses between males and female carers, the various eating disorders and the age of both carer and sufferer. Lastly, a larger sample size would allow for the investigation of the role of adaptive, as well as maladaptive, coping strategies.

Additionally, given previous research suggests that carers of patients with a psychotic disorder indicates that long-standing carers are more optimistic and positive about their role than carers of patients in the initial stages of the illness (Onwumere et al., 2008), future research recruiting carers of patients with a recent diagnosis (i.e., less than three months) and following them longitudinally would be valuable. This study design would allow for the examination of the early stages of the caring role, and how carers may adapt to their new situation.
In addition, the current study found that there was a reduction in carer needs over time, particularly in relation to requiring information about their loved one’s treatment. Further longitudinal, qualitative research is needed in order to examine the processes and reasons for these reductions in carer needs over time.

Further, an examination the long-term effectiveness of interventions aimed at reducing expressed emotion and maladaptive coping strategies, and addressing carer needs, on reductions of carer burden and psychological distress would be valuable. Preliminary research indicates that collaborative care workshops, aimed at teaching carers adaptive coping strategies and skills to reduce expressed emotion, are successful in reducing burden and psychological distress at a three month follow-up (Sepulveda, Lopez, Todd, et al., 2008). Lastly, further investigation of sufferer perceptions of burden would be useful; particularly what determines possible discrepancies between carer self-report and sufferer perspectives. Such an investigation would provide information that could be used to develop intervention programs designed to reduce familial conflict or stress.

Conclusions

The current thesis had three main aims. Firstly, to longitudinally examine carer burden and psychological distress in eating disorder carers. Secondly, to investigate social support and coping strategies as mediators of carer burden and distress. Lastly, to explore the differences in perceptions of carer burden in the person with the eating disorder and their carer. Two studies were conducted to achieve these aims.

The current thesis proposed a mediation model of eating disorder carer burden and psychological distress that was based on existing literature. This mediation model guided Study 1 of this thesis. The current thesis has shown that caring for someone with an eating disorder is associated with considerable levels of carer burden and psychological distress. In addition, this burden and distress is ongoing and remains high. The current research has also demonstrated that carer needs, maladaptive coping strategies and expressed emotion are important predictors of burden and distress, both cross-sectionally and longitudinally. Further, maladaptive coping strategies are a mediator on the outcome of carer burden and psychological distress. As such, intervention programs and support
services need to focus on addressing unmet needs of carers, teaching them to rely less on maladaptive coping strategies, and discuss with them strategies to reduce their level of expressed emotion.

Longitudinal qualitative data from the current research also reflects the longitudinal quantitative findings. Carers have ongoing difficulties with their caring role and also with the treatment that their loved one is receiving. Further, carers appear to be more focussed on the person they are caring for, rather than themselves, possibly due to their high level of emotional overinvolvement. Thus, carers need to be helped to re-prioritise their own lives and be given ‘permission’ to engage in aspects of their life, such as family, social and work commitments, rather than focussing on caring as their only role.

Lastly, the current thesis demonstrates that patients with an eating disorder underestimate the level of burden their carers’ experience. Further, preliminary trends indicate that sufferer symptom severity may contribute to patient perspectives of burden and level of discrepancy between carer self-report and sufferer perspectives of burden. These findings indicate that burden is an interactive process that is influenced by both carer and sufferer. Additionally, problems areas where there is a higher level of agreement between carer and sufferer could potentially become the focus of collaborative interventions and treatment programs.
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APPENDIX A

ETHICS APPROVAL – STUDY 1
Research Services
Office of the Deputy Vice-Chancellor (Research) (Melbourne Campus)

MEMORANDUM

TO: Dr Ross King
School of Psychology, Geelong

cc: Kerri Coomber

FROM: Executive Officer, Deakin University Human Research Ethics Committee (DU-HREC)

DATE: 7 November 2007

SUBJECT: Project EC 266-2007  (Please quote this project number in future communication.)
Caring for individuals with an eating disorder: a longitudinal study

This application was considered at the DU-HREC meeting held on 29 October 2007.

Approval has been given for Kerri Coomber, under the supervision of Dr Ross King, School of Psychology, to undertake this project for a period of three years from 7 November 2007.

The approval given by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the approval. It is your responsibility to contact the Executive Officer immediately should any of the following occur:

- Serious or unexpected adverse effects on the participants
- Any proposed changes in the protocol, including extensions of time.
- Any events which might affect the continuing ethical acceptability of the project.
- The project is discontinued before the expected date of completion.
- Modifications are requested by other HREC's.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

DU-HREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Research Involving Humans (1999).

P.P.

Silvia Rametta
On behalf of DU-HREC
(03) 9251 7123
APPENDIX B

EXAMPLE OF ONLINE ADVERTISEMENT – STUDY 1
Caring for individuals with an eating disorder: Family and friends

Finding out that a loved one has an eating disorder can be devastating for family and friends. Carers can experience social isolation, increased psychological distress, an increased in the level of expressed emotion with the family environment, a sense of guilt and self-blame, and difficulties finding adequate support for themselves. This experience can last for months, or years. Despite this, little attention has been given to the experience of carers. Therefore, we are conducting a study that will examine the long-term impact of caring for someone with an eating disorder.

Who are we looking for?

Carers (over the age of 18) of individuals with a diagnosed eating disorder are invited to participate.

What will you be asked to do?

Participants will complete 3 questionnaires at 3 time points over a 9 month period. These questionnaires will ask about your background and current living situation; the symptoms of your loved one; who supports you; how you cope as a carer of someone with an eating disorder; if there has been any effect on your relationship with your loved one; your needs as a carer; the positive and negative effects of caregiving; and your current health in general.

The first questionnaire, and more detailed information, can be found at:

http://www.deakin.edu.au/psychology/research/edcarers/survey

The research is being conducted by Ms Kerri Coomber, PhD (Psychology) candidate at Deakin University, Australia, under the supervision of Dr Ross King. For more information please contact Kerri Coomber on kerri.coomber@deakin.edu.au or Ross King on ross.king@deakin.edu.au
APPENDIX C

EXAMPLE NEWSPAPER ADVERTISEMENT – STUDY 1
Parents, partners of friends caring for someone with an eating disorder can find this experience to be emotionally taxing, and that much time and effort is needed to help the sufferer recover.

Deakin University invites carers of people with an eating disorder to share their experience in a 9 month study. Over this time you will mailed out 3 sets of questionnaires to complete. Confidentiality of your responses is assured.

If interested, please contact Kerri Coomber on (03) 5227 8426 or klcoo@deakin.edu.au or contact Dr Ross King on (03) 5227 8481 or rking@deakin.edu.au
APPENDIX D

QUESTIONNAIRE TIME ONE – STUDY 1
GENERAL INFORMATION SHEET

The following section asks for demographic and descriptive information about yourself and the person you are caring for.

*Yourself*

1. What is your gender? Male / Female

2. What is your age in years? ____________________________________

3. What is your relationship to the person you care for (e.g. mother, father, partner)?
   ________________________________

4. If you are a parent, how many children do you have (including the person you care for), or if you are a partner, do you have any children and, if so, how many?
   ____________________________________________________________

5. If you have children, what are their ages?
   ____________________________________________________________

6. What are your average hours of paid employment per week (e.g. full time, 20 hours)?
   ____________________________________________________________

7. Please list all the treatment commitments you have, both with whom and for how long (e.g. Psychologist appointment 1 hour per week)
   ____________________________________________________________

8. How important is it to you that the person you care for change?

<table>
<thead>
<tr>
<th>Not important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

9. How confident are you that you are able to help the person you are caring for change?

<table>
<thead>
<tr>
<th>Not confident</th>
<th>Very confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
The person you care for

1. What is their gender? **Male / Female**

2. What is their age? ____________________

3. Do they live at home with you? **Yes / No**

4. How many hours of contact per week do you have with this person? ________

5. What is their eating disorder diagnosis? _______________________________

6. What is their current BMI or current weight and height? ________________

7. Do they show a fear of gaining weight and/or fatness? (please circle)
   
   - No fear or distress
   - Mild fear and distress
   - Moderate fear and distress
   - High fear and distress
   - Severe fear and distress

8. Do they describe their body as being fat despite conflicting evidence or being told otherwise? (please circle)
   
   - Never
   - Rarely
   - Sometimes
   - Often
   - Always

9. Do they engage in binge eating? (please circle)
   
   - Not at all
   - 3-4 times a month
   - Once a week
   - 2-3 times per week
   - 2-3 times a day
   - More than 5 times a day

10. Do they engage in purging behaviour? (please circle)
    
    - Not at all
    - 3-4 times a month
    - Once a week
    - 2-3 times per week
    - 2-3 times a day
    - More than 5 times a day

11. If they engage in purging behaviours please tick the methods you are aware of that they use?
    
    - Vomiting
    - Laxatives
    - Diet Pills
    - Diuretics
    - Enemas
    - Insulin

12. How many hours per day do they exercise? ________________________

13. What kind of exercise do they engage in? ________________________

14. If female, and if known, have they missed more than three consecutive menstrual periods? **Yes / No**
15. How long have they had their illness? _____________________________

