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Doctoral Thesis

Family Carers and Mental Health: the Role of Self-Compassion

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Word Count

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Thesis Abstract	277	0	277
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Critical Appraisal	3577	841	4418
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This thesis conforms to the permitted maximum word-length.

Thesis Abstract

The self-conscious emotions of guilt and shame are often experienced by family members who care for a relative with a mental health difficulty. This may drive certain behaviours, characterised as emotional overinvolvement (EOI). EOI is consistently associated with poorer outcomes among people experiencing mental health difficulties and their relatives.

One factor associated with guilt and shame in the wider literature is self-compassion. The focus of this thesis is on examining self-compassion in family carers of people with mental health difficulties, so as to determine whether this is an appropriate focus for interventions. It is hoped that the work undertaken in this thesis will inform the support offered by clinicians, both to carers and their relatives.

The first study is comprised of a qualitative meta-synthesis, which explores the experiences of family members partaking in family interventions for eating disorders.

Research has considered family interventions from the client's perspective, but it appears that no qualitative review has considered the impact of such interventions on relatives.

Interventions provided a space for validation, safe exploration of painful emotions, and an opportunity to regain parts of themselves that had perhaps been lost in the midst of providing care.

The second study explores the relationship between guilt and shame, and EOI in family carers. It also examines whether self-compassion moderates the relationship between guilt/shame and EOI. Although all variables were highly correlated with each other, there was no significant moderating effect of self-compassion on the relationship between the predictor variables of guilt and shame, and EOI. Further space for reflecting on the findings

and implications can be found in section three of the thesis, which comprises a critical appraisal of the research paper.

Declaration

This thesis documents research undertaken between October 2016 and August 2017, in

partial fulfilment of the Lancaster University Doctorate in Clinical Psychology. The work

presented here is my own, except where due reference has been made. This thesis has not

been submitted for the award of a higher degree elsewhere.

Signature:

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The Experiences of Relatives Partaking in Family Interventions for Eating Disorders: A Qualitative Meta-Synthesis.

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European Eating Disorders Review (see Appendix 1-A)

FAMILY INTERVENTIONS FOR EATING DISORDERS

1-2

Abstract

Objectives: To explore the experiences of family members taking part in family

interventions for eating disorders.

Method: Five databases (PsycINFO, Academic Search Complete, Proquest (dissertation and

theses), CINAHL, and Pubmed) were searched. Qualitative papers which met inclusion

criteria were read to assess their suitability. A cited article search and reference list search

was also conducted and twelve appropriate papers were identified and included.

Results: Four overarching themes were identified from the analysis. These were: (i) being

heard (ii) family as a team against the eating disorder (iii) easing the burden of responsibility

with compassion and (iv) the role of doubt and reassurance. The first theme, being heard,

included two subthemes: (a) between participants: connection and disconnection, and (b)

between families and the treatment team: support and empowerment. Each theme and

subtheme are discussed in detail.

Conclusion: Families often felt isolated prior to family interventions, which was exacerbated

by multiple losses within their support network. Family members also reported an enmeshed

relationship with their relative. Family interventions appeared to facilitate a shift towards the

family being perceived as a cohesive unit, and a source of mutual support against the eating

disorder. Over the course of interventions, relatives began to regain parts of their identity that

had perhaps been lost as a result of providing care. For some, ongoing doubt persisted in

relation to the future and their ability to cope. Implications for clinical psychology practice

are discussed.

Keywords: meta-ethnography, qualitative, eating disorder, family, intervention.

It has been estimated that unpaid carers save the United Kingdom £132 billion per year (Buckner & Yeandle, 2015). This suggests that there is a sound financial rationale for ensuring that family carers are included within treatment plans and offered support. Families have an important role in supporting relatives who have a mental health difficulty, and it is unsurprising that this role often adversely affects their psychological wellbeing and quality of life (Ennis & Bunting, 2013; Organisation for Economic Co-operation and Development, 2011; Shah, Wadoo, & Latoo, 2010; World Health Organisation, 2001).

One concept associated with family carers is expressed emotion (EE). EE refers to attitudes based on emotional overinvolvement (EOI) and critical comments (CC), which are directed towards relatives with a mental health difficulty (Leff & Vaughn, 1985). Although EE was originally found in carers of people diagnosed with schizophrenia (Brown, Carstairs, & Topping, 1958; Vaughn & Leff, 1976), it is present in relatives of people with a range of mental health difficulties (Butzlaff & Hooley, 1998; Chambless & Steketee, 1999; Hooley, Orley, & Teasdale, 1986; Tarrier, Sommerfield, & Pilgrim, 1999). High EE has also been found in carers of a relative with an eating disorder (Zabala, Macdonald, & Treasure, 2009). High EE refers to scores above cut-off points on measurement scales. In relation to the Camberwell Family Interview (Vaughn & Leff, 1976), the gold-standard measure of EE, a classification of high EE is made on the basis of ratings in relation to criticism, hostility, and EOI. For example, in relation to schizophrenia, a relative would be deemed to exhibit high EE if they make six or more critical remarks, any remark classed as hostile, or scores 3 or more on a 0-5 scale of overinvolvement (Hooley & Parker, 2006). Other measures of EE, such as the Family Questionnaire (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002) aim to meet the standards of the Camberwell Family Interview (Vaugh & Leff, 1976) with equivalent cut off scores.

The potential role of EE in families affected by an eating disorder is illustrated in the Cognitive-Interpersonal Maintenance Model of anorexia (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). This model posits that features of anorexia lead to difficulties relating to others, and furthermore, the nature of the symptoms and behavioural presentation of the person effects how others interact with them. These relational patterns maintain the symptoms of anorexia (Treasure & Schmidt, 2013). The model also illustrates the role of control, with both the carer and relative frequently attempting to defend their viewpoint, becoming increasingly focused on details and losing sight of the wider, long-term situation (Treasure & Schmidt, 2013). This struggle for control and defensive relational patterns can promote inflexible approaches to understanding and responding to the eating disorder and exacerbate distress. In support of this, it has been found that mothers of someone with an eating disorder often exhibit significant distress (displayed as self-blame and helplessness) and high levels of EOI (Whitney & Eisler, 2005). It has also been found that high EE can influence the success of therapeutic interventions (Butzlaff & Hooley, 1998).

In light of the role of EE on maintaining the distress of both carer and relative, it has become a focus for family interventions in eating disorder services. As well as the beneficial effect family involvement in treatment can have on the prognosis of the eating disorder, it is also important to consider wider benefits of supporting family members. Guidance recommends that, wherever possible, people with an eating disorder should be supported as outpatients rather than utilising inpatient provision (NICE, 2017). This inevitably places significant responsibility and pressure onto families, which is likely to contribute to stress and distress among family carers. In light of the known increases in psychological distress and mental health difficulties among family carers, it can be argued that there is a moral and ethical responsibility to support these individuals wherever possible.

A multitude of family interventions for eating disorders have been developed, though the majority of these relate to supporting families affected by anorexia. The first familybased approach to treating anorexia was developed by Minuchin et al. (1975), who found that 86% of clients who were part of a family therapy intervention made a full recovery. This formed the basis for future family interventions, and the start of the Maudsley studies. One such study, conducted by Russell, Szmukler, Dare, & Eisler (1987), built on Minuchin et al. (1975)'s ideas, and compared outpatient family therapy to individual supportive therapy. More favourable outcomes were found among those who underwent family therapy (Russell et al., 1987).

Family interventions for families affected by bulimia have largely arisen from interventions for anorexia. For example, a manualised FBT (Family-Based Treatment) approach for anorexia (Lock & Le Grange, 2001) has been adapted to support adolescents with bulimia (Le Grange & Lock, 2009). The main difference noted between family interventions for anorexia and bulimia has been described as an increased focus on collaboration between the person with bulimia and their family (Nadeau & Leichner, 2009), rather than placing the control temporarily with the parents, as is common observed in interventions for anorexia.

A recent meta-analysis has explored the efficacy of family therapy, in contrast to individual treatment for adolescents with eating disorders (Couturier, Kimber, & Szatmari, 2013). Although family interventions did not have an immediate advantage over individual treatment at the end of the intervention, they did have a long-term effect, with significant benefits found at six and twelve month follow up (Couturier et al., 2013). Consequently, interventions which include the family do appear to be beneficial. Recent NICE Guidelines for eating disorders (NICE, 2017) emphasise the need for flexibility in order to best meet the needs of the individual with the eating disorder. While it is important to consider the balance between the benefits obtained by the family of a longer, more tailored approach with the financial cost of implementing such an intervention, the potential costs (financial and emotional) relating to the impact of carer distress must also be considered. Relatives are often included in interventions for eating disorders, however their experience of such

interventions is not well-understood.

Family interventions for eating disorders emphasise strengthening the role and power of the parents, encouraging them to control mealtimes and feeding regimes (Lock & Le Grange, 2013). In addition, they are required to re-conceptualise patients' behaviours, viewing the anorexia as the difficulty, rather than the person. Family behaviours and emotions are scrutinised and discussed as part of the intervention, and therefore, although the interventions aim to help families as well as the individuals affected by eating disorders, there are, potentially, substantial pressures and responsibilities laid before them. Despite this, evidence suggests that relatives may benefit from such interventions (Hibbs, Rhind, Leppanen, & Treasure, 2015; Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008) and therefore some positive experiences are likely to accrue. It is unclear how families experience these interventions, but such experiences may well have implications for their implementation. This meta-synthesis aimed to clarify the perspectives of family members, and give some guidance to practitioners in the field.

Method

A synthesis of relevant papers was conducted by following the meta-ethnographic approach developed by Noblit and Hare (1988). This approach is thought to be the most established and well-developed method for the synthesis of qualitative data (Britten, Campbell, Pope, Donovan, & Morgan, 2002). The technique involves using induction and interpretation to understand the way in which studies are related to each other, whilst preserving the original interpretations within each study. It is these interpretations that are translated across studies to create the synthesis, which aims to produce higher-level explanations of phenomena, and a more coherent understanding of the topic being studied. Meta-ethnography should give direction to future research (Britten et al., 2002). Noblit and Hare's (1988) seven-stage process for conducting a meta-ethnography was employed.

Reflexivity and epistemology

The philosophical underpinnings of meta-synthesis are based on constructionism, due to its focus on understanding how people develop and reconstruct knowledge about a topic (Reid, Sinclair, Barr, Dobbs, & Crealey, 2009). Within the current meta-synthesis, the construction of findings emerges at three points. Participants within individual studies develop their own knowledge and meanings (first-order constructs). The researchers of each study then order their findings in line with their knowledge and lived experience, inherently affecting their interpretation of their findings (second-order constructs). Finally, the person undertaking the meta-synthesis considers the first and second order constructs, in the context of their own lived experience and knowledge, to develop third-order constructs. Thus the findings of this review should not be considered as the only possible interpretation of available data. Contextual differences between researchers mean that a number of different interpretations could be reached by synthesising the findings of included papers. My own

lived experience and beliefs are important to consider as they are likely to impact on how I perceive and interpret the findings of other papers (Creswell & Miller, 2000). I believe that family, and those important to an individual, hold important views that can impact on wellbeing. In addition, distress is often a reciprocal phenomenon; the distress of a family member can impact on the distress of the client, and vice versa. I am aware that these beliefs might influence my own interpretations and assumptions, however I have remained aware of this throughout the meta-ethnographic process. I have also kept a reflective journal, noting any of my own reflections and thoughts which might influence the way I synthesise data. It is hoped that by doing this, the current meta-synthesis represents an inclusive, fair review of the area.

Developing the research question

The question this meta-synthesis sought to answer was:

"What are the experiences of relatives partaking in family interventions for eating disorders?"

This is a broad question. Initially, the idea of focusing on a single family intervention was considered, however given the number of new and adapted approaches being developed, it was prudent to explore the experience of family members across interventions. This allowed the strengths and weaknesses of various approaches to be included and facilitated a new way to understand how family members experience interventions for eating disorders. Ultimately, it was hoped that this would help shape future relevant interventions.

Search strategy

Inclusion criteria: (1) Papers must have been published in English (2) Papers must have used qualitative methodology for at least part of their data collection. Any qualitative

methodology could be used (3) Papers must have explored a method of intervention that includes family members or partners (4) Papers must have explored the perspectives of family members or partners (5) Papers must have explored the experiences of individuals from a first person perspective. In addition, the following exclusion criteria were applied: (1) Papers which only used quantitative methods (2) Papers which only explored the experience of the person with an eating disorder during family interventions (3) Papers which only included researcher commentary on their view of participant's experience (4) Papers which looked at both the client and the family's views, but did not distinguish between the two perspectives during the write up.

Although the inclusion of different qualitative methodologies has been questioned on the basis that synthesising findings is more challenging (Noblit & Hare, 1988), the current review sought to include the full range of qualitative methodologies so as to provide as complete a synthesis as possible (Paterson, Thorne, Canam, & Jillings, 2001; Sandelowski, Docherty, & Emden, 1997).

Search terms were truncated where appropriate (Sandelowski & Barroso, 2005). The search was conducted by the author, and the search strategy was reviewed by an Academic Liaison Librarian. Titles, abstracts and keyword searches were completed using the thesaurus of each database. A broad-based strategy was used, as shown by the inclusion of the keywords *qualitative*, *finding* and *interview*. These terms have been suggested by Shaw et al. (2004), and it has been found that this strategy produces results comparable to much greater numbers of papers being identified. See Table 1 for keywords searched in each database.

[TABLE 1 ABOUT HERE]

The following databases were searched: PsycINFO, Academic Search Complete,
Proquest (dissertation and theses), CINAHL, and Pubmed. See Appendix 1-B for a list of full
search terms for each database. No age limit of publication was imposed. A further hand
search was conducted by looking through the reference lists of shortlisted papers and a cited
article search was also conducted to ensure any further relevant papers were included.
Following this, a total of 12 papers were included. See Figure 1 for an illustration of the
search process, and Table 2 for information about each study.

[FIGURE 1 ABOUT HERE]

[TABLE 2 ABOUT HERE]

Appraising the quality of selected papers

Each included paper was evaluated using the Critical Appraisal Skills Programme (CASP) (Public Health Resource Unit, 2006). CASP has been effectively used in other metasyntheses to determine the quality of included papers (e.g. Campbell et al., 2003). CASP examines research quality across ten domains. The first two questions consider (1) whether there is a clear statement of aims, and (2) the appropriateness of using qualitative methodology to explore the research aims. All shortlisted papers passed these screening questions, and were therefore assessed on the eight further areas. A mark of 1 (*weak*), 2 (*moderate*) or 3 (*strong*) was assigned for each area. This scale allows studies to be compared with each other on each area assessed (Duggleby et al., 2010). Two researchers independently rated each paper, and a discussion of assigned scores followed. Further discussion occurred where there was disagreement in ratings, until an agreement was reached. No papers were excluded on this basis of scores. Instead, CASP ratings facilitated the critical evaluation of papers, and an appraisal of the quality of the write-up. The maximum possible score a paper could achieve was 24. See Table 3 for CASP scores.

[INSERT TABLE 3 ABOUT HERE]

Synthesis and interpretation of shortlisted papers

Hard copies of each shortlisted paper were read in depth as part of the process of determining their quality, and this served as the first stage of the synthesis process. A list of quotes, metaphors and concepts was created in order to begin to understand how the papers were related to each other. Through this process, it became clear that there were many similarities between papers, which were then grouped together. Further reading and examination of these groups enabled the researcher to develop an overarching interpretation of papers, which was encompassed into the key themes and subthemes of the metaethnography. These are described below. This method has been used effectively in many previous meta-syntheses (e.g. Murray & Forshaw, 2013), and it facilitated the development of overarching themes in this review in accordance with the principles of qualitative research (Noblit & Hare, 1988).

Second order constructs were examined chronologically, in order to develop a timeline of papers and to put the papers in context with each other. A constant comparison of these constructs was completed in order to develop an overarching interpretation of papers. These show how each construct fits with each other and shows the development of the metaethnography, from individual quotes to the overarching relationship between papers. These form the key themes and subthemes of the meta-ethnography, which are discussed below.

Results

The shortlisted studies utilised a variety of methodologies. The most common analysis methods were interpretative phenomenological analysis (IPA), used in four studies (Bezance & Holliday, 2014; Macdonald et al., 2011; Voriadaki et al., 2015; Whitney et al., 2012), and thematic analysis, which also used in four studies (Goodier et al., 2014; Linacre et al., 2016; Macdonald et al., 2015; Sepulveda et al., 2008). The remaining four studies used different methodologies, for example grounded theory (Rhodes et al., 2009). Six studies explored perspectives of carers of people diagnosed with anorexia nervosa (Bezance & Holliday, 2014; Engman-Bredvik et al., 2016; Rhodes et al., 2009; Voriadaki et al., 2015; Whitney et al., 2012; Wiese, 2014), and the remaining studies explored a mix of diagnosis, including eating disorder not otherwise specified, bulimia nervosa, and binge eating disorder. Most carers were supporting relatives who were teenagers, although some studies included those who supported relatives who were younger or older. For example, Wiese (2014), who included clients between 10 and 21 years, and Linacre et al. (2016) who included clients between 18 and 30 years of age.

Seven studies took place in the United Kingdom (Bezance & Holliday, 2014; Linacre et al., 2016; Macdonald et al., 2011; Macdonald et al., 2015; Sepulveda et al., 2008; Voriadaki et al., 2015; Whitney et al., 2012), with the remaining studies taking place in the United States (McCullough, 2012; Wiese, 2012), Australia (Goodier et al., 2014; Rhodes et al., 2009), and Sweden (Engman-Bredvik et al., 2016). Studies used a number of different interventions, and although there are many similarities between these, a number of different labels were used to describe them. There were two main differences between interventions; those that involved meeting and working with other families (for example, multi-family therapy in Engman-Bredvik et al., 2016) and those who did not, and worked directly with healthcare professionals (for example, Bezance & Holliday, 2014), and interventions which focused on practical strategies (for example Bezance & Holliday, 2014) in contrast to those which used more traditional therapeutic methods as part of their intervention (for example,

Whitney et al. (2012) which used family sculpts). Further information about the studies is displayed in Table 2.

Four overarching themes were identified. These are: (i) being heard (ii) family as a team against the eating disorder (iii) easing the burden of responsibility with compassion and (iv) the role of doubt and reassurance. The first theme, being heard, includes two subthemes: (a) between participants: connection and disconnection, and (b) between families and the treatment team: support and empowerment. Consequently, this theme has been divided into two parts and discussed separately below. See Table 4 for contribution of papers to each theme.

[INSERT TABLE 4 ABOUT HERE]

(i) Being heard

For many individuals, family interventions provided a safe space to express difficult aspects of providing support to a relative with an eating disorder. Safety was an important factor underlying relationships between participants, and between individuals and the professionals working with them.

(a) Between participants: connection and disconnection.

Some studies included a space for families to meet as a group, and to share their experiences. Hearing others' stories, and in turn being heard allowed groups to feel safe.

This appeared to be fundamental in allowing people to be able to express their feelings: "I think everyone was really open and frank. I think that really fostered that kind of atmosphere of sharing and caring for each other." (Goodier et al., 2014, p. 371).

For some people, family interventions afforded the first opportunity to feel safe enough to express difficult experiences; in a sense, to give themselves permission to be heard, because they knew other families within the group would understand their stories:

I think for us, knowing that we felt like there was this feeling of a safety net here, everyone here understood what we were going through. We felt like we were in this like, sorority of . . . It was like oh my God! (McCullough, 2012, p. 134).

Safety between families allowed people's experiences to be normalised and validated: "It was a relief that other families' [experiences] were very similar to our own. Many of her actions I could directly relate to other girls." (Voriadaki, Simic, Espie, & Eisler, 2015, p.12).

I felt that some of the behaviour that I thought were peculiar to us and were really, you know, strange, I was kind of reassured that that was all part of the illness that made me feel we weren't, it wasn't just us. (Macdonald, Murray, Goddard, & Treasure, 2011, p. 480).

This platform allowed people to connect with others, and reveal vulnerability with other members of the group. This was often met with compassion, allowing individuals to feel heard and validated. A reciprocal caring relationship frequently developed between people in the intervention, fostering hope for the future: "I feel the group is bonding and as if we all care about each other. The girls are now really helping each other. It feels very positive that we will succeed." (Voriadaki et al., 2015, p. 14). It is important to recognise that groups were able to achieve a sense of safe support even when individuals communicated via more remote methods of communication:

One time I posted one little question on the forum and it was, I don't know, after dinner or something. So then, like two hours later I go back, somebody answered it, and I actually had tears coming out of my eyes. "Oh, there is somebody out in the world who wants to help me right now with the thing that I'm struggling with." So, even though I didn't know them, I mean never saw them, never will meet them, that

somebody would post a response to my little question, it was huge, and it made a huge difference. (Wiese, 2014, p. 108).

It appears that an important component in developing safe communication is witnessing others' interest in the person's story and a desire to support them; perhaps this differs very much from people's experiences prior to the intervention, which frequently included feeling alone and isolated: "It is lonely . . . because friends were frightened to come. When someone has a broken leg, you get "Get well" cards. When somebody has anorexia, you don't." (Bezance & Holliday, 2014, p. 392).

Most people referred to benefiting from connecting with other families. However, situations where the distress of other families arose in a space that perhaps did not feel contained or boundaried, did not allow for their own stories to be fully heard and validated:

I did for a while read some of the other stories, but then, after while, it's like, "God, do I need to know everyone else's horror story? Is that really going to help me?...

Because there's some horrible stories out there and it was hard enough without letting in everyone else's pain. (Wiese, 2014, p. 108).

It also appeared that difficulties identifying with the stories of others fuelled disconnection from the group and contributed to not feeling heard: "I kind of thought their story was so different to ours with their child being so sick . . . I think that family is not a normal family and think it's not that appropriate to use them to talk to people." (Rhodes, Brown, & Madden, 2009, p. 190).

(b) Between families and the treatment team: support and empowerment.

The relationship between families and the professionals working with them was important in shaping the experience of families going through interventions. For most, this

experience was positive, and an important contributor to people feeling safe within the intervention. Having clarity relating to roles and expectations appeared to be important in facilitating trust in professionals, and being able to meet with staff to discuss the roles people would assume allowed for relatives to feel confident in the team:

They were very good at setting us at ease and explaining what they were and . . . what they were there to do, and laying out exactly what was going to happen going forward you certainly felt at the end of it that, oh these are people that know what they're doing. They're gonna come and help us. (Bezance & Holliday, 2014, p. 394).

