A Qualitative Analysis of the Experience of Caring for an Individual with an Eating Disorder

A thesis submitted to The University of Manchester for the degree of Doctor of Clinical Psychology in the Faculty of Medical and Human Sciences

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Contents

Paper 1. Literature Review

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List of Tables

List of Figures

List of Appendices

Abstract

The thesis sought to explore the experience of caring for an individual with an eating disorder. It is comprised of three standalone papers. Paper one and two have been prepared for submission to a journal and in accordance with the journal guidelines. Paper one is a systematic literature review synthesising qualitative studies relating to the experience and impact of caring for, or living with an individual with an eating disorder. Databases were systematically searched and twenty studies were included in the review. Nine core themes emerged from the meta-synthesis. Eating disorders were found to have a pervasive impact on family members mediated by a number of factors. Cognitive appraisals affected the caregiving experience and responses to the individual. The experience of caregiving was continually reappraised leading to a process of adaptation over time.

Paper two is a qualitative study which sought to examine caregivers' accounts of managing Anorexia Nervosa with an emphasis on accommodation responses. Eight participants were interviewed and transcripts were analysed using a grounded theory approach. A theory of the processes by which accommodation responses operate was developed which emphasised the importance of caregivers' emotional resources in mediating responses. Difficulty managing anorexia nervosa led to low perceived efficacy and diminished resources. Subsequently caregiving aims shifted in line with accommodation responses. Carers recognised accommodation as counterproductive to recovery and experienced internal conflict (dissonance) which was reduced using a number of cognitive and behavioural strategies. The clinical implications of the findings are discussed with reference to existing literature.

Paper three is a critical review of the research process, focusing on the experience of undertaking qualitative research. Personal reflections of the process, as well as the implications of the research for the researcher's professional practice and for the wider profession are discussed.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

Copyright Statement

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Paper 1.

The Experience of Caring for, or Living with an Individual with an Eating Disorder.

A Meta-Synthesis of Qualitative Studies

Paper 1 has been prepared for submission to Clinical Psychology and Psychotherapy in accordance with the guidelines for contributors (Appendix 1).

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Abstract

Eating Disorders (ED) has the highest mortality rate of psychiatric disorders and a high incidence of comorbidity. Due to the average age of onset care typically befalls family members. However, despite the severity of the disorder and the burden placed on the family, research into the caregiving experience is still developing. Studies have shown caregivers of individuals with ED to experience high levels of distress, burden and expressed emotion. Recent theoretical models have underscored the importance of caregivers' responses as a maintenance factor for the ED, and family therapy has proved efficacious. However, the literature pertaining to the experience of family members living with, or caring for an individual with an ED has not been systematically reviewed. This review aimed to synthesise qualitative studies relating to the caring experience and its impact, thereby gaining an understanding from the perspective of the individuals themselves. Relevant search terms were utilised to systematically search key databases. Twenty studies, with a total sample of 239 participants met the inclusion criteria. Nine core themes emerged from the synthesis, forming the basis of an explanatory theory. The ED was found to have a pervasive impact upon family members, mediated by a number of factors. Cognitive appraisals affected the caregiving experience and responses to the individual. The experience of caregiving was continually reappraised leading to a process of adaptation. The majority of studies identified unmet carer needs. The implications of the findings are discussed with reference to existing theoretical models and in terms of clinical practice.

Key Practitioner Message:

- Eating Disorders have a pervasive impact upon carers/family members.

- Cognitive appraisals and the understanding of the eating disorder affect the experience of caregiving and responses to the individual.

- Factors such as support and coping mediate the impact upon family members. However, carers often describe feeling unsupported and excluded from services.

- Family members should be supported, listened to and advised. Skill based interventions to help carers manage the ED are recommended.

- As burden of care often befalls family members, inclusion in treatment and information sharing is therefore, important.

Keywords: Eating Disorders, Caring, Meta-synthesis, Impact, family.

Introduction

Caring for an individual with mental health needs is a source of significant stress, which is mediated by variables such as caregiver appraisals (Lobban, Barrowclough & Jones, 2003; Barrowclough & Hooley, 2003), symptom severity (Baronet, 1999), illness duration and support (Saunders, 2003). The impact of caregiving in terms of carer distress and subjective burden is relatively well established and has been the subject of a number of reviews (Baronet, 1999; Ohaeri, 2003; Saunders, 2003). However, much of the available research has focused on caregiving within specific disorders, such as schizophrenia (Martens & Addington, 2001; Barrowclough, Marshall, Lockwood, Quinn & Sellwood, 1998), dementia (Dunkin & Anderson-Hanley, 1998) and affective disorders (Kalra, Kamath, Trivedi & Janca, 2008; Perlick et al, 2007). In contrast, the evidence base documenting the caregiving experience for an individual with an Eating disorder (ED) is still developing and comparatively under researched. This is perhaps surprising given Anorexia Nervosa (AN) is a life-threatening illness cited to have the highest mortality rate of all psychiatric disorders (Nielsen, 2001) and a high incidence of comorbidity (Braun, Sunday & Halmi, 1994). Furthermore, the average age of onset is in adolescence and therefore, the responsibility of care tends to befall parents typically caring for their child within the community (recommended by National Institute for Clinical Excellence, 2004). These factors are likely to add to the burden of care.

Historically research has focused on the role of the family in the pathogenesis of eating disorders. Hoskins and Lam (2001) note a 'common pattern' in aetiological research whereby a 'typology' has been argued to set the anorexic individual and their family apart in terms of psychological factors. For example, studies of attachment have cited a link between insecure patterns of attachment and the development of EDs (O'Kearney, 1995; Ward, Ramsay & Treasure, 2000). The number of theoretical models propagating a link between family organisation and the development of EDs has been noted and discussed by Eisler (2005), who criticised these models on conceptual and methodological grounds, and condemned them as unduly blaming. Indeed, observed

changes within family functioning have historically been interpreted as a causal aetiological factor, as opposed to a consequence of caring for an individual with an ED. However, more recent conceptual models and research have begun to critically re-evaluate this view. For example, Nilson, Engström & Hägglöf (2012) in a prospective study found changes in ED symptoms to precede changes in family climate.

Schmidt and Treasure's (2006) cognitive-interpersonal maintenance model and Fairburn's (1993) Interpersonal Psychotherapy (IPT) for Bulimia Nervosa (BN) emphasises maintaining rather than aetiological factors for ED. IPT focuses on interpersonal difficulties which can keep the individual "trapped" in ED behaviours. Such difficulties include role transitions, grief, interpersonal deficits and interpersonal conflict (Apple, 1999). Schmidt and Treasure's cognitive-interpersonal maintenance model for AN also includes an interpersonal dimension, 'the response of close others' as one of their four proposed maintenance factors. They assert that the symptoms and behaviours associated with the ED can elicit strong emotions in the caregiver and family of the individual, which may lead to high expressed emotion (EE) including criticism and hostility towards the cared for individual and emotional over-involvement. Furthermore, families may become organized around, and accommodate the needs of the individual and symptoms of the condition (Schmidt & Treasure, 2006; Eisler, 2005). Accommodating the ED has been found to correlate with caregiving burden and psychological distress (Sepulveda, Kyriacou and Treasure, 2009). A quantitative systematic review of burden, psychological distress and EE in caregivers of individuals with ED found high levels of each of these factors in the majority of the reviewed studies (Zabala, Macdonald & Treasure, 2009). Indeed, a pilot study found higher levels of psychological distress and reported loss in carers of individuals with AN, than caregivers of individuals with psychosis (Treasure et al, 2001) and high levels of unmet need (Haigh & Treasure, 2003). Furthermore, Zabala et al, (2009) conclude there is some evidence that EE, psychological distress and burden impact the prognosis and treatment of the ED, underlining the importance of the caregiving role. Moreover, evidence supports the efficacy of systemic treatments such as family therapy (Simic & Eisler, 2012).

However, despite empirical evidence noting the significant impact caring has on the emotional and psychological wellbeing of the carer, and the importance of the caregiving role in terms of ED outcome, to the author's knowledge no systematic review has yet been undertaken to synthesise the experience of caring for individuals with an ED. One narrative review, primarily focusing on how family lives are impacted by an ED and the theoretical processes involved was published by Whitney and Eisler in 2005. The empirical evidence was reviewed in terms of an existing conceptual theory propounded by one of the authors, Eisler (2005), with further reference to Schmidt and Treasure's (2006) cognitive-interpersonal maintenance model. Whitney and Eisler identified processes by which family life and identify becomes 're-organised' around the ED, citing food as dominating family interactions, activities and relationships, and mealtimes as a source of strain and conflict (Cottee- Lane, Pistrang & Bryant-Waugh 2004; Whitney et al, 2005). They note families can become preoccupied with present difficulties and may accommodate illness-related behaviours and seek to avoid conflict. Ineffectual 'fixed patterns of responding' are described to develop over time which can be difficult to alter. Research consistently reports caregivers to experience strong negative emotions, in particular helplessness and guilt, which in turn have been linked to psychological distress (Gilbert, Shaw & Notar, 2000; Cottee- Lane et al, 2004; Whitney et al, 2005).

However, as stated by Whitney and Eisler (2005) the review was restricted by the limited number of then available studies. Since its publication, the author of the present review is aware of further studies subsequently published, particularly with regard to the caregiving experience of siblings (Areemit, Katzman, Pinhas & Kaufman, 2010) and partners (Huke & Slade, 2006). Furthermore, the aforementioned review was not conducted systematically and appeared to utilise both quantitative and qualitative research to fit and extend an existing theoretical framework, as opposed to developing a theory from the synthesis of the reviewed empirical findings. The aim of this paper is to systematically review and synthesize the experience of caregiving for an individual with an ED, although the review will primarily focus upon AN due to the relative dearth of

literature relating to caring for individuals with BN. In accordance with this aim, only qualitative research from the perspective of the caregiver will be included for review, thereby, giving a 'voice' to the individuals' concerned. Researchers have emphasised the importance of undertaking further research focusing on the experience of caregiving (Zabala et al, 2009; Hoskins and Lam, 2001), in particular, accounts from the individuals themselves, which Foltz-Gray (1998) describe as 'enlightening.' A general dearth of such accounts is noted and therefore, a review synthesising and refining the existing literature into an explanatory theory may further our understanding of carers needs and help to inform systemic approaches to support carers. The specific research question to be addressed by the review was: 'what is the experience and impact of caring for, or living with an individual with an ED'.

Methods

The review aimed to elucidate the experience and impact of caring for, or living with an individual with an ED, with a particular focus upon AN. The review was undertaken in four stages. Firstly, the literature was systematically searched utilising search terms devised in accordance with the aims of the review. Following this, relevant studies were identified through the application of the inclusion and exclusion criteria. Identified studies were subsequently appraised in terms of quality. Finally, the results of the studies included in the review were synthesised.

Systematic Literature Search

To avoid duplication and to establish the utility of the present review, an initial scope of the literature was undertaken by searching the Cochrane Database of Systematic Reviews, Google Scholar and the DARE, NHS EED and HTA databases (http://www.crd.york.ac.uk) to identify any existing reviews addressing caring for an individual with an ED. One systematic review was identified appraising carer burden, EE and psychological distress (Zabala et al, 2009). However, this was a quantitative

review and therefore, did not directly consider the experience of the carer, the focus of the present review.

The following databases were systematically searched against the inclusion and exclusion criteria up until the end of January 2013: Web of Science, AMED, EMBASE, Medline, PsycINFO and Social Sciences Citation Index (SSCI). The reference lists of the identified studies were manually searched. Additionally, all articles citing the included studies were examined for their relevance.

Search terms

The search terms were developed by drawing up a list of synonyms for the target population (e.g. carers of individuals with EDs), study design (qualitative) and outcome of interest (e.g. impact or experience of caring) (Petticrew & Roberts, 2006). The population was divided into terms relating to EDs and terms to elicit the carer or family members' perspective. Identifying qualitative research is acknowledged to be more difficult, in part due to inconsistent indexing (Petticrew & Roberts, 2006; Barroso et al, 2003). Therefore, to improve the sensitivity of the search, extensive terms were employed based on the Hawaii Medical Library evidence-based filters for CINAHL (Petticrew & Roberts, 2006) and Shaw et al (2004) in order to retrieve studies utilising a qualitative or mixed methodology. A full list of search terms with details of how these were combined is found in Appendix 2.

Inclusion and exclusion criteria

Studies which met the following inclusion criteria were included in the review:

- Studies employing a qualitative methodology (e.g. interviews or focus groups) or mixed design (provided the qualitative results were reported separately).
- Published peer-reviewed empirical studies written in English.

16

- Articles published from 1970 to 28th January 2013 (search date), as prior to 1970 the development of rigorous qualitative methods was still in its infancy (e.g. Grounded Theory: Glaser & Strauss, 1967).

- Studies specifically focusing on EDs (e.g. AN, Bulimia Nervosa (BN) or Eating Disorders Not Otherwise Specified).

- Carers or family members of individuals with an ED as the primary informants.

- Studies with a focus on the impact of an ED on family relationships and/or family functioning, or the experience of caring for/living with an individual with an ED.

Studies which met the following criteria were excluded from the review:

- Studies utilising a quantitative design, or mixed method design where qualitative results were not reported separately.

- Unpublished or non-peer reviewed articles.

- Non-empirical articles (e.g. theoretical discussions).

- Case studies

- Articles not written in English.

- Articles published prior to 1970.

- Studies lacking a specific focus on EDs.

- Studies which do not employ carers or family members of individuals with an ED as the primary informants.

- Studies which do not focus on the impact of an ED on family relationships and/or family functioning, or the experience of caring for/ living with an individual with an ED.

Search Results

After entering the search terms in the aforementioned electronic databases a total of 1591 articles were identified (which included an initial scope of the literature utilising Google scholar). The search was further refined to 1157 after excluding all duplicates (n = 311) and removing irrelevant journals ('oncology', 'urology' and 'radiology') from the Web of Science and SSCI database. The titles of the identified articles were initially

read to ascertain their potential relevance to the review, consequently 970 were excluded.   The abstracts of the remaining studies (n = 187) were read with reference to the inclusion and exclusion criteria, based on this a further 151 articles were excluded. A total of 36 articles were subsequently read in full, of these 16 met the inclusion criteria and were included in the review. The reference lists of the included articles were hand searched and a further 4 suitable articles identified. No further studies were identified by examining articles citing the included studies. A total of 20 studies were included in the review. The flow diagram in figure 1 details the selection process.

Figure 1 here

Assessment of quality

A review synthesising studies of low quality may lead to a flawed review, jeopardising its credibility (Walsh and Downe, 2006). Therefore, the methodological rigour of the included studies was appraised using an adapted version of the Critical Appraisal Skills Programme (CASP, 2010; appendix 3) and Walsh and Downe (2006) checklist (appendix 4). These checklists were selected from the available tools as they both provide a clear and accessible framework from which to assess quality. Furthermore, Walsh and Downe (2006) methodically developed their checklist by 'mapping' together essential elements from existing frameworks. The CASP is also one of the most widely utilised tools. However, there is a significant overlap between these two checklists. Therefore, similar items from each were combined in order to devise a more succinct and practicable10 item assessment tool, which retained unique items from each to ensure quality was rigorously and comprehensively assessed. All 20 studies were rated using this tool (appendix 5) and assigned a quality classification from A-C (with 'A' denoting studies scoring highly on the quality assessment, 'B' moderately scoring studies and 'C' low scoring studies). All 20 studies were classified as either category A or B; therefore, none were excluded from the review as a result of low methodological quality. To verify the reliability of the ratings, a representative proportion of the included studies (20%) were randomly selected to be re-rated by an independent

researcher utilising the checklist. There was 95% agreement between the ratings, suggesting adequate inter-rater reliability.

Meta-synthesis

Methods for the synthesising qualitative research are less established than quantitative counterparts. Therefore, the most widely used and well-established guidelines, developed by Noblit and Hare (1988) and expounded by Walsh and Downe (2005) were utilised as a template to synthesise the studies (appendix 6). This structured approach enables the development of new insights and understanding, whilst preserving the integrity and meaning of the original data. The first step required a thorough reading of the 20 studies in order to identify the key themes, concepts and phrases from each (appendix 7). These themes were compared and contrasted to identify similarities and differences. The findings of the studies were then 'translated into one another' using overarching concepts to encapsulate commonalities ('reciprocal translations') or to account for discordant ('refutational translations') or overlapping findings. Finally, these translations were synthesised to develop a new understanding and an explanatory theory (figure 2).

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Results

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Study Characteristics

Twenty studies met the inclusion criteria and were included for review. All of the reviewed studies were assessed as having adequate quality, with a low to medium risk of methodological flaws. Subsequently, study findings were given equal weighting during the synthesis. However, if discrepancies between findings arose, consideration was given to the quality of the study and methodology employed.

Five of the articles reviewed were not primary studies and utilised a duplicate sample to other studies included in the review. Nevertheless, these articles were retained as they were considered pertinent to the review question and reported separate findings with a

different focus. Most of the reviewed studies aimed to explore the experiences of family members' caring for or living with an individual with an ED. Some studies adopted an emphasis upon particular aspects of the experience, including treatment, support, the recovery journey, caregiving responses and the impact of the ED. Included studies were undertaken in Australia, Canada, the United Kingdom and Israel, by researchers from various disciplines including nursing, psychiatry and clinical psychology. Across the studies data was collected from 239 participants, primarily via interview. Alternate methods of data collection included focus groups or free writing tasks. One study utilised a mixed methodology, however, the qualitative results were reported separately. The majority of participants were parents of individuals diagnosed with AN. However, studies also included parents or partners of individuals diagnosed with BN. Several studies were unclear as to whether the ED had been verified. Participants were reported to be between the ages of 27-66 years of age. Four of the included studies focused on the experience of siblings of individuals with AN (n = 36; reported age range: 11-18). Female participants were over-represented within the reviewed studies. Characteristics of the included studies are outlined in table 1 and a summary of key themes from each study is presented appendix 7.

Table 1 here

Summary of synthesis

Nine core themes emerged from the synthesis of the studies namely: *ED onset*, *cognitive appraisals and processes*, *support from services*, *efforts to understand the ED*, *coping and resources*, *managing the ED*, *perceived ED characteristics*, *impact of caring* and *evaluating the impact and adapting*. Studies containing each of these themes are presented in table 2

These themes formed the basis of an explanatory theory (figure 2). In summary, caregiving or living with an individual with an ED had a pervasive impact on family members. Cognitive appraisals relating to the understanding of the ED had a direct impact on the caregiving experience (e.g. feelings of self-blame). This understanding

also affected caregivers' perceptions of ED characteristics, responses to the individual, information seeking, need for support and coping strategies. All these factors were intertwined and mediated the impact of the ED. Family members' experiences across the course of caring were continually re-appraised, subsequently the understanding of the ED was found to be fluid. Over time a process of adaptation occurred, whereby carers altered their perspectives and responses to the ED. These core themes and their inter-relationships are described in detail below.

Table 2 here

Figure 2 here

1. ED Onset

Gradual recognition of the ED

Eight studies discussed the experience of the onset of the ED. These papers all described a gradual process of recognition or 'slow realisation' that there was 'a problem' (paper 1). Although five of these studies referred to carers noticing behavioural changes, recognition was impeded by misattributions. For instance, symptoms of the ED were commonly appraised as adolescent-related behaviour. Carers also described not associating the behaviours with an ED due to insufficient knowledge or being 'unprepared.'

"I thought, well this is what being a teenager's all about, she's decided she can take more control, she's decided she wants to be a vegetarian, so again I didn't take an awful lot of notice." (Mother, paper 13)

"I really didn't realise that it was an eating disorder for quite a long time. I suppose it never really occurred to me. I was quite ignorant about it really." (Female participant, paper 14).

Identification of the ED was further hindered by perceived characteristics of the disorder (a theme discussed below). Carers in four studies described the affected individual engaging in secrecy or deception to hide the ED, or denying symptoms when confronted.

"She wore baggy clothes, so we didn't realise." (Paper 6).

Eventual recognition of the ED was preceded by an increase in symptom severity which carers sought professional support for. However, a further delay in diagnosis was described due to General Practitioners (GPs) misdiagnosing or dismissing symptoms.

"I went to the GP in July saying I was concerned that she wasn't putting on weight. I went back to the GP and he said wait 'til puberty sets in. I'm still cross that the GP hadn't confirmed it early on because I kept saying to him." (Mother, paper 13).

Initial impact

All eight studies addressing the onset of the ED also reported the initial impact of the diagnosis. Caregivers experienced an array of negative emotions, with the exception of some participants in study 6 who reported feeling 'relief' upon diagnosis, as this provided an 'explanation.' Negative emotions reported included shock (paper 6; paper 10), helplessness (paper 14), mistrust (paper 4) and anger (paper 13; paper 6). However, the most prominent reaction was guilt and self-blame (reported in six studies). Guilt appeared to result from caregivers' cognitive appraisals of their actions, characterised by the perception that they "ought to have seen it coming" (paper 2). Delayed recognition of the ED together with their inability to prevent further deterioration led to self-reproach. In study 2, guilt was also linked to mothers' perceptions of their maternal role and the perceived mismatch between these and the ED.

"I felt negligent that we had missed it, it had happened right under our eyes, why didn't we pick this up earlier – how did we let it get to this stage?" (Paper 6)

"Finally there is the feeling of guilt. Did I notice the start of the disorder? Did I act quickly enough to get medical help? Did I do anything at all that was helpful?" (Paper 7).

2. **<u>Cognitive Appraisals and processes</u>**

Appraisals of the caregivers' contribution to the ED

Endeavours to make sense of the ED were apparent in twelve of the reviewed studies. Family members tended to analyse and question the possible causes. Subsequently, participants formed maladaptive beliefs, particularly earlier on in the course of the ED, attributing responsibility for its development to their actions. Moreover, parents were inclined to admonish themselves for the delay in recognising the ED and questioned their actions in terms of their child's upbringing.

"I believed that a lot of my personal actions were responsible for a lot of the pain that had come into my daughter's life." (Mother, paper 2).

"I think as a mum you sort of think have I done something, have I done something to make her like this." (Mother, paper 14).

Appraisals of personal culpability led family members to experience guilt, self-blame and feelings of responsibility towards the individual with the ED. Subsequently, carers endeavoured to support the individual practically and emotionally. Well siblings described feeling obligated to care for their affected sibling and to support their parents.

"I've always been like that; I'm responsible for everything. I always thought back to all the things I ever said 'am I a bad sister?'" (Sibling, Paper 16).

Some siblings in paper 17 perceived parental guilt as impairing their parents' ability to instil appropriate boundaries and thereby, manage the ED effectively. Despite appraisals of culpability being widely reported, some studies described these to alter over the course of the ED, with most carers in study 14 reportedly coming to the conclusion that the ED was not their fault.

Worry and rumination

In nine studies, family members expressed worries relating to the ED. Primarily these concerned the possibility of the individual with the ED dying. Other reported worries include the impact of the ED on the affected individual's future opportunities and social development, practical concerns with regard to finding and funding treatment, fear of relapse, and concerns about the impact of the ED on other family members (e.g. siblings).

"I find it quite depressing actually, you know, you sort of think 'what on earth is going to happen next with this?'… Also there's the issue of her education …you do wonder, you don't know whether she'll ever get back to school, and if she does, will she stay at school, will it just not work out and end up back again? You just don't know." (Parent, Paper 10)

In addition to rumination regarding the cause of the ED, two papers report carers' thoughts to become preoccupied with the cared for individual. Subsequently, paper 10 reports this preoccupation to impact upon parents' availability for other children; these changes within the family system were corroborated by siblings.

Understanding of the ED

Appraisals relating to the carer or sibling's understanding of the ED were described in just over half of the reviewed papers. These appraisals varied but generally fell along a continuum in terms of the amount of control the affected individual was perceived to have. Four papers described participants endorsing the belief that the individual lacked control over the ED and in turn, over their behaviour and 'thought processes'. Individuals professing this belief tended to appraise the ED as a psychological or biological 'illness'.

"It's like any other illness, like appendicitis, it's a sickness and you've got to seek help. But it's just a sickness of the brain." (Parent, paper 3)

"You have to put up with it as you know they can't help it." (Male Partner, paper15)

A reported consequence of embracing such a belief was the tendency not to blame or hold the individual responsible for their behaviour. However, appraising the ED as uncontrollable impacted negatively on caregivers' emotional wellbeing and predisposed carers to feel pessimistic regarding the prospect of recovery. Five papers described associated perceptions of reduced self-efficacy.

"I felt helpless because I just knew how devastating it can be and I could warn her but I couldn't do anything for her." (Parent, paper 1).

"You just want to help her as much as you can. Nothing you do or say makes a difference." (Father, paper 12).

Five papers described appraisals at the other end of the spectrum, whereby the ED was perceived to be 'a choice'. Some partners and siblings believed the ED to be a form of 'attention seeking'. Consequently some participants 'blamed' the individual. All partners in paper 15 endorsed holding the belief that the individual 'should' have been able to control the ED at one time; however, these appraisals altered over the course of caring.

"It is appalling because she has chosen it." (Mother 7, paper 12).

"That's why she keeps on going, 'cause she gets attention from my parents, the hospital, her friends, and I think she likes all that." (Sibling, paper 20).

Simultaneous appraisals were described in two papers, whereby, participants appraised the ED as both uncontrollable and a choice. A few papers described perceptions of the ED as a 'separate entity' to the individual. For some this was described as a conscious decision which empowered participants to externalise negative feelings and attribute these to the ED, rather than the individual.

"I've got anger towards the disease (whilst) I cherish her, I think what we've got is too strong to give away because I can separate bulimia from her." (Male partner, paper 15).

Two papers described carers initially constructing the disorder as a 'simple' eating issue. However, this view altered over the course of the ED as its complexity became apparent. Other appraisals identified from three of the reviewed papers, include the ED as an unknown factor. Some carers reported not knowing enough about the ED which led to subsequent difficulties identifying, distinguishing and responding to the ED behaviours.

"At their age how do you balance what's normal teenage, she's a cow and (what is the anorexia)? What's part of which? What do you make allowances for and what do you not make allowances for? And that's been the hardest part" (Parent, paper 3)

Fluid appraisals

In five of the studies, cognitive appraisals relating to the ED and the experience of caring for, or living with the affected individual were described as changing over time. Constructions of the ED generally altered with experience and increased knowledge. Study 15 referred to these appraisals as falling along a 'spectrum' in terms of the perceived control the affected individual had over the ED, describing some individuals beliefs to 'oscillate'.

"I just thought the person was just attention seeking and they could stop it whenever they wanted (however) now it's a proper disease to have." (Male Partner, paper 15).

Two of the studies identified some participants to hold multiple simultaneous appraisals regarding the ED which could also be contradictory.

"Yeah it's like, when people are saying 'what is wrong with those people; why don't they just control it.' You kind of feel defensive but you're thinking the same thing." (Sibling, Paper 16)

Appraisals and action

Appraisals of the ED and its related behaviours were identified by five studies as a 'major factor' influencing participants' responses to the individual. Attributions regarding the individual's responsibility for, and control over the ED were cited to mediate responses (paper 15). For example carers perceiving the individual as not responsible for their actions endeavoured to understand and tolerate ED behaviours (Paper 3). Whereas, appraising the individual as responsible for the ED led to criticism and blame.

Three studies described examples of typical responses as a result of constructing the ED as a separate entity. These included actions whereby carers were 'tough' on the ED, but 'kind' to the individual (paper 3). Difficult behaviours and negative emotions were attributed to the ED, enabling carers to remain empathic yet resist the wishes of the individual to promote recovery (paper 8).

"Once you separate you can fight it. While you're seeing it as being one you can't fight yourself, it made things here a lot easier because once I could differentiate between the two of them; and then you would say, is this you talking or her? It made (for) a lot less confrontation." (Parent, paper 3).

Other examples of the effect of caregiver appraisals on subsequent actions include efforts to alter parental practices due to parental attributions of self-blame (paper 2) and seeking information and guidance as a result of appraising the ED as an unknown.

3. Efforts to understand the ED

Seeking information

The majority of the reviewed studies described carers as 'desperately' seeking information regarding the ED in order to understand its causes, find solutions and better manage the disorder. Carers were reported to "glean information from everywhere" (paper 10) by undertaking various activities to increase their knowledge. These included reading books, magazines and searching for information on the internet. Carers consulted various sources for advice and guidance including professionals, friends, relatives, support groups and individuals with direct ED experience. Furthermore, carers sought information from the affected individual through discussion, or by observing and monitoring their behaviours.

"We are resourceful, we've got friends who know the system, we are computer literate, so we can access the internet and we can gather information. We are professional people so we can do our own research and find out the whys and wherefores." (Father, Paper 10).

Seeking information and advice was also utilised as a means of coping and informed carers' understanding of, and responses to the ED.

"Two of the teachers I work with, both of their wives have been anorexic at some stage. So it was interesting to, to just get the different views and it helped you to continue to be positive and continue approaching it." (Parent, Paper 8).

However, information was not always deemed useful by carers. For example, information was cited to reinforce maladaptive appraisals with regard to maternal culpability (study 2). Additionally, some carers found negative information to elicit negative emotions (paper 1), with a few participants in paper 15 preferring to avoid ED information.

"I read three books on that weekend, talk about depressing, and I think I spend most of the weekend crying, (I felt) an overwhelming despair." (Parent, paper 1).

In half of the studies describing the experience of siblings, participants reported a desire and need for further information to help them make sense of the ED. Paper 16 reported siblings to feel "left out" by parents in this respect. Interestingly, in paper 18 parents described withholding information from siblings with the aim of protecting them from the impact and seriousness of the condition.

Difficulty Understanding

Despite attempts to seek information regarding the ED, in almost half of the reviewed studies family members expressed their continued struggle to understand the ED related behaviours, such as secrecy and deception, as well as the cause and maintaining factors for the disorder. The complexity and seriousness of the ED was cited as one explanation for this confusion. However, despite this perceived complexity, parents in paper 13 were reportedly able to articulate multifaceted explanations for the disorder.

"It's a very complex thing that no one really seems to understand, which is a bit of a source of frustration as well because there doesn't really seem to be any real understanding of how to cure this illness." (Parent, paper 3)

4. **Managing the ED**

Efforts to meet the individual's needs

The majority of the reviewed studies described carers to direct their efforts towards meeting the needs of the individual with the ED. These efforts tended to fall into three further subthemes: practical support, emotional support and accommodation and enabling.

- **Practical support**

Carers extended considerable practical support to meet the needs of the affected individual. A great deal of effort and time was spent negotiating the healthcare system in order to secure treatment. Caring required numerous sacrifices, with occupational, leisure and social activities often reorganised or suspended in order to prepare and supervise meals, take the individual to appointments or undertake hospital visits. Carers also extended financial support, including funding treatment, travel expenses and dietary requirements.

"I had to give up work to care for my daughter" (Parent, paper 6).

"It's cost me a fortune over the years just supporting her living with me" (paper 14).

Although parents described offering practical support to siblings to help them manage the impact of the ED (paper 18), siblings noticed discrepancies in parental expectations and treatment, particularly in terms of the practical and financial support given to their unwell sibling. This subsequently engendered feelings of resentment and frustration (paper 17; paper 20).

