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**Supporting someone with an Eating Disorder: A Systematic
Review of Caregiver Experiences of Eating Disorder Treatment
and a Qualitative Exploration of Burnout Management within
Eating Disorder Services**

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Doctorate in Clinical Psychology

The University of Edinburgh

May 2016

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INTRODUCTION TO THE PORTFOLIO

This portfolio contains three chapters: a systematic review, a journal article and an extended methods chapter. The focus of this thesis was the experiences of those who support someone who has an eating disorder.

Eating disorders as outlined in the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5) include Anorexia Nervosa (AN) and Bulimia Nervosa (BN). Recent additions to the DSM-5 also included Binge Eating disorder, Pica, Rumination Disorder and Avoidant/Restrictive Food Intake Disorder (ARFID; American Psychiatric Association, 2013). It has been reported that individuals with an eating disorder frequently experience severe health complications as well as high rates of mental health comorbidities such as anxiety, major depressive or other mood disorders and behavioural disorders (Sachs & Mehler, 2015; Hudson, Hiripi, Pope, & Kessler, 2007; Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011). Furthermore, recovery rates for eating disorders have been found to be low with relapse upon first receiving treatment being high (Steinhausen, 2002). Additionally, Arcelus, Mitchell, Wales and Nielsen (2011) reported a mean mortality rate of 5.10% for AN in their metanalysis. Steinhausen, Weber, & Phil (2009) reported on the global outcomes of BN and found that only 45% achieved full recovery throughout the studies.

Most eating disorder interventions involve input from mental health professionals. Although rarely studied, it has been postulated that patients with an eating disorder may routinely present with demographic and intervention related characteristics which could place mental health professionals at high risk of experiencing work related stress and burnout (Warren, Schafer, Crowley & Olivardia, 2013).

Additionally, many of the interventions also involve input from the patient's family members or caregivers. It has been shown that supporting someone with an eating disorder has been associated with several negative consequences including physical and mental ill health and poor quality of life (De La Rie *et al.*, 2005). Given that little is known about the experiences of those who support someone with an eating disorder this thesis will focus on the perspectives of caregivers and mental health professionals.

The journal article within this portfolio explores the factors which may contribute to burnout, factors which may protect against burnout and ways of managing work related

stress for staff who work in eating disorder services. It was not possible to conduct a review of the literature regarding this population due to a lack of prior research in this area. Therefore, the systematic review reports on the experiences of caregivers, such as family members, who care for someone with an eating disorder with the aim of exploring their experiences of eating disorder interventions and working with health professionals. The review topic was chosen due to its relevance in the management of eating disorders.

The systematic review and journal article conform to the author guidelines issued by the Clinical Psychology and Psychotherapy journal (included in Appendix A). The extended methodology chapter adheres to the guidelines issued within the University of Edinburgh Doctorate in Clinical Psychology Handbook.

THESIS ABSTRACT

Aims: Eating disorder recovery is often supported by caregivers and mental health professionals. This research portfolio focuses on the experiences of supporting someone with an eating disorder from the perspective of the caregivers and also mental health professionals. The aims of this research portfolio are: Firstly, to systematically review the published qualitative literature relating to the experiences of caregivers supporting someone during eating disorder treatment; and secondly, to investigate the factors which may contribute to burnout, the factors which may protect against burnout and ways of managing work related stress for healthcare professionals who work in an eating disorder service.

Method: A systematic review and meta-synthesis of caregiver experiences with eating disorder treatment was conducted. Searches identified 1927 studies of which 12 met the inclusion criteria for the study. Quality assessment revealed a number of strengths and also some limitations of the studies. For the research study ten healthcare professionals were interviewed on their experiences of supporting people with an eating disorder and ways of managing work related stress/burnout in this role. Interpretative Phenomenological Analysis was used to analyse the data.

Results: Five major themes were identified from the systematic review: “access to treatment”, “key features of treatment”, “support for the caregiver”, “encounters with health care professionals” and “the future – hopes and fears”. The research study identified seven super-ordinate themes: “Dealing with Client Physical Health Risks”, “Working to Different Goals from the Client”, “Awareness of own Eating Patterns”, “Personal Accomplishment”, “Working Together as a Team”, “Working with Caregivers” and “Ways of Managing Work Related Stress”.

Conclusions: The systematic review highlighted a number of clinical implications including the importance to caregivers of early intervention, the provision of practical, tailored information, support for the caregiver, the need for caregivers and professionals to work collaboratively and the importance of instilling hope in caregivers. The research study highlights potential contributors to burnout in eating disorder services as well as positive or protective factors to burnout. It also highlights ways of managing burnout through ensuring a work-life balance, utilising self-care strategies, self-reflection and realising recovery is not ‘all or nothing

Lay Summary

Eating disorder recovery is often supported by family members and mental health professionals. This research portfolio focuses on the experiences of supporting someone with an eating disorder from the perspective of the family members and also the mental health professionals.

The first part of the portfolio aimed to systematically review the literature relating to the perceptions of eating disorder treatments and services/professionals from the perspective of the family members of those with an eating disorder. Journal and database searches identified 1927 studies of which 12 met the criteria for the review. Five major themes were identified from the review: “access to treatment”, “key features of treatment”, “support for the caregiver”, “encounters with health care professionals” and “the future – hopes and fears”. The review highlighted a number of implications including the importance to family members of early intervention, the provision of practical, tailored information, support for the family members, the need for family members and professionals to work together and the importance of instilling hope in family members.

The second part of the research portfolio aimed to investigate the experience of burnout and ways of managing or preventing work related stress for professionals working with someone with an eating disorder. Ten healthcare professionals were interviewed on their experiences of supporting someone with an eating disorder and ways of managing work related stress/burnout in this role. The interviews were analysed and five main themes were identified: ““Dealing with Client Physical Health Risks”, “Working to Different Goals from the Client”, “Awareness of own Eating Patterns”, “Personal Accomplishment”, “Working Together as a Team”, “Working with Caregivers” and “Ways of Managing Work Related Stress”. This research study highlights potential contributors to burnout in eating disorder services as well as positive or protective factors to burnout. It also highlights ways of managing work related stress through ensuring a work-life balance, using self-care strategies, self-reflection and realising that recovery is not ‘all or nothing’.

SYSTEMATIC REVIEW

Title

Perceptions of Eating Disorder Treatments from the Perspective of Caregivers: A Qualitative Meta-synthesis

Word Count: 7136

ABSTRACT

Caregivers of people with an eating disorder are often involved in their support and treatment, however little is known about their experiences or perceptions of eating disorder treatments and the service providers/professionals who deliver them. A systematic review of qualitative studies of caregiver experiences of eating disorder treatment, including working with service providers and health care professionals, was conducted. Searches identified 1927 studies of which 12 met the inclusion criteria for the review. Five major themes were identified from a synthesis of the study results: “access to treatment”, “key features of treatment”, “support for the caregiver”, “encounters with health care professionals” and “the future – hopes and fears”. The review has a number of clinical implications including the importance to caregivers of early intervention, the provision of practical, tailored information, support for the caregiver, the need for caregivers and professionals to work collaboratively and the importance of instilling hope in caregivers.

Key Practitioner Message:

- Caregivers report many benefits of being involved in treatment and working collaboratively with health care professionals.
- Caregivers need tailored, practical information to help in their supporting role.
- During intervention, time should be dedicated to strengthen family interactions and support caregivers to place boundaries around the eating disorder whilst maintaining their caring relationship.
- Interventions should take into account the impact the eating disorder has on caregivers and aim to empower them to tackle the eating disorder, provide them with emotional support and facilitate the sharing of experiences of those who are/have been in the same position.

Keywords:

Eating Disorder Treatment, Caregivers, Qualitative, Meta-synthesis

INTRODUCTION

Initial onset of eating disorders has been found to typically occur during adolescence or early adulthood (Fairburn & Harrison, 2003). Given that many individuals of this age range live with family members and that it has been recommended that treatment for most people with an eating disorder be administered on an outpatient basis, attention has focused on the involvement of family in caring for someone with an eating disorder as well as the impact this caring role may have on the family member (Whitney, Currin, Murray, & Treasure, 2012). This has been highlighted in the NICE guidelines in relation to anorexia nervosa, which state that “the therapeutic involvement of siblings and other family members should be considered in all cases because of the effects of Anorexia Nervosa (AN) on other family members” (pp.12, National Institute for Clinical Excellence & National Institute for Clinical Excellence, 2004).

Caring for someone with an eating disorder has been associated with mental and physical ill health and poor quality of life in addition to experiencing feelings of guilt over illness onset, self-doubt over how to manage the illness and anxiety about physical deterioration (De LA Rie *et al.*, 2005; Perkins, Winn, Murray, Murphy, & Schmidt, 2004).

Furthermore, caregivers have higher levels of depression, anxiety and perceived caregiving burden than those supporting someone with other psychiatric illnesses (Graap *et al.*, 2008; Treasure *et al.*, 2001; Zabala, Macdonald, & Treasure, 2009); although it should be noted that this evidence tends to be based upon those with more severe eating disorder symptoms and therefore may not be representative of all eating disorder patients and their caregivers. It has also been found that caregivers report a lack of information and guidance on how to tackle the symptoms of an eating disorder (Haigh & Treasure, 2003; Winn, Perkins, Murray, Murphy, & Schmidt, 2004), which also perpetuates significant distress (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014; Zabala *et al.*, 2009).

Caregivers' emotional reactions to the symptoms of an eating disorder may unintentionally play a role in maintaining them (Treasure *et al.*, 2008). In their cognitive maintenance model of AN, Schmidt and Treasure, (2006) propose that high expressed emotion (criticism, hostility and overprotection) and accommodating and enabling behaviours (such as accepting the use of kitchen scales to weigh out food) perpetuate the eating disorder. The model, which Goddard *et al.* (2011) state can be applied transdiagnostically, describes a causal chain whereby high levels of carer unmet needs and a reduced ability to cope

contribute to carers' high expressed emotion and ineffective strategies in managing symptoms.

In response to the fact that family members will often be the main support for someone with an eating disorder, and the potentially maintaining affect they may have on the disorder, several treatments which utilise a family approach have been developed along with interventions to help support family members in their caring role (Macdonald, Murray, Goddard, & Treasure, 2011). Family interventions developed to treat eating disorders include structural family therapy, systems therapy, family based treatment (FBT), strategic family therapy, Multi-Family Therapy (MFT) and behavioural family therapy (Fisher, Hetrick, & Rushford, 2010). Each has a different emphasis on causative and maintaining factors and different therapeutic targets and outcomes (Fisher *et al.*, 2010). Le Grange, Lock, Loeb, and Nicholls (2010) conclude that, based on several studies, family involvement seems to be valuable in reducing both psychological and medical morbidity especially for younger individuals who are at an early stage in their eating disorder. Furthermore, family intervention appears to be acceptable to both caregivers and patients, which Le Grange *et al.*, (2010) postulate could explain the lower attrition rates in adolescent intervention studies (15%) compared to adult intervention studies where dropout rates average 50%.

Couturier, Kimber and Szatmari's (2013) systematic review and meta-analysis focussed on studies which followed the Maudsley model/Family Based Therapy (FBT) for adolescents with eating disorders. FBT is a problem solving approach that views the family system as fundamental to recovery (Bezance & Holliday, 2014; Bezance & Holliday, 2013). It is time intensive and carers need to become skilled in supporting their adolescent to eat and regain weight (Bezance & Holliday, 2014). Treasure *et al.*, (2007) have added to the intervention by developing a family based treatment which aims to empower caregivers to encourage their child to eat by teaching and sharing the therapeutic skills used by professionals (Bezance & Holliday, 2014). Couturier *et al.*, (2013) found that although there was not a significant difference between FBT and individual therapy at end of treatment when measured at the 6-12 month follow-up, FBT was shown to give superior results. This demonstrates that FBT may be superior to individual treatment in maintaining remission (Coururier *et al.*, 2013). However, the main limitations of this review relate to the lack of available research in the area of family therapy for eating

disorders with only 12 randomised trials being found and small sample sizes described in the studies utilised for the review (Couturier *et al*, 2013).

In addition to caregivers being involved in the treatment of the eating disorder, interventions have also been developed which help support the family member. Some of these interventions focus on family members' unhelpful patterns of reaction and interaction and are based upon the maintenance model along with general information on eating disorders (Cairns, Styles, & Leichner, 2007; Grover *et al.*, 2011). Hibbs, Rhind, Leppan and Treasure *et al.* (2015) conducted a meta-analysis of these interventions and found that they improved levels of carer distress, burden and expressed emotion. Furthermore, they demonstrated that the changes were sustainable over time. They described a trend for interventions that offered more therapeutic input to have larger effects; however, there was insufficient evidence from the studies to conclude that the interventions had any effect on patient well-being (Hibbs *et al.*, 2015).

In addition to quantitative methodology, qualitative approaches to elucidating caregiver views on treatment has also been utilised in order to help enhance their involvement in treatment. Indeed, Korhonen, Hakulinen-Viitanen, Jylhä, and Holopainen (2013) argue that in health care many phenomena, such as how intervention and healthcare services are perceived by those using the services and factors that facilitate adherence to treatment, cannot be captured using quantitative study designs.

The majority of qualitative studies within the area of eating disorders have focused on the experience of having AN and more recently the perspectives of AN treatment and recovery from the view of the person with AN. As a result a small number of qualitative systematic reviews have been published which have synthesised the results from a number of these studies to contribute to service development and to understand the causes of treatment termination and relapse for this client group (Bezance & Holliday, 2013; Blay, 2009).

Only one systematic review, recently published by Fox, Dean and Whittlesea (2015), has focussed on qualitatively exploring caregiver perspectives. Fox *et al.*'s (2015) review examined the caring experience and impact of living with or caring for someone with an eating disorder and concluded the eating disorder has a pervasive impact upon family members. However to date there have not been any systematic reviews which have

focussed on treatment and service provision from the perspective of those caring for a family member with an eating disorder.

Given that caregivers are often the main source of support for people with an eating disorder during their treatment and recovery and given the valuable contribution of qualitative research to treatment and service development the aim of this paper is to systematically review the experiences of eating disorder treatments and services/professionals from the perspective of caregivers or family members. Specifically, the review question is: What are the experiences of caregivers supporting someone during eating disorder treatment and what do they want from treatment.

METHODS

Search Strategy

A search of the literature was conducted between June and July 2015. No date restrictions were applied and all available years were systematically searched against the inclusion and exclusion criteria up until the end of July 2015 on Google Scholar and the following databases: MEDLINE, CINAHL, PsycINFO, Psychology and Behavioural Sciences Collection, and the Cochrane Library and Web of Science. All of the studies identified were examined in relation to the predetermined inclusion and exclusion criteria. The reference lists of the studies which met the inclusion criteria were manually searched with potential studies examined for their relevance. Additionally, hand searches of the International Journal of Eating disorders, European Eating disorders Review, Journal of Eating disorders, Advances in Eating Disorders Theory, Research and Practice and Eating Disorders: the Journal of Treatment and Prevention from 2000 were also undertaken.

To help identify relevant search terms, several key texts were consulted (e.g. Cooke, Smith, & Booth, 2012; Shaw *et al.*, 2004). Search terms were chosen to encapsulate all articles qualitatively exploring eating disorder treatment from the perspective of caregivers. For the purposes of this review 'treatment experience' was defined as either the experience of being involved with an intervention which targets eating disorders or the experience of working with health care professional in relation to a loved ones eating disorder.

The following keywords were used in combination as search terms: “eating disorders” OR “anorexia” OR “bulimia” OR “ED-NOS” AND “qualitative” OR “experience” OR “views” OR “interview” OR “mixed design” OR “perceptions” AND “treatment” OR “services” AND “caregiver” OR “carer” OR “parent” OR “mother” OR “father” OR “sibling” OR “partner” OR “spouse” OR “family member”.

Inclusion and Exclusion Criteria

Studies were included if they *met all* the following criteria:

- Used qualitative techniques for data collection and analysis either on their own or as part of a mixed-method methodology.
- Included views of caregivers (e.g. parents, family member or partner) involved in the care of a person with an Eating Disorder and distinguished caregiver-only data.
- Specifically focused on Eating Disorders (e.g. Anorexia Nervosa, Bulimia Nervosa, or Eating Disorders Not Otherwise Specified).
- Addressed the views or experiences of caregivers with regards to eating disorder treatment.
- Were written in English

Studies were excluded if they met *at least* one of the following criteria:

- They used solely quantitative research methods (e.g. surveys with forced choice responses)
- Eating Disorders were not the primary problem
- Not published in a peer-reviewed journal

A total of 1927 (excluding duplicates) studies were initially sourced and their titles screened in accordance to the review criteria. From this, 1858 studies were excluded. The abstracts of the remaining 69 articles were read, a further 6 articles were identified from hand searches and reference list searches of these papers. 53 of these papers were excluded as they did not meet the criteria on the basis of their abstract. The remaining 22 articles were read in full with ten being excluded for the following reasons: one was a collection of essays which were not further analysed, one did not focus on caregiver perceptions, two did not utilise qualitative techniques, four did not focus on treatment experience and 2 of the papers utilised mixed caregiver and patient focus groups making it difficult to distinguish individual voices.

To ensure that the selected studies did indeed conform to the inclusion and exclusion criteria a random selection of nine of the papers deemed to meet the criteria were checked by the studies' co-authors.

A flow chart depicting the number of studies identified and excluded at each stage of the process is shown in Figure 1.