The clarity brought by practical strategies led to relatives feeling more confident in being around the person with the eating disorder and contributed to feeling more equipped to support their relative in eating. Clarity and consistency in approach by staff teams also built up trust and safety: "The integration of the team is just great. Consistency. There was a constant message." (McCullough, 2012, p. 137). Consistency of approach, and feeling that the treatment team had the knowledge and skills to support the family helped relatives to feel reassured: "The impact of outpatient care was huge. . .The regular meetings and advice helped greatly. There was an orderliness about the routine, step by step advancement to getting A to a better place." (Macdonald et al., 2015, p. 5).

Safety was created when the intervention felt collaborative, and when families felt included within the intervention. It appeared that family interventions sometimes led to carers feeling powerless, and many who were supported by staff teams who were collaborative felt better able to cope with the power imbalances between staff and carers: "you can't ignore that parent and the parent's feelings . . . They have to realize how powerless you are. That actually you don't necessarily want that power to be taken, to be further eroded." (Bezance & Holliday, 2014, p. 397). This appears to express the impact of

the eating disorder on the loss of identity as a relative, and how it is important inclusion is in the process of feeling safe.

I can't really overstate how important it was for me to feel like I was a valued person in the team. That was the hugest difference for me and I think that's probably just because of prior experience that I had where I felt discounted but still ultimately responsible, because it's your kid, right...So, for me, just feeling that support was the biggest difference in terms of me feeling confident, I guess, and able to do what I needed to do. (Wiese, 2014, p. 85).

Safety also developed by therapists' responsiveness to the needs of the family, and through ensuring that the intervention was tailored to the values and principles of each family. This appeared to be instrumental in helping relatives feel heard: "I know there is someone there to talk to if I need it, being able to express things absolutely fully. Well, say the worst things that have happened or have been said. I feel at total liberty to be totally honest and not hold things back." (Rhodes et al., 2009, p. 188). It was also important that the therapist protected the role of the parent: "(Therapist) tells Jess 'look I am just here to listen or advise or whatever, but really you have to listen to your Mum'. So I think that's a good thing. She's not taking that role away from me." (Rhodes et al., 2009, p. 186).

Where relatives did not feel heard within the intervention, alternative sources of support were found which tailored the intervention to the family: "We ended up finding a doctor, who with the family-based therapist, was much more interested in listening to me, not let me run the show completely because I wanted to work collaboratively." (Wiese, 2014, p. 87). This highlights the importance of feeling understood and heard. Being tailored to the needs of the family appeared to be particularly pertinent for those interventions which were aimed at a specific subgroup. To illustrate, one intervention focused on parents, which left

partners feeling excluded: "and then there's nothing at all is there about partners really. It's all parents." (Macdonald et al., 2011, p. 482). This supports the idea that each group of relatives have unique experiences, and it is important that these are considered in order to help the participant feel heard. For example, participants in one study felt that it would have been beneficial to consider parental difficulties among those who are separated from their partner separately. (Whitney, Currin, Murray, & Treasure, 2012).

(ii) Family as a team against the eating disorder

Over the course of many interventions, a transition occurred whereby families began to feel united, and individuals felt part of the family team. This developed in the context of many people feeling isolated and alone in their journey of supporting their relative. There were a number of factors that facilitated family unity, including a gradual ability to see the person as separate to the context of their eating disorder: "It's like the devil that's got into my daughter" (Bezance & Holliday, 2014, p. 393). Being able to externalise the eating disorder, viewing it as an "uninvited guest" (Engman-Bredvik, Suarez, Levi, & Nilsson, 2016, p. 192) allowed the eating disorder to become the focus of difficult emotions, rather than the person with the eating disorder: "If I didn't have the backing of the meetings I think I would have reacted very differently. But I see that it's anorexia, not Amy, so it's a lot easier to keep cool, calm and collected." (Rhodes et al., 2009, p. 185). The externalisation process also allowed relatives to feel more assured in their own ability to deal with the challenges inherent in supporting someone with an eating disorder: "The separating the person from the disorders . . I feel a bit more confident to be able to go back home and deal with things on our own." (Goodier et al., 2014, p. 371).

Family interventions allowed individuals to understand the perspectives of other members of their family. This was facilitated by exercises done as part of the intervention, for example family sculpts: ". . . it actually sort of started to articulate without using words, the size of the problem and her feelings and where she was . . . how did we relate to each

other." (Whitney et al., 2012, p. 136). Other exercises, such as role reversal role-playing, allowed individuals within families to gain insight into how their relatives might feel: "In the role play I did feel powerful being my daughter. It's strange...that's how she is at the dinner table, so that must be how she feels." (Voriadaki et al., 2015, p. 14). Perspective taking fostered empathy for each other, and this helped families to begin to view themselves as a team.

Many participants felt that family interventions allowed all individuals to have a space to speak, and in turn, to be understood. This helped the family unit to become more cohesive. Siblings also gained insight where they were included as part of the intervention, and helped them to separate their brother or sister from the eating disorder:

I believe that it is difficult for a 15 year old boy to have understanding (of AN). He says: "isn't she going to get well soon so that we can get away from this?" and "how long is it going to last?" But maybe that he now has a greater understanding that it is not she (his sister) who reacts in a certain way, rather it is the disease that takes her over. (Engman-Bredvik et al., 2016, p. 193).

The space provided by interventions allowed parents to understand both their own views and those of their partner. This also fostered cohesion, allowing parents to feel that they were "on the same page" (Engman-Bredvik et al., 2016, p. 193). There was an acknowledgement of the importance of parents working as a team: "One thing that stands out is helping me to let Ashlee's dad be more involved. It's like we had to make it work together; we couldn't get her weight to go up." (Rhodes et al., 2009, p. 186).

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Over the course of interventions, the responsibility of working with the person to overcome their eating disorder became shared, allowing each member of the family to understand the full extent their role could have within the family. As the family progressed into becoming a team, so each person within it felt their support network increase: "I gain support from my daughters, siblings and sometimes (more so latterly) from my partner – her father" (Macdonald et al., 2015, p. 5). Cohesion within the family also facilitated communication:

And I have a really amazing husband who is sitting right next to me; he is really wonderful to really have supported me, even though he was far away. He supported me tremendously during that time. And we probably communicated better than if we were in person because we were forced to in those morning check-ins and evening check-ins. He was just so amazing and helpful to me. (Wiese, 2014, p. 89).

Where interventions provided tools, families were often able to use these together with their relative to improve communication: "Well actually we started reading the book together at one point." (Macdonald et al., 2011, p. 480).

It is important consider that family cohesion emerged out of the strain placed on individuals and relationships as a consequence of the eating disorder. This strain often led to marital difficulties: "Marriage breakdown...trying to maintain stable home life for myself, A and son" (Macdonald et al., 2015, p. 4), but many felt that the intervention led to a sense of collective empowerment, and that they that had received a "stamp of approval to be united" to help their relative with their eating disorder (McCullough, 2012, p. 111).

(iii) Easing the burden of responsibility with compassion.

Throughout the papers, a pattern emerged relating to carers' self-perception. Initially, many faced interventions with difficult emotions, including guilt and fear (McCullough, 2012), but this seemed to shift towards feeling empowered as the intervention progressed:

"So I think empowering the parent and just supporting them in the ability that they already have to take care of their kids is a critical piece [of treatment success]." (Wiese, 2014, p. 84).

This change developed in the context of strong feelings of responsibility among carers relating to their role as a relative and a responsibility to be able to get their relative to eat. Feelings of powerlessness accompanied this responsibility, and the intervention was, for some, a signal that they had failed in their role. This appeared to be particularly prevalent among carers who were mothers: "Just trying to get her to eat actually doesn't work at all. . .I kind of think that nothing I do helps really." (Bezance & Holliday, 2014, p. 392).

Over the course of the interventions, expectations individuals held of themselves appeared to adjust, and they began to view themselves with greater self-compassion: "Learning to accept that I can't get it right all the time and to be a "good enough" carer has helped tremendously." (Linacre, Green, & Sharma, 2016, p. 301); "It was just listening and not feeling like I had to solve (patient)'s problems in one conversation . . . That was quite a revelation. (Whitney et al., 2012, p. 137)."

Carers were able to see the function self-care as a way of enhancing the support they could offer to their relative: "I know I have to protect myself. . .to be of any good to A. I need to be centred/positive." (Macdonald et al., 2015, p. 4). Self-compassion also appeared to help foster self-awareness, and insight in the impact of their behaviour on their relative:

I was unaware how my behaviour was affecting my loved one and accommodating the disorder prior to attending. The difference attending made to the atmosphere in the home and to my own general health and wellbeing has been immense. I would have cracked up without it. (Linacre et al., 2016, p. 301).

Given the context of loss that many individuals experienced prior to the intervention, many felt that they were able to recover parts of themselves that had been lost as a result of the eating disorder:

Somehow they took away from me that, anxiety I had . . . did teach me to feel a bit more strong. Go out and do my hair or look after me instead of waking up in the morning and not even wash my face because X needed me . . . they made me feel like . . . it's not just X there is actually me here and somewhere if you look around. (Bezance & Holliday, 2014, p. 396).

Carers had a sense of realism about the road ahead, but were able to consider strategies introduced to them during the intervention, and how these could be used to enhance their self-care: "It has also given me a more realistic view of the future – but with hope that in time things will improve. I have learnt to look after myself better – and learnt the importance of this." (Linacre et al., 2016, p. 301).

Along with enhanced self-care practices, the benefits obtained for individuals as a result of interventions fostered the self-confidence and resilience to implement and maintain boundaries with their relatives. This helped carers to protect their own self-identity, reducing levels of enmeshment between themselves and their relatives often described prior to intervention: "I've maybe been just a little bit firmer. I say 'look you've got no choice, you're going to get better if I keep reminding you and pushing you, and then I'll stop.' So I'm a bit stronger." (Goodier et al., 2014, p. 371).

(iv) The role of doubt and reassurance

Another common theme across the papers included a desire for reassurance from the treatment team. This appeared both as a desire for feedback, and a desire for the intervention to continue for longer. To illustrate, one carer wanted "advice to how to support her (X) in

between appointments . . . cos obviously at the end of the day they are with you." (Bezance & Holliday, 2014, p. 395). In another study, carers wanted "more time to practice skills in a "safe" environment", and "more time to cover existing topics". (Linacre et al., 2016, p. 302).

Where support was offered by the treatment team to individuals, this was sometimes appraised as being inadequate, or that it did not offer the guidance families hoped for:

I guess I was a bit disappointed in her [the FBT therapist] in that she was there by phone support if we needed her, but it just didn't - it didn't seem like specifics were given about who to handle things. That direct coaching wasn't really there. The knowledge was given as far as the fact that this may work or that may work, but no real direction, I guess. (Wiese, 2014, p. 82).

It appeared that seeking reassurance may have reflected self-doubt in individuals' own ability to act as caregivers, as suggested by quotes which explicitly express their own concerns about whether they are doing right: "Fears even when things are OK that we're missing something and it won't be OK for long." (Macdonald et al., 2015, p.5). Given the complexity of the role, and the multiple demands the caregiving role places on a family member, it is understandable that several hoped for more practical suggestions from the treatment team: "I don't know, any sort of ideas or techniques, when an anorexic person gets angry or upset or shuts down. You wonder what you're supposed to do." (Whitney et al., 2012, p. 138).

Across papers, it appeared that families sought reassurance as the end of the intervention neared. The support carers felt during the intervention appeared to help foster a sense of hope, but there appeared to be anxieties about the support and hope being temporary, and that carers and their families might return to the isolated position many found themselves

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in at the start of the intervention. Carers reported feeling fear about how families might cope without the support of the treatment team, once the intervention had finished:

And now we're getting her back a little bit. But there is that fear that we might have a slide. I said to my husband I don't want outreach to leave us until she is, until she has recovered completely. I don't want them to hand us back to CAMHS¹. (Bezance & Holliday, 2014, p. 394).

Given this, it is understandable that many families sought ongoing support that extended beyond the intervention. Again, this may reflect carers' doubts about their own ability to manage challenging situations on their own: "It is crucial to have some sort of back up support/help line so carers can at least talk about some of the issues raised." (Sepulveda, Lopez, Macdonald, & Treasure, 2008, p. 324).

¹Child and Adolescent Mental Health Services

Discussion

The themes found in the review provide a broad overview of family members' experiences of family interventions for eating disorders. The analysis has highlighted that the eating disorder journey is one that all those connected to the individual embark upon. Initially, relatives frequently reported feeling isolated from those around them, which was exacerbated by the experience of multiple losses, both in terms of employment and relationships with friends and family. This contributed to an increasingly intense and enmeshed relationship between relatives and their relative with an eating disorder. Over the course of interventions, there appeared to be a shift from families being a collection of individuals to a cohesive unit. Communication within the family increased, and activities which encouraged perspective taking were helpful in fostering compassion, both for themselves and their relatives. Individuals began to regain parts of themselves that might have felt lost through the carer role, including engaging with self-care activities. However, for many, there was ongoing doubt and apprehension about the future. It appeared that perhaps the improvements noted during the intervention process were understood by relatives as being a product of the support received during the process, and without this, they doubted their ability to maintain progress.

Not surprisingly, relatives emphasised their sense of responsibility to get their relative to eat. In this context, family interventions could be argued to be a double-edged sword; some carers felt that interventions signified a failure in their role, whilst others welcomed the support of other people. The idea of interventions being viewed as a threat to relatives' roles was particularly apparent for mothers, who often felt that the ongoing difficulties experienced by their child signified that they had somehow failed in their role and identity as a mother to protect their child from harm and distress.

This review found particular elements of family interventions that appeared to be especially valuable to family members. The first theme, "being heard", demonstrated that the

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relational aspect of family interventions allowed relatives to connect with other people who understand their journey. This included other families taking part in the intervention, and the treatment team. Family interventions also facilitated perspective-taking, and from this an understanding of the shared burden of caring. Given the context of carers frequently feeling isolated prior to the intervention, feeling part of a team appeared to be particularly powerful for relatives. Cohesion was also facilitated by externalising the eating disorder from the person; this provided an outlet for the difficult, but understandable, emotions that relatives experience, whilst also facilitating the person with the eating disorder to become part of the team.

Over the course of the interventions, a growing awareness developed of the importance of self-care, both in its ability to regain parts of the self that had been lost, but also in developing assertiveness and confidence in their carer role. This is summarised in the third theme, "easing the burden of responsibility with compassion". It was clear that the eating disorder journey can become overwhelming, and that in the midst of this, it appeared easy for carers to lose the focus on themselves in attempting to support their relative as best as they can. Family interventions provided a space for carers to understand the importance of looking after themselves as carers, and to provide practical strategies for ensuring they could do this. Perhaps interventions also gave permission for carers to focus on their own wellbeing, and that this did not signify a lack of care towards their relative by focusing on their own wellbeing alongside their relative's wellbeing. Family interventions appeared to be important in providing support to relatives, and many relatives experienced doubt in their ability to continue to support their relative after the intervention ended. This is captured in theme four, "the role of doubt and reassurance". There appeared to be value in gaining validation and reassurance from others that this was something they were able to continue beyond the intervention.

In light of these findings, it appears that the role of empowerment and encouragement of parents is a valuable part of the interventions, in line with the aim of family interventions (Lock & Le Grange, 2013). It is also interesting to consider these themes in the context of the

Cognitive-Interpersonal Maintenance Model of Anorexia (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). This model highlights the relational patterns often found between clients and their carers, and how these can serve to maintain the eating disorder. This review found that interventions change the pattern of relating within families (for example, through increased cohesion and the family increasingly working together), and furthermore, by externalising the eating disorder from the client, it appears that the battle for control became less intense as a result. This provides support for the ideas put forward in the Cognitive-Interpersonal Maintenance Model (Schmidt & Treasure, 2006; Treasure and Schmidt, 2013).

Clinical implications

Many families found interventions that considered relational dynamics useful, as it allowed both insight into their own role within the family, and also facilitated family cohesion. It was clear that exploring relationships within the family unit was best done in environments where individuals felt safe to reveal vulnerability. Individuals felt that safety was often achieved where people were able to identify with both other group members, and the professionals working with them. This highlights the importance of tailoring the intervention to families, allowing them a space to be heard.

For many people, family interventions offered them the first opportunity to explore emotions, and it appeared overwhelming to do so if the safety of the space was not established. This can be considered in light of relational patterns in the context of eating disorders, where families can "fight for control" in relation to mealtimes (Schmidt & Treasure 2006). This may lead to a family environment where thoughts about displaying emotions are polarised; either attempts to gain control lead to a position where people do not reveal emotions, or relatives feel drawn into providing reassurance to try and avoid conflict (Schmidt & Treasure, 2006). In either position, it would be expected that relatives might develop feelings of powerlessness, which might explain why it was so important for families to feel that the interventions were congruent with their values and principles. This review highlights that working collaboratively to include relatives in discussions about their

expectations, hopes and goals for the intervention is useful in this respect. The challenges of meeting the best hopes of families must also be considered; for example, many people felt interventions needed to be longer. Offering follow-up or "top up" appointments might help families to experience the ending of interventions as being empowering and supportive. It also appeared that tailoring the intervention to the aims of the family was likely to yield better outcomes. Exploring this with families prior to the start of the intervention could provide development of collaborative goals. Given that some families appeared to benefit from practical support, whilst others found emotional elements of interventions helpful it would be helpful to consider this with families. It is possible that this could change over time; for example, focusing on practical strategies might feel more comfortable for families in the early stages of the intervention, but with increased familiarity as the intervention goes on, exploring relational and emotional experiences might feel more possible. Therefore, it is important to review the goals set with families at regular intervals.

Many individuals were able to utilise self-care techniques to develop self-compassion. This benefitted not just the relative, but also the family and the person with the eating disorder. Equally, many relatives were apprehensive about the end of the intervention, and what this meant for themselves, their family and their relative with an eating disorder. Given the multiple experiences of loss experienced by many as a result of the eating disorder, it is possible that family interventions have the potential to enact feelings of rejection already experienced. It would be expected that such re-enactments could exacerbate the self-doubt and apprehensions noted within the analysis. This might impact on the longevity of the benefits of the interventions, for example self-care, as it might be difficult for people to maintain practices over time. It would be interesting for future research to consider the long-term effects of interventions and whether the benefits described in the analysis persist over time. Considering with relatives what self-care practices have helped, and working with them to consider how these can be maintained might be helpful in ensuring these continue.

Current NICE Guidelines (NICE, 2017), recommend MANTRA (Maudsley Anorexia Nervosa Treatment for Anorexia) for adults diagnosed with anorexia. It is suggested that this consists of 20 sessions, with the last ten sessions being flexible to meet the needs of the client and their family. However, it appears that the focus of including families in interventions is, primarily for the benefit of the client. This is highlighted by the suggested that family members are involved in order to "help the person". It is important to also focus on the effect of caring on family members, and to ensure that relatives feel fully included in the intervention, in light of the effect of caring on their wellbeing.

Strengths and limitations

The aim of this review was to consider the experiences of family members partaking in family interventions for eating disorders. As such, it has not evaluated each specific family intervention, but has identified themes common across approaches in order to understand how families experience support. To illustrate, the review enabled an evaluation of particular aspects of interventions that people found helpful, and additionally, what underpinned the success of such interventions.

Identifying helpful elements of therapy, regardless of the specific approach, enables a general view of what constitutes good support to relatives. This means that the search allowed a breadth of papers to be included, covering multiple approaches, family roles and eating disorder diagnoses. It was interesting that common themes emerged despite the breadth of papers covered. The cost of this is that the review is unable to understand the experiences of specific relative roles (for example, the specific experience of parents or siblings). Families are diverse and this review is representative of the people who would take part in family interventions. However, the breadth of the search means that it is difficult to detect subtle differences between diagnoses or carer groups. For example, the mechanisms which underlie the success of interventions for anorexia might be different to those which benefit carers of people with bulimia. It would be very difficult for this review

to detect these and in fact, the literature is probably not extensive enough to do this.

A further limitation of the study relates to one author conducting the search and determining which papers were included in the review. Conducting the search jointly with another researcher may have avoided biases based on individual opinions, particularly in light of the breadth of the search already noted.

One limitation of the study relates to difficulties understanding the long-term effects of family interventions, both in terms of the effect on families, and the person with the eating disorder. This is particularly pertinent in light of the difficulties described by families as they neared the end of interventions. The effects of relational patterns such as EE are well-researched in families affected by an eating disorder, and it would be interesting to see whether family members experience long-term changes in these patterns following family interventions. Included studies largely focused on the treatment of adolescents, and therefore it is unclear whether a similar pattern of findings would occur where the client group is older.

It is also important to consider the largely positive findings of relatives' experiences of family interventions. It is possible that this, in part, may reflect recruitment bias.

Participants with positive views might be more likely to be recruited to the research post-intervention, and those with more negative views or poorer outcomes may not be fully represented in these studies. Despite this, a number of studies did gather participant experiences during the course of family interventions, and therefore researchers could not have selected participants on the basis of how favourable their experience was.

Finally, it is noted that within theme three, self-compassion emerged as a construct which developed over interventions. Given the author's prior interest in self-compassion, and the subsequent research paper exploring the construct, it is possible that this has influenced how the author analysed the papers, and this is a limitation of the review. However, measures to reduce the risk of this occurring were taken; for example, the author kept a reflective journal at all stages of the review. Conducting the analysis jointly with another author would have been a further measure that could have been taken

Conclusion

This review has explored the experiences of family members who have taken part in family interventions for eating disorders. The meta-synthesis revealed a chronology of these experiences. Family interventions help to foster both an understanding of how these interactions may maintain the eating disorder, but also generate new, more helpful ways of relating with each other. There also appears to be particular benefits of interventions that helped carers develop resilience. It is possible that these could become a greater focus of family interventions in the future.