- **Emotional support**

Providing emotional support to the affected individual was considered an important role and discussed in nine of the reviewed articles. Carers described giving their time to the individual, encouraging them to talk about their emotions and providing reassurance. Emotional support was described as stressful by two partners (paper 14). Carers appraising the ED as an emotional issue responded with emotional support and endeavoured to regulate their own emotions to avoid upsetting the individual (paper 3). Moreover, parents strove to emotionally support siblings in order to mediate any negative impact of the ED (study 18). 'Overprotective' parental responses were noted in two papers, these were perceived by siblings (study 17) as hindering the individual's recovery.

"She'd be ringing me up, are you coming in to have lunch with me? Please come in and have lunch with me. I'm so lonely, so I'd go in, you know, twice a day on those days that I had off." (Parent, paper 3).

- **Accommodation and enabling**

In seven studies, family members described their considerable efforts to accommodate the affected individuals' perceived needs and special requirements. Efforts included buying specific foods, observing rigid meal routines and avoiding specific activities (e.g. eating at restaurants).

"You'd be shopping all over because we knew the supermarkets and the shops that would have exactly the brands that she wanted, and it had to be the same size. You couldn't buy a bigger tin and cut the quantity in half." (Parent, paper 3).

Due to the individual's perceived vulnerability, parents in paper 3 described making allowances in order to avoid upsetting the individual further. Moreover, mothers in

paper 2 endeavoured to "compensate" for perceived contributions to the development of the disorder.

"Trying to compensate, trying to protect her, make things easy and to fix any unhappy situations. So I thought you know this is my fault. I did it wrong." (Mother, paper 2).

Siblings' experience of accommodation was briefly described (study 17; study 20). Some siblings reported complying with the needs of the affected individual, whilst others felt parents expected them to adapt. In paper 17 siblings described their parents' accommodation of the ED as 'fuelling' the disorder.

Efforts to avoid conflict

In nine studies efforts to avoid conflict by family members were reported. These efforts generally fell into two sub-themes discussed below.

- **Tolerating and ignoring behaviours**

Family members were reported to consciously ignore or tolerate difficult ED related behaviours in order to avoid confrontation and further upset. Some carers described excusing deviant behaviours or found instilling boundaries difficult due to ensuing conflict.

"Last year we had such horrible fights most nights and it's really hard to know how strong to be with your child because the behaviour you'd expect of others, and then they see you as being lenient because you don't want these big arguments that you're never going to win, it's just awful." (Parent, Paper 6).

Siblings were also described as reluctant to tell parents about any deviant behaviour witnessed so as to avoid conflict (paper 16). Moreover, some siblings (paper 17) reported parents to be dismissive of voiced ED concerns.

"...if I were to say oh I know my sister was puking last night or whatever. She would be like oh may be not and always try and kind of make it seem ok." (Sibling, paper 17).

- **Walking on egg shells**

Three studies described carers as cautious regarding what they said or did around the individual with the ED. Reasons reported included avoiding upsetting the individual, fear of exacerbating the condition or concerns about the impact of conflict upon the relationship. One consequence of this was described in paper 15, whereby, partners felt unable to express their thoughts and feelings.

"To this day, I'm still treading carefully, I do pussyfoot around a lot." (Parent, paper 1)

"You're always careful what you said to her, what you did around her, she'd snap your head off." (Parent, paper 3).

Moreover, in study 18 parents endeavoured to avoid conflict whilst siblings were present to 'protect' them and maintain normality. In contrast to this, siblings in paper 17 reported assuming a mediation role during conflict.

Efforts to influence behaviour

In eleven studies, carers were reported to engage in a wide range of activities to influence the behaviour of the cared for individual. These could be categorised as either direct or indirect methods.

- **Direct**

Six papers outlined direct modes of influencing the affected individuals' behaviour. These included attempts to encourage the individual to gain weight or to engage in treatment through the use of explanation, reasoning, persuasion and the application of pressure. Carers also adopted various 'ploys' (e.g. rewards) to encourage the individual to gain weight. In order to prevent access to certain foods carers utilised physical obstacles. In limited circumstances, carers were reported to 'force' the individual to eat or to comply with treatment. Negative consequences were also threatened to influence compliance (e.g. hospitalisation). Often direct means to influence behaviour led to confrontations which left carers feeling frustrated and angry.

"She had to believe me more than she believed herself over the fact that she would not 'balloon out' and that it would not be detrimental to her to eat." (Parent, Paper 3)

"On a weekly basis we used to go and see (the psychologist) and drag (the child) kicking and screaming along the corridor." (Parent, Paper 13)

- **Indirect**

Indirect means of influencing the behaviour of the individual with the ED were discussed in nine studies. These included monitoring the individual's treatment compliance and soliciting the help of others to carry out this task, for example, siblings and teachers. To affect behavioural change carers endeavoured to secure appropriate treatment and attempted to influence this by seeking information, negotiating with

health professionals or intervening when treatment was perceived as ineffective. Attempts to mediate the individual's environment and social interaction were also described, for instance, carers reportedly hid foods and encouraged others to avoid certain topics. Some carers also engaged in deception in order to solicit the individual to attend appointments or to eat certain foods.

"We are reduced now to labelling and bagging up food and hiding food." (Female participant, paper 14).

"I try to look for high energy calorie food for her. But I didn't want her to know what I'm doing." (Parent, paper 3).

Difficulties managing the ED

The majority of the reviewed articles reported family members to experience difficulties managing the ED. Carers tended to experience feelings of powerlessness and frustration as a result of perceived fruitless attempts to influence behaviour, attempts which were often met with anger and resistance. Such responses from the affected individual were generally perceived as characteristics of the ED, although in practice carers reported difficulties separating the ED from the person, which at times could lead carers to react emotionally.

"...but if (the child) refuses to eat her meal, when she was very ill, then I'd shout, everybody else would cry and it's just the knock-on effect to the whole family." (Mother, paper 13).

"You tend to put them together. The disease and (my daughter). It's very hard to be this rational person that says, "That is the disease talking. That is not (my daughter)." (Parent, paper 8).

Other cited difficulties included conflicting advice and a lack of support and guidance from services, leaving carers unsure as to how to manage the ED.

"You're thinking on your feet all the time. That's the hardest thing, you're constantly thinking is what I'm doing in this situation, in this minute, is this right?" (Male partner, paper 14)

"You come home and you think 'right, it's just me. I'm it. I'm the support network.' I'm not nine health professionals and that is really daunting." (Parent, paper 11).

Siblings also reported difficulties managing the ED. These included negotiating what information to share with parents whilst remaining loyal to their sibling (paper 16), managing the demands and expectations of parents (paper 20) and coping with conflict and frustration arising from inconsistent familial responses to the disorder (paper 17).

5. **Perceived ED characteristics**

Resistance to change

In nine papers resistance associated with the ED was discussed. Features characterizing this resistance included the use of denial, deception and secrecy to conceal the ED symptoms and avoid weight gain. Perceived lack of motivation was cited to disrupt and hamper treatment engagement. Studies described these characteristics as eliciting feelings of mistrust and hurt, in turn compromising family relationships.

"It became too much for me the difficulty of the eating part of it and watching her waste away and listening to her try to stand there and try to justify that she doesn't have a problem." (Sibling, paper 17)

"She also became quite devious. You know you'd say have you eaten the biscuit and she'd look me in the eye and say I've eaten it and then I'd say what's up your sleeve and it was awful and there was the biscuit up the sleeve." (Mother, Paper 13).

High stakes

Ten papers described the perceived potential consequences of the ED upon the affected individual. Across these papers participants generally reported concerns regarding lost opportunities and the potential death of their loved one and therefore, perceived the 'stakes' as 'high' (a theme coined in paper 13). This potential outcome caused family members to experience intense negative emotions, including distress and fear. Paper 4 described these feelings to compromise participants' ability to cope with the disorder effectively.

"We have to feed her, we can't watch her kill herself." (Parent, paper 4)

"I was in tears saying 'I can't watch you do this; I can't watch you kill yourself." (Paper 6).

Interpersonal characteristics

The ED was perceived to impact the affected individual interpersonally, a subtheme discussed in twelve papers. The individual was described by family members as 'controlling' or 'manipulative' and perceived to dominate family life. A few papers referred to the ED "taking over" the individual and becoming a barrier in relationships. Reduced engagement in social activity was also noted. These characteristics were observed to place a strain on interpersonal relationships.

"Your child is possessed by this eating disorder, it is not your child in the same way, what you've got is an imposter sitting in your child." (Mother, paper 13).

The individual was perceived by some participants to have undergone a 'regression' becoming childlike, demanding and dependent. Several papers referred to perceptions of the affected individual as 'vulnerable' and unstable, consequently eliciting care and support from family members.

"As a mother you hope your children will become gradually more independent, but the reverse seems to be the case." (Mother, paper 7).

6. Support from services

Difficulty accessing appropriate resources

In seven papers the challenges accessing appropriate services and securing support were discussed. Carers tended to describe this as an arduous and lengthy process, requiring a great deal of time, effort and personal resources. However, some carers reported exceptions to this general experience describing rapid access to care (paper 9).

"It's a long road and sometimes you're hitting your head against a brick wall for a long time." (Parent, Paper 11)

Upon securing treatment for the individual, carers initially reported relief and hope. However, the difficulty negotiating the system to find treatment and subsequently renegotiating it when treatment was discontinued or perceived as inappropriate, left carers feeling unsupported, frustrated and pressured. Frequently the initial contact with services was perceived as unhelpful. Carers described a dearth of information, a lack of specialist services and inappropriate treatment provision, although carers in paper 10

generally reported a positive experience of family therapy. Subsequently, carers sought information and support from alternative sources, often turning to charities and support organisations which were commonly viewed as helpful.

"...and I thought oh good, isn't it lovely? You know, we're being cared for at last. And then boom! We were being discharged, like that, I burst into tears again and ran." (Parent, paper 11)

Interactions with health professionals

Thirteen papers referred to family members' experiences of health professionals. Carers frequently described negative interactions with professionals in which they felt misunderstood, scrutinized and blamed. Such negative interactions were reported to add to the negative impact of the ED and increase their own feelings of self-blame and guilt. However, exceptions were reported in two papers with carers occasionally giving positive accounts.

"Looking back I can see the difference between that (the eating disorder) and my (disabled) son. Nobody was judgemental with our son." (Parent, paper 5).

"There's a culture of mother blaming" (Mother, paper 11).

Some carers reported professionals to demonstrate a lack of expertise and knowledge, providing families with insufficient or conflicting advice. However, despite this general dissatisfaction, all carers in paper 10 reported at least one health professional they could turn to for support. Furthermore, mixed experiences were reported in paper 14 and the majority of carers were described as experiencing 'good advice' from specialists in paper 13.

"She had a framework she wanted us (his family) to fit, she would take the situation and make it fit and she was making the most bizarre interpretations and I would be writhing inside." (Father, paper 10)

"When things were really bad (the professional) at (the specialist hospital) was wonderful. She was the person that I could ring and that was very, very helpful." (Parent, paper 13).

Excluded from treatment

In paper 9 a minority of carers reported positive accounts of involvement in the treatment of the cared for individual. However, across eight papers the majority of carers described feeling excluded or 'shut out' of treatment. Often this exclusion was attributed to confidentiality legislation, which created a perceived 'wall of silence' leaving carers feeling uninformed regarding the individual's treatment and prognosis. In two papers, carers reported feeling discouraged from being involved in the individual's care. Attempts to elicit information were described as unsuccessful. This exclusion left carers feeling frustrated and stood in stark contrast to carers' post-discharge experience whereby, they were left to solely manage the individual's care.

"The message to parents is 'I'm seeing your child, I'm taking over from you … it's insulting to a person like me … I'll do whatever it takes. But don't shut me out and treat me like a moron." (Parent, paper 11).

"…sometimes something would happen and I'd think, 'well what do I say, how do I approach it? I don't want to make it worse.' I did phone her a couple of times and she'd say 'I'm sorry but I can't discuss (patient) with you' and I'd say 'but all I want to know is will I make it worse if I say this?" (Parent, paper 10).

7. <u>Coping and Resources</u>

Support

The majority of the reviewed papers made reference to family members' experiences of support. Due to the limited perceived formal support available, participants frequently sought support from informal networks such as family, friends and support groups. A number of papers emphasised the utility of this support in coping with the demands of the disorder and its emotional impact. Moreover, the importance of family unity and collaborative working was stated by carers in several articles. However, carers generally reported extended family and friends to lack understanding regarding the disorder and the experience of caring, although their support and empathy was valued. Due to this lack of understanding, together with apprehension regarding others reactions and the shame associated with perceived stigmatization, participants tended to limit their support networks. This reduced social support increased participants feelings of social isolation and frustration. Two studies also described siblings to avoid seeking support from family networks perceived as 'overburdened', utilising instead other informal support.

"I find it difficult to talk about Hannah's illness with people, partly because I feel like I'm a failure if I need to share my worries or ask for help and partly because the few friends I have confided in, only one has offered any real support." (Parent, paper 7).

"We had tremendous support from family and close friends but I don't think they could really comprehend what it was all about, I mean they couldn't understand it." (Parent, paper 13)

Support groups and organisations were highly valued by carers for providing reassurance, empathy, understanding and non-judgemental support. Carers viewed these groups as an opportunity to exchange experiences and ideas. By contrast, partners

described difficulties accessing such groups (paper 15) due to feelings of shame. Similarly, siblings expressed their need for support groups (paper 17).

"I think the support group was a saviour for me, they were always there, available to talk to." (Parent, paper 1)

Behavioural and Cognitive Strategies

Just over half the papers described cognitive and behavioural coping strategies employed by family members. Participants described endeavours directed towards moderating their thinking in order to avoid becoming overwhelmed. This entailed efforts to remain hopeful and optimistic through positive thinking. Carers described avoiding dwelling on negative possibilities or negative feelings (e.g. guilt) by focusing on positive aspects, strengths or via downward comparisons. Some carers referred to maintaining a focus on the 'here and now', finding future oriented thinking challenging.

"(I try to) hang in there and find something positive in each day." (Paper 8)

"I don't think about how it might have been but I try to stay grounded in the now." (Paper 14)

Some family members referred to attempts to externalise the ED, separating it from the affected individual in order to maintain a positive relationship. Distraction and avoidance were also employed as a coping strategy, with some participants utilising work to avoid preoccupation with the disorder or to avoid difficult situations (e.g. mealtimes). Siblings also utilised avoidance to cope, creating distance between themselves and their affected sibling to moderate negative feelings and safeguard their own well-being (paper 17; 19; 20). Siblings were perceived by some parents to cope with the ED well, although it was acknowledged that some responded by bottling up

their feelings or distancing themselves (paper 10). Corroboratively siblings in two papers described supressing their feelings, explaining this in paper 16, as avoiding drawing attention to themselves and burdening family.

"I think I coped by crying or by going to bed. By going to bed I didn't have to deal with all the other demands, as well as the demands of the illness." (Paper 6)

A couple of studies advocated the importance of maintaining interests and activities outside of the ED, yet this was acknowledged by carers to be difficult.

"I'll be supportive and I'll do what I can but I still got my own life and you've got to, that's the only way you can stay sane." (Female participant, Paper 14).

Carer Resources

Personal resources augmenting participants' ability to cope were discussed in six papers. Studies described the resourcefulness and skills of carers which facilitated the securing of information and treatment. Carer qualities' were also described which sustained participants through their experiences, these included resilience, courage, motivation, hope, love and loyalty. Siblings in paper 17 referred to their unique qualities which facilitated their effectiveness as a 'mediator' within the family.

"… We never, ever felt like giving up. There was never a moment that we felt like giving up. There was always, we're going to beat this. That was our catchcry." (Parent, paper 1).

8. __The impact of caring__

Positive impact

Twelve studies identified positive consequences as a result of living with, or caring for an individual with an ED. The most frequently cited consequence, being an increase in the family alliance and improved family relationships. However, this was referred to as a 'tenuous' process (paper 5) and positives were cited as 'coexisting' with negative consequences (paper 15). Indeed, several articles acknowledged that whilst some participants experienced family unification, others experienced relationship strains (discussed below).

"Ironically we are probably closer now than we have ever been." (Parent, Paper 7)

"I think we have become more close because we know each other more and I guess you can say the darker sides even though it sounds dramatic." (Sibling, paper 17)

The personal growth of carers and siblings, together with increased knowledge and skills were referred to as positive outcomes in seven papers. An increase in empathy for, and understanding of mental health difficulties was also cited.

"…I'm changing, I'm growing through this experience, it's given me understanding of different perspectives." (Parent, Paper 1).

Identity, emotional and mental health

Almost all of the reviewed articles address the impact of caring for, or living with an individual with an ED on emotional wellbeing and mental health. These articles describe an array of emotional consequences, with half the articles reporting some participants to experience overwhelming and intense emotions, characterised by feelings

of distress and an inability to cope. Cited triggers for this distress include the perceived severity of the ED (paper 6), pressures (paper 1; paper 5), unsuccessful efforts to influence recovery, balancing competing demands and conflicting roles (siblings: paper 16; paper 20).

"She was just a skeleton. She couldn't walk and couldn't do anything, (I was) crushed, absolutely crushed. I was devastated." (Paper 6).

"I can't cope with it and I'm not a "I can't cope" kind of person." (Parent, paper 1)

Anger and frustration was reported in half of the reviewed papers and frequently linked to difficulties negotiating treatment. Furthermore, perceived lack of progress, difficulty understanding ED characteristics and stigma also elicited frustration.

"You just get really frustrated and angry, you know, with her." (Paper 14).

"... I got very angry when people would stop and stare at her, nudge their companion to look as well." (Parent, paper 12).

The experience of living with or caring for the affected individual impacted on participants' mental health, with five papers reporting some participants to experience anxiety and depression. Four studies also described carers' experience of fear with regard to possible relapse and the unknown course of the disorder. Feelings of hopelessness and powerlessness were described due to carers perceiving the ED as uncontrollable.

45

"My husband towards the end was nearly having a nervous and physical breakdown." *(Parent, paper 5).*

"I felt helpless because I just knew how devastating it can be." *(Parent, paper 1)*

Perceived pressure and burden of living with or caring for the affected individual was referred to in almost half of the studies. Several studies linked burden to a lack of support or fear regarding the outcome of the ED. Siblings expressed burden in the context of strain related to their role, feelings of responsibility and perceived parental expectations (paper 16; paper 17; paper 20).

"As the mother you try to be there to listen to your husband's problems and your children's and sometimes that takes up so much time that you get no space at all and you end up feeling totally drained." *(Mother, paper 13)*

Six studies discussed family members' experience of grief and loss as a result of perceived changes in their relationship with the affected individual due to the ED. Guilt and self-blame were also described, particularly in the context of perceived responsibility for the ED.

"But sometimes I am struck by a picture of John aged 10, all rosy cheeks and smiles, up to no good and full of energy. At these times I indulge myself in thinking of what he could be now if he was not anorexic. And at these times I grieve." *(Parent, paper 7).*

"So how does a mother feel? Failed, useless, bad, stupid, guilty, guilty, guilty." *(Mother, Paper 12).*

In two papers siblings referred to a sense of injustice and feelings of resentment with regard to differential parental expectations and treatment. The impact of the ED on siblings' identity was discussed in all four papers investigating the sibling's experience. All of which described 'uncharacteristic' shifts in the sibling's role. Newly assumed roles include that of the 'healthy child' (paper 16), 'mediator/protector' (paper 17) and 'parental' roles (paper19). These changed roles, together with perceived expectations impacted siblings' identity and were a source of internal conflict and mixed emotions. Two studies referred to the ED as impacting on some siblings' perceptions of body image and attitudes towards food.

"I know it's not easy and it really affects everything in your life. She, it does affect the way I see myself and it does affect the way I see the world; the way I see my sister, our relationship." (Sibling, paper 16)

Physical Health

The physical health of some family members was reported in seven studies to be affected by living with and managing the ED. Supporting the individual practically and emotionally, left some carers "physically exhausted" and "drained". Several articles also referred to the sleep deprivation experienced by some family members, with some siblings reporting increased ill-health (e.g. colds) and poor concentration (paper 17).

"I was so exhausted I couldn't cope with taking my daughter to hospital and having a part-time job." (Parent, Paper 14)

Conflict and stained relationships

Fourteen studies made reference to conflicts within the family and strained relationships as a result of managing and living with the ED. Frequent confrontations and conflicts were described surrounding food and mealtimes.

Arguments and rifts were also cited to result from changes within the family system due to the demands of caring, whereby other family relationships were neglected thereby, reducing intimacy and increasing resentment and friction. Changes in parental and sibling relationships as a result of the ED were also noted by some siblings, who described decreased unity and emotional realignment as parents focused on the affected individual.

"...for me to be able to deal with Sarah, I do have to change the way I interact with my partner and my younger daughter, I certainly can't give them as much time and I'm not as relaxed with them." (Parent, paper 6).

"Your illness has separated all of us." (Parent, paper 7).

Pervasive impact

The all-consuming and pervasive nature of caring for and living with an individual with an ED was apparent from 14 articles. These studies described how family life revolved around the ED and in particular, mealtimes. All aspects of day to day life were implicated, including relationships, emotional and physical wellbeing, social and occupational functioning and financial concerns. Carers sacrificed occupational, leisure and social activities to fulfil the demands of caring, altering routines and investing substantial time and energy.

"I was living and breathing it the whole time." (Parent, paper 13).

"Anorexia engulfs not only the sufferer but all those who come into contact with them." (Parent, paper 7)

"It flows into everything in the family, everything you do." (Paper 6)

Some siblings also described the ED to have an all-encompassing and pervasive impact on their daily lives, affecting their mood, identity, family relationships, home-life, academic functioning and motivation. Some siblings were reported to make sacrifices as a result of the ED. A lack of normalcy was described in family life, particularly surrounding meals.

"I just can't go out to lunch with her, or shopping because it triggers her ... there's just no normalcy 'cause everything revolves around the eating disorder." (Sibling, paper 17).

9. <u>Evaluating the impact and adapting</u>

Evaluating strategies, treatment and progress

Over half of the reviewed papers described carers to evaluate the impact of treatment, past management strategies and responses in terms of the progress made by the affected individual. Subsequently, constructions relating to the ED altered as participants evaluated the effectiveness of their attempts to influence recovery. Learning and new information were appraised and reintegrated, with carers adopting a 'suck it and see' approach to managing the ED (paper 8). Perceived progress led some carers to experience relief. Whereas, perceived lack of progress tended to elicit frustration and altered responses.

"There's been a lot of progress in recent months... there seems to be a lot of results coming out steadily and slowly and it's going to take a very long time but I think it's the most positive thing" (Partner, paper 9).

Shifting perspectives and responses

What was apparent from half of the papers reviewed was the tendency for individuals living with or caring for the affected individual to alter their perspectives regarding the ED over the course of the illness and in turn their responses. Eight papers described carers learning to 'step back' from the ED and 'let go' in terms of allowing the affected individual to take more responsibility and control for their own behaviour.

"if you are always making decisions for them, always getting between them and the problem, they will never achieve anything in their own lives." (Paper 14).

Some carers also described the importance of holding realistic expectations in terms of recovery and learning to accept the ED and associated changes.

"We wanted our (daughter back). And it took a long time to realise that this is actually impossible, it's never going to happen. So you've got to move beyond..." (Parent, paper 8).

"It's like growing to live with it" (Partner, paper 15).

Several papers described carers' realisation that guilt and self-blame were unhelpful. Perceptions of the ED also altered, with some carers changing their focus away from the disorder as an eating issue and perceiving it as a separate entity.

Eight papers described participants altered responses to managing the ED. Commonly participants referred to negotiating and setting firm boundaries between them and the affected individual. For some carers this involved finding a balance between being 'too connected' and 'too distant' (paper 2) whereby, parents encouraged the individual to

become more independent. Some carers described developing new parenting skills as a result of 'trial and error' or professional input. The importance of deciding on their degree of involvement, emotionally pulling back and maintaining their own interests was discussed by several studies. A consistent, united approach was advocated.

"I was always very quick to say, "Right, now this is what I am doing but tomorrow morning or evening if you want to sit down that's fine, but right now I really do have this commitment. Unless it is really urgent this is what I need to be doing now. That was really hard for her because she was used to me being there and used to being rescued." (Mother, paper 2).

"If you're not going to eat this, ok (daughter) don't eat it, you're going to hospital. Whereas before I would coax and cajole and I gradually clawed myself back to being what I should have been." (Parent, paper 1).

Discussion

This review sought to synthesise accounts of caring for, or living with an individual with an ED in order to develop understanding of this experience and its impact. This is the first review of this subject matter to be undertaken systematically. Nine core themes emerged from the synthesis of 20 studies, which formed the basis of an explanatory theory. The review found caregiving or living with an individual with an ED to have a pervasive impact on family members, affecting their relationships, sense of identity, physical, emotional and mental health. Cognitive appraisals relating to the understanding of the ED had a direct impact on the caregiving experience. Furthermore, the understanding of the ED affected caregivers' perceptions of ED characteristics, responses to the individual, information seeking, need for support and other coping strategies. All these factors were intertwined and mediated the impact of the ED. Family members' experiences of all these factors were continually re-

appraised, subsequently the understanding of the ED was found to be fluid. Moreover, the impact of caregiving was evaluated in terms of the success of management strategies and treatment, leading to a process of adaptation whereby, carers altered their perspectives and responses over time.

Quantitative studies lend support to the findings of the review, particularly in terms of the impact of an ED on family members. For example, in a quantitative review Zabala et al, (2009) found high levels of psychological distress and burden in caregivers of individuals with EDs. Similarly, studies in the present review reported family members to experience an array of negative emotions including distress, anxiety and depression, which were linked to various aspects of caring including characteristics of the ED, perceived severity, caregiving burden and lack of support. Moreover, Kyriacou, Treasure and Schmidt (2008) found perceived caregiving burden and interpersonal strains to predict levels of carer distress. Studies in this review reported caring to have a significant impact on interpersonal and family relationships, which were described as strained. Frequent conflict was cited around mealtimes and relationship difficulties were linked to changes within the family system as a result of caring. The review also highlighted reported changes in sibling and parental relationships due to parents increased focus on the affected individual. Living with and caring for an individual with an ED was described to have a pervasive impact on family life. These results are compatible with a theoretical framework proposed by Eisler (2005) (see Whitney and Eisler, 2005 for a review), which describes the family to become 'reorganised' around the symptoms of the ED, impacting on relationships, social activities and family life.

The review highlighted the importance of appraisals relating to the ED and their subsequent impact on the caregiving experience and responses to the individual. These findings corroborate Szmulker et al's, (1996) caregiving model which emphasises the importance of 'illness appraisals' upon distress. Furthermore, Whitney, Haigh, Weinman & Treasure (2007) found increased negative caregiving appraisals in carers attributing responsibility for the ED to the individual, as well as higher levels of distress. In the present review, carers appraising the ED as 'a choice' were described to express higher levels of criticism and blame towards the individual. This finding corroborates reviews of EE (Barrowclough & Hooley, 2003).

Furthermore, Schmidt and Treasure's (2006) cognitive-interpersonal maintenance model emphasises the role of EE in caregiver responses, describing criticism and hostility to result from a battle for 'control' around mealtimes resulting in caregiver 'defeat'. Moreover, emotional over-involvement due to concerns regarding the individual's wellbeing and a desire to avoid conflict was linked to accommodation of the ED. This review lends support to this model, with the majority of studies outlining carers' difficulties managing the ED, with efforts to influence behaviour often met with resistance and conflict. Some studies described carers' difficulties separating ED behaviours from the individual, resulting in emotional carer reactions. Interpersonal difficulties, including conflict have been cited as a possible maintenance factor for BN (IPT: Fairburn, 1993). Feelings of hopelessness and powerlessness as a result of difficulties managing the ED were also reported, a finding corroborated by Whitney and Eisler (2005). The review details carers' efforts to avoid conflict and the importance ascribed by carers to the role of emotionally supporting the individual.

A number of factors were found to mediate the impact of the ED, including carer support and coping strategies. Szmukler et al's (1996) caregiving model also cites social support as a mediating factor. The studies included in the review described a general lack of formal support and advice for carers, as well as difficulties negotiating the healthcare system, stigma, a perceived lack of understanding from others and exclusion from treatment. Siblings also reported a lack of support and feeling excluded. Similarly, in the development of a carers' needs assessment measure, Haigh and Treasure (2003) reported high levels of unmet carer needs. Previous research has linked decreased support to negative caregiving experiences and found stigma predictive of distress (Whitney et al, 2007).

A key and novel finding from the review was the process by which the caregiving experience changes across the course of the ED. The review highlighted a process of adaptation, whereby, carers re-evaluated the impact of the ED over time, particularly in terms of the consequences and efficacy of caregiving approaches upon ED symptoms. Constructions relating to the ED altered as experiences and new learning were reintegrated with existing knowledge. Altered perspectives led to shifting caregiver

responses as carers adopted a trial and error approach to the ED. Over its course carers were described as beginning to accept the ED, with some studies reporting carers as beginning to negotiate and set firmer boundaries or reduce their level of emotional involvement. This finding fits with Treasure, Gavan, Todd & Schimdt's (2003) assertion that carers develop an 'illness model' which includes information as to the understanding of the ED, its consequences and perceived controllability. This model is described to develop iteratively concordant with caregiver experiences and asserted to impact caregiving responses.

Implications

This review highlights the importance of family members' understanding of the ED which impacts caregiving responses and the caregiving experience. Therefore, interventions designed to address ED appraisals will help to improve carers' ability to manage the ED as well as carer wellbeing. Existing carer interventions targeting coping skills, responses and carers understanding of the ED have shown promise in terms of reduced caregiving burden and distress (Sepulveda, Lopez, Todd, Whitaker & Treasure, 2008).

The review documented a lack of support and information for carers and siblings, as well as experiences of exclusion from services. The importance of supporting carers needs and including carers in services has been underlined in the Carers Act (1995) and National Service Framework for Mental Health (Department of Health, 1999). However, a recent report highlighted the continued reluctance of health professionals to share information with carers due to anxieties regarding patient confidentiality (Department of Health, 2013). This report emphasised the importance of information sharing in terms of supporting patient care. The reviewed studies described exclusion from services as compounding carers' feelings of stigma and difficulties coping, therefore, underlining the importance of including carers in treatment and providing support to carers to help them manage the ED. Support groups were valued by carers, particularly in terms of reducing stigma.

Only four studies addressed the experience of siblings living with an individual with an ED. These studies described the burden placed on siblings and impact on them

emotionally. Although some studies described parental efforts to support siblings, generally siblings' needs were unmet and a lack of information and support described. Further studies are required to address the impact of ED on siblings, and interventions designed to support siblings and augment their understanding of ED are indicated.

Strengths and Limitations

As an emerging approach, debate exists surrounding the implementation of meta-synthesis as a means to summarise and understand experiential phenomena. Indeed Sandelowski, Docherty and Emden (1997) criticise the premise of meta-synthesis on grounds of reductionism, questioning its capacity to preserve the 'integrity' of the original findings. Related to this, Noblit and Hare (1988) contend that it is only possible for studies employing the same qualitative methodology to be synthesised and 'translated' into one another. Thereby, a potential limitation of this study is the inclusion of studies with multiple designs, although other researchers emphasise the importance of inclusivity based on the premise that knowledge is a constructed phenomenon with multiple perspectives (Sherwood, 1997). Moreover, Walsh and Downe (2005) assert the goal of meta-synthesis as developing new insights as opposed to searching for a 'truth' or achieving parsimony. Therefore, it is contended that this meta-synthesis has furthered insight into carers' experiences, offering useful implications for practice. Furthermore, attempts have been made to preserve the veracity of the findings of included studies by adhering to Noblit and Hare's (1988) analytic technique, further developed by Walsh and Downe (2005). This technique facilitates the development of new insights whilst preserving 'commonalities' and 'differences' within the original data. It is also the most well established and widely used method. Moreover, the design and quality of each study was acknowledged as part of the quality assessment and considered during the synthesis (Sandelowski et al, 1997).