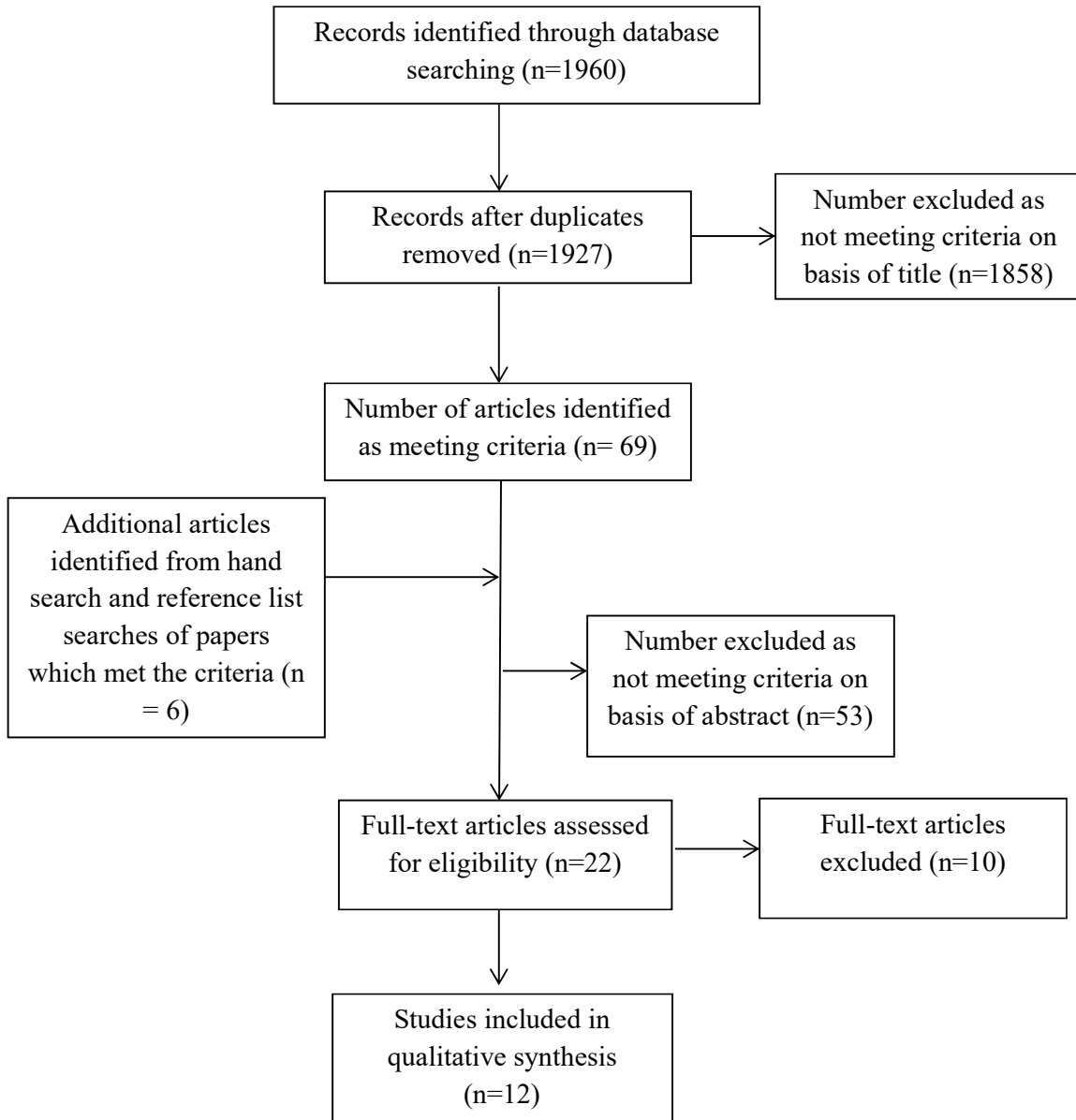


Fig 1. Flow chart of search process

Assessment of Quality

Although there are many suggested criteria for appraising the quality of research there is not an agreement of what makes a qualitative study ‘good enough’ (Dixon-Woods *et al.*, 2007). Furthermore, recommended criteria for appraising quality vary considerably and it has been argued that appraisal checklists do not seem to give consistent judgements (Dixon-Woods *et al.*, 2007). Therefore in selecting an appropriate method of quality appraisal a number of key articles were consulted as well as a number of different appraisal tools (Cesario, Morin, & Santa-Donato, 2002; Hannes, 2011; Walsh & Downe, 2006). Following this it was decided that a modified version of the Critical Appraisal Skills Program (CASP, 2002) would be utilised. The CASP consists of ten questions which concern clarity of aims; appropriateness of qualitative methodology, research design, recruitment strategy and data collection method; consideration of reflexivity and ethical issues; rigor of analysis; clarity of findings; and the value of the research (CASP, 2002). Following each of the ten questions there follows a (number of) prompt(s) for the reviewer to use when addressing the question (CASP, 2002). To enhance the application of the CASP additional elements (theoretical framework, believability and evaluation/outcome) of the Evaluation Tool for Qualitative Studies (ETQS) were utilised. An outline of the adapted tool with the questions which are relevant to this review is given in Appendix B.

For the purpose of this review each paper was assessed using the adapted CASP for its relative strengths and weaknesses. Although many assessments of quality often focus on assigning a numerical “score” it was decided that categorically saying one study is stronger than another and making an interpretation accordingly would be difficult with this type of review given that research questions, populations and methods tend to differ subtly between qualitative studies. Nine of the papers were also appraised by an independent reviewer who has experience with qualitative research. The reviewers compared their appraisal assessments discussing the relative strengths and weaknesses of each study and reconciled any differences in judgements through debating the rationale for their decisions.

Data Extraction and Synthesis

There are several approaches which can be chosen for the synthesis of qualitative studies, for the purposes of this review the views of caregivers with regards to eating disorder treatment/service provision were analysed and collated through framework synthesis. This

method utilises an *a priori* framework that is chosen by the researchers, based upon previous research (Mytton, Ingram, Manns, & Thomas, 2014). It is essentially a deductive approach although, in addition to areas identified in the framework, new areas may be developed and incorporated as they emerge from the data (Barnett-Page & Thomas, 2009).

This particular method was selected due to its highly structured approach to organising and analysing data and the formation of data displays which can be viewed and assessed by people other than the primary analyst (Dixon-Woods *et al.*, 2011). Furthermore, this method was selected over other techniques such as meta-ethnography as it is less time-consuming given the timeframe of the review and has been highlighted as being more directly relevant to policymakers and those developing interventions than techniques with a more constructivist orientation such as Meta-Narrative or Meta-Ethnography approaches (Barnett-Page & Thomas, 2009; Dixon-Woods *et al.*, 2011).

Based on the reading of selected international literature (Anastasiadou *et al.*, 2014; Graap *et al.*, 2008; Haigh & Treasure, 2003; Hibbs *et al.*, 2015; Tierney, 2012) and discussions between all authors, factors that could potentially influence caregivers experiences and views of treatment and professionals were identified; this resulted in a preliminary conceptual framework (see appendix C). This initial framework was used as the basis against which data extracted from included studies were compared in order to confirm, extend or refute the concepts in the initial framework. The included studies were coded according to the framework and revisited as the framework was refined. The framework was then tabulated as a map of the nature and range of the concepts, for example, the inclusion of sub-themes or to facilitate comparison between themes (Barnett-Page & Thomas, 2009). The final stage was to critically examine the populated framework, finding associations between themes and providing explanations for the findings across the studies to elucidate caregivers' perspectives of eating disorder treatments and professional input.

RESULTS

Study Characteristics

An overview of the studies included in the review is given in Table 1. Of the twelve studies reviewed, nine used semi-structured interviews to collect data (Bezance & Holliday, 2014; Dimitropoulos, Klopfer, Lazar, & Schacter, 2009; Engman-Bredvik,

Suarez, Levi, & Nilsson, 2015; Goodier *et al.*, 2014; Macdonald *et al.*, 2011; Rhodes, Brown, & Madden, 2009; Tierney, 2005; Whitney, Currin, Murray, & Treasure, 2012; Winn *et al.*, 2004), two used unstructured interviews (Honey *et al.*, 2007; McMaster, Beale, Hillege, & Nagy, 2004) and one used multiple data gathering methods (Voriadaki, Simic, Espie, & Eisler, 2015). A range of qualitative analysis methods were used, with three of the studies utilising thematic analysis (Goodier *et al.*, 2014; McMaster *et al.*, 2004; Tierney, 2005), four of the studies using Interpretative Phenomenological Analysis (Bezance & Holliday, 2014; Macdonald *et al.*, 2011; Voriadaki *et al.*, 2015; Whitney *et al.*, 2012) and two studies using a grounded theory approach (Dimitropoulos *et al.*, 2009; Rhodes *et al.*, 2009). The remaining studies used an Empirical Psychological Phenomenological approach (Engman-Bredvik *et al.*, 2015) and content analysis (Winn *et al.*, 2004). Honey *et al.*, (2007) did not specify a particular analysis method other than stating they utilised a recursive model which involved interviews which are conversational in style and began data analysis with a content analysis.

Eight of the studies focussed on the views of parents (Bezance & Holliday, 2014; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Honey *et al.*, 2007; McMaster *et al.*, 2004; Rhodes *et al.*, 2009; Tierney, 2005; Voriadaki *et al.*, 2015); of these seven focussed on the views of both mothers and fathers (Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Honey *et al.*, 2007; McMaster *et al.*, 2004; Rhodes *et al.*, 2009; Tierney, 2005; Voriadaki *et al.*, 2015) and one focussed solely on the views of mothers (Bezance & Holliday, 2014). Three of the studies reported on the views of a mixture of caregivers including partners and siblings (Macdonald *et al.*, 2011; Whitney *et al.*, 2012; Winn *et al.*, 2004) and one study reported on the views of adult siblings (Dimitropoulos *et al.*, 2009). The number of participants ranged between nine (Bezance & Holliday, 2014) and thirty-four (Rhodes *et al.*, 2009).

The majority of studies (eight) reported on the experiences of caregivers of someone with Anorexia Nervosa (Bezance & Holliday, 2014; Dimitropoulos *et al.*, 2009; Engman-Bredvik *et al.*, 2015; Honey *et al.*, 2007; Rhodes *et al.*, 2009; Tierney, 2005; Voriadaki *et al.*, 2015; Whitney *et al.*, 2012), one focussed on Bulimia Nervosa (Winn *et al.*, 2004) and the remaining three did not state a particular diagnosis other than 'eating disorder'.

Six of the studies were of outpatients (Bezance & Holliday, 2014; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Macdonald *et al.*, 2011; Rhodes *et al.*, 2009; Voriadaki *et al.*,

2015), one inpatients (Dimitropoulos *et al.*, 2009), one both outpatients and inpatients (Tierney, 2005) and four of the studies did not specify where the sample was drawn from (Honey *et al.*, 2007; McMaster *et al.*, 2004; Whitney *et al.*, 2012; Winn *et al.*, 2004). Seven of the papers specified the type of treatment, which included family based interventions and skills training (Bezance & Holliday, 2014; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Rhodes *et al.*, 2009; Voriadaki *et al.*, 2015; Whitney *et al.*, 2012). Five of the papers related to unspecified treatment/professional input (Dimitropoulos *et al.*, 2009; Honey *et al.*, 2007; McMaster *et al.*, 2004; Tierney, 2005).

Recruitment methods varied across the papers. Several of the studies invited those who were currently receiving, or had previously received, treatment within an Eating Disorders service (Bezance & Holliday, 2014; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Honey *et al.*, 2007; Tierney, 2005; Voriadaki *et al.*, 2015). Three of the studies recruited from larger empirical or randomised control studies (Dimitropoulos *et al.*, 2009; Rhodes *et al.*, 2009; Whitney *et al.*, 2012). The remaining studies utilised eating disorder charities, websites and carer support groups (Macdonald *et al.*, 2011; McMaster *et al.*, 2004; Winn *et al.*, 2004).

Of the 12 studies, six were conducted in the UK (Bezance & Holliday, 2014; Macdonald *et al.*, 2011; Tierney, 2005; Voriadaki *et al.*, 2015; Whitney *et al.*, 2012; Winn *et al.*, 2004) four in Australia (Goodier *et al.*, 2014; Honey *et al.*, 2007; McMaster *et al.*, 2004; Rhodes *et al.*, 2009), one in Canada (Dimitropoulos *et al.*, 2009) and one in Sweden (Engman-Bredvik *et al.*, 2015).

Table 1 gives an overview of the study characteristics in relation to the setting of the study, the participant characteristics, qualitative model, data collection method, treatment type aims and the strengths and weaknesses of the study.

Author (year) Country/Setting	Participants N, Perspective, ED features	Qualitative Model and Data Collection Method	Treatment type	Aims
Bezance & Holliday (2014) United Kingdom	9 mothers of adolescents (aged 13- 16), primary diagnosis of Anorexia Nervosa or Eating Disorder Not Otherwise Specified of an AN type (EDNOS- AN)	Interpretative Phenomenological Analysis (IPA) Semi-Structured Interviews. Included a series of open-ended questions to gather retrospective and current accounts of participants' experiences.	Home Treatment (HT) - Outpatient Includes intensive monitoring, supervision of meals at home, or additional individual/family support which usually lasts approximately 8 weeks.	Explore the experiences of mothers receiving HT as part of treatment for their daughters' AN.
Dimitropoulos <i>et al.</i> (2009) Canada	12 adult siblings Anorexia Nervosa	Grounded Theory Semi-Structured Interviews.	Unspecified inpatient treatment	Explore the unique experiences and challenges of siblings of women with anorexia nervosa (AN).
Engman- Bredvik. <i>et al.</i> (2015) Sweden	6 mothers and 6 fathers of female adolescents (12-17 years old) Anorexia Nervosa	Empirical Psychological Phenomenological method (EPP) Semi-structured interviews carried out 1 to 2 months after the concluding Multi-Family Therapy session.	Multi-Family Therapy (MFT) - Outpatient Manual based eclectic and comprehensive treatment approach which combines elements from several therapeutic schools. It is a group treatment for six to eight families with 10 whole-day meetings spread out over a year. The main purpose is to improve and corroborate familial coping	To investigate MFT as part of AN treatment from a parental perspective.

			and intervention in the context of AN, and also to prevent social isolation and stigmatization.	
Goodier <i>et al.</i> (2014) Australia	6 mothers, 1 step mother and 4 fathers of children (aged 11-14) DSM IV diagnosed Eating Disorder.	Inductive Thematic Analysis Semi-structured telephone Interview	Parent Skills Training Treatment (PSTT) - Outpatient Adapted version of the programme developed in the UK for carers of individuals with eating disorders. Involved 14 hours of group treatment including meals.	Examine the experience of parents of children with eating disorders after having participated in a skills-based training intervention.
Honey <i>et al.</i> (2007) Australia	16 mothers and 8 fathers of daughters (aged 14-20) with Anorexia Nervosa	Recursive Model/Unspecified Analysis method In-depth interviews were conducted using a recursive model in which the interviews are unstructured and conversational in style	Unspecified ED treatments	What support do parents of teenage girls with anorexia want from clinicians?

Macdonald <i>et al.</i> (2011) United Kingdom	8 mothers, 2 sisters, 9 partners and 6 fathers Eating Disorder	Interpretative Phenomenological Analysis Semi-structured interviews.	DVD/manual/coaching skills training programme Outpatient	Explores the experiences of a sample of carers who took part in an RCT examining the effects of a DVD/manual/coaching skills training programme for carers of people with EDs.
McMaster <i>et al.</i> (2004) Australia	19 mothers and 3 fathers Eating Disorder	Thematic Analysis Open-ended un-structured interview	Health professional input – unspecified treatment	This paper focuses on the experiences of parents concerning their involvement with health professionals and others encountered on their journey.
Rhodes <i>et al.</i> (2009) Australia	34 parents Anorexia Nervosa	Grounded Theory Interviews conducted using a limited number of open questions (semi-structured).	Family Based Treatment Outpatient	Explore the use of parent-to-parent consultation as an augmentation to the Maudsley model
Tierney (2005) United Kingdom	8 mothers and 5 fathers. Anorexia Nervosa	Thematic Analysis Semi-structured interviews	Unspecified Inpatient and outpatient treatment	What are the experiences of parents with a child who has received treatment for anorexia in adolescence?
Voriadaki <i>et al.</i> (2015) United Kingdom	6 mothers and four fathers. Anorexia Nervosa	Interpretative Phenomenological Analysis (IPA) Multiple data-gathering methods: rating scales,	Multi-family therapy (MFT) Outpatient	To contribute to the understanding of the process of change that takes place in MFT for adolescent AN.

		daily journals, focus group and researcher observations		
Whitney <i>et al.</i> (2012) United Kingdom	17 parents, 4 siblings, 1 husband, 1 daughter. Anorexia Nervosa	Interpretative Phenomenological Analysis (IPA) Interviews directed by a topic guide	Family intervention	Examine treatment efficacy, carer satisfaction and the process of change associated with two family interventions
Winn <i>et al.</i> (2004) United Kingdom	15 parents and 5 partners. Bulimia Nervosa	Content Analysis Semi-structured interviews	Unspecified	Considers carers' experience of services, informal help received and support from professionals

Table 1. Characteristics of included papers

Results of Quality Assessment

Nine of the papers were also assessed by a co-rater who agreed with the researcher's evaluation of each paper in all but one area for one of the papers, however this was discussed in more detail and a consensus reached. An overview of how each paper met the criteria of the adapted CASP tool is given in table 2.

Table 2. Quality Assessment Overview

Article	Quality Assessment Based on Adapted CASP Tool										Number of criterion fully met
	1	2	3	4	5	6	7	8	9	10	
Bezance & Holliday (2014)	+	+	++	++	++	++	++	++	++	++	8
Dimitropoulos <i>et al.</i> (2009)	+	++	++	++	++	++	+	++	++	++	8
Engman-Bredvik. <i>et al.</i> (2015)	+	++	+	+	+	++	++	++	++	+	5
Goodier <i>et al.</i> (2014)	+	++	++	+	++	++	++	++	++	++	8
Honey <i>et al.</i> (2007)	+	++	++	++	+	+	+	+	+	+	3
Macdonald <i>et al.</i> (2011)	++	++	++	++	++	++	++	++	+	++	9
McMaster <i>et al.</i> (2004)	+	+	+	+	+	-	-	+	+	+	0
Rhodes <i>et al.</i> (2009)	++	++	++	++	++	+	++	+	++	++	8
Tierney (2005)	++	++	++	+	++	++	++	++	++	+	8
Voriadaki <i>et al.</i> (2015)	++	++	++	++	+	++	+	++	+	++	7
Whitney <i>et al.</i> (2012)	++	++	++	++	++	++	+	++	++	+	8
Winn <i>et al.</i> (2004)	+	+	+	++	++	++	-	+	+	+	3

Rating: ++ = criterion present, + = criterion partially present, - = criterion absent

Quality Assessment Based on Adapted CASP

1. Research Design
2. Recruitment Strategy
3. Data Collection
4. Data Analysis
5. Clarity of Findings
6. Credibility

7. Reflexivity
8. Believability
9. Evaluation/Outcome
10. Theoretical Framework

Regarding recruitment strategy Dimitropoulos *et al.* (2009), Goodier *et al.* (2014) and Voriadaki *et al.* (2015) provided a thorough discussion of recruitment and participant selection. Additionally, Engman-Bredvik *et al.* (2015), Honey *et al.* (2007) and Whitney *et al.* (2012) describe why some of the participants did not want to take part in the study. McMaster *et al.* (2004) and Winn *et al.* (2004), however, provided limited discussion concerning recruitment making it unclear if the participants selected were the most appropriate to address the research question.