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Table 1. Keyword Search Terms

Diagnosis	Eating disorder, Anorexia, Bulimia, Binge Eating, purging	
Intervention	Intervention, treatment, psychoeducation, approach, therapy	
Methodology	Qualitative, interview, finding	
Participant	Carer, family, family members, parent	

Figure 1. Illustration of Search Process

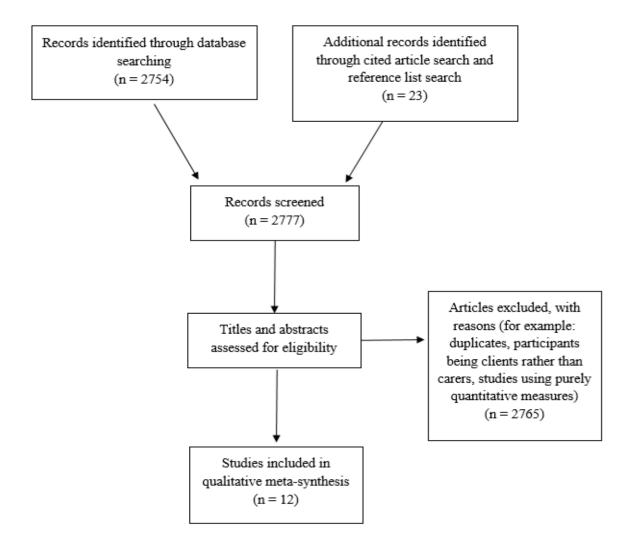


Table 2. Information about shortlisted papers

	Country	Aim/Purpose	Participants	Intervention type	Eating disorder diagnosis	Age of relative	Methodology
Bezance & Holliday (2014)	UK	To explore mothers' experience of Home Treatment	Nine mothers	Home Treatment	Anorexia nervosa	13 to 16 years old	IPA
Engman-Bredvik et al. (2016)	Sweden	To investigate MFT as part of AN treatment from a parental perspective	Twelve parents (six mothers and six father)	Multi-family therapy	Anorexia nervosa	12 to 17 years old	Empirical psychological phenomenological method
Goodier et al. (2014)	Australia	To examine the experience of parents of children with eating disorders after having participated in a skillsbased training intervention	Eleven parents and caregivers (six mothers, one stepmother and four fathers).	Parent Skills Training Treatment	Three AN- restricting subtype Three EDNOS- AN like Two EDNOS- unspecified.	11 to 14 years old.	Inductive thematic analysis
Linacre et al. (2016)	UK	To understand carers views on how the workshops were received.	Nine parents One spouse	Adapted Maudsley Method approach.	Three Anorexia, Three Bulimia, Binge Eating Disorder and a combination of Anorexia and Bulimia.	Between 18-30 years old.	Mixed methods. Qualitative component – thematic analysis.

Macdonald et al. (2011)	UK	To examine the effects of a DVD/manual/coaching skills training programme for carers of people with eating disorders.	Eight mothers Two sisters Three male partners	Skills training programme	Nine Anorexia, one Bulimia, five Anorexia and Bulimia One BED	Age range 15- 51 years old, mean age = 23 years.	IPA
			Six fathers		Three No diagnosis available		
Macdonald et al. (2015)	UK	To examine the experiential perspective from caregivers and their adolescent relatives of having participated in a	149 client/caregiver dyads.	Experienced Caregivers Helping Others (ECHO).	Anorexia nervosa EDNOS	13-21 years of age.	Thematic analysis.
		carer skills training intervention.			Anorexia type.		
McCullough (2012)	USA	To examine the experiences of parents of adolescents with eating disorders who engage in phase one of a modified Maudsley based treatment approach.	Parents aged between 46-53.	Modified Maudsley Method Approach	Five Anorexia, three EDNOS	12-18 years of age.	Phenomenological analysis.
Rhodes et al. (2009)	Australia	To explore the use of parent-to-parent consultation as an augmentation to the Maudsley model.	Thirty-four parents	Parent-to-parent consultation in addition to Maudsley approach	Anorexia nervosa	Mean range of clients = 14 years of age.	Grounded theory
Sepulveda et al. (2008)	UK	To examine the feasibility and	Fourteen carers (13 females and one	DVD and Telephone	Eleven	Mean age of 17.2 years	Thematic analysis

		acceptability of DVD- based skills training, supplemented with telephone coaching for carers of a relative with an ED.	male). Mean age of carers = 52.1 years (range 41-66 years).	coaching-based skills training.	Anorexia Two Bulimia.	(range 14-27 years).	
Voriadaki et al. (2015)	UK	To contribute to our understanding of the process of change that takes place in MFT for adolescent anorexia.	Six mothers and four fathers	Maudsley Family Therapy	Anorexia Nervosa	Between 15 and 16 years old.	IPA
Whitney et al. (2012)	UK	To examine treatment efficacy, carer satisfaction and process of change in carers of people with anorexia who participated in a RCT comparing individual family work and multifamily workshops.	Twenty-three of which 17 = parents; four = siblings; one = husband; one = daughter.	Family Day Workshops and Individual Family Work	Anorexia Nervosa	Mean age = 25; range = 18-53.	IPA
Wiese (2014)	USA	To investigate the experiences of parents who have participated in family-based treatment for a child or adolescent diagnosed with anorexia nervosa.	Fifteen parents (13 = biological mothers; two = biological fathers), aged between 44- 59 years (mean = 50 years).	Family-based treatment	Anorexia nervosa	10-21 years of age.	Modified analytic induction

Table 3. CASP Scores for each shortlisted paper

	Research design	Recruitment strategy	Data collection	Participant /researcher relationship	Ethics issues	Data analysis	Clarity of findings	Research value	Total
Bezance & Holliday (2014)	3	2	2	2	2	3	3	2	19
Engman-Bredvik et al. (2016)	3	3	3	3	2	3	3	2	22
Goodier et al. (2014)	3	2	3	2	3	3	3	3	22
Linacre et al. (2016)	2	2	2	1	1	3	3	3	17
Macdonald et al. (2011)	3	3	3	3	1	3	3	3	22
Macdonald et al. (2015)	2	3	2	1	2	3	3	3	19
McCullough (2012)	3	3	3	3	3	3	3	3	24
Rhodes et al. (2009)	2	3	3	2	2	3	3	2	20
Sepulveda et al. (2008)	3	2	2	1	2	2	3	2	17
Voriadaki et al. (2015)	3	3	3	1	3	3	3	3	22
Whitney et al. (2012)	3	3	3	2	2	3	3	2	21
Wiese (2014)	3	3	3	1	2	3	2	3	20

Table 4. Contribution of papers to each theme

	Being Heard		Family as a team against the eating disorder	Easing the burden of responsibility with compassion	The role of doubt and reassurance
	Between participants: connection and disconnection	Between families and the treatment team: support and empowerment		,	
Bezance & Holliday (2014)	✓	√	√	√	√
Engman- Bredvik et al. (2016)	✓		✓		
Gooder et al. (2014)	✓		✓	✓	✓
Linacre et al. (2016)	✓		✓	✓	✓
Macdonald et al. (2011)	✓	✓	✓	✓	
Macdonald et al. (2015)		✓	✓	✓	✓
McCullough (2012)	✓	✓	✓		✓
Rhodes et al. (2009)	✓	✓	✓		
Sepulveda et al. (2008)				✓	✓

Voriadaki et al. (2015)	✓		√		√
Whitney et al. (2012)	✓	✓	✓	✓	✓
Wiese (2014)	✓	✓	✓	✓	✓

Appendix 1-A

European Eating Disorders Review – Author Guidelines

Manuscript Submission

European Eating Disorders Review has now adopted ScholarOne

Manuscripts, for online manuscript submission and peer review. The new system brings with it a whole host of benefits including:

- Quick and easy submission
- Administration centralised and reduced
- Significant decrease in peer review times

From now on all submissions to the journal must be submitted online at http://mc.manuscriptcentral.com/erv. Full instructions and support are available on the site and a user ID and password can be obtained on the first visit. If you require assistance then click the Get Help Now link which appears at the top right of every ScholarOne Manuscripts page. If you cannot submit online, please contact Maurine Balansag in the Editorial Office (EEDRedoffice@wiley.com).

Illustrations must be submitted in electronic format. Save each figure as a separate file, in TIFF or EPS format preferably, and include the source file. We favour dedicated illustration packages over tools such as Excel or Powerpoint. Grey shading (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. Supply artwork at the intended size for printing. The artwork must be sized to the text width of 7 cm (single column) or 15 cm (double column).

Manuscript style. All submissions, including book reviews, should be double-spaced and clearly legible.

The first page should contain the **title** of the paper, full names of all authors, the address where the work was carried out, and the full postal address including telephone, fax number and email to whom correspondence and proofs should be sent. The name(s) of any **sponsor(s)** of the research contained in the paper, along with **grant number(s)** should also be included.

The second sheet should contain an **abstract** of up to 150 words. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should

contain no citation to other published work. Include up to five keywords that describe your paper for indexing purposes.

- **Research articles** reporting new research of relevance as set out in the aims and scope should not normally exceed 6000 words with no more than five tables or illustrations. They should conform to the conventional layout: title page, summary, introduction, materials and methods, results, discussion, acknowledgements and references. Each of these elements should start on a new page. Authors may not find it necessary to use all of these subdivisions, and they are listed here only as aguide.
- **Review articles:** Systematic and meta-analytic review papers are welcomed if they critically review the available literature in a topic than will enhance clinical practice. Articles should have clear focus and enough number of studies should be available for a substantive review paper. Studies that only describe or list previous studies without a critical overview of the literature will not be considered.
 - •Word Limit: 5,000 (excluding abstract, references, tables or figures).
 - Abstract: 250 words.
 - •References: 50.
 - Figures/Tables: 5 maximum, but should be appropriate to the material

covered. Additional tables might be included as supplementary information, if needed.

Review articles must follow the <u>PRISMA</u> Guidelines. Authors may want to have a look at the review check lists that reviewers when assessing review articles.

Brief reports should concisely present the essential findings of the
author's work and be compromised of the following sections: Abstract,
Introduction and Aims, Method, Results, Discussion, and References.
 Tables and/or figures should be kept to a minimum, in number and size,
and only deal with key findings. In some cases authors may be asked to
prepare a version of the manuscript with extra material to be included in
the online version of the review (as supplementary files). Submissions in
this category should not normally exceed 2500 words in length.

Brief reports bring with them a whole host of benefits including: quick and easy submission, administration centralised and reduced and significant decrease in peer review times, first publication priority (this type of manuscript will be published in the next available issue of the journal).

Case Reports The journal does not accept case reports for publication.
 Authors of case reports are encouraged to submit to the Wiley Open
 Access journal, Clinical Case Reports www.clinicalcasesjournal.com
 which aims to directly improve health outcomes by identifying and disseminating examples of best clinical practice.

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

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

Example: Charlotte and Emily Bronte were polar opposites, not only in their personalities but in their sources of inspiration for writing (Taylor, 1990).

Use the last name only in both first and subsequent citations, except when there is more than one author with the same last name. In that case, use the last name and the first initial.

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

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

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

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

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

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

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

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

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

Example: Patterns of byzantine intrigue have long plagued the internal politics of community college administration in Texas (Douglas *et al.*, 1997)

When the reference is to a work by six or more authors, use only the first

author's name followed by et al. in the first and all subsequent references.

The only exceptions to this rule are when some confusion might result because of similar names or the same author being cited. In that case, cite enough authors so that the distinction is clear.

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

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

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

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

I. Parenthetical references may mention more than one work, particularly when ideas have been summarized after drawing from several sources.

Multiple citations should be arranged as follows.

Examples:

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

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

References should be listed in the following style:

Journal Article

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

Book

Paloutzian, R. F. (1996). *Invitation to the psychology of religion* (2nd ed.).

Boston: Allyn and Bacon.

Book with More than One Author

Natarajan, R., & Chaturvedi, R. (1983). Geology of the Indian Ocean .

Hartford, CT: University of Hartford Press.

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

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

Web Document on University Program or Department Web Site

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

Stand-alone Web Document (no date)

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

Journal Article from Database

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

Abstract from Secondary Database

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

Article or Chapter in an Edited Book

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

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Appendix 1-B

Specific search terms for each database

PsycINFO	((((TI "Eating Disorder*") OR (TI "Anorexi*")) OR (TI "Bulimi*" OR TI "Binge Eating" OR TI "Purging"))) OR (((AB "Eating Disorder*") OR (AB "Anorexi*")) OR (AB "Bulimi*" OR AB "Binge Eating" OR AB "Purging"))) OR ((((DE "Eating Disorders") OR (DE "Anorexia"))) OR (DE "Bulimia" OR DE "Binge Eating" OR DE "Purging (Eating Disorders)"))) AND (((((DE "Intervention")))) OR (DE "Treatment")) OR (DE "Psychoeducation")) OR DE ("Approach*") OR DE ("Therapy"))) OR (((((TI "Intervention")))) OR (TI "Treatment")) OR (AB "Psychoeducation")) OR AB ("Approach*") OR AB ("Therapy"))) OR ((((TI "Intervention")))) OR (((TI "Qualitative")))) OR (((TI "Gree*")))) OR ((((TI "Gree*")))) OR ((((TI "Gree*"))))) OR (((((TI "Gree*"))))) OR (((((TI "Care*")))))) OR (((((TI "Care*")))))) OR ((((((TI "Care*")))))) OR ((((((TI "Care*")))))))
	"Famil*") OR (AB "Family Members") OR (AB "Parent*")))
Academic	((DE "intervention*") OR (DE "treatment*") OR (DE "Therap*") OR (DE "Psychoeducation") (DE "Approach*")) OR ((AB
Search	"intervention*") OR (AB "treatment*") OR (AB "Therap*") OR (AB "Psychoeducation") (AB "Approach*")) OR ((TI "intervention*")
Complete	OR (TI "treatment*") OR (TI "Therap*") OR (TI "Psychoeducation") (TI "Approach*")) AND ((DE "eating disorder*") OR (DE "anorexi*") OR (DE "bulimi*") OR (DE "purging")) OR ((TI "eating disorder*") OR (TI "anorexi*") OR (TI "bulimi*") OR (TI "purging")) OR ((AB "eating disorder*") OR (AB "anorexi*") OR (AB "bulimi*") OR (AB "purging")) AND ((DE "Care*") OR (DE "Famil*") OR (DE "Family Member*") OR (DE "Parent*")) OR ((TI "Care*") OR (TI "Famil*") OR (TI "Family Member*") OR (TI "Parent*")) OR ((AB "Care*") OR (AB "Famil*") OR (AB "Family Member*") OR (AB "Parent*")) AND (DE ("Qualitative") OR (DE "Interview*") OR (DE "Finding*")) OR ((AB "Qualitative") OR (AB "Interview*") OR (AB "Finding*")) OR ((TI "Qualitative") OR (TI "Interview*") OR (TI "Finding*"))
Proquest	(SU.EXACT("Families & family life") OR SU.EXACT("Parents & parenting")) AND (SU.EXACT("Bulimia") OR SU.EXACT("Eating
dissertations and theses	disorder*") OR SU.EXACT("Anorexia") OR Binge eating) AND (SU.EXACT("Therapy") OR "Intervention*" OR "Treatment*" OR "Approach*") AND (SU.EXACT("Qualitative research") OR Finding* OR Interview*)
CINAHL	((((TI "Eating Disorder*") OR (TI "Anorexi*")) OR (TI "Bulimi*" OR TI "Binge Eating" OR TI "Purging"))) OR (((AB "Eating Disorder*") OR (AB "Anorexi*")) OR (AB "Bulimi*" OR AB "Binge Eating" OR AB "Purging"))) OR ((((DE "Eating Disorders") OR (DE "Anorexia"))) OR (DE "Bulimia" OR DE "Binge Eating" OR DE "Purging")) AND (((((DE "Intervention"))) OR (DE "Treatment")) OR (DE "Psychoeducation")) OR DE ("Approach*") OR DE ("Therapy"))) OR ((((((TI "Intervention")))) OR (TI "Treatment"))) OR (TI "Psychoeducation")) OR AB ("Approach*") OR AB ("Therapy"))) AND ((((DE "Qualitative"))) OR (DE "Interview*"))) OR (DE "Finding*")

)) OR (((TI "Qualitative") OR (TI "Interview*") OR (TI "Finding*"))) OR (((AB "Qualitative") OR (AB "Interview*") OR (AB "Finding*"))) AND (((((DE "Care*") OR (DE "Famil*") OR (DE "Family Members") OR (DE "Parent*"))) OR (((((TI "Care*") OR (TI "Famil*") OR (TI "Famil*") OR (TI "Family Members") OR (AB "Famil*") OR (AB "Family Members") OR (AB "Parent*")))
Pubmed	((((("Qualitative Research"[Mesh]) OR ("Interview, Psychological"[Mesh]) OR "Interviews as Topic"[Mesh]) OR finding[Text Word])) AND (((("Family"[Mesh]) OR "Family Relations"[Mesh]) OR "Parents"[Mesh]) OR "Siblings"[Mesh] OR "Spouses"[Mesh])) AND (((("Feeding and Eating Disorders"[Mesh]) OR "Anorexia Nervosa"[Mesh]) OR "Binge-Eating Disorder"[Mesh]) OR "Bulimia Nervosa"[Mesh])) AND (approach[All Fields] OR ("therapy"[Subheading] OR "therapeutics"[MeSH Terms] OR treatment[Text Word]) OR intervention[All Fields])

Caregivers' Emotional Overinvolvement (EOI) and Guilt and Shame: The Role of Self-Compassion.

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Word count (minus tables, references, appendices): 5793

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Prepared in accordance with notes for contributors for:

Psychology and Psychotherapy: Theory Research and Practice (see Appendix 2-A)

Abstract

Objectives: Guilt and shame are associated with emotional overinvolvement (EOI) in carers of people with long-term mental health problems. Self-compassion has been noted to be protective against the impact of shame and guilt. It was hypothesised that self-compassion would moderate the impact of shame and guilt on EOI in a relevant group of carers.

Design: Informal family carers (n = 72) were recruited via Twitter, carer groups and webpages. A cross-sectional design using self-report measures was implemented to examine the relationship between emotional overinvolvement and guilt and shame, and to examine the effect of self-compassion on this relationship.

Methods: Potential participants were provided with information about the study.

Participants were able to take part either online, or by hand. Freepost return envelopes were provided to ensure participants incurred no financial cost if they chose to take part in this way.

Results: Guilt, shame, EOI and self-compassion were all significantly correlated with each other. Multiple linear regressions revealed unique main effects of self-compassion, guilt and shame on EOI scores, but no significant moderating effects of self-compassion on the relationship between guilt and shame, and EOI. T-tests revealed that male carers were able to be significantly more self-compassionate than female carers, who exhibited significantly more EOI than male carers.

Conclusions: Guilt, shame and EOI appear to be closely related to each other, and should remain targets for interventions. However, interventions which focus purely on developing self-compassion may not be the most successful way of reducing EOI.

Practitioner Points

- Family interventions that target shame and guilt might have clinical benefit through supporting carers to develop greater self-compassion. However, other approaches are likely to be needed in order to observe changes in family dynamics through reducing EOI.
- There appear to be gender differences in self-compassion and EOI, with female carers reporting less self-compassion than male carers, but higher EOI. This may leave female carers more vulnerable to the psychological effects of providing care for a relative, and consequently particular effort should be made to include female carers in family interventions.

Expressed emotion (EE) is an umbrella term summarising the emotional and behavioural responses observed in people providing care to a family member (Barrowclough & Hooley, 2003). When EE is 'high', outcomes across a range of mental health outcomes are worse (Butzlaff & Hooley, 1998; Hooley & Teasdale, 1989). EE comprises of two core components; critical comments (CC) and emotional overinvolvement (EOI). CC is characterised by critical, resentful, or judgmental comments made by carers in relation to their relative's presentation (Leff & Vaughn, 1985). EOI manifests in the behavioural responses of carers, which are often characterised by over-intrusive, involved and protective responses. In practice, this might be experienced as excessively anxious, emotionally laden conversations towards the individual receiving support (Barrowclough & Hooley, 2003; Leff & Vaughn, 1985). It has been found that relatives scoring high in EOI present as more intrusive in response to the client, more demanding of their time, and/or may be more dominating (Bentsen et al., 1996). Psychological interventions with families aimed at reducing EE have a marked impact on outcome in schizophrenia (Pharoah, Mari, Rathbone, & Wong, 2010) and bipolar affective disorder (Miklowitz et al., 2007).

Carers exhibiting high EOI experience negative outcomes in relation to both their physical and psychological wellbeing (Breitborde, López, Chang, Kopelowicz, & Zarate, 2009; Jansen, Gleeson, & Cotton, 2015). In relation to specific diagnoses, such as early psychosis, those with greater levels of EOI are more likely to perceive caregiving negatively than those with lower levels of EOI (Jansen et al., 2014). It has also been found that carer EOI was correlated with family stress, and that EOI at baseline predicted caregiver burden and family stress at follow up 7 months later (Álvarez-Jiménez et al., 2010). Rates of EOI differ between countries and cultures, and indeed the relationship between EOI and poor outcomes is also inconsistent across cultures. For example, in Pakistan a greater number of families are classified as being high in EOI (Ikram, Suhail, Jafery, & Singh, 2011) in comparison to the UK (Vaughn & Leff, 1976). A review of the cultural specificity of EOI found that, for carers from countries described as "Asian" (Singh, Harley & Suhail, 2013, p.

457), only one out of six studies found a significant relationship between EOI and poor outcomes (Singh, Harley & Suhail, 2013). These papers were conducted in Israel (Marom, Munitz, Jones, Weizman, & Hermesh, 2002; 2005), India (Leff et al., 1987; Leff et al., 1990) and Hong Kong (Ng, Mui, Cheung, & Leung, 2001). This has important clinical implications for targeting EOI to improve client and carer wellbeing. For example, it is important to establish the pattern of EOI in a given culture, in order to understand whether high EOI is related to poor outcomes and whether particular, culturally based protective factors may be salient. In turn, these considerations should influence targets for interventions.

The attributions that family carers make are important in the development of EOI and CC, as well as the emotional states that underpin such attributions (Jenkins & Karno, 1992; Robins & Schriber, 2009). In relation to attributions underpinning CC, carers who exhibit CC may describe their relative as having greater responsibility and control over their psychological wellbeing (Barrowclough & Hooley, 2003; Renshaw, Chambless, & Steketee, 2006). Furthermore, experiences of feeling ashamed are linked to the development of criticism and hostility towards their relative (Gilbert, 1998; Tangney 1995). The concept of shame is linked to the fear of negative judgment from others (Gilbert, 2007); consequently, thoughts about how others might evaluate their success as a carer could elicit feelings of shame, if they believe that others will be critical of them in this regard.

The self-conscious emotions of guilt and shame are thought to be emotional drivers of EOI. These emotions frequently occur in carers of people with a mental health difficulty (Natale & Barron, 1994). It has also been found that guilt and shame were associated with high EOI in carers (Wasserman, Weisman de Mamani, & Suro, 2012). A recent systematic review suggested that shame is associated with both CC and EOI, whereas guilt which is specific to the caregiving role is probably associated with EOI only (Cherry, Taylor, Brown, Rigby, & Sellwood, 2017). In addition, it has been found that attributing personal behaviour to internal unstable and controllable causes is believed to result in guilt; attributing behaviour to internal stable and uncontrollable causes is hypothesised to result in shame (Tracy &

Robins, 2006).