In order to maintain the methodological rigour of the meta-synthesis, a systematic literature search was undertaken to capture all relevant articles. In view of the difficulties retrieving qualitative studies (Barroso et al, 2003) comprehensive search terms were employed. This yielded a high number of studies, although the specificity of

the search was low. In the interests of inclusivity and due to a lack of qualitative research, non-primary studies were included in the review. Therefore, particular samples of carers may have been over-represented which may have had a bearing on the synthesis. However, it is contended that these non-primary studies offered additional important insights into the experience of caring. Furthermore, the majority of the reviewed studies focused on caregiving for individuals with AN. Although similarities have been cited between ED classifications (Fairburn & Bohn, 2005) research has asserted that anorexia nervosa (AN) is a unique phenotype within ED (Collier & Treasure, 2004). Therefore, the findings of the results apply more specifically to caring for individuals with AN and as such, the applicability of the results beyond this classification is uncertain, and should be viewed with caution. Due to the limited body of research, this review has included studies of family members caring for, or living with individuals with mixed ED diagnoses, therefore, any differences in the caregiving experiences may not have emerged.

In the interests of including good quality studies, only peer reviewed papers were included in the synthesis. However, as Walsh and Downe (2005) note, many qualitative studies are published in alternative formats and therefore, these will not have been included. It is acknowledged these may have offered additional insights; however, a recent emphasis has been placed on the importance of including quality studies to promote the credibility of qualitative reviews (Walsh & Downe, 2005; Campbell et al, 2003). To this end, inclusivity was balanced against the need to maintain rigour. Furthermore, studies included in the review were assigned a quality rating, although this is acknowledged to be contentious within qualitative research due to the nature of the methodology. Objectivity and consistency when assessing the quality of the studies was promoted utilising a tool derived from the CASP and Walsh and Downe (2006) checklists. However, as stated by Walsh and Downe (2006) a checklist merely provides an 'indication' of quality as opposed to a 'guarantee'. Indeed, wide variation was noted in terms of the fidelity of the included studies to their stated methodologies and yet, due to the scoring of the quality checklists, this was not always captured. However, Sandelowski and Barroso (2002) argue that the findings of a paper are not necessarily compromised due to a lack of rigour in one criterion.

Further difficulties arose once a paper had been assigned a quality rating in terms of interpreting its significance, as the current checklists provide no accompanying classification to denote the meaning of a score. For the purposes of this review, a general classification system was devised and utilised as a guide, however, this classification system has not been validated.

To uphold the rigour of the meta-synthesis, the researcher endeavoured to maintain fidelity to the original data, mindful throughout of their active role in the interpretation and synthesis of the studies. Furthermore, the quality ratings of a representative sample of papers were independently reviewed to ascertain their credibility. Moreover, the final synthesis was 'externally validated' by corroborating this with existing literature (Jensen and Allen, 1994) and through an independent clinician (experienced in the field) reviewing its clinical 'fittingness'. Internal validation was maintained by utilising original quotes from the studies as exemplars.

Despite these measures, it is acknowledged that the researcher's experiences and perspectives will have had a bearing on the synthesis. Reflexivity was maintained via discussions in supervision and the use of transparency throughout the synthesis process (for example, utilising theme tables). Transparency and clear documentation throughout all stages of the review promoted the replicability and 'auditability' of the meta-synthesis (Jensen and Allen, 1996).

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Figure 1. Flow chart outlining the process of study identification
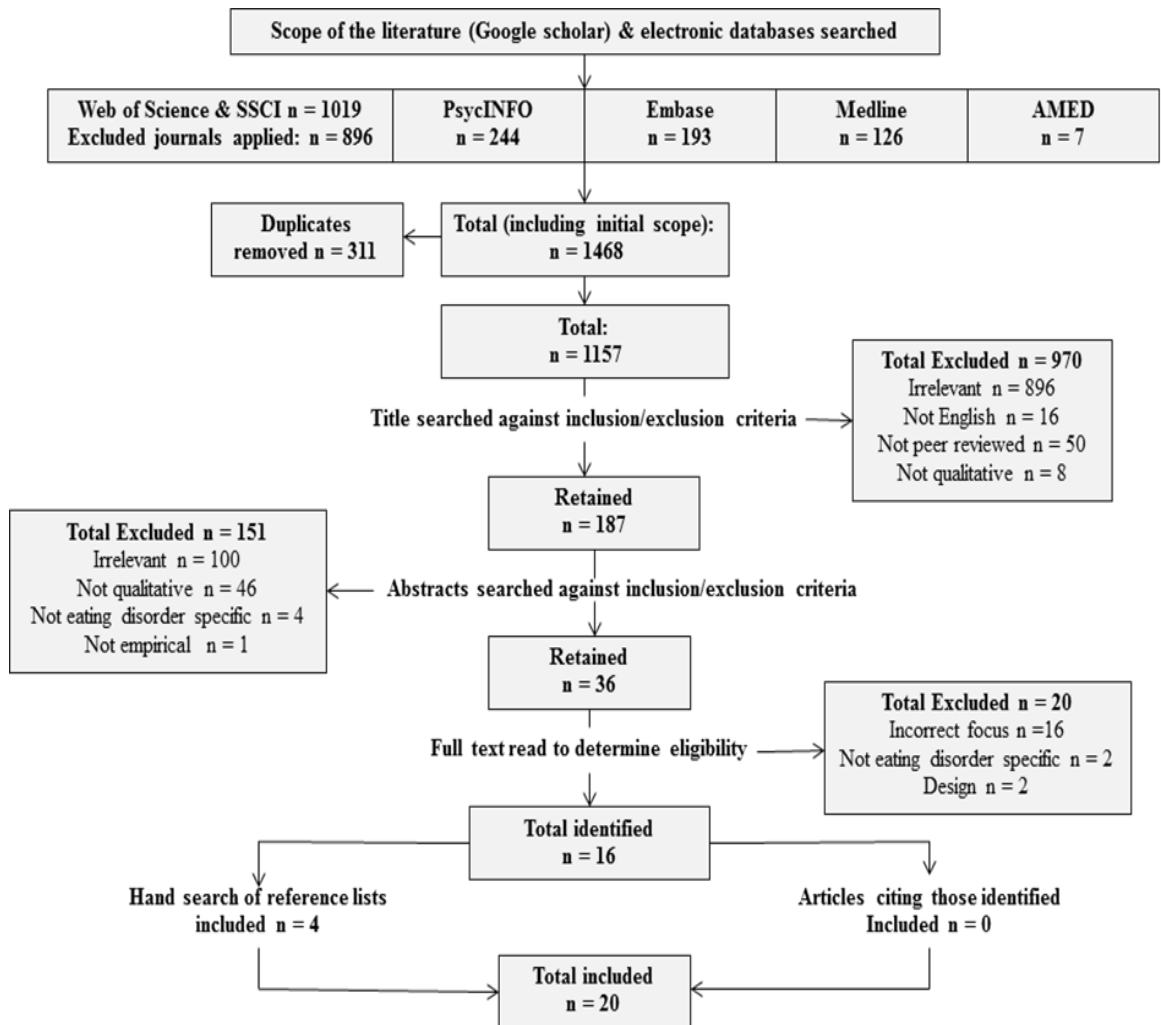
Table 1. Characteristics of reviewed studies

Reference	Title	Perspective	Sample	Data collection	Analysis	Aim	Quality Rating
Beale, McMaster & Hillege (2004/5) Study 1	Eating Disorders: A qualitative analysis of the parents' journey	Parents of individuals living with or recovered from an ED	22	Open-ended, un-structured interview	Thematic analysis	Describe the journey of parents with a child with an ED	B
Hoskins & Lam (2001) Study 2	The impact of daughters' eating disorders on Mothers' sense of self: contextualizing mothering experiences	Mothers of individuals recovered from AN	3	Open-ended interview	Contextualised interpretative methodology (informed by discursive and constructionist theory)	Explore the influence of daughters' anorexia on mothering identities.	A
Honey & Halse (2005) Study 3	Parents dealing with Anorexia Nervosa: Actions and Meanings	Parents of individuals receiving treatment for & diagnosed with AN.	22	In-depth interviews utilising a recursive model	Grounded Theory	Exploration of parental appraisals of AN & how these influence their responses	B
Sharkey-Orgnero (1999) Study 4	Anorexia Nervosa: A qualitative analysis of parents' perspectives on recovery.	Daughters recovering from AN and their parents	9 daughters, 10 sets of parents (10 mothers & 8 fathers) and 1 sibling.	Semi-structured interviews	Grounded Theory	Develop a theory of the parenting processes which facilitate recovery from AN	B

Hillege, Beale & McMaster (2006) Study 5	Impact of eating disorders on family life: individual parents' stories.	Parents of individuals living with or recovered from an ED	Duplicate sample from Beale et al, (2004/5)	Open-ended, un-structured interview	Thematic analysis	Explore the impact of an ED on family life.	B
Highet, Thompson & King (2005) Study 6	The Experience of living with a person with an eating disorder: the impact on the carers.	Carers of individuals with AN and BN)	24	Focus Groups & semi-structured interview	Thematic analysis	Explore and identify experiences of carers living with a person with an eating disorder	B
Treasure et al, (2001) Study 7	The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis.	Parents of individuals diagnosed with AN & receiving inpatient treatment	20	Mixed design including a free letter written task on 'what it is like to care for someone with AN"	Thematic Analysis	Compare the experience of caring for an individual with AN to caring for an individual with psychosis.	B
Honey & Halse (2006a) Study 8	The specifics of coping: parents of daughters with anorexia nervosa	Parents of daughters receiving treatment for & diagnosed with AN	Duplicate Sample from Honey & Halse (2005)	In-depth interviews utilising a recursive model	Grounded theory	Examine the coping strategies parents utilise and compare these to general coping theory.	B
Winn, Perkins, Murray, Murphy & Schmidt (2004) Study 9	A qualitative study of the experience of caring for a person with Bulimia Nervosa. Part 2: carers' needs and experiences of services and other support.	Carers (15 parents & 5 partners) of females with BN	Duplicate sample from Perkins et al, (2004).	Semi-structured interviews	Thematic analysis	Consider carers' experience of services & support received.	B

Tierney (2005) Study 10	The treatment of adolescent anorexia nervosa: a qualitative study of the views of parents	Parents of daughters with a current/past diagnosis of AN who had received inpatient or outpatient treatment	14 participants (6 sets of parents and 2 mothers)	Semi-structured interviews	Thematic analysis	Explore the experiences of parents with a child who had received treatment for AN in adolescence	A
McMaster, Beale, Hillege & Nagy (2004) Study 11	The parent experience of eating disorders: interactions with health professionals.	Parents of individuals living with or recovered from an ED	Duplicate sample from Beale et al, (2004/5)	Open-ended, un-structured interview	Thematic analysis	Explore the experiences of parents with a daughter with ED in terms of their involvement with health professionals	B
Whitney et al (2005) Study 12	Experience of caring for someone with anorexia nervosa: qualitative study	Parents of individuals receiving inpatient care and diagnosed with AN.	40	Free letter writing task	Grounded theory	To Understand the experience of caregiving for an individual with AN	B
Cottee-Lane, Pistrang & Bryant-Waugh (2004) Study 13	Childhood onset anorexia nervosa: the experience of parents	Parents of children in treatment for, and diagnosed with AN.	11	Semi-structured interviews	Interpretative Phenomenological Analysis	Describe parents' experiences of having a child with AN	A
Perkins, Winn, Murray, Murphy & Schmidt (2004) Study 14	A qualitative study of the experience of caring for a person with Bulimia Nervosa. Part 1: the emotional impact of caring	Carers (15 parents & 5 partners) of females with BN	20	Semi-structured interviews	Thematic analysis	Explore the experience of caregiving for individuals with BN	A
Huke & Slade (2006) Study 15	An exploratory investigation of the experiences of partners living with people who have Bulimia Nervosa	Partners living with an individual diagnosed with BN	8	Semi-structured interview	Interpretative Phenomenological Analysis	Explore the experiences of partners living with an individual with BN	A

Areemit, Katzman, Pinhas & Kaufman (2010) Study 16	The experience of siblings of adolescents with eating disorders	Siblings (10-18 years old) living with individuals with a diagnosed ED.	10	Semi-structured focus groups	Grounded theory	Qualitatively & quantitatively explore the experiences and quality of life of siblings of an individual with an ED	B
Dimitropoulos, Klopfer, Lazar & Schacter (2009) Study 17	Caring for a sibling with Anorexia Nervosa: A qualitative study	Adult siblings of individuals with AN.	12	Semi-structured interviews	Grounded theory	Explore the experiences of adult siblings of individuals with AN	B
Honey & Halse (2006b) Study 18	Looking after well siblings of adolescent girls with anorexia: an important parental role	Parents of daughters receiving treatment for & diagnosed with AN	Duplicate Sample from Honey & Halse (2005)	In-depth interviews utilising a recursive model	Grounded Theory	Investigate parents behaviour towards siblings of individuals with AN.	B
Latzer, Ben-Ari & Galimidi (2002) Study 19	Anorexia Nervosa and the family: effects on younger sisters to anorexia nervosa patients	Girls (age 11-18) living with older sisters receiving treatment for AN	9	Semi-structured interviews	Content analysis	Explore the younger sister's subjective experience regarding her sibling with AN	B
Garley & Johnson (1994) Study 20	Siblings and eating disorders: a phenomenological perspective	Siblings (aged 15-18) of an individual receiving treatment for AN	5	Un-structured interviews	Phenomenological Approach	Increase awareness of the sibling experience in families with a child with an ED	B

Table 2. List of studies with identified themes

	Study Number																			
Themes	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**
1.ED Onset																				
Gradual recognition	yes	yes	-	yes	-	yes	yes	-	-	yes	-	-	yes	yes	-	-	-	-	-	-
Initial impact	yes	yes	-	yes	-	yes	yes	-	-	yes	-	-	yes	yes	-	-	-	-	-	-
2. Cognitive appraisals & processes																				
Fluid appraisals	-	yes	yes	yes	-	-	-	-	-	-	-	-	-	-	yes	yes	-	-	-	-
Understanding of the ED	yes	-	yes	yes	-	yes	-	yes	-	yes	-	yes	yes	-	yes	yes	-	-	-	yes
Appraisals of the caregiver contribution to ED	yes	yes	-	-	-	yes	yes	yes	-	-	yes	yes	yes	yes	-	yes	yes	-	-	yes
Worry & rumination	yes	-	-	-	yes	-	-	-	-	yes	-	yes	yes	-	-	yes	yes	yes	yes	-
Appraisals and action	-	yes	yes	yes	-	-	-	yes	-	-	-	-	-	-	yes	-	-	-	-	-
3. Efforts to understand the ED																				
Seeking information	yes	yes	yes	yes	-	yes	-	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	-	-	yes
Difficulty understanding	-	yes	yes	yes	-	-	yes	-	-	-	-	yes	yes	-	yes	yes		-	-	yes
4. Managing the ED																				
Efforts to meet the individual's needs	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	-	yes	yes	-	yes	yes	-	yes
Practical support	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	-	yes	yes	-	yes	yes	-	yes
Accommodation & enabling	-	-	yes	-	-	yes	-	-	-	-	-	yes	-	yes	yes	-	yes	-	-	yes
Emotional support	-	-	yes	-	-	-	yes	yes	-	yes	-	-	-	yes	yes	-	yes	yes	-	yes
Efforts to avoid conflict	yes	-	yes	yes	-	yes	-	-	-	-	-	-	-	-	yes	yes	yes	yes	yes	-
Tolerating & ignoring behaviours	-	-	yes	yes	-	yes	-	-	-	-	-	-	-	-	yes	yes	-	-	-	-
Walking on egg shells	yes	-	yes	-	-	-	-	-	-	-	-	-	-	-	yes	-	-	-	-	-
Efforts to influence behaviour	yes	-	yes	yes	-	-	yes	yes	-	-	-	-	yes	yes	yes	yes	yes	yes	-	-
Direct	-	-	yes	yes	-	-	yes	-	-	-	-	-	yes	-	yes	yes	-	-	-	-
Indirect	yes	-	yes	yes	-	-	-	yes	-	-	-	-	-	yes	yes	yes	yes	yes	-	-
Difficulties managing ED	-	-	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	-	yes

Study Number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
5. Perceived ED characteristics																				
Interpersonal characteristics	yes	-	-	-	-	yes	yes	-	-	-	-	yes	yes	yes	yes	yes	yes	yes	yes	yes
Resistance to change	yes	-	yes	yes	-	-	-	-	-	-	yes	-	yes	yes	yes	yes	yes	-	-	-
High stakes	yes	-	-	yes	-	yes	-	-	-	-	-	yes	yes	yes	-	yes	yes	-	yes	yes
6. Support from services																				
Difficulty accessing appropriate resources	yes	-	yes	-	-	yes	-	-	yes	yes	yes	-	-	-	-	-	yes	-	-	-
Interactions with health professionals	yes	yes	yes	yes	yes	yes	-	yes	yes	yes	yes	-	yes	-	yes	-	yes	-	-	-
Excluded from treatment	-	yes	yes	-	yes	yes	-	yes	yes	yes	yes	-	-	-	-	-	-	-	-	-
7. Coping & resources																				
Carer Resources	yes	-	-	-	-	-	yes	yes	-	yes	yes	-	-	-	-	-	yes	-	-	-
Support	yes	yes	-	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	-	yes	yes	yes	yes	-	yes
Behavioural & Cognitive strategies	-	yes	-	-	-	yes	-	yes	-	yes	-	yes	-	yes	yes	yes	yes	-	yes	yes
8. The impact of caring																				
Positive impact	yes	yes	-	-	yes	-	yes	yes	-	-	-	yes	-	yes	yes	yes	yes	-	yes	yes
Identity, emotional & mental health	yes	yes	-	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Physical health	yes	-	-	-	-	yes	-	-	-	yes	-	yes	yes	yes	-	-	yes	-	-	-
Conflict & strained relationships	-	-	-	-	yes	yes	yes	yes	-	yes	-	yes	yes	yes	yes	yes	yes	yes	yes	yes
Pervasive impact	yes	-	-	-	yes	yes	yes	yes	-	yes	-	yes	yes	yes	-	yes	yes	yes	yes	yes
9. Evaluating the impact & adapting																				
Evaluating strategies, treatment & progress	yes	yes	yes	yes	-	-	-	yes	yes	yes	-	-	yes	yes	yes	-	yes	-	-	-
Shifting perspectives & responses	yes	yes	yes	yes	-	-	-	yes	-	yes	-	-	yes	yes	yes	-	yes	-	-	-

Figure 2. Model to illustrate the relationships between core themes
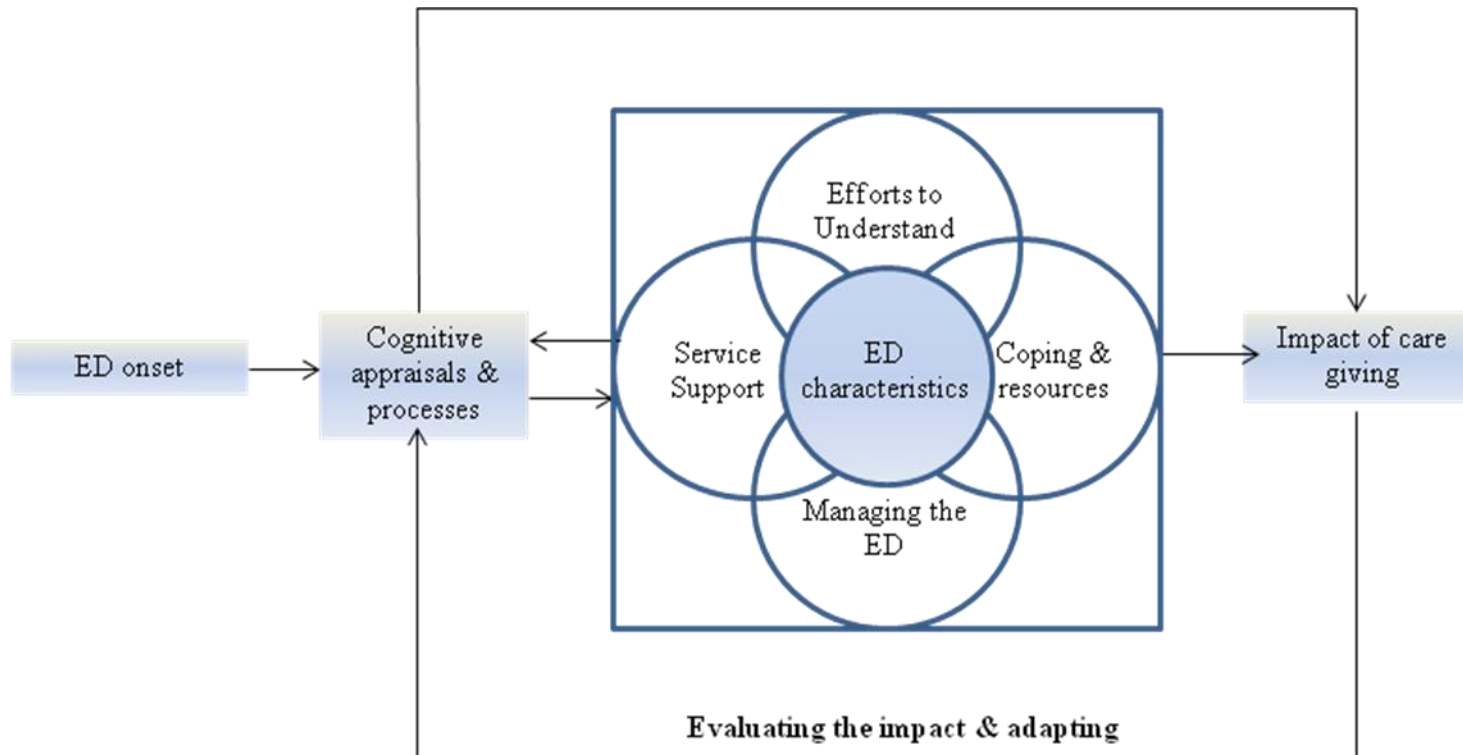
Paper 2.

A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa

Paper 2 has been prepared for submission to Clinical Psychology and Psychotherapy in accordance with the guidelines for contributors (Appendix 1).

Word Count (excluding tables, figures and references):

10151

Abstract

Anorexia Nervosa (AN) continues to remain poorly understood within eating disorders. Recent research and theory have moved away from understanding its aetiological causes, addressing instead potential maintaining factors. This study is focused on interpersonal maintenance factors: the response of close others. Relatives of those with AN typically carry the main burden of care and research has found high levels of carer distress and unmet needs. Recent theories have proposed this emotional impact to contribute to expressed emotion and other unhelpful caregiver interactions which inadvertently maintain AN. One such understudied response is accommodation, described as a 'process' whereby caregivers 'assist or participate' in symptomatic behaviours of the cared for individual. There is a dearth of research relating to accommodation within eating disorders, in particular qualitative accounts. This study utilised a grounded theory methodology to explore caregivers' responses to managing AN, focusing in particular on carers' experience of accommodation. Eight participants with experience of caring for an individual diagnosed with AN were interviewed. Participants were recruited from a national eating disorders charity and regional eating disorder service. A number of themes emerged, including the importance of caregivers' emotional resources in mediating accommodation responses. Low perceived efficacy over AN contributed to caregiver burnout. Decreased emotional resources influenced a shift in caregiving aims conducive with accommodation. Nevertheless, carers perceived accommodation as counterproductive to recovery and consequently experienced internal conflict (cognitive dissonance). Dissonance was reduced using a number of cognitive and behavioural strategies. The implications of these findings are discussed with reference to existing literature.

Key practitioner message:

- AN can be difficult to manage. Over time carers can feel powerless and their emotional resources diminish.

- Diminished resources led to a shift in caregiving aims and responses. Subsequently carers accommodated AN related behaviours.

- Carers recognised accommodation as counterproductive and experienced internal conflict (dissonance). This was reduced using a number of strategies.

- Skill based interventions designed to empower carers to manage difficult AN behaviours are recommended.

- Motivational Interviewing to develop discrepancies between caregiving aims and responses may promote a shift in the caregiving approach.

Keywords: Anorexia Nervosa, Eating Disorders, Accommodation, Enabling.

Introduction

Anorexia Nervosa (AN) is arguably a distinct phenotype within eating disorders (Collier & Treasure, 2004) which remains poorly understood. Early theories conceptualised AN as a product of 'psychosomatic families' (Minuchin, Rosman & Baker, 1978), an understanding which led to the development and application of family therapy within eating disorders (ED). Family interventions are currently recommended for adolescents by the National Institute for Health and Clinical Excellence (NICE, 2004) and consistent evidence supports its efficacy particularly in terms of relapse rates (Lock et al, 2010; Eisler, Simic, Russell & Dare, 2007; Simic & Eisler, 2012). However, Eisler (2005) asserts an 'unwarranted leap' is often made by researchers when citing the efficacy of family interventions as evidence for such 'blaming' aetiological theories. Indeed no clear predisposing family structure has been established (Eisler, 1995; Vandereycken, 2002) and observed changes within family functioning have been critically re-evaluated as a consequence of, rather than cause of AN. Indeed, one of the few prospective studies supports this view, finding changes in ED symptoms in the direction of recovery, to precede changes in family environment (Nilson, Engström & Hägglöf, 2012).

Schmidt and Treasure's (2006) cognitive-interpersonal maintenance model emphasises maintaining rather than aetiological factors, and proposes four intra and interpersonal factors for AN namely, 'cognitive rigidity', 'experiential avoidance', 'pro-anorectic

beliefs' and 'response of close others'. This study is focused on the interpersonal factor, 'the response of close others' as empirically this is relatively understudied.

The emotional impact of caring for an individual with mental health problems is well established (Baronet, 1999) and high levels of distress, including anxiety and depression, have been consistently evidenced in carers of individuals with EDs (Zabala, Macdonald & Treasure, 2009; Kyriacou, Treasure & Schmidt, 2008a; Whitney, Haigh, Weinman & Treasure, 2007). Indeed, a comparative study found rates of psychological distress to be higher in AN caregivers than in a carers of individuals with psychosis (Treasure et al, 2001). Schmidt and Treasure (2006) assert this emotional impact to lead to high levels of expressed emotion (EE) towards the cared for individual, characterised by criticism, hostility and emotional over-involvement. High EE is the central focus of their interpersonal maintenance factor.

A systematic review found high levels of EE in carers of individuals with ED (Zabala et al, 2009) which have been implicated in treatment and outcome (Butzlaff & Hooley, 1998; Eisler et al, 2007). Different patterns of EE have been allied to AN characteristics, for instance, resistance in the sufferer is affiliated with carer criticism (Kyriacou, Treasure & Schmidt, 2008b). Similarly, Schmidt and Treasure (2006) describe caregiver criticism to result from a 'battle for control' around mealtimes, typically ending in caregiver 'defeat' and further entrenched AN behaviours. Whereas, emotional over-involvement is arguably underpinned by caregiver anxiety and distress due to the physical manifestations of AN and perceived vulnerability of the individual (Kyriacou et al, 2008b). According to Schmidt and Treasure (2006), carers seek to reduce this distress by avoiding conflict and providing comfort and reassurance to the individual. Subsequently, AN behaviours remain unchecked and begin to 'dominate' family life as the carer accommodates these by adapting family routines or tolerating behaviours.

Eisler (2005) identifies a similar framework by which family processes alter during caregiving, expounding its empirical support in a narrative review (Whitney & Eisler, 2005). Family life is described to become reorganisation around the ED, with food dominating family interactions, activities and relationships. Consequently, families can become preoccupied with present difficulties, may accommodate AN behaviours and seek to avoid conflict. Ineffectual 'fixed patterns of responding' are described to develop, which focus on 'the here and now' and can be difficult to alter. Caregivers responses to the individual with AN and in particular, the processes by which these operate are still emerging within the field of ED. Whitney and Eisler (2005) note the relatively small body of literature addressing caregivers' experiences, subsequently urging the reviewed conceptual framework to be regarded with a 'degree of caution'. Similarly, Schmidt and Treasure (2006) cite the need for further research to hone the processes and interactions by which unhelpful responses operate. 'Accommodation', referred to by Eisler (2005) and Schmidt and Treasure (2006) in their respective models, is one such understudied interaction.

Accommodation or 'enabling' is defined as an unintentional 'process' whereby carers 'assist or participate' in the affected individual's symptomatic behaviours (Albert et al, 2010), thereby, reinforcing them. Most empirical research has been undertaken in the fields of substance misuse and obsessive compulsive disorder (OCD). The importance of addressing carer accommodation has been underlined due to its associations with symptom severity and treatment outcome (Substance Misuse: Thomas & Ager, 1993; OCD: Storch et al, 2008 & 2007; Van Noppen & Steketee, 2009). Three main caregiving responses were identified by Orford et al, (1998) namely, 'engage', 'tolerate' or 'withdraw', which fluctuate across the course of caring (Steinglass, Bennett, Wolin & Reiss, 1987). Withdrawal was used interchangeably with accommodation and found to have the poorest outcomes (Orford et al, 2001). Studies have also reported an adverse relationship between accommodation and carers' mental and emotional health (OCD: Albert et al, 2010; Ramos-Cerqueira et al, 2008. Substance misuse: Orford et al, 2001).

Within EDs caregivers can become caught up in organising their lives around and complying with rule-bound symptomatic behaviours. For example family members may assist or participate in rituals such as the weighing out of food (Sepulveda, Kyriacou & Treasure, 2009). To our knowledge Sepulveda and colleagues, are the first to explore accommodation quantitatively in ED and report the following to characterise accommodation responses within a sample of carers: avoidance and modification of routines, providing reassurance, complying with meal rituals, turning a blind eye and perceiving the ED to control family life. Accommodation was found to correlate with anxiety, depression, caregiving burden, duration of contact and EE.

Several qualitative studies exploring the caregiver experience have made reference to accommodation responses. Honey and Halse, (2005) report accommodation in the most detail, describing carers to 'consciously' tolerate difficult behaviours or interact with the individual with AN cautiously to avoid confrontation. Carers also described endeavouring to comply with special requirements, rigid routines and providing emotional support to the individual. Caregiver appraisals were found to influence their responses to the individual, with tolerating responses linked to perceptions of the individual as possessing little control over their ED behaviours. Highet, Thompson & King, (2006) described increased AN severity to elicit carer distress. Subsequently, carers described difficulties implementing boundaries in response to difficult behaviours. Qualitative studies consistently referred to carers' feelings of powerless over ED (Highet et al, 2006; Honey and Halse, 2005; Huke & Slade, 2006; Whitney et al, 2006; Cottee-Lane, Pistrang & Bryant-Waugh, 2004). Subsequently some partners in Huke & Slade, (2006) were described to 'step back' and 'walk on egg shells' for fear of exacerbating symptoms.