Most of the studies specified how the data were collected (Bezance & Holliday, 2014; Dimitropoulos *et al.*, 2009; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Honey *et al.*, 2007; Rhodes *et al.*, 2009; Voriadaki *et al.*, 2015). Whitney *et al.* (2012) gave a very clear discussion of data collection and consideration was given to alterations to the interview schedule following piloting.

With regards to the researchers' potential bias and influence during formulation of the research questions, data collection and data analysis, only Tierney (2005) provided a description of the researcher's own role and reflexivity and ways of overcoming any potential bias. Bezance and Holliday (2014) reported keeping a reflective diary to collate thoughts, observations and ideas about the research and described being interviewed twice by another IPA researcher to gather information on the researchers' personal, academic, clinical and research background and to explore pre- and post- their expectations and predictions about the outcome and findings of the study. However, the study does not detail what the reflections from the diary and interviews were and how this affected the findings.

Most of the papers provided a good description of data analysis with Macdonald *et al.* (2011) providing an explanation of how the data presented were selected from the original sample. However, Goodier *et al.* (2014), McMaster *et al.* (2004) and Tierney (2005) did not describe the analysis in sufficient depth to determine how the categories/themes were derived from the data. Many of the studies provided information regarding the credibility of their findings, for example through the use of triangulation, respondent validation or using more than one analyst (Dimitropoulos *et al.*, 2009; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014;

Macdonald *et al.*, 2011; Tierney, 2005; Whitney *et al.*, 2012). However, McMaster *et al.* (2004) provided limited discussion of the credibility of the study's findings.

Most of the studies described the clinical implications as well as potential future research. Winn *et al.* (2004) provided a good discussion of the contribution of the study especially in relation to current practice and making recommendations. Many of the studies situated their research within current knowledge and theoretical models such as the cognitive maintenance or Maudsley model (Bezance & Holliday, 2014; Goodier *et al.*, 2014; Macdonald *et al.*, 2011; McMaster *et al.*, 2004; Rhodes *et al.*, 2009). However, Engman-Bredvik *et al.* (2015) and Tierney (2005) provided limited discussion of previous research and the theoretical frameworks.

Summary of Themes

The initial themes identified in the *a priori* framework (Appendix C) were updated accordingly and several subthemes within each area were identified. Labels were given to themes according to their content rather than retaining labels used in the studies themselves. Where papers identified similar themes but gave different labels, or where there were a variety of sub-themes clustered around the same subject, these were brought together under a common term. For example, all data relating to participants' communication with other family members and insights into relationships within the family were brought together under a theme of "family dynamics".

Using this methodology, five themes were identified: access to treatment, key features of treatment, support for the caregiver, encounters with health care professionals and the future – hopes and fears. Within these areas a total of thirteen subthemes were identified. Only themes/subthemes which appeared in 50% or more of the studies were classified as a main theme/subtheme and are described below. A summary of the themes, including minor themes, are given in Appendix D.

Access to Treatment

Eight (66%) of the studies described caregivers' experiences accessing treatment for those they care for (Bezance & Holliday, 2014; Engman-Bredvik *et al.*, 2015; Honey *et al.*, 2007;

Macdonald *et al.*, 2011; McMaster *et al.*, 2004; Tierney, 2005; Whitney *et al.*, 2012; Winn *et al.*, 2004). The most evident component of accessing treatment was early intervention.

Early Intervention

The need for intervention to begin early following the onset of the eating disorder was highlighted in seven of the studies (Bezance & Holliday, 2014; Engman-Bredvik *et al.*, 2015; Macdonald *et al.*, 2011; McMaster *et al.*, 2004; Tierney, 2005; Whitney *et al.*, 2012; Winn *et al.*, 2004). Participants in Tierney's (2005) study described needing to be resourceful and keep trying in order to receive treatment: they reported that when they finally received professional input their loved one's condition had deteriorated. The long wait to treatment and need to be proactive in gaining access to treatment was also evident in McMaster *et al.*'s (2004) study.

Key Features of Treatment

This theme relates to the aspects of treatment which caregivers identified as being relevant, what they found helpful and unhelpful and what they needed from treatment. Eleven (91%) of the studies made reference to this theme (Bezance & Holliday, 2014; Dimitropoulos *et al.*, 2009; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Honey *et al.*, 2007; Macdonald *et al.*, 2011; Rhodes *et al.*, 2009; Tierney, 2005; Voriadaki *et al.*, 2015; Whitney *et al.*, 2012; Winn *et al.*, 2004). The most evident 'key features of treatment' were information and practical guidelines, family dynamics and boundaries.

Information and practical guidelines

The benefits of receiving information about eating disorders, their impact and treatment were highlighted in eight of the papers (Bezance & Holliday, 2014; Dimitropoulos *et al.*, 2009; Goodier *et al.*, 2014; Honey *et al.*, 2007; Macdonald *et al.*, 2011; Tierney, 2005; Whitney *et al.*, 2012; Winn *et al.*, 2004). Participants in Winn *et al.*'s (2004) study identified the need for more information on the disorder and why it had developed. The caregivers in Bezance and Holliday's (2014) study felt reassured by the provision of information but wanted more information about how to deal with certain situations and what to expect. Indeed many of the papers identified the need for tailored information which is relevant to their situation and which can be applied practically at home.

Family dynamics

The impact of treatment on family dynamics including how the family communicate with each other and the relationship between family members was evident in seven of the papers (Dimitropoulos *et al.*, 2009; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Macdonald *et al.*, 2011; Rhodes *et al.*, 2009; Voriadaki *et al.*, 2015; Whitney *et al.*, 2012; Winn *et al.*, 2004). The participants in Dimitropoulos *et al.*'s (2009) study wanted to know how to facilitate a more open and effective style of communicating. The caregivers in Goodier *et al.*'s (2014) and Macdonald *et al.*'s (2011) studies reported improved family communication through guidance and learning communication strategies during treatment. For the participants in Whitney *et al.*'s (2012) study, treatment helped create balance through giving a voice to less dominant family members and learning to listen and speak without becoming confrontational. Within Rhodes *et al.*'s (2009) and Winn *et al.*'s (2004) studies, treatment facilitated parental collaboration and working together.

Boundaries

Previous research has shown that caregivers can inadvertently maintain the eating disorder through accommodating and enabling behaviours such as only buying in foods which are 'acceptable' to the eating disorder or becoming preoccupied with monitoring food and exercise and avoidance of issues which may be difficult. The theme of placing 'boundaries' on these behaviours was found in six of the papers (Bezance & Holliday, 2014; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Macdonald *et al.*, 2011; Rhodes *et al.*, 2009; Voriadaki *et al.*, 2015). For the participants in Bezance and Holliday's (2014) study caring for their child with AN had taken over their lives and treatment had enabled them to reinstate boundaries and move away from the enmeshed and accommodating position. Learning to 'be firm' or set boundaries was also reiterated in Goodier *et al.*'s (2014), Rhodes *et al.*'s (2009) and Volidaki *et al.*'s (2015) studies.

Support for the Caregiver

This theme relates to what the caregivers themselves gain from treatment. Eleven (91%) of the studies made reference to this theme (Bezance & Holliday, 2014; Dimitropoulos *et al.*, 2009; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Honey *et al.*, 2007; Macdonald *et al.*, 2011; Rhodes *et al.*, 2009 Tierney, 2005; Voriadaki *et al.*, 2015 Whitney *et al.*, 2012; Winn *et al.*, 2004). The main subthemes were empowerment, sharing experiences with others in the same position and receiving emotional support.

Empowerment

A sense of empowerment and increased confidence from treatment was evident in six of the studies (Bezance & Holliday, 2014; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Macdonald *et al.*, 2011; Voriadaki *et al.*, 2015; Whitney *et al.*, 2012). Whitney *et al.* (2012) identified that caregivers felt empowered when they were able to implement skills they had learned, such as reflective listening. Participants in Goodier *et al.*'s (2014) study reported being stronger, more confident and better informed.

Sharing experiences with others in the same position

The subtheme of sharing experiences with others in the same position was highlighted in eight of the papers (Dimitropoulos *et al.*, 2009; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Macdonald *et al.*, 2011; Rhodes *et al.*, 2009; Voriadaki *et al.*, 2015; Whitney *et al.*, 2012; Winn *et al.*, 2004). For participants in Dimitropoulos *et al.*'s (2009) study hearing from others 'in the same boat' helped normalise their struggles. Through sharing their experiences and hearing the experiences of others in the same position caregivers felt less alone. Winn *et al.* (2004) identified that caregivers believed that only those with direct experience of bulimia nervosa could really understand what it was like to live with someone with an eating disorder and believed they would benefit from talking with someone who had been in a similar situation to themselves.

Emotional Support

Caregivers identified a need for emotional support, to be able to share their feelings, receive reassurance and express themselves in six of the papers (Bezance & Holliday, 2014; Engman-Bredvik *et al.*, 2015; Honey *et al.*, 2007; Macdonald *et al.*, 2011; Rhodes *et al.*, 2009; Winn *et al.*, 2004). For some of the caregivers this emotional support came from peers who they were able to open up to and felt reassured by. Others described wanting more formal support through professionals or through counselling, although some of the participants in Winn *et al.*'s (2004) study did not feel that professional therapy was necessary. The participants in Rhodes *et al.*'s (2009) study described an intense emotional bond with 'consultants' (other parents whose child was in recovery); this study also identified that for those who were 'sole custodial' parents, receiving emotional support from the therapist and focusing on the things they found distressing rather than solely on weight restoration was helpful. Caregivers in Macdonald *et al.*'s (2011) study described a lessening of stress and anxiety and those in Bezance and Holliday's (2014) study described regaining a sense of themselves.

Encounters with Healthcare Professionals

Eight (66%) of the studies reported caregivers' encounters with healthcare professionals (Bezance & Holliday, 2014; Dimitropoulos *et al.*, 2009; Honey *et al.*, 2007; McMaster *et al.*, 2004; Rhodes *et al.*, 2009; Tierney, 2005; Whitney *et al.*, 2012; Winn *et al.*, 2004). The most evident component of caregivers' encounters with healthcare professionals was joint working.

Joint Working

This subtheme relates to working jointly with professionals and being involved versus feeling left out and not being kept up to date with treatment. This subtheme was highlighted in eight of the studies (Bezance & Holliday, 2014; Dimitropoulos *et al.*, 2009; Honey *et al.*, 2007; McMaster *et al.*, 2004; Rhodes *et al.*, 2009; Tierney, 2005; Whitney *et al.*, 2012; Winn *et al.*, 2004). Caregivers in Honey *et al.*'s (2007) study reported feeling undermined in their role as caregiver and wanted to be kept informed and be listened to with regards to input and treatment decisions. This feeling was also evident in McMaster *et al.* (2004), Bezance and Holliday (2014) and Tierney's (2005) studies with caregivers feeling excluded and receiving little feedback from professionals.

On the other hand, caregivers in Rhodes *et al.*'s (2009) study reported that the therapist had helped them to be involved, that they worked well together and they appreciated that the therapist did not try to take the role of parent away. Whitney *et al.* (2012) identified that a direct and supportive style of communication between the healthcare professional and caregiver was perceived as being respectful. The caregivers in Dimitropoulos *et al.*'s (2009) study wanted a discussion with healthcare professionals about what their roles and responsibilities would be. Caregivers in Winn *et al.*'s (2004) study had a mixture of experiences with regards to working with professionals and being involved with treatment.

The Future – Hopes and Fears

Six (50%) papers discussed the future after treatment with some caregivers being hopeful and others fearing what the future would hold (Bezance & Holliday, 2014; Engman-Bredvik *et al.*, 2015; McMaster *et al.*, 2004; Rhodes *et al.*, 2009; Tierney, 2005; Voriadaki *et al.*, 2015; Whitney *et al.*, 2012). Perceived progress during treatment as well as hearing from other caregivers who have progressed following treatment appears to instil hope in caregivers (Rhodes *et al.*, 2009; Voriadaki *et al.*, 2015). Participants in Engman-Bredvik *et al.*'s (2015) study reported that exercises focussing on the future and dreams were appreciated as they gave hope. They also found insights into risk of relapse and being prepared for subsequent

drawbacks valuable. The caregivers in Bezance and Holliday's (2014) study reported that treatment instils hope but felt anxiety about the future as they believed the eight week program they participated in was "not sufficient". Participants in McMaster *et al.*'s (2004) study described feeling isolated and having to 'pick up' the care that had been provided in hospital after discharge. The caregivers in Tierney's (2005) study feared a relapse of the eating disorder and in some cases relapses had occurred.

Impact of Heterogeneity on Results

Eight of the papers focused on the perspectives of caregivers of people with anorexia nervosa with the other four papers focusing on the perspectives of caregivers of people with bulimia nervosa or eating disorders in general (rather than specifying a particular form). Furthermore, eight of the papers focused on the perspectives of parents with the other four papers focusing on the perspectives of siblings or a mixture of siblings, partners and parents.

Despite this heterogeneity most of the themes identified were represented across AN papers and non-AN papers and across parents as caregivers and non- or mixed parent caregivers. The exception to this was the theme of 'The Future – Hopes and Fears' was not identified by any of the papers from non- or mixed parent caregivers.

Impact of Quality Assessment on Results

Ten of the studies either partially met or fully met all of the quality criteria (Bezance & Holliday, 2014; Dimitropoulos *et al.*, 2009; Engman-Bredvik *et al.*, 2015; Goodier *et al.*, 2014; Honey *et al.*, 2007; Macdonald *et al.*, 2011., Rhodes *et al.*, 2009; Tierney, 2005; Voriadaki *et al.*, 2015 and Whitney *et al.*, 2012). Of the remaining two studies McMaster *et al.* (2004) partially met eight of the quality criteria and Winn *et al.* (2004) partially met or fully met nine of the quality criteria. Taking these two studies out of the analysis the sub-themes 'information and practical guidelines', 'family dynamics', 'boundaries', 'empowerment' and 'sharing experiences with others in the same position' would remain and therefore are the themes which are represented by the strongest studies within the review."

DISCUSSION

Main Findings and Clinical Implications

The main objective of the current paper was to systematically review the perceptions of eating disorder treatments from the perspective of caregivers. Twelve papers were reviewed

which highlighted five main themes: access to treatment, key features of treatment, support for the caregiver, interactions with health care professionals and the future – hopes and fears.

The results from this review indicate the importance for caregivers of early intervention in eating disorders treatment. Previous research has shown that recovery from AN diminishes the longer the illness has persisted (Von Holle *et al.*, 2008). Furthermore, Russell, Szmukler, Dare and Eisler (1987) and Lock, Couturier and Agras (2006) found good outcomes from family therapy which was given early in the course of the illness. Treasure and Russell, (2011) postulate that as the disorder progresses poor nutrition and high levels of stress are disruptive to brain maturation which may make it harder to recover. Given that onset typically begins during adolescence when they are likely to be living with family members' perhaps early intervention programmes should also be aimed at family members as well as the person who may develop the eating disorder.

Caregivers in the current review expressed a need for more 'practical' advice tailored to their situation. Previous research has also found that caregivers want more information on eating disorders with Haigh and Treasure, (2003) reporting that caregivers express a need for information about how to help their loved one recover from the illness. Additionally, this review highlighted the impact of treatment on family dynamics such as improving communication and family relationships. The evidence base has shown that an eating disorder can impact on family functioning, for example the family becoming stuck in unhelpful interactions (Treasure *et al.*, 2008). Related to this, previous research has shown that family coping styles may inadvertently maintain the eating disorder through patterns of high expressed emotion and accommodating or enabling behaviours (Anastasiadou *et al.*, 2014). This review found that through intervention caregivers felt more comfortable placing boundaries and being 'firm' with the eating disorder. An implication of these findings could be ensuring that family interactions are strengthened and accommodating and enabling behaviours are minimised by supporting the caregiver to place boundaries during intervention.

The current review highlights the importance of support for the caregiver themselves during intervention. Prior research has shown that caring for someone with an eating disorder is associated with mental and physical ill health, poor quality of life, a lack of confidence in dealing with the eating disorder and feelings of guilt and isolation (De La Rie *et al.*, 2005; Santonastaso, Saccon & Favaro, 1997; Sepulveda, Whitney, Hankins, & Treasure, 2008). It

would appear that successful interventions can empower the caregiver to tackle the eating disorder, enable the caregiver to feel less isolated through sharing experiences with others who are in the same position and provide them with emotional support.

The findings of this review highlight the need for health professionals to work collaboratively with caregivers. In particular the need for professionals to recognise the significance of the parental role, providing caregivers with feedback and involving them in the intervention process. Whitaker and Macdonald (2008) state that the aim of the new Maudsley model of working with families is to build an alliance between the carers, the service user and the health professionals working with them. As some of the studies included in the review utilised the Maudsley model or FBT approach it may be that the collaborative ethos was valued by those participating. Involving caregivers will give them the opportunity to develop knowledge and skills needed for tackling the eating disorder and therefore may reduce difficulties upon discharge and help prevent relapse.

The current review has highlighted the mixed feelings caregivers have when thinking about the future particularly in relation to hopes for recovery and fears regarding relapse. Previous studies have shown that relapse is a significant difficulty for those with an eating disorder with relapse rates ranging from 22% to 51% across outcome studies of anorexia nervosa and bulimia nervosa (Keel, Dorer, Franko, Jackson, & Herzog, 2005). Therefore, a possible aim of interventions could be to instil hope in caregivers and minimise the anxiety surrounding the future through emphasis on the progression achieved and relapse prevention.