16. Are they currently receiving treatment? **Yes / No**

17. How many times have they been admitted to hospital? ________________

18. How _important_ is it to the **person you care for** that they change?

<table>
<thead>
<tr>
<th>Not important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>2</td>
<td>8</td>
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<td>8</td>
<td>2</td>
</tr>
<tr>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

19. How _confident_ is the **person you care for** that they can change?

<table>
<thead>
<tr>
<th>Not confident</th>
<th>Very confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>2</td>
<td>8</td>
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<td>8</td>
<td>2</td>
</tr>
<tr>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>
This questionnaire lists different ways in which families try to cope with everyday problems. For each item please indicate how often you have reacted to the person you care for in this way. There are no right or wrong responses. It is best to note the first response that comes to mind.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Never/Very</th>
<th>Rarely</th>
<th>Rarely</th>
<th>Often</th>
<th>Very</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I tend to neglect myself because of him/her</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>I have to keep asking him/her to do things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I often think about what is to become of him/her</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>He/she irritates me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I keep thinking about the reasons for his/her illness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>I have to try not to criticise him/her</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I can’t sleep because of him/her</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>It’s hard for us to agree on things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>When something about him/her bothers me, I keep it to myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>He/she does not appreciate what I do for him/her</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>I regard my own needs as less important</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>He/she sometimes gets on my nerves</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>I’m very worried about him/her</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>He/she does some things out of spite</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>I thought I would become ill myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>When he/she constantly wants something from me, it annoys me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>He/she is an important part of my life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>I have to insist that he/she behave differently</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I have given up important things in order to be able to help him/her</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>I’m often angry with him/her</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**BRIEF COPE**

We are interested in finding out how you currently cope with caring for an individual with an eating disorder. There are lots of ways to try and deal with a stressful situation. The following questions ask what you generally do and feel to cope with caring for someone with an eating disorder. Please circle the response in terms of how often you use each one.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>A moderate amount</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I’ve been concentrating my efforts on doing something about the situation I’m in</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>I’ve been taking action to try to make the situation better</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>I’ve been trying to come up with a strategy about what to do</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>I’ve been thinking hard about what steps to take</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>I’ve been trying to see it in a different light, to make it seem more positive</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>I’ve been looking for something good in what is happening</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>I’ve been accepting the reality of the fact that it has happened</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>I’ve been learning to live with it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>I’ve been making jokes about it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>I’ve been making fun of the situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>I’ve been trying to find comfort in my religion or spiritual beliefs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>I’ve been praying or meditating</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13</td>
<td>I’ve been getting emotional support from others</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14</td>
<td>I’ve been getting comfort and understanding from someone</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15</td>
<td>I’ve been trying to get advice or help from other people about what to do</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>Not at all</td>
<td>A little bit</td>
<td>A moderate amount</td>
<td>A lot</td>
</tr>
<tr>
<td>---</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------</td>
<td>--------------</td>
<td>-------------------</td>
<td>-------</td>
</tr>
<tr>
<td>16.</td>
<td>I’ve been getting help and advice from other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17.</td>
<td>I’ve been turning to work or other activities to take my mind off things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18.</td>
<td>I’ve been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19.</td>
<td>I’ve been saying to myself “this isn’t real”</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20.</td>
<td>I’ve been refusing to believe that it has happened</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21.</td>
<td>I’ve been saying things to let my unpleasant feelings escape</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22.</td>
<td>I’ve been expressing my negative feelings</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23.</td>
<td>I’ve been using alcohol or other drugs to make myself feel better</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24.</td>
<td>I’ve been using alcohol or other drugs to help me get through it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25.</td>
<td>I’ve been giving up trying to deal with it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26.</td>
<td>I’ve been giving up the attempt to cope</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27.</td>
<td>I’ve been criticising myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28.</td>
<td>I’ve been blaming myself for things that happen</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
SOCIAL SUPPORT QUESTIONNAIRE

The following questions ask about people who provide help or support. Please answer each question in relation to caring for someone with an eating disorder. Each question has two parts. For the first part, list all the people you can count on for help or support in the manner described. Please only state their relationship to you, not their name. For the second part, circle how satisfied you are with the overall support you have. If you have no support for a question, write “no one” but still rate your satisfaction.

1. Whom can you count on to distract you from your worries?

_________________________________________________________________
_________________________________________________________________

How satisfied are you with this support?

<table>
<thead>
<tr>
<th>Very dissatisfied</th>
<th>Moderately dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Moderately satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
</table>

2. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

_________________________________________________________________
_________________________________________________________________

How satisfied are you with this support?

<table>
<thead>
<tr>
<th>Very dissatisfied</th>
<th>Moderately dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Moderately satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
</table>

3. Who accepts you totally, including both your best and worst points?

_________________________________________________________________
_________________________________________________________________

How satisfied are you with this support?

<table>
<thead>
<tr>
<th>Very dissatisfied</th>
<th>Moderately dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Moderately satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
</table>
4. Whom can you really count on to care about you, regardless of what is happening to you?

_________________________________________________________________
_________________________________________________________________

How satisfied are you with this support?

Very dissatisfied  Moderately dissatisfied  Somewhat dissatisfied  Somewhat satisfied  Moderately satisfied  Very satisfied

5. Whom can you really count on to help you feel better when you are feeling generally down?

_________________________________________________________________
_________________________________________________________________

How satisfied are you with this support?

Very dissatisfied  Moderately dissatisfied  Somewhat dissatisfied  Somewhat satisfied  Moderately satisfied  Very satisfied

6. Whom can you count on to console you when you are very upset?

_________________________________________________________________
_________________________________________________________________

How satisfied are you with this support?

Very dissatisfied  Moderately dissatisfied  Somewhat dissatisfied  Somewhat satisfied  Moderately satisfied  Very satisfied
**GENERAL HEALTH QUESTIONNAIRE**

We would like to find out about how your health has been in general *over the past few weeks*. Please rate each question by circling the response that best describes you.

<table>
<thead>
<tr>
<th>Have you recently:</th>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Less than usual</th>
<th>Much less than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Been able to concentrate on what you’re doing?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Lost much sleep over worry?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>3. Felt constantly under strain?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Felt you couldn’t overcome your difficulties?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Been feeling unhappy or depressed?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Been losing confidence in yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Been thinking of yourself as a worthless person?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Felt capable of making decisions about things?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less than usual</td>
<td>Much less than usual</td>
</tr>
<tr>
<td>8. Been able to face up to your problems?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. Felt that you are playing a useful part in things?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. Been able to enjoy your normal day-to-day activities?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12. Been feeling reasonably happy, all things considered?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
EATING DISORDER SYMPTOM IMPACT SCALE

The following pages contain a number of statements that commonly apply to persons who care for relatives or friends with an eating disorder. We would like you to read each one and decide how often it has applied to you over the past one month. It is important to note that there are no right or wrong answers. Also, it is best not to spend too long on any one statement. Your first reaction will usually provide the best answer.

<table>
<thead>
<tr>
<th>During the past month how often have you thought about</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>How your friends/relatives have stopped visiting</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Losing your friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Feeling unable to go out for evenings, weekends or on holiday</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Cancelling or refusing plans to see friends or relatives</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Feeling that I should have noticed it before it became so bad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Feeling that I have let her/him down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Feeling that there could have been something I should have done</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Thinking that perhaps I wasn’t strict enough</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Thinking about where I went wrong</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Her/him being physically and/or verbally aggressive</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Her/him having an out of control temper</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Her/him being controlling or manipulative</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Her/him lying or stealing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
When the sufferer was living with you at home during the past month, how often: (if the sufferer was not living at home with you during the past month, please refer to the last time she/he was living at home)

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you experience difficulties preparing meals (i.e. making separate meals for family members, not having correct ingredients)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Were there arguments with other family members about how to handle mealtimes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Were there arguments or tension during mealtimes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did food disappear from the cupboards</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you spend long periods of time shopping for food</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you have difficulties with blocked drains, plumbing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Were there bad smells and poor hygiene in the bathroom</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you have to turn up the heat due to her/his feeling cold</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you check on her/him to ensure that she/he was okay</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you notice or think about how the illness was affecting her/him physically (i.e. see her/him fall, faint, struggle up the stairs)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you notice or think about how the illness was affecting her/him mentally</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
CARERS’ NEEDS ASSESSMENT MEASURE

The following pages contain a number of statements in relation to needs that commonly apply to people who care for relatives or friends with an eating disorder. It is important to note that there are no right or wrong answers.

1. Information about eating disorders

Please circle your answer to the following questions using the responses below:

0 = No I haven’t received enough information and I would like to receive more
1 = I don’t require information about this area
2 = Yes, I have received sufficient information

Have you received enough information about the following areas?

a) Eating disorders in general
b) Local self-help groups
c) Individual/family support groups
d) Helplines
e) Where to get help and/or advice
   Counselling/psychotherapy opportunities
f) available to you
g) Coping strategies
   ‘Success stories’, i.e. people who have recovered
h) from an eating disorder
i) Different treatment options
j) Current treatment plan
k) Future treatment plan
l) Prognosis of the person you are caring for
m) How to meet others ‘in the same boat’
n) What to do/who to contact in case of a relapse

In terms of passing on information to carers, do you think the following are useful?