In terms of conceptualising how EOI might be underpinned by guilt and shame, it has been hypothesised that carers with high EOI may seek to protect their relatives from perceived harm or distress by becoming overinvolved (Barrowclough & Hooley, 2003). This is supported by research which has found that carers with high EOI reported experiencing guilt and self-blame (Bentsen et al., 1998). A higher number of self-blaming attributions were also found in carers who experienced greater EE (Peterson & Docherty, 2004).

Shame occurs in relation to self-judgment and negative evaluations of others (real or perceived; Robins & Schriber, 2009). The difficulties associated with shame often lead it to be considered as a maladaptive emotion. One such difficulty occurs when people experiencing shame feel powerful negative feelings and seek to protect themselves by externalising these feelings onto other people (Brown, 2004; Tracy & Robbins, 2006). The behavioural consequence of this might then be the critical comments associated with EE (Gausel, Vignoles, & Leach, 2016).

In contrast to shame, guilt has been considered as a way of reducing painful feelings of being responsible and to blame for an event (Gilbert, 2007; Hatfield, 1981). For example, mothers of people diagnosed with schizophrenia frequently experience guilt associated with blaming themselves for their child's diagnosis (Natale & Barron, 1994). Guilt has been conceptualised as an adaptive emotion as it is hypothesised that it fosters empathy and connection (Tangney & Tracy, 2012). However, when guilt becomes prolonged and heightened, or occurs in response to situations where the individual is not responsible for any difficulty, it can lead to significant distress (Tangney & Tracy, 2012). Consequently, guilt may underpin EOI as carers attempt to repair, or make amends for experiences that they feel responsible (Hatfield, 1981).

An emerging concept thought to influence shame and guilt is self-compassion. Self-compassion has been defined as "the ability to hold one's feelings of suffering with a sense of

warmth, connection, and concern" (Neff & McGehee, 2010, p. 226). It has been argued that self-compassion has the capacity to modify the physiological systems that underlie caregiving and attachment (Gilbert, 1992). As would be expected, interventions that support people to develop self-compassion can reduce distress associated with a variety of mental health difficulties (Hoffman, Grossman, & Hinton, 2011). The development of self-compassion arises through the promotion of soothing, calming responses to negative outcomes (Johnson & O'Brien, 2013). Individuals who find it difficult to be self-compassionate are more likely to experience shame and poorer treatment outcomes (Ferreira, Pinto-Gouveia, & Duarte, 2013; Kelly, Carter, Zuroff, & Borairi, 2013). The therapeutic approach of compassionfocused therapy (CFT) was created to work with shame and self-criticism (Gilbert, 2009). The approach posits that there are three systems that people operate from: the threat, drive and soothing systems. It is argued that those who find it difficult to manage threat and shamebased emotions are more likely to be stuck in the drive system, leading them to become proactive in their attempts to fix difficulties (Gilbert, 2009, 2010; Gilbert & Irons, 2005). This is consistent with the idea that individuals with high EOI may find it difficult to move away from the threat system. Therefore, should self-compassion show relevance in this context, it might be a suitable target for psychological intervention (Gilbert, 2010). The present study explored the extent to which self- compassion moderates the relationship

The present study explored the extent to which self- compassion moderates the relationship between EOI and guilt and shame. Given existing research findings, it was hypothesized that:

- EOI, guilt, shame, and self-compassion will be closely correlated with each other.
- 2. Carers who are able to be compassionate to themselves are able to exhibit less EOI, despite still experiencing guilt and shame.

The hypothesized relationship between key variables can be presented diagrammatically as follows:

[INSERT FIGURE 1 HERE]

[INSERT FIGURE 2 HERE]

Method

Participants

Individuals were included if they were aged over 18, and provided care for a relative diagnosed with a long-term mental health difficulty. Carers were conceptualised as relatives who gave unpaid, regular support to their relative. There was no limitation imposed in relation to mental health diagnosis, as it has been found that expressed emotion predicts outcomes across diagnoses (Barrowclough & Hooley, 2003). Participants were excluded if their sole diagnosis was either neurological in nature (for example, vascular dementia), a learning disability or acquired brain injury. Participants were recruited through Twitter and through carer support organisations. Regional, national and international organisations were identified through Google searches and looking at the follower lists of organisations on Twitter. Examples of organisations contacted include: Rethink support groups, First Steps Derbyshire, and BPD Carer¹. Organisations were contacted both by email and by telephone. See Ethics Section page 4-19 for approved recruitment email.

Measures

Demographic Information Sheet.

Participants were asked to complete a demographic information sheet, which included questions on themselves and the person they provided care for. Questions included: "How are you related to the person you provide care for (for example, mother, brother)?" and "What is the nature of their mental health issue/diagnosis". See Ethics Section page 4-25 for approved demographic information sheet.

The Caring and Related Emotions (CARE) Scale.

The CARE Scale (Messham, Finlayson, & Sellwood, submitted) is a self-report measure which comprises four subscales (shame, blame (towards the individual with a mental

¹ This groups supports people caring for someone with a diagnosis of borderline personality disorder and refers to itself as "BPD Carer"

health diagnosis), guilt, and externalisation). It contains descriptions of 16 hypothetical scenarios that might arise as part of the experience of providing care. Responses to each scenario are rated on a 5-point Likert scale based on how they would anticipate responding, and ranged from 1 (*very unlikely*) to 5 (*very likely*). Previous research has found good test-retest reliability for each subscale (guilt r = .82; shame r = .89; blame r = .95 and externalisation r = .76; Messham et al., submitted), and high internal consistency (Cronbach's $\alpha = .90$ for the guilt subscale; Cronbach's $\alpha = .91$ for the shame subscale; Cronbach's $\alpha = .90$ for the blame subscale; Messham et al., submitted). See Appendix 2-B for a copy of the CARE scale.

The Family Questionnaire (FQ).

The FQ Scale (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002) is a 20 item self-report scale used to measure CC and EOI. Each subscale contains 10 statements, which are rated on a 4 point Likert scale ranging from *never/very rarely* to *very often*. The measure is strongly correlated with the Camberwell Family Interview (CFI, Leff & Vaughn, 1985), which is frequently considered to be the *gold standard* measure of expressed emotion (Hooley & Parker, 2006). It has high test-retest reliability and internal consistency for both the EOI subscale (r = .91; Cronbach's $\alpha = .80$) and CC subscale (r = .84; Cronbach's $\alpha = .92$; Wiedemann et al., 2002). See Appendix 2-C for a copy of the FQ.

The Self-Compassion Scale (SCS).

The SCS (Neff, 2003) measures self-compassion by assessing responses to suffering. The scale consists of six constructs: self-kindness, common humanity, mindfulness, self-judgment, isolation and over-identification (Neff, 2016). The SCS consists of 26 items which are rated on a 5-point Likert scale, with scores ranging from 1 ($Almost\ Never$) to 5 ($Almost\ Always$). It has high test-retest reliability (r = .93; Neff, 2003), and has also been found to

have high internal consistency (Cronbach's α = .93; Raes, Pommier, Neff, & Van Gucht, 2011). See Appendix 2-D for a copy of the SCS.

Procedure

Carer groups were contacted through Twitter, or by telephone or email to ask if they would support the study. Regional, national and international carer groups were approached, and were provided with the participant information sheet and link to take part online (see Ethics Section page 4-20 for a copy of the participant information sheet). The offer of receiving hard copies of questionnaires was also highlighted in conversations with carer groups in order for the study to be as inclusive as possible. From this, groups either "retweeted" details of the study, or circulated the information sheet and details of the study by email, by newsletter or through discussion at group meetings. Three groups requested hard copies of questionnaire packs, and then distributed these to interested individuals. In addition to the information sheet, consent form, measures, and debrief sheet, hard packs also included a freepost return envelope. Groups and participants were encouraged to contact the researcher with any questions or concerns throughout the process.

Analysis

A-priori power calculations using G*power 3.1 stated that a minimum of 68 participants would be needed to detect an effect size of 0.15, with a power level of .80. This study used a standard α level of p=.05, two tailed. All analyses were performed in SPSS version 23 (IBM Corp, 2015). Data were tested to ensure assumptions of parametricity were met (Field, 2013). Pearson's correlation analysis was conducted to determine the relationships between variables. Multiple linear regressions were conducted in order to understand the relationships between the independent variables (guilt and shame) and the dependent variable (EOI). Finally, a moderation analysis was undertaken in order to determine whether self-compassion moderates the relationship between guilt and shame, and EOI.

Results

Assumptions of parametricity and measures

Initially, datasets were checked to ensure they met assumptions of normality. Kurtosis and skewness values indicated normal distributions for all variables (see Appendix 2-E for descriptives output for key variables). Visual examination of histogram plots, boxplots and QQ plots for EOI, guilt, shame and self-compassion also suggested that the data were normally distributed. Please see Appendix 2-F for distribution outputs for EOI; Appendix 2-G for distribution outputs for guilt; Appendix 2-H for distribution outputs for shame and Appendix 2-I for distribution outputs for self-compassion. A Shapiro-Wilk's test revealed normal distribution for every variable except shame. However, given that all other tests indicated normal distribution for this variable, and in light of the robust nature of regression to non-normally distributed data, no transformation of data was undertaken. Please see Appendix 2-J for Shapiro-Wilk values for each variable. High internal consistency was also achieved for all scales used in the study; the CARE scale Cronbach's α = .93; (guilt subscale α = .92; shame subscale α = .90; blame subscale α = .90; externalisation subscale α = .72); SCS Cronbach's α = .94; Family Questionnaire Cronbach's α = .88 (EOI subscale α = .75; CC subscale α = .89).

Participant Characteristics

Seventy-two participants took part in the study and were included in the analysis.

Fifty-eight participants were female (80.56%) and their mean age was 51.26 years (SD = 13.35; range 24-78 years). These figures exclude one female participant who had an obvious error in reporting their age. Thirteen participants were male (18.06%), their mean age was 50.46 years (SD = 13.13; range 29-67 years). One participant did not provide demographic

information. The relationship of the carer to the client consisted of two dominant groups – parents and spouses/partners (see Table 1).

[INSERT TABLE 1 HERE]

Nineteen further responses were excluded, of which 14 were excluded due to missing data (five participants completed half of one measure; eight participants completed one measure; one participant completed the self-compassion scale and half of the CARE scale). Three were excluded due to the only diagnosis being neurodegenerative in nature, and two participants were excluded due to the client being under 16 years of age.

The mean age of person with mental health difficulty was 35.97 years old (SD = 16.04; range 16-76 years). Two participants provided the ages of two relatives they provided care for; the mean of these ages were used for the above calculation. Two further participants did not provide the age of their relative. Seventy-one participants reported their relative's primary diagnosis (see Table 2). Twenty-one participants cared for people with multiple mental health diagnoses, and of this, 9 had an eating disorder as one of the diagnoses. A further 17 carers provided support for a relative with a sole diagnosis of an eating disorder and 10 carers supported someone with a diagnosis on the schizophrenia spectrum. Less frequently occurring diagnoses were bipolar disorder (eight carers), personality disorder (eight carers), depression (five carers) and post-traumatic stress disorder (one carer).

[INSERT TABLE 2 HERE]

Twenty-eight clients were male, and 42 clients were female. Two participants did not provide information on the gender of the client. The mean duration of clients' mental health difficulty was 12.34 years (SD = 10.62; range <1 – 45 years). Two participants provided duration of two mental health difficulties; for the purposes of descriptive analysis, the longest duration was included. One participant gave a range of between 15-20 years, for this individual a mean was taken. Four participants stated the mental health difficulty had been diagnosed a number of years "plus" ago; in these datasets, the year given was included. Two participants did not provide details of the duration of the mental health difficulty.

Correlation analysis – Testing Hypothesis 1

Preliminary correlational analysis revealed positive correlations between the emotions of shame and guilt, and EOI (r = .477, p < .001; r = .556, p < .001 respectively). Guilt and shame were also highly correlated with each other (r = .721, p < .001). Self-compassion was negatively correlated with EOI (r = -.429, p < .001), guilt (r = -.420, p < .001) and shame (r = -.399, p < .001). That is, those who were higher in self-compassion were less likely to experience feelings of guilt and shame, or to exhibit EOI (see Table 3).

[INSERT TABLE 3 HERE]

Multiple Linear Regressions – Testing Hypothesis 2

Guilt and shame were highly correlated, and therefore both variables were tested separately using multiple linear regressions, bootstrapped to 5000 cases. For each variable, model one considered the unique main effect of both the predictor variable and self-compassion on EOI, and model two considered the effect of the interaction between the centred predictor variable and centred self-compassion on EOI.

The assumption of homoscedasticity was confirmed by examining a scatterplot of the standardised residuals, which indicated that residuals were randomly scattered around a horizontal line, with no systematic clusters or pattern (please see Appendix 2-K for scatterplot displaying homoscedasticity of the regression model). Furthermore, a plot of the standardised residuals versus the predicted values indicated a linear relationship between all outcome and predictor variables (please see Appendix 2-L for plot displaying linear relationship between the predictor (guilt, shame) and outcome (EOI) variables). Variance Inflation Factor (VIF) values for the regression models also suggested that there were no

problems with multi-collinearity within the dataset (please see Appendix 2-M for output tables displaying VIF values).

Guilt.

This model examined the predictive relationship between guilt and self-compassion on EOI scores. Overall, model one explained 35.6% of the variance of EOI scores, F (2, 69) = 19.071, 2 = .356, p<.001. Model one (see Table 4) showed unique main effects of both self-compassion (β = -.238, p = .029, [BC95%CI -2.958, -.166]), and guilt (β = .456, p<.001, [BC95%CI .079, .217]). Looking at model two, the interaction term did not significantly predict EOI scores, (β = -.081, p = .411, n.s. [BC95%CI = -.135, .056] after accounting for the main effects of guilt and self-compassion (see Table 5). The interaction term explained only a further 0.6% of the variance in EOI scores (π ² change = .006). Therefore, though both guilt and self-compassion independently significantly predict EOI scores, there was no significant moderation effect of self-compassion on the relationship between guilt and EOI.

[INSERT TABLE 4 HERE]

[INSERT TABLE 5 HERE]

Shame.

This model examined the predictive relationship between shame and self-compassion on EOI scores. Overall, model one (see Table 6) explained 29.6% of the variance of EOI scores, F (2, 69) = 14.492, π^2 = .296, p<.001. Model one showed unique main effects of both self-compassion (β = -.284, p = .012, [BC95%CI -3.313, -.424]), and shame (β = .364, p=.002, 95% [BC95%CI .048, .196]). Looking at model two, the interaction term did not significantly predict EOI scores, (β = -.008, p = .938, n.s. [BC95%CI = -.110, .102]) after accounting for the main effects of shame and self-compassion (see Table 7). Adding the

interaction term to the model did not explain any additional variance in EOI scores (r^2 change = .000). Therefore, though both shame and self-compassion independently significantly predict EOI scores, there was no significant moderation effect of self-compassion on the relationship between shame and EOI.

Further analyses

Given the high correlations observed between variables, but non-significant moderation analyses, further analyses were undertaken in order to extract more information from the results. A blockwise hierarchical regression with self-compassion in block one found that self-compassion explained 17.3% of the variance of EOI scores, F (1, 70) = 15.827, $\pi^2 = .184$, p<.001. Block one also showed a unique main effect of self-compassion ($\beta = -.429$, p<.001, [95%CI -4.238, -.1408]). Adding guilt and shame into block two showed that these constructs explained 33.4% of the variance in EOI scores, F (2, 68) = 9.470, $\pi^2 = .352$, p<.001. Guilt was found to have a significant main effect after accounting for self-compassion ($\beta = .380$, p = .010 [95%CI .031, .216]), however there was no main effect of shame once guilt and self-compassion were accounted for ($\beta = .114$, p = .423, n.s. [95%CI - .056, .133)]. See Table 8 for model summary output and Table 9 for coefficients output table between self-compassion, and shame and guilt.

[INSERT TABLE 8 HERE]

[INSERT TABLE 9 HERE]

A further blockwise hierarchical regression was developed, with three blocks to separate shame and guilt. It was found that shame explained 11.1% of the variance of EOI scores, F (1, 69) = 10.915, rr^2 = .296, p = .002. Once self-compassion was accounted for, shame had a significant main effect on EOI (β = .364, p = .002, [95%CI .048, .196]). Guilt

explained 6.6% of the variance in EOI scores, F (1, 68) = 7.065, π^2 = .396, p = .010. Once accounting for self-compassion and shame, guilt continued to have a significant effect on EOI scores (β = .380, p = .010, [95%CI .031, .216]). These analyses show that the relationship between shame and EOI became non-significant once guilt and self-compassion were accounted for within the regression. However, separating out the constructs into separate blocks revealed that the effect of guilt remained significant even after shame and self-compassion were controlled for. See Table 10 for model summary output and Table 11 for coefficients output table between self-compassion, shame and guilt when entered as separate blocks.

[INSERT TABLE 10 HERE]

[INSERT TABLE 11 HERE]

In addition to blockwise hierarchical regression, independent measures t-tests were also conducted. Data were split according to carers' gender and relationship to their relative. No statistically significant effect was found of carers relationship on any construct, however carer gender did appear to be implicated in EOI scores, with female carers (M=30.00, SD = 4.30829) exhibiting significantly more EOI than male carers (M=27.1538, SD = 3.78255); t (69) = 2.197, p = .031, and higher EE scores (a total of CC and EOI scores); t (69) = 2.132, p = .037. Carer gender also influenced self-compassion, with male carers (M = 3.4404, SD = .50289) scoring significantly higher in self-compassion than female carers (M = 3.0316, SD = .67278); t (69) = 2.061; p = .043. See Table 12 for output table showing relationship between carer gender and self-compassion, EOI scores and total EE scores.

[INSERT TABLE 12 HERE]

In summary, the initial hypothesis relating to variables being closely correlated is supported, however, in contrast to hypothesis 2, there was no moderating effect of self-compassion on the relationship between either guilt or shame on EOI.

Discussion

The aim of the current study was to examine the relationship between the emotions of guilt and shame on EOI, and further, to explore whether self-compassion has a moderating effect on the relationship between these constructs. Significant correlations were found between all variables, with negative correlations found between self-compassion and EOI, guilt and shame. That is, those who exhibited greater EOI were more likely to experience guilt and shame, and were less likely to be self-compassionate. Multiple linear regressions showed that there were significant main effects of guilt and shame on EOI, with guilt explaining 35.6%, and shame explaining 29.6% of the variance of EOI scores. Both of these results were significant at .001 level.

These results are consistent with previous research, and provide support for the idea that guilt and shame predict EOI. Guilt may drive a desire to make amends for wrongdoings (Wasserman et al., 2012) and keep their relative safe from distress or harm, leading to a pattern of behaviour that might be considered as overinvolved (Barrowclough & Hooley, 2003). Carers may also feel a sense of responsibility for their relative's distress, and the associated guilt arising from this might drive EOI (Gilbert, 2007). In contrast, shame is linked to self-criticism and concerns around how other people might perceive them (Gilbert, 1998; 2007; Tangney & Dearing, 2002). Therefore, the relationship between shame and EOI might be explained by carers' attempts to repair and re-shape their evaluations of how others perceive them, by becoming overinvolved. The findings highlight the likelihood that carers are likely to experience guilt and shame, and find it harder to show compassion towards themselves, and it is important to consider this in the context of clinical work with this population. Providing psychoeducation in relation to this to show that other carers also experience these difficulties may help carers to feel less alone with their feelings.

Adding the interaction terms of guilt x self-compassion and shame x self-compassion led to a non-significant change in the amount of variance in EOI scores explained by this

interaction. Consequently, there was no moderating effect of self-compassion on the relationship between either guilt or shame on EOI. Despite this, self-compassion was significantly, negatively correlated with EOI, and with guilt and shame. Consequently the idea that people low in self-compassion are more likely to experience shame is supported (Ferreira et al., 2013; Kelly et al., 2013). As such, family interventions based on developing self-compassion are likely to alleviate distress, but may not influence self-reported behavioural presentations, as, in this study, self-compassion was not able to moderate the effect of guilt or shame on EOI. In summary, guilt and shame are likely to be successful targets for interventions, but this may be achieved in ways other than traditional compassionfocused therapy (Gilbert, 2009). Practical interventions which focus on improving selfconfidence in carers' ability to successfully support their relative may yield reductions in EOI by reducing guilt and shame, for example. However, it is important to consider these findings tentatively and further research exploring the relationship between self-compassion, EOI, guilt and shame is needed. Clinicians also need to be aware of the risk of implicitly attributing responsibility for mental health problems to caregivers; this is likely to heighten feelings of guilt and shame, and exacerbate distress.

In relation to the sample, cultural and ethnic background data was not collected.

Given that there are clear cultural differences and interpretations of the impact of EOI, these results should be considered with caution in the context of providing interventions to minority groups, and in other cultures across the world. Future research would benefit from collecting this type of data from populations with diverse ethnic and cultural backgrounds.

Strengths and limitations

Participants in the study were recruited through Twitter and charitable/advocacy organisations. It has been argued that Twitter can improve access and inclusion of hard to reach groups (O'Connor, Jackson, Goldsmth, & Skirton, 2014). Equally, it is possible that individuals who seek support through these platforms may have greater levels of EOI and/or

guilt and shame, leading to a self-selection bias. It can therefore be questioned whether the participant sample are representative of the wider family carer population. Perhaps recruiting individuals from clinical services may alleviate the potential bias of recruiting directly from self-help groups. Indeed, visual examination of the histogram plotting EOI scores show that, whilst the distribution of scores is normal, there is a skew towards the higher EOI scores. Recruiting through services and informing all carers of the research would have enabled a more representative sample to have been gathered. It might be expected that the distribution of EOI scores would be less skewed, which would increase the validity of the results. The limited range in EOI scores, at the upper end of the scale, may also have led to a type 2 error with respect to the moderation analyses. With a more representative sample, with a wider range of scores, a significant impact of self-compassion on the relationship between guilt and shame and EOI may have been identified. One possible way to achieve this would have been to recruit through services. This might also have enabled a wider range of ages to take part in the study, as it is possible that more mature carers are not as active on social media (the main recruitment channel used by this study). It might be expected that a younger sample who have perhaps been in a caring role for less time would experience less EOI.

A high proportion of participants supported a relative diagnosed with an eating disorder, though this was not deliberately sought by the researcher. It has been argued that relational patterns and battles for control frequently occur in the relationships between family carers and their relatives (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013; Whitney & Eisler, 2005). It may be that attempts to gain control might also manifest in seeking to make sense of family dynamics and emotional patterns, and that, consequently, carers of someone with an eating disorder might be more likely to take part in research to clarify such issues. It is unclear whether this is representative of the wider family carer population.