Strengths and Limitations

This review systematically collates the views of participants from twelve different studies in order to explore the perceptions of eating disorder treatments and services/professionals from the perspective of caregivers. The papers included in the study were all scrutinised using the adapted CASP tool which highlighted many strengths related to methodological validity. Furthermore, these strengths were also identified by an independent co-rater.

There still remains however, some controversy surrounding the critical appraisal of qualitative literature for use in reviews with some authors arguing that quality appraisal is not compatible with qualitative research methodology (Toye *et al.*, 2013). Of relevance to this review the CASP tool selected has limitations; Hannes (2011) compared three quality appraisal tools concluding that out of the three tools the CASP was the least sensitive to

validity particularly in the areas of descriptive, interpretative and theoretical validity. The reason for selecting the CASP was due to its applicability to a range of qualitative approaches, ease of availability and its frequent use in a number of published qualitative systematic reviews. Furthermore, it has been argued that the guidance and anchors given within the CASP can help to reduce ambiguity surrounding a question so that similar interpretation of the question can be achieved between two raters and can facilitate the critical appraisal particularly for novice reviewers (Newton, Rothlingova, Gutteridge, LeMarchand, & Raphael, 2012). In order to overcome some of the limitations, in this review the CASP was adapted to include some of the elements from the Evaluation Tool for Qualitative Studies (ETQS) which were not evident in the CASP.

A second potential limitation of the review is the heterogeneity of the studies included in regards to setting, participants and treatment model. However, given that several common themes did emerge regardless of this heterogeneity suggests that the themes are indeed of some significance. Related to the heterogeneity of the studies is the mixture of eating disorder presentations. It may be that the experience and treatments available for those caring for someone with anorexia nervosa is different from those caring for someone with bulimia nervosa. However, Fairburn, Cooper and Shafran (2003) recommend a 'trans-diagnostic' approach to eating disorders, arguing that common mechanisms are involved in the persistence of bulimia nervosa, anorexia nervosa and the atypical eating disorders. Therefore, the experiences of caregivers may not be that dissimilar.

Future Research

Many of the studies included in the current review focussed on caregivers to someone with AN, therefore in order to confirm that a trans-diagnostic approach is valid future qualitative studies could focus more on the experiences of those who care for someone with bulimia nervosa, binge eating disorder or other specified feeding or eating disorders and comparing these views to those who care for someone with AN. Furthermore, most of the studies focused on caregivers of adolescents therefore future research could focus on the experience of caring for an adult with an eating disorder. Related to this, the evidence base for therapies such as FBT is based upon adolescents with AN, it would be interesting to see if the positive preliminary evidence can be replicated with adults or those with another form of eating disorder. Finally, as it has been recognised in the NICE guidelines that siblings be involved the eating disorder intervention as only two of the studies included in the review represented

sibling views it would be interesting to find out more about their experiences of being involved in their siblings' treatment.

Conclusion

This review aimed to answer the question: What are the experiences of caregivers supporting someone during eating disorder treatment and what do they want from treatment? It has been found that caregivers report many benefits of being involved in the eating disorder treatment and working collaboratively with health care professionals. Their experiences highlight that caregivers need tailored, practical information to help them in their supporting role and that during treatment time should be dedicated to strengthen family interactions and support caregivers to place boundaries around the eating disorder whilst maintaining their caring relationship. Finally, treatment should take into account the impact the eating disorder has on caregivers and aim to empower them to tackle the eating disorder, provide them with emotional support and facilitate the sharing of experiences of those who are/have been in the same position.

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JOURNAL ARTICLE

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Burnout and its Management within Eating Disorders Services: A Qualitative Investigation

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ABSTRACT

Staff burnout is associated with emotional exhaustion, depersonalisation and a reduced sense of personal accomplishment. Few studies have explored staff experiences of working with people with an eating disorder or their experiences of managing burnout. The aim of this study therefore was to qualitatively explore factors which may contribute to staff burnout, factors which may protect against staff burnout and ways of managing work related stress for staff working with people with an eating disorder. Twenty one staff members working with people with an eating disorder completed an initial questionnaire to ascertain levels of burnout and use of self-care methods. Ten of these participants were interviewed with the study utilising Interpretative Phenomenological Analysis to describe staff experiences. Seven super-ordinate themes were identified: “Dealing with Client Physical Health Risks”, “Working to Different Goals from the Client”, “Awareness of own Eating Patterns”, “Personal Accomplishment”, “Working Together as a Team”, “Working with Caregivers” and “Ways of Managing Work Related Stress”. The findings support previous studies and highlight the importance of continued research in this area.

Key Practitioner Message

- Potential contributors to burnout in eating disorder services include dealing with the physical health risks which people with an eating disorder may experience, working towards different goals to the client and also an increased awareness of own eating patterns.
- Positive or protective factors to burnout when working with someone with an eating disorder include feelings of personal accomplishment and working as part of a team.
- Family members of someone with an eating disorder may add pressure to staff members, however they can also be valuable in eating disorder treatments and work alongside staff members
- Burnout can be managed through ensuring a work-life balance, utilising self-care strategies, self-reflection and realising that recover is not ‘all or nothing’.

Key Words

Burnout, Eating Disorder, Staff, Qualitative

INTRODUCTION

Burnout has been conceptualised as a psychological syndrome characterised by emotional exhaustion, depersonalisation or cynicism and a diminished sense of personal accomplishment that develops in response to prolonged occupational stress and a reduction in personal coping resources (Maslach, Jackson, & Leiter, 1996). Morse, Salyers, Rollins, Monroe-DeVita, and Pfahler (2012) note that across several studies around 21-67% of mental health workers experience high levels of burnout. Maslach and Leiter (2008), argue that understanding burnout is imperative given that it is associated with several negative health and work related consequences. Indeed, correlation studies have shown that burnout is related to decreased work productivity and an increase in staff absences and job turnover (Lozinskaia, 2002; Fahrenkopf *et al.*, 2008). Furthermore, burnout has also been associated with physical and mental health difficulties including insomnia, anxiety, depression, impaired memory, neck and back pain and interpersonal and marital difficulties (Peterson *et al.*, 2008; Swider & Zimmerman, 2010).

Furthermore, it has been proposed that burnout can negatively affect patient care. For example, in their study, Holmqvist and Jeanneau (2006) reported that high levels of emotional exhaustion and depersonalisation were associated with negative attitudes such as being distant or rejecting towards patients. Such negative attitudes have been related to poorer outcomes among patients with mental health difficulties (Gowdy, Carlson & Rapp, 2003). It should be noted however that many of the studies investigating the impact of burnout both on staff wellbeing and patient care utilise cross-sectional methods meaning that it is difficult to ascertain whether the conditions are the result of burnout rather than non-causal correlates or perhaps antecedents (Morse *et al.*, 2012).

Preventing and Managing Burnout

Recently researchers have begun to focus on ways of preventing and managing burnout (Bamonti *et al.*, 2014). Alkema, Linton and Davies (2008) argue that promoting self-care could be one way to enhance job satisfaction and reduce burnout. Indeed, self-care among practising clinicians has been increasingly promoted as an ethical duty to maintain health functioning and decrease the risk of burnout (Barnett, Baker, Elman, & Schoener, 2007). Bamonti *et al.* (2014) postulate that self-care may include many different behaviours, such as ensuring a balance between personal and professional demands and participating in healthy

lifestyle exercises (e.g., diet, exercise, sleep). They add that awareness of signs of distress and seeking social support or mental or other health services when required is vital to self-care.

Among the few studies that have assessed mental-health professional self-care, Mahoney (1997) reported the most frequently utilised behaviours as exercising, having a hobby, reading for pleasure, taking holidays and praying or meditating. Mahoney (1997) also suggested clinicians practise self-care through professional and peer supervision, networking and mentoring. According to Barnett and Cooper (2009), it is fundamental that self-care is seen as a preventative measure rather than a reactive approach.

In addition to focusing on burnout Morse *et al.* (2012) argue that research should look to the positive facets of working such as the ways mental health workers experience compassion, joy, meaning and fulfilment in their jobs. It is postulated that by focussing on these areas more will be understood about factors which protect against burnout.

Eating Disorder Services and Staff Burnout

Although rarely studied, it has been hypothesised that patients with an eating disorder may routinely present with demographic and intervention related characteristics which could place staff at high risk for burnout (Warren, Schafer, Crowley & Olivardia, 2013). For example patients with an eating disorder frequently experience severe physical health complications, comorbid disorders, relapses in treatment, low motivation to change and higher rates of mortality than any other psychiatric disorder (Katzman, 2005; Brewerton, 2007; Berkman, Vitousek, Watson & Wilson, 1998; Arcelus, Mitchell, Wales and Nielsen, 2011).

Furthermore, existing research has shown that those treating patients with an eating disorder are personally affected. Clinicians frequently report emotional reactions to patients and changes in their relationships with food, eating, and appearance (Burket & Schramm, 1995; Warren, Crowley, Olivardia, & Schoen, 2008).

Despite these assumptions, Warren *et al.* (2013) reported relatively low levels of depersonalisation/cynicism and high levels of personal accomplishment following a quantitative analysis of survey data from 296 eating disorder treatment providers in the USA. However, they also found that more than half of the sample was in the moderate to high range of emotional exhaustion. Their findings mirrored those of Satir, Thompson-Brenner, Boisseau and Crisafulli (2009), whose sample of eating disorder clinicians highlighted strong feelings of warmth and low levels of negative attitudes toward patients. Limitations of the

study included the self-selecting sample which is subject to selection bias and may have excluded clinicians with high levels of burnout for many reasons (e.g., they are too overworked to complete study measures). Additionally, data were cross-sectional, which does not allow for direct causal inferences (Warren *et al.* 2013).

Markedly, the majority of studies on burnout utilise quantitative methods and identify risk and protective factors by correlating survey responses or demographic data with scores on the Maslach Burnout Inventory (MBI; Maslach *et al.*, 1996) which measures the three related concepts of emotional exhaustion, depersonalisation/cynicism and sense of personal accomplishment. However, the cross-sectional survey method used does not allow for the conclusion of causation (Rutherford & Oda, 2014). Furthermore, the quantitative findings can only give a limited account of the experience of burnout and ways of managing it. Rutherford and Oda (2014) argue that qualitative methods could enhance these findings by gaining a deeper understanding of what factors contribute to the risk of burnout, which factors may protect against burnout and the ways staff manage burnout.

Recently, Davey, Arcelus and Munir (2014) investigated work demands experienced by health care workers in an adult eating disorder inpatient unit. Interviews with participants highlighted difficulties combining physical and therapeutic care, and the impact on the therapeutic relationship caused by patient ambivalence and organisational demands. Positively, Davey *et al.*, (2014) described the benefits of formal and informal support for staff and reported on participant job satisfaction in relation to rewarding aspects of the role and the positive feelings experienced when a patient recovers. The authors describe a number of limitations of their study, including the focus on only one inpatient unit which may limit the generalisability of the findings and also prohibit the exploration of the experiences of other members of staff whose teams follow a different treatment model from this inpatient unit.

Warren, Schafer, Crowley and Olivardia (2012) utilised an open-ended questionnaire to investigate the risk factors and management of burnout in eating disorder treatment providers. They reported that the most common contributors to burnout were the nature of the disorder (e.g., slow progress, chronicity, relapse, symptom severity) and difficult patient characteristics (e.g., personality conflict, comorbid conditions, ambivalence about change), followed by work-related factors (e.g., time commitment, additional work demands, lack of organisational support or resources), therapist variables (e.g., negative affect), financial issues (e.g., inadequate compensation, patients' financial constraints), difficulty working with

patients' families (e.g., parents in denial), and treating these disorders in a culture that reinforces eating pathology (Warren *et al*, 2012).

Furthermore, they found that to avoid and manage burnout, 92% of service providers reported engaging in self-care behaviours (exercise, social support, engaging in hobbies, taking time off from work, relaxing, taking vacations, sleeping). Participants also reported limiting caseloads (e.g., hours worked a week, types of patients), engaging in personal therapy, increasing participation in professional activities (e.g., continuing education), engaging in a spiritual or religious practice, and maintaining a sense of humour (Warren *et al*. 2012). Consistent with these efforts to personally reduce or avoid their own burnout, the most frequently cited advice treatment providers had for early career clinicians was to make use of supervision. Unfortunately, there are several limitations of the study; for example, the use of questionnaires meant that the answers provided by participants were limited to the space provided to write their answer and also prohibited any follow-up questions to participants which would be possible during an interview.

Following their review, Paris and Hoge (2010) concluded that “a primary challenge for the mental health field is to ... build a more robust knowledge base about the prevalence, causes, and effects of burnout in this field” (p. 526). Given that mental health care professionals are at high risk for burnout, combined with the negative consequences of burnout and the lack of research within the area of eating disorders, exploring experiences of managing and preventing burnout with staff who work in eating disorders is needed. Additionally, in order to design interventions to address burnout in eating disorder services and elsewhere, a thorough understanding of both protective and contributory factors is essential. Therefore, the aims of this study were to explore with staff the factors which may contribute to burnout, factors which may protect against burnout and ways of managing work related stress.

METHODS

Design

An interpretative phenomenological analysis (IPA) epistemology and methodology was utilised for the study and analysis of interview data. IPA was selected due to the research being concerned not only with the individuals' subjective reports of their experiences but also interpreted by the researcher and incorporating psychological knowledge such as existing literature (Willig, 2008). An additional quantitative element of the study involved the completion of an online questionnaire. This allowed the level of burnout and engagement

with self-care strategies to be established. The findings from the questionnaires were also used to develop the focus of the interview schedule.

Sample

Purposive sampling was used to identify the participants for the study. This sampling method entails sample selection based on participant knowledge of or experience in the topic of interest, and possession of characteristics identified by the researchers as selection criteria (Brotherson, 1994). To be included in the study participants had to be currently working with people with an eating disorder for a minimum of six months, aged 18 or over and have a good command of the English Language in order to engage with interview questions.

Participants in this study were NHS staff in the North of Scotland who work with people with an eating disorder in either an outpatient or inpatient setting. Twenty one members of staff out of a possible pool of fifty five completed the Maslach Burnout Inventory – Human Services Survey (MBI-HSS) and Self-Care Assessment Worksheet (SCAW; Pearlman & Saakvitne, 1995). This gives a 38% response rate which is slightly higher than the 33% response rate for online surveys suggested by Nulty (2008). Ten participants from the twenty one who completed the questionnaires took part in the interviews. Due to issues of confidentiality the demographics of the participants have not been reported.

Procedure

A short presentation outlining the aims of the study, what participating in the study would involve and the inclusion/exclusion criteria was delivered to staff working within eating disorder services via staff meetings for the inpatient and outpatient eating disorders teams. Additionally, information pertaining to the study was emailed to potential participants by the North of Scotland Eating Disorder Managed Clinical Network's (MCN) secretary (see Appendix E). Following this staff were sent, by the MCN secretary, a link inviting them to complete the online questionnaire. Consent was obtained by staff 'opting in' to the study.

At the end of the questionnaire participants were asked if they consented to being contacted to participate in the interviews by providing their email address. Participants were also sent a reminder email via the MCN secretary asking them to contact the researcher should they wish to take part in the interviews. Those who agreed to take part in the interviews were then contacted by the researcher via email, and provided with further information on the study and to arrange a date and time for the interviews to take place. The interviews all took place within a private room on NHS premises and lasted between 18 and 52 minutes.

Ethical Considerations

The study was approved by the Research and Development office for each of the study sites. Additionally, approval was given by the University of Edinburgh’s DClinPsychol Ethics Committee. A fuller discussion of the ethical considerations of the study is given in the extended methodology section. Copies of the approvals are given in appendices F and G.

Data Collection

Questionnaire Data

Participants completed online versions of the following questionnaires:

Maslach Burnout Inventory—Human Services Survey (MBI-HSS; Maslach et al., 1996)

The MBI-HSS includes three subscales addressing emotional exhaustion (EE), depersonalization (DP), and personal accomplishment (PA). The MBI-HSS includes 22 items that describe feelings of burnout and enable respondents to rate the frequency of their burnout-related feelings. Items are responded to using a 7-point Likert scale ranging from 0 (*never*) to 6 (*daily*). Maslach *et al.* (1996) reported high reliability and validity of the MBI-HSS with coefficients of reliability for each of the subscales: emotional exhaustion, .90; depersonalization, .79; and personal accomplishment, .71. Test-retest reliability coefficients for the subscales were .82 for emotional exhaustion, .60 for depersonalization, and .80 for personal accomplishment. The MBI-HSS, according to Ackerley, Burnell, Holder, and Kurdek (1988), has good and well researched psychometric properties that reveal a range of burnout levels experienced by a diverse group of mental health professionals including psychiatrists, psychologists, counsellors, and psychotherapists. Table 1 shows the established cut-off scores for each category (Maslach *et al.*, 1996).

Table 1. Burnout: MBI-HSS Cut-off Scores

	Emotional Exhaustion	Depersonalisation	Personal Accomplishment*
High	27 or over	13 or over	39 or over
Moderate	17-26	7-12	32-38
Low	0-16	0-6	0-31

* Higher score denotes greater sense of personal accomplishment.

Permission to use the MBI-HSS was sought and approval given by MindGarden (see Appendix H).

Self-Care Assessment Worksheet (SCAW; Saakvitne and Pearlman, 1996)

Saakvitne and Pearlman (1996) developed the SCAW to measure frequency of engagement in six self-care categories: physical, psychological, emotional, spiritual, professional workplace, and balance. This instrument was originally developed to assist people who experienced difficulties related to vicarious traumatisation. This self-report questionnaire asks participants to rate self-care activities with scores ranging from 1 to 5 based on frequency (1 = *never occurs* and 5 = *frequently occurs*). Higher scores on each subscale indicate higher participation in self-care activities. No psychometric properties have been established for the SCAW (Alkema *et al.*, 2008). Information on the number of items in each subscale, and the possible range of scores for the subscales is provided in Table 2.