<table>
<thead>
<tr>
<th>Carers’ support groups</th>
<th>Yes (please tick)</th>
<th>No (please tick)</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Buddy’ support/peer support</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Carers’ conferences</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Helplines</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Leaflets</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
2. Support from organisations

Please circle your answer to the following questions using the responses below:

0 = No, but I’d like to receive more support
1 = I don’t require support from this person/organisation
2 = Yes, I have received enough support

Have you received a sufficient amount of support from the following people/associations?

a) Self-help group
b) Other support group (e.g. individual/family)
c) Eating Disorders Association
d) Helpline

3. Support for yourself

Please circle your answer to the following questions using the responses below:

0 = No, but I would like to have been able to
1 = No, but I don’t mind
2 = Yes

Have you been able to:

a) Seek professional support for yourself?
b) Tell the person you are caring for that you need support
c) To contact someone else in a similar situation, such that you can offer each other support
d) Meet any other people who have recovered from an eating disorder
e) Seek support with meal times (e.g. advice on how to approach meal times, how to bring the family back together at meal times etc.)?
4. Treatment

Did the treatment of the person you are caring for start early enough? **YES / NO**

If ‘No’, please give details
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Have you been kept sufficiently informed of the person you are caring for’s treatment? **YES / NO**

If ‘No’, please give details
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Do you think that there is sufficient follow-up treatment (e.g. visits from social workers, day patient units) for people with eating disorders? **YES / NO**

If ‘No’, what additional follow-up treatment do you think should be offered?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

5. Information general practitioners have about eating disorders

Please circle your answer to the following questions using the responses below:

0 = No, I would like to receive more
1 = I don’t require information from my GP about this area
2 = Yes
Do you think that your GP has given you enough information about the following areas?

a) Eating disorders in general 0 1 2
   The symptoms and signs of eating disorders 0 1 2

b) The available treatment options 0 1 2
   Organisations you can contact for help/advice 0 1 2

c) Referrals to specialists in eating disorders 0 1 2

6. Training general practitioners receive about eating disorders

Please circle your answer to the following questions using the responses below:

0 = No, and I think he/she should be given more training in this area
1 = I don’t think that GPs require training in this area
2 = Yes

Do you think that your GP has received sufficient training in the following areas?

a) Diagnosing an eating disorder 0 1 2
   How to respond to a person who presents with an eating disorder 0 1 2

b) The importance of a quick referral 0 1 2
   Where to refer someone with an eating disorder 0 1 2

**Thankyou for your time**

Please place this questionnaire, along with your consent form, in the supplied reply paid envelope and return them by mail.
APPENDIX E

QUESTIONNAIRE TIME TWO AND THREE: GENERAL INFORMATION
SHEET – STUDY 1
GENERAL INFORMATION SHEET

The following section asks for demographic and descriptive information about yourself and the person you are caring for.

Yourself

1. What is your age in years? ________________________________

2. What are your average hours of paid employment per week (e.g. full time, 20 hours)? ________________________________

3. Please list all the treatment commitments you have, both with whom and for how long (e.g. Psychologist appointment 1 hour per week)

_________________________________________________________________
_________________________________________________________________

4. How important is it to you that the person you care for change?

<table>
<thead>
<tr>
<th>Not important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
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<td>2</td>
<td></td>
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<td>5</td>
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<td>6</td>
<td></td>
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<tr>
<td>7</td>
<td></td>
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<tr>
<td>8</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

5. How confident are you that you are able to help the person you are for change?

<table>
<thead>
<tr>
<th>Not confident</th>
<th>Very confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
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<tr>
<td>3</td>
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<td>4</td>
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<td>5</td>
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<td>6</td>
<td></td>
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<tr>
<td>7</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

6. What has changed in the last 4 ½ months, and how has this impacted you? (e.g. found a support group; started new treatment program)

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
The person you care for

1. What is their age? ____________________

3. Do they live at home with you? Yes / No

4. How many hours of contact per week do you have with this person? ____________________

5. What is their eating disorder diagnosis? _______________________________________

6. What is their current BMI or current weight and height? ____________________

7. Do they show a fear of gaining weight and/or fatness? (please circle)
   No fear or distress  Mild fear and distress  Moderate fear and distress  High fear and distress  Severe fear and distress

8. Do they describe their body as being fat despite evidence or being told otherwise? (please circle)
   Never  Rarely  Sometimes  Often  Always

9. Do they engage in binge eating? (please circle)
   Not at all  3-4 times a month  2-3 times per week  Every day  More than once a day

10. Do they engage in purging behaviour? (please circle)
    Not at all  3-4 times a month  Once a week  2-3 times per week  2-3 times a day  More than 5 times a day

11. If they engage in purging behaviours please tick the methods you are aware of that they use?
    Vomiting  Laxatives  Diet Pills  Diuretics  Enemas  Insulin
    □  □  □  □  □  □
12. How many hours per day do they exercise? ____________________________

13. What kind of exercise do they engage in? ____________________________

14. If female, and if known, have they missed more than three consecutive menstrual periods? **Yes / No**

15. How long have they had their illness? ________________________________

16. Are they currently receiving treatment? **Yes / No**

17. How many times have they been admitted to hospital? _________________

18. How *important* is it to the **person you care for** that they change?

<table>
<thead>
<tr>
<th>Not important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

19. How *confident* is the **person you care for** that they can change?

<table>
<thead>
<tr>
<th>Not confident</th>
<th>Very confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX F

PLAIN LANGUAGE STATEMENT AND CONSENT FORM: PAPER-BASED VERSION, TIME ONE – STUDY 1
My name is Kerri Coomber and I am conducting a research project with Dr Ross King, a senior lecturer in the School of Psychology towards a PhD at Deakin University. This means that I will be preparing a thesis. I would like to invite you to participate in this research.

Please read this Plain Language Statement carefully. Once you understand what the project is about and if you agree to take part, you will be asked to sign the Consent Form.

As you will be aware, caring for someone with an eating disorder is an emotionally taxing experience. Surprisingly, little research has been conducted to address this issue, especially the changes over time. This study will survey the caregiving experience over a 9 month period in order to understand how this changes over time. As you know, caring for someone with an eating disorder has many demands which impact upon your general health and level of experienced burden. Availability and satisfaction with social support, the different ways you may cope with the situation, your needs as a carer, such as information, and how you are able to deal with everyday problems can all impact upon you as a carer.

You are invited to participate in this research project because you are a carer of an individual with an eating disorder. Possible benefits of the research project include an opportunity for you as a carer to tell your story and convey the extent to which caring for an individual with an eating disorder affects you physically and emotionally. As such, a better understanding of the carer experience may be gained so that appropriate support or programs can be implemented.

Participation in this project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw with no consequence to you. If you do decide to withdraw from this project, please return the withdrawal of consent form.

Participation in this project will involve completion of the same questionnaire three times over the course of 9 months. You will need to complete the initial questionnaire with follow up ones at 4½ months and 9 months later. You will also need to provide your contact details on the Consent Form provided so that follow-up questionnaires can be posted to you. This information will be coded and kept separately to your questionnaire to maintain confidentiality. Each questionnaire will be divided into two main sections.

1. A General Information Sheet asking for information about:
   - Yourself, including gender, age, and employment status
   - The person you care for, including things like their age, gender, diagnosis, and treatment
2. Six questionnaires addressing such things as:
   - The level of social support that you currently have
     (e.g. Whom can you count on to console you when you are very upset?)
• How you deal with everyday problems with the person you care for
  (e.g. I have to try not to criticise him/her)
• How you are currently coping with caring for someone with an eating disorder
  (e.g. I've been getting emotional support from others)
• How your general health has been lately
  (e.g. Lost much sleep over worry?)
• Your experiences of burden while caring for someone with an eating disorder
  (e.g. Feeling that there could have been something I should have done?)
• Some typical signs or behaviours that the person you care for may exhibit
  (e.g. Were there arguments or tension during mealtimes?)
• Your needs as a carer of someone with an eating disorder, in relation to
  information, support, treatment and your GP
  (e.g. Have you received enough information about the following areas?)

This questionnaire will take approximately 1½ hours to complete. We appreciate that the questionnaire is lengthy and emphasise that you do not have to complete it all at the one time. Please take your time to go through it. Once completed, you can return the questionnaire package using the supplied reply paid envelope. You will be sent out the next questionnaire 4.5 months from the return date of this questionnaire.

We understand that some of the information asked is personal and that you may feel uncomfortable in answering these questions. If at any stage you feel distressed while answering these questions you are free to withdraw. Alternatively, you are free to avoid answering questions which are felt to be too personal or intrusive with no consequence. In the event that you do become distressed, please contact your GP, Lifeline (13 11 14), the Eating Disorders Foundation of Victoria Inc. (03 9885 0318, non-metro 1300 550 236, www.eatingdisorders.org.au), or The Centre of Excellence in Eating Disorders (03 8387 2669 or www.rch.org.au/ceed). The last two contacts provide free professional support for those people whose lives are affected by eating disorders.