As described above, many reasons for accommodation within AN have been theorised and include conflict avoidance (Whitney & Eisler, 2005; Treasure et al, 2008), helplessness (Sepulveda et al, 2009) and distress reduction (Schmidt & Treasure, 2006).

Caregiver's appraisals and understanding of the AN, together with perceptions as to its implications have also been proposed to affect the caregiving experience and responses (Treasure, Gaven, Todd and Schmidt, 2003; Treasure et al, 2008; Whitney et al, 2007). However, empirically little is known about the determinants of accommodation and the processes by which it operates. Furthermore, the experience of accommodation from the caregiver's perspective remains poorly understood.

Study Aims

The review of the literature has highlighted the main theories surrounding the role of caregivers' responses and the importance of these in terms of maintaining AN. Accommodation has been discussed within these overarching theories (Schmidt & Treasure, 2006; Eisler, 2005). However, the process by which this particular unhelpful response operates has been surmised on the basis of limited empirical research. To our knowledge only one study has specifically addressed accommodation, utilising a quantitative approach (Sepulveda et al, 2009). However, as stated by the authors this methodology may have constrained a fuller appreciation of the processes involved. Qualitative research has begun to explore the caregiving experience with some reference to accommodation. For example, Honey and Halse (2005) found a link between a wish to avoid confrontation and tolerance of difficult behaviours. However, this is only a partial account of the processes involved. To date the subjective experience and processes by which accommodation operates has not yet been fully examined from the carers' perspective.

Therefore, this study aims to explore accounts of individuals who are currently, or have cared for an individual with a diagnosis of AN. The study intends to focus on caregivers' experiences of managing and responding to AN, with a specific emphasis on accommodation responses. Participants understanding of and beliefs around their responses to AN will be examined. Elliott, Fischer and Rennie (1999) advocate the use

of qualitative methodologies where gaps exist in the understanding of a subject. Furthermore, an inductive methodology facilitates the detailed exploration of the subject matter whilst retaining the unique perspective of the participants (Elliott et al, 1999; Hodgetts & Wright, 2007). This study will adopt a grounded theory approach as it is intended that a theory 'grounded' in the results of the study will be developed. It is hoped this study will generate knowledge in the absence of precise accounts of accommodation and inform future research.

Methods

Grounded Theory as outlined by Charmaz (2006) was utilised to represent and understand participants' responses to individuals with AN, with an emphasis on accommodation. This involved utilising a 'constant comparative' method to develop conceptual categories and an explanatory theory.

Reflexivity

In accordance with the principles of grounded theory, the researcher 'actively shapes' the research process and 'interacts' with the data (Charmaz, 1990). Therefore, the need for reflexivity whereby, the researcher's perspectives, experiences and values are examined is essential. The researcher is a 31 year old, married, white British female with no dependents. She has no personal experience of EDs or formal caring experience. However, she has liaised with carers of individuals with neurodegenerative disorders in both a clinical and research capacity. This work was highly emotive at times, with the researcher feeling empathy for both the affected individual and the carer. The researcher has a clinical interest in attachment theory, Cognitive Analytic Therapy and constructing clinical diagrammatic formulations. It is acknowledged that these experiences informed the research process and have arguably facilitated the collection and analysis of data, particularly participant engagement and theoretical development.

The research was supervised by an experienced Clinical Psychologist and researcher working within EDs.

DATA COLLECTION

Data collection and analysis took place over a five month period. Participants were recruited from a 27 bed inpatient ED unit in the Northwest of England, which only treated individuals with diagnosed EDs. The national UK ED charity 'Beat' was also utilised to facilitate recruitment. Ethical approval was sought and obtained from the regional National Health Service ethics committee (appendix 8) and hospital research and development committee (R&D).

Participants were included in the study if they met the following criteria: Individuals over the age of 18 with current or past experience of providing care, defined as unpaid help and support to an individual diagnosed with AN. All participants were fluent in English and able to provide written informed consent. Participants were excluded from the study if they had a communication or sensory impairment which would impede participation, or had participated in the Maudsley Collaborative Care Skills Training, an intervention designed to target caregiving approaches.

Recruitment

Once ethical approval was granted, the researcher provided information (appendix 9) about the study together with participant information sheets (appendix 10), contact consent forms (appendix 11) and return stamped addressed envelopes to Beat. Staff subsequently dispatched these by post to 44 carers in the Northwest of England who had registered their interest in taking part in future research. The study was also advertised on Beat's website (appendix 12) and in their monthly newsletter distributed by e-mail to approximately 319 contacts. Carers interested in taking part could contact the researcher directly, register their interest online or return a contact consent form. Ten carers

contacted the researcher (by phone, post or e-mail) to decline or express their interest in participation, of which four took part in the study.

Participants were also recruited via a regional inpatient unit. The researcher distributed approximately 30 participant information sheets (appendix 13) and contact consent forms to staff (family therapist and nurses). These were given to carers during routine clinical contact. The researcher also attended the beginning of carer meetings to publicise the study and to distribute information sheets. Six carers expressed an interest in participating, of which four took part.

All interested carers were contacted by the researcher to discuss the requirements of the research, including potential risks and benefits. All participants were given the opportunity to ask questions and considered participation for a minimum of 48 hours prior to giving informed consent (appendix 14). Prior to the interview, all participants completed a demographic questionnaire (appendix 15) and the Brief Symptom Inventory (BSI: Derogatis & Melisaratos, 1983). The BSI is a 53 item self-report measure designed to assess psychological symptoms during the past 7 days. Nine symptom dimensions are measured, together with 3 global indices. The Global Severity Index (GSI) assesses overall psychological distress and is reported to have excellent reliability.

Interviews took place at a convenient time and location for participants. Six interviews took place in participants' homes (with the researcher following a 'safe visiting' protocol, appendix 16) and two were conducted over the telephone at the request of participants. Both methods of data collection yielded rich data and therefore, were not considered to impact the results. All interviews were audio recorded and lasted between 51 and 93 minutes, with an average length of 74 minutes. Upon completion of participation a post-interview consent form was completed (appendix 17) and all

participants were given details of support organisations (appendix 18). Participants disclosing low mood were encouraged to visit their GP (distress protocol, appendix 19). A reflective journal was kept throughout the research process and brief memos made after each interview.

Participants

A sample of eight participants (two male, six female) took part in the study. All participants were white British and ranged in age from 49-74 years old, with a mean age of 57. With the exception of one participant, all carers were married. Two sets of married parents caring for their daughters took part in the study and were interviewed separately. Participants completed the BSI in order to situate the sample in terms of levels of psychological distress. Two participants' Global Severity Index Total (GSI T) score indicated a clinical level of psychological distress, with another participant's approaching significance (table 1). These participants scored highly on depression and anxiety subscales. One participant caring for her sibling had personal experience of an ED, having been previously diagnosed with AN. She was not currently in receipt of treatment and no significant differences were noted in terms of the data collected.

The majority of participants were currently caring for their daughter diagnosed with AN, with varying levels of contact and support reported. One participant had cared for her identical twin (now deceased as a result of AN related health difficulties), whilst another had cared for her daughter who was now perceived to be recovered. Including participants at different stages of caring, enabled the collection of rich data. Participants reflecting back upon their experiences gave open and frank accounts which provided valuable insights in terms of the study aims.

Cared for individuals were between 26-50 years of age, with an average age of onset of 17. All were reported to be diagnosed with either AN restricting subtype or AN binge-purge subtype. Although diagnoses were not verified, most were currently in receipt of inpatient treatment or had been in the past. Severity of symptoms was routinely enquired about as part of the interview. Sample characteristics are presented in table 1 and 2 (below).

(Table 1 and 2 here)

Interview Schedule

In accordance with grounded theory, semi-structured interviews were undertaken guided by an interview schedule. The interview schedule (appendix 20) was composed of a number of open-ended questions, supplemented by probes in order to elicit participants' experiences and views. The schedule was developed after a search of the relevant literature and in conjunction with supervision. The researcher was conscious the interview should progress along the lines of a 'directed' conversation (Charmaz, 2006), therefore, neutral questions were utilised to open the interview and facilitate engagement, followed by general questions to explore carer distress, burden, emotional expression and responses to AN. A positively framed question concluded the interview.

Consistent with the principles of grounded theory, the interview schedule was continually reviewed and following supervision, revised to incorporate emerging themes. Additional questions explored participants' understanding of the AN and the impact of these on their responses to the individual.

Data Analysis

Data was analysed according to the principles of grounded theory as explicated by Charmaz (2006). Interviews were professionally transcribed verbatim. The researcher ascertained the accuracy of each by listening to the audios several times whilst reading the transcripts. Data collection and initial analysis (in terms of memo-writing) took place concomitantly, helping to identify potential emerging themes to explore in subsequent interviews. Each transcript was analysed using 'open coding', whereby, each line was assigned a code to encapsulate and condense its meaning (transcript excerpt: appendix 21). This enabled the researcher to stay 'grounded' in the data. Throughout initial coding the researcher remained attentive to similarities and differences, writing memos to raise questions about the data and record initial ideas as to emergent categories. Initial codes were compared and contrasted and subsequently grouped into categories using focused coding. These categories were raised and defined into concepts and subsequently built into conceptual models through a process of 'constant comparison' and 'continued questioning,' in order to ascertain the relationships between these (e.g. axial coding), the conditions by which these operate (Charmaz, 1990) and links to existing theory. Memos, diagrams (appendix 22) and supervisory discussions facilitated and directed this process.

Historically this process continues until categories are 'saturated' and no new theoretical insights emerge. However, Dey (1999) challenges the underlying premise of data 'saturation', promoting instead the concept of 'theoretical sufficiency'. This was used as a guiding principle for recruitment, whereby the study aimed to collect satisfactory data in order to develop categories and an integrative theory.

Validity and reliability

To enhance methodological rigour, guidelines for qualitative research (Elliott et al, 1999) were adhered to. Reflexivity was sustained through the use of a reflective journal.

Direct quotes were utilised to illustrate themes, thereby, reducing subjectivity and promoting transparency. Credibility checks were undertaken, these included an independent researcher (with qualitative experience) checking a coded transcript to verify the researcher's interpretations. There was 98% agreement regarding codes. Divergences' were discussed however no change to the analysis was required. Additional deliberation and verification of coding took place in supervision.

Results

A number of core categories emerged from the data which formed the basis of the conceptual model for accommodation (Figure 1). Categories comprised factors contributing to accommodation responses which included caregivers' 'understanding of AN', perceived carer 'role', 'responsibilities' and 'aims', 'difficult behaviours' and 'impact and emotional reserve'. Decreased emotional reserve formed an axial code which mediated accommodation responses. Categories also emerged which directly related to the experience of accommodating. These comprised the 'internal conflict' described by carers as a consequence of accommodating AN and the cognitive and behavioural 'efforts' employed by carers to reduce this. These categories are discussed in full below, together with a summary of the main findings

Summary of findings

Across the fluctuating *course of AN* participants shared how their initial *understanding of AN* evolved. This understanding influenced participants' perceptions as to their *caring role, responsibilities* and *aim*s. Efforts were initially orientated towards recovery, carers' foremost aim. This entailed the employment of *direct approaches* to influence the affected individual's food intake. However, these approaches were met with '*difficult behaviours'* (e.g. resistance). Carers described difficulties separating these from the person and an ensuing battle of wills which exacerbated resistance. All carers

described their efforts as futile and believed themselves to be powerless over AN. Over time, unmet aims educed low perceived control, which together with decreased support, high levels of caring demands and a predominately avoidant style of coping, impacted carers physically and psychologically, leading to reduced *emotional reserve*. Consequently, carers described re-prioritising their caregiving aims and *accommodating* AN behaviours. Carers recognised this approach as 'siding with AN' and counterproductive to recovery. Accommodation clashed with carers' principles eliciting *internal conflict* and uncomfortable emotions. However, carers felt unable to alter this approach or instil boundaries due to perceptions of the individual as unpredictable and vulnerable. Carers therefore, employed alternative *efforts to reduce internal conflict*. Eventually, carers described reaching a 'limit' and switching back to direct approaches due to increased AN severity and/or 'burnout'.

Figure 1 here

Course of AN

- Fluctuating "yo-yoing" Course

The majority of participants described a gradual identification of AN symptoms due to efforts to conceal these by the individual. Initial concerns centred on weight loss and changed eating habits, including dieting or the gradual removal of food groups. Increased symptom severity often precipitated an "alarm call" whereby carers awakened to AN. All participants described the course of AN as a long and arduous journey, throughout which the individual's weight continually "yo-yo's." Fluctuations in the individual's functioning were observed by the majority of participants. Relapses were

depicted as uncontrollable, with participants' initial positive expectations regarding recovery, gradually giving way to new understandings of AN as impervious and 'complex.' Participants referred to the cyclical nature of AN and its negative impact upon hope across its course. Fluctuating responses to AN were described, with those caring over a longer duration attempting to adopt a decreased focus on food and less confrontational approach.

"Because it's like, you have hope initially that it's going to be sorted out and now you think, you know it's gone on for such a long time, and you had … readmissions … so it feels almost like you're on a conveyor belt and going round the system." (Mother, P8).

Understanding of AN

- Difficulty understanding

The difficulty understanding AN is reflected in the multiple, and sometimes conflicting explanations given by participants. Initial appraisals of AN tended to centre on food coupled with appraisals of AN as "a choice". These beliefs led to a perception of AN as within the individual's control, prompting personalised explanations for challenging behaviour and angry exchanges. As AN progressed, explanations became more comprehensive, with AN perceived as either a biological or psychological illness outside of the individual's control. However, most participants held additional explanations; citing AN to operate as a means of control or as a "coping mechanism". All participants perceived themselves as powerless over AN and its related behaviours.

"You just couldn't believe that (daughter) had found this way of coping with her life, you know, why did she choose this route?" (Mother, P5)

"It's a medical condition, er, that has a natural history and a course of its own, (daughter) can't control it." (Father, P7)

Most participants endeavoured to separate difficult behaviours from the individual, externalising these to AN. However, in practice this was challenging for participants. Those more able to externalise however, tended to express decreased anger towards the individual.

"...you didn't think about it being the AN, you just saw the words, or heard the words coming out of your child's mouth and your anger and upset ... was aimed at (daughter) it wasn't aimed at the AN." (Mother, P4)

- Searching for a cause

All participants sought understanding in relation to AN and its cause. However, most perceived the cause as elusive positing a combination of possible internal and external triggers, including separations, stressors and genetic or neurological predispositions. Over half of the parents interviewed ascribed blame to their parenting practices and consequently experienced strong feelings of guilt which influenced their perceived caring role and responsibilities (discussed below).

"...part of the way we behaved, erm, or parented or whatever, may have, either, erm, sort of developed her personality in a way that sort of lended itself to, to the AN or sort of contributed in some way." (Mother, P8)

<u>Lost Daughter</u>

All carers reported the affected individual to undergo a change in personality after the onset of AN, displaying uncharacteristic "difficult" behaviours. Carers described the individual to have "two sides", generally attributing negative characteristics to the AN. All carers report a changed relationship post-AN, with the individual disengaging from shared activities, becoming more withdrawn and "shutting" the carer out. Most carers expressed great sadness at this perceived lost relationship.

"It's the illness that makes her like this, you know, the proper (daughter) when she isn't that ill is very kind, she's a lovely person … but the anorexic (daughter) is very difficult" (mother, P5)

- Vulnerable

All carers described the cared for individual as "vulnerable" both physically and emotionally, with several carers expressly mindful of the risk of death and commenting on the individual's physical fragility. Subsequently carers feared for the individual's welfare and made lifestyle adaptations in order to supervise and emotionally support the individual.

"…she didn't have to have somebody out with her… but, erm, because she was so physically unwell, you felt you had to go with her. I suppose it was always the keeping her safe bit" (mother, P6)

All participants described the individual's increased dependence, with most referring to the individual as having regressed emotionally and behaviourally, exhibiting childlike

or "teenage" behaviour. Over half the carers interviewed described the individual as unable to function independently and unable to make logical choices for themselves.

"...you tend to think that you've gone back ten years ... erm, but you know, with a mid-twenty year old, you tend to think you should have really moved on from that now." (Father, P3).

- "Difficult" behaviours

The cared for individual was described by participants to exhibit "difficult" behaviours, the most prominent of which being their efforts to resist recovery. All carers detailed this resistance which included refusing food, obstructing carer efforts and disengaging from treatment. In their efforts to resist recovery, all carers reported the individual as utilising deception and secrecy, with parents depicting their daughters as "shutting" them out.

"...just tried to reason with her, and you still, you got the brick wall..." (Mother, P4)

Over half the carers described the cared for individual as "ruling the roost," perceiving the individual to utilise AN-related behaviours to control and manipulate others. Most carers described the individual to frequently become hostile and lose their temper.

"... it was very stressful for everybody, she was ruling the roost. She was demanding, she was at the verbally aggressive stage." (Mother, P6)

Carer Roles and Responsibility

Perceived caring roles were influenced by participants' perceptions of the individual as "vulnerable", "childlike" and "resistant," as well as changing appraisals of AN (influenced by its course). Carers perceived their primary role as facilitating the recovery of the individual, characterised by the individual gaining weight and resuming typical eating patterns. To this end, all participants perceived it as their responsibility to support the individual practically. Perceptions of the individual as "ill" and vulnerable promulgated the role of safeguarding the individual's welfare. Subsequently, most participants expressed the responsibility to support the individual emotionally, endeavouring to place the individual's needs first and make life "comfortable" for them. In particular, two participants perceiving their parenting to have contributed to the AN expressed the importance of this role and found instilling boundaries more difficult. All parents upheld the view that they should be there for their daughter unconditionally. Other roles esteemed by carers include maintaining "normality" in family life, particularly for the wellbeing of siblings. Several carers reported family members or health professionals as reinforcing these perceived carer roles.

"…Well at the end of the day, you just want, you'd just do anything to sort of help them get better." (Father, P3)

"… this child was very vulnerable and very weak … I wanted to be there really and that was my role to look after her (laugh) even as old as she is." (Mother, P4).

- Multiple aims

Various aims were described by participants in their approach to AN resulting from perceived carer roles. Initially carers directed their efforts towards recovery. However, as the course of AN unfolded these aims remained unfulfilled, engendering a new

perception of AN as 'resistant' to carer efforts. A general sense of resignation was born out of this altered understanding and subsequently, new aims associated with accommodating AN-related behaviours came to the fore. Carers adopted the attitude that eating "something" was better than "nothing" and prioritised a need for normality in family life, something previously lacking. Subsequently carers endeavoured to avoid unnecessary conflict to maintain the family "equilibrium". Moreover, carers described decreased emotional resources and began to value their own self-preservation, adopting responses which "made life easier" and "saved time". Other carers focused on improving the individual's quality of life and prised the rebuilding of their relationship with the individual, perceived to have been negatively impacted by conflict. However, these altered aims were incompatible with advancing the individual's recovery, thereby resulting in 'inner conflict' (discussed below).

"I think as a carer you have two things that you want, one is that you want your relative, loved ones well-being and you want them to get better and you want them to get back to how it was, but well, she never did. But you also want peace, you know, you will do anything for peace and … of course later, when you get really tired you just crave sleep." (Sibling, P2).

Direct Approaches

In order to facilitate recovery, carers aimed to encourage the individual to eat using direct approaches (e.g. confrontation, "straight talking" and "standing up" to AN). A few carers attempted to enforce compliance using force or by applying negative consequences. Many carers employed the use of supervision at mealtimes and persuasion in order to "coax" the individual to eat. Carers endeavoured to increase the individual's insight through the use of reasoning or rationalisation.

Interestingly, it was noted that these attempts were largely ineffectual, resulting in increased resistance, anger and aggression. Many carers described frustration at not being able to influence AN, which coupled with difficulties externalising challenging behaviours, resulted in carers "shouting back" or "losing their temper." Subsequently carers described an ensuing 'battle of wills' whereby, mealtimes became "battlefields" and scenes of conflict. Several carers described "going round in circles" before coming to an impasse. Over time, all carers perceived their ability to effect change as low.

"...you're going round in circles (laugh). I mean, the whole, the whole time it, you are going round in circles really. You know, you, you reach your stalemate at a mealtime, you back off" (Mother, P4)

"Well you, you just try help as best as you can. But at the end of the day, you're trying to get her to eat food, they don't eat, and then you end up arguing really" (Father, P3)

Impact and Emotional Reserve

Low perceived control and support, together with a high perceived burden of care impacted carers' emotional and physical wellbeing, leading to reported burnout. Reduced emotional resources precipitated altered carer aims.

-   Perceived control

As a result of frustrated attempts to influence compliance all carers described feeling "powerless" over AN, perceiving it as uncontrollable.
Consequently, as their loved one began "fading away" carer's described feeling like a 'helpless bystander,' conveying their sense of desperation. This powerlessness was further compounded by their exclusion from treatment (due to confidentiality), leaving carers feeling unsupported, "useless" and "in the dark."

"... not have any control over them (symptoms), and for them to get at a very, very strong stage, erm, trying to explain against, is sort of trying to convince a suicide

bomber that actually, all the country should try and get on together and lets all sit down
and talk about it." (Father, P7)

- Support

Most participants decried the absence of formal support for carers noting a lack of
guidance for managing AN, which compounded uncertainty as to how to respond. Upon
admission to services, a number of participants experienced temporary "relief" due to
reduced burden and responsibility. Many carers interviewed reported family therapy as
supportive in terms of information and support (with the exception of one carer).
Participants generally described a lack of understanding regarding AN amongst friends,
extended family and the general public, with some reporting inconsiderate comments,
unhelpful advice and stigma. Some carers utilised support from understanding family
members or friends. Differential spousal approaches to AN were reported by over half
the participants, resulting in inconsistent responses, decreased support and marital
strains. All carers emphasised the need for more support and guidance.

"We never were together on something ... they sort of rode the coach and horses
between us, because there was no definite." (Mother, P1)

- Coping

The majority of carers felt compelled to 'soldier on' in order to fulfil their caring
responsibilities and any parental obligations to other children. This was achieved by
focusing on practical tasks and "keeping busy". Others attempted to "blank it out" using
distraction or by avoiding the subject of AN. Over half the carers described suppressing
their emotions mindful of the potential impact of these on the individual or other family
members. Subsequently, many carers neglected their own needs and self-care leading to
burnout.

- Demands of caring

Numerous practical caring demands were described by participants. These included
frequent and long commutes to facilitate the individual's treatment, to visit them in

hospital or to attend treatment reviews. Carers also undertook the supervision of protracted mealtimes. In order to fulfil these perceived obligations, carers often kept unsociable hours, making adaptations to family, occupational and social activities. Due to the perceived vulnerability of the individual, most carers described preoccupation with the individual's wellbeing and "constant" anxiety. Consequently, many described being 'on standby' should they need to step into their caring role. This involved remaining in close proximity to the individual, sacrificing holidays, avoiding future plans and maintaining a constant support network around the individual. Due to this perceived vulnerability, the majority of carers lent considerable emotional support to the individual, including giving advice, reassurance, and supporting decision making. Subsequently, some carers described feeling "too involved." The majority of carers reported difficulties "juggling" these perceived care needs with competing family, social and occupational demands, as well their own needs.

"I couldn't take a drink or anything in case I got called. I was always on standby." (Mother, P6)

"so that was a big, big commitment and really hard, and really tiring, and you got to the weekends almost sort of on your knees." (Mother, P4)

"she still relies a lot on me to double guess and double check, she calls us the A-Team really because she knows that we're always there." (Mother, P5)

- Impact and burnout

AN was described as dominating family life, impacting on mealtimes, relationships and family interactions. Many carers reported strained spousal relationships, linking this to reduced time spent together; parents also described difficulties attending to the needs of siblings and extended family. Feelings of sadness and "hurt" were expressed regarding the changed relationship with the cared for individual. Participants also disclosed feelings of frustration and anger concerning challenging AN behaviours and the pervasive impact of AN on family life.

Carers reported reduced emotional resources, disclosing overwhelming emotions and depression. Many described feelings consistent with 'burnout' referring to "exhaustion", "compassion fatigue" and reduced resilience. As a consequence of depleted emotional resources (permeated by feelings of powerlessness) carers approach to AN shifted in line with altered values. Reprioritized aims included, preserving carer energy, salvaging relationships, making life "comfortable" and re-establishing "normality" (reducing conflict).

"I'm fed up with this, fed up with it completely. I think it's the crappiest illness out, I'd never wish it on anyone." (Mother, P4)

"You do get very tired, you have probably heard that many times, you know, so you stop caring yourself really." (sibling, P2)

Accommodating and Tolerating AN Behaviours

Carers referred to switching their focus away from food and 'taking a step back'. This modified approach was couched in terms of an altered understanding of AN (as unrelated to food), reprioritised aims, as well as "acceptance" of their inability to influence change. Consequently, all carers accommodated AN behaviours to some extent.

"I know the food isn't the real issue … I did back off the food angle after a few years, when I did begin to learn this wasn't working. None of my strategies worked." (Mother, P1)

"latterly, while she was at home we tended to erm, let her do what she wanted… if you tried to respond to any of her ways, she would just become aggressive… well I suppose me as the mother, I tried to keep the peace, I tried to keep the house going as normal … tried to keep everybody on an even keel, including myself." (Mother, P6)

- Turning a blind eye

In the process of avoiding confrontation and reducing pressure to eat, carers ignored or tolerated difficult behaviours. This included turning a blind eye to inappropriate calorie intake and accepting unconvincing excuses. Indeed, one parent literally turned a blind eye, forbidden to look at her daughter's plate. Many carers described "biting their tongue" or "treading on egg shells" to reduce conflict.

"It's a bit like when your child's little and the bedroom's a mess, it's not worth it, just shut the door and let them get on with it." (Mother, P4).

"You're watching your words all the time." (Mother, P8)

- "Colluding"

Carers described the cared for individual to have many rules around food intake and described ways in which they actively accommodated or "colluded" with these. Carers reported adapting family meals to accommodate the individual's restrictive diet, this entailed the preparation and purchasing of foods the individual found acceptable. Several carers referred to purchasing foods which were knowingly inappropriate. Some participants described meals being eaten separately from the family, with one carer making arrangements for the individual to eat with extended family due to perceived difficulties eating with parents. Several carers complied with rules relating to food preparation, facilitating or participating in the measuring out of food. All carers described adapting mealtimes and social activities around the individual's perceived needs and wants. This included altering the timings of meals, reduced attendance at family events and avoiding meals out. One carer who also experienced AN described a process of co-enabling, whereby, food rules and regimes were jointly observed.

"I actually colluded with my sister not eating the right things." (Sibling, P2)

"Measuring absolutely (everything)… it had to be a set figure …it was mainly her doing it, erm, sometimes you took over and did it …" (Father, P3)

"you know full well that they should have semi skimmed milk and not skimmed milk, you end up buying skimmed milk. You end up, when she was very, very poorly buying Melba toast, I mean why?" (Mother, P4)

Internal conflict – "Inside your screaming"

All carers conveyed uncertainty regarding accommodation as an approach to AN, expressing varying degrees of reservation as to its value. Indeed many acknowledged this approach to yield little benefit in terms of actual calorie intake, with some noting the effort and burden involved. The majority of carers perceived tolerating or accommodation as failing to address the AN and therefore, counterproductive to long-term recovery. Despite this, all participants acknowledged benefits in terms of reducing conflict and promoting short-term quality of life.

"..but at the same time you know, that, that really, obviously has some effect, it doesn't solve it." (Mother, P5)

One participant likened these conflicting aims to a "constant battle" between sides of a fence, with accommodation perceived as "siding" with AN and neglecting the "recovery side". In accordance with carers reprioritised aims, "siding with AN" was linked to promoting the day to day comfort of the individual and maintaining normality. Many carers simultaneously recognised these two sides to approaching AN, perceiving accommodation as nonsensical, and increased symptom severity as difficult to ignore. Others recognised the importance of instilling boundaries and adopting a firm approach, describing accommodation to conflict with their principles and perceived responsibility to address AN.

"I had like two sides to me, I had my mother instinct and my one to get her better ... it was always a constant battle between the two." (Mother, P6).

As a result of acting in opposition to these valued aims, the majority of carers experienced internal conflict, described by one carer as "inside your screaming". These feelings consisted of self-criticism, anger and frustration. Others described feeling depressed, defeated or anxious. These uncomfortable feelings, which further decreased carers' emotional resources, were reduced using cognitive and behavioural strategies (described below).

"You don't react, because it made it worse, but inside you're screaming" (Mother, P4)

"wasn't doing her any good, I wasn't being strong enough. Erm … I got angry at myself … it made me really upset … I suppose depressed, erm, that I was being pulled down, that I wasn't being strong enough to fight her, or to fight the AN." (Mother, P6).

Efforts to reduce internal conflict
- Justification based on consequences

All carers justified accommodation in terms of its perceived benefits, citing positive outcomes such as reduced conflict, minimised difficult behaviours and a semblance of normality. Several commented on the benefits to themselves, in terms of saved time and reduced burden.

"Well you sort of knew that what she was saying was unreasonable and you knew that what you were doing was unreasonable but it was actually just easier to go along with it, it was just easier." (sibling, P2)

A significant outcome prised by all carers was the individual eating, albeit limited amounts in many instances. Carers adopted the stance that "something was better than nothing," the perceived alternative to not accommodating. Although food rules were perceived as undesirable, several carers argued this was inconsequential compared to food consumption. Others valued the individual taking part in family meals or special occasions as a result of accommodation.

"Well you were just trying to get her to eat something, and at the end of the day, eating something was better than nothing. So you just went along with it really." (Father, P3)

Other valued consequences include perceived quality of life for the individual and an improved relationship.

"Well I knew how to make things lovely for (sister), I knew what she would want .. if you have days where you can only eat porridge well you just eat porridge." (sibling, P2)

"If we can stay off food ...we're talking, absolutely fine" (Mother, P4)

- Reduced responsibility

A high proportion of carers reduced their internal conflict by externalising their actions, attributing their response to characteristics of the individual (e.g. "manipulative") or to the AN. The vast majority of carers also highlighted a lack of support from services as contributing to their difficulty managing AN.

"She can talk her way out of anything, you know, she is a clever girl" (Mother, P5)

"... AN like bullied us all into just being so submissive that we've just accepted anything that (daughter) throws at us." (Mother, P4)

All carers described their powerlessness over AN, noting the futility of other approaches. Carers therefore, reduced their responsibility for accommodation by conveying their lack of choice over their response. Some carers conveyed this lack of choice as feeling trapped.

"You actually do end up agreeing to things that you, that you end up boxed up a corner." (Mother, P4)

Carers also justified their response in terms of the individual's adult status, citing the importance of respecting the individual's choices and treating the individual as an adult.

"I would probably just think well she's an adult, if she wants to make that decision then let her make that decision." (Mother, P8)

- Coping strategies

Avoidant coping strategies were employed by carers to decrease internal conflict, including reducing their proximity to the individual or suppressing and avoiding feelings.

Wishful thinking was described with carers hoping the individual would gain insight of their own accord.

"There's always that hope that, well if I buy the melba toast maybe she'll have 6 of them and she might have a piece of cheese on them … or you buy it and they realise how pathetic it is when it's on the plate, there might be a eureka moment …" (Mother, P4)

- Consider Boundaries

A number of carers considered implementing firmer boundaries or negative consequences. However, carers were apprehensive as to how the individual would react, citing fears for the individual's welfare due to their perceived vulnerability.