Table 2. Number of items in each area of the SCAW

Self-Care Area	Number of Items	Minimum Score	Maximum Score
Physical Care	14	14	70
Psychological Care	10	10	50
Emotional Care	9	9	45
Spiritual Care	15	15	75
Workplace Care	10	10	50
Balance	2	2	10

Permission to use the SCAW was sought and approval given by the publishing company associated with it (see Appendix I)

Interviews

Data from participants were collected using semi-structured interviews which were recorded using a digital voice recorder. The core components of the semi-structured interview were developed by drawing on existing literature on burnout and discussion with the co-authors, and related to the main research aims: contributory factors which add to or lower the risk of burnout and management of burnout/work related stress. Although the interview did focus on areas of interest related to the aims of the study it was not prescriptive and the exploration of topics as they emerged was permitted. The interviews began with a broad question on ‘what is it like to work with people with an eating disorder?’ Once rapport had been established with participants more focussed, sensitive questions such as ‘how do you think your work with this client group affects you personally?’ were posed. Throughout the interview probes such as ‘can you tell me more about...’ were used to obtain further information. An example of the interview schedule is given in Appendix J.

Data Analysis

Questionnaires

Descriptive statistics were used to explore the levels of burnout and staff self-care. The frequency distribution of EE, DP and PA scores for participants who did and did not participate in the interviews were compared by examining the percentage of participants who scored in the high, medium and low ranges of burnout for each of the MBI-HSS subscales. Data were screened for normality using the Shapiro-Wilk test. EE and DP data were found to be normal and were analysed using the independent t-test. PA data were non-normal and therefore the non-parametric equivalent, the Mann-Whitney U was utilised. Where P-values were <0.05, the differences were considered statistically significant.

Levels of staff engagement in self-care strategies for participants who did and didn't participate in the interviews were compared by totalling the scores on each of the subscales and comparing this to the maximum possible score for that subscale.

Identifiable data were available for nine of the participants who participated in the interview. One of the interview participants' data was not identifiable as they did not leave their email address on the questionnaire but contacted the researcher to take part in the interview. Therefore their data is included with the non-interview data.

Interviews

The interviews were analysed using an IPA approach. This process was directed by the guidelines outlined by Smith, Flowers and Larkin (2009). Firstly, the interviews were transcribed verbatim with each of the interview scripts being analysed one at a time. Each transcript was read and reread and the researcher began to make initial exploratory comments from the text. These comments were used to begin to develop emergent themes within each individual transcript. These themes were then organised and explored in greater detail with each theme being examined in relation to other themes in order for interrelationships between them to be recognised. Finally, the themes were combined across the different transcripts in order to identify shared themes that captured the participants' experiences of burnout and managing work related stress. Computer software (Dedoose) was used to organise and manage the anonymised data into the potential super-ordinate and sub-ordinate themes. The extracts presented within the study were selected as they highlighted the essence of recurrent themes or because they gave the most powerful, insightful or articulate expressions of the particular theme (Dickson-Swift, James, Kippen & Liamputtong, 2007).

Demonstrating Quality

For quality assurance Yardley's (2000, 2008) criteria was adhered to. The researcher was sensitive to the research context by situating the findings of the current study within the existing literature and examining their own role and potential bias during data collection. The analysis was detailed and reflective and the researcher was able to demonstrate the validity of the emergent themes through the use of detailed supportive quotations from the participants. A summary of the themes were sent to all of the participants and their feedback sought. Furthermore the coding of the analysis was discussed with the co-authors of the study. In order to reflect upon the researcher's own role in the research a reflective journal was maintained throughout. Finally, the theoretical and clinical impact of the study's findings were carefully considered and reported.

RESULTS

Questionnaire Results

Maslach Burnout Inventory-Human Services Survey (MBI-HSS)

The frequency distribution of EE, DP and PA scores for participants who did and did not participate in the interviews are given in figure 1 and 2. Two (22.2%) of the participants who completed the interview met the threshold for high EE, zero (0%) for high DP and two (22.2%) for low sense of PA. Three of the participants (25%) who did not participate in the interview met the threshold for high EE, zero (0%) for DP and 2 (16.6%) for low sense of PA. Mean and Median levels for each of the scores are given in Table 4. No significant differences were found between the two groups for EE scores ($t(19)=0.10, p=0.92$), DP scores ($t(19)=0.62, p=0.54$) or PA scores ($U=41.5, p=0.537$)

Interviewed Participants

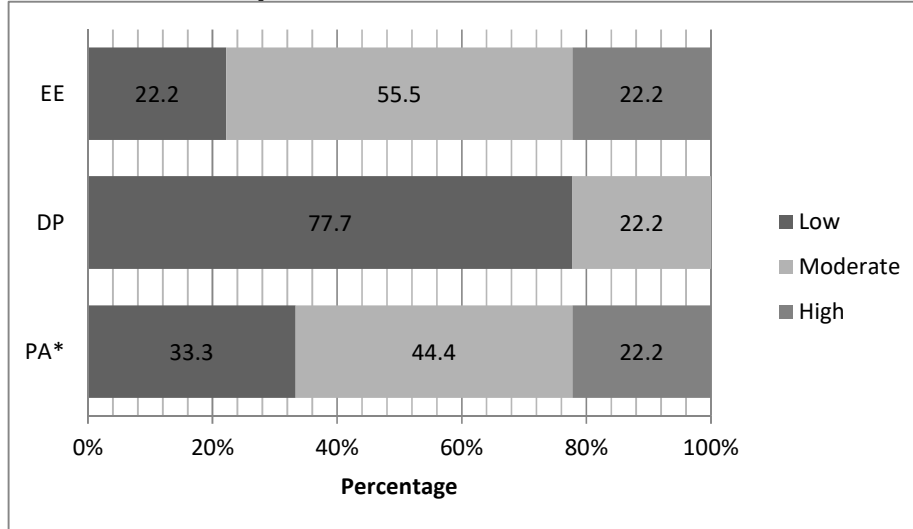


Fig. 1 Frequency distribution of EE, DP and PA scores of participants who participated in the interview.

Non-Interviewed Participants

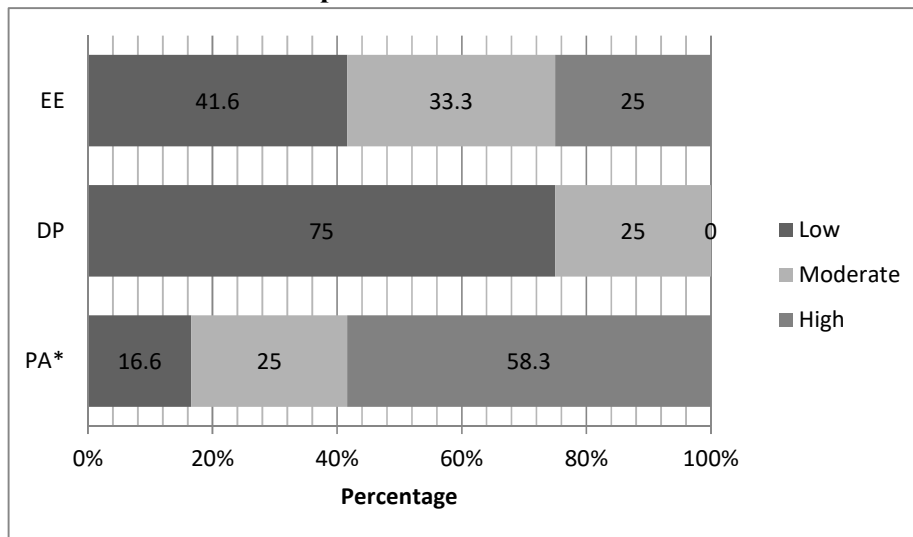


Fig.2 Frequency distribution of EE, DP and PA scores of participants who participated in the interview.

Table 3. Means, SD and Medians for each subscale

	Interviewed				Non-Interviewed			
	N*	Mean	SD	Median	N*	Mean	SD	Median
EE	9	22.7	8.6	20.0	12	22.3	10.8	20.5
DP	9	4.5	2.7	4.0	12	3.6	3.4	3.0
PA**	9	34.2	7.3	36.0	12	37.3	5.2	39.5

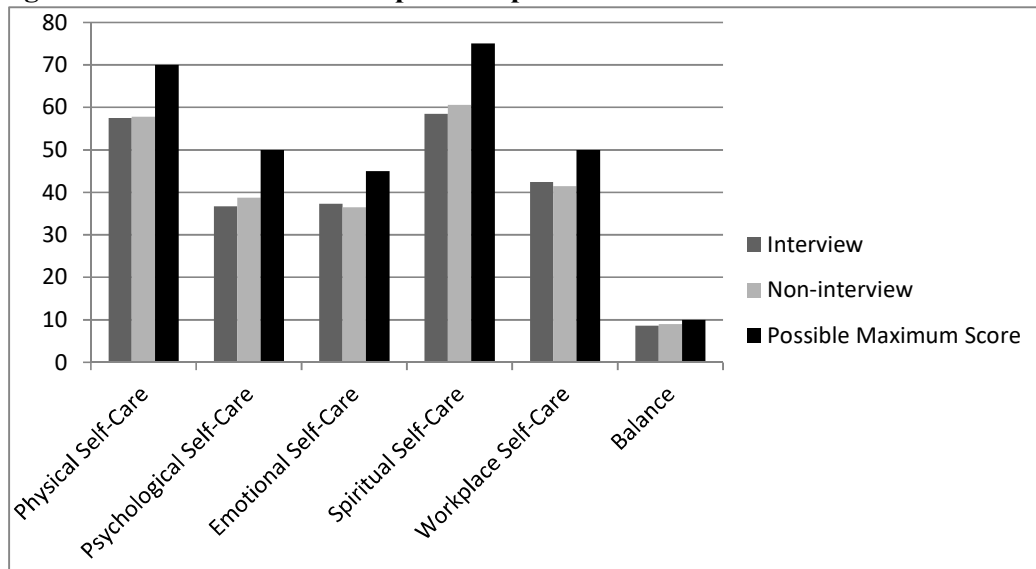
* One of the interview participants' data is included with the non-interviewed data as it could not be distinguished

** Higher score denotes greater sense of personal accomplishment.

Self-Care Assessment Worksheet (SCAW)

The mean scores within each of the subscales for participants who did complete the interviews and those who didn't are given alongside the possible maximum score in Figure 3. High scores on each subscale indicate a high level of engagement in self-care activities whilst low scores indicate a low level of engagement.

Fig. 3 Mean SCAW scores compared to possible maximum score



Interview Results

Seven super-ordinate and nine sub-ordinate themes emerged from the data. The super-ordinate themes related to: dealing with client physical health risks, working to different goals from the client, awareness of own eating patterns, personal accomplishment, working together as a team, working with caregivers and ways of managing work related stress. A summary of all of the super-ordinate and sub-ordinate themes is given in Table 5. For a theme to be regarded as a super-ordinate theme it had to be present in five or more of the interviews (Smith *et al.*, 2009). There has been no attempt to rank these themes by order of importance.

Table 5. Main Super-ordinate and Sub-ordinate Themes

Super-ordinate Theme	Sub-ordinate Theme
Dealing with Client Physical Health Risks	
Working to Different Goals from the Client	Client Motivation Client “Sabotaging Progress” Slow Progress and Relapse The impact of working to different goals
Awareness of own Eating Patterns	
Personal Accomplishment	
Working Together as a Team	Sharing with Colleagues Supervision
Working with Caregivers	
Ways of Managing Work Related Stress	Work-Life Balance and self-care strategies Self-Reflection It’s not ‘All or Nothing’

Super-ordinate Theme 1: Dealing with Client Physical Health Risks

Eight of the participants described the difficulties associated with supporting people who experience physical health difficulties related to the eating disorder. Some of those participants described the ‘high stakes’ attached to working with someone who is physically unwell and the responsibility felt by the clinician working with that person.

“It can be really distressing I guess because when you work with people in the inpatient unit you see people who are potentially at deaths door” (P235)

“In mental health you are not necessary dealing with life or death situations whereas in this line of work you often are. If the person doesn’t eat then potentially their safety is at risk. It would be hopeful that people would be treated before they die but there has been cases where people have died so you are often saving people’s lives without sounding dramatic.”(P076)

Participant 361 described what it is like to work with someone who is very low weight and know what the potential consequences of this low weight could be.

“well for example just now we have someone who has a very very low weight that’s very stressful because from research and evidence ... someone with a very low weight they can have a heart attack at any point they could drop down dead so that’s stressful” (P361)

For some of the participants the physical health difficulties are an additional complexity which may not be present in other areas of mental health.

“the thing with this client group is, I mean with eating disorders compared to other mental health illnesses... you do have the physical risk as well as the mental risk so you have to take two of those things on board” (P814)

Participant 814 later described how overwhelming it can be to work with several people who are experiencing physical health complications related to the eating disorder.

“It’s always the medical issues and things that need to be dealt with so that’s a bit of pressure. If you get a high volume of really unwell patients over a short period of time you have to have space you can’t say ‘oh I can’t see them’ you have to have space in your diary to see them and sometimes that can be 3 or 4 quite unwell ones and you’re trying to juggle that” (P814)

In addition to the risks posed by the physical health difficulties it appears that these difficulties can impact on being able to work therapeutically with the individual.

“Some interventions can’t be done until someone has been there for a while and they have been re-nourished” (P860)

Super-ordinate Theme 2: Working to Different Goals from the Client

Nine of the participants described their experience of what it is like to work with someone who does not want a similar outcome to themselves. The subordinate themes related to client motivation, slow progress and relapse, ‘sabotaging’ progress and the impact of working to different goals.

Client Motivation

For some of the participants the nature of the eating disorder meant that they felt the patient’s thoughts and behaviours were almost impossible to change. Some of the participants reflected upon the challenge of trying to implement change and ‘battle’ against the eating disorder.

“With eating disorders people can be very very fixed in their thinking and their behaviours and that can be very frustrating... it can be very difficult to change those things” (P908)

“It’s more mentally challenging than physically challenging because the illness is so overpowering and because from the word go you’re asking patients to do something that they don’t want to do” (P361)

To overcome the frustration associated with resistance to change participants appeared to externalise the eating disorder and view it as a ‘bully’. This may have helped the clinician empathise with the client and view the eating disorder as being the antagonist rather than the client.

“it is such a difficult client group the patients are so resistant to change, anorexia is such a bullying illness” (P578)

Sabotaging Progress

Some of the participants talked about the ways patients may ‘sabotage progress’ in order to avoid engaging with the intervention. This appears to cause the additional stress of almost having to be ‘one step’ ahead of the patient and be aware of the strategies they may use to prevent the intervention progressing.

“For example someone says that they have eaten their meal but they have hidden their meal” (P361)

“kinda worried not that they are going to trick you or something but that ... they’ve not told you the truth about their meal plan or something so I kind of get worried about that” (P120)

Working with behaviours which can be seen as duplicitous may be difficult to manage, however for some the participants empathising with the patient or distinguishing the eating disorder behaviour from the person appeared to help them manage these behaviours.

“just remember that the patient might act in a way that is difficult to deal with but if I had a fear of a wasp and somebody brought in a wasp I would probably behave in a way that wouldn’t be really nice and it’s just remembering that patients are genuinely really frightened of food” (P076)

“Never trust the eating disorder and try and see the person without the illness, see the person coming through” (P693)

Slow Progress and Relapse

Some of the participants talked about the length of time it took for those they supported to recover from the eating disorder. They also described the frustration and stress they felt when the person they are working with makes some progress and appears to be recovering but then later relapses.

“so lots’ of parts to it and I think that’s portrayed by how long it takes to treat people and how long it takes them to recover” (P693)

“another stressor is probably when you’re working quite hard with someone and you are doing quite well and then they take a step backwards in their progress and their treatment and you think oh we were working so well and they have taken a step backwards well that can be quite stressful as well I think” (P120)

The Impact of Working to different goals

Within the interviews, working to different goals is significant in terms of the perseverance needed and the effect on the clinician if what they deem as ‘progress’ is not made. Some of the participants described finding the experience of working to contrasting goals exhausting and frustrating.

“it’s tiring it can be frustrating... you just think ‘oh no here we go again’ and we are going to have a lengthy discussion about this again, that aspect of it is quite exhausting” (P254)

“it is hard when you’re constantly doing the same thing all the time and you’re not seeing much change that can be quite tough” (P908)

For others, the slow recovery and patient ambivalence to change resulted in a belief that they had to try to do more and more and feeling the pressure when what they try does not appear to help the client.

“There are times as well where you try a lot of different things and it’s still it’s not helping the patient and that’s stressful” (P361)

Participant 076 described feeling like they needed to work harder and do more to help the person recover and eventually this led to them blaming themselves when little progress was made.

“for whatever reason I just feel like I need to do more, there’s nothing I can do that is enough, I should be reading more... I don’t know if it’s just partly because they can be so unmotivated and you just really want to help them therefore you say if that’s not worked then it’s probably my fault” (P076)

“it can be very frustrating and it can sometimes make you question your own ability because you put a lot of work in and ultimately if the person doesn’t want to work on their eating disorder then it can feel kind of like soul destroying almost” (P076)

Super-ordinate Theme 3: Awareness of own Eating Patterns

Six of the participants described the potential impact that working in an eating disorders service could have on their own body image and ways of eating.

“you do start to look more at what you eat naturally as well... there are patients who have a big problem with body image so you do become more aware of your own as well... so my relationship with food has changed and also with body image and thinking about things I wouldn’t normally have thought about for example how do I eat my meal” (P361)

Some of the participants also talked about their experience of working with other members of staff who were affected by an eating disorder.

“we’ve certainly had members of staff who have worked with us who have had an eating disorder and people who are actually unwell and shouldn’t be in the environment” (P254)

However, for participant 120 this increased awareness of eating patterns and body image appears to be a positive factor as through working in the service they were also able to

become more aware of the potential negative impact of being preoccupied with eating patterns and body image.