Storage of data collected will adhere to University regulations and be kept in secure storage for six years. Any identifying information will be destroyed by shredding upon completion of the research project. A report of the study may be submitted for publication, as may a presentation at a conference, but individual participants will not be identified in such a report, as only anonymous data will be reported.

If you require further information or have any questions concerning participation, you can contact Dr Ross King on 03 5227 8481 or rking@deakin.edu.au. Also, if you would like to be informed of the aggregate research findings please contact Dr Ross King on the above telephone or email, or myself on 03 5227 8426 or klcoo@deakin.edu.au

This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Deakin University.

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact The Manager, Office of Research Integrity, Deakin University, 221 Burwood Highway, Burwood Victoria 3125, Telephone: 9251 7129, Facsimile: 9244 6581; research-ethics@deakin.edu.au You will need to tell them the name of one of the researchers given above and quote the project number EC 266-2007.
Deakin University Plain Language Statement and Consent Form
Consent Form
Version 2 Dated 07/03/2008

Full Project Title: Caring for individuals with an eating disorder: A longitudinal study

I have read and I understand the Plain Language Statement version 2 dated 07/03/2008.

I freely agree to participate in this project according to the conditions in the Plain Language Statement.

I freely agree to allow the use of my data from the Building Hope workshop evaluation.

I have been given a copy of the Plain Language Statement to keep.

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant’s Name (printed) …………………………………………………………

Signature … ……………………………………………………   Date ………………

Participant’s Address:

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

Participant’s Phone and/or Email

……………………………………………………………………………………

Note: All parties signing the Consent Form must date their own signature.

Please return the consent form with your questionnaire.
Deakin University Plain Language Statement and Consent Form

Revocation of Consent Form

___________________________________________________________

Full Project Title: Caring for individuals with an eating disorder: A longitudinal study

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise my relationship with Deakin University.

Participant’s Name (printed) ………………………………………………………………………

Signature………………………………………… ……………

Date............................
APPENDIX G

ETHICS APPROVAL – STUDY 2
Research Services  
Office of the Deputy Vice-Chancellor (Research) (Melbourne Campus)

MEMORANDUM

TO: Dr Ross King  
School of Psychology, Geelong Waterfront

FROM: Deakin University Human Research Ethics Committee (DU-HREC)

DATE: 10 August 2009

SUBJECT: Project EC 84-2009  
(carer burden and eating disorders: perspectives of sufferers)

(Please quote this project number in future communication.)

The application for this project was considered at the DU-HREC meeting held on 22 June 2009.

Approval has been given for Kerri Louise Coomber, under the supervision of Dr Ross King, School of Psychology, to undertake this project for a period of three years from 10 August 2009.

The approval given by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the approval. It is your responsibility to contact the Executive Officer immediately should any of the following occur:

• Serious or unexpected adverse effects on the participants
• Any proposed changes in the protocol, including extensions of time.
• Any events which might affect the continuing ethical acceptability of the project.
• The project is discontinued before the expected date of completion.
• Modifications are requested by other HREC's.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

DU-HREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research (2007).

Vicky Bates, Secretary
On behalf of DU-HREC
03 9251 7123
APPENDIX H

EXAMPLE ADVERTISEMENT – STUDY 2
Caring for someone with an eating disorder: Different perspectives

My name is Kerri Coomber and I am completing a PhD in Psychology at Deakin University, Australia. I am looking at the experience of caring for someone recovering from an eating disorder. While we now know a lot about what this is like, we don’t know whether the person in recovery and the carer see the experience of recovery and caregiving similarly or whether their experience is different. I’d like to invite you to share your perspective.

Both carer and the person with an eating disorder would each complete a short questionnaire. You won’t see each other’s responses and what you say will have any identifying information kept separate. You will provide a code so I can match up your questionnaires.

The carer questionnaire asks you about how the eating disorder affects you, as a carer, how you deal with everyday problems related to the eating disorder, and how your general health has been lately. This questionnaire will take you approximately 20 minutes to complete.

The questionnaire that the person with an eating disorder will complete will ask you about your eating disorder, where you feel you are on the road to recovery, and how you think the eating disorder affects your carer. This questionnaire will take you about 20 to 30 minutes to complete.

If you have an eating disorder, or you are a carer of someone with an eating disorder and you would like to take part, please go to the following website:

www.deakin.edu.au/psychology/research/EDCarerStudy/

Or, alternatively if you would like paper-based questionnaires, please contact me.

Contact details:
Ms Kerri Coomber
kcoomber@deakin.edu.au
(03) 5227 8426

This project has full ethics approval (DU- HREC: EC 84-2009)
APPENDIX I

CARER QUESTIONNAIRE – STUDY 2
GENERAL INFORMATION SHEET

The following section asks for demographic and descriptive information about you

1. What is you gender? Male / Female

2. What is your age in years? _________________________________

3. What is your relationship to the person you care for (e.g. mother, father, partner)? _________________________________________________________

4. If you are a parent, how many children do you have (including the person you care for), or if you are a partner, do you have any children and, if so, how many?
   _________________________________________________________

5. If you have children, what are their ages?
   _________________________________________________________

6. What are your average hours of paid employment per week (e.g. full time, 20 hours)?
   _________________________________________________________

7. Please list all the treatment commitments regarding the person you care for, both with whom and for how long (e.g. Psychologist appointment 1 hour per week)
   ____________________________________________________________________________
   ____________________________________________________________________________

8. How many hours contact do you have with the person you care for each week?
   _________________________________________________________

9. How important is it to you that the person you care for change?
   
   Not important                                           Very important
   0 1 2 3 4 5 6 7 8 9 10

10. How confident are you that you are able to help the person you are caring for change?
    
    Not confident                                           Very confident
    0 1 2 3 4 5 6 7 8 9 10
# EATING DISORDER SYMPTOM IMPACT SCALE

The following pages contain a number of statements that commonly apply to persons who care for relatives or friends with an eating disorder. We would like you to read each one and decide how often it has applied to you over the past one month. It is important to note that there are no right or wrong answers. Also, it is best not to spend too long on any one statement. Your first reaction will usually provide the best answer.

<table>
<thead>
<tr>
<th>During the past month how often have you thought about</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Nearly</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>How your friends/relatives have stopped visiting</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Losing your friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Feeling unable to go out for evenings, weekends or on holiday</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Cancelling or refusing plans to see friends or relatives</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Feeling that I should have noticed it before it became so bad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Feeling that I have let her/him down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Feeling that there could have been something I should have done</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Thinking that perhaps I wasn’t strict enough</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Thinking about where I went wrong</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Her/him being physically and/or verbally aggressive</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Her/him having an out of control temper</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Her/him being controlling or manipulative</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Her/him lying or stealing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
When the sufferer was living with you at home during the past month, how often: (if the sufferer was not living at home with you during the past month, please refer to the last time she/he was living at home)

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you experience difficulties preparing meals (i.e. making separate meals for family members, not having correct ingredients)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Were there arguments with other family members about how to handle mealtimes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Were there arguments or tension during mealtimes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did food disappear from the cupboards</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you spend long periods of time shopping for food</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you have difficulties with blocked drains, plumbing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Were there bad smells and poor hygiene in the bathroom</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you have to turn up the heat due to her/his feeling cold</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you check on her/him to ensure that she/he was okay</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you notice or think about how the illness was affecting her/him physically (i.e. see her/him fall, faint, struggle up the stairs)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you notice or think about how the illness was affecting her/him mentally</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
FAMILY QUESTIONNAIRE

This questionnaire lists different ways in which families try to cope with everyday problems. For each item please indicate how often you have reacted to the person you care for in this way. There are no right or wrong responses. It is best to note the first response that comes to mind.

1. I tend to neglect myself because of him/her
   Neve/Very
   Rarely
   Often
   Very
   1 2 3 4

2. I have to keep asking him/her to do things
   Never/Very
   Rarely
   Often
   Very
   1 2 3 4

3. I often think about what is to become of him/her
   Never/Very
   Rarely
   Often
   Very
   1 2 3 4

4. He/she irritates me
   Never/Very
   Rarely
   Often
   Very
   1 2 3 4

5. I keep thinking about the reasons for his/her illness
   Never/Very
   Rarely
   Often
   Very
   1 2 3 4

6. I have to try not to criticise him/her
   Never/Very
   Rarely
   Often
   Very
   1 2 3 4

7. I can’t sleep because of him/her
   Never/Very
   Rarely
   Often
   Very
   1 2 3 4

8. It’s hard for us to agree on things
   Never/Very
   Rarely
   Often
   Very
   1 2 3 4

9. When something about him/her bothers me, I keep it to myself
   Never/Very
   Rarely
   Often
   Very
   1 2 3 4

10. He/she does not appreciate what I do for him/her
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4

11. I regard my own needs as less important
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4

12. He/she sometimes gets on my nerves
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4

13. I’m very worried about him/her
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4

14. He/she does some things out of spite
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4

15. I thought I would become ill myself
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4

16. When he/she constantly wants something from me, it annoys me
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4

17. He/she is an important part of my life
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4

18. I have to insist that he/she behave differently
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4

19. I have given up important things in order to be able to help him/her
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4

20. I’m often angry with him/her
    Never/Very
    Rarely
    Often
    Very
    1 2 3 4
**GENERAL HEALTH QUESTIONNAIRE**

We would like to find out about how your health has been in general *over the past few weeks*. Please rate each question by circling the response that best describes you.