It is possible that there could be a desirability bias relating to the CARE scale (Messham et al., submitted). Given that the questions assess challenging emotions, participants may feel that particular answers are more socially acceptable and will be viewed

with less judgment than those which may, in reality, represent their thoughts and feelings. It is difficult to determine whether this has occurred in the present study, though given the anonymous nature of the study, efforts to avoid this were made.

Power calculations revealed that a minimum of 68 participants would be needed to achieve a power level of .80. This study recruited 72 participants, and therefore the study was sufficiently powered to undertake multiple regression analysis. However, no power calculation was undertaken for the moderation analysis, and it is possible that many more participants would have been needed in order to detect a moderating effect of self-compassion on guilt/shame and EOI. For example, one study has suggested that at least 120 participants would be required in order to detect medium or large moderating effects (Aguinis, 1995). However, it might be expected that a small, non-significant moderating effect of self-compassion would be found with the achieved sample size if guilt and shame affected EOI through self-compassion. Given that the study did not find any moderation of the relationship between guilt or shame and EOI, it is unlikely that a larger sample size would have revealed a moderating effect of self-compassion.

This area of research might benefit from studies that examine how carers scoring high in EOI are experienced by their relative. Could it be, for example, that carers who experience guilt and shame are more likely to respond to questions in a self-critical manner, leading to skewed responses? Exploring responses from both carers and their relatives would allow a more detailed picture of the relational dynamics associated with guilt, shame, EOI and self-compassion to develop. This would, in turn, facilitate an understanding of how to target these variables through psychological interventions. A greater understanding of the impact of self-compassion on the relationship between guilt and shame and EOI, could be achieved through conducting a mixed methods study. This would involve a qualitative component to explore the client's experiences of care. A further limitation is that the study did not ask participants to disclose their cultural background. Research has demonstrated that the relationship between EOI and poorer outcomes is inconsistent across cultures (Singh, Harley, & Suhail, 2013), and

therefore it would have been valuable to collect data on participant's cultural background to examine whether differences existed between cultures.

Conclusion

This research has highlighted the strong relationships between guilt, shame and EOI. It is important to consider the results in light of the human functions of guilt and shame; guilt has been conceptualised as part of the caring system (Gilbert 1992), and consequently, it is understandable that family carers might present in a way categorised as EOI, as an attempt to care and support their relative (Van Os, Marcelis, Germeys, Graven, & Delespaul, 2001). Carers who are high in EOI may become self-critical of the support they provide, whilst also feeling to blame for the development of the difficulty (Brookfield, Keith, Reilly, & Sellwood, 2014). In this context, it is understandable that EOI might develop in an attempt to manage these thoughts and feelings. It is easy to see that this could lead to a maintenance cycle of distress, where a carer becomes unable to maintain their level of support, leading to further self-criticism and self-judgment, perpetuating EOI as an attempt to support their relative. In addition, this highlights the need for clinicians to approach caregivers with caution when offering help. It is possible that they may inadvertently collude with feelings of guilt and shame by suggesting that there are 'better ways of caring', leading to further overinvolvement.

It is clear that shame and guilt are still significantly correlated with EOI, and therefore remain targets for interventions. Adopting a non-pathologising, validating stance is likely to reduce feelings of guilt and shame among carers, and maximise the benefit of therapeutic interventions.

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Figure 1. Hypothesised moderating effect of self-compassion on guilt and EOI

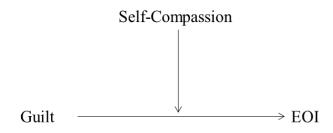


Figure 2. Hypothesised moderating effect of self-compassion on shame and EOI

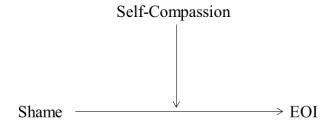


Table 1. Participant relationship to the relative they provide care for

Relationship to client	Frequency	Percent
Parent	39	54.17
Spouse/Partner	21	29.17
Sibling	3	4.17
Child	3	4.17
No answer provided	2	2.78
Participant provides care to multiple family members	2	2.78
Former boyfriend	1	1.39
Cousin	1	1.39

 ${\it Table 2. Frequency of mental health diagnosis}$

Diagnosis	Frequency	Percent
Multiple MH diagnoses	21	29.17
Eating Disorder	17	23.61
Bipolar Disorder	8	11.11
Personality Disorder	8	11.11
Depression	5	6.94
Schizophrenia	4	5.56
Psychosis	3	4.17
Paranoid Schizophrenia	2	2.78
Schizoaffective Disorder	1	1.39
PTSD	1	1.39
Psychotic Depression	1	1.39
No diagnosis provided	1	1.39

Table 3. Correlation Matrix showing relationships between variables

Correlations

		Emotional	Self-		
		Overinvolvement	Compassion	Shame	Guilt
Emotional Overinvolvement	Pearson Correlation	1	429 ^{**}	.477**	.556**
	Sig. (2-tailed)		.000	.000	.000
	N	72	72	72	72
Self-Compassion	Pearson Correlation	429 ^{**}	1	399**	420**
	Sig. (2-tailed)	.000		.001	.000
	N	72	72	72	72
Shame	Pearson Correlation	.477**	399**	1	.721**
	Sig. (2-tailed)	.000	.001		.000
	N	72	72	72	72
Guilt	Pearson Correlation	.556**	420**	.721**	1
	Sig. (2-tailed)	.000	.000	.000	
	N	72	72	72	72

^{**.} Correlation is significant at the 0.01 level (2-tailed).

Table 4. Model Summary SPSS output for Guilt

Model Summary^c

					Change Statistics					
		R	Adjusted R	Std. Error of	R Square	F			Sig. F	
Model	R	Square	Square	the Estimate	Change	Change	df1	df2	Change	
1	.597ª	.356	.337	3.57781	.356	19.071	2	69	.000	
2	.602 ^b	.362	.334	3.58601	.006	.685	1	68	.411	

a. Predictors: (Constant), Guilt, Self-Compassion

b. Predictors: (Constant), Guilt, Self-Compassion, GuiltcxSCC

c. Dependent Variable: Emotional Overinvolvement

Table 5. Coefficients SPSS output table for Guilt

Coefficients^a

		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B		Collinearity Statistics	
			Std.				Lower	Upper		
Mod	del	В	Error	Beta	t	Sig.	Bound	Bound	Tolerance	VIF
1	(Constant)	27.335	3.253		8.402	.000	20.845	33.825		
	Self- Compassion	-1.562	.700	238	2.232	.029	-2.958	166	.823	1.214
	Guilt	.148	.035	.456	4.288	.000	.079	.217	.823	1.214
2	(Constant)	27.476	3.265		8.415	.000	20.960	33.991		
	Self- Compassion	-1.579	.702	240	- 2.250	.028	-2.979	179	.823	1.215
	Guilt	.143	.035	.441	4.074	.000	.073	.213	.799	1.251
	GuiltexSCC	040	.048	081	828	.411	135	.056	.969	1.032

a. Dependent Variable: Emotional Overinvolvement

Table 6. Model Summary SPSS output for Shame

Model Summary^c

					Change Statistics						
		R	Adjusted R	Std. Error of	R Square	F			Sig. F		
Model	R	Square	Square	the Estimate	Change	Change	df1	df2	Change		
1	.544ª	.296	.275	3.74128	.296	14.492	2	69	.000		
2	.544 ^b	.296	.265	3.76852	.000	.006	1	68	.938		

a. Predictors: (Constant), Self-Compassion, Shame

b. Predictors: (Constant), Self-Compassion, Shame, ShameCxSCC

c. Dependent Variable: Emotional Overinvolvement

Table 7. Coefficients SPSS output table for Shame

Coefficients^a

	Coefficients											
		Unstandardized		Standardized	ndardized		95.0% Cd	onfidence	Collinea	arity		
		Coeffi	cients	Coefficients			Interva	I for B	Statist	ics		
			Std.				Lower	Upper				
Mo	del	В	Error	Beta	t	Sig.	Bound	Bound	Tolerance	VIF		
1	(Constant)	30.542	3.152		9.689	.000	24.254	36.831				
	Shame	.122	.037	.364	3.304	.002	.048	.196	.841	1.189		
	Self- Compassion	-1.869	.724	284	- 2.581	.012	-3.313	424	.841	1.189		
2	(Constant)	30.573	3.199		9.556	.000	24.189	36.958				
	Shame	.122 -1.876	.038	.362	3.193	.002	.046	.197	.805	1.242		
	Self- Compassion		.734	285	- 2.554	.013	-3.341	410	.829	1.206		
	ShameCxSCC	004	.053	008	078	.938	110	.102	.956	1.046		

a. Dependent Variable: Emotional Overinvolvement

Table 8. Blockwise Hierarchical Regression output between Self-Compassion, and Shame and Guilt: Model Summary

Model Summary

					Change Statistics						
		R	Adjusted R	Std. Error of	R Square	F			Sig. F		
Model	R	Square	Square	the Estimate	Change	Change	df1	df2	Change		
1	.429ª	.184	.173	3.99748	.184	15.827	1	70	.000		
2	.602 ^b	.362	.334	3.58695	.178	9.470	2	68	.000		

a. Predictors: (Constant), Self-Compassion

b. Predictors: (Constant), Self-Compassion, Shame, Guilt

Table 9. Blockwise Hierarchical Regression output between Self-Compassion, and Shame and Guilt: Coefficients

Coefficientsa

	Coefficients										
		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B				
							Lower	Upper			
Mod	el	В	Std. Error	Beta	t	Sig.	Bound	Bound			
1	(Constant)	38.309	2.243		17.076	.000	33.835	42.784			
	Self-Compassion	-2.823	.709	429	-3.978	.000	-4.238	-1.408			
2	(Constant)	26.744	3.343		8.000	.000	20.074	33.415			
	Self-Compassion	-1.475	.710	224	-2.078	.042	-2.891	058			
	Guilt	.123	.046	.380	2.658	.010	.031	.216			
	Shame	.038	.047	.114	.806	.423	056	.133			

a. Dependent Variable: Emotional Overinvolvement

Table 10. Blockwise Hierarchical Regression output between Self-Compassion, Shame and Guilt: Model Summary

Model Summary

					Change Statistics				
		R	Adjusted R	Std. Error of	R Square	F			Sig. F
Model	R	Square	Square	the Estimate	Change	Change	df1	df2	Change
1	.429ª	.184	.173	3.99748	.184	15.827	1	70	.000
2	.544 ^b	.296	.275	3.74128	.111	10.915	1	69	.002
3	.602 ^c	.362	.334	3.58695	.066	7.065	1	68	.010

a. Predictors: (Constant), Self-Compassion

b. Predictors: (Constant), Self-Compassion, Shame

c. Predictors: (Constant), Self-Compassion, Shame, Guilt

Table 11. Blockwise Hierarchical Regression output between Self-Compassion, Shame and Guilt: Coefficients

Coefficientsa

				Jenicients"				
		Unstand	dardized	Standardized	ndardized		95.0% Confidence	
		Coeffi	cients	Coefficients			Interva	l for B
							Lower	Upper
Mod	lel	В	Std. Error	Beta	t	Sig.	Bound	Bound
1	(Constant)	38.309	2.243		17.076	.000	33.835	42.784
	Self-Compassion	-2.823	.709	429	-3.978	.000	-4.238	-1.408
2	(Constant)	30.542	3.152		9.689	.000	24.254	36.831
	Self-Compassion	-1.869	.724	284	-2.581	.012	-3.313	424
	Shame	.122	.037	.364	3.304	.002	.048	.196
3	(Constant)	26.744	3.343		8.000	.000	20.074	33.415
	Self-Compassion	-1.475	.710	224	-2.078	.042	-2.891	058
	Shame	.038	.047	.114	.806	.423	056	.133
	Guilt	.123	.046	.380	2.658	.010	.031	.216

a. Dependent Variable: Emotional Overinvolvement

Table 12. Independent Samples t-test output: Self-Compassion, EOI, EE, and Carer Gender

Independent Samples Test

Independent Samples Test										
		Levene								
		for Equ	-							
		Varia	nces			t-te	st for Equali	ty of Means		
									95% C	onfidence
						Sig.			Interv	al of the
						(2-	Mean	Std. Error	Diffe	erence
		F	Sig.	t	df	tailed)	Difference		Lower	Upper
Self-	Equal									
Compassion	-	1.539	.219	-	69	.043	40878	.19837	-	01303
·	assumed			2.061					.80452	
	Equal									
	variances not			-	22.787	.021	40878	.16510	-	06706
				2.476	22.707	.021	40070	.10310	.75049	00700
EOI	assumed Equal									
201	variances	.008	.931	2.197	69	.031	2.84615	1.29544	.26182	5.43049
	assumed	.008	.931	2.131	03	.031	2.04013	1.23344	.20102	5.45049
	Equal									
	variances not			2.388	19.644	.027	2.84615	1.19190	.35701	5.33530
	assumed									
EE total	Equal									
Score	variances	.362	.549	2.132	69	.037	5.56366	2.60903	.35879	10.76853
	assumed									
	Equal									
	variances not			2.247	18.887	.037	5.56366	2.47645	.37829	10.74903
	assumed									

Appendix 2-A

Psychology and Psychotherapy: Theory, Research and Practice – Guide for Authors

Author Guidelines

Psychology and Psychotherapy: Theory Research and Practice (formerly The British Journal of Medical Psychology) is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. We welcome submissions from mental health professionals and researchers from all relevant professional backgrounds. The Journal welcomes submissions of original high quality empirical research and rigorous theoretical papers of any theoretical provenance provided they have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders.

Submission of systematic reviews and other research reports which support evidence-based practice are also welcomed, as are relevant high quality analogue studies. The Journal thus aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies (including both process and outcome research) where mental health is concerned. Clinical or case studies will not normally be considered except where they illustrate particularly unusual forms of psychopathology or innovative forms of therapy and meet scientific criteria through appropriate use of single case experimental designs.

All papers published in Psychology and Psychotherapy: Theory, Research and Practice are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

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2. Length

All articles submitted to PAPT must adhere to the stated word limit for the particular article type. The

journal operates a policy of returning any papers that are over this word limit to the authors. The word

limit does not include the abstract, reference list, figures and tables. Appendices however are included

in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the

clear and concise expression of the scientific content requires greater length (e.g., a new theory or a

new method). The authors should contact the Editors first in such a case.

Word limits for specific article types are as follows:

• Research articles: 5000 words

Qualitative papers: 6000 words

• Review papers: 6000 words

• Special Issue papers: 5000 words

3. Brief reports

These should be limited to 1000 words and may include research studies and theoretical, critical or

review comments whose essential contribution can be made briefly. A summary of not more than 50

words should be provided.

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous

(double blind) peer review. We also operate a triage process in which submissions that are out of scope

or otherwise inappropriate will be rejected by the editors without external peer review to avoid

unnecessary delays. Before submitting, please read the terms and conditions of submission and the

declaration of competing interests. You may also like to use the <u>Submission Checklist</u> to help you

prepare your paper. If you need more information about submitting your manuscript for publication,

please email Melanie Seddon, Senior Editorial Assistant at papt@wiley.com or phone +44 (0) 1243 770 108

- 5. Manuscript requirements
- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use this template.

 When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the Project CRediT website for a list of roles.
- The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.

- All Articles must include Practitioner Points these are 2-4 bullet points, in addition to the abstract, with the heading 'Practitioner Points'. These should briefly and clearly outline the relevance of your research to professional practice.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.
- Manuscripts describing clinical trials must be submitted in accordance with the CONSORT statement on reporting randomised controlled trials (http://www.consort-statement.org).
- Manuscripts describing systematic reviews and meta-analyses must be submitted in accordance with the PRISMA statement on reporting systematic reviews and meta-analyses (http://www.prisma-statement.org).

For guidelines on editorial style, please consult the <u>APA Publication Manual</u> published by the American Psychological Association.

6. Multiple or Linked submissions

Authors considering submitting two or more linked submissions should discuss this with the Editors in the first instance.

7. Supporting Information

PAPT is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found at http://authorservices.wiley.com/bauthor/suppmat.asp

8. Copyright and licenses

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services, where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

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If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs.

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- Creative Commons Attribution Non-Commercial License OAA
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To preview the terms and conditions of these open access agreements please visit the <u>Copyright FAQs</u> and you may also like to visit the <u>Wiley Open Access and Copyright Licence</u> page.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) or Austrian Science Fund (FWF) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with your Funder requirements.

For more information on this policy and the Journal's compliant self-archiving policy please visit our Funder Policy page.

9. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper. A copy of the Colour Work Agreement form can be downloaded here.

10. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

11. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via

Wiley Online Library, as well as deposited in the funding agency's preferred archive. For the full list of terms and conditions, see http://wileyonlinelibrary.com/onlineOpen #OnlineOpen Terms
Any authors wishing to send their paper OnlineOpen will be required to complete the payment form available from our website at: https://onlinelibrary.wiley.com/onlineOpenOrder

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

12. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit http://authorservices.wiley.com/bauthor/ for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

13. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following web site:

http://www.adobe.com/products/acrobat/readstep2.html. This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred.

Further instructions will be sent with the proof. Hard copy proofs will be posted if no e-mail address is

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available. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

14. Early View

Psychology and Psychotherapy is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. E.g., Jones, A.B. (2010). Human rights Issues. *Human Rights Journal*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Further information about the process of peer review and production can be found in this document.

What happens to my paper? Appeals are handled according to the procedure recommended by

COPE.

Appendix 2-B

The Caring and Related Emotions (CARE) Scale

The CARE Questionnaire Instructions

- Below is a list of events that may or may not have happened during the time you have cared for your relative.
- You should answer each question in relation to how you would respond *if the situation occurred today*.
- Each one has a list of statements that we would like you to rate for how likely you might think or feel in that way in response to the circumstances described. Please put a *circle* around each of your answers.
- There are no right or wrong answers. We just need to know how relatives in a caring role think and feel about these kind of events. Please be as honest as possible as this is most helpful for us.
- If a scenario has not happened, just make your best guess about how you would respond if it happened today.
- All your scores are anonymous.
- Please complete all ratings for the responses a) to d), for all of the questions.

In the following situations, how likely is it you would think or feel all of the following responses...

Your relative doesn't take their medication in the way prescribed, or not at all				
I feel that to some extent this was down to me. I should have encouraged him/her to manage their medication.	not likely very likely 1—2—3—4—5			
He/she should be taking more responsibility for their treatment so that they can be as well as possible.	not likely very likely 1—2—3—4—5			
Many people don't take medication as prescribed, this may be because they don't like the side-effects.	not likely very likely 1—2—3—4—5			
Others will see the impact of this and would think less well of us.	not likely very likely 1—2—3—4—5			

Your relative has experienced a period of relapse				
Others will think less of us because of this situation.	not likely very likely 1—2—3—4—5			
Good days and bad days are to be expected.	not likely very likely 1—2—3—4—5			
I could have done something to help prevent this.	not likely very likely 1—2—3—4—5			
He/she could have done something to avoid getting into this situation.	not likely very likely 1—2—3—4—5			

You have other regular commitments (such as work) alongside caring for your relative, and their mental health declines				
I can't always be there for them to help stop this from happening, and I may not have been able to prevent it anyway.	not likely very likely			
I am selfish for leaving them.	not likely very likely 1—2—3—4—5			
I could have prevented this by spending more time with them.	not likely very likely 1—2—3—4—5			
They need to learn to look after themselves.	not likely very likely 1—2—3—4—5			

Looking back to when your relative first	experienced mental health difficulties
I thought about what others would think and avoided my friends.	not likely very likely 1—2—3—4—5
We've been really unlucky to have this happen to us.	not likely very likely 1—2—3—4—5
I should have done more to help them.	not likely very likely 1—2—3—4—5
He/she could have done more to prevent this from happening.	not likely very likely 1—2—3—4—5

When your relative's dia	When your relative's diagnosis was first made				
He/she could have done more to prevent this from happening.	not likely very likely 1—2—3—4—5				
I didn't want to admit it to myself, or tell other people about it.	not likely very likely 1—2—3—4—5				
It was a relief to know what was wrong.	not likely very likely 1—2—3—4—5				
I was responsible for this happening.	not likely very likely 1—2—3—4—5				

Your relative has been acting unusually whilst in public with you (e.g. shouting, agitated, responding to voices)				
I am not a good enough carer to be able to help them properly.	not likely very likely 1—2—3—4—5			
They should be able to control their own actions.	not likely very likely 1—2—3—4—5			
They have a lot going on so it's understandable for them to be frustrated.	not likely very likely 1—2—3—4—5			
I feel like I have done something to cause this.	not likely very likely 1—2—3—4—5			

There have been times when he/she has stayed in bed too long or lacked motivation			
I should be doing more to help them.	not likely very likely 1—2—3—4—5		
If they did more constructive things they would feel a lot better.	not likely very likely 1—2—3—4—5		
This is part of their mental health difficulties and in some ways is to be expected.	not likely very likely 1—2—3—4—5		
I felt like it's my fault for not supporting them enough to prevent this.	not likely very likely 1—2—3—4—5		

During a ward round, it hasn't been a positive week/month				
My relative didn't try to help themselves as much as they could have.	not likely very likely 1—2—3—4—5			
There is a lot going on for my relative, it's reasonable for them to have ups and downs.	not likely very likely 1—2—3—4—5			
I would feel uncomfortable because I might have been able to do more to help.	not likely very likely 1—2—3—4—5			
I think the staff and/or others will think that we are poor at coping.	not likely very likely 1—2—3—4—5			

Your relative has attemp	Your relative has attempted to harm themselves				
I should have done more to prevent it from happening, I want to do more to make it up.	not likely very likely 1—2—3—4—5				
I would feel ashamed.	not likely very likely 1—2—3—4—5				
This can happen when people are really distressed, and there are people better placed to help if this happened.	not likely very likely 1—2—3—4—5				
They should have asked for help if they were becoming this distressed.	not likely very likely 1—2—3—4—5				

Your relative blames your family for his/her mental health difficulties								
They might have a point and perhaps I could have done things differently.	not likely very likely 1—2—3—4—5							
I think they should look at their own role in their mental health difficulties.	not likely very likely 1—2—3—4—5							
I would worry that people might think badly of us.	not likely very likely 1—2—3—4—5							
They are just taking it out on us, it could just be a part of their mental health difficulties or general frustration.	not likely very likely 1—2—3—4—5							

When talking to your friends, your relative's mental health difficulties come into the conversation					
I explain that he/she could do more things to help themselves.	not likely very likely 1—2—3—4—5				
I worry about what the other person is thinking and find I cut short conversations about this.	not likely very likely 1—2—3—4—5				
I think I could have done things differently in order to prevent them.	not likely very likely 1—2—3—4—5				
It is good to be able to explain it because it's not talked about enough.	not likely very likely 1—2—3—4—5				

People tend to be wary of your relative as he/she sometimes seems odd in public							
I believe people judge us negatively.	not likely very likely 1—2—3—4—5						
The public don't always understand what is going on for people with mental health difficulties and don't know how to respond.	not likely very likely 1—2—3—4—5						
My relative can control this more, they just choose not to.	not likely very likely 1—2—3—4—5						
I should be able to help them more.	not likely very likely 1—2—3—4—5						

During a conversation with your relative they became angry/upset							
They shouldn't be so sensitive and have better control over their emotions. not likely very likely 1—2—3—4—5							
Other families seem to manage without having these problems, why can't we?	not likely very likely 1—2—3—4—5						
They can become agitated/distressed quite easily because there are many things going on for them, including their mental health problem.	not likely very likely 1—2—3—4—5						
I felt uneasy that I have said something to upset them.	not likely very likely 1—2—3—4—5						

You recognize that you've been less patient of your relative's mental health difficulties							
It's natural to find it hard, and I need time off from this sometimes.	not likely very likely 1—2—3—4—5						
If they hadn't have behaved this way then I wouldn't have been inpatient.	not likely very likely 1—2—3—4—5						
I am concerned that if other people were to see these problems they would think negatively of me.	not likely very likely 1—2—3—4—5						
I should do something to make them and me feel better about it.	not likely very likely 1—2—3—4—5						

Your relative has been struggling to take care of their own basic needs such as: eating properly, washing themselves and/or doing their laundry							
I should have helped them be more independent.	not likely very likely 1—2—3—4—5						
I think if people knew, they would think badly of us.	not likely very likely 1—2—3—4—5						
Their mental health problems make even quite simple things rather difficult.	not likely very likely 1—2—3—4—5						
He/she can do these things for themselves; they are just not doing what they should.	not likely very likely 1—2—3—4—5						

Your relative became unwell and you decided to ring services (e.g. community mental health team, police) to help						
I would feel like I have let them down.	not likely very likely 1—2—3—4—5					
My relative could have prevented this from happening and then I wouldn't have had to call.	not likely very likely 1—2—3—4—5					
Other people will look down on me because I couldn't handle the situation and I called people that they don't think I should have.	not likely very likely 1—2—3—4—5					
I know services can be helpful to support us and our relative.	not likely very likely 1—2—3—4—5					

Appendix 2-C

The Family Questionnaire (FQ)

This questionnaire lists different ways in which families try to cope with everyday problems. For each item, please indicate how often you have reacted to the patient in this way. There are no right or wrong responses. It is best to note the first response that comes to mind. Please respond to each question, and mark only one response per question.