“I was quite concerned when I first started that it would have an effect on my eating patterns and the way I thought about food but to be honest I think it’s made me healthier in a way around food because I see them and how stressed they get and I think what’s the point really?”(P120)

Super-ordinate Theme 4: Personal Accomplishment

Despite the difficulties outlined above nine of the participants in the study reported a sense of personal accomplishment and found it rewarding when patients do show signs of recovery and were able to ‘beat’ the eating disorder and live what they would describe as ‘successful lives’. This may be especially significant given that the participants met the patients during the most difficult period of the patients’ lives. For the participants being able to support the patients during this time and to have a positive impact on their patients’ lives to the extent that they can put the eating disorder behind them and achieve what they want in their lives is incredibly satisfying.

“you know we’ve had patients who have wanted to die we’ve had patients that have been so unwell that they have been close to dying and we’ve seen those patients get married, patients who have had kids, patients who have managed to get a job and live their life that is most rewarding definitely... to play a role in helping someone to start a life again is really rewarding” (P361)

For participants the investment they made in terms of perseverance and managing risk appeared to have ‘paid off’ and they are able to experience some of the positive elements of working with people with an eating disorder.

“the other side of it is the success it is nice to see people get better, I’ve just met a patient coming over who has maintained her weight for a year” (P693)

Super-ordinate Theme 5: Working Together as a Team

All of the participants discussed their experience of working as part of a team. The two subordinate themes relate to sharing with colleagues and supervision.

Sharing with Colleagues

For some of the participants working as part of a team gave them a sense of being able to share the responsibility of supporting someone with an eating disorder and also to share any concerns they may have about those they are working with.

“Well I think one of the things that is really useful is talking to my colleagues about the things I’m worried about or that I’m stressed about or that I am frustrated with and sharing those things is really useful because it’s not something you can discuss outside the NHS”
(P908)

“I would also say to remember that ok it is a job and it is a team ok you are responsible to a certain extent for your caseload but you are a member of a team and you don’t have to take it all on board it can be distributed and it should” **(P710)**

“I think we’ve got a very good supportive network here definitely because although we have our own caseloads there are cases we work in partnership with other practitioners so you’re not just managing the patient on your own” **(P814)**

In order to be able to share with colleagues it was important for the participants that the other members of their team were available and approachable.

“They are all brilliant, they will sit down and chat to you if they see you are stressed out... I feel now like I can talk to them if I need help so that’s really useful” **(P120)**

Some of the participants also discussed the skill mix of working in a multidisciplinary team and the opportunity to share and learn from colleagues.

“it is a really good team to work with they are very open at sharing their experience and knowledge and teaching and I have learned such a lot and although it can be quite challenging at times I just love learning from the other people... I really do enjoy that part”
(P860)

Supervision

Eight of the participants discussed the importance of supervision to help them formally discuss the sometimes difficult and complex cases they hold and also to discuss their own levels of stress. It would also appear that supervision can help acclimatise staff to the role by allowing them to discuss any concerns with someone who is in a position to reassure them.

“but also a really really important thing is about supervision and not holding onto any anxieties so that if you are new and you are worried about a patient and stressed about it not to keep it to yourself to really look at supervision because really naturally you’re going to be anxious about patients, they will cause you anxiety and stress but it is important to talk about why you are anxious and to explain that you don’t need to be anxious and it’s just the experience but you need supervision” **(P814)**

Some of the participants also described their experience of team supervision. For those participants being able to formally discuss issues with the team helped not only with patient concerns but also allowed for team dynamics to be thought about and any difficulties within the team to be discussed.

“We have group supervision where everyone nurses, allied health professionals, the consultants, the managers, whoever can get to it to discuss the stresses because when you have a multidisciplinary team it may appear that some groups are doing more than others and this can split the group but with supervision together we can work through it” (P578)

Super-ordinate Theme 6: Working with Caregivers

The experience of working with caregivers was described by eight of the participants. Some of the participants appeared to empathise with the caregiver’s situation and are sympathetic to the distress caregivers must experience caring for a loved one who has an eating disorder.

“it’s also hard to see the family members on their last legs sometimes on their last breath trying to manage it because you think you are a whole team here and we’re feeling exhausted and you’ve got your job, the children and now you’re a carer for this individual at home on a regular basis” (P254)

For some of the participants the distress experienced by the caregivers was another pressure on the clinician to support the patient and ensure that they recover.

“as I said earlier a lot of our patients are ambivalent about getting better and that can cause a lot of distress for the parents... family members can maybe try and take it out on us and say ‘what are you guys doing about my daughter’... that’s really one of the most stressful bits” (P814)

“often because they (the caregivers) are so concerned about them and so worried they can put the extra pressure on you so they can be saying ‘why aren’t you seeing them more, why aren’t you doing this, so why aren’t you telling her to eat more’ so all that kind of stuff” (P076)

Another factor which can be challenging when working with caregivers is navigating issues of confidentiality.

“we also get families who... make a lot of contact with the service who are very worried about their family member understandably but it can be difficult in an adult service because you can’t always give information out and there are conflicts with that that may be difficult” (P908)

Some of the participants, however, described working with caregivers as positive experience. Given that the clinician and the patient can sometimes be working to different goals it would appear that having caregivers who have similar goals to the clinician can be reassuring and can allow the caregiver to act almost like a ‘co-therapist’.

“I’ve found working with families good, perhaps that’s just my luck but I’ve actually found it helpful and it’s helped the patients move forward” (P710)

“one of the things is families... there the people in their lives can be really really positive because they can be such a good support they can come in and you can say to them if you can encourage patient x to have their tea this week that would be really really helpful” (P076)

Super-ordinate Theme 7: Ways of Managing Work Related Stress

This super-ordinate theme relates to the different ways that participants manage any work related stress. Three sub-themes were identified which were of particular relevance to this theme: work-life balance and self-care, self-reflection and it's not 'all or nothing'.

Work Life Balance and Self-Care

All of the participants described managing work related stress by ensuring that they had an adequate work/life balance which they saw as being integral to self-care. Some of the participants achieved this by ensuring that they did not take on any additional work or through managing their work diary.

“having a work life balance means coming to work for 9 and going home at 5 so you know not working yourself in the evening” (P814)

“I'm time limited so for example if I am off work because of a public holiday I don't try to fit patients in I just say I can't see you this week” (P254)

For the participants it was also important that they were able to 'switch off' from work by taking time for themselves, doing things they enjoyed and spending time with friends and family.

“being able to have time to yourself to have time to do things you enjoy doing and for me that's lots of different things it's about spending time with family, it's about laughing, it's about enjoying cooking, it's about seeing friends, it's about putting yourself first sometimes” (P254)

“for me it means getting out and about with friends reading other things going out for walks you know having meals just socialising you know with others doing others and not thinking about work” (P860)

Self-Reflection

Six of the participants talked about the importance of self-reflection and monitoring their own emotional well-being in order to take action to manage the stress.

“trying to recognise I suppose knowing the signs that are particular to me that I'm getting a bit overwhelmed by things and trying to put things in place to help myself so generally that's what I would do” (P908)

“it's about taking notice so if you start to stop doing things that you liked doing and changes to energy levels and stress and if you're stuck thinking about patients then it is important to

talk about those things and kind of start of early and find ways to be supportive to deal with that in different ways” (P254)

For participant 578 being reflective and aware of their own reactions to certain issues at work are important. They also discussed encouraging any staff member who may be experiencing their own difficulties in relation to the role to seek their own therapeutic support.

“I would say if you have issues that come up for you in any way shape or form that are personal... it’s not for me in this particular client group but when I worked in other areas patients I have worked with have touched some of my issues I wouldn’t hesitate to say to somebody go and get your own therapy support” (P578)

It’s not ‘all or nothing’

All of the participants reflected that recovery for the patients is not ‘all or nothing’. Several of the participants acknowledged that as recovery can be a lengthy process for some of the patients it was important to take time to reflect on and celebrate the ‘small steps’ to recover that the patients take rather than focusing on ‘fixing’ everything.

“I often find that because they often have so many other comorbid things that you can actually help with a lot of things... often for people with an eating disorder it is so absorbed with all aspects with their life if you can help them with what seems like one simple thing like stopping vomiting or whatever it may be it can then have such a massive impact on the rest of their lives and I think that’s really positive” (P076)

Some of the participants also described a process of acclimatising to the role and accepting that for some patients’ recovery can take a long time but that this is ok and is the nature of the eating disorder rather than a reflection of their competency as a health professional.

“eating disorders can be difficult because they are a difficult client group, many of them are very ambivalent about getting better so sometimes it feels like you’re doing the hard work and your trying to push them to recover and they are not but I guess for me I understand that’s the nature of the illness and I’ve learned to kind of accept that and not let it get in the way of it enjoying my job because that’s the nature of the illness” (P814)

It would appear however that this understanding only comes after working in the area for some time and gaining experience with working with people with an eating disorder.

“There’s not 100 percent correct ways of doing things and you just learn that through experience” (P860)

DISCUSSION

The present study reported on staff burnout levels and engagement with self-care strategies as well as identifying factors which may contribute to staff burnout, factors which may protect

against staff burnout and ways of managing work related stress for staff working with people with an eating disorder.

The quantitative data from the MBI showed relatively low levels of depersonalisation amongst staff. Furthermore, over half of the participants reported moderate or high levels of personal satisfaction. Conversely, the study showed that more than half of the sample was in the moderate to high range for emotional exhaustion. These findings are in line with those reported by Warren *et al* (2013) who described low levels of depersonalisation, high levels of personal accomplishment and moderate to high levels of emotional exhaustion. As there was no significant difference in levels of burnout between those who were interviewed and those who were not interviewed, it would appear that those interviewed were representative of the sample.

The current study has also highlighted fairly high levels of engagement with self-care practices including, spiritual care, emotional care, psychological care, physical care, workplace care and balance. Alkema *et al.* (2008), concluded from his study that taking part in a range of self-care strategies, not just one or two, can help health care providers in managing symptoms of burnout.

Factors which may contribute to burnout

Three of the themes identified in this study may relate to factors which contribute to burnout: dealing with client physical health risks, working to different goals from the client and awareness of own eating patterns. Consistent with Warren *et al.* (2012) and Davey *et al.*'s (2014) study, participants found the physical health risks associated with eating disorders difficult to navigate. In particular, the serious health complications and risk of mortality which isn't as prevalent in other mental health difficulties.

Also in line with the evidence base, participants in this study found it difficult to work therapeutically with someone who was working to a different goal to them. Patient ambivalence, slow progress and relapse and the potential that they may actively sabotage any progress made appeared to incite in participants a belief that they had to try harder and put in more effort in order to help the patient recover. This resulted in feelings of frustration and exhaustion. These findings compliment those found in Davy *et al.*'s (2014) study which reported that a major therapeutic challenge for staff was managing patient's low motivation towards treatment. This experience may also link to emotional exhaustion which is one of

the facets of Maslach *et al.*'s (1996) definition of burnout. According to Maslach *et al.* (1996) emotional exhaustion is being overextended and depleted of emotional and physical resources by the demands of one's job. It may be therefore that the experience of doing more and more to support the patient results in the depletion and overextension of staff's emotional and physical resources and may explain the moderate levels of emotional exhaustion within the current sample.

Another area highlighted in the current study which may contribute to staff burnout is an increased awareness of staff's own eating patterns. Similarly, Warren *et al* (2008) reported that for seventy percent of their sample their view of food had changed since working with people with eating disorders. However, the current study also points to the potential benefit of being exposed to the distress which accompanies a preoccupation with food and encourages staff to avoid becoming focused on dieting at the expense of other valued areas of their lives. This is also in line with Warren *et al.*'s (2008) study which showed that some of the participants gained more of an insight into potential issues with food which resulted in a healthier relationship with food.

Factors which may prevent burnout

Two of the themes identified within this study may relate to factors which prevent burnout: personal accomplishment and working together as a team. Consistent with the findings of Davey *et al.* (2014) participants in the current study found some of the patient-related aspects of their role rewarding. Given the difficulties with patient physical health complications, ambivalence, slow recovery and relapse it is perhaps not surprising that the participants experienced a great sense of achievement when those that they are working with do show signs of recovery. Maslach *et al.* (1996) have established that low levels of personal accomplishment are one aspect of burnout. Reduced levels of personal accomplishment have been defined as feeling ineffective, incompetent, or dissatisfied with the importance of ones work (Warren *et al.*, 2012). Therefore, for participants in the current study, feeling that they have an important positive impact on patient recovery may be a protective factor in the development of burnout and may explain the moderate to high levels of personal satisfaction in the this study.

Participants in the current study felt well supported within their role, one of the areas which appeared to facilitate this was working as part of and receiving support from their clinical team through sharing and supervision. This is an important finding given the relationship

between a lack of social support from co-workers and burnout (Schaufeli and Buunk, 2003). Participant's in Davey *et al.*'s (2014) reported that both formal and informal support gave them the opportunity to seek advice from other professionals, explore patient-staff relationships and ventilate feelings. Furthermore, Willard-Grace *et al.* (2014) found that perceptions of a better team culture were significantly associated with less staff exhaustion in a sample of primary care clinicians. They concluded that promoting a team culture may be a significant strategy to protect against burnout.

Working with family

Participants in the current study had mixed experiences of the involvement of family members in treatment. For some of the participants working with family members was a positive experience as they worked alongside staff in supporting the individual with the eating disorder recover. For other participants the involvement of family members led to an increased pressure to ensure that the patient made a quick recovery. There is little research on therapist views of working with family members within the eating disorder literature. Research which has focussed on family member's experience of working with health care professionals has shown that family members often feel excluded from their loved ones care by healthcare professionals and that they appreciated being involved in the intervention process (Bezance & Holliday, 2014; Rhodes, Brown & Madden 2009). Couturier *et al.* (2013) reported on therapist views of implementing Family Based Therapy (FBT) for eating disorders. The participants in their study described parental motivation to participate in the therapy as a key factor in implementing FBT. It may be therefore in the current study that family members who are motivated to support and be actively involved in change enhance the intervention.

Ways of Managing Work Related Stress

Staff in the current study described a number of ways they manage work related stress including creating a work-life balance through the use of self-care strategies, using self-reflection to notice when they are stressed at work, being able to celebrate the small steps to recovery that patients make and accepting that it may take some time to acclimatise to the role.

These findings compliment those of Warren *et al.* (2012) who reported that 92% of their sample utilised self-care strategies such as social support and engaging in hobbies to help

manage work related stress. Furthermore, one quarter of their participants recommended that therapists should maintain a work-life balance.

The notion of accepting that eating disorder recovery can be a lengthy process with the possibility of patient relapse is also in accordance with Davey *et al.*'s (2014) study where participants demonstrated a degree of acceptance of relapse and viewed it as part of a longer process of recovery. They also noted that this acceptance came with more years of experience.

Limitations

Although the current research highlights some important findings, it has some limitations. Firstly, by only including participants who currently work in eating disorder services those members of staff who perhaps did experience high levels of burnout and subsequently left their role were not represented. Related to this it may be that some of the negative factors associated with burnout were underreported due to the influence of social desirability with participants not being comfortable discussing negative aspects of their job role or client group during the interviews.

Another potential limitation relates to the heterogeneity of the sample. Although everyone who participated in the interviews worked with adults with eating disorders, participants were recruited from both inpatient and outpatient teams. It could be therefore that the experience is different in these two environments. For example Hay *et al.* (2013) report that inpatient programmes are typically multidisciplinary and comprise of a series of nutritional counselling and supervised meals, combined with individual and group psychotherapy and medical care. Conversely Hay *et al.* (2013) report that outpatient care does not provide regular meal supervision and that it is usually less frequent (e.g. occurring one or two times a week) with care less likely to include therapists of multiple disciplines.

Further limitations relate to the quantitative element of the study. Although the questionnaires were used to establish levels of burnout and engagement with self-care strategies and also to inform the interview schedule the small sample size made generalisability of these results to the larger staff population difficult. Furthermore, as the reliability and validity of the SCAW has not been tested the results gained from this measure may be limited.

Clinical Implications and Future Directions

Despite the limitations these findings have important implications for clinical practice and future research. As working as part of a team appears to protect against some of the contributors to burnout, this could be an area which is focussed on by those who manage eating disorder departments in order to develop teams which are able to manage caseloads and responsibilities together and ensure that no staff member is left feeling isolated. Future research could also focus on what makes a successful team and ways of enhancing team cohesion within mental health teams.

This study also highlights the importance of managing work related stress through self-care strategies such as balancing work loads, self-reflection, acceptance of the difficult aspect of the role and utilising supervision. Therefore, the inclusion of these elements during staff training as well as being incorporated into supervision sessions could ensure staff have the awareness of these important aspects in their work role.

Future research could also focus on developing and evaluating burnout prevention and intervention training for staff working in eating disorders. Some interventions for preventing managing burnout have already been developed. For example, a fairly recent development has been the use of Acceptance and Commitment Training (ACTr). ACTr is based upon Acceptance and Commitment Therapy (ACT) principles and aims to increase the psychological flexibility of staff through engaging more fully with the present moment and behaving in line with personal values (Hayes *et al.*, 2004). Positive findings in relation to lowering staff burnout and enhancing self-care from this training have been highlighted for staff working in substance misuse services and clinical psychology trainees (Hayes *et al.*, 2004; Pakenham., 2015)

Another interesting finding from the study was staff experiences of working with caregivers. Although there has been research examining the views of caregivers towards eating disorders staff there has been a dearth of research examining eating disorder professionals experience of working with patient caregivers and therefore more research is needed in this area.

Clinically, several eating disorder treatments such as Family Based Therapy (FBT) aim to involve caregivers in treatment through building alliances between the caregivers, patient and the health professionals working within the team (Whitaker and Macdonald, 2008).

Therefore, it is important for those delivering these treatments to be aware of the potential

stressors of working with caregivers as well as being able to capitalise on the benefits of having them involved.

The current study focussed on the experiences of staff who are currently working with people with an eating disorder, therefore future research could focus on the experiences of those staff who have left their eating disorders post. Finally, all of the staff interviewed for this study worked with adults with an eating disorder; therefore it would be interesting to hear the experiences of staff who work with children/adolescents with an eating disorder.

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EXTENDED METHODOLOGY

The following chapter provides additional information regarding the methodology of the journal article; therefore in order to avoid duplication of the methods section only new information will be presented.