*Have you recently:*  

<table>
<thead>
<tr>
<th>Question</th>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Less than usual</th>
<th>Much less than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
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<td>6.</td>
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<td>7.</td>
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<td>8.</td>
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<td>9.</td>
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<tr>
<td>10.</td>
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<tr>
<td>11.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td></td>
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</tr>
</tbody>
</table>

1. Been able to concentrate on what you’re doing?
2. Lost much sleep over worry?
3. Felt constantly under strain?
4. Felt you couldn’t overcome your difficulties?
5. Been feeling unhappy or depressed?
6. Been losing confidence in yourself?
7. Been thinking of yourself as a worthless person?
8. Felt capable of making decisions about things?
9. Been able to face up to your problems?
10. Felt that you are playing a useful part in things?
11. Been able to enjoy your normal day-to-day activities?
12. Been feeling reasonably happy, all things considered?
APPENDIX J

ANOREXIA NERVOSA QUESTIONNAIRE – STUDY 2
GENERAL INFORMATION SHEET

The following section asks for demographic and descriptive information about you.

1. What is your gender?  
   Male / Female

2. What is your age in years? _________________________________________

3. Who is completing the carer questionnaire for this study (e.g. mother, father)? ___________________________________________________________________

4. How much time (in hours) do you spend with the person who cares for you each week? _________________________________________________________________

5. What type of eating disorder do you have? _____________________________

6. How long have you had your illness? _________________________________

7. Are you currently receiving treatment? Yes / No

8. How many times have you been admitted to hospital for an eating disorder? ______

9. How important is it to you that you change?

   Not important          Very important
   0  1  2  3  4  5  6  7  8  9  10

10. How confident are you that you can change?

   Not confident          Very confident
   0  1  2  3  4  5  6  7  8  9  10
Each of the items below is made up of five statements. For each item, please read the five statements carefully. Then circle the letter next to the statement which best describes your current attitude or behaviour (not how you have been in the past or how you would like to be).

1) The following statements refer to gaining weight:
   a) As far as I am concerned, I do not need to gain weight
   b) In some ways I think that I might be better off if I gained weight
   c) I have decided that I will attempt to gain weight
   d) At the moment I am putting a lot of effort into gaining weight
   e) I am working to maintain the weight gains I have made

2) The following statements refer to body weight:
   a) As far as I am concerned, I do not need to weigh at least ______kg. (insert your minimal normal weight)
   b) In some ways I think that I might be better off if I weighed at least ______kg.
   c) I have decided that I will attempt to reach at least ______kg.
   d) At the moment I am putting in a lot of effort to reach at least ______kg.
   e) I am working to maintain a weight of at least ______kg.

3) The following statements refer to parts of your body which may particularly concern you in terms of weight gain (such as hips, thighs, stomach etc.):
   a) There is no way I would be prepared to gain weight on these body parts
   b) Sometimes I think that I would be prepared to gain weight on these body parts
   c) I have decided that I am prepared to gain weight on these body parts
   d) I am presently trying to gain weight on these body parts
   e) I am working to maintain the weight I have gained on these body parts

4) The following statements refer to your appearance:
   a) I do not want to be a normal weight because I would be less satisfied with my appearance at a weight of at least _____kg. (insert your minimal nominal weight)
   b) I have occasionally thought about being a normal weight because in some ways I would be more satisfied with my appearance at a weight of at least _____kg.
   c) I have decided to reach a normal weight because I would be more satisfied with my appearance at a weight of at least _____kg.
   d) I am presently trying to reach a normal weight because I am more satisfied with my appearance at a weight of at least _____kg.
   e) I am working to maintain a normal weight because I am more satisfied with my appearance at a weight of at least _____kg.

5) The following statements refer to you health:
   a) I do not need to be normal weight because there are no risks to my health when I weigh below _____kg. (insert you minimal normal weight)
   b) I have occasionally thought about being a normal weight because of the risks to my health when I weigh below _____kg.
e) I have decided to reach a normal weight because of the risks to my health when I weigh below ______kg.
d) I am presently trying to reach a normal weight because of the risks to my health when I weigh below ______kg.
e) I am working to maintain a normal weight because of the risks to my health when I weigh below ______kg.

6) The following statements refer to the importance of body shape and weight:
   a) I do not exaggerate the importance of my body shape or weight in determining my happiness
   b) Sometimes I think that I exaggerate the importance of my body shape or weight in determining my happiness and success
   c) I have decided that I need to reduce the importance that I place on my body shape or weight in determining my happiness and success
   d) I often try to challenge the importance that I place on my body shape and weight in determining my happiness and success
   e) I have succeeded in reducing my tendency to place too much importance on my body shape or weight in determining my happiness and success

7) The following statement refer to a fear of fatness:
   a) My fear of becoming fat is not excessive
   b) I occasionally think that my fear of becoming fat is excessive
   c) I have decided that I need to do something about the fear I have becoming fat because it is controlling me
   d) I know that my fear of becoming fat has caused problems and I am now trying to correct this
   e) I have succeeded in reducing my fear of becoming fat and want it to stay this way

8) The following statements refer to weight loss:
   a) I would prefer to lose more weight
   b) Sometimes I think that it might be time to stop losing weight
   c) I have decided that it is time to stop losing weight
   d) I am trying to stop losing weight
   e) I have managed to stop losing weight and hope to stay this way

9) The following statements refer to body fat versus muscle:
   a) I might think about gaining muscle on purpose, but I would never think about gaining fat on purpose
   b) Sometimes I think that I may need to gain some fat even though I would prefer to have only muscle
   c) I have decided that to be healthy I need to have some fat on my body
   d) I realise that I need to have some fat on my body and am working to achieve this
   e) I have managed to increase the level of fat on my body which I am trying to maintain

10) The following statements refer to the rate of weight gain:
    a) There is no way I would be prepared to gain at least 1 kg a week
    b) Sometimes I think I would be prepared to gain at least 1 kg a week
c) I have decided that in general it would be best for me to gain at least 1 kg a week
d) I am putting in a lot of effort to gain at least 1 kg a week
e) I am working to maintain my weight but would be prepared to gain at least 1 kg a week if necessary

11) The following statements refer to certain shape and weight standards which you may have for evaluating your body (such as only be satisfied with your body when your stomach is flact or when you are below a certain weight):
   a) The standards I use to evaluate my body are not too strict
   b) Sometimes I think that the standards I use to evaluate my body may be too strict
   c) I have decided that the standards I use to evaluate my body are too strict and need to change
   d) I am putting in a lot of effort to change the strict standards which I use to evaluate my body
   e) I have managed to let go of the strict standards which I used in the past to evaluated my body and am hoping to keep it this way

12) The following statements refer to certain foods which you may avoid eating (such as food high in calories or fat, red meat, or dairy products):
   a) There are certain foods which I strictly avoid and would nor even consider eating
   b) There are certain foods which I try to avoid, although sometimes I think that it might be okay to eat them occasionally
   c) I think that I am too strict in the foods which I allow myself to eat and have decided that I will attempt to eat foods which I usually avoided
   d) I am putting a lot of effort to regularly eat foods which I would usually avoid
   e) I used to avoid eating certain foods which I now eat regularly

13) The following statements refer to daily food consumption:
   a) There is no need for me to eat 3 standard size meals and a snack each day
   b) Sometimes I think that I should eat 3 standard size meals and a snack each day
   c) I have decided that I need to eat 3 standard size meals and a snack each day
   d) I am putting in a lot of effort to eat 3 standard size meals and a snack each day
   e) I am working to maintain a current eating pattern which includes 3 standard size meals and a snack each day

14) The following statements refer to time spent thinking about food and your weight (such as thought about becoming fat, counting the calories or fat content of food, or calculating the amount of energy used when exercising):
   a) There is nothing wrong with the amount of time I spend thinking about food and my weight
   b) The amount of time I spend thinking about food and my weight is a problem sometimes
   c) I have decided that I need to use strategies to help me reduce the amount of time I spend thinking about food and my weight
   d) I am using strategies to help me reduce the amount of time I spend thinking about food and my weight
   e) I used to spend too much time thinking about food and my weight which I have managed to reduce and am working to keep it this way
15) The following statements refer to certain eating behaviours (such as needing to eat food at a specific rate or time, moving food around on the plate, being unable to eat all the food on a plate, taking longer than others to eat meals, having difficulties eating with others, needing to chew food a certain number of times or needing to stick to the same food plan each day):
   a) There is nothing that I need to change about the way I eat my meals
   b) I sometimes think that I need to change aspects of the way I eat my meals
   c) I have decided that I will try to change aspects of the way I eat my meals
   d) I am putting in a lot of effort to change aspects of the way I eat my meals
   e) I have succeeded in changing aspects of the way I eat my meals and want it to stay this way