"Sometimes you just got to say no … it's hard enough to do that, with, when you haven't got other issues going on, but extremely hard to do that if you then think that person might go off the rails, you know do something stupid." (Mother, P8).

- "Explode"

The majority of carers described internal conflict building, particularly as the severity of the individual's symptoms increased. Some carers described reaching a point whereby they were unable to tolerate these feelings or referred to the individual "crossing a line".

Subsequently some carers reprioritised aims or "exploded," leading to the individual's behaviour being confronted.

 "...you know I got to a point where I couldn't contain my anger anymore, and my, my, emm safety valve was (gone)." (Sibling, P2)

"...getting to the stage, to the pre-admission, then eventually it's usually (wife) ... quite rightly feels she's got to risk a tantrum and risk a nuclear explosion." (Father, P7).

Alternatively, a couple of carers described relinquishing responsibility for the individual's care, arranging for the individual to live independently or organising additional caring support.

"that was the, the click switch for me, that was like, I'm, I'm just not putting up with this anymore ... I think that was the last straw." (Mother, P6)

These efforts to reduce internal conflict appeared more successful for some participants, particularly those who strongly ascribed to the belief they had no control over AN or highly prised aims over and above recovery.

Discussion

This study aimed to explore caregivers' experiences of managing and responding to AN, with a particular emphasis on accommodation responses. To our knowledge it is the first study to explore accommodation utilising a qualitative methodology. The findings of the study are discussed with reference to existing literature.

Determinants of accommodation

Although theorised, determinants of accommodation remain under researched within EDs. The findings from this study highlight the importance of participants' perceived caring role, responsibilities and aims in determining caregiving responses. Moreover, Hoskins and Lam (2001) also described perceived maternal roles and responsibilities to affect carer responses and interact with their understanding of AN. In the present study appraisals as to the cause and symptoms of AN determined not only participants' perceived responsibilities but also the subsequent approach adopted.

The influence of caregivers' understanding of AN in shaping their responses is expounded in previous research (Honey & Halse, 2005; Treasure et al, 2003). As found in Huke and Slade (2006), carers in this study described multiple and evolving appraisals of AN across its course, consequently various caregiving roles and responsibilities were described. Interestingly, Whitney et al, (2007) report carers to perceive themselves as having greater responsibility for the 'care' and 'control' of AN than the affected individual. It is perhaps unsurprising therefore, that participants in this study cited their key aim as facilitating the individual's recovery, employing direct approaches to fulfil this goal. Adopting a direct 'authoritative' response to an 'externalised' AN is advocated by the Maudsley Approach to family therapy (Lock , Le Grange, Agras & Dare, 2001). However, concordant with other studies, carers reported a direct approach to elicit 'resistance' (Sharkey-Orgnero, 1999; Cottee-Lane et al, 2004). Due to reported challenges externalising AN a battle of wills ensued culminating in conflict and unmet aims. This finding corroborates Schmidt and

Treasure's (2006) cognitive-interpersonal maintenance model whereby, a hostile and critical interaction is linked to a 'battle for control' around mealtimes, typically ending in caregiver 'defeat' and further entrenched AN. High EE caregiving responses have been evidenced in ED (Zabala et al, 2009) and linked to difficult or high EE behaviours in cared for individuals (Kyriacou et al, 2008b; Cook, Kenny & Goldstein, 1991). Previous research supports the importance of caregivers' understanding of these difficult behaviours in determining responses. Concordant with this study, increased EE has been found in caregivers attributing responsibility for difficult behaviours to the individual (Barrowclough & Hooley, 2003; Whitney et al, 2005; Treasure et al, 2003).

Accommodation has been associated with high EE in caregivers (Sepulveda et al, 2009; Van Noppen & Steketee, 2009). In the present study, decreased emotional resource appeared to mediate the relationship between EE and subsequent accommodation responses. Low perceived efficacy as a consequence of frustrated carer aims, together with decreased support, avoidant coping and high caring demands contributed to carers reported distress and burnout. Similar factors were cited to mediate to carers' perceived stress in Szmukler et al's, (1996) caregiving framework, namely social support and self-efficacy.

Previous research consistently corroborates carers' descriptions of powerlessness and low perceived control (Whitney & Eisler, 2005; Highet et al, 2006; Honey & Halse, 2005; Huke & Slade, 2006; Whitney et al, 2005; Cottee-Lane et al, 2004). Based on the self-regulation model (Levanthal, Diefenbach & Leventhal, 1992), Treasure et al, (2003) assert carers develop an 'illness model' which affects caregiving responses. This model develops iteratively and integrates information as to the understanding of AN, it's consequences and perceived controllability. In this study, carers' evolving understanding of AN as 'uncontrollable' based on perceived adverse consequences fits with this concept. Perceptions of powerlessness have been linked to frustration (Whitney & Eisler, 2005; Treasure et al, 2008), EE (Treasure et al, 2008; Barrowclough, Lobban, Hatton & Quinn, 2001), distress (Whitney et al, 2007; Goddard et al, 2011) and altered responses (Huke & Slade, 2006).

Carers also described high levels of burden related to caring demands, which impacted carers physically and psychologically. High levels of burden were reported in a recent review (Zabala et al, 2009) and have been associated with carer distress (Kyriacou et al, 2008a). The perceived dependency of the individual has also been linked to distress and caring strains (Whitney et al, 2007). Carers in the present study described the individual as vulnerable and 'childlike,' eliciting a dynamic of emotional over-involvement due to anxiety regarding the individual's welfare. Anxiety was also found in Kyriacou et al, (2008b) to underpin emotional over-involvement. Consequently, AN dominated family life as carers assumed a 'standby' position and made numerous adaptations in order to emotionally and practically support the individual. These findings lend support to Eisler's (2005) framework whereby, carers became 'reorganised' around AN. Emotional over-involvement has been found to predict accommodation in OCD (Van Noppen & Steketee, 2009) and within ED accommodation has been associated with EE and caregiving burden (Sepulveda et al, 2009). In the present study emotional over-involvement and burden were linked to altered caregiving aims associated with the process of accommodation, these included making life 'comfortable' for the individual and conserving carer energy.

Carers described an absence of support, a lack of understanding from others and stigma. Spousal differences in the understanding of AN and approach were also reported which contributed to relationship strain. Stigma and relationship strain have been linked to caregiving distress (Whitney et al, 2007; Kyriacou et al, 2008a). Carers described 'soldiering on' and avoidant coping styles in order to fulfil caregiver roles and circumvent the likelihood of upsetting the individual with AN. Subsequently, carers neglected their own needs. Unmet carer needs and a lack of carer support were found in Haigh and Treasure (2003).

Decreased support, low perceived control, avoidant coping and high caregiving burden impacted on carers' emotional resources. Consequently, carers described feelings of distress, depression and burnout. Participants therefore, re-prioritised caring aims

adapting their approach from directly 'engaging' with AN, to 'tolerating' or accommodating behaviours (Orford et al, 1998). Carer aims underpinning accommodation, such as the desire to restore 'normality,' avoid conflict or the exacerbation of AN were concordant with previous literature (Whitney & Eisler, 2005; Honey & Halse, 2005; Treasure et al, 2008). The link between accommodation and carer mental health has been evidenced within ED (Sepulveda et al, 2009), OCD (Albert et al, 2010) and substance misuse (Orford et al, 2001).

Experience of Accommodation

Carers described switching their focus away from food and 'taking a step back'. A similar approach was described in Huke & Slade (2006). Concordant with Honey & Halse (2005), accommodation was conveyed as a 'conscious' decision for some carers, founded on altered caregiving aims and understanding of AN. Accommodation of AN consisted of similar responses to those cited in Sepulveda et al, (2009) and included: 'turning a blind eye' to inappropriate behaviours, 'colluding' or complying with mealtime rules and adapting family life. Some carers acknowledged accommodation to increase their burden, particularly as AN continued to dominate family life (Eisler, 2005). Additional adverse consequences were noted as carers recognised accommodation as counterproductive to long-term recovery. However, carers cited short-term benefits associated with accommodation (e.g. reduced conflict). This focus on the 'here and now' was expounded by Eisler (2005).

Carers described 'cognitive dissonance' (Festinger, 1957; Cooper & Fazio, 1984) associated with accommodation. Many perceived accommodation to conflict with their principles and perceived responsibility to address AN. One carer described experiencing dissonance as a "constant battle" between conflicting caregiving roles and aims, with accommodation perceived as 'siding with AN'. Cognitive dissonance between perceived caregiving responsibilities and responses gave rise to an unpleasant internal conflict, aptly described by one carer as 'inside your screaming'. Inner conflict

consisted of self-criticism, anger, frustration, depression and anxiety. Calvocoressi et al, (1999) also found carers to recognise the limitations of accommodation and to experience distress when accommodating OCD symptoms. Furthermore, Sepulveda et al, (2009) describe similar accounts from carers accommodating ED symptoms and report significant correlations between accommodation, anxiety and depression. However, further research is required to ascertain the direction of this reported effect.

In accordance with cognitive dissonance theory (Festinger, 1957) participants sought to reduce this internal conflict. Some described considering alternative approaches, including instilling firmer boundaries. However, due to the perceived vulnerability of the individual carers feared exacerbating AN (Treasure et al, 2008), therefore, perpetuating internal conflict. Similarly, Highet et al, (2006) described carers' difficulty knowing when to instil boundaries due to the perceived needs of the individual. Therefore, despite recognising the futility of accommodation, carers felt unable to alter their responses. This fits with Eisler's (2005) framework whereby, a fixed pattern of responding is described which is recognised as ineffectual (Whitney& Eisler, 2005).

Subsequently, carers sought to reduce dissonance without behaviour change. In line with Cooper & Fazio (1984), participants justified their responses in terms of perceived consequences. Beneficial outcomes evaluated favourably by carers included the importance of the individual eating "something rather than nothing," which was the perceived alternative to not accommodating AN. Other cited benefits included reduced conflict and reduced carer burden. The importance of perceived consequences in determining carer actions was also described by Treasure et al, (2003).

Participants sought to reduce their responsibility for accommodating AN by externalising their actions, assigning responsibility to characteristics of the individual (e.g. "manipulative") or by blaming the condition. Similarly, Sepulveda et al, (2009) note carers accommodating AN to feel 'manipulated'. All participants conveyed having little choice over accommodation, citing their powerlessness over AN and the futility of alternative strategies. Carers also ascribed their difficulty managing AN to a lack of

support from services. Unmet carer needs and reduced carer support was noted by Haigh and Treasure (2003). Avoidant coping, including withdrawal (discussed in Treasure et al, 2008), was also described by carers as a means to reduce internal conflict.

Efforts to reduce internal conflict had mixed results. Carers more entrenched in their understanding of AN as 'uncontrollable' described less dissonance. Whereas, some carers reported increased cognitive dissonance as AN severity increased or their emotional resources depleted. These carers described reaching a tipping 'point', whereby, internal conflict was reduced by altering their response (e.g. "exploding" or confronting the AN). Fluctuating responses across the course of caring were also noted in Steinglass et al, (1987).

Implications

The findings from this study, in particular the role of depleted emotional resources in relation to accommodation, underline the importance of empowering and supporting carers to undertake this complex task. Caregivers' feelings of burnout were significantly influenced by perceptions of low efficacy as a result of adverse consequences (e.g. frequent conflicts). These results support the need for carer interventions, such as the Maudsley 'Collaborative Care Workshops' (Sepulveda, Lopez, Todd, Whitaker & Treasure, 2008) which endeavour to teach carers skills to manage ED behaviours, such as externalising and 'rolling with resistance'.

The key finding of this study is the cognitive dissonance experienced by carers as a result of accommodating AN. Consequently, in order to empower caregivers to alter 'fixed' and unhelpful responses, a motivational interviewing (MI) approach (Miller, 1983) is indicated, whereby, dissonance can be explored and discrepancies between caregiver behaviour and goals developed. Interestingly, Rhodes, Brown & Madden (2009) reported carers to value parent-to-parent consultation which utilised an MI

approach. However, further studies are needed to explore the efficacy of MI in terms of empowering caregivers and altering caring responses.

Limitations

There are a number of potential limitations to the study. A homogeneous sample of participants took part in terms of ethnicity, socio-demographics and gender; this may have impacted the data. Furthermore, several members of the same family were recruited; consequently the data may have reflected family specific dynamics. However, it is contended that including both husband and wife allowed exploration of spousal caring differences.

Participants were recruited via two routes, which allowed for a variety of carer experiences. However, recruitment via Beat made verification of diagnoses more problematic. Participants at different stages of caring were recruited which may have affected the data, particularly in terms of carers' ability to recall caring experiences. Previous research has indicated length of caring to affect caregiving experiences (Whitney et al, 2007), therefore, a variety of participants at different stages arguably allowed for a fuller exploration of accommodation in AN.

A smaller sample of participants took part in the study and therefore, data saturation was not achieved. However, Dey (1999) questions the underlying premise of data saturation and instead recommends qualitative studies achieve theoretical 'sufficiency.' The categories which emerged from the study denoted the collected data and worked towards the concept of sufficiency; however, this theoretical framework will need further analysis and testing utilising both qualitative and quantitative methodologies. In particular, the experiences of male participants were under represented. Gender differences in terms of caregiver experiences have been found in previous studies (Kyriacou et al, 2008a) and potential differences in gender roles and responsibilities may affect accommodation. It has also been suggested contact time may impact accommodation (Sepulveda et al, 2009). These factors are important avenues for further exploration.

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Table 1. Demographic data for participants

Participant Identifier	Recruited from	Age	Gender	Occupation status	Marital status	Level of education	Number of children	GSI T
P1	Beat	74	F	Retired	Married	Degree	2	52
P2	Beat	60	F	PT	Unmarried	Post graduate	0	106*
P3	ED unit	55	M	FT	Married	Degree	3	15
P4	ED unit	50	F	PT	Married	Diploma/vocational	3	11
P5	ED unit	58	F	FT	Married	NVQ/A-level	2	62
P6	Beat	57	F	PT	Married	Diploma/vocational	2	35
P7	Beat	50	M	FT	Married	Degree	3	12
P8	ED unit	49	F	PT	Married	Diploma/vocational	3	103*

FT = Full time. PT = Part Time. ED = eating disorder.

*Caseness for psychological distress

Table 2. Demographic data for cared for individuals

Participant Identifier	Diagnosis	Gender	Age range	Age of diagnosis	AN duration (years)	Number of hospital admissions	Current Treatment	Relationship to carer	Contact frequency
P1	AN-B/P	F	46-50	13	10	1	Recovered	Daughter	Weekly indirect contact
P2	AN-R	F	Deceased	19	30	1	Deceased	Sibling	Previously living together
P3 & p4	AN-R	F	26-30	23	3	2-3	Inpatient	Daughter	Living with daughter. Inpatient: weekly direct contact. Daily indirect contact
P5	AN-R	F	31-35	13	20	6	Inpatient	Daughter	Inpatient: Varied contact
P6	AN-R	F	26-30	18	18	7	Outpatient	Daughter	Daily contact (direct or indirect)
P7 & P8	AN-B/P	F	26-30	17-18	8-10	6	Inpatient	Daughter	Living with daughter. Inpatient: varied contact

AN-R = AN nervosa restricting sub-type. AN-B/P = AN nervosa binge-purge sub-type.

Direct contact = face to face/in person. Indirect contact = telephone or other medium

Figure 1. Grounded theory representation of accommodation in AN

COURSE   OF   ANOREXIA

Understanding of Anorexia

"Difficult" Behaviours
"Brick wall"
"Tantrums"

Difficulty Separating from person

Carer Roles & responsibility

Multiple Aims

Unmet aims

Battle of wills

Accommodation & Turning a blind eye

Changed aims

Unmet aims

Direct approaches

Impact & Emotional Reserve
Support
Coping
Perceived Control
Demands

"Vulnerable"
Childlike

"Siding with AN"

"Constant battle"

"Recovery side"

Internal conflict ...
"inside I'm screaming"

Increased severity
Burnout

Reached limit

Consider boundaries

Efforts to reduce

"Explode"

Justification based on consequences

Reduced responsibility

Coping strategies

127

Paper 3.

A Critical Review of the Qualitative Research Process Examining

Carers Responses to Anorexia Nervosa

Word count: 4524

Abstract

In this paper I have critically reviewed the process of undertaking a qualitative exploration of caregivers' experiences of managing Anorexia Nervosa (AN). I have appraised these experiences sequentially according to the order in which they were carried out and offer personal reflections of the research process. The paper concludes with the clinical implications of the results of the study, as well as the personal implications of the research journey in terms of my work as a Clinical Psychologist.

Developing the research

Past clinical and research experiences influenced the choice of research and the design of the project. Having previously had contact with carers as part of a pharmacological research trial for neurodegenerative disorders, I was struck not only by the practical demands of caring but also the enormous emotional toll placed on carers watching their loved one go through a process of significant change. The empathy this experience elicited stayed with me and led to an interest in contributing to research involving carers. Clinically, I am drawn to systemic models and attachment theory. The paradigm of family therapy has been significantly developed within the field of Eating Disorders (ED) (see Eisler, 2005 for a review) and traditionally, family factors (including attachment) have been implicated in the aetiology and maintenance of the disorder (Minuchin, Rosman & Baker, 1978; O'Kearney, 1995). Therefore, researching interpersonal maintenance factors for ED neatly married both research and clinical interests.

Qualitative or Quantitative methodology

Existing research into accommodation within AN and indeed, other fields such as substance misuse have typically employed quantitative research methods to elucidate understanding of this interpersonal interaction. The processes by which accommodation operates within AN have been surmised, but not empirically examined. The project supervisor was aware of an existing, recently developed scale (Accommodation and

Enabling Scale for Eating Disorders: Sepulveda, Kyriacou & Treasure, 2009) to measure accommodation. Utilising this scale the project initially sought to determine predictors of accommodation within AN. However, due to setbacks in terms of ethics and in view of the power necessary for such a study against the backdrop of restrictive doctoral time scales, this project was not deemed feasible. Subsequently, the project and its aims were reconsidered. An alternative, qualitative methodology was selected as the most appropriate to meet these revised aims (discussed below). This revised project encountered further setbacks in terms of ethics, subsequently a third unrelated project was considered (and documents drawn up), however, I did not choose to undertake this project feeling more drawn to a study exploring caregivers experiences and responses.

The process of altering the project presented many challenges, primarily in terms of time pressures. Having devoted time to develop the research and to undertake the ethical approval process, I felt invested in the original project. Therefore, altering projects was a difficult decision to make and a source of some anxiety as I was mindful of the constrained timescales and my relative unfamiliarity with qualitative methods. However, mixed feelings were present, as initially I had been keen to undertake research involving direct contact with carers, to get a sense of what accommodation was like from their perspective. A qualitative methodology subsequently afforded this opportunity which I embraced and welcomed.

After a scope of the literature regarding caring in AN, I was struck by the lack of research generally into the experience of carers. This was particularly surprising given that care typically befalls parents due to the age of onset, as well as the high mortality rates associated with AN compared to other mental health conditions (Nielson, 2001) and the high levels of distress present in carers (Treasure et al, 2001). Therefore, exploring the experience of accommodation from the carer's perspective and acquiring detailed descriptions of their beliefs and understanding in relation to managing AN, was deemed to be an important and novel addition to the evidence base. Furthermore, as

gaps exist in the literature with regard to accommodation, in particular the processes by which it operates qualitative methodologies were indicated (Elliott, Fischer & Rennie, 1999), specifically grounded theory (discussed below).

Qualitative paradigms seek to generate explanations for experiential events grounded in the accounts of the individuals themselves (Noblit & Hare, 1988). Rich and detailed descriptions enable the researcher to take into account both the context to, and meaning of events from the individual's perspective. For instance, paper 2 found the understanding of the AN to impact on caring roles and aims, influencing subsequent management strategies. These understandings and aims were found to be fluid, changing with new experiences and altered emotional resources. Quantitative methodologies may be less likely to capture these dynamic and multifaceted processes due to preconceived hypotheses which determine the measures selected and subsequently constrain participants' responses. Furthermore, such measures are more likely to capture a single snapshot in time. Previous quantitative studies of accommodation have excluded potential confounding variables such as individuals with psychiatric conditions (e.g. Albert et al, 2010). However, higher levels of distress including depression and anxiety have been found in participants as a consequence of caring. Therefore, important contextual factors to the area of study may be excluded from examination. In contrast, qualitative methodologies seek to examine the 'lived experience' and therefore, all data is considered relevant. Indeed, paper 2 found caregiving burnout (including depression and anxiety) to mediate subsequent accommodation responses, an insight which could have been omitted had individuals been excluded on the basis of psychological distress.

The inductive methodology selected was grounded theory as this aims to synthesise and develop a conceptual interpretation of the 'lived experience' of participants (Charmaz, 1990). This approach therefore, allows for the development of a theoretical framework 'grounded' in the data which can further understanding of the subject area. The

theoretical framework subsequently developed in paper 2 has explanatory utility in terms of explicating the processes involved in accommodation and presents further lines of research enquiry, thereby, fulfilling the research aims.

Interview Schedule

Developing the interview schedule felt like a pivotal task in the research processes, as this tool was initially perceived as the means from which all my data would subsequently spring. Having limited experience of qualitative methods, this perception was informed by knowledge of quantitative methodologies, whereby the researcher faithfully adheres to data collection tools such as validated measures. However, through supervision, reading and the research process itself, the realisation grew that the interview schedule, although important, was only a starting point from which further lines of enquiry develop (Charmaz, 2006, p.26) and the schedule was later revised to reflect this (discussed below).

One of the definitive factors of Grounded Theory was the avoidance of 'preconceived ideas' (Glaser, 1998). Thus a 'blank slate' approach was historically advocated to minimise the likelihood of leading the data collection process or subsequently forcing data into predetermined categories. However, due to the academic rigour of the doctoral programme, it is necessary to undertake a literature search prior to data collection and analysis. Thus it was challenging balancing epistemological fidelity with academic expectations. The experience exemplified the challenges of 'real world' research whereby, faithfully adhering to assumptions of research paradigms is difficult in practice. Moreover, the underlying premise of a 'blank slate' approach, whereby, researchers are free from preconceived ideas or theories has been criticised. As Charmaz (2006) states, the 'assumptions researchers bring to their research and enact during the process are not neutral' (p.9). Due to the active role of the researcher, reflexivity is fundamental to the research process which was maintained through the use

of a reflective journal and supervision. Having familiarised myself with the standardised measure for accommodation due to the original research project, it was acknowledged that this had an influence on the development of the schedule. However, Blumer (1969) describes and validates 'sensitizing concepts' as providing a useful 'loose frame' to guide ideas and interview questions. It is argued such concepts provide a 'starting point' as opposed to leading data (Charmaz, 2006, p.16). Existing theoretical knowledge and its influence upon the research process were reflected upon in supervision.

To elicit rich data the interview schedule adopted open-ended questions. Clinical experience of using socratic questioning helped to devise the interview schedule and generate supplementary probe questions within the interview. To facilitate the development of a 'directed conversation' I endeavoured to adopt a 'funnel' approach as recommended by Charmaz (2006, p.30), whereby, neutral open questions framed the beginning of the interview, graduating to more emotive questions once engagement was established. From the literature search and previous clinical experience I was aware of carers feeling stigmatized and misunderstood. I was also mindful that the area of research, interpersonal maintaining factors, could be construed as blaming. Therefore, I was careful when devising the interview questions and the participant information sheets to avoid reinforcing any stigmatizing or negative past experiences. I therefore, sought feedback regarding the schedule from supervisors. The ethics committee was also useful in terms of checking both the schedule and participant information sheets from a lay viewpoint.

To conclude the interview and resume a 'normal conversational level' (Charmaz, 2006, p.30), I endeavoured to utilise positively framed questions. However, in the main this did not elicit positive responses from participants, but led participants to reflect on the lack of positives associated with their experiences. This underlined the immense challenges involved when caring for a loved one with AN.

Recruitment

Due to the initial change in research project recruitment of participants took place across a short time span. This presented a number of challenges in terms of achieving data saturation and maintaining fidelity to the constant comparative method.

In order to facilitate recruitment, the inclusion criterion was widened. The study therefore, included individuals who had prior experience of caring for a loved one, but were not currently caring. This may have impacted the data in terms of the carers' ability to accurately recall their experiences. Furthermore, the study included a carer who had been diagnosed in the past with AN and the individual she had been caring for had died due to AN complications. It is likely that these experiences affected her perception of caring and subsequent management of the AN. Although initially I had reservations about widening the inclusion criteria, after discussion in supervision and further reflection it was deemed these individuals' perspectives were still valid and of interest to the research question. Indeed, according to constructivist approach which informs the version of grounded theory utilised (Charmaz, 2006) all experience is constructed and accordingly, 'everything is data' (Glaser, 2002). Interestingly, these participants contributed some invaluable insights into the experience of accommodation. The study found carers accommodating to AN behaviours to experience internal conflict due to cognitive dissonance. This cognitive dissonance was subsequently reduced utilising cognitive and behavioural strategies. Individual's reflecting back on their experiences were more open and candid about the internal conflict previously experienced, perhaps as they were less 'defended' as it was not a current conflict. Therefore, these shared accounts were insightful. Additionally, previous research has found differences in terms of the impact of AN upon caregivers across its course (Whitney, Haigh, Weinman & Treasure, 2007) and therefore, including individuals at various stages is more likely to capture these differences.

Diagnoses of the cared for individual were not verified as part of the research. Verification of diagnoses would require explicit consent from the cared for individual, which due to the method of recruitment was not possible. This method was selected to expedite the recruitment of participants due to fixed time constraints. However, recruiting carers via service user consent (in order to verify diagnoses) may have led to carers with more complex or strained relationships with the cared for individual being excluded from the study. Interestingly most of the carers who took part, reported being excluded or 'shut out' by the individual who was described as 'private.' Subsequently, it is possible had service users been approached, they may have declined their consent for their carers to participate in view of these dynamics, therefore, losing rich data.

I endeavoured to ascertain the severity of AN and diagnoses by focusing my efforts on recruiting carers via an inpatient unit. However, to protect carer and patient confidentiality recruitment was reliant on staff members and therefore, outside of my control making this more challenging. Carers were also recruited via a national charity; therefore, AN severity was determined by asking routine questions pertaining to the number of inpatient and hospital admissions. Indeed, the cared for individuals all had a number of inpatient stays and carers disclosed severity of symptoms in terms of body mass index and restrictive diets (e.g. one individual was living on 'Fortisips' alone).

The key feature of Grounded Theory is the constant comparative method, whereby analysis of data takes place concurrently with data collection. This therefore, enables emerging concepts to 'shape' subsequent data collection (Charmaz, 1990). Due to doctoral deadlines, recruitment took place over a short space of time and therefore, this proved difficult to adhere to. This experience once again underlined the challenges of 'real world' research. However, I endeavoured to observe the methodology as far as practically possible by frequently listening to the interviews, utilising memos written

alongside data collection, as well as supervision to reflect on potential emerging themes. These emerging themes informed an alteration of the interview schedule.

Historically recruitment continues until data saturation is achieved and no new theoretical insights emerge. Again, due to constrained doctoral timescales, this was not feasible. However, Dey (1999) challenges the underlying premise of 'data saturation', noting that in order to truly demonstrate and verify this principle, one would have to collect all possible data. Dey (1999) subsequently, advocates the notion of 'theoretical sufficiency' which this study aimed to achieve. The resulting grounded theory is representative of the data collected. However, there is certainly scope for the developed model to be further tested and nuances in the data to be further explored. For example, gender role differences and its influence upon accommodation, and differences in accommodation responses across the course of AN. However, this could be said of all emerging theories, which typically provoke additional questions for future research to explore.

Interviews

Prior clinical experience and skills facilitated building a rapport with interviewees, particularly with one carer who took time to open up and share their experiences. For example, the use of reflective and open questions, together with non-verbal communication and empathy facilitated engagement. However, prior clinical skills and experiences also posed challenges in terms of role confusion. I was conscious throughout the interviews of remaining firmly within my role as a researcher, which was to facilitate the development of a narrative as opposed to facilitating change. I therefore, endeavoured to adopt a very neutral yet empathic stance. This was particularly challenging given the emotive topics being discussed. Indeed, several carers became tearful during the interviews and many frequently admonished themselves for past responses. At these times it was particularly difficult to adhere to my role as researcher and not to slip into the role of therapist. Participants were revealing very

personal and emotive experiences and therefore, the research interview mirrored a clinical interview in terms of content in many ways and yet I was unable to provide any subsequent clinical assessment or intervention. Excerpts from my reflective journal illustrate these conflicts:

'*... Felt like an initial assessment session but unusual, almost intrusive in a way ... I'm gleaning all this rich information, and at times discussing powerful emotions and yet offering no intervention in return, just leaving the individual in their home to reflect on, and sit with their feelings.*'

Supervision was a particularly helpful forum to discuss these role conflicts. Through supervision I began to acknowledge and accept that no human interaction is neutral and began utilising more statements of understanding and validation during some interviews in order to normalise difficult carer experiences. This felt like a more comfortable balance and further facilitated carer engagement.

Indeed the research interview itself had parity with a clinical interview in many ways. For example, it provided a non-judgemental space for carers to share their experiences and be actively heard, for some this was the first time they had opened up about their experiences. Furthermore, in order to collect rich data and 'go beneath the surface' of carers' experiences probe questions were utilised (Charmaz, 2006, p.26). Probes served to elucidate carers' beliefs and understanding regarding accommodation. Consequently, through reflecting on their experience some carers made new insights and connections. For instance, the results of the study outlined how carers experienced cognitive dissonance associated with accommodation, which was reduced using a number of strategies. Through the use of probes, this cognitive dissonance was brought into participants' awareness and subsequently explored further as part of the research, leading to recognition in some instances. The use of interview questions and probes to delve deeper into the individual's experience reminded me of Method of Levels (Powers, 1972; Carey, 2006) a therapy based on Perceptual Control Theory (Powers et al 1960) in that shifts in awareness and perception took place leading to inner conflicts

being reflected upon. For example, as a result of the research interview one participant commented; *"now you're picking, pulling it to pieces, it actually makes you realise that you've just accepted it…quite frightening actually, isn't it? Talking to you, you suddenly realise, have we adapted our whole life around this anorexia or is the anorexia like bullied us all into just being so submissive that we've just accepted anything that (daughter) throws at us."*

Subsequently, this experience demonstrated how epistemologies advocating neutrality fail to recognise the active role of the researcher and underscored how all human interaction is a dynamic process.

At participants request two interviews took place over the telephone. As a researcher I found these interviews the most challenging to navigate. Although the lack of face to face contact seemed to pose no difficulties for the participants in terms of opening up, engaging and sharing their experiences. However, I found it more difficult in terms of knowing when to interject silences and found myself more cautious with regard to asking questions and probes as I was unable to read non-verbal cues and missed nuances in terms of facial expressions. Additionally, in order to convey active listening this had to be done verbally, which changed the rhythm of the interview. However, despite these challenges, rich data was actually generated from these interviews. I did wonder whether the non-face to face contact had benefits in terms of participants feeling able to share more candidly their personal experiences. Moreover, I asked more clarifying questions to check I understood the individual's meaning due to the lack of non-verbal cues, which may have contributed to the richness of the data. Excerpts from my reflective diary portray some of the difficulties navigating a telephone interview:

'… Much more difficult! It's hard to pick up on non-verbal messages and pitch my questions because I can't see their facial expressions. I want to convey empathy at emotional moments but this is tricky to do with just your voice. It feels harder to establish rapport. It feels like it lacking the all-important personal touch.'