Design – IPA

IPA was selected due to the research being concerned not only with the individuals' subjective reports of their experiences but also interpreted by the researcher and incorporating psychological knowledge such as existing literature (Willig, 2008). The IPA approach acknowledges that participants are experts on their own experiences whilst being mindful of the dynamic role of the researcher in interpreting these experiences (Willig, 2008). Additionally, as IPA is an inductive approach which does not focus on testing hypotheses it fits well with the studies aims to explore the experiences of burnout and managing work related stress for staff working with people with an eating disorder (Reid, Flowers & Larkin, 2005).

Furthermore, IPA is idiographic, meaning it is focused and concentrated on the particular (Willig, 2008). This involves looking for detailed accounts and perceptions of groups of participants who have similar experiences and who can elucidate their own experiences and sense making about the experiences, and then can be compared and contrasted with one another as a means of looking for patterns, shared experiences, and divergences. This approach has also been chosen due to its ability to collect in-depth information which may be difficult to assess quantitatively (Barker, Pistrang & Elliot, 2002) and has been used in other research related to eating disorders (Fox & Diab, 2015).

Reflective Practice

The reflections and stance of the researcher are seen as being fundamental to IPA research. Reflective practice aims to make the constructed nature of research outcomes transparent to the reader (Ortlipp, 2008).

Research Context

The researcher is a White female who undertook the research as part of her Doctorate in Clinical Psychology. At the time of the research the researcher worked as a Trainee Clinical Psychologist in an outpatient eating disorders service which she chose as part of her third year placement. The researcher was aware that her own frame of reference may have some

bearing on how the data was interpreted compared to someone who has never worked in an eating disorders service. This awareness of the researcher's role was one of the reasons an IPA approach was selected. Steps were taken to reduce the researcher's bias such as respondent validation and also the researcher maintained a reflective journal throughout the research process.

Researchers Reflections

The following reflections are written in the first person in order to highlight that these were the individual thoughts and reflections of the researcher.

One of the elements of IPA which initially attracted me to using an IPA approach for my project was the acknowledgement of the part of the researcher in the analysis. This felt particularly pertinent for my project as I was working as a Trainee Clinical Psychologist in an eating disorder service interviewing other staff members. At first I was cautious that perhaps my experience of working with people with an eating disorder would impact on how I interpreted the experiences of others. This is outlined in the excerpt from my reflective journal below:

“During the interview today I found myself debating between sticking strictly to the interview schedule and ‘going off script’ more to generate a fuller account and find out more about the participants perspective. I knew that I should be flexible with the schedule but was concerned that I might interject some of my own experiences of working with people, lead the discussion too much or ‘put words in their mouths’. In the end I actually didn’t find it that difficult to go with the participant and use basic prompts to find out more about their personal experience” (Extract 1, 19/08/2015)

However, as the project progressed I became more and more aware of the benefits of having this insight when interpreting the views of staff members which I think allowed me a deeper appreciation of how they experienced work related stress and working with people with an eating disorder. Furthermore, whilst I was able to acknowledge the similarities between my experience and the participant's experience, I was also able to see where the two diverged.

“As I was making the exploratory notes for participant x I suddenly remembered the interview and noticing how similar our experiences of the first few months working with people with an eating disorder were, then as the participant (who has now been working in eating disorders for several years) began discussing how they now experience working with people with eating disorders (with more confidence and being able to support others who are new to the team) I realised that I am not at that stage yet and I found myself wondering what that would be like” (Extract 2, 04/12/2015)

After the initial relief of actually ‘having’ data to analyse my reflections focussed on the process of analysis itself. The one part which I seemed to find most challenging was the generation of common themes from individual accounts. This is highlighted in the extract from my reflective journal below:

“I seem to be finding it difficult to combine the individual themes into a more common shared theme, in particular I am concerned that I will lose the ‘individual voice’ by trying to encapsulate their experience into an overarching theme.” (Extract 3, 15/01/2016)

I found it interesting that this tension was also noted by Wagstaff *et al.* (2014) in their paper on researcher’s reflections on using IPA. They noted that “while IPA allows for variation within a theme, the emphasis on commonality of experience seemed inconsistent with the idiographic thrust of IPA” (p.6). I found that ensuring all of the participants were represented through the use of verbatim quotes helped ease this conflict.

Ethical Considerations

The NHS Research and Ethics Committee confirmed that as the project involved staff and not patients their approval would not be needed. However, approval was granted by and the project registered with the Research and Development office for each of the participating sites (see Appendix F). The University of Edinburgh’s DCLinPsychol. Ethics Committee approval was also sought and approval given (see Appendix G).

In addition to seeking ethical approval, several ethical issues were also considered. Firstly, to ensure informed consent participants were provided with the information sheet outlining information on the research, what it would involve (including any potential risks) and proposed methods of dissemination (see Appendix E). Participants completing the online survey were made aware that by completing the questionnaire they were consenting to participate. The participants who agreed to be interviewed were again given the opportunity to read the information sheet and were asked to complete a consent form (see Appendix K). Additionally, participants were given a minimum of 24 hours to decide whether or not to take part.

With regards to confidentiality, participants were made aware that the information gathered about them would be anonymised and no personal identifiable information presented in the research paper. In terms of the recordings of the interviews, the digital voice recorder was

kept locked in a filing cabinet in NHS property with all interviews transcribed on NHS property, anonymised and deleted after.

Finally, although the research was not expected to cause harm to participants, it was recognised that participants could potentially find discussing their stressful experiences at work distressing. Participants were made aware of this potential in the information sheet and instructed that should they feel distressed during the interview the researcher would provide them with a list of possible support for example GP, Occupational Health, Supervisor or Line Manager.

Demonstrating Quality

It is now considered essential that the quality of qualitative research is evaluated. Smith, Flowers and Larkin (2009) argue that this should be done in relation to criteria which are regarded as appropriate to qualitative research. For the purposes of this study Yardley's (2000, 2008) approach has been utilised due to the broad range of the criteria and the variety of ways it establishes quality. These criteria have also been disseminated as part of a quality evaluation guide to IPA papers by Smith *et al.* (2009).

Sensitivity to Context

Yardley (2000, 2008) contends that a good qualitative research project will demonstrate sensitivity to the theoretical and socio-cultural context. One facet of this as stipulated by Smith *et al.* (2009) is that the relevant literature is used to direct the study. During all stages of the research process the researcher was sensitive to the existing literature within the area of burnout and also in the area of eating disorders. This literature has also been referred to in the introduction to the study and also in the discussion of the results to help situate the findings of the current study.

Additionally, the use of IPA within the study adheres to sensitivity to context due to the thorough data collection process and in depth awareness of the interview process including the ability to demonstrate empathy and awareness of any power differences between the researcher and participant (Smith *et al.*, 2009). As previously stated the researcher worked as a Trainee Clinical Psychologist in one of the teams from which participants were recruited which may have impacted upon the issues the staff members were willing to discuss. However, it was emphasised to participants that all the data pertaining to the study would be kept secure and anonymised.

Commitment and Rigour

This principle relates to the delivery of a sufficient level of detailed analysis to ensure the validity of the results (Smith *et al* 2009). The use of purposive sampling ensured a fairly homogenous sample of staff whilst the inclusion of staff from different professions and different stages in their career allowed a broad range of possible perspectives. Furthermore, a theme was only deemed a super-ordinate theme if it was present in extracts from at least half of the participants as recommended by Smith (2011). Furthermore, the researcher was able to demonstrate the validity of the emergent themes through the use of detailed supportive quotations from the participants.

In order to assess whether the findings accurately portrayed the participants' views a summary of the themes was sent to participants for validation and to help ensure a lack of researcher bias. Six of the participants responded to the researchers request for validation with all six of the participants agreeing with the themes. Additionally, the combination of quantitative and qualitative findings also provides a source of validation particularly when exploring participant engagement with self-care strategies.

Transparency and Coherence

An electronic and paper trail of the various facets of the research has been maintained throughout the research process which is available for independent audit. Furthermore, each stage of the research process has been described clearly within the write up of the study including details on sampling, recruitment, the interview process and analysis. The inclusion of participant quotes also allows the reader to evaluate the researcher's interpretation of individual accounts and an example from one of the transcripts is given in Appendix L to demonstrate the style of analysis undertaken.

In order to reflect upon the researcher's own role in the research and to make their own experiences and opinions an acknowledged part of the research process a reflective journal was maintained throughout.

Impact and Importance

Yardley's (2000, 2008) final principle relates to the impact and importance of the research. Warren, Schafer, Crowley and Olivardia (2012) argue that as mental health professionals are at high risk for burnout, the negative consequences of burnout and given the unique intervention challenges presented by people with an eating disorder exploring the experiences

of burnout in eating disorder staff are critical. Therefore, given the dearth of research within this area the findings from this study can be viewed as being important. Furthermore, the theoretical and clinical impacts of this study's findings are carefully considered within the discussion section.

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APPENDICES

Appendix A: Clinical Psychology & Psychotherapy – Author Guidelines

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APPENDIX A: Clinical Psychology & Psychotherapy – Author Guidelines

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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)**.
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- 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.

Types of Articles

- **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 (a maximum of 1200 words) that typically contain interesting clinical material. These should use (validated) quantitative measures and add substantially to the literature (i.e. be innovative).

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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:

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In-text Citations

The APA system of citing sources indicates the author's last name and the date, in parentheses, within the text of the paper. Cite as follows:

1. **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.

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

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

3. **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. . .

4. **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).

5. **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. . .

6. **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.

7. **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).

8. **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. . .

9. **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).

Reference List

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:

1. **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
2. **Book**
Paloutzian, R. F. (1996). *Invitation to the psychology of religion* (2nd ed.). Boston: Allyn and Bacon.
3. **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 initial citation, when all are listed) and in all parenthetical citations of material with six or more authors.
4. **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
5. **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>
6. **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.<http://www.psywww.com/psyrelig/psyrelpr.htm>
7. **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.<http://www.psywww.com/psyrelig/psyrelpr.htm>
8. **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.<http://www.psywww.com/psyrelig/psyrelpr.htm>

APPENDIX B: Quality Criteria

Questions which relate to methodological ability of study to address review questions	Yes	Can't Tell	No
<p>1. Research Design Is a qualitative methodology appropriate? Is there a clear description of the context or is the setting adequately described so the reader can relate the findings to other settings?</p> <p>Consider:</p> <ul style="list-style-type: none"> • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants 			
<p>2. Recruitment Strategy Is the sampling suitable and are participant characteristics clearly described. Is there a clear description of how the sample was selected and why?</p> <p>Consider:</p> <ul style="list-style-type: none"> • If the research 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). 			
<p>3. Data Collection Did the study provide a clear and systemic account of data collection methods?</p> <p>Consider:</p> <ul style="list-style-type: none"> • 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 methods 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 			
<p>4. Data Analysis Was the data analysis sufficiently rigorous?</p> <p>Consider:</p>			

<ul style="list-style-type: none"> • 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 			
<p>5. Clarity of findings Is there a clear statement of findings?</p> <p>Consider:</p> <ul style="list-style-type: none"> • If the findings are explicit • If there is adequate discussion of the evidence both for and against the researchers arguments 			
<p>6. Credibility Are steps taken to ensure credibility (e.g. triangulation, respondent validation, negative cases and others involved in analysis).</p>			
<p>7. Reflexivity Has Reflexivity been demonstrated? Has the relationship between researcher and participants been adequately considered?</p> <p>Consider:</p> <ul style="list-style-type: none"> • If the researcher critically examined their own role, potential bias and influence during <ul style="list-style-type: none"> (a) Formulation of the research questions (b) 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 			
<p>8. Believability Is adequate evidence provided to support the analysis (validity and reliability)?</p>			
<p>9. Evaluation/Outcome Is the conclusion justified given the conduct of the study.</p>			
<p>10. Theoretical Framework</p> <p>Consider: What theoretical framework guides or informs the study? In what ways is the framework reflected in the way the study was done? How do the authors locate the study within the existing knowledge base?</p>			

APPENDIX C: *a priori* Framework

Concepts derived for coding	Definitions
Access to treatment	For example pathway to treatment, access to different services such as specialist services, appropriate support commencing early enough
Evaluation of the Treatment for the Person with an ED	What do carers find helpful and unhelpful about the ED treatment?
Support for self	What support can carers themselves receive e.g. formal carer intervention, support groups? What is helpful/unhelpful about these?
Support from healthcare professionals and services	Important characteristics of health professionals, collaboration between health professional and carer's, experience of transition from child to adult services
Treatment specific experiences	For example experiences of utilising a CBT approach or participating in family therapy.
Carer's needs	For example need for information, need for guidance, need for treatment options, need for strategies for managing a caring role.

APPENDIX D: Summary of Themes

ACCESS TO TREATMENT		
	Early Intervention*	<i>Not taken seriously</i>
Bezance & Holliday (2014)	Intervention began too late resulting in inpatient care being needed	Parent concerns were invalidated
Dimitropoulos et al. (2009)		
Engman-Bredvik. et al. (2015)	Would have benefited if they had access to treatment earlier on	
Goodier et al. (2014)		
Honey et al. (2007)		Appreciated clinicians taking time to listen to concerns rather than trivialising their problems
Macdonald et al. (2011)	The materials would have been even more useful at the beginning of the illness	
McMaster et al. (2004)	Finding help was a long arduous journey had to try and try again for help	Not take seriously, misdiagnosed
Rhodes et al. (2009)		
Tierney (2005)	Need to be resourceful and keep trying, be proactive Had to go back to professionals several times by which point condition had deteriorated	
Voriadaki et al. (2015)		
Whitney et al. (2012)	Family work would have been helpful following the onset of the illness	
Winn et al. (2004)	Need to receive information about ED early on Expending considerable time and energy before treatment provided	

* Main theme within 'access to treatment'

KEY FEATURES OF TREATMENT					
	Information and practical guidelines *	Family dynamics*	Boundaries*	Empathy and externalising the ED	Role Plays
Bezance & Holliday (2014)	Reassured by provision of information and “different things to try” but wanted more information to deal with certain situations and what to expect		Enabled mothers to reinstate boundaries and move away from enmeshment and accommodating behaviours		
Dimitropoulos et al. (2009)	Provide information and discuss how it applies to them	Want to know how to facilitate a more open and effective style of communicating		Want to find out what it is like for affected sibling and why it is challenging to overcome	
Engman-Bredvik. et al. (2015)		Improved family dynamics	Reflected on co-dependency and what reinforces the disease	Difficult to differentiate between the disease and child’s ‘true self’ Naming the disease ‘evil monster’, removing ‘uninvited guest’	
Goodier et al. (2014)	Too much theoretical content want more demonstrations and practical activities	Improved communication through learning communication strategies	Helped boundary setting particularly to deal with difficult behaviour related to the ED		Felt “unsure” or “embarrassed” during role plays
Honey et al. (2007)	Want information about what anorexia is and the impact on the family Information on strategies to use at home				
Macdonald et al. (2011)	Difficulties putting information into practice in daily life	Improved communication with loved one through guidance	Less colluding		Distracted by the perceived unrealistic nature of role plays

McMaster <i>et al.</i> (2004)					
Rhodes <i>et al.</i> (2009)		Parents collaborating	Treatment encouraged them to be 'strict' with their daughter Gain emotional distance from child takes some distress from re-feeding	Separating their child from the anorexia helped them parent in a calm and collected way	
Tierney (2005)	Practical sessions help resolve problems that occur at home				
Voriadaki <i>et al.</i> (2015)			Learn new skills in 'being firm'	Feel angry when realising how powerful the voice of AN can be – how isolating for daughter	Found role play enlightening
Whitney <i>et al.</i> (2012)	Want practical advice – what to do	Important to get other family perspectives especially siblings Following intervention communicated more effectively			
Winn <i>et al.</i> (2004)	Need for information about the disorder and why it developed	Family working together			

*Main themes within 'key features of treatment'

SUPPORT FOR THE CAREGIVER			
	Empowerment	Sharing experiences with others in the same position	Emotional Support
Bezance & Holliday (2014)	Increased confidence and sense of self		
Dimitropoulos <i>et al.</i> (2009)		Hearing from others 'in the same boat' helps normalise their struggles	
Engman-Bredvik. <i>et al.</i> (2015)	Derived strength from one another Improved competence in parental role	Feel less 'lonely' after hearing from other families in same situation	Emotional support from peers important – able to share feelings
Goodier <i>et al.</i> (2014)	Increased feelings of efficacy	Share experiences, gain helpful ideas, normalisation of experiences makes them feel less alone	
Honey <i>et al.</i> (2007)			Want emotional support from professionals and other parents
Macdonald <i>et al.</i> (2011)	Increased confidence and self-esteem	Less alone, not the only people in the world going through the illness	Others showing empathy Insufficient interpersonal support in DVD only
McMaster <i>et al.</i> (2004)			
Rhodes <i>et al.</i> (2009)		The similar experiences of parent consultants allowed consultees to feel they were not alone	Emotional support and reassurance
Tierney (2005)			Opportunity to express themselves in neutral environment
Voriadaki <i>et al.</i> (2015)	Confident and efficacious	"Not the only family"	
Whitney <i>et al.</i> (2012)	Carers felt empowered when they were able to implement skills they had learned	Sharing experiences with another family reduced feelings of isolation and guilt	
Winn <i>et al.</i> (2004)		Need to talk and share experiences	Need for reassurance and guidance

WORKING WITH HEALTHCARE PROFESSIONALS		
	<i>Blame</i>	Joint working*
Bezance & Holliday (2014)	Feel judged by professionals	Feeling redundant, lack of feedback and uncertain of what part they needed to play
Dimitropoulos et al. (2009)	Want professionals to reassure that they are not to blame	Discussion and about their roles and responsibilities would be beneficial
Engman-Bredvik. et al. (2015)		
Goodier et al. (2014)		
Honey et al. (2007)	Felt as if they were treated as “bad parents” as if they had caused the illness	Want to be kept informed and be listened to with regards to input and treatment decisions. Feel undermined in the role as caregiver want to be supported in this role
Macdonald et al. (2011)		
McMaster et al. (2004)	Made to feel like they were at fault and to blame Felt scrutinised led to feelings of guilt	Felt excluded from treatment regime. Feeling shut out and actively discouraged from being involved with no respect for the role of the parent
Rhodes et al. (2009)		Therapist helped parents to be involved and work together. Appreciation that the therapist did not try to take the role of parent away
Tierney (2005)		Not feeling involved and a lack of feedback from professionals Need to communicate with other professionals
Voriadaki et al. (2015)		
Whitney et al. (2012)	Feeling judged or blamed	
Winn et al. (2004)		Lack of communication with professionals vs active involvement and open communication

*Main theme from ‘working with healthcare professionals’

THE FUTURE – Hopes and Fears	
Bezance & Holliday (2014)	Treatment instils hope Anxiety about the future as 8 week program “not sufficient”
Dimitropoulos <i>et al.</i> (2009)	
Engman-Bredvik. <i>et al.</i> (2015)	Exercises focussing on the future and dreams were appreciated and gave hope. Insights into risk of relapse and being prepared for subsequent drawbacks are valuable.
Goodier <i>et al.</i> (2014)	
Honey <i>et al.</i> (2007)	
Macdonald <i>et al.</i> (2011)	
McMaster <i>et al.</i> (2004)	Feeling isolated and having to ‘pick up’ the care that had been provided in hospital after discharge. Need to be resourceful
Rhodes <i>et al.</i> (2009)	Development of confidence that they might also be able to progress as a result of treatment
Tierney (2005)	Difficulty imagining what future will hold and fear that they could “slip back”
Voriadaki <i>et al.</i> (2015)	Perceived progress gives hope
Whitney <i>et al.</i> (2012)	
Winn <i>et al.</i> (2004)	

APPENDIX E: Participant Information Sheet



Participant Information Sheet – Survey and Interview

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please ask if anything is not clear.