16) The following statements refer to feeling associated with eating (such as feeling guilty, anxious or bloated) and not eating (such as feeling successful, in control or spiritually stronger):
   a) There is not need for me to change the feelings I associated with eating and not eating
   b) I sometimes think that I need to change the feelings I associate with eating and not eating
   c) I have decided that I will try to change the feelings I associate with eating and not eating
   d) I am putting in a lot of effort to change the feelings I associate with eating and not eating
   e) I have succeeded in changing the feelings I associate with eating and not eating and want it to stay this way

17) The following statements refer to methods which you may use to control your weight (such as restricting your eating, exercising, vomiting, taking laxatives or other pills). You may select more than one statement for the different methods that you use to control your weight. Please indicate which weight control method/s you are referring to in the blank space/s provided:
   a) There is nothing seriously wrong with the methods ________________________________ I use to control my weight
   b) I have been thinking that there may be problems associated with the methods ________________________________ I use to control my weight
   c) I have decided that I will attempt to stop using certain methods ________________________________ I use to control my weight
   d) I am putting in a lot of effort to stop using certain methods ________________________________ I use to control my weight
   e) I have managed to stop using certain methods ________________________________ I use to control my weight and I would like to keep it this way

18) The following statements refer to certain emotional problems (such as feeling depressed, anxious, or irritable):
   a) I so not have any emotional problems which I need to work on
b) I sometimes think that I may have certain emotional problems which I need to work on

c) I have certain emotional problems which I have decided to work on

d) I am actively working on my problems

e) My emotional problems have improved and I am trying to keep it this way

19) The following statements refer to certain characteristics (such as perfectionism, low self-esteem or feeling a need for control):

a) I do not have any problems in the way I approach life which I need to work on

b) I sometimes think I may have certain problems in the way I approach life which I need to work on

c) I have certain problems in the way I approach life which I have decided to work on

d) I am actively working on problems in the way I approach life

e) The problems in the way I approach life have improved and I am trying to keep it this way

20) The following statements refer to relationship problems (such as relationships with family and friends):

a) I do no have any problems in my relationships with others which I need to work on

b) I sometimes think that I may have certain problems in my relationships with others that I need to work on

c) I have certain problems in my relationships with others which I have decided to work on

d) I am actively working on my problems in my relationships with others

e) The problems in my relationships with other have improved and I am trying to keep it this way
The following questions are concerned with the past four weeks (28 days) only. Please read each question carefully. Please answer all the questions.

Questions 1 to 12: Please circle the appropriate number on the right. Remember that the questions only refer to the past four weeks (28 days) only.

<table>
<thead>
<tr>
<th>On how many of the past 28 days…</th>
<th>No days</th>
<th>1-5 days</th>
<th>6-12 days</th>
<th>13-15 days</th>
<th>16-22 days</th>
<th>23-27 days</th>
<th>Every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Have you been deliberately <strong>trying</strong> to limit the amount of food you eat to influence your shape or weight (whether or not you have succeeded)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>2 Have you gone for long periods of time (8 waking hours or more) without eating anything at all in order to influence your shape and weight?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>3 Have you tried <strong>to exclude from your diet</strong> any foods that you like in order to influence your shape and weight (whether or not you have succeeded)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>4 Have you <strong>tried to follow definite rules regarding your eating</strong> (for example, a calorie limit) in order to influence your shape or weight (whether or not you have succeeded)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>5 Have you <strong>had a definite desire to have an empty stomach</strong> with the aim of influencing your shape or weight?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6 Have you <strong>had a definite desire for a totally flat stomach</strong>?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7 Has thinking about <strong>food, eating or calories</strong> made it very difficult to concentrate on things you are interested in (for example, working, following a conversation, or reading)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
On how many of the past 28 days…

8 Has thinking about shape or weight made it very difficult to concentrate on things you are interested in (for example, working, following a conversation, or reading)?

<table>
<thead>
<tr>
<th></th>
<th>No days</th>
<th>1-5 days</th>
<th>6-12 days</th>
<th>13-15 days</th>
<th>16-22 days</th>
<th>23-27 days</th>
<th>Every day</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

9 Have you had a definite fear of losing control over eating?

10 Have you had a definite fear that you might gain weight?

11 Have you felt fat?

12 Have you had a strong desire to lose weight?

<table>
<thead>
<tr>
<th></th>
<th>No days</th>
<th>1-5 days</th>
<th>6-12 days</th>
<th>13-15 days</th>
<th>16-22 days</th>
<th>23-27 days</th>
<th>Every day</th>
</tr>
</thead>
<tbody>
<tr>
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<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

Questions 13-18: Please fill in the appropriate number in the space on the right of each question. Remember that the questions only refer to the last four weeks (28 days).

Over the past four weeks (28 days)…

13 Over the past 28 days, how many times have you eaten what other people would regard as an unusually large amount of food (given the circumstances)?

14 …On how many of these times did you have a sense of having lost control over your eating (at the same time that you were eating)?

15 Over the past 28 days, on how many DAYS have such episodes of overeating occurred (i.e. have you eaten an unusually large amount of food and have had a sense of loss of control at the time)?

16 Over the past 28 days, how many times have you made yourself sick (vomit) as a means of controlling your shape or weight?

17 Over the past 28 days, how many times have you taken laxatives as a means of controlling your shape and weight?

18 Over the past 28 days, how many times have you exercised in a “driven” or “compulsive” way as a means of controlling your weight, shape or amount of fat, or to burn off calories?

Questions 19-21: Please circle the appropriate number. Please note that for these questions the term “binge-eating” means eating what others would regard as an unusually large amount of food for the circumstances, accompanied by a sense of having lost control over eating.

19 Over the past 28 days, on how many days have you eaten in secret (i.e. furtively)?

…Do not count episodes of binge eating

<table>
<thead>
<tr>
<th></th>
<th>No days</th>
<th>1-5 days</th>
<th>6-12 days</th>
<th>13-15 days</th>
<th>16-22 days</th>
<th>23-27 days</th>
<th>Every day</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
20. On what proportion of the times that you have eaten have you felt guilty (felt that you’ve done wrong) because of its effect on your shape or weight?  
… Do not count episodes of binge eating  

<table>
<thead>
<tr>
<th>None of the times</th>
<th>A few of the times</th>
<th>Less than half</th>
<th>Half of the times</th>
<th>More than half</th>
<th>Most of the time</th>
<th>Every time</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

21. Over the past 28 days, how concerned have you been about other people seeing you eat?  
… Do not count episodes of binge eating  

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Markedly</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Questions 22-28: Please circle the appropriate number on the right. Remember that the questions only refer to the last four weeks (28 days).

<table>
<thead>
<tr>
<th>Over the past 28 days…</th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Markedly</th>
</tr>
</thead>
<tbody>
<tr>
<td>22. Has your weight influenced how you think about (judge) yourself as a person?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23. Has your shape influenced how you think about (judge) yourself as person?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24. How much it would have upset you if you had been asked to weigh yourself once a week (no more, or less, often) for the next four weeks?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25. How dissatisfied have you been with your weight?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26. How dissatisfied have you been with your shape?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27. How uncomfortable have you felt seeing your body (for example, seeing your shape in the mirror, in a shop window, reflection, while undressing or take a bath or shower)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
28 How uncomfortable have you felt about others seeing your shape or figure (for example, in communal changing rooms, when swimming, or wearing tight clothes)?

| 0 | 1 | 2 | 3 | 4 | 5 | 6 |

What is your weight at present? (Please give your best estimate) ______________

What is your height? (Please give your best estimate) ______________________

If female: Over the past three-four months have you missed any menstrual periods? _______________ If so, how many? _______________

Have you been taking the “pill”? ______________
The following pages contain a number of statements that commonly apply to persons who care for relatives or friends with an eating disorder. We would like you to read each one and decide how often you think it has applied to your carer over the past one month. It is important to note that there are no right or wrong answers. Also, it is best not to spend too long on any one statement. Your first reaction will usually provide the best answer.

<table>
<thead>
<tr>
<th>During the past month how often do you think the person who cares for you has thought about:</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>How their friends/relatives have stopped visiting.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Losing their friends.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Feeling unable to go out for evenings, weekends or on holiday.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Cancelling or refusing plans to see friends or relatives.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Feeling that they should have noticed it before it became so bad.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Feeling that they have let you down.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Feeling that there could have been something they should have done.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Thinking that perhaps they weren’t strict enough.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Thinking about where they went wrong.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>You being physically and/or verbally aggressive.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>You having an out of control temper.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>You being controlling or manipulative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>You lying or stealing.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
When you were living at home with you carer during the past month (if you were not living at home during the past month please refer to the last time you were living at home), how often do you think your carer experienced the following:

<table>
<thead>
<tr>
<th>Difficulties preparing meals (i.e. making separate meals for family members, not having correct ingredients)</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Arguments with other family members about how to handle mealtimes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Arguments or tension during mealtimes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Food disappearing from the cupboards</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Spending long periods of time shopping for food</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Difficulties with blocked drains, plumbing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Bad smells and poor hygiene in the bathroom</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Having to turn up the heat due to you feeling cold</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Checking on you to ensure that you were okay</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Noticing or thinking about how the illness was affecting you physically (i.e. see you fall, faint, struggle up the stairs)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Noticing or thinking about how the illness was affecting you mentally</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Thank you so much for your time

Please return this questionnaire with your consent form/s in the supplied A4 reply paid envelope
APPENDIX K

BULIMIA NERVOSA QUESTIONNAIRE (BNSOCQ COMPONENT) – STUDY 2
BNSOCQ

Each of the items below is made up of five statements. For each item, please read the five statements carefully. Then circle the letter next to the statement which best describes your current attitude or behaviour (not how you have been in the past or how you would like to be).