		Never/ very rarely	Rarely	Often	Very often
1	I tend to neglect myself because of him/her	О	О	О	0
2	I have to keep asking him/her to do things	O	O	O	O
3	I often think about what is to become of him/her	O	О	O	O
4	He/she irritates me	O	О	O	O
5	I keep thinking about the reasons for his/her illness	O	О	O	O
6	I have to try not to criticize him/her	O	О	O	O
7	I can't sleep because of him/her	O	О	O	O
8	It's hard for us to agree on things	O	О	O	O
9	When something about him/her bothers me, I keep it to myself	O	O	O	O
10	He/she does not appreciate what I do for him/her	O	О	O	O
11	I regard my own needs as less important	O	О	O	O
12	He/she sometimes gets on my nerves	O	О	O	O
13	I'm very worried about him/her	O	О	O	O
14	He/she does some things out of spite	O	О	O	O

	Never/ very rarely	Rarely	Often	Very often
15 I thought I would become ill myself	О	О	О	О
16 When he/she constantly wants something from me, it annoys me	O	O	0	O
17 He/she is an important part of my life	O	O	O	O
18 I have to insist that he/she behave differently	O	О	O	O
19 I have given up important things in order to be able to help him/her	O	O	O	O
20 I'm often angry with him/her	O	О	0	O

Appendix 2-D

The Self-Compassion Scale (SCS)

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost never 1	2	3	4	Almost always 5
1. I'm d	isapproving and judg	gmental about my	y own flaws and in	adequacies.
2. When	n I'm feeling down I	tend to obsess an	nd fixate on everyt	hing that's wrong.
3. When	n things are going bac	dly for me, I see	the difficulties as 1	part of life that
every	one goes through.			
4. When	n I think about my ina	adequacies, it ten	nds to make me fee	el more separate and
cut of	ff from the rest of the	e world.		
5. I try t	to be loving towards i	myself when I'm	feeling emotiona	l pain.
6. When	n I fail at something i	mportant to me I	become consume	d by feelings
of ina	adequacy.			
7. When	I'm down and out, I	remind myself th	nat there are lots of	f other people in the
world	d feeling like I am.			
8. When	times are really diff	icult, I tend to be	e tough on myself.	
9. When	n something upsets m	e I try to keep m	y emotions in bala	ince.
10. When	n I feel inadequate in	some way, I try	to remind myself	that feelings
of ina	adequacy are shared b	by most people.		
11. I'm i	ntolerant and impatie	ent towards those	e aspects of my per	rsonality I don't like.
12. When	n I'm going through	a very hard time,	, I give myself the	caring and
tende	erness I need.			
13. When	n I'm feeling down, l	I tend to feel like	most other people	e are probably
happi	ier than I am.			
14. When	n something painful l	happens I try to t	ake a balanced vie	ew of the situation.
15. I try	to see my failings as	part of the huma	n condition.	
16. When	n I see aspects of my	self that I don't l	ike, I get down on	myself.
17. When	n I fail at something i	important to me	I try to keep thing	s in perspective.

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18. When I'm really struggling, I tend to feel like other people must be having an
easier time of it.
19. I'm kind to myself when I'm experiencing suffering.
20. When something upsets me I get carried away with my feelings.
21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.
22. When I'm feeling down I try to approach my feelings with curiosity and openness.
23. I'm tolerant of my own flaws and inadequacies.
24. When something painful happens I tend to blow the incident out of proportion.
25. When I fail at something that's important to me, I tend to feel alone in my failure.
26. I try to be understanding and patient towards those aspects of my personality I
don't like.

Appendix 2-E

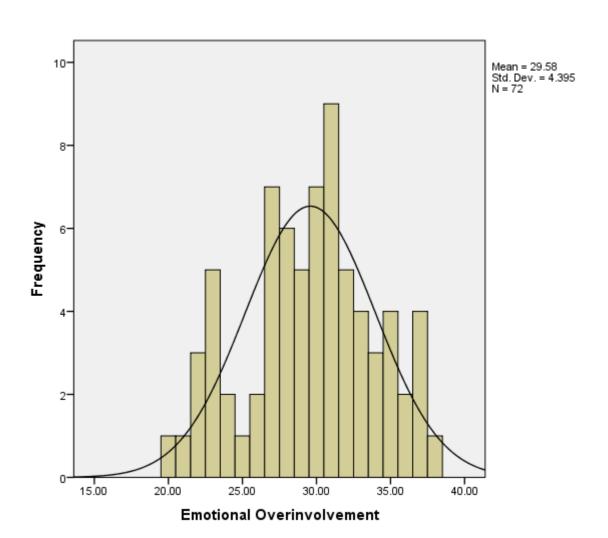
Descriptive Table for Key Variables

Descriptive Statistics

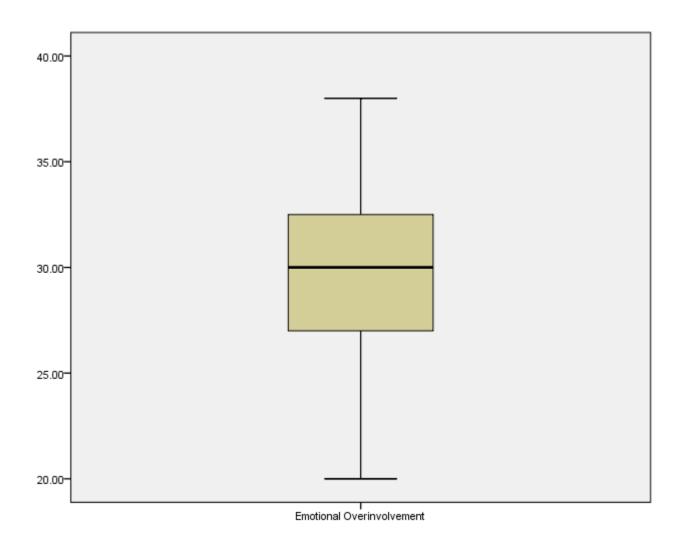
	N	Minimum	Maximum	Mean	Std. Deviation	Skew	ness	Kurto	osis
							Std.		Std.
	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Error	Statistic	Error
Self-Compassion	72	1.53	4.26	3.0916	.66867	328	.283	736	.559
Guilt	72	22.00	73.00	47.7917	13.54693	.163	.283	863	.559
Shame	72	18.00	68.00	39.4444	13.09434	.378	.283	851	.559
Emotional	70	20.00	20.00	20 5022	4 20540	474	202	504	550
Overinvolvement	72	20.00	38.00	29.5833	4.39510	174	.283	581	.559
Valid N (listwise)	72								

Appendix 2-F

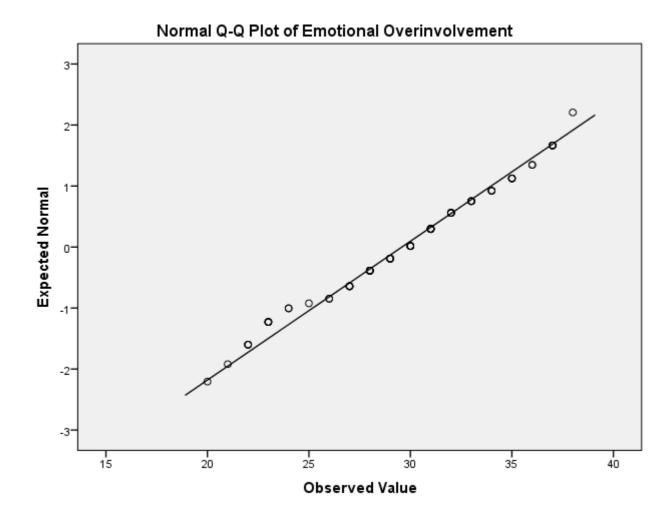
Distribution of Emotional Overinvolvement Scores



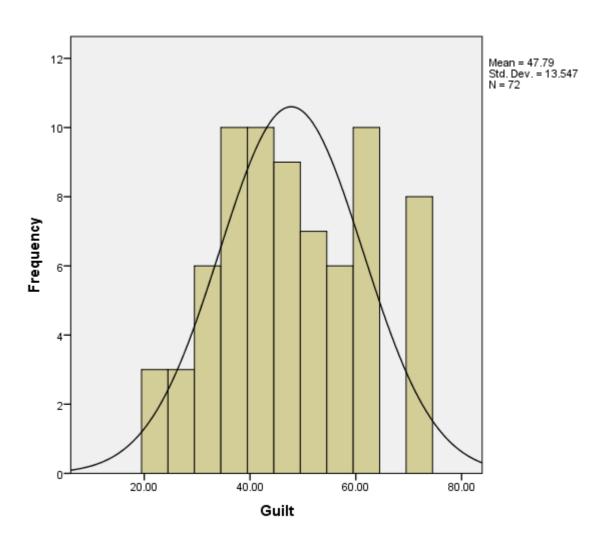
Boxplot for Emotional Overinvolvement Scores



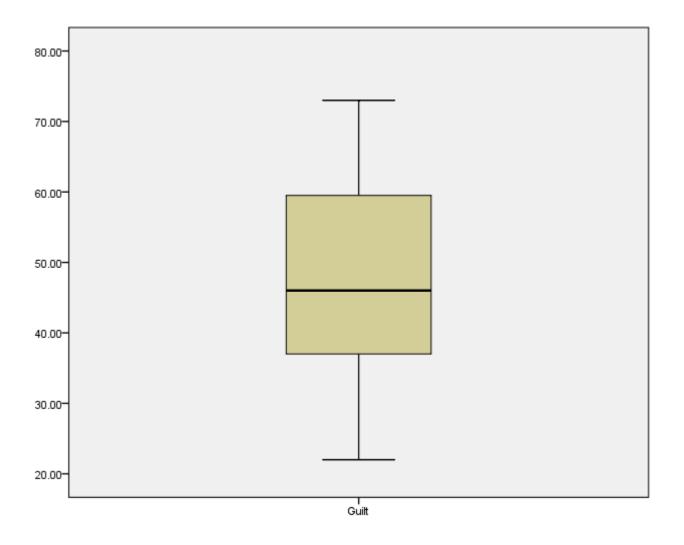
QQ Plot for Emotional Overinvolvement Scores



Appendix 2-G
Distribution of Guilt Scores

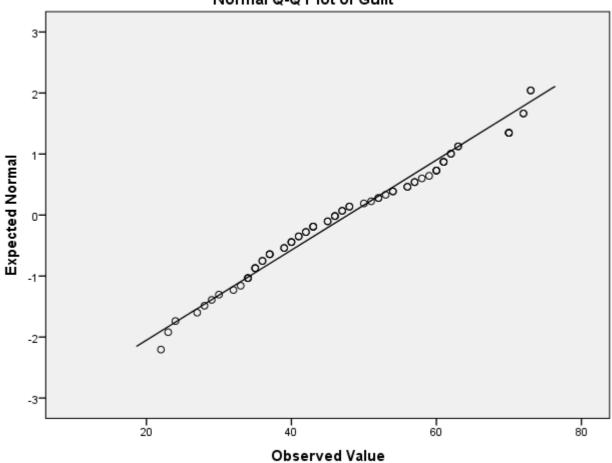


Boxplot for Guilt Scores

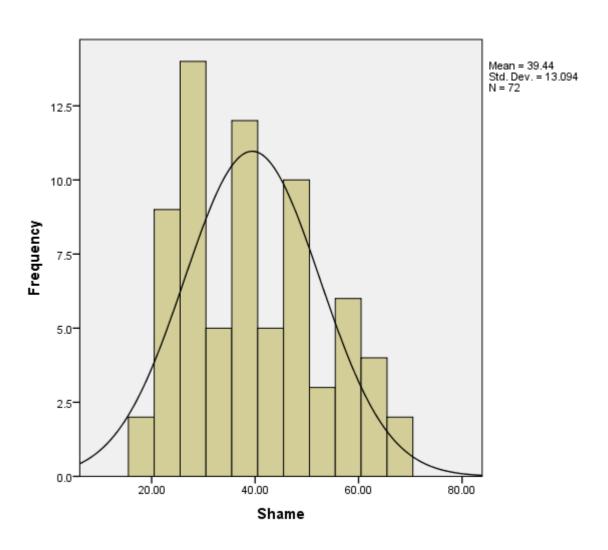


QQ Plot for Guilt Scores

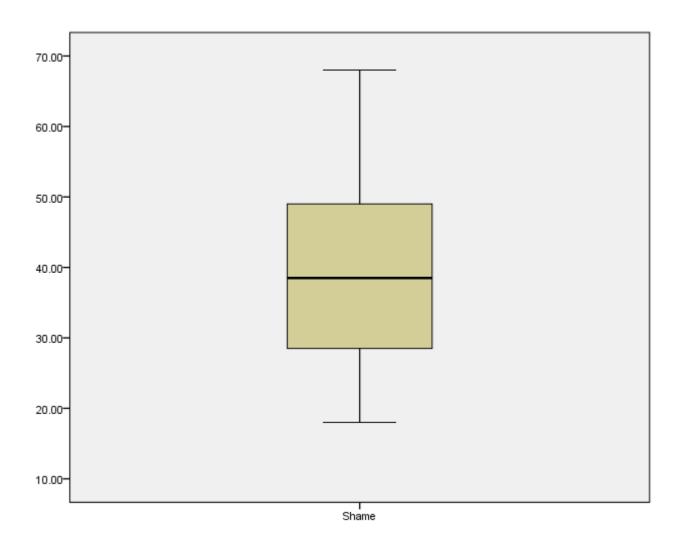




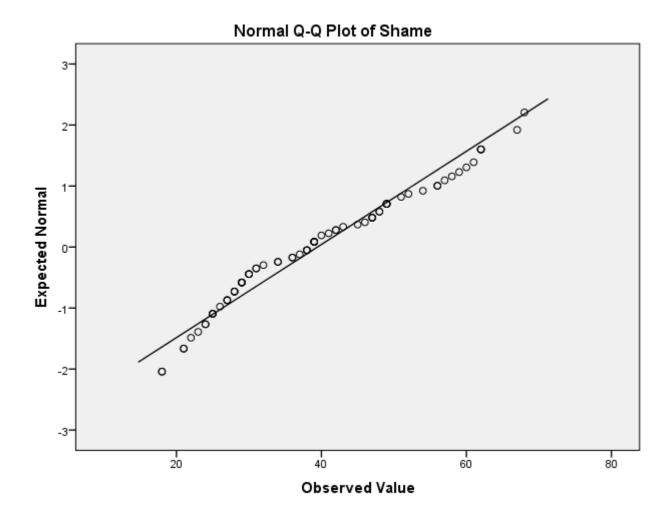
Appendix 2-H
Distribution of Shame Scores



Boxplot for Shame Scores

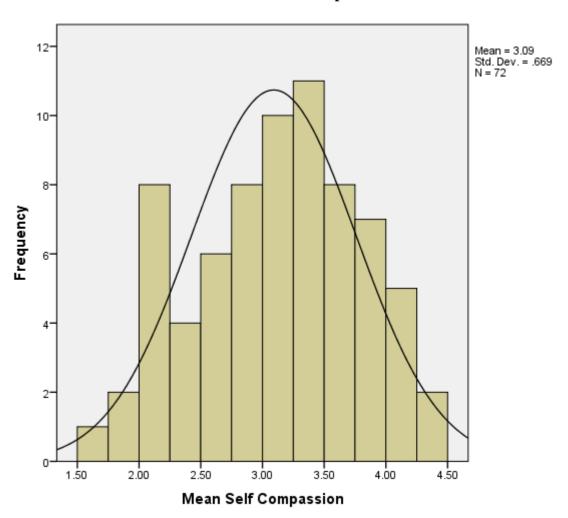


QQ Plot for Shame Scores

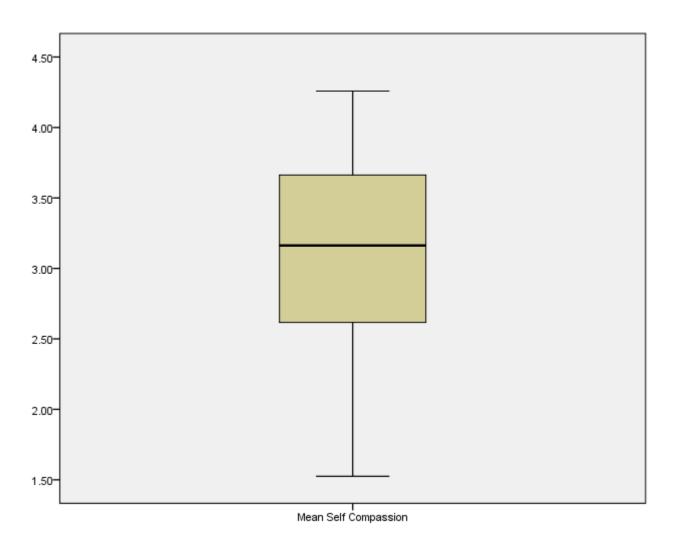


Appendix 2-I

Distribution of Self-Compassion Scores

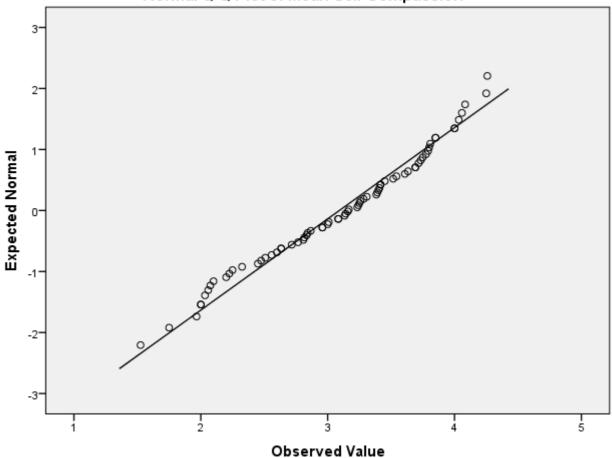


Boxplot for Self-Compassion Scores



QQ Plot for Self-Compassion Scores





Appendix 2-J
Shapiro-Wilk Normality Tests for EOI, Guilt, Shame, and Self-Compassion

Tests of Normality

	Kolmogorov-Smirnov ^a			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Emotional Overinvolvement	.079	72	.200*	.975	72	.164
Guilt	.083	72	.200*	.969	72	.073
Shame	.116	72	.019	.957	72	.015
Self-Compassion	.071	72	.200*	.971	72	.093

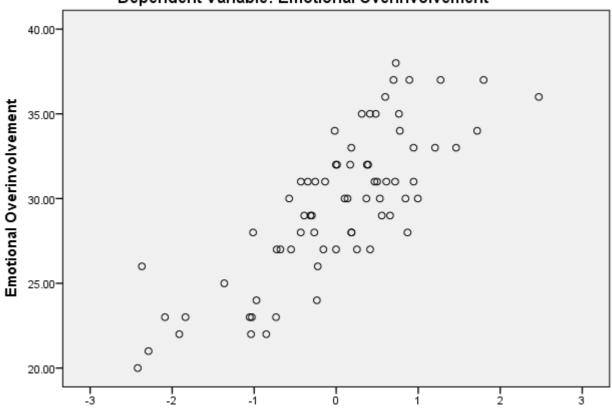
^{*.} This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Appendix 2-K
Homoscedasticity of the Regression Model

Scatterplot

Dependent Variable: Emotional Overinvolvement

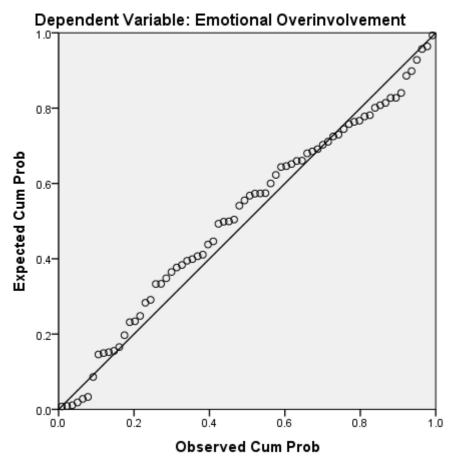


Regression Standardized Residual

Appendix 2-L

Plot displaying linear relationship between the predictor and outcome variables

Normal P-P Plot of Regression Standardized Residual



Appendix 2-M

VIF Scores for Key Variables

Coefficients^a

		Collinearity Statistics			
Model		Tolerance	VIF		
1	Guilt	.459	2.178		
	Shame	.469	2.132		
	Self Compassion	.804	1.243		

a. Dependent Variable: Emotional Overinvolvement

Section Three: Critical Appraisal

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Emotional over-involvement (EOI) has been the focus of a great deal of research. In carers it is linked to poorer physical and psychological wellbeing (Breitborde, Lopez, Chang, Kopelowicz, & Zarate, 2009), and it also predicts distress in clients (Barrowclough & Hooley, 2003). Recent studies have examined the relationship between EOI and guilt and shame, and have found strong relationships between these variables (see Cherry, Taylor, Brown, Rigby, & Sellwood, 2017 for a review). Shame and EOI have been found to be particularly correlated (Messham, Finlayson, & Sellwood, submitted), however guilt is also related to EOI when it is experienced in relation to the occurrence of their relatives mental health difficulties (Brookfield, Keith, Reilly, & Sellwood, submitted). Given the associations between these emotions and EOI, and in light of the impact of EOI on carer and client distress, the present research sought to understand whether self-compassion might influence the relationship between guilt and shame, and EOI.