Analysis

Due to concurrent analysis usually taking place alongside data collection, this task is usually broken down into stages and therefore, more manageable. However, as a result of the aforementioned difficulties in terms of time constraints, the majority of interview coding took place at one stage. Subsequently, after initial coding I was faced with over four thousand codes which felt very overwhelming. Supervision helped enormously in normalising this experience within qualitative research. It is at this point I took a very active role in the research process in order to understand how these codes related to one another (axial codes) and build higher order codes into a conceptual model. Clinical formulations skills were invaluable in making sense of the data. I drew diagrams for each interview in order to map out the relationship between codes and then compared and contrasted these to one another through a process of 'constant comparison' in order to ascertain relationships and the conditions by which these operate (Charmaz, 1990). Upon completion of the final model I felt a great sense of achievement and relief.

Due to the active role I played in the analysis of the data, reflexivity was crucial. Furthermore, having already undertaken a systematic literature review of the research area, reflexivity was even more essential to ensure data was not forced into preconceived categories. Therefore, discussion and reflection during supervision facilitated this reflexivity. During the period of analysis I avoided working on the systematic literature review in order to minimise this influence on my thinking. Furthermore, I utilised memos made throughout the process of data collection and analysis, as well as my reflective journal to help stay 'grounded' in the data. However, as neutrality is unrealistic, undoubtedly my clinical experiences and interests impacted the analysis despite endeavours to remain reflexive. In particular I have an interest in cognitive analytic, cognitive behavioural models and formulation. My interest in psychological models, and skills in formulation influenced the process by which I went about developing themes. For example, codes for each interview were diagrammatically mapped out in order to elucidate and understand their relationships. Despite endeavours

to remain neutral, psychological interests, particularly in cognitive models may have biased my interpretation of the relationship between these codes. However, perfectionistic personality traits meant these maps were intricately detailed as I strove to accurately encapsulate the rich information. The process itself was very lengthy, involving times of overwhelming emotions punctuated by confusion, frustration and what felt like stagnation. These were interspersed with precious moments of insight and renewed hope. Excerpts from my reflective diary depict this:

'Feeling overwhelmed, where do I start? … It's as if I'm running on the spot and getting no where. I feel like I'm trying to complete a huge jigsaw puzzle with pieces missing.'

However, the resulting grounded theory produced from this arduous process was detailed and comprehensive. The conceptual model also resembled a clinical formulation outlining the cognitive and systemic factors leading to, and maintaining accommodation. Therefore, my clinical interests and skills certainly shaped and guided the process of the analysis and therefore, had a bearing on the subsequent diagrammatic presentation of the findings. However, I felt these interests and clinical skills facilitated the process of formulating concepts. Furthermore, perfectionistic tendencies led to a methodical and rigorous approach to the analysis being adopted, resulting in a grounded theory which was in-depth and captured participants experiences.

In order to enhance methodological rigour guidelines for qualitative research were adhered to (Elliott et al, 1999) which included credibility checks via an independent researcher to verify my interpretations. Lincoln and Guba (1985) advocate the importance of 'member checks' to ascertain the credibility of the results in terms of representing participants' experiences. Initially I had intended to undertake member checks to augment the rigour of the study. However, time constraints of the doctorate prohibited this. Moreover, the pros and cons of member checking were discussed in supervision. Indeed, the premise on which member checking rests is that one version or underlying 'truth' exists. However, the constructivist grounded theory approach asserts

truth is constructed and therefore, there are multiple accounts of truth. Subsequently, the utility of member checks to verify validity has been called into question (Seale, 1999).

Clinical Implications

Through undertaking this research and becoming immersed in the rich data collected relating to carers' experiences, I have developed an enormous empathy for the challenges faced by these individuals. In particular, I was struck by the lack of formal support for carers, which seems to consist of family therapy or ad hoc carer support groups. However, what limited support there was available seemed inconsistent and to operate on a 'postcode lottery'. Furthermore, the exclusion of carers from the treatment process seemed inequitable given the responsibility which typically befalls carers for the individuals' aftercare. Current legislative and National Health Service frameworks (Carers' Act, 1995; Department of Health, 1999) advocate the assessment of carers' needs, yet in the experience of those participating in this research, their needs were left unmet which compounded their caregiving burden. The research therefore, underlined the importance of providing support to carers, particularly given that their interpersonal interactions with the individual can reinforce unhelpful AN behaviours or conversely, promote recovery (Schmidt & Treasure, 2006). Moreover, carers should be included in the treatment of individuals as much as possible whilst respecting confidentiality. As most carers in the study commented, they did not in fact want to know confidential details. Carers instead requested the opening up of the lines of communication in terms of professionals advising carers regarding management strategies and in turn, carers wanted to share relevant information with professionals' to facilitate collaborative working. Indeed, a recent report stated that 'good sharing of information is just as important as protecting confidentiality' in terms of patient care (Department of Health, 2013).

This study highlighted the importance of interventions to empower carers to manage and respond to AN behaviours. Existing carer interventions designed to target caregiver beliefs and responses have shown promise (Sepulveda, Lopez, Todd, Whitaker & Treasure, 2008), however these are not currently generally available. Furthermore, the cognitive dissonance carers described in paper 2 when accommodating AN behaviours indicates a Motivational Interviewing approach (Miller, 1983) may be beneficial to explore and develop these discrepancies and encourage altered responses.

Implications for my practice

Going forward in my work as a Clinical Psychologist, this research has underscored how important the caregiver's role is in terms of systemic influences upon the service user and the impact of the service user's difficulties upon the family system and carer mental health. I was personally struck through my interactions with caregivers by the enormous and unrelenting challenges they face and surprised by their lack of support. Subsequently, I will be mindful to assess caregivers' needs and signpost/refer to the relevant support services. As far as possible I will endeavour to include carers in the assessment process and supply carers with psychoeducational information. With the consent of the service user, I will share relevant information to their treatment if indicated by the formulation and considered beneficial to their care. Furthermore, in terms of service delivery I would like to ensure the needs of carers are considered and promoted.

Conclusions

Utilising a qualitative method enabled me to become immersed in the data and subsequently in participants' experiences. Qualitative methods require the researcher to take an active role in making sense of, and interpreting these experiences. Therefore, I connected with these experiences personally. Subsequently, I feel I have developed a real empathy and understanding of the caregiving experience of those taking part which

provide significant insights to take forward as a clinical practitioner. Although my prior quantitative research experience is limited, I do not feel the level of involvement with the process was the same. Furthermore, I think the skills of a Clinical Psychologist are inherently suited to, and transferable to this methodology, particularly in terms of the interview process, reflexivity and formulating the conceptual model. The process was extremely labour intensive and at times anxiety provoking; however, I feel the insights gained empirically from the perspective of the lived experience of the individuals themselves are invaluable, I would therefore, utilise a similar approach in the future.

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Appendix 1.

Contributor guidelines for the journal 'Clinical Psychology and Psychotherapy'

Clinical Psychology & Psychotherapy: Author Guidelines

Manuscript style. The language of the journal is (British) English. All submissions must have a title, be printed on one side of A4 paper with numbered pages, be double-line spaced and have a 3cm wide margin all around. Illustrations and tables must be printed on separate sheets, and not incorporated into the text.

MANUSCRIPT STYLE

The language of the journal is English. 12-point type in one of the standard fonts: Times, Helvetica, or Courier is preferred. It is not necessary to double-line space your manuscript. Tables must be on separate pages after the reference list, and not be incorporated into the main text. Figures should be uploaded as separate figure files.

- During the submission process you must enter the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including email, telephone and fax, of the author who is to check the proofs.

- Include the name(s) of any **sponsor(s)** of the research contained in the paper, along with **grant number(s)** .

- Enter an **abstract** of up to 250 words for all articles [except book reviews]. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work.

- All articles should include a **Key Practitioner Message** — 3-5 bullet points summarizing the relevance of the article to practice.

- Include up to six **keywords** that describe your paper for indexing purposes.

Research Articles: Substantial articles making a significant theoretical or empirical contribution.

Reviews: Articles providing comprehensive reviews or meta-analyses with an emphasis on clinically relevant studies.

Assessments: Articles reporting useful information and data about new or existing measures.

Practitioner Reports: Shorter articles that typically contain interesting clinical material.

Book Reviews: Published on invitation only. Critical summaries of recent books that are of general interest to readers of the journal.

Reference style . The APA system of citing sources indicates the author's last name and the date, in parentheses, within the text of the paper.

A. A typical citation of an entire work consists of the author's name and the year of publication .

Example: Charlotte and Emily Bronte were polar opposites, not only in their personalities but in their sources of inspiration for writing (Taylor, 1990). Use the last name only in both first and subsequent citations, except when there is more than one author with the same last name. In that case, use the last name and the first initial.

B. If the author is named in the text, only the year is cited .

Example: According to Irene Taylor (1990), the personalities of Charlotte. . .

C. If both the name of the author and the date are used in the text, parenthetical reference is not necessary .

Example: In a 1989 article, Gould explains Darwin's most successful. . .

D. Specific citations of pages or chapters follow the year .

Example: Emily Bronte "expressed increasing hostility for the world of human relationships, whether sexual or social" (Taylor, 1988, p. 11).

E. When the reference is to a work by two authors, cite both names each time the reference appears .

Example: Sexual-selection theory often has been used to explore patters of various insect matings (Alcock & Thornhill, 1983) . . . Alcock and Thornhill (1983) also demonstrate. . .

F. When the reference is to a work by three to five authors, cite all the authors the first time the reference appears. In a subsequent reference, use the first author's last name followed by *et al* **. (meaning "and others")** .

Example: Patterns of byzantine intrigue have long plagued the internal politics of community college administration in Texas (Douglas *et al* ., 1997) When the reference is to a work by six or more authors, use only the first author's name followed by *et al* . in the first and all subsequent references. The only exceptions to this rule are when some confusion might result because of similar names or the same author being cited. In that case, cite enough authors so that the distinction is clear.

G. When the reference is to a work by a corporate author, use the name of the organization as the author.

Example: Retired officers retain access to all of the university's educational and recreational facilities (Columbia University, 1987, p. 54).

H. Personal letters, telephone calls, and other material that cannot be retrieved are not listed in References but are cited in the text .

Example: Jesse Moore (telephone conversation, April 17, 1989) confirmed that the ideas. . .

I. Parenthetical references may mention more than one work, particularly when ideas have been summarized after drawing from several sources. Multiple citations should be arranged as follows.

Examples:

- List two or more works by the same author in order of the date of publication: (Gould, 1987, 1989)
- Differentiate works by the same author and with the same publication date by adding an identifying letter to each date: (Bloom, 1987a, 1987b)
- List works by different authors in alphabetical order by last name, and use semicolons to separate the references: (Gould, 1989; Smith, 1983; Tutwiler, 1989).

All references must be complete and accurate. Where possible the DOI for the reference should be included at the end of the reference. Online citations should include date of access. If necessary, cite unpublished or personal work in the text but do not include it in the reference list. References should be listed in the following style:

Journal Article

Gardikiotis, A., Martin, R., & Hewstone, M. (2004). The representation of majorities and minorities in the British press: A content analytic approach. *European Journal of Social Psychology, 34* , 637-646. DOI: 10.1002/ejsp.221

Book

Paloutzian, R. F. (1996). *Invitation to the psychology of religion* (2nd ed.). Boston: Allyn and Bacon.

Book with More than One Author

Natarajan, R., & Chaturvedi, R. (1983). *Geology of the Indian Ocean* . Hartford, CT: University of Hartford Press.

Hesen, J., Carpenter, K., Moriber, H., & Milsop, A. (1983). *Computers in the business world* . Hartford, CT: Capital Press. and so on.

The abbreviation *et al.* is not used in the reference list, regardless of the number of authors, although it can be used in the text citation of material with three to five authors (after the inital citation, when all are listed) and in all parenthetical citations of material with six or more authors.

Web Document on University Program or Department Web Site

Degelman, D., & Harris, M. L. (2000). *APA style essentials* . Retrieved May 18, 2000, from Vanguard University, Department of Psychology Website: http://www.vanguard.edu/faculty/ddegelman/index.cfm?doc_id=796

Stand-alone Web Document (no date)

Nielsen, M. E. (n.d.). *Notable people in psychology of religion* . Retrieved August 3, 2001, from http://www.psywww.com/psyrelig/psyrelpr.htm

Journal Article from Database

Hien, D., & Honeyman, T. (2000). A closer look at the drug abuse-maternal aggression link. *Journal of Interpersonal Violence, 15* , 503-522. Retrieved May 20, 2000, from ProQuest database.

Abstract from Secondary Database

Garrity, K., & Degelman, D. (1990). Effect of server introduction on restaurant tipping. *Journal of Applied Social Psychology, 20* , 168-172. Abstract retrieved July 23, 2001, from PsycINFO database.

Article or Chapter in an Edited Book

Shea, J. D. (1992). Religion and sexual adjustment. In J. F. Schumaker (Ed.), *Religion and mental health* (pp. 70-84). New York: Oxford University Press.

*The Digital Object Identifier (DOI) is an identification system for intellectual property in the digital environment. Developed by the International DOI Foundation on behalf of the publishing industry, its goals are to provide a framework for managing intellectual content, link customers with publishers, facilitate electronic commerce, and enable automated copyright management.

Illustrations. Upload each figure as a separate file in either .tiff or .eps format, the figure number and the top of the figure indicated. Compound figures e.g. 1a, b, c should be uploaded as one figure. Grey shading and tints are not acceptable. Lettering must be of a reasonable size that would still be clearly legible upon reduction, and consistent within each figure and set of figures. Where a key to symbols is required, please include this in the artwork itself, not in the figure legend. All illustrations must be supplied at the correct resolution:

- Black and white and colour photos - 300 dpi
- Graphs, drawings, etc - 800 dpi preferred; 600 dpi minimum
- Combinations of photos and drawings (black and white and colour) - 500 dpi

Appendix 2.

List of search terms employed in the systematic literature search

Terms employed in the systematic literature search

Design	Search Terms
Qualitative	1. 'qualitative'
Ethnographic Research	2. 'ethnog$'
Phenomenological Research	3. 'phenomenol$' or 4. 'lived experience' or 5. 'life experience$'
Grounded Theory	6. 'grounded theor$' or 7. 'grounded stud$' or 8. 'grounded research'
Constant comparative method	9. 'constant compar$'
Purposive sample	10. 'purpo$ sampl$'
Focus groups	11. 'Focus group$'
Observational Methods	12. 'Participant observ$'
Field Studies	13. 'field stud$' or 14. 'field research'
Narrative	15. 'narrative$'
Discourse analysis	16. 'discourse analysis'
Content Analysis	17. 'content analysis'
Theoretical sample	18. 'cluster sample'
Mixed design	19. 'multi-method' or 20. 'multi-modal'
Interpretative phenomenological analysis	21. 'interpretative phenomenological analysis' or 22. 'IPA'
Eating Disorders	
Anorexia Nervosa	23. 'anorexia$'
Bulimia Nervosa	24. 'bulimia$'
Eating Disorder	25. 'Eating disorder$'
Eating Disorder Not Otherwise Specified	26. 'EDNOS' or 27. 'NOS' or 28. 'no$ otherwise specified'
Perspective	
Service user	29. 'service user' or 30. 'patient'
carer	31. 'carer$'
Family	32. 'famil$' or 33. 'relation'
parent	34. 'parent$' or 35. 'father$' or 36. 'mother$' or 37. 'maternal' or 38. 'paternal'
sibling	39. 'Sibling$' or 40. 'brother$' or 41. 'sister$'
partner	42. 'partner' or 43. 'spouse'
Impact of caring	
impact	44. 'functioning' or 45. 'impact' or 46. 'burden'
coping	47. 'coping' or 48. 'wellbeing' or 49. 'adjustment'
response	50. 'response' or 51. 'reaction' or 52. 'expressed emotion' or 53. 'enabling' or 54. 'accommodation'
experience	55. 'experience'
relationship	56. 'relationship'
Combination of search terms	(or/1-21) and (or/23-26) and (or/29-42) and (or/44-56)

Appendix 3.

Critical Appraisal Skills Programme checklist

Critical Appraisal Skills Programme (CASP, 2010)

Qualitative research checklist

Screening Questions
1. **Was there a clear statement of the aims of the research?**
Consider:
   • *What the goal of the research was*
   • *Why is it important*
   • *Its relevance*	

2. **Is a qualitative methodology appropriate?**
Consider:
   • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants*
Detailed questions
3. **Was the research design appropriate to address the aims of the research?**
Consider:
   • *If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?*	

4. **Was the recruitment strategy appropriate to the aims of the research?**
Consider:
   • *If the researcher has explained how the participants were selected*
   • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study*
   • *If there are any discussions around recruitment (e.g. why some people chose not to take part).*	

5. **Were the data collected in a way that addressed the research issue?**
Consider:
   • *If the setting for data collection was justified*
   • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)*
   • *If the researcher has justified the meth-*	

ods chosen • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?* • *If methods were modified during the study. If so, has the researcher explained how and why?* • *If the form of data is clear (e.g. tape recordings, video material, notes etc.)* • *If the researcher has discussed saturation of data*	
6. Has the relationship between researcher and participants been adequately considered? *Consider:* • *If the researcher critically examined their own role, potential bias and influence during:* ○ *Formulation of the research questions* ○ *Data collection, including sample recruitment and choice of location* • *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	
7. Have ethical issues been taken into consideration? *Consider:* • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* • *If approval has been sought from the ethics committee*	
8. Was the data analysis sufficiently rigorous? *Consider:*	

If there is an in-depth description of the analysis process *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?* *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* *If sufficient data are presented to support the findings* *To what extent contradictory data are taken into account* *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	
9. Is there a clear statement of findings? *Consider:* *If the findings are explicit* *If there is adequate discussion of the evidence both for and against the researcher's arguments* *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)* *If the findings are discussed in relation to the original research question*	
10. How valuable if the research? *Consider:* *If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?* *If they identify new areas where research is necessary* *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research maybe used*	

Appendix 4

Quality Assessment Checklist (Walsh & Downe, 2006)

Quality Assessment Checklist (Walsh & Downe, 2006)

Summary criteria for appraising qualitative research studies

Stages	Essential Criteria	Specific Prompts
Scope and Purpose	Clear statement of, and rationale for, research question/aims/purpose Study thoroughly contextualised by existing literature	• Clarity of focus demonstrated • Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing • Link between research and existing knowledge demonstrated • Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both
Design	Method/design apparent, and consistent with research intent Data collection strategy apparent and appropriate	• Rationale given for use of qualitative design • Discussion of epistemological/ontological grounding • Rationale explored for specific qualitative method (e.g. ethonography, grounded theory, phenomenology) • Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims • Setting appropriate • Were data collection methods appropriate for type of data required and for specific qualitative method? • Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? • Was triangulation of data sources used if appropriate?
Sampling Strategy	Sample and sampling method appropriate	• Selection criteria detailed, and description of how sampling was undertaken • Justification for sampling strategy given • Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained

Analysis	Analytic approach appropriate	- Approach made explicit (e.g. thematic distillation, constant comparative method, grounded theory) - Was it appropriate for the qualitative method chosen? - Was data managed by software package or by hand and why? - Discussion of how coding systems/conceptual frameworks evolved - How was context of data retained during analysis - Evidence that the subjective meanings of participants were portrayed - Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance - Did research participants have any involvement in analysis (e.g. member checking) - Evidence provided that data reached saturation or discussion/rationale if it did not - Evidence that deviant data was sought, or discussion/rationale if it was not
Interpretation	Context described and taken account of in interpretation Clear audit trail given Data used to support interpretation	- Description of social/physical and interpersonal contexts of data collection - Evidence that the researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena - Sufficient discussion of research processes such that others can follow 'decision trail'. - Extensive use of field notes entries/verbatim interview quotes in discussion of findings - Clear exposition of how interpretation led to conclusions
Reflexivity	Researcher reflexivity demonstrated	- Discussion of relationship between researcher and participants during fieldwork - Demonstration of researcher's influence on stages of research process - Evidence of self-awareness/insight - Documentation of effects of the research on researcher - Evidence of how problems/complications met were dealt with

Ethical dimensions	Demonstration of sensitivity to ethical concerns	• Ethical committee approval granted • Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants • Evidence of fair dealing with all research participants • Recording dilemmas met and how resolved in relation to ethical issues • Documentation of how autonomy, consent, confidentiality, anonymity were managed
Relevance and transferability	Relevance and transferability evident	• Sufficient evidence for typicality specificity to be assessed • Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies • Discussion of how explanatory propositions/emergent theory may fit other contexts • Limitations/weaknesses of study clearly outlined • Clearly resonates with other knowledge and experience • Results/conclusions obviously supported by evidence • Interpretation plausible and 'makes sense' • Provides new insights and increased understanding • Significance for current policy and practice outlined • Assessment of value/empowerment for participants • Outlines further directions for investigations • Comment on whether aims/purposes of research were achieved

Appendix 5

Quality ratings of included studies

Quality rating of included studies

Study Number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1. The study includes family members who care/cared for, or live/lived with an individual with an eating disorder as the primary participants.	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2. There is a clear statement of the research aims and a rationale as to its importance and relevance.	1	1	1	1	1	1	1	1	1	0.5	1	0.5	1	1	1	0.5	1	1	1	1
3. A clear and appropriate methodology employed consistent with the research aims.	0.5	1	1	1	1	0.5	0.5	1	0.5	1	1	0.5	1	1	1	0.5	1	1	1	1
4. A description and rationale is given for the recruitment strategy, which is consistent with the research aims. The selection criteria are outlined and any disparity between the planned and actual sample is explained.	0.5	1	0.5	1	0.5	0.5	0.5	1	0	1	0.5	0.5	1	0.5	1	1	0.5	0.5	0.5	0.5
5. A clear outline of how (e.g. semi-structured interview) and in what form (e.g. tape recording) data was collected. Justification given for the method of data collection. Description of how interviews were conducted or any method modifications. Data saturation discussed.	0.5	1	1	1	0.5	0.5	0.5	1	0	1	0.5	0.5	1	1	1	0.5	1	1	0.5	1
6. Explicit and detailed description of the data analysis approach and process. Explanation of how data was managed (e.g. software utilised). Clear development of coding/themes derived from the data. Sufficient data presented to support findings. Contradictory data discussed.	0.5	1	1	0.5	1	0.5	0.5	1	0.5	1	1	1	1	1	1	1	1	1	0.5	1
7. Researcher reflexivity evidenced. Consideration of the researcher's role, potential bias and influence on the research process. Discussion of the relationship between researcher and participants. Acknowledgement of how the researcher responded to events or any difficulties during the study.	0	1	0	0	0	0	0	0	0	1	0	0	0	0	0.5	0	0	0	0	0.5

Study Number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
8. Ethical issues taken into account and documented, including ethical approval, informed consent, confidentiality and anonymity. Discussion of any issues raised by the study.	1	0	0	0.5	1	0.5	0	1	0	0.5	0.5	0.5	0.5	1	0.5	1	0.5	0	0	0
9. The findings are explicitly stated and discussed in terms of the original research question. There is adequate discussion of supporting and opposing evidence. A sufficient explication of the research process and decisions which led to the conclusions drawn. Extensive use of verbatim interview quotes/field notes. Discussion of the credibility of the findings (e.g. respondent validation, multiple raters).	0.5	1	0.5	0.5	1	1	0.5	0.5	1	1	1	1	1	1	1	0.5	1	0.5	0.5	1
10. Discussion of the relevance and contribution of the study to existing knowledge/theory and implications for practice. Areas for future research proposed. Limitations/weaknesses of the study cited. Conclusions drawn supported by the evidence.	1	0.5	1	1	0.5	0.5	0.5	0.5	1	0.5	0.5	1	1	1	1	1	1	0.5	0.5	1
Total Score	6.5	8.5	7	7.5	7.5	6	5	8	5	8.5	7	6.5	8.5	8.5	9	7	8	6.5	5.5	8
Category	B	A	B	B	B	B	B	B	B	A	B	B	A	A	A	B	B	B	B	B

Scoring Key:

A: total score 8.5-10 = low likelihood of methodological flaws (higher quality)

B: total score 5 − 8 = Moderate likelihood of methodological flaws (moderate quality)

C: total score <5 = higher likelihood of methodological flaws (lower quality)

Appendix 6.

Meta-synthesis Guidelines

'Analytic Technique' for meta-synthesis

An excerpt from Walsh & Downe (2005)

'Determine how studies are related, or dissonant through a compare and contrast exercise'

1. 'Practically this process begins with the first reading of the studies and is completed with the creation of a grid of key concepts. These findings are then juxtaposed to both identify homogeneity of categories/codes/themes and crucially, to note discordance and dissonance. Jensen and Allen (1996) identify two processes here. The first, or hermeneutic, aspect consists of accurately capturing individual or cultural constructions. This is the art of respecting and representing context as intended through the original research. Second is the dialectic aspect, which relates the studies to each other. This can be achieved through juxtaposition of the parameters identified by the compare and contrast exercise.'

'Reciprocal Translation'

2. 'The next phase begins the translation of one study's findings into another, using metaphors and concepts that could be applied to both. Sometimes commonalities will be only too apparent and reciprocal translations are relatively straightforward. At other times they will stand in opposition as a 'refutational translation' (Noblit & Hare, 1988), or they may overlap without being substitutional. Refutation and overlap may contribute to another, emergent, category or understanding which has not been identified in the original accounts. It is crucial to the method that differences are not glossed over or subsumed. Deviant data may be the raw material of another perspective, making a new space for understanding.'

'Synthesis of translation'

3. 'The final phase is synthesizing the translations to elucidate more refined meanings, exploratory theories and new concepts. Clusters of metaphors become progressively more refined and a consensus emerges as to core themes or explanatory, mid-level, or substantive theory (Sherwood 1997b, Strauss & Corbin, 1998, Campbell et al. 2003). The synthesis needs to reflect the tension between contradictory or alternative explanations if reciprocal translations suggest a lack of congruence. Ultimately, the final synthesis will be the grounds on which the value of the meta-synthesis is judged and it therefore needs to convey explicitly how the whole is greater than the sum of the constituent parts.'

Appendix 7.

Key themes from the reviewed studies

Summary of key themes from the reviewed studies

Study	Main Themes
Beale, et al, (2004/5) Study 1	**Journey initiation:** Slow realisation. Denial & secrecy. Dismissed by health professionals. Left to search for answers. ED deterioration (pressure). Lack of information (stressor). **Inaccessibility of appropriate resources:** sought help & information. Assistance from support organisations. **Efforts for the child:** Sustained whole journey & aimed toward recovery. Intervened when care inappropriate. Effort impacted all aspects of lives. Fear regarding the unknown. Pressure in absence of help. Stress due to negotiating & re-negotiating journey. Anger & frustration. Guilt exacerbated by perceived blame. Self-blame increased burden, despair, helplessness. Motivated & resourceful. Resilience. **Parental strengths**: hope, resourcefulness, determination, love. Family focused/united. Strengths helped parents cope. Positive aspects journey.
Hoskins & Lam (2001) Study 2	**Caring, Responsibility & Culpability:** Unprepared ('ought to have seen it coming'). Self-blame, culpability & guilt, reinforced by searching for a cause. Maternal responsibility to 'make life good'. Feeling misunderstood/not accepted by professionals. **Striving for perfection:** Being the perfect mother (e.g. compensating for disappointments; striving to meet daughter's needs). **Shifting perspectives** as a result of internalised self-blame and changed parenting. Instilling boundaries.
Honey & Halse (2005) Study 3	**Daughter-directed activities:** Searching for help & treatment, practical support, tolerating & ignoring behaviours (to avoid confrontation). Cautious responses. Accommodating (e.g. avoiding situations, altering routines, providing specific foods). Persuading, encouraging, explaining & pressuring daughter to eat. Other tactics: rewards for weight gain, monitoring diet/exercise, deception & distraction. Forcing compliance (parental authority, threats & constraints). Feeling powerless. Emotional support. Regulating own reactions/emotions. Influencing environments & interactions. Negotiating treatment. Sharing information. Responses influenced by **constructions** of AN which could be contradictory, multiple & changeable: (initial belief) **AN as an eating issue**: pressured eating (ineffective strategy, changed with experience) **AN as a biological illness**: remit of health professionals. Did not blame daughter. Powerless. Difficulty distinguishing between AN behaviour & others. **AN as mental illness/addiction**: beyond control of individual & rational thought. Perceived rationalising/explaining/persuading as ineffective. **AN as a psychological/emotional issue**: provided emotional support, sought psychological treatment, avoided upset. **AN as a choice**: influenced treatment options. Removed secondary gains. **AN as a separate entity**: Kind to daughter, tough on AN. **AN as unknown**: conflicting or unhelpful advice from 'experts'. Difficulty knowing what to do/believe.
Sharkey-Orgnero (1999) Study 4	**Core concept: 'awakening,'** becoming aware of the AN. Making excuses for daughter's behaviour/avoiding confrontation. Lack of trust. **Reacting phase:** realization of AN. Search for professional help and cause, activities to increase knowledge and understanding. Efforts to change daughter's behaviour. Mistrust. Feelings of Frustration and helplessness. AN appraised as a 'family problem'. **Acting Phase:** Realisation issue unrelated to food. Family cohesion emphasised. Emotion-free confrontation. Encourage individual to take responsibility. **Maintaining Phase:** Help seeking. Feeling blamed. Letting go. Observing, encouraging and supporting individual. Open to changes. **Preventing Phase:** self-esteem building, public and professional education.

Hillege et al, (2006) Study 5	**Family unification or disintegration:** Brought families together (tenuous process). Other times pulled families apart. Family unit changes. Rifts. Fractured social interaction reducing coping mechanisms. **Inability to cope:** Emotional pressures/burden. Feeling unable to cope. **Inconsiderate comments:** Unhelpful comments increased pressure/frustration. Increased parental anxiety. Lack of understanding led to coping alone. **Social isolation:** Choosing to manage alone, feeling excluded by others & professionals. Isolation compounded coping resources. **Financial impacts:** Hidden costs. Concern about meeting treatment costs.
Highet et al, (2005) Study 6	**Suspicion of an eating disorder**: barriers to recognition due to misattribution/secrecy/hiding. **Recognising the signs** Seeking evidence. Resentment & distrust. Desperation. Identification = relief, shock, fear, anger & disbelief. Guilt & blame (whether contributed to the ED & the time taken to detect). **Living with the ED:** All-consuming and demanding. Identity as carer. Controlling ED related behaviours. Excluding others. Feelings of confusion, frustration & alienation. Stigma. Responsibility. Shame/humiliation. Emotional distress. Burden. Lack of understanding & support. **Family and relationship dynamics:** Difficulty maintaining relationships. Conflict. Boundaries (confusion & resentment). **Sibling relationships:** Strained. **Intimacy:** Distant/avoidant. Question relationship. ED taking over/changed relationship. **Social relationships:** controlling. Social decline. Heightened sensitivity to scrutiny. Needs accommodated. **Carer mental health:** Grief/loss. Distress. Helplessness. No control. **Carer Support:** Barriers to & excluded from services. Frustration. Intense/lengthy. Hopelessness. Alternative sources of support.
Treasure et al, (2001) Study 7	-Experience of loss & difficulty coping. - Impact of the AN on all the family ("separating" & "engulfing"). - Difficulty managing AN behaviours (difficulty separating AN from person, tolerating frustration & accepting change). - Dependent nature of AN (regression). - Social stigma, shame, self-blame, feelings of failure & guilt (contribution to the illness, actions & responses). - Positive dimensions (familial support/bonds, hope, love & acceptance).
Honey & Halse (2006) Study 8	**Explanatory work:** Seeking information & advice to understand AN behaviours and inform responses. Finding out about the individual: monitoring activities. Barriers: restricted access to treatment information. Evaluating past strategies (impact on weight & behaviour). Conflicting advice. Trial & error approach. Comparing & integrating information with existing appraisals, experiences and contextual factors to determine responses. **Thinking work to cope (believed attitudes affected their behaviour & that of their daughter):** Separating anorexia from person: aided empathy & enabled parents to act contrary to daughter's wishes (attributing resistance to AN). Thinking positively: one day at a time & trying not to dwell on secondary issues. Resisting guilt/self-blame. Realistic expectations regarding the future & recovery process. Acceptance. **Capacity work (maintaining ability to care):** Managing other activities (sacrifice or reorganisation) to cope with AN demands. Skill learning to manage behaviours (e.g. negotiation & becoming stricter).