1) The following statements refer to body weight:
   f) As far as I am concerned, I do not need to weigh at least ______kg. (insert your minimal normal weight)
   g) In some ways I think that I might be better off if I weighed at least ______kg.
   h) I have decided that I will attempt to reach at least ______kg.
   i) At the moment I am putting in a lot of effort to reach at least ______kg.
   j) I am working to maintain a weight of at least ______kg.

2) The following statements refer to parts of your body which may particularly concern you in terms of weight gain (such as hips, thighs, stomach etc.):
   a) There is no way I would be prepared to gain weight on these body parts
   b) Sometimes I think that I would be prepared to gain weight on these body parts
   c) I have decided that I am prepared to gain weight on these body parts
   d) I am presently trying to gain weight on these body parts
   e) I am working to maintain the weight I have gained on these body parts

3) The following statements refer to the importance of body shape and weight:
   a) I do not exaggerate the importance of my body shape or weight in determining my happiness
   b) Sometimes I think that I exaggerate the importance of my body shape or weight in determining my happiness and success
   c) I have decided that I need to reduce the importance that I place on my body shape or weight in determining my happiness and success
   d) I often try to challenge the importance that I place on my body shape and weight in determining my happiness and success
   e) I have succeeded in reducing my tendency to place too much importance on my body shape or weight in determining my happiness and success

4) The following statement refer to a fear of fatness:
   a) My fear of becoming fat is not excessive
   b) I occasionally think that my fear of becoming fat is excessive
   c) I have decided that I need to do something about the fear I have becoming fat because it is controlling me
   d) I know that my fear of becoming fat has caused problems and I am now trying to correct this
   e) I have succeeded in reducing my fear of becoming fat and want it to stay this way

5) The following statements refer to weight loss:
   a) I would prefer to lose more weight
b) Sometimes I think that it might be time to stop losing weight
c) I have decided that it is time to stop losing weight
d) I am trying to stop losing weight
e) I have managed to stop losing weight and hope to stay this way

6) The following statements refer to body fat versus muscle:
   a) I might think about gaining muscle on purpose, but I would never think about
gaining fat on purpose
   b) Sometimes I think that I may need to gain some fat even though I would prefer to
have only muscle
c) I have decided that to be healthy I need to have some fat on my body
d) I realise that I need to have some fat on my body and am working to achieve this
e) I have managed to increase the level of fat on my body which I am trying to
   maintain

7) The following statements refer to certain shape and weight standards which you
   may have for evaluating your body (such as only be satisfied with your body
   when your stomach is flat or when you are below a certain weight):
   a) The standards I use to evaluate my body are not too strict
   b) Sometimes I think that the standards I use to evaluate my body may be too strict
c) I have decided that the standards I use to evaluate my body are too strict and
   need to change
d) I am putting in a lot of effort to change the strict standards which I use to
   evaluate my body
e) I have managed to let go of the strict standards which I used in the past to
evaluated my body and am hoping to keep it this way

8) The following statements refer to certain foods which you may avoid eating
   (such as food high in calories or fat, red meat, or dairy products):
   a) There are certain foods which I strictly avoid and would nor even consider eating
   b) There are certain foods which I try to avoid, although sometimes I think that it
   might be okay to eat them occasionally
c) I think that I am too strict in the foods which I allow myself to eat and have
decided that I will attempt to eat foods which I usually avoided
d) I am putting a lot of effort to regularly eat foods which I would usually avoid
e) I used to avoid eating certain foods which I now eat regularly

9) The following statements refer to daily food consumption:
   a) There is no need for me to eat 3 standard-size meals and a snack each day
   b) Sometimes I think that I should eat 3 standard-size meals and a snack each day
c) I have decided that I need to eat 3 standard-size meals and a snack each day
d) I am putting in a lot of effort to eat 3 standard-size meals and a snack each day
e) I am working to maintain a current eating pattern which includes 3 standard-size
   meals and a snack each day

10) The following statements refer to time spent thinking about food and your
    weight (such as thought about becoming fat, counting the calories or fat content
    of food, or calculating the amount of energy used when exercising):
a) There is nothing wrong with the amount of time I spend thinking about food and my weight
b) The amount of time I spend thinking about food and my weight is a problem sometimes
c) I have decided that I need to use strategies to help me reduce the amount of time I spend thinking about food and my weight
d) I am using strategies to help me reduce the amount of time I spend thinking about food and my weight
e) I used to spend too much time thinking about food and my weight which I have managed to reduce and am working to keep it this way

11) The following statements refer to certain eating behaviours (such as needing to eat food at a specific rate or time, moving food around on the plate, being unable to eat all the food on a plate, taking longer than others to eat meals, having difficulties eating with others, needing to chew food a certain number of times or needing to stick to the same food plan each day):
   a) There is nothing that I need to change about the way I eat my meals
   b) I sometimes think that I need to change aspects of the way I eat my meals
   c) I have decided that I will try to change aspects of the way I eat my meals
   d) I am putting in a lot of effort to change aspects of the way I eat my meals
   e) I have succeeded in changing aspects of the way I eat my meals and want it to stay this way

12) The following statements refer to binge-eating episodes (the consumption of large amounts of food and with a feeling of loss of control) that you have:
   a) It is impossible to stop my binge eating because I’m not going to control it
   b) I am not sure whether I am going to stop my binge eating
   c) I am becoming increasingly confident that I am going to stop my binge eating
   d) I am confident that I am going to stop my binge eating
   e) I am confident that I can use strategies to stop my binge eating if it appears again

13) The following statements refer to the fear of not being able to stop eating when you have started meals like breakfast, lunch, snacks or dinner:
   a) It is impossible to stop eating once I have started
   b) I am not sure whether I am going to stop eating once I have started
   c) I am becoming increasingly confident that I am going to stop eating once a meal is finished
   d) I am confident that I am going to stop eating once the meal is finished
   e) I have managed to stop eating once the meal is finished

14) The following statements refer to feeling associated with eating (such as feeling guilty, anxious or bloated) and not eating (such as feeling successful, in control or spiritually stronger):
   a) There is not need for me to change the feelings I associated with eating and not eating
   b) I sometimes think that I need to change the feelings I associate with eating and not eating
c) I have decided that I will try to change the feelings I associate with eating and not eating

d) I am putting in a lot of effort to change the feelings I associate with eating and not eating

e) I have succeeded in changing the feelings I associate with eating and not eating and want it to stay this way

15) The following statements refer to food restriction during meals to control your weight:

a) There is nothing seriously wrong in food restriction to control my weight

b) I have been thinking that there may be problems associated with food restriction to control my weight

c) I have decided that I will attempt to stop using food restriction to control my weight

d) I am putting in a lot of effort to stop using food restriction to control my weight

e) I have managed to stop using food restriction to control my weight and hope to stay this way

16) The following statements refer to methods which you may use to control your weight (such as exercising, vomiting, taking laxatives or other pills). You may select more than one statement for the different methods that you use to control your weight. Please indicate which weight control method/s you are referring to in the blank space/s provided:

a) There is nothing seriously wrong with the methods (______________________________) I use to control my weight

b) I have been thinking that there may be problems associated with the methods (______________________________) I use to control my weight

c) I have decided that I will attempt to stop using certain methods (______________________________) I use to control my weight

d) I am putting in a lot of effort to stop using certain methods (______________________________) I use to control my weight

e) I have managed to stop using certain methods (______________________________) I use to control my weight and I would like to keep it this way

17) The following statements refer to certain emotional problems (such as feeling depressed, anxious, or irritable):

a) I do not have any emotional problems which I need to work on

b) I sometimes think that I may have certain emotional problems which I need to work on

c) I have certain emotional problems which I have decided to work on

d) I am actively working on my problems

e) My emotional problems have improved and I am trying to keep it this way

18) The following statements refer to certain characteristics (such as perfectionism, low self-esteem or feeling a need for control):

a) I do not have any problems in the way I approach life which I need to work on
b) I sometimes think I may have certain problems in the way I approach life which I need to work on
c) I have certain problems in the way I approach life which I have decided to work on
d) I am actively working on problems in the way I approach life
e) The problems in the way I approach life have improved and I am trying to keep it this way

19) The following statements refer to relationship problems (such as relationships with family and friends):
   a) I do no have any problems in my relationships with others which I need to work on
   b) I sometimes think that I may have certain problems in my relationships with others that I need to work on
   c) I have certain problems in my relationships with others which I have decided to work on
   d) I am actively working on my problems in my relationships with others
   e) The problems in my relationships with other have improved and I am trying to keep it this way

20) The following statements refer to your taking part in treatment:
   a) It is impossible that I follow the treatment programme
   b) I am not sure whether I am going to follow the treatment programme
   c) I am becoming increasingly confident that I am going to follow the treatment programme
   d) I am confident that I am going to follow the treatment programme
   e) I am confident that I’m going to use the strategies I gained from the treatment programme if my problems recurred
APPENDIX L

CARER PLAIN LANGUAGE STATEMENT AND CONSENT FORM – STUDY 2
My name is Kerri Coomber and I am conducting a research project with Dr Ross King, a senior lecturer in the School of Psychology towards a PhD at Deakin University. This means that I will be preparing a thesis. I would like to invite you to participate in this research.