There are two parts to this study which are outlined in this information sheet.

Burnout and its Management within Eating Disorders Services: A Qualitative Investigation.

It is estimated that between 21-67% of mental health workers experience high levels of burnout. Although highly understudied, it has been argued that patients with eating disorders commonly present with demographic and intervention related characteristics that may place staff at high risk for burnout. Recently researchers have begun to focus on ways of preventing and managing burnout, for example through staff self-care. There has been considerable, if at times conflicting research on burnout in mental health workers but very little consideration of what might be the impact on staff working with people with eating disorders.

What is the purpose of the study?

The purpose of this study is to explore with staff members their understanding and experience of working with people diagnosed with an eating disorder and how staff might manage any associated stress. The study will also explore how stress might be managed within these services. Identifying common themes in the experiences of staff members working in this environment could help further focus training and supervisory processes and future research.

Why have I been invited?

You have been invited to take part because you are a member of staff working in the North of Scotland with people who have an eating disorder.

Do I have to take part?

No, it is up to you to decide to take part. You are free to withdraw at any time, without giving a reason. Whether or not you take part would not affect your job or legal rights.

What will happen if I decide to take part?

Within the next few weeks you will be sent an email asking if you wish to take part in the study. You can choose to take part by clicking the link on the email which will take you to a short online survey. The survey should take no longer than 15-20 minutes to complete. Completion of the survey will be taken as evidence that you consent to participate in this part of the study.

At the end of the survey you will be asked if you would like to participate in the second part of the study which is an interview further exploring your views on factors which add to or

lower the risk of stress and ways of managing or preventing stress when working with this client group and any experience you have had with stress or burnout. You can show your interest in participating in the interview by providing your email address for the researcher to contact you. You are able to just take part in the survey without being obliged to take part in this second part of the study.

If you agree to take part in the interview you will be emailed to arrange an appointment for you to meet with the researcher to participate in the interview. You will be given at least 24 hours to decide whether or not to take part. If the number of people agreeing to be interviewed exceeds the sample needed then you will be emailed to let you know that you will not be required for an interview.

Before participating in the interviews you will have the opportunity to discuss the study with the researcher and ask any questions you may have. The researcher (Emma Fowler-Stewart) will then ask you sign a consent form. The interviews should last no longer than 45-60 minutes. The interviews will be recorded and typed up word for word by the researcher. The recordings will then be deleted and the typed up version anonymised so that no identifiable information will remain.

A few months later the researcher will ask you to complete a short questionnaire to gain your perspectives on the findings.

What are the possible disadvantages and risks of taking part?

Taking part in this study requires some of your time, which may be inconvenient for you. Although unlikely, if during the interview part of the study sensitive information is divulged or any emotional distress experienced the researcher will offer information on who you could contact for further assistance such as your GP, Occupational Health, your supervisor and/or line-manager.

What are the possible benefits of taking part?

We cannot promise the study will help you directly but we hope that the information we gain from this study could help in the future to identify and work with effective training programmes and support for staff as well as having service implications for patients. Taking part will give you the opportunity to think and talk about some of your experiences in working with people with an eating disorder.

What will happen if I decide I no longer wish to take part?

You can decide to withdraw from the study at any stage. Even if you have already taken part you can notify the researcher if you wish to withdraw.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be anonymised and kept confidential. The anonymised coded data will be stored securely on NHS premises for five years after completion of the study.

What will happen to the results of the study?

The results will be written up as part of a doctoral qualification and are intended to be published in a scientific journal. *You will not be personally identified in any of the results.* If you would like a summary of the research findings these can be sent to you.

Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded through the University of Edinburgh and NHS Grampian.

Who has reviewed the study?

The study has been reviewed through the University of Edinburgh and the NHS Research and Development Office.

Further information and contact details

If you have any further questions about the study please contact

If you would like to discuss this study with someone independent of the study team please contact:

If you wish to make a complaint about the study please contact

APPENDIX F: R&D Approval



Dear Mrs Fowler-Stewart

Management Permission for Non-Commercial Research

STUDY TITLE: Burnout and its prevention and management with Eating Disorder Services:
A qualitative investigation
PROTOCOL NO: V3; 11/05/15
REC REF: N/A
NRS REF: NRS15/MH156

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the Research Governance Framework for Health and Community Care (2006, 2nd edition), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

It is particularly important that you inform us when the study terminates.

The R&D Office must be notified immediately and any relevant documents forwarded to us if any of the following occur:

- A change of Principal Investigator, Chief Investigator or any additional research personnel
- Premature project termination
- Any amendments – substantial or non-substantial (particularly a study extension)
- Any change to funding or any additional funding

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

Yours sincerely

Dear Mrs Fowler-Stewart,

R & D MANAGEMENT APPROVAL – TAYSIDE

<p>Title: Burnout and its prevention and management with Eating Disorder Services: A qualitative investigation.</p> <p>Chief Investigator: Mrs Emma Jayne Fowler-Stewart</p> <p>Principal Investigators/Local Collaborator: Mrs Emma Jayne Fowler-Stewart (Generic NHS SSI Form)</p> <p>Tayside Ref: 2015PZ02 NRS Ref: NRS15/MH156</p> <p>REC Ref: N/A</p> <p>Sponsor: University of Edinburgh</p> <p>Funder: Unfunded</p>

Many thanks for your application to carry out the above project here in NHS Tayside. I am pleased to confirm that the project documentation (as outlined below) has been reviewed, registered and Management Approval has been granted for the study to proceed locally in Tayside.

Approval is granted on the following conditions:-

- ALL Research must be carried out in compliance with the Research Governance Framework for Health & Community Care, Health & Safety Regulations, data protection principles, statutory legislation and in accordance with Good Clinical Practice (GCP).
- All amendments to be notified to TASC R & D Office.
- All local researchers must hold either a Substantive Contract, Honorary Research Contract, Honorary Clinical Contract or Letter of Access with NHS Tayside where required (http://www.nihr.ac.uk/systems/Pages/systems_research_passports.aspx).
- TASC R & D Office to be informed of change in Principal Investigator, Chief Investigator or any additional research personnel locally.
- Notification to TASC R & D Office of any change in funding.
security policies, until destruction of this data.
- All eligible studies will be added to the UKCRN Portfolio <http://public.ukcrn.org.uk/>. Recruitment figures for eligible studies must be recorded onto the Portfolio every month: This is the responsibility of the lead UK site. If you are the lead, or only, UK site, we can provide help or advice with this. For information, contact Sarah Auld – (01382) 3 83822 – sarah.auld@nhs.net or Liz Livingstone – (01382) 3 83872 – elivingstone@nhs.net.
- Annual reports are required to be submitted to TASC R & D Office with the first report due 12 months from date of issue of this management approval letter and at yearly intervals until completion of the study.
- Notification of early termination within 15 days or End of Trial within 90 days followed by End of Trial Report within 1 year to TASC R & D Office.
- You may be required to assist with and provide information in regard to audit and monitoring of study.

Please note you are required to adhere to the conditions, if not, NHS management approval may be withdrawn for the study.

Approved Documents

Document	Version	Date
Protocol	3	11/05/15
Participant Information Sheet – Survey and Interview	3	05/05/15
Consent Form	2	05/05/15
Interview Schedule	2	05/05/15

May I take this opportunity to wish you every success with your project.

Please do not hesitate to contact TASC R & D Office should you require further assistance.

Yours sincerely



Dear Mrs Fowler-Stewart,

Management Approval for Non-Commercial Research

I am pleased to tell you that you now have Management Approval for the research project entitled: **'Burnout and its Prevention and Management with Eating Disorder Services: A Qualitative Investigation'** [Protocol V3 11/05/15]. I acknowledge that:

- The project is sponsored by the University of Edinburgh.
- The project does not require external funding.
- Research Ethics Committee approval is not required for the project as it involves NHS staff only.
- The project is Site-Specific Assessment exempt.

The following conditions apply:

- The responsibility for monitoring and auditing this project lies with the University of Edinburgh.



This study will be subject to ongoing monitoring for Research Governance purposes and may be audited to ensure compliance with the Research Governance

Framework for Health and Community Care in Scotland (2006, 2nd Edition), however prior written notice of audit will be given.

- **Mrs Fowler-Stewart requires a Letter of Access prior to starting the project at this site. This will be forthcoming in the next few days.**
- All amendments (minor or substantial) to the protocol or to the REC application should be copied to the NHS Highland Research and Development Office together with a copy of the corresponding approval letter.
- The paperwork concerning all incidents, adverse events and serious adverse events, thought to be attributable to participant's involvement in this project should be copied to the NHS Highland R&D Office.
- Monthly recruitment rates should be notified to the NHS Highland Research and Development Office, detailing date of recruitment and the participant trial ID number. This should be done by e-mail on the first week of the following month.

Yours sincerely,

APPENDIX G: University of Edinburgh Ethical Approval



SCHOOL of HEALTH IN SOCIAL SCIENCE
CLINICAL AND HEALTH PSYCHOLOGY

The University of Edinburgh
Medical School
Doorway 6, Teviot Place
Edinburgh EH8 9AG

Telephone 0131 651 3969
Fax 0131 650 3891
Email submitting_ethics@ed.ac.uk

Emma Jayne Fowler
Trainee Clinical Psychologist

09 June 2015

Dear Emma,

Application for Level 1 Ethical Approval

Project Title: Burnout and its management within Eating Disorder Services: A Qualitative Investigation

Academic Supervisor: Emily Newman / Ethel Quayle

Thank you for submitting the above research project for review by the Department of Clinical and Health Psychology Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 7th June 2015.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

APPENDIX H: Permission to use Maslach Burnout Inventory

**Approval for Remote Online Use
of a Mind Garden Instrument**

Effective date is July 1, 2015 for:
Emma Jayne Fowler-Stewart

You submitted your statement for remote online use at 12:56 pm EDT on June 29, 2015.



www.mindgarden.cc

APPENDIX I: Permission to use Self-Care Assessment Worksheet

From: [REDACTED]
Date: 23 June 2015 17:55:16 BST
To: [REDACTED]
Cc: [REDACTED]
Subject: RE: Request to use the Self-Care Assessment Worksheet (SCAW) for Thesis purposes

June 23, 2015

Emma Fowler
University of Edinburgh
Old College, South Bridge
Edinburgh EH8 9YL
UNITED KINGDOM

RE: Transforming the Pain: A Workbook on Vicarious Traumatization

Thank you for your request to use the Self-Care Assessment Worksheet from TRANSFORMING THE PAIN: A WORKBOOK ON VICARIOUS TRAUMATIZATION in your dissertation "Burnout and its prevention and management within Eating Disorder Services." This letter will grant you one time, nonexclusive rights to use the material in your dissertation, and in all copies to meet university requirements, subject to the following conditions:

1. Full acknowledgment of the title, author, copyright and publisher is given as follows;

From TRANSFORMING THE PAIN: A WORKBOOK ON VICARIOUS TRAUMATIZATION by Karen W. Saakvitne. Copyright © 1996 by the Traumatic Stress Institute/Center for Adult & Adolescent Psychotherapy LLC. Used by permission of W.W. Norton & Company, Inc.

2. You must reapply for permission if your dissertation is later published.
3. You may reproduce no more than 10% of our book in your dissertation.

Best Regards,

[REDACTED]

APPENDIX J: Interview Schedule

Prior to interview, the Chief Investigator will go through the information sheet again with the participant and obtain informed consent.

The following questions will be used to guide and facilitate a discourse between the Chief Investigator and each participant. Prompts will be used minimally to encourage further information from participants.

- What is it like to work with people with an eating disorder?
Prompt for: Positive aspects of working with client group
Stressors associated with working with client group
- How do you feel your work with this client group affects you on a personal basis?
Prompt for: During working hours? How do you cope with this? Why is this helpful?
Outside working hours? How do you cope with this? Why is this helpful?
- Are there any other aspects of your work role, other than direct client work which is either positive or a stressor?
- How do you manage work related stress?
- How well supported do you feel at work
Prompt for: Are there any ways in which you feel this could be improved? How?
- Do you have any ideas for how support for professionals who work with this client group could be improved more generally?
Prompt: How?
- Finally, is there anything else that you would like to add to any of your responses?

APPENDIX K: Participant Consent Form



CONSENT FORM

Title of Project: Burnout and its Management within Eating Disorders Services: A Qualitative Investigation

Name of Researcher: Emma Fowler

This consent form is for the interview part of the study only

Please initial all boxes

- 1. I confirm that I have read and understand the information sheet dated
(version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my job or legal rights being affected.
- 3. I understand the interviews will be recorded and typed word for word. I give permission this to be done.
- 4. I understand the recordings will be destroyed once the interviews have been analysed
- 5. I am aware of the potential risks and benefits of taking part.
- 6. I agree to take part in the above study.
- 7. After the data have been analysed, the researcher would like to contact some of the participants for their perspectives on the findings. Do you consent to being contacted after the study for this purpose (Y/N)?
- 8. I understand that relevant sections of data collected during the study may be looked
- 9. at by individuals from the regulatory authorities and from the Sponsor (University of Edinburgh) or from NHS Grampian where it is relevant to my taking part in this research.
- 10. I give permission for those individuals to have access to my data.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent.	Date	Signature

APPENDIX L: Transcript Example

Emergent Theme	Original Transcript	Exploratory Comments
<p>Motivation of patient Working to different goals Managing work stress – personal impact?</p> <p>ED not for everyone</p> <p>Process of acceptance</p> <p>Physical Health Risks - Balancing physical health risks and mental health risks</p> <p>Balancing demands</p> <p>Co-morbidity</p>	<p>I: Can you tell me what is it like to work with people who have an eating disorder?</p> <p>P: I like my job however eating disorders can be difficult because they are a difficult client group many of them are very ambivalent about getting better so sometimes it feels like you're doing the hard work and your trying to push them to recover and they are not and em but I guess for me I understand that's the nature of the illness and I've learned to kind of accept that and not let it get in the way of it enjoying my job because that's the nature of the illness em I think this job is not for everybody absolutely not and I've spoken to many clinicians who would say how on earth do you work with eating disorders because I think some practitioners em can work well in eating disorders I think it's not for other practitioners so I think this job is not suitable for everybody em but I think I'm a patient person so em I like it but I think I've just come to accept that it is a difficult client group to treat and it's not just because patients don't get better it's no reflection on me as a person or my capabilities as a clinician.</p> <p>I: Anything else you can think of?</p> <p>P: Em the thing with this client group is I mean with eating disorders compared to other mental health illnesses you do have the physical risk as well as the mental risk so you have to take two of those things on board so for example you have as well as the physical health issues with patients that maybe are unwell you have to deal with the mental risk and when you have for example a patient with a borderline personality disorder or somebody who is very medically unwell that can cause a bit of anxiety and we are not an emergency service so we have to sometimes kind of</p>	<p>Motivation of patients – what is it like to work with someone who doesn't want the same outcome as you? How does this impact on therapeutic relationship? “trying to push” does this become frustrating, exhausting?</p> <p>Ways of managing it – taking a step back, seeing motivation to change as being part of the ED</p> <p>Working in ED not for everyone – what are others perceptions of ED?</p> <p>Acceptance that ED are difficult client group? Is it a process which staff need to go through? Not taking slow progress personally</p> <p>Physical risks – holding physical risks and mental health difficulties at same time.</p> <p>Balancing BPD, ED and physical health difficulties – does this get overwhelming?</p> <p>‘Not an emergency service’ – can only do so much to support medical emergencies – when does something</p>

<p>Working with family members</p> <p>Stressful aspects of the role</p> <p>Balancing demands</p>	<p>try to deal with that to the best that we can but that can cause some anxiety that you have to deal with two aspects of mental illness and physical illness as well</p> <p>The other thing that can be stressful is working with the family members because some patients don't want family members involved in their care and as I said earlier a lot of our patients are ambivalent about getting better and that can cause a lot of distress for the parents and parents or family members can maybe try and take it out on us and you know 'what are you guys doing about my daughter' and em that's really one of the most stressful bits is having to deal with the family members and as well have those boundaries with confidentiality at the same time as wanting to let the parents know we are doing our best to take care so sometimes it can be difficult, I think the most difficult bit for me sometimes is dealing with families they get very angry and 'what are you doing about this' so probably that's one of the most stressful bits is dealing with family members</p>	<p>become an 'emergency'?</p> <p>Working with family members – stressful – holding family anxieties. Act as mediator between patient and family? Families anxiety leads them to blame professionals?</p> <p>'Demands' from family, do they expect more as it is a 'specialist service'?</p> <p>Navigating issues of confidentiality</p> <p>Pressure to show what you are doing – to 'get results' Stuck in the middle between family and person with ED?</p>
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