	Working together to deal with AN. Utilising social or practical support. Self-care (although difficult due to AN demands). setting boundaries.
Winn et al, (2004) Study 9	**Experience of services: Service provision:** care unavailable (lack specialist services, support groups & aftercare). Mixed experiences regarding information. **Treatment access:** waiting for treatment (some reported rapid access); difficulty negotiating the system. **Evaluation of treatment:** Incorrect treatment approach, perceived as ineffective. (Some reported good treatment). **Carer involvement**: Confidentiality led to lack of communication. Frustration - unable to offer information to support treatment. Some positive accounts of involvement. **Quality of services:** Some reported lack of ED expertise, others that expertise was available. Generally positive view of GP service. Unprofessional staff encounters reported. **Support received by carers: Family & friends:** working together helped individual and carer to cope. Supportive extended family/friends. Limited support network due to lack of ED understanding, unsympathetic responses & shame. **Health care professionals/services:** Support groups generally helpful. Some benefited from individual therapy; others found this unbeneficial/unnecessary. **Carers' needs For information:** regarding understanding of ED & treatment approaches. Insufficient information & lack ED publicity. **For guidance:** advice/reassurance. Unsure doing right thing. **To talk about difficulties.** Believed support group would reduce isolation & be an opportunity to share information/experiences with individuals who understood.
Tierney (2005) Study 10	**Accessing services:** AN symptoms increased, realised unable to cope (anxious, disempowered) sought professional input. Multiple visits to GP as AN dismissed/misdiagnosed. Diagnosis led to alarm. No information provided. Proactive & searched for information. Lack of appropriate service provision. Professionals with little specialist experience, lack of input/activities. Hospitalisation = initial relief & guilt, daughter consumed thoughts. Emotional/physical toll of regular visits. Not available for siblings. **Attitudes towards psychosocial interventions:** Most valued family therapy. Concern treatment overly focused on food. **Encounters with professionals:** Lack of information regarding treatment (despite requests) left parents isolated (hindering caring competency). Multiple professionals but poor joint working. Rigid approaches. All could rely on one professional (sympathetic & supportive). **Perceived progress:** Uncertainty about prognosis/course. Frustration with lack of progress. Unrealistic initial expectations. Remaining positive. Progress enabled parents to move away from AN. Anxiety regarding relapse. Relapse = anguish. Emotionally encouraging individual. Child in treatment = future orientated thinking difficult.
McMaster et al, (2004) Study 11	**Finding help:** Skills utilised to find information. Difficulty sourcing formal support, help elicited from support organisations. Added stress & frustration. Relief upon securing help. Excluded from treatment, feelings of isolation/anger. Unhelpful information/consultation from health professionals. **Feeling 'shut out':** discouraged from involvement in treatment, 'wall of silence'. Contrast to discharge - left to cope with care. Exclusion compounded feelings of self-blame. **Engagement with health professionals**: Negative interactions. Occasional positive interactions reported. **Images portrayed by health professionals:** Aware of health professionals holding stereotypes of ED patients (e.g. manipulative). Feeling scrutinized/alienated. Negative experiences led to resentment. **Being resourceful & finding alternatives:** Initial relief, followed by distress at having to find alternative help. After discharge managing care alone, lonely.

	Formal support network. **Not giving up:** overcoming obstacles & burdens for individual's recovery.
Whitney et al (2005) Study 12	**Illness perceptions: characteristics of AN:** confused as to cause. Self-blame (e.g. aspects of upbringing). Perceived illness as chronic & pessimistic about recovery. Negative perceived AN consequences (physical, social & psychological). Daughter perceived as demanding & dependent. **patient, carer & treatment control**: Believed patient had ability to overcome AN. Others perceived child as 'victim' of AN with no control. Parents own helplessness in controlling AN (e.g. unproductive attempts). Relief daughter receiving treatment. **illness coherence:** Perplexed regarding underlying mechanisms of AN despite attempts to understand it. Bewilderment due to complexity & severity of AN. **Impact of the illness: effect on family:** Manipulated & controlled by AN. Dependent relationship (over-involvement) & unreasonable demands. Conflict. Impact on carers' mental/physical health. Difficulty making plans. **Emotional & cognitive processes: emotional response:** negative emotions (sadness, fear, distress, anger, hostility, self-blame, guilt, failure, inadequacy, hopelessness), preoccupation and sleep deprivation. Angry at stigma. Reluctance to discuss AN due to stigma. Mothers: support from empathetic close friends. Fathers: express greater affection towards daughter & desire to support them. **Cognitive strategies:** hope & optimism, distraction, cognitive restructuring. Wishful thinking. Externalising AN. **Maladaptive beliefs:** Self-blame (causal misperception), efficacy misperceptions (helplessness & patient blame). **Maladaptive responses:** Exaggerated responses: overprotective or over-anxious responses.
Cottee-Lane et al, (2004) Study 13	**Understanding the ED: Slow recognition** (due to not knowing enough). Recognition when symptoms escalated. Guilt at not being aware & accessing earlier treatment. Failure of GPs to recognise symptoms (misattributed), aggrieved at treatment delay. **Analysing it:** Desire & effort to understand AN (causes & maintaining factors). Attempts to further knowledge. Articulated multitude possible triggers & predisposing factors but remained perplexed. **The impact of the eating disorder The dreadful monster:** Negative effect of AN – taking over & controlling child. Personality change/unrecognizable. Devious behaviour. Sadness/distrust. Difficulty managing behaviour whilst maintaining positive relationship. Fear relapse. **High stakes:** concern & distress child's well-being (risk death). Concerns about social development, loss of activities. **A living nightmare:** Pervasive & overwhelming, family life disrupted (revolving around attempts to feed), Life style changes – giving up activities/life on hold. Mealtimes stressful, battleground & time consuming. Tried to maintain normality. Parents exhausted physically/mentally. **Managing the ED & its impact: You can lead a horse to water:** Encouraging child to gain weight & reduce exercise. Difficult to influence child. AN leading child to sabotage their efforts. Efforts ineffective - parental frustration, fear & desperation. Not knowing what to do. Seeking advice from others (including professionals). Conflicting advice - confused. Good advice from specialists. **Taking control to manage AN.** Being firm, consistent & united. Agreeing mealtime strategy. Child initially resistant. Delicate process. No choice. **Support & understanding:** essential to coping. Support from partners/friends/parents & specialists. Not easy to find support. Sources support lacked understanding. Opportunities to connect with other parents invaluable.
Perkins et al, (2004) Study 14	**Impact of discovery:** Gradual process of detection. Suspicions dismissed by individual. Difficulty distinguishing ED behaviours. Self-blame (should have identified ED sooner). Powerful & negative emotions upon discovery & helplessness. **Ongoing impact of caregiving: Emotional & physical responses:** Majority mothers felt responsible but most believed not fault. Pervasive negative emotions throughout caring. Some felt unable to cope. Impacted on health. Progress = relief.

	Practical difficulties: food-related activities (mealtimes, buying certain foods, hiding food). Financial impact. **Relationships:** BN as emotional barrier, difficulties communication & managing BN behaviours. Dependency of the individual. Reassuring individual (stressful). Negative impact on other family relationships, neglecting others. **Lost opportunities:** regret for individual & own lost opportunities. **Coping strategies:** positive thinking, acceptance, maintaining own interests, acquiring information, avoiding certain thoughts. Partners: taking step back & allowing individual to take control of ED. **Positive impact:** Closer to the cared for person. Family relationships improved/closer. Increased strengths. Skills to manage own difficulties/better understand others.
Huke & Slade (2006) Study 15	**Living with secrecy & deception: Valuing openness by sometimes getting secrecy:** hurtful, difficulty trusting, struggling to understand. Few empathised with shame. **Strain of not knowing:** (due secrecy/deception). Feeling powerless. **Questioning whether others should know:** Mixed feelings. Shame = reluctance to tell family/friends. Burden covering up for partner. **Struggling to understand & find reasons Wanting to know:** attempts to learn more (talking partner/reading). **Not feeling able to understand:** Struggling to make sense of ED despite efforts to understand. **Attributing responsibility and blame:** Spectrum beliefs: separate entity (carer externalised negative emotions/empathised); believing partner should control ED/responsible (blaming response). Beliefs changed over time/oscillates. Belief & attributions influence responses. **Discovering your powerlessness Concern for partner & trying to create change:** Attempting to Influence behaviour (directly/indirectly) led to confrontation and carer frustration/anger. **Feeling you may make things worse:** (tip toe around, walking on eggshells, avoid conflict). Unable to express difficult feelings/thoughts fear of exacerbating ED. **Emotional experience of powerlessness:** unable to help (feeling useless, frustrated, angry & disappointed). Lack of control. **Learning to stand back:** Believing unable to influence behaviour – leave to professionals/partner **It's like growing to live with it Deciding on degree of involvement:** supporting partners. Involvement varied. **Feeling things are getting better** but recognising progress gradual. Treatment = Hope. **Needing to accept their partner's eating difficulties** (reflecting things could be worse & making downward comparisons). **Experiencing strains and strengths in relationship Perception of level of impact:** Carer & relationship strain due to BN. Extent varied. **Living with the low mood and insecurity:** Carer mood interdependent on partners. Concerned about how to respond to partner's reassurance seeking ("draining/tiring"). **Impact on intimacy:** Few described strained intimacy. **Strengths in relationship:** Wanting to be there. Respect for partner. Feeling close to them. Good times helping keep them together.
Areemit et al, (2010) Study 16	**Struggling to understand ED:** Efforts to understand ED. Conflicting simultaneous appraisals: ED for attention & not being able to help it. **Acute awareness ED:** Sensitized to statements about size/shape. **Challenges understanding non-ED behaviours:** obsessive behaviours bothered siblings more than ED. **Increased family conflicts:** Parents arguing with sibling & one another. Negotiation & secrecy in conflicts. Sibling bribed to eat = unfair. Witnessed sibling's lies regarding food/exercise. Undisclosed due to Loyalty to sibling & avoiding arguments. Stressful mealtimes/family activities. Some thought ED brought family closer together. **Compassion/concern:** Physical changes frightening & worry regarding risks (death). Wanting to protect & defend sibling. Compassion for other families with ED. Frustration/unsympathetic at times. **Feelings of loss & sacrifice:** loss family, normal childhood, sibling relationships & identity. Role change, feeling responsible (for themselves & sibling). Parental

	expectations. Feeling excluded/uninformed regarding ED. Avoiding emotional disclosures (to avoid attention), becoming undemanding – silent child. Some understood more about themselves due to ED. **Sense of responsibility:** Self-blame/fear contributing to ED. Conflict witnessing ED behaviours – divided loyalties to sibling & parents. Felt responsible ED/helping parents. Monitoring/supervising roles. Confronting parents when sibling 'gets away' with ED behaviours. **Pervasiveness ED:** all aspects life (family, home, school, activities, mood and identity). **Duality:** Ally with parents or sibling. Simultaneous/oscillating beliefs. Love & compassion & anger & frustration. Hope & despair. Wanting control but feeling powerless. Wanting to help and to run away. ED = family distress & brought families closer.
Dimitropoulos et al, (2009) Study 17	**Mediator & protector:** between sibling & family, particularly in times of family conflict. Recognised vulnerability of sibling. Perceived parental ineffectiveness contributed to this role. **Familial factors influencing/reinforcing above role: Denial of illness:** parents ignoring signs AN. Invalidation of concerns. Did not seek emotional support from parents about symptoms. Family conflict/tension. **Inconsistent family responses:** Conflict from different approaches within family. Siblings avoided discussing AN to avoid conflict. **Accommodation/enabling:** disagreed with responses, perceived to fuel AN. Differential parental treatment/expectations = resentment/frustration. **Parents eliciting sibling assistance:** In caring. Did not breach sibling confidentiality unless danger perceived or unable to manage. **Sense of loyalty/compassion for parents:** Concern for parents. AN interfered parents' quality of life & parental self-blame preventing clear boundaries between them & AN. **Consequences & benefits of ED to sibling:** ED symptoms= negative emotions (fear, anger/anguish). Concealment/denial difficult remaining close to AN sibling. Lack of normality. Powerlessness/helplessness regarding changes in sibling. Siblings own physical/emotional health affected. Closer to AN sibling. Families strengthened/resilient. Increased knowledge/compassion. Broadening own support network to cope. **Coping strategies:** Externalising illness (could relate to AN sibling better, reduced anger). Distance/disengaging from sibling if overwhelmed for own well-being. Firm boundaries (own preservation). Utilised support (extended family). **Formal Social support:** Professionals should reassure siblings (not to blame/ not responsible). Provide information about AN. Guidance how to communicate AN sibling. Sibling & parent/sibling support groups needed.
Honey & Halse (2006) Study 18	**Maintaining Normality** in daily lives of siblings. **Compensating for changes** in family life by providing activities for siblings, reorganising roles & enlisting support of family/friends. **Providing additional support:** Parental concern about psychological/emotional impact of AN. **Protecting siblings** from AN by withholding information (e.g. seriousness), avoiding conflict when sibling present, removing siblings from situations. **Managing the consequences:** Taking siblings to therapists, addressing sibling issues & feelings, liaising with school.
Latzer, Ben-Ari & Galimidi (2002) Study 19	**Structural processes:** Family focus on AN. Family subsystems formed. **Family dynamic processes:** Changes in family unity. Avoidance of AN discussion within family/conflict. Change in roles – parents supervise eating, siblings parental roles, AN sibling "baby". New patterns interaction: emotional over-involvement, avoidance, anxiety, closeness & distance dynamics. AN sibling's need for support/closeness. Food = interactive component among all members. **Emotional processes:** increased tension/negative feelings – frequent food related conflicts. Parents sad/tense. AN sibling variable/unstable. Siblings = declining omnipotence. **Change in life functions:** Decline in daily functioning (school, motivation for activities).

	Body Image: Negative about dieting (uncontrollable). Ambivalent about thinness, body as changeable. **Narrative of the illness: Fear** (sibling & parents losing individual). AN as new member of the family: influencing/dominating all. **Duality:** being torn between emotional extremes. AN leading to dysfunctional symptoms in family.
Garley & Johnson (1994) Study 20	**Perspective:** <u>Understanding AN:</u> (struggling) – need for more information/inadequate knowledge. AN Appraisals: attention seeking/manipulative. <u>Effect on self:</u> negative comparisons to AN sibling. (body/eating/will power). <u>View of future</u>**:** thoughts of loss. Optimistic view, some ambivalence about recovery. **Disruption:** shifts in family relationships, intense conflict/chaotic environment, intrusiveness of AN, loss, neglect, anguish (due to emotional realignment in family). Closer to sibling/more distant. **Role strain:** responsibility/need to care/mothering role (burden). Self-blame. Protectiveness (AN sibling as vulnerable). Feeling impotent. **Special status:** AN sibling privileged family position – more attention/indulged. Injustice, frustration, resentment. Mothers consumed – overlooked their needs. Expected to adapt to needs of ill sister. Suppressing own feelings. **Coping with the illness:** feeling overwhelmed by expectations. Frustrated/unfairly treated. Normalise, accommodate or avoid AN. Support from outside immediate family. Withhold emotions from family (overburdened). Occasional positives: personal maturation, empathy. **Pervasiveness** (all-encompassing, unable control involvement, inescapable) **& conflicting emotions** (torn between feelings pity/empathy & resentment/anger = leading to guilt/self-reproach).

Appendix 8.

Ethics Committee Approval Letter

Ethical Approval Letter

NRES Committee North West - Greater Manchester East

3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7820
Facsimile: 0161 625 7299

07 January 2013

Mrs Anna Ajulo
Division of Clinical Psychology
University of Manchester
2nd Floor Zochonis Building
Brunswick Street
 Manchester
M13 9PL

Dear Mrs Ajulo

Study title:	**Enabling in Anorexia: A Qualitative Study**
REC reference:	**12/NW/0888**
IRAS project ID:	**121295**

Thank you for your e-mail of 04 January 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.   The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator: Elaine Hutchings, nrescommittee.northwest-gmeast@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Advertisement		02 January 2013
Evidence of insurance or indemnity		
Interview Schedules/Topic Guides	3	02 January 2013
Investigator CV	Mrs Anna Ajulo	31 October 2012
Investigator CV	Mr John Fox	31 October 2012
Investigator CV	Dr Julia Coleby	
Letter from Sponsor		29 November 2012

Letter of invitation to participant	Beat Version 3	02 January 2013
Other: Conditions of sponsors sign-off FMHS	3	30 August 2011
Other: University Subcommittee approval letter		21 December 2011
Other: Brief Symptom Inventory (BSI) & article		
Other: Beat & Clinic recruitment flowchart	4	02 January 2013
Other: Contact Numbers	2	02 January 2013
Other: Protocol Safe Visiting	2	02 January 2013
Other: Protocol Risk and Distress	3	02 January 2013
Participant Consent Form: Carer consent form	3	02 January 2013
Participant Consent Form: Contact consent form	2	02 January 2013
Participant Consent Form: Post Interview Consent Form	2	02 January 2013
Participant Information Sheet: Clinic Carer Participant Information Sheet	3	02 January 2013
Participant Information Sheet: Beat Carer Participant Information Sheet	3	02 January 2013
Participant Information Sheet: Online Information sheet and contact form	3	02 January 2013
Protocol	4	02 January 2013
Questionnaire: Demographic Questionnaire	2	02 January 2013
Questionnaire: Inclusion & Exclusion checklist	2	02 January 2013
REC application	121295	29 November 2012
Response to Request for Further Information		04 January 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review
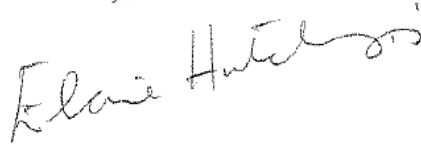
12/NW/0888	Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

Elaine Hutchinson

pp

Mr Francis Chan
Chair

Email:nrescommittee.northwest-gmsouth@nhs.net

Enclosure: "After ethical review – guidance for researchers"

Copy to: *Mrs Catherine Barrow, University of Manchester*

                  Professor Joe Reilly, Tees Esk & Wear Valleys NHS Foundation Trust

Substantial Amendment Approval

NHS
Health Research Authority

National Research Ethics Service
NRES Committee North West - Greater Manchester East

3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7831
Fax: 0161 625 7299

12 February 2013

Mrs A Ajulo
Division of Clinical Psychology
University of Manchester
2nd Floor Zochonis Building
Brunswick Street
 Manchester
M13 9PL

Dear Mrs Ajulo

Study title:	**Enabling in Anorexia: A Qualitative Study**
REC reference:	**12/NW/0888**
Amendment number:	**121295/411094/13/479/17776**
Amendment date:	**06 February 2013**
IRAS project ID:	**121295**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The Committee found no ethical issues with this amendment.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	Version 5	30 January 2013
Notice of Substantial Amendment (non-CTIMPs)	121295/411094/13/479/17776	06 February 2013

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

12/NW/0888:	Please quote this number on all correspondence

Yours sincerely

Signed on behalf of
Mr Francis Chan
Chair

E-mail: nrescommittee.northwest-gmeast@nhs.net

Enclosures:	List of names and professions of members who took part in the review
Copy to:	Professor Joe Reilly, Tees Esk & Wear Valleys NHS Foundation Trust
	Mrs Catherine Barrow, University of Manchester

Appendix 9.

Invitation to participate (Beat Carers)

Letter inviting 'Beat' carers to participate

Division of Clinical Psychology
University of Manchester
2nd Floor Zochonis Building
Brunswick Street
M13 9PL
07716469268
0161 3060400

Dear **insert carer's name**,

Re: Research study - A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa

We are writing to all individuals registered on the Beat Network caring for an individual with Anorexia Nervosa, to inform you about the above named research study running at the University of Manchester and approved by an NHS ethics committee. We are writing to you as you may be eligible to take part in this research.

The findings of this study may identify helpful ways of interacting and supporting an individual with Anorexia Nervosa; it is hoped the research findings will inform workshops to support carers in this task.

We understand that caring for someone with Anorexia can be a positive experience and also recognise that it can carry with it a lot of responsibility and burden due to the nature of the illness. At times the carer may understandably feel overwhelmed and cope by reacting in a variety of ways to the individual they care for; some of these may be more or less helpful. This study will look at the different ways carers interact with an individual with anorexia, in particular assisting with the person's anorexia related behaviours as much less is known about this. For example, the carer might organise their life around the person's eating habits and by doing so, these behaviours may become a typical part of family life.

Using an interview, this study aims to find out more about how carers experience, respond to and describe the anorexia related behaviours of the person they care for. It will also ask about the impact caring for someone with anorexia has on you and your family in terms of your relationships, feelings and caregiver burden. Sharing your experiences might increase understanding in this area and it is hoped this will help professionals to better support carers and families of people suffering with Anorexia.

Taking part in this study will involve being interviewed informally by the researcher. This interview will last between 60-90 minutes and will take place at the University of Manchester. If you are unable to travel, the researcher could visit you at your home to conduct the

185

interview.   The conversation will be audio taped so the researcher can listen to it and transcribe it for the purposes of the research.

If you would like to be contacted by the researcher to discuss the study and participation please complete and return the enclosed contact consent form in the stamped addressed envelope provided. Alternatively, you can complete this form online: https://apps.mhs.manchester.ac.uk/surveys/Default.aspx and entering survey id number 98LHlp51

Please do not hesitate to contact the researcher directly if you have any further questions or wish to discuss the study. The researcher, Anna Ajulo can be contacted at the Division of Clinical Psychology, 2nd Floor Zochonis Building, University of Manchester, Brunswick Street, M13 9PL, telephone 07716469268 or 0161 3060400, e-mail anna.ajulo@postgrad.manchester.ac.uk.

Thank you for taking the time to read this letter,

Yours Sincerely,

Anna Ajulo
Trainee Clinical Psychologist

A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa

Beat Carer Letter Version 3, December 2012

Appendix 10.

Beat Participant Information Sheet

Carer's Participant Information Sheet

Study Title: A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa.

Researchers: The research study involves undertaking an interview. The chief investigator is a Trainee Clinical Psychologist, Anna Ajulo based at the University of Manchester and employed by Manchester Mental Health and Social Care Trust.

The researcher is supported by a research team of clinical psychologists, Dr John Fox (academic supervisor) from the University of Manchester and Dr Julia Coleby (field supervisor) employed by Tee Esk and Wear Valleys NHS Foundation Trust.

Contact Details: Anna Ajulo, Division of Clinical Psychology, 2nd Floor Zochonis Building, Brunswick Street, M13 9PL. **Telephone**: 0161 3060400 or 07716469268 **E-mail: anna.ajulo@postgrad.manchester.ac.uk**

Thank you for taking the time to read this information sheet. We would like to invite you to take part in a research study for carers of individuals with Anorexia Nervosa. Before you decide whether to take part it is important you understand why the research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with others if you wish. If any of the information is unclear or you would like further information please contact me. Please take your time to decide whether you wish to take part (we recommend a minimum of 48 hours).

What is the purpose of the study?
We understand that caring for someone with anorexia can be a positive experience and it can also carry with it a lot of responsibility and burden due to the nature of the illness. At times the carer may understandably feel overwhelmed and cope by reacting in a variety of ways to the individual they care for; some of these may be more or less helpful. This study will look at the different ways carers interact with an individual with anorexia, in particular assisting with the person's anorexia related behaviours, as much less is known about this. For example, the carer might organise their life around the person's eating habits and by doing so, these behaviours may become a typical part of family life.

188

Using an interview, this study aims to find out more about how carers experience, respond to and describe the anorexia related behaviours of the person they care for. It will also ask about the impact caring for someone with anorexia has on you and your family in terms of your relationships, feelings and caregiver burden. Questions will also enquire about your view of how severe the anorexia is. Sharing your experiences might increase understanding in this area and help professionals to better support carers and families of people suffering with Anorexia.

Why have I been asked to take part?
You have been invited to take part because you are a main carer for an individual diagnosed with Anorexia Nervosa and are registered on the Beat carer's network. Alternatively, you may have viewed the study advertisement on the Beat website. It is felt that you could make a valuable contribution to the research project by sharing your experiences of caring for an individual with Anorexia.

Do I have to take part?
No. It is up to you whether you decide to take part or not. Participation is entirely voluntary. If you decide to take part you will be given a copy of this information sheet by the researcher and asked to sign a consent form. You are free to withdraw from the study at any time (even if you have signed the consent form) and you do not need to give a reason why. If you decide not to take part or decide to withdraw from the study, this will not affect the standard of care you or the individual you care for receives.

If you would like to be contacted by the researcher to discuss the study and participation please complete and return the enclosed contact consent form. This can also be completed online by going to: https://apps.mhs.manchester.ac.uk/surveys/Default.aspx and entering survey id number 98LHlp51

Alternatively, you can contact the researcher directly to discuss the study.

What will it involve for me?
If you wish to take part in the study and are eligible to participate, a convenient time to meet with you will be arranged. You will read through this information sheet and will be given the opportunity to ask questions. If you still wish to take part you will sign a consent form agreeing to participate. Two questionnaires will be given to you to answer: one asking about your demographic information and another about your emotional wellbeing and any symptoms of distress over the past week. These will take approximately 15 minutes to

complete. You will then be interviewed informally by the researcher. This interview will last between 60-90 minutes and will take place in a private room at the University of Manchester. Reasonable travel expenses incurred by taking part in the study will be reimbursed, provided receipts are supplied where applicable. If you are unable to travel, the researcher could visit you at your home to conduct the interview. Interview questions will ask about your mood, caregiver burden, the severity of the anorexia, emotional expressiveness and how you respond to the anorexia related behaviours of the person you care for. The conversation will be audio taped so the researcher can listen to it and transcribe it for the purposes of the research. Once the interview is finished you will be asked to sign another consent form confirming that you still wish to participate. This consent form will also ask you whether you would be willing to check the emerging findings of the study known as a 'member check', this is completely optional. If you select 'yes' you will be sent a summary of the developing study findings for comment.

Will the information be confidential and anonymous?

Yes, all the information you give will be kept strictly confidential and will not be shown to, or shared with anyone outside of the research team. All information will be anonymised using a coding system. This means your identity will remain private. All data will be stored securely at the University of Manchester. Tapes will be destroyed at the end of the study. Direct quotes may be used in the write-up of the study, but will be used in such a way so as not to reveal the identity of individuals.

Limits to confidentiality:

All information will remain confidential. However, should you disclose anything which raises concerns about possible harm coming to you or others, than this information may need to be shared with the relevant individuals or agencies to keep you or others safe. You will be asked on the consent form to provide details of your GP for this purpose. This information will be removed after participation if it is not required. Any identified risks will initially be discussed in supervision with the researcher's academic or field supervisor (both experienced clinicians) and advice followed. If it is deemed appropriate you may be contacted and encouraged to speak to your GP and to access other support services. If the risks raised relate to the protection of vulnerable adults, these would be reported to social services or the relevant safeguarding team. Where possible, you will be kept informed of all actions taken.

Data Monitoring

Relevant sections of the data collected during the study may be looked at by individuals from the University of Manchester or from regulatory authorities, where it is relevant to your taking part in this research. This is for data monitoring purposes only.

Capacity to consent

If you consent to be contacted by the researcher to discuss your possible participation and it is found that you are no longer able to give your informed consent to participate, then no further contact will be made.

What are the possible advantages and disadvantages of taking part in the studies?

The interview may give you a chance to reflect on your own experiences of caring for an individual with anorexia and the impact this has on you and your family. We hope that the information you provide may give us a greater understanding of the helpful ways of interacting and supporting a person with anorexia; information which may be used by mental health professionals to better support carers in this complex task and inform the development of carer workshops.

It is possible that disclosing your personal experiences may result in some distress. The researcher interviewing you will be sensitive to this and if necessary may stop the interview. If you become distressed you may stop the interview at any time without having to provide a reason. If you have any concerns during or following the interview you will have the opportunity to discuss these. If necessary, you will be able to contact one of the clinical psychologists on the research team to discuss any concerns regarding the research or speak to your GP. Alternatively, please call the Beat helpline on 0845 634 1414 or e-mail: help@b-eat.co.uk. Additionally you will be given a list of support services and their contact numbers. You are free to withdraw from the study at any point, without having to provide a reason why.

What if there is a problem?

If you have any concerns regarding any aspect of this study, you should speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University of

Manchester Research Practice & Governance Co-ordinator on 0161 2757583 or 0161 2758093 or e-mail research-governance@manchester.ac.uk

What will happen to the results of the research study?

It is intended that the results of the study will be published in a relevant peer-reviewed scientific journal and other publications accessed by health professionals and service users. All participants are able to receive a copy of the results. Results will be fed back to staff at the research sites and presented at relevant conferences.

Who has reviewed the studies?

This research has been reviewed and approved by the National Research Ethics Service (NRES) Committee North West – Greater Manchester East. This NHS ethics committee protects the rights, safety and well being of participants.

If you would like any further information or to speak to a member of the research team, please telephone: 07716469268 / 0161 3060400, e-mail: anna.ajulo@postgrad.manchester.ac.uk or write to: Division of Clinical Psychology, 2nd Floor Zochonis Building, Brunswick Street, M13 9PL.

If you would like a member of the research team to contact you about participating in the study please complete and return the enclosed contact consent form (also available online) and provide your contact details.

THANK YOU FOR YOUR TIME.

Please retain this information sheet for your records.
Participant Information Sheet (Beat Carers)

A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa.

Beat Carer Participant Information Sheet (PIS) version 3, December 2012

Appendix 11.

Contact Consent Form

CONTACT CONSENT FORM

Study Title: **A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa**

Name of researcher: Anna Ajulo, Trainee Clinical Psychologist, University of Manchester.

Name (please write your name)...

Please Initial Box

1. I confirm that I **would like** to be contacted by the researcher to discuss the above named study and possible participation.

2. I understand that my decision to be contacted by the researcher is voluntary and will not affect whether or not I decide to take part in the study.