Please read this Plain Language Statement carefully as it contains detailed information about the research project. You may also wish to discuss the project with a relative or friend. Feel free to do this. Once you understand what the project is about and if you agree to take part, you will be asked to sign a Consent Form.

As a carer of someone with an eating disorder, you will be aware of the considerable burden associated with the carer role. This project will be to asking people with an eating disorder about their perceptions what you do in order to take care, and look after your loved one, while they recover.

You are invited to participate in this research project because you are a carer of an individual with an eating disorder. Possible benefits of the research project include an opportunity to gain an understanding of your experience as a carer.

Participation in this project is voluntary. If you, or the person you care for, do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw with no consequence to you. If you do decide to withdraw from this project, please return the withdrawal of consent form.

There are two parts to this project: The first part invites you to fill in a brief questionnaire that will take you approximately 20-30 minutes to complete. If you decide to allow the use of your information for this study, please complete the attached consent form and questionnaire and return them via the supplied reply paid envelope. The questionnaire consists of:

- A general information sheet about yourself, including gender, age, and employment status
- How you deal with everyday problems with the person you care for
  
  *(e.g. I have to try not to criticise him/her)*
- How your general health has been lately
  
  *(e.g. Lost much sleep over worry?)*
- Your experiences of burden while caring for someone with an eating disorder
  
  *(e.g. Feeling that there could have been something I should have done?)*
The second part invites the person you care for to complete a questionnaire asking them what they think that you, as their carer, experience within this role. They will also be asked for information about their symptoms and their stage of change. The person you care for will be provided with their own Plain Language Statement for them to read which gives detailed information about the study. Please also discuss this study with the person you care for.

The questionnaire that the person you care for will complete will be coded in order to match their responses with yours. Further, the consent forms will be kept separately to your, and the person’s in your care, questionnaires.

This project is fully funded by the School of Psychology, Deakin University. Storage of data collected will adhere to University regulations and be kept in secure storage for six years from publication. Any identifying information will be destroyed by shredding upon completion of the research project. A report of the study may be submitted for publication, as may a presentation at a conference, but individual participants will not be identified in such a report, as only anonymous data will be reported.

If you require further information or have any questions concerning participation, you can contact Dr Ross King on 03 5227 8481 or rking@deakin.edu.au. Also, if you would like to be informed of the aggregate research findings please contact Dr Ross King on the above telephone or email, or myself on 03 5227 8426 or klcoo@deakin.edu.au

This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Deakin University.

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact: The Manager, Office of Research Integrity, Deakin University, 221 Burwood Highway, Burwood Victoria 3125, Telephone: 9251 7129, Facsimile: 9244 6581; research-ethics@deakin.edu.au.
Please quote project number EC 84-2009
Date: 6 May 2009
Title: Carer burden and eating disorders: Perspectives of sufferers

I have read, and I understand the attached Plain Language Statement.

I freely agree to complete a brief questionnaire

I have been given a copy of the Plain Language Statement to keep.

The researcher has agreed not to reveal my identity and personal details, including where information about this project is published, or presented in any public form.

Participant's Name (printed) ………………………………………………………………………

Signature …………………………………………………………….  Date ……………………

Please return this form with your questionnaire in the supplied reply paid envelope.
Date: 6 May 2009
Title: Carer burden and eating disorders: Perspectives of sufferers

I hereby wish to WITHDRAW my consent to participate in the above research project and understand that such withdrawal WILL NOT jeopardise my relationship with Deakin University.

Participant's Name (printed) ........................................................................................................

Signature .................................................................................................................. Date ..............

Please mail this form to:

Kerri Coomber
School of Psychology
Deakin University
Geelong VIC 3217
APPENDIX M

SUFFERER PLAIN LANGUAGE STATEMENT AND CONSENT FORM – STUDY 2
My name is Kerri Coomber and I am conducting a research project with Dr Ross King, a senior lecturer in the School of Psychology towards a PhD at Deakin University. This means that I will be preparing a thesis. I would like to invite you to participate in this research.

Please read this Plain Language Statement carefully as it contains detailed information about the research project. You may also wish to discuss the project with a relative or friend. Feel free to do this. Once you understand what the project is about and if you agree to take part you will be asked to sign a Consent Form.

As someone with an eating disorder, you may be aware that the eating disorder may have an effect on the person who cares for you. I am interested in finding out what you think this affect may be.

You are invited to participate in this research project because you have an eating disorder. Possible benefits of the research project include an opportunity for you to learn about the experience of your carer.

Participation in this project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw with no consequence to you. If you do decide to withdraw from this project, please return the withdrawal of consent form.

There are two parts to this project: The first part invites the person who cares for you to give consent to allow us to use the information they provided in the longitudinal study for this study. They will also complete a brief questionnaire for this study.

The second part invites you to complete a questionnaire asking you what you think that the person who cares for you experiences within this role. Please feel free to discuss this study with the person who cares for you so you understand what the project is about, and how the person who cares for you is involved.

If you decide to take part, you will be required to complete a consent form and a questionnaire. The questionnaire that you will be required to complete will take about ½ to 1 hour to finish and you will be required to complete it independently to the person who cares for you. The questionnaire will ask you for the following information:

- Information about yourself such as age, eating disorder diagnosis, current treatment, and number of hospital admissions
- Where you feel you are on the road to recovery
  - e.g. Sometimes I think that I may need to gain some fat even though I would prefer to have only muscle
• Your eating disorder symptoms
  o e.g. Over the past 28 days, how many times have you taken laxatives as a means of controlling your shape and weight?

• What you believe your parent/guardian experiences as a carer
  o e.g. During the past month how often do you think the person who cares for you has thought about you being controlling or manipulative

Once completed you can return the questionnaire, along with your consent form, in the supplied reply paid envelope.

We understand that some of the information asked of you is personal, and may be upsetting. You may feel uncomfortable in answering these questions. If at any stage you feel distressed while answering these questions you are free to withdraw. Alternatively, you are free to avoid answering questions which are felt to be too personal or intrusive with no consequence. In the event that you do become distressed, please talk to your parents/guardians, contact your GP, Lifeline (13 11 14), the Eating Disorders Foundation of Victoria Inc. (03 9885 0318, non-metro 1300 550 236, www.eatingdisorders.org.au), or The Centre of Excellence in Eating Disorders (03 8387 2669 or www.rch.org.au/eced). The last two contacts provide free professional support for those people whose lives are affected by eating disorders.

The questionnaire that you will complete will be coded in order to match your responses with the information from your carer’s questionnaire. Further, all consent forms will be kept separately to your, and your carer’s, questionnaires.

This project is fully funded by the School of Psychology, Deakin University. Storage of data collected will adhere to University regulations and be kept in secure storage for six years from publication. Any identifying information will be destroyed by shredding upon completion of the research project. A report of the study may be submitted for publication, as may a presentation at a conference, but individual participants will not be identified in such a report, as only anonymous data will be reported.

If you require further information or have any questions concerning participation, you can contact Dr Ross King on 03 5227 8481 or rking@deakin.edu.au. Also, if you would like to be informed of the aggregate research findings please contact Dr Ross King on the above telephone or email, or myself on 03 5227 8426 or klcoo@deakin.edu.au.

This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Deakin University.
Date: 6 May 2009

Title: Carer burden and eating disorders: Perspectives of sufferers

I have read, and I understand the attached Plain Language Statement.

I freely agree to participate in the study as outlined in the Plain Language Statement.

I have been given a copy of the Plain Language Statement to keep.

The researcher has agreed not to reveal my identity and personal details, including where information about this project is published, or presented in any public form.

Participant's Name (printed) ………………………………………………………………………

Signature ……………………………………………………… Date ……………………

Please return this form with your questionnaire in the supplied reply paid envelope.
Date: 6 May 2009
Title: Carer burden and eating disorders: Perspectives of sufferers

I hereby wish to WITHDRAW my consent to participate in the above research project and understand that such withdrawal WILL NOT jeopardise my relationship with Deakin University.

Participant's Name (printed) …………………………………………………………………………………

Signature …………………………………………………………… Date …………………

Please mail this form to:

Kerri Coomber
School of Psychology
Deakin University
Geelong VIC 3217