Previous research has found that interventions which focus on developing self-compassion are linked to a reduction in distress across multiple mental health difficulties (Hoffman, Grossman, & Hinton, 2011), and furthermore, compassion-focused therapy (CFT) targets shame and self-criticism to improve wellbeing (Gilbert, 2000). Consequently, in the present study it was predicted that self-compassion would be negatively correlated with guilt, shame and EOI. It was unclear whether carers high in self-compassion would exhibit less EOI, despite experiencing guilt and shame, and consequently this was also explored.

EOI in the wider context and its implications

As has been discussed previously, the focus of research in relation to EOI has been on carers of people diagnosed with schizophrenia. However, the construct also has implications for carers of those diagnosed with an eating disorder; for example, it has been found that carers of people diagnosed with anorexia had significantly higher scores on the General Health Questionnaire than those supporting someone with psychosis (Treasure et al., 2001). Given the threat to physical health posed by anorexia, it has been found that those around the

person are often fearful of the consequences of the eating disorder, and that this can be a significant factor explaining the pattern of behavior often seen in EOI, such as overprotectiveness (Whitney et al., 2005). It was also found that mothers who supported daughters with eating disorders experienced significant distress, which often manifested in self-blame and feelings of helplessness. This was accompanied by high EOI (Whitney et al., 2005). This is supported by subsequent research; for example, over 60% of carers of people with anorexia had high levels of EOI, compared with 3% of parents from a comparison group of parents of healthy individuals (Kyriacou, Treasure, & Schmidt, 2008). The same study also found that anxiety and depression in parents, and the challenging behaviours of the person with anorexia explained over 60% of the variance of EOI (Kyriacou et al., 2008). This provides support for the themes found in the literature review; for example, carers frequently reported feeling helpless, or powerless to improve things for their relative. The findings also suggest that family interventions which attempt to reduce EOI may need to target carer mood and quality of life. It has been found that skills-based interventions, including psychoeducation, have been successful at reducing parental distress, as well as reducing levels of EE (Uehara, Kawashima, Goto, Tasaki, & Someya, 2001). This provides further support to the idea raised within the literature review that practical interventions might be particularly beneficial to families, particularly at the beginning of the intervention.

Research has explored parental experiences of interacting with healthcare professionals, and has found that parents have often felt "blamed and shamed" for their relatives' eating disorder (Sharkey-Orgnero, 1999, p.132). Although recent family interventions have emphasized the importance of including parents within interventions, and of empowering them throughout the process, it is important for clinicians and services to understand the impact of their approach on carers. It highlights the ease with which services can inadvertently undermine the autonomy of parents, and how damaging this could be in the context of parents already potentially feeling helpless. This is important in the context of

describing EOI and doing so in a manner that will not further feelings of guilt and shame.

Providing information to normalise and validate the emotional responses of carers may help relatives to understand the function of EOI in a non-blaming context.

It is important to note that most of the traditional studies on EOI have taken place in Western countries. However, the relationship between high EOI and poor outcomes has not been consistently found across cultures, and furthermore, the definition of EOI is likely to vary between cultures (Jenkins & Karno, 1992). This has important implications for the way EOI is measured, and whether it is considered to be pathological in nature. For example, it has been argued that the Western criteria for high EOI could not be applied to Chinese cultures, where family norms relating to familial interdependence, and relational patterns between parents and their children are different to those typically observed in the West (Cheng, 2002). Another clinical and research implication is the potential for those determining levels of EOI to be influenced by their own cultural background. One way of overcoming this in research work would be to utilize two researchers from different cultures, who would rate and then discuss differences in their scores and interpretations. In clinical practice, it would be important for clinicians to explore family norms specific to the client and their family, recognizing that patterns which might lead to a classification of high EOI might not necessarily be associated with poorer outcomes for the client.

Key findings and their implications

The initial correlational analysis revealed relationships between all variables (guilt, shame, self-compassion and EOI). That is, all variables were significant at the p<.001 level. Unique main effects of guilt, shame and self-compassion were found, however, there was no moderating effect of self-compassion on either guilt and EOI, or shame and EOI. Subsequent

blockwise hierarchical regressions found that once guilt and self-compassion were accounted for, the main effect of shame became non-significant. However, entering self-compassion into block one, shame into block two and guilt into block three revealed that all three had significant effects on EOI. Independent measures t-tests also revealed that female carers were significantly more likely to exhibit EOI than male carers, but that male carers were significantly more self-compassionate than female carers. These findings are aligned with previous research findings (e.g. Wasserman, Weisman de Mamani, & Suro, 2012; Yarnell et al., 2015).

The correlational analysis revealed strong associations between the predictor variables of guilt and shame and self-compassion; those who demonstrated self-compassion were less likely to experience high levels of guilt and shame. They were also less likely to exhibit high EOI. It might be expected that self-compassion is linked with greater self-acceptance, and in turn this may lead to fewer occasions of feeling the need to strive and do more for their relative. Guilt and shame were positively associated with EOI; perhaps those who experience these emotions feel driven to 'repair' or 'make amends' for self-perceived failings in the way they have supported their relative, thus becoming increasingly involved in their relative's care. It was somewhat surprising that self-compassion did not have a moderating effect on the relationship between guilt/shame and EOI. Given that compassion-focused therapy targets shame by developing self-compassion (Gilbert, 2009), it would be expected that those who are lower in shame as a result of developing self-compassion, would exhibit less EOI, and that this would be predicted by levels of self-compassion. However, it is important to note that more participants may have been needed to achieve sufficient power to detect any moderating effect of self-compassion (see Aguinis, 1995).

Though interventions which focus on increasing self-compassion are likely to reduce guilt and shame, they may not affect the relational and behavioural patterns between carers

and relatives. Shame, in particular, has been found to be linked to poorer psychological wellbeing (Woods & Proeve, 2014) and has therefore become the target of interventions other than compassion-focused therapy. For example, "opposite action" from dialectical behaviour therapy (DBT) has been linked to reduced shame (Rizvi & Linehan, 2005), and techniques associated with acceptance and commitment therapy (ACT), including cognitive defusion and identifying goals and values were found to help reduce shame over time (Luoma, Kohlenberg, Hayes, & Fletcher, 2012). Both methods described within DBT and ACT groups help individuals to develop acceptance of shame rather than avoiding the emotion. On reflection, it is possible that avoidance of painful self-conscious emotions might further drive the need to focus on alleviating their relatives' distress, by becoming more and more involved in their care, as a way of avoiding the focus being placed on themselves. By learning to accept and 'sit with' these emotions, perhaps the striving to 'do more' is reduced. It might therefore be the case that acceptance might moderate the relationship between guilt/shame and EOI, rather than self-compassion, and that interventions which help carers to develop acceptance of painful emotions may show greater benefits in shaping the way carers and relatives interact with each other. This could form the focus of future research in this area.

It is also important to consider the difference between scoring high on a self-compassion measure, and this translating practically into the lives of carers. For example, it is possible that individuals who scored highly on the self-compassion scale (Neff, 2003) are able to recognise, endorse and subscribe to self-compassionate statements, but in practice may find it difficult to consistently demonstrate this by engaging in thoughts and behaviours that foster self-care. From this, practical approaches which help carers think about how to put self-compassion 'into practice' might benefit both themselves and their relative. In fact,

focussing on carers' self-care is a component of some family based interventions which show favourable outcomes (Barrowclough & Tarrier, 1992).

The emotional, social and physical costs of providing care to a relative must be considered, particularly in light of current pressures facing both the NHS and wider society. For example, reduced opportunities for social support through community organisations (Hastings, Bailey, Bramley, Gannon, & Watkins, 2015; Jones, Meegan, Kennett, & Croft, 2016) may increase carer burden and the intensity of the relationship between carers and their relatives. It would seem appropriate to consider that this might lend itself to increased EOI, as the opportunities for both carers and relatives to seek support from others diminishes. Greater intensity in the relationship between the carer and their relative might be a source of continued guilt and shame for carers, as they become increasingly focused on their behaviour within the relationship (and self-perceived shortcomings in the care they provide), potentially perpetuating the effect of EOI. Thus, carers feel increasing guilt and shame, leading them to become increasingly involved to try and alleviate these feelings, but in the process of doing so experience further guilt and shame. Consequently, opportunities to engage both carers and their relatives in alternative avenues of support may alleviate the intensity of the relationship, allowing carers to feel more supported in their role. The results also highlighted carer gender differences in EOI and self-compassion. Previous research has found that the characteristics that female carers ascribe to themselves often follow stereotyped female gender characteristics, which make it hard to consider the idea of reducing involvement in care (Kramer, 2005). Interventions which help carers shape their self-identity, perhaps through exploring values and personal goals might facilitate a reduction in cohesion with traditional gender roles.

Carers' perception of stress appears to be dependent on its appraisal and on their self-perceived ability to cope (Møller, Gudde, Folden, & Linaker, 2009). Perhaps interventions

which focus on providing practical skills to enhance coping skills would support carers to feel more skilled in being able to cope with the challenges of a carer role (thereby altering their perception of their ability to cope, and in turn changing how stress is perceived).

Supplementary data collection

The scales used in this research collected data on additional variables; blame, externalisation, and critical comments. The self-compassion scale also collects data on six subscales: self-judgment, isolation, over-identification, common humanity, mindfulness and self-kindness. It was beyond the scope of this research to explore these variables in greater detail, and indeed a sufficiently powerful analysis of these variables would require a dataset that would be beyond the scope of this research to recruit. Please find Appendix 3-A for the correlation matrix including all variables.

Reflections on recruitment and participant feedback

It was decided that recruitment would occur through charitable organisations, rather than through NHS services. Relevant organisations were contacted, either through their Twitter pages or by the contact details listed on their websites. This facilitated inclusion of participants (O'Connor, Jackson, Goldsmth, & Skirton, 2014), and allowed carers who were not actively involved in attending NHS appointments to take part. I was concerned that by recruiting in this way, my sample might be skewed towards younger carers, as I was unsure whether older carers would be as active on social media. However, participants ranged from 24 to 78 years of age, and therefore a wide range of participants was achieved, although this may not have been truly representative. At all points throughout the study I highlighted the option to take part by hand, and twelve carers did utilise this option.

Over the course of collecting data, I received feedback from three participants. Two participants raised concerns about the measures used in the study; one participant stated that the wording in the CARE scale was "stigmatising", and another individual who received a hard copy of the questionnaire informed their carer group that, in her opinion, the questions were "too probing" to answer without having emotional support built into the process. These points were to some extent reflective of my own concerns about conducting quantitative research. I was aware of the emotive topic area, and wanted to ensure that participants were given as much support as possible in light of the data-collection methods. For this reason, a number of organisations were listed both on the participant information sheet and the debrief sheet (see Ethics Section, page 4-20 and 4-28 for copies). I also provided my contact details on both forms and encouraged participants to contact me with any concerns or queries. It was also made clear that participants did not have to answer any questions they did not feel comfortable completing. In relation to the CARE scale query, I was aware that this measure is designed to assess guilt, shame, blame, and externalisation. These emotions are difficult to examine quantitatively, and I have passed the feedback onto the scale's developers to explore whether the working of items could perhaps be amended for future research.

The third piece of feedback related to broader aspects of the study, including difficulties answering how long they have provided care and answering questions on the CARE scale *if the situation occurred today* (as requested on the instructions), when their experience of events occurred a number of years earlier. They highlighted that their emotional response, if it were to happen today, would be different to their response at the time the event happened for them. Both of these points highlight the subjective nature of emotional experiences, and how care evolves over time. It also highlights the tension between the concept of caring as an inherent part of a family member's role, and the idea of caring for a relative in relation to their mental health difficulty. The extent of the differences

between caring in these two contexts will vary for each individual and must be considered when evaluating the findings.

Personal reflections on the research

There were elements of the research that I found personally challenging. My previous research experience in carer populations lends itself more to qualitative research, and I value being able to explore lived experiences and the meaning people ascribe to their caring experience. I believe that there are many elements of the research area that are subjective and are dependent on understanding carers' personal experiences. However, given that the role of self-compassion on guilt/shame and EOI is a new area for research, a quantitative approach enabled us to grasp a thorough understanding of the relationships between key variables. For example, this research suggests that self-compassion does not moderate the relationship between guilt/shame and EOI; this is a complex finding and one which may have been difficult to reach through a qualitative framework. It also provides a clear base to inform future research in this area.

I was aware of the concept of emotional overinvolvement, and the power of this label as suggesting that carers are perhaps doing something wrong by caring in the way that they do. Although the study was not advertised using this label, I was aware of the importance of ensuring that carers did not feel judged, and encouraged feedback in any conversation I had with carers or organisations. Furthermore, I also consider EOI to be an entirely understandable concept, and a marker of a family member who cares deeply about their relative. I was, therefore, cautious about pathologising relational patterns that are to be expected within a family, whilst also balancing its association with poorer outcomes for both carers and their relatives.

Throughout the study, I have reflected on some pertinent questions. I wondered what constitutes caring, and how this concept is likely to be defined differently between participants. Participant feedback which questioned the length of time someone has been a carer highlighted the subjective nature of this concept. It can be argued that caring is an inherent part of a family relationship, and it appeared for some participants it was difficult to distinguish between caring prior to their relative's diagnosis, and caring afterwards. For example, some participants responded to this question by providing two dates; one from the time they were diagnosed, and one from the time they first felt their relative began to experience difficulties. This also led me to question the nature of mental health difficulties and the concept of diagnosis, with some participants stating that they provided care for their relative prior to a diagnosis being given. I wondered whether this suggested that carers had experienced a time where they were not supported by services, and whether this contributed to their desire, or need, to become involved.

As part of the research methodology, three scales were used to measure EOI, guilt/shame and self-compassion. I was mindful of how the use of scales to measure human emotions might be experienced by participants. Interestingly, I received a number of emails from individuals who were informed of the research and who had read the information sheet which contained a link to the study. Despite this, participants emailed indicating their willingness to take part, and asked how to do so. Although I did question (and check) the clarity of the information sheet (please see Appendix 3-B for a copy of the online information sheet), I also wondered if this contact was suggestive of individuals seeking further interaction; for example, did the study elicit emotional responses which participants wanted to explore, and subsequently led to them making contact? I believe this is something that future research could explore using a qualitative design.

Conclusion

This research is, to the best of my knowledge, the first study to explore the effect of self-compassion on the relationship between guilt/shame and EOI. Significant correlations were found between all variables, suggesting that the concepts are closely related to each other. However, self-compassion did not have any moderating effect for either guilt or shame on EOI. There are a number of possible reasons for this; perhaps the study was insufficiently powered to detect a moderating effect of self-compassion, leading to there being no observable effect of self-compassion on the relationship between shame/guilt and EOI. Equally, it might also be evidence of the difference between reporting self-compassion and transferring this to self-care practices. The reduction in social opportunities to find support from within their communities might mean that the relationship between carer and relative becomes more intensive, lending itself to a pattern of behaviour that might be considered 'overinvolved'. Furthermore, looking at the pattern of EOI scores, although the data are normally distributed, scores are pushed towards the higher end of the graph (see Appendix 3-C for histogram). This is likely to reduce the variance of both EOI and other variables, and may be related to the nature of recruitment being self-selected. Perhaps future studies could use sampling methods that ensure a broad range of EE variables are obtained. It would also be beneficial for future research to examine the overlap between items on scales, in order to determine whether this may explain the lack of any moderating effect (particularly for shame, for which the interaction between shame and self-compassion accounted for no additional variance in EOI scores (rr^2 change = .000)).

There have been a number of issues that I have reflected on throughout the research process. I am extremely grateful for the feedback received from participants, and I hope these will shape the continued development of the CARE scale. It also highlighted the importance of remaining curious about the concept of caring; what this means to each person, and how

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this might differ over time and context. Supporting carers to identify personal values in line with an ACT model, or providing practical support in relation to self-care practices may be important tools in helping to alleviate the distress for both carers and relatives associated with EOI.

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Appendix 3-A

Correlation Matrix showing relationships between all variables

Correlations

				Correlati	ions									
		Emotional Overinvolvem ent	Guilt	Shame	Blame	Externalisatio n	Critical Comments	Self Kindness	Common Humanity	Mindfulness	Self Compassion	Overidentificat ion	Isolation	Self Judgment
Emotional	Pearson Correlation	1	.556**	.477**	.222	.332**	.515**	450**	222	175	429**	.348**	.519**	.298*
Overinvolvement	Sig. (2-tailed)		.000	.000	.061	.004	.000	.000	.061	.140	.000	.003	.000	.011
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Guilt	Pearson Correlation	.556**	1	.721**	.225	.264"	.267*	334***	066	004	420**	.460**	.506**	.588**
	Sig. (2-tailed)	.000		.000	.057	.025	.024	.004	.583	.975	.000	.000	.000	.000
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Shame	Pearson Correlation	.477**	.721**	1	.432**	.220	.424**	232*	193	128	399**	.388**	.549**	.377**
	Sig. (2-tailed)	.000	.000		.000	.063	.000	.050	.105	.285	.001	.001	.000	.001
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Blame	Pearson Correlation	.222	.225	.432**	1	.061	.442**	.034	.020	.052	040	.122	.089	.076
	Sig. (2-tailed)	.061	.057	.000		.610	.000	.779	.866	.663	.737	.308	.458	.528
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Externalisation	Pearson Correlation	.332**	.264	.220	.061	1	.208	108	.210	.151	008	.094	029	.208
	Sig. (2-tailed)	.004	.025	.063	.610		.079	.368	.076	.206	.948	.433	.807	.079
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Critical Comments	Pearson Correlation	.515**	.267*	.424**	.442**	.208	1	254	120	155	253	.181	.311**	.167
	Sig. (2-tailed)	.000	.024	.000	.000	.079		.031	.314	.192	.032	.128	.008	.160
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Self Kindness	Pearson Correlation	450**	334**	232	.034	108	254*	1	.577**	.568**	.852**	653**	550**	713**
	Sig. (2-tailed)	.000	.004	.050	.779	.368	.031		.000	.000	.000	.000	.000	.000
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Common Humanity	Pearson Correlation	222	066	193	.020	.210	120	.577**	1	.646**	.736**	502 ^{**}	487**	331**
	Sig. (2-tailed)	.061	.583	.105	.866	.076	.314	.000		.000	.000	.000	.000	.005
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Mindfulness	Pearson Correlation	175	004	128	.052	.151	155	.568**	.646**	1	.756**	586**	518	329**
	Sig. (2-tailed)	.140	.975	.285	.663	.206	.192	.000	.000		.000	.000	.000	.005
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Self Compassion	Pearson Correlation	429**	420**	399**	040	008	253 [*]	.852**	.736**	.756**	1	864**	798**	761**
	Sig. (2-tailed)	.000	.000	.001	.737	.948	.032	.000	.000	.000		.000	.000	.000
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Overidentification	Pearson Correlation	.348**	.460**	.388	.122	.094	.181	653**	502 ^{**}	586**	864**	1	.669**	.700**
	Sig. (2-tailed)	.003	.000	.001	.308	.433	.128	.000	.000	.000	.000		.000	.000
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Isolation	Pearson Correlation	.519**	.506**	.549**	.089	029	.311**	550**	487**	518 ^{**}	798**	.669**	1	.540**
	Sig. (2-tailed)	.000	.000	.000	.458	.807	.008	.000	.000	.000	.000	.000		.000
	N	72	72	72	72	72	72	72	72	72	72	72	72	72
Self Judgment	Pearson Correlation	.298*	.588**	.377**	.076	.208	.167	713**	331**	329**	761**	.700**	.540**	1
	Sig. (2-tailed)	.011	.000	.001	.528	.079	.160	.000	.005	.005	.000	.000	.000	
	N	72	72	72	72	72	72	72	72	72	72	72	72	72

^{**.} Correlation is significant at the 0.01 level (2-tailed).

^{*.} Correlation is significant at the 0.05 level (2-tailed).

Appendix 3-B

Copy of Online Information Sheet



Study title: Emotions in carers of people with long-term mental health difficulties

My name is Kate Empson and I am conducting this research as a student in the Doctorate in Clinical Psychologome, United Kingdom,

What is the study about?

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to read an online consent form. You will then be asked to complete a questionnaire. This should not take any longer than 15-20 minutes to complete. This must be completed in a single setting; if you were to close the webpage then answers completed to that point would be lost. Once you have finished the questionnaire, you have completed the study. You will not be asked to participate in any follow-up butules.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Even if you agree to take part, you can withdraw your consent at any point white you complete the questionnaire. After this time, it will not be possible to withdraw consent.

Will my data be Identifiable?

No. Your responses are anonymous, meaning that data cannot be traced back to you, and the data collected for this study will be stored securely. The raw responses will be stored on a password protected, secure platform.

What will happen to the results?

The results will be summarised and reported as a Thesis and may be submitted for publication in an academic or professional journal.

There are no known risks to taking part in the research, though you will be asked questions on topics that you may find distressing. However, you are free to leave the study at any time should you become upset.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. However, your answers will help us to improve future care and support for clients, their families and friends.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can lobtain further information about the study if I need it?

If you have any questions about the study, please contact the principal investigator. Kate Empson

k.empson@lancaster.ac.uk 07852 518411

Details of organisations offering support

SANE Tel: 0300 304 7000

Mind Telephone: 0300 123 3393 Text: 86463

Rethink Advice and Information Service Telephone: 0300 5000 927

Please note these details will be repeated at the end of the study, however if any questions raise significant distress you are advised to contact your GP for support, or discuss them with someone you trust.