3. If you consent to be contacted, please indicate how you would like the researcher to contact you (please tick).

   Telephone (daytime) ☐   **Telephone (evening)** ☐

   E-mail ☐   **Post** ☐

4. Please provide the relevant contact details for the researcher to contact you:

   Address: ....
   City/Town: ....
   County: ....
   Post Code: ....
   Telephone (Daytime): ....
   Telephone (Evening): ....
   E-mail: ....

5. I agree to be contacted by the researcher to discuss the above named research study and possible participation.

_____   _____   _____
   Name of Participant   *Date*   *Signature*

1 copy for signatory; 1 copy for the researcher

A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa

Contact Consent Form Version 2, December 2012   1

Appendix 12.

Study Advertisement

Carer Study:
'A qualitative study examining the ways in which carers respond when caring for people with Anorexia Nervosa.'

Are you a Carer of an individual with Anorexia Nervosa?
Then you may be eligible to take part in this study for carers run by researchers at the University of Manchester.

The findings of this study may identify helpful ways of interacting with, and supporting an individual with Anorexia Nervosa; it is hoped the research findings will inform workshops to support carers in this task. This study will look at the different ways carers interact with the person they care for. Carers will be asked to take part in a tape-recorded interview with the researcher which will take approximately 60-90 minutes. The interview will ask you about how you experience, respond to and describe the anorexia related behaviours of the person you care for. It will also ask about the impact caring for someone with anorexia has on you and your family in terms of your relationships, feelings and caregiver burden.

To find out more information please log on to
https://apps.mhs.manchester.ac.uk/surveys//TakeSurvey.aspx?SurveyID=98LHlp51 to view the participant information sheet. If you are interested in participating in the study and would like the researcher to contact you to discuss this, please complete the online contact consent form. Alternatively, please feel free to contact the researcher directly to discuss the study using the contact details below.

If you have any questions about this study please contact the researcher Anna Ajulo (Trainee Clinical Psychologist) at: Division of Clinical Psychology, 2nd Floor Zochonis Building, University of Manchester, Brunswick Street, M13 9PL, 0161 3060400, 07716469268, anna.ajulo@postgrad.manchester.ac.uk
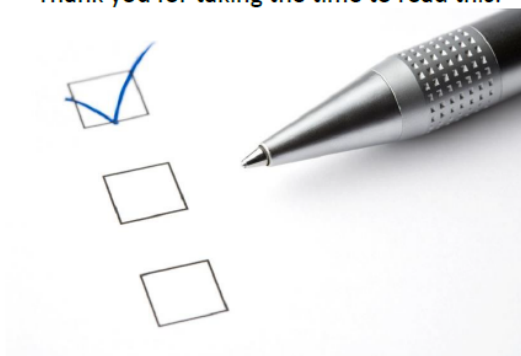
Thank you for taking the time to read this.

A qualitative study examining the ways in which carers respond when caring for people with Anorexia Nervosa.
Beat advert Version 3, December 2012

Appendix 13.

Clinic Participant Information Sheet

Carer's Participant Information Sheet

Study Title: A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa

Researchers: The research study involves undertaking an interview. The chief investigator is a Trainee Clinical Psychologist, Anna Ajulo based at the University of Manchester and employed by Manchester Mental Health and Social Care Trust.

The researcher is supported by a research team of clinical psychologists, Dr John Fox (academic supervisor) from the University of Manchester and Dr Julia Coleby (field supervisor) employed by Tee Esk and Wear Valleys NHS Foundation Trust.

Contact Details: Anna Ajulo, Division of Clinical Psychology, 2nd Floor Zochonis Building, Brunswick Street, M13 9PL. **Telephone**: 07716469268 or 0161 3060400
E-mail: anna.ajulo@postgrad.manchester.ac.uk

Thank you for taking the time to read this information sheet. We would like to invite you to take part in a research study for carers of individuals with Anorexia Nervosa. Before you decide whether to take part it is important you understand why the research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with others if you wish. If any of the information is unclear or you would like further information please contact me. Please take your time to decide whether you wish to take part (we recommend a minimum of 48 hours).

What is the purpose of the study?
We understand that caring for someone with anorexia can be a positive experience and it can also carry with it a lot of responsibility and burden due to the nature of the illness. At times the carer may understandably feel overwhelmed and cope by reacting in a variety of ways to the individual they care for; some of these may be more or less helpful. This study will look at the different ways carers interact with an individual with anorexia, in particular assisting with the person's anorexia related behaviours, as much less is known about this. For example, the carer might organise their life around the person's eating habits and by doing so, these behaviours may become a typical part of family life.

Using an interview, this study aims to find out more about how carers experience, respond to and describe the anorexia related behaviours of the person they care for. It will also ask about the impact caring for someone with anorexia has on you and your family in terms of your relationships, feelings and caregiver burden. Questions will also enquire about your view of how severe the anorexia is. Sharing your experiences might increase understanding in this area and help professionals to better support carers and families of people suffering with Anorexia.

Why have I been asked to take part?
You have been invited to take part because you are a main carer for an individual being treated for Anorexia Nervosa at Priory Hospital Cheadle Royal, Priory Hospital Preston or West Park Hospital. It is felt that you could make a valuable contribution to the research project by sharing your experiences of caring for an individual with Anorexia.

Do I have to take part?
No. It is up to you whether you decide to take part or not. Participation is entirely voluntary. If you decide to take part you will be given a copy of this information sheet by the researcher and asked to sign a consent form. You are free to withdraw from the study at any time (even if you have signed the consent form) and you do not need to give a reason why. If you decide not to take part or decide to withdraw from the study, this will not affect the standard of care you or the individual you care for receives.

If you would like to be contacted by the researcher to discuss the study and participation please complete and return the contact consent form. This can also be completed online by going to: https://apps.mhs.manchester.ac.uk/surveys/Default.aspx and entering survey id number 98LHlp51

Alternatively, you can contact the researcher directly to discuss the study.

What will it involve for me?
If you wish to take part in the study and are eligible to participate, a convenient time to meet with you will be arranged. You will read through this information sheet and will be given the opportunity to ask questions. If you still wish to take part you will sign a consent form agreeing to participate. Two questionnaires will be given to you to answer: one asking about your demographic information and another about your emotional wellbeing and any symptoms of distress over the past week. These will take approximately 15 minutes to complete. You will then be interviewed informally by the researcher. This interview will last

between 60-90 minutes and will take place in a private room at the clinic, or alternatively at the University of Manchester. Reasonable travel expenses incurred by taking part in the study will be reimbursed, provided receipts are supplied where applicable. If you are unable to travel, the researcher could visit you at your home to conduct the interview. Interview questions will ask about your mood, caregiver burden, the severity of the anorexia, emotional expressiveness and how you respond to the anorexia related behaviours of the person you care for. The conversation will be audio taped so the researcher can listen to it and transcribe it for the purposes of the research. Once the interview is finished, you will be asked to sign another consent form confirming that you still wish to participate. This consent form will also ask you whether you would be willing to check the emerging findings of the study known as a 'member check', this is completely optional. If you select 'yes' you will be sent a summary of the developing study findings for comment.

Will the information be confidential and anonymous?

Yes, all the information you give will be kept strictly confidential and will not be shown to, or shared with anyone outside of the research team. All information will be anonymised using a coding system. This means your identity will remain private. All data will be stored securely at the University of Manchester. Tapes will be destroyed at the end of the study. Direct quotes may be used in the write-up of the study, but will be used in such a way so as not to reveal the identity of individuals.

Limits to confidentiality:

All information will remain confidential. However, should you disclose anything which raises concerns about possible harm coming to you or others, than this information may need to be shared with the relevant individuals or agencies to keep you or others safe. You will be asked on the consent form to provide details of your GP for this purpose. This information will be removed after participation if it is not required. Any identified risks will initially be discussed in supervision with the researcher's academic or field supervisor (both experienced clinicians) and advice followed. If it is deemed appropriate you may be contacted and encouraged to speak to your GP and to access other support services. If the risks raised relate to the protection of vulnerable adults, these would be reported to social services or the relevant safeguarding team. Where possible, you will be kept informed of all actions taken.

Data Monitoring

Relevant sections of the data collected during the study may be looked at by individuals from the University of Manchester or from regulatory authorities, where it is relevant to your taking part in this research. This is for data monitoring purposes only.

Capacity to consent

If you consent to be contacted by the researcher to discuss your possible participation and it is found that you are no longer able to give your informed consent to participate, then no further contact will be made.

What are the possible advantages and disadvantages of taking part in the studies?

The interview may give you a chance to reflect on your own experiences of caring for an individual with anorexia and the impact this has on you and your family. We hope that the information you provide may give us a greater understanding of the helpful ways of interacting and supporting a person with anorexia; information which may be used by mental health professionals to better support carers in this complex task and inform the development of carer workshops.

It is possible that disclosing your personal experiences may result in some distress. The researcher interviewing you will be sensitive to this and if necessary may stop the interview. If you become distressed you may stop the interview at any time without having to provide a reason. If you have any concerns during or following the interview you will have the opportunity to discuss these. If necessary, you will be able to contact one of the clinical psychologists on the research team to discuss any concerns regarding the research or speak to your GP. Alternatively, please call the Beat helpline on 0845 634 1414 or e-mail: help@b-eat.co.uk. Additionally you will be given a list of support services and their contact numbers. You are free to withdraw from the study at any point, without having to provide a reason why.

What if there is a problem?

If you have any concerns regarding any aspect of this study, you should speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University of

Manchester Research Practice & Governance Co-ordinator on 0161 2757583 or 0161 2758093 or e-mail research-governance@manchester.ac.uk

What will happen to the results of the research study?

It is intended that the results of the study will be published in a relevant peer-reviewed scientific journal and other publications accessed by health professionals and service users. All participants are able to receive a copy of the results. Results will be fed back to staff at the research sites and presented at relevant conferences.

Who has reviewed the studies?

This research has been reviewed and approved by the National Research Ethics Service (NRES) Committee North West – Greater Manchester East. This NHS ethics committee protects the rights, safety and well being of participants.

If you would like any further information or to speak to a member of the research team, please telephone: 0161 3060400 / 07716469268, e-mail: anna.ajulo@postgrad.manchester.ac.uk or write to: Division of Clinical Psychology, 2nd Floor Zochonis Building, Brunswick Street, M13 9PL.

If you would like a member of the research team to contact you about participating in the study please complete and return the enclosed contact consent form (also available online) and provide your contact details.

THANK YOU FOR YOUR TIME.

Please retain this information sheet for your records.

A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa

Clinic Carer Participant Information Sheet (PIS) version 3, December 2012

Appendix 14.

Participant Consent Form

MANCHESTER
1824
The University of Manchester

PRIORY

CONSENT FORM

Participant Identification Number for this study *(please leave blank)*: ....

Study Title: A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa

Name of researcher: Anna Ajulo, Trainee Clinical Psychologist, University of Manchester.

Name of Participant (please write your name)...

Please Initial Box

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason. I understand that this will not affect my medical care or legal rights.

3. I understand that all data collected will be anonymised and will not be shared with anyone outside of the research team.

4. I understand that for monitoring purposes, relevant sections of my data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the relevant NHS trust. I give my permission for these individuals to have access to my records.

5. I understand that the interviews will be tape recorded and the tapes transcribed by members of the research team.

6. I understand that the results of the study will be published in a peer reviewed journal and that anonymised quotes may be reported. I understand that all identifiable personal data will be anonymised.

7. I understand that if I disclose any information during the interview which raises concerns regarding my safety or the safety of others, that relevant services may need to be informed, including my GP. Please provide details of your GP for this purpose:

GP's name: .... **GP Telephone Number:**...

Doctor Surgery address: ....

If you would like a copy of the study results please provide an e-mail or postal address:

....

PLEASE TURN OVER

1

A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa
Carer Consent Form Version 3, December 2012

Appendix 15.

Demographics Questionnaire

A qualitative study examining the ways carers respond when caring for individuals with Anorexia Nervosa_Demographics Questionnaire (version 2, December 2012)

DEMOGRAPHIC QUESTIONNAIRE

Thank you, you are eligible to take part in the study. Please complete the demographic questionnaire below
This next section will ask you questions about yourself and the person you care for. This information is for data collection purposes.

1. **Where did you find out about the research project?**
   *
   - ○ B-Eat
   - ○ Westpark Hospital
   - ○ Sion
   - ○ Cheadle Royal
   - ○ Other, please specify

2. **Please state your age?**
   * The value must be greater than or equal to 18.

3. **What is your gender?** *
   - ○ Male
   - ○ Female

4. **What is your Nationality?**

5. **Please describe your ethnicity**

6. **Please state your first language (e.g. English)**

7. **Please select from the list below your current occupational status** *
   - ○ Full time
   - ○ Part Time
   - ○ Self-employed
   - ○ Homemaker
   - ○ Retired
   - ○ Student
   - ○ Unemployed
   - ○ Other, please specify

8. **Please state your current occupation**

9. **Please describe your marital status***
   - Unmarried/single
   - Married
   - Civil Partnership
   - Common Law/living with partner
   - Widowed/survivor of civil partnership
   - Divorced/Dissolved
   - Seperated
   - Other, please specify

10. **What is the highest level of qualification you have received?***
    - No GCSE'S/O'levels
    - GCSE's/O'levels
    - NVQs/A-levels
    - Diploma/vocational qualification
    - Bachelor Degree
    - Postgraduate degree
    - Other, please specify

11. **How many dependents do you have? (Please enter a number)***

12. **Have you ever experienced an eating disorder yourself? If yes, please briefly describe below**

A qualitative study examining the ways carers respond when caring for individuals with Anorexia Nervosa_Demographics Questionnaire (version 2, December 2012)

About the person you care for ...

Below are some questions about the person you care for, please complete these for data collection purposes.

13. **How old was the person you care for when they were first diagnosed with Anorexia Nervosa? (Please enter an approximate number)**

14. **How many years has the individual you care for had anorexia? (Please enter an approximate number)**

15. **If known, how many hospital admissions has the individual you care for had due to anorexia (please enter an approximate number)?**

16. **Is the individual you care for currently receiving treatment for anorexia? If yes, please briefly describe ...**

17. **What gender is the person you care for?***
   - ○ Male
   - ○ Female

18. **What is your relationship to the person you care for? The person I care for is my ...***
   - ○ Son/Daughter
   - ○ Husband/Wife
   - ○ Civil partner
   - ○ Partner
   - ○ Girlfriend/Boyfriend
   - ○ Brother/sister
   - ○ Niece/Nephew
   - ○ Granddaughter/Grandson
   - ○ Cousin
   - ○ Friend
   - ○ Other, please specify

19. **Which category below includes the age of the person you care for?***
   - ○ 17 or under
   - ○ 18-20
   - ○ 21-25
   - ○ 26-30
   - ○ 31-35
   - ○ 36-40
   - ○ 41-45
   - ○ 46-50
   - ○ 51-55
   - ○ 56-60
   - ○ over 60

20. **Please indicate the average number of hours you spend with the person you care for per day?***
   - ○ 1 hour
   - ○ 2 hours
   - ○ 3 hours
   - ○ 4 hours
   - ○ 5 hours
   - ○ 6 hours
   - ○ 7 hours
   - ○ 8 hours
   - ○ 9 hours
   - ○ over 10 hours

21. **Is this contact usually ...***
   - ○ Face to face
   - ○ By telephone
   - ○ Social networking/e-mail
   - ○ Other, please specify

22. **Do you live with the person you care for?**
   - ○ Yes
   - ○ No
   - ○ Other, please specify

23. If known, please state the height of the person you care for (Please state cms or ft and ins)

24. If known, please state the weight of the person you care for (state Kgs or St and lbs) ...

THANK YOU FOR COMPLETING THE QUESTIONNAIRE

Appendix 16.

Safe Visiting Protocol

Protocol for safe visiting

Home visits to potential participants to conduct the research will be avoided where possible. The researcher will endeavour to conduct these during working hours at clinic sites or the University of Manchester. However, for individuals unable to travel either to a clinic site or to the University of Manchester, home visits may be undertaken. In order to minimise risk to the researcher, the following protocol will be adhered to:

Proactive strategy

Prior to any visits, the researcher will supply a nominated member of the research team with the following details: the visiting researcher's contact details including telephone numbers, their car details (make, colour and registration) and next of kin. The participant's home address will be given together with the appointment time. The researcher will arrange to call the nominated individual at a specified time to inform them the appointment has ended and they are 'safe.' No further action will be required.

Reactive strategy

If the visiting researcher fails to call the nominated individual at the agreed time, the nominated individual will attempt to contact the researcher utilising the contact numbers supplied (including next of kin). Should the nominated individual fail to establish contact with the visiting researcher, the police will be notified.

Should the researcher become concerned about risk to themselves during a visit, the researcher will endeavour to politely leave. If this is not possible, the researcher will attempt to call the nominated individual during the appointment and state an emergency code word. Upon hearing this code word, the nominated individual will notify the police.

Page 1

A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa.

Safe Visiting Protocol Version 2, December 2012

Appendix 17.

Post Interview Consent Form

CONSENT FORM

Participant Identification Number for this study *(please leave blank)*: ....

Study Title: A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa.

Name of researcher: Anna Ajulo, Trainee Clinical Psychologist, University of Manchester.

Name of Participant (please write your name)...

Please Initial Box

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason. I understand that this will not affect my medical care or legal rights.

3. I understand that all data collected will be anonymised and will not be shared with anyone outside of the research team.

4. I understand that for monitoring purposes, relevant sections of my data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the relevant NHS trust. I give my permission for these individuals to have access to my records.

5. I understand that the interviews will be tape recorded and the tapes transcribed by members of the research team.

6. I understand that the results of the study will be published in a peer reviewed journal and that anonymised quotes may be reported. I understand that all identifiable personal data will be anonymised.

7. I agree to my interview being used for the above named research study

8. I agree to quotes from the interview being reported and published in a peer reviewed journal.   **Yes** ☐   **No** ☐

9. Would you like to take part in the 'member check'? This is entirely optional. If you select 'yes', you will be sent a summary of the emerging study findings for comment.

        Yes ☐   **No** ☐

_____   _____   _____
    Name of Participant   *Date*   *Signature*

1 copy for participant; 1 copy for the researcher

A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa
Post Interview Consent Form Version 2, December 2012

1

Appendix 18.

Details of Support Services (given to carers)

Participant Contact Numbers

- **Anna Ajulo,** Researcher & Trainee Clinical Psychologist (Monday – Friday 9am-5pm): **07716469268**

- **Dr John Fox,** Research Supervisor/ Lecturer, University of Manchester: **0161 306 0400**

- **Research Complaints:** University of Manchester Research Practice & Governance Co-ordinator **0161 2757583/0161 2758093**

- **Beat helpline** (Monday – Friday 10.30am-8.30pm/Saturdays 1.00pm-4.30pm) **0845 634 1414**

- **Samaritans** (24 hour help) **08457 909090**

- **NHS Direct** (24 hour help) **0845 46 47**

- **Crisis Resolution Home Treatment** (24 hours): **North Manchester: 0161 720 2045**

  South Manchester: 0161 277 1224/ 0161 277 1223

  Central Manchester: 0161 276 5368

- **Manchester Adult and Children's Services: 0161 234 5001**

If urgent please go to A&E or contact your GP

Appendix 19.

Distress Protocol

Protocol for Risk and Emotional Distress

Proactive strategy

Confidentiality will be clearly explained on participant information sheets and consent forms. Exceptions to confidentiality will be specified, such as the identification of risk issues (defined as possible harm to self or others). Interview questions will be sensitively worded to minimise the possibility of emotional distress. Furthermore, as the participant group are carers and not a clinical sample, the vulnerability of the participant group is significantly reduced and is not considered high risk.

All participants will be advised that they can choose whether or not to answer questions and can stop the interview/withdraw from the study at any time (without having to provide an explanation). When giving consent, participants will be asked whether they have a GP and asked to provide their GP's details (it will be made clear that contact with the GP will only be made where risk to self or others is identified). The GP details will be removed once participation is complete.

Reactive strategy

If a risk issue to self or others is identified, or the participant shows emotional distress the interview will be stopped.

In cases of emotional distress the researcher will acknowledge the distress and will ask the participant whether they would like a break or to end the session. The researcher will assess the level of distress. The participant will be encouraged to contact their GP, or emergency GP number if out of hours. The participant will be offered assistance with this if necessary. The researcher will ensure all participants have a GP and will be in possession of their contact details. The individual will also be signposted to other services (please refer to the list of agencies supplied to each participant).

As the research does not include an intervention component, the researcher would not provide any direct psychological intervention for any participant who becomes distressed as a result of the research. However, the researcher as a Trainee Clinical Psychologist has experience of managing individuals who become emotionally distressed and is supervised by a Chartered Clinical Psychologist. In cases of emotional distress the researcher will offer to remain with the participant and provide support until distress has reduced or contact has been made with the GP or other services. For all interviews the researcher will be able to contact the supervisor to seek supervision and will adhere to advice.

The decision to access/accept support will remain with the research participant; however confidentiality may be broken in order to notify relevant services of risk information (e.g. GP) in order to safeguard participant welfare. In cases of disclosed or identified risk to self, the researcher will assess the level of risk (in conjunction with supervision) and share this information where indicated.

Assessing Risk to self: If the participant discloses risk to self, the researcher will ask about their mood and any suicidal ideation. If suicidal ideation is endorsed, the frequency and severity will be briefly ascertained, together with intent and protective factors. Social support will be briefly assessed.

If the participant demonstrates or endorses a level of emotional distress deemed by the researcher (in conjunction with supervision) to put the participant at risk of harm (for example, high risk of suicide), appropriate contact will be made with their GP and the community mental health team by the researcher. The participant will be kept informed of all actions undertaken where possible. If suicidal intent is endorsed and the risk is deemed imminent, the researcher will offer to accompany the participant to access mental health services through A&E or their out of hours GP. Alternatively, the participant will be encouraged to remain on the premises whilst the researcher seeks supervision and notifies relevant services.

Risk to others: The project involves carer participation, as such risks raised may relate to the protection of vulnerable adults. If any such risks were identified the researcher will request details of the person cared for from the participant and after seeking supervision, will liaise with the relevant safeguarding team and/or social services. If advised by supervisors, the safeguarding team or social services, relevant risk information may be shared with the clinic team in order to safeguard the vulnerable adult. If permissible, participating carers would be kept informed of any action undertaken if this is not deemed to conflict or compromise the welfare of the vulnerable adult.

Short-term or long-term distress: Participants will be given a contact number for the researcher or research supervisor should they experience any distress in the short or long term as a result of the research. Participants will be encouraged to access support services and signposted to these (e.g. GP).

In all cases of risk to self or others, immediate supervision will be sought with academic supervisor, Dr John Fox or field supervisor Dr Julia Coleby; experienced clinical psychologists in the field of eating disorders (contactable by mobile phone). Advice and guidance will be followed by the researcher (trainee clinical psychologist). Where possible, the participant will be kept informed of all actions taken and sent copies of correspondence.

A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa.

Risk Protocol Version 3, December 2012

Appendix 20.

Interview Schedule

Semi-structured Interview Schedule

The aim of this research is to examine carer's experiences of enabling and accommodation whilst caring for an individual with anorexia nervosa. The following-topics will be the main focus of the interview; however, this schedule is not fixed. Further information will be sought by the use of follow-up probe questions.

Opener:

1. Could you describe when you first noticed the anorexia related behaviours of the person you care for?

Carer Distress (Anxiety & depression) and carer burden:

1. Would you be able to describe how caring for (*insert name*) impacts on you and how you've been feeling

   (Probe: Positive and negative emotions, family relationships, family life, sources of coping & support, experience of services)

Expressed Emotion

1. Please could you tell me about your relationship with (*insert name*)

   (Probe: communication, experiencing and expressing feelings, own needs, pre AN).

Perceived Severity

1. Can you describe (*insert name*)'s current functioning in areas of everyday life?

   (Probe: education/work, relationships, activities, hobbies, coping, independence, well-being: e.g. confidence, mood)

Enabling/Accommodation:

1. Can you describe any rules (*Insert name*) has around eating/mealtimes.

   (Probes: portions, preparation of food, what is eaten, how and when)

2. Could you tell me a bit about how you or your family respond to (*insert name*)'s anorexia related behaviours? How does (*insert name*) react?

   (Probe: helpful responses, other approaches)

3. In what ways have you modified your activities and life because of anorexia?

   (Probe: work/social/family life/activities)

Closing :

1. Could you describe some of the strengths you have developed through caring for someone with anorexia?

    Added question:

    Some of the carers we have spoken to have different ways of explaining anorexia. How do you understand the anorexia?

    (Probe: impact of explanation on carer (feelings, thoughts, interactions)).

A qualitative study examining the ways in which carers respond when caring for individuals with anorexia nervosa

Interview Schedule, Version 3, December 2012

Appendix 21.

Anonymised Transcript Excerpt

Interview Excerpt to illustrate coding

Memos			Codes
	25.	changed?	
27. perceptions of daughter	26.	P: oh it's changed a lot. Erm, when she was at home, which is	26. caring role changed
28. difficult characteristic/behaviour attributed to daughter (internalised)?	27.	about .. 5 years ago, erm, it was horrendous, it was very stressful for	27. caring: unbearable /horrendous
	28.	everybody, she was .. ruling the roost. She was demanding, she was at	28. stressful for everyone. 28. Ruling the roost. Demanding
29. difficult behaviours viewed as a stage – not permanent?	29.	the verbally aggressive stage, erm, ... (sigh) erm , it was, it was just,	29. different stages of behaviour/AN (verbally aggressive)
30. difficult behaviours = stressed = frequent conflicts/ strained relationships	30.	everybody was .. so stressed out, everybody was at each others	30. everybody stressed
	31.	throats. Yeah, erm	31. conflict/strained relationships
	32.	I: it sounds very difficult.	
	33.	P: it was very, very, very difficult, yep, and you just keep putting up	33. v. difficult to manage
30. daughter responsible for stress?	34.	with it.	34. Response = put up with it.
37. why changed approach in later stage? Burnout?	35.	I: and when you say you sort of put up with it, how did you tend to	
	36.	respond to those difficult behaviours?	
	37.	P: erm .. .. … … latterly, while she was at home we tended to	37. later stages – changed approach
39. other responses – confrontation?	38.	erm .. let her do what she wanted. Erm, .. if, you knew that if you tried	38. accommodated wants/routines
	39.	to respond to any of her .. ways, that she would just become	39. other responses elicit aggression
41. identity as a mother = promote happiness/ Normality/ avoid conflict	40.	aggressive. Mmm. So it was, you tried, well I suppose me as the	41: mother's perceived role = keep peace
	41.	mother, I tried to keep the peace, I tried to keep .. the house going as	42. mother's aim: maintain normality
43. struggling to keep self together – emotional toll. Influencing accommodation	42.	normal, as per normal (laugh) but .. er .. tried to keep everybody	43. maintain equilibrium of self/others. Promote happiness
	43.	happy, tried to keep everybody on an even keel, including myself.	
	44.	I: right. And what did keeping the peace tend to involve?	
	45.	P: erm .. letting her have her routine as she wanted it, erm, ...	45. accommodating routines
	46.	not, well everything just really rotated round (client), rotated round her	46. impact – life revolved around individual/ritual
	47.	and her routine, and .. what you could touch in the kitchen, what you	47. refraining from touching things
	48.	couldn't touch in the kitchen, erm, the house .. erm everything had to	48. ensuring order in house
	49.	be in its place, because she's OCD with it as well. erm .. .. and it was, it	

57. resistance internalised to individual?	50. was just basically you living with her rather than her living with us.	50. taking over house – her rules. Role reversal.
	51. I: right. And do you mind if I ask a bit about what some of her	
	52. routines were?	
	53. P: erm, well she always had a set meal time. she always had .. erm	53: food rules: set times
	54. .. .. .. well it went through different stages, but I suppose the latter part	54. rules went through stages
62: confrontation = ineffective (conflict or increased resistance)	55. when she was really bad it was, she had, she was .. erm under a	55. Perceived as very ill. Exercise limits
	56. consultant, and she had .. .. set amounts of time she was allowed to	57. resistance: pushing exercise limits
	57. walk erm, but she always wanted to overstep those, erm, do a little bit	59. endeavours to enforce compliance
	58. longer, so you were always aware that she wasn't supposed to doing	62. confrontation. Responded with excuses.
	59. that and you were trying to stop her doing it, erm,	63. confrontation elicited anger.
65: eating perceived as a weapon/ manipulative. Perceived as method of control?	60. I: and what did that tend to involve, when you were aware of her	64. confrontation: increased resistance (refuse eat)
	61. doing that?	65. food resistance perceived as manipulative
65. food resistance perceived as within individual's control? Internalised as individual?	62. P: .. well if you said anything, she just either made an excuse or ..	66. individual aware of carer concerns re: eating
	63. she got angry. Or if she were doing it, something extra, or she wouldn't	68. recognition individual could be left alone yet feelings of having to supervise
	64. eat, if I had tackled her about something, you know you had .. erm it	70. perceived parental responsibility to safeguard individual.
	65. was always using the eating as erm ammunition. Cos she knew	70: individual perceived as physically vulnerable
	66. obviously that you were worried about her, erm, ... er .. .. and she	72: carer = 2 sides
	67. always had, well ..	73: mother instinct conflicting with aim of recovery
	68. (sigh) I suppose, she didn't have to have somebody out with her all the	74: on-going/battle between sides
74: conflicting identities? Conflicting aims?	69. time, although it was .. .. agreed that that's what would happen. But	
	70. erm, because she was so physically unwell, you felt you had to go with	
	71. her. I suppose it was always the keeping her safe bit. Erm .. you know	
	72. the, you had like .. I had like 2 sides to me, I had my mother instinct	
	73. and my one to get her better, and it was, for me it was always a	
	74. constant battle between the two.	76. conflicting

	75.	I: can you say a bit more about each side?	sides likened to a fence
	76.	P: well I always called it my fence, and I never knew which side of	77. unsure which side of fence to be on/how to respond
78: sought advice from professional?	77.	the fence I had to be on, or .. I always (laugh) erm, .. when I spoke to	
	78.	professionals I always spoke about my fence and that, erm, she was	78. discussed with professionals
79: daughter & AN synonymous – internal attribution for behaviour	79.	alright if I was on .. erm .. her side of the fence if you like, I was on the	79. daughter ok if on her side, (synonymous with AN's side).
	80.	anorexia side. Erm, because she could manipulate you so much. You	80. daughter perceived as v. manipulative & responsible for carer frequently siding with AN.
77. perplexed as to how to repond	81.	tended to fall into that side if you like, a lot.	
	82.	I: and what did being on that side look like, what did that involve?	83. AN side – giving in.
80. Difficult characteristic attributed to daughter.	83.	P: erm .. it meant you were giving in to her illness. Which made me	83. AN as an illness. 84. elicited internal conflict: anger/frustration with self
80. daughter's characteristics blamed for carer response	84.	really angry with myself and .. .. erm .. I got really frustrated and	
	85.	angry, erm .. .. .. er I was .. so mixed up with my own feelings that I	85. feeling mixed up
	86.	didn't know what I was supposed to do and what I wasn't supposed to	86. unsure right/wrong response
	87.	be doing, erm .. (sigh) .. .. and I just tried to stay on the middle but it	87. solution – endeavoured stay neutral
	88.	was really very difficult. It was difficult to do that.	

Appendix 22.

Example diagram depicting the relationships between codes for one interview

A diagram depicting the relationships between codes for one interview