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Roger Pickup Tel: +44 (0)1524.583746
Associate Dean for Research Emall: r.plekup@fancaster.ae.uk
Faculty of Health and Medicine
(Oivision of Biomedical and Life Sciences)
Lancaster University
Lancaster

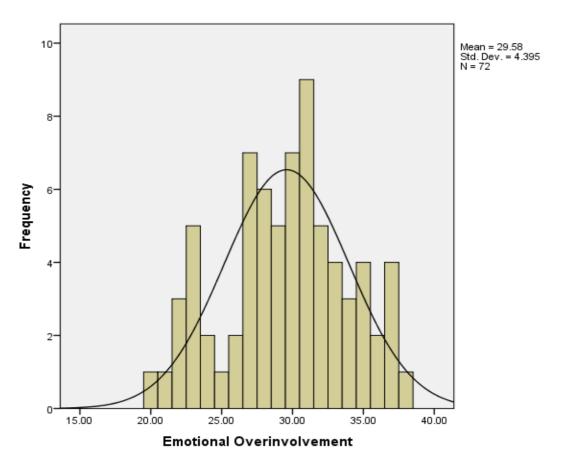
Thank you for taking the time to read this information sheet.

Please click the following link to take part in the study:

Or copy the following link into your browser address bar; -

https://eu.qualtrics.com/SE/?SID=SV_a2Wr25BIUodBanz

Appendix 3-C
Distribution of EOI scores



Section Four: Ethics Proposal and Supporting Documentation

Kate Empson

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word count (minus appendices): 4,805

Ethics Application Form



Faculty of Health and Medicine Research Ethics Committee (FHMREC) Lancaster University

Application for Ethical Approval for Research[1]

for additional advice on completing this form, hover cursor over 'guidance'

Title of Project[2]: Caregivers' Emotional Over-Involvement (EOI) a Compassion.	nd Guilt, Blame and Shame: the role Self-				
Name of applicant/researcher: Kate Empson					
ACP ID number (if applicable)*: n/a	Funding source (if applicable) n/a				
Grant code (if applicable): n/a					
*If your project has <i>not</i> been costed on ACP, you will also need to complete the Governance Checklist [link].					
Type of study					
Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Complete sections one, two and four of this form					
Includes <i>direct</i> involvement by human subjects. Complete sections one , <i>three</i> and four of this form					
SECTION ONE					
1. Appointment/position held by applicant and Division within FH	M Trainee Clinical Psychologist, Division of				

E-mail: k.empson@lancaster.ac.uk

Telephone: (please give a number on which you can be contacted at short notice)

Health Research

2. Contact information for applicant:

isian of Haalib Daggard, C.Flaga Furnasa Callaga Laggardan

Address: Faculty of Health & Medicine, Division of Health Research, C Floor, Furness College, Lancaster University, Lancaster, Lancaster, LA1 4YG

3. Names and appointments of all members of the research team (including degree where applicable)

Professor Bill Sellwood, Research Director, Department of Health Research Dr Christine Day, Clinical Psychologist

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete FHMREC form UG-tPG, following

the procedures set out on the FHMREC website					
PG Diploma Masters by research PhD Thesis PhD Pall. Care					
PhD Pub. Health PhD Org. Health & Well Being PhD Mental Health MD					
DClinPsy SRP [if SRP Service Evaluation, please also indicate here:] DClinPsy Thesis					
4. Project supervisor(s), if different from applicant: Professor Bill Sellwood (Research Director), Dr Christine Day (Clinical Psychologist)					
5. Appointment held by supervisor(s) and institution(s) where based (if applicable): Professor Bill Sellwood, Research Director, Department of Health Research, CO20, C Floor, Furness College, Lancaster University.					
Dr Christine Day, Clinical Psychologist,					
SECTION TWO Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants					
Anticipated project dates (month and year[3]) Start date: End date:					
2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language[4]):					
Data Management For additional guidance on data management, please go to Research Data Management webpage, or email the RDM support email: rdm@lancaster.ac.uk 3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.					
4a. How will any data or records be obtained?					
4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' no 4c. If yes, where relevant has permission / agreement been secured from the website moderator? no 4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? no					
4e. If no, please give your reasons					
5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc[5])? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998.					
6a. Is the secondary data you will be using in the public domain? no 6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.					
Please answer the following question <i>only</i> if you have not completed a Data Management Plan for an external funder					

- 7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE[6]?
- 7b. Are there any restrictions on sharing your data[7]?

8. Confidentiality and Anonymity

- a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?
- b. How will the confidentiality and anonymity of participants who provided the original data be maintained?
- 9. What are the plans for dissemination of findings from the research[8]?
- 10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes direct involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words [9]):

Many people who care for someone with a long-term mental health difficulty feel under great pressure. This in turn can affect how they help the person they care for. We are trying to discover whether guilt, shame and emotional over-involvement are related to particular styles of care and whether self-compassion protects against some of these negative emotions. If self-compassion is important in alleviating distress, then it is important for clinical psychology to understand this construct within the caregiver population. It is also hoped that the results could stimulate new ways of working for services, improving outcomes both for clients and caregivers. The research will use a quantitative, exploratory, cross-sectional design. Self-report measures will be used to explore the relationship between emotional over-involvement and guilt and shame, and to examine the effect of self-compassion on this relationship.

2. Anticipated project dates (month and year only[10])

Start date: January 2017 End dateMid-June 2017

Data Collection and Management

For additional guidance on data management, please go to Research Data Management webpage, or email the RDM support email: rdm@lancaster.ac.uk

Please describe the sample of participants to be studied (including maximum & minimum number, age, gender[11]):

A minimum sample size of 68 will be required to detect a medium effect size ($F^2 = 0.15$) with a probability level of 0.05, and a statistical power level of 0.80. The maximum number of participants sought will be 120; though it is unlikley this number of people will be recruited, there will be limited added value of recruiting more than 120 participants.

Inclusion criteria.

- Participants must be aged 18 or over
- Provide at least 10 hours per week of face to face care.

- Participants must be able to understand English in order to provide informed consent and understand the measures.
- Complete at least one of the measures included within the study.
- Participants must provide for a friend/relative with any long-term mental health condition

Exclusion criteria.

- Participants will not be able to take part in the study if their friend/relative's mental health difficulties were classified as arising from a learning disability, dementia or traumatic brain injury. Examples of mental health difficulties include (but are not limited to): obsessive-compulsive disorder, schizophrenia, eating disorders, and chronic depression.
- 4. How will participants be recruited and from where? Be as specific as possible[12]. Ensure that you provide the full versions of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Participants will be recruited through online charitable/advocacy groups for carers. These include (but are not limited to):

These may be accessed via social media (Twitter and Facebook). I will use my professional Twitter account to publicise the study, and to communicate with carer's groups. I will not use my personal facebook account in any way, though other individuals may share details of the study through their own facebook accounts if they wish. The principal investigator will also attend relevant carers groups (with prior permission from the group) to discuss the research and provide a hard copy of the participant information sheet, consent form, measures, and debrief form to interested participants.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Consent will be obtained prior to participation in the study. This will be given in the form of completing a consent form (provided either online or by paper, depending on the platform the participant chooses). The principal investigator's details will be provided on the participant information sheet, which will be given prior to the consent form. This allows prospective participants ask any questions they may have before giving consent.

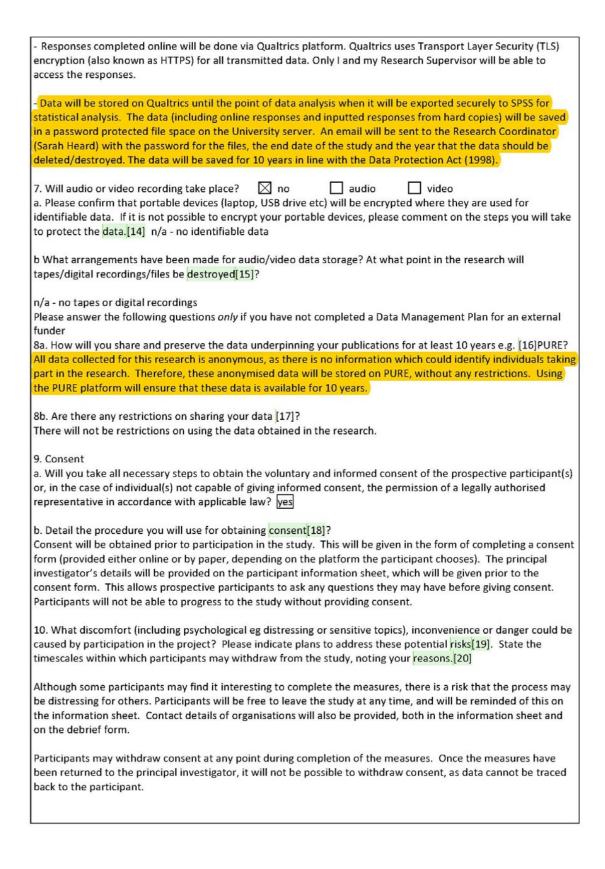
The questionnaires that will be used within the study are: the Family Questionnaire (The FQ, Wiedemann, Rayki, Feinstein, & Hahlweg, 2002), the Caring and Related Emotion scale (the CARE scale, Messham, Finlayson, & Sellwood, in prep), and the Self-Compassion Scale (Neff, 2003). Please see appendix for copies of these measures.

After examining associations between key variables using correlations, multiple regression will be used to examine the relationships between EOI and the hypothesised predictor variables, in particular guilt and shame. Before using multiple regression, the assumptions regarding suitability for such analyses will be checked using appropriate statistical tests. If the data set allows, a moderation analysis will also be conducted in order to determine whether self-compassion reduces the impact of shame and guilt on EOI.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998[13].

The data collected for this study will be stored securely and only the researchers conducting this study will have access to it.

- Hard copies of scales completed by hand will be kept in a locked cabinet, based in the department. In line with guidance published by the Medical Research Council, the hard copies of scales will be retained for 10 years, after which point they will be destroyed.



11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take[21]).

There are no significant risks to the researcher, however part of the recruitment strategy involves attending carer's groups (with prior consent), on my own. Where this happens, the Lancaster University Lone Worker policy will be followed. This involves notifying a colleague where and when the meeting will be taking place, informing them when the meeting will be over and giving them the researcher's contact details to use if the researcher has not contacted their colleague following the meeting.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study[22].

There are no direct benefits in taking part, although people may find participating interesting.

- Details of any incentives/payments (including out-of-pocket expenses) made to participants[23]:
 No incentives
- 14. Confidentiality and Anonymity
- a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality[24].

Participants responses are anonymous, and data cannot be traced back to any individual. The data collected for this study will be stored securely and only my supervisors and I will have access to the data. Any copies of questionnaires completed by hand will be kept in a locked cabinet.

15. If relevant, describe the involvement of your target participant group in the design and conduct of your research[25].

Two individuals in a carer role were contacted and provided feedback in relation to the study, allowing it to be refined in light of their comments (for example, both completed the study in approximately 15 minutes, and this information has been included within the participant information sheet).

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis [26].

The research will be disseminated by being written up into a thesis. Furthermore, it is proposed that the research will be submitted to a peer reviewed journal for publication. The research will also be presented to staff and trainees on the Clinical Psychology Doctorate Programme in 2017.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study[27]? Are there any matters about which you wish to seek guidance from the FHMREC?

SECTION FOUR: signature

Applicant electronic signature[28]: Kate Empson

Date 10/11/16

Student applicants: please tick to confirm that you have discussed this application with your supervisor, and that they are happy for the application to proceed to ethical review \square

Project Supervisor name (if applicable): Professor Bill Sellwood

Date application discussed 16/11/16

You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application

Submission Guidance

- 1. Submit the following materials for your study if relevant:
 - Your full research proposal (background, literature review, methodology/methods, ethical considerations).
 - b. Advertising materials (posters, e-mails)
 - c. Letters/emails of invitation to participate
 - d. Participant information sheets [29]
 - e. Consent forms[30]
 - f. Questionnaires, surveys, demographic sheets
 - g. Interview schedules, interview question guides, focus group scripts
 - h. Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing handbooks or measures which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

- Collate the FHMREC form and any relevant materials listed above into a single word document. Submit
 this document by email to Diane Hopkins guidance comments are hidden by going into 'Review' in the menu above then choosing show
 markup>balloons>show all revisions in line.
- 3. Submission deadlines:
 - a. Projects including direct involvement of human subjects [section 3 of the form was completed]. The *electronic* version of your application should be submitted to Diane Hopkins by the committee deadline date. Committee meeting dates and application submission dates are listed on the <u>FHMREC website</u>. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
 - b. The following projects will normally be dealt with via chair's action, and may be submitted at any time. [Section 3 of the form has not been completed, and is not required]. Those involving:
 - i. existing documents/data only:
 - ii. the evaluation of an existing project with no direct contact with human participants;
 - iii. service evaluations.

Ethics Approval Letter



Applicant: Kate Empson Supervisor: Bill Sellwood Department: Health Research FHMREC Reference: FHMREC16039

06 February 2017

Dear Kate

Re: Caregivers' Emotional Over-Involvement (EOI) and Guilt, Blame and Shame: the role Self-Compassion.

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or
 arising from the research to the Research Ethics Officer at the email address below
 (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse
 reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:-Email:-

Yours sincerely,

Dr Diane Hopkins

Research Integrity and Governance Officer, Secretary to FHMREC.

Research Protocol



Caregivers' Emotional Over-Involvement (EOI) and Guilt, Blame and Shame: the role Self-Compassion.

Research Protocol

Principal Investigator: Kate Empson, Trainee Clinical Psychologist

Research Supervisor: Professor Bill Sellwood

Field Supervisor:

Background

Expressed emotion in carers of people with long-term mental health problems is associated with poor outcomes (Barrowclough & Hooley, 2003). Emotional over-involvement (EOI) is a core component of Expressed Emotion and involves excessive emotional responses, including over-protective behaviour (Leff & Vaughn, 1985) and over-identification with their relative (Barrowclough & Hooley, 2003). In caregivers of people with first-episode psychosis, EOI was found to be a significant predictor of the distress of both clients (see Barrowclough & Hooley, 2003 for a review) and carers themselves (Jansen et al., 2015).

The impact of EOI appears to be long-lasting, as EOI has been found to predict family stress and caregiver burden 7 months after initial measures were taken (Alvarez-Jimenez et al., 2010). It appears that guilt and shame may be emotional drivers underlying EOI, and it has been found that feelings of guilt and shame are frequently experienced among caregivers of people with mental health conditions (e.g. Natale & Barron, 1994). It has also been found that caregivers' level of guilt may be linked to their levels of EOI towards a relative with a diagnosis of schizophrenia (Bentsen et al., 1998). A more recent study found that higher levels of self-blame, shame and guilt among caregivers predicted greater expressed emotion, including EOI (Wasserman & Weisman de Mamani, 2012).

The present study will explore the effect of self-compassion on the relationship between guilt and shame and EOI. Self-compassion can be defined as "the ability to hold one's feelings of suffering with a sense of warmth, connection, and concern" (Neff & McGehee, 2010, p. 226). It has been argued that self-compassion affects the physiological systems that underpin caregiving and attachment (Gilbert, 1989). Furthermore, a Compassionate Mind Training Programme, utilised by individuals who experienced high levels of shame, facilitated reductions in self-criticism and shame and an increased ability to attend to feelings of warmth (Gilbert & Procter, 2006). With this in mind, could self-

ETHICS

compassion shield caregivers from the effects of guilt and shame, thereby allowing them to experience less EOI?

The research has a number of implications for clinical psychology. A greater understanding of the effect of self-compassion will enable us to generate new ideas of working that could alleviate distress, both for clients and their carers. Furthermore, it has been found that carers' guilt and shame could be targets for interventions (Cherry, Brown, Taylor, & Sellwood, in prep).

Aims

The project aims to explore the extent to which self-compassion affects the relationship between emotional over-involvement and guilt, blame and shame in carers of people with a long-term mental health condition. Specifically, the research will explore the following questions:

- What effect does self-compassion have on levels of guilt, blame and shame in carers?
- Does self-compassion moderate EOI despite experiencing guilt, blame and shame?

Design

Cross-sectional survey

The research uses a quantitative, exploratory cross-sectional research design. Self-report measures will be completed to explore the relationship between emotional overinvolvement and guilt and shame, and to examine the effect of self-compassion on this relationship.

Participants

Participants will be informal caregivers of people with a long-term mental health condition (informal caregivers defined as a friend/relative who has at least weekly contact with the individual to provide care/support in a non-professional, unpaid manner).

Participants will be recruited through online charitable/advocacy groups for carers, and the principal investigator will also attend relevant carers' groups (with prior permission from the group) to discuss the research and provide a hard copy of the participant information sheet, consent form, measures, and debrief form to interested participants. A priori power calculations indicate that, in order to adequately detect a medium effect size of 0.15 between predictor variables of guilt and shame on emotional over-involvement, with a .80 power level and a standard α level of .05, 68 participants were required for a multiple linear regression containing two predictor variables.

The inclusion and exclusion criteria are as follows:

Inclusion criteria

- Participants must be aged 18 or over
- Participants must be able to understand English in order to provide informed consent and understand the measures.
- Participants must have at least weekly contact with the individual to provide care/support
- Complete at least one of the measures included within the study.
- Participants must provide for a friend/relative with any long-term mental health condition ("long-term" defined as having being present for at least six months)

Exclusion criteria

Participants will not be able to take part in the study if their friend/relative's mental
health difficulties were classified as arising from a learning disability, dementia or
traumatic brain injury.

Data analysis

After examining associations between key variables using correlations, multiple regression will be used to examine the relationships between EOI and the hypothesised

predictor variables, in particular guilt and shame. Before using multiple regression, the assumptions regarding suitability for such analyses will be checked using appropriate statistical tests. If the data set allows, a moderation analysis will also be conducted in order to determine whether self-compassion reduces the impact of shame and guilt on EOI.

Consent will be obtained prior to participation in the study. This will be given in the form of completing a consent form (provided either online or by paper, depending on the platform the participant chooses). The principal investigator's details will be provided on the participant information sheet, which will be given prior to the consent form. This allows prospective participants ask any questions they may have before giving consent.

Measures

The questionnaires that will be used within the study are: The Family Questionnaire (The FQ, Wiedemann, Rayki, Feinstein, & Hahlweg, 2002), the Caring and Related Emotion scale (the CARE scale, Messham, Finlayson, & Sellwood, in prep), and the Self-Compassion Scale (Neff, 2003).

The Family Ouestionnaire (FO) (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002)

The FQ correlates highly with the Camberwell Family Interview (Leff & Vaughn, 1985), which is viewed as the conventional way of measuring EE (Hooley & Parker, 2006). It also has good test-retest reliability and high internal consistency (all Cronbach's $\alpha > .79$; Weidermann et al., 2002), The FQ comprises of two subtests – EOI and critical comments. Each subtest contains 10 statements, which are rated on a 4-point Likert scale.

Self-compassion scale (SCS) (Neff, 2003)

The SCS assesses individuals' responses to suffering using: self-kindness, self-judgement, common humanity, isolation, mindfulness and over-identification, and these form the six constructs of the SCS measure (Neff, 2016). The SCS has been found to have

high test-retest reliability, with an overall score of 0.93, and scores for subtests ranging from 0.80 to 0.88. It consists of 26 items, which are rated on a 5-point Likert scale.

The Caring and Related Emotion Scale (CARE scale) (Messham, Finlayson, & Sellwood, in prep)

This self-report measure contains 16 hypothetical scenarios that could occur when an individual cares for their relative. Four subscales are included within the CARE Scale (shame, blame (towards client), guilt and externalisation). Responses are rated on a 5-point Likert scale. Recent research (Messham et al., in prep) found that the CARE scale had high test-retest reliability, with strong correlations between the guilt/self-blame scale (r = .82) shame scale (r = .89) blame scale (r = .95) and the externalisation scale (r = .76).

High reliability was also found for the guilt/self-blame scale (Cronbach's α = .90), shame scale (Cronbach's α = .91) and the blame scale (Cronbach's α = .90). Reliability for the externalisation subscale was lower, at .57

These measures will be provided online via dedicated link. Participants completing the measures by hand will received printed copies of the measures to complete.

Ethical issues

Although some participants may find it interesting to complete the measures, there is a risk that the process may be distressing for others. Participants will be free to leave the study at any time, and will be reminded of this on the information sheet. Contact details of organisations will also be provided, both in the information sheet and on the debrief form.

Data storage

The data collected for this study will be stored securely and only the researchers conducting this study will have access to it.

ETHICS

- Hard copies of scales completed by hand will be kept in a locked cabinet and will be destroyed after ten years, in line with guidance published by the Medical Research Council.
- Responses completed by computer will be encrypted.

Service user involvement

I plan to contact a person in a carer role through an identified carer's organisation.

I will ask them to read through the proposal/study and provide feedback which will be used to refine the study

Project management

It is planned that the Principal Investigator and Research Supervisor will arrange fortnightly updates via email or telephone. Face to face meetings will occur on a monthly basis, although both email and face to face updates will increase as needed.

Dissemination

The research will be submitted to a peer reviewed journal for publication. The research will also be presented to staff and trainees on the Clinical Psychology Doctorate Programme in 2017 and may be presented at conferences

Timetable

November 2016: Submit ethics application for December meeting.

November 2016: Compile list of carer's groups to approach following ethical approval

December 2017: Submit first draft of introduction and method to research supervisor

January 2017: Start data collection

February 2017: Submit second draft introduction and method to research supervisor

Mid March 2017: Finish data collection

Mid-End March 2017: Data cleansing and analysis

Mid April 2017: Submit first draft results and discussion to research supervisor

Start May 2017: Submit second draft results and discussion to research supervisor

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Appendix 4-A

Recruitment email to Carer Groups

Dear (name if known, if not then the name of the Carer's group),

My name is Kate Empson, and I am a Trainee Clinical Psychologist based at Lancaster University. I am currently conducting a research project, supervised by Professor Bill Sellwood, which aims to better understand people's feelings about their role as a carer for a friend/relative with a long-term mental health condition. Please see the attached information sheet for further details of the study.

I am contacting you to ask whether you would be able to provide details of my study to your group. This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University, and involves completing a questionnaire. This can be accessed by <u>clicking here</u>. Alternatively, if you prefer, I would be happy to attend your group and provide hard copies of the questionnaire to interested carers.

If you have any queries or concerns, please do not hesitate to contact me on the contact details provided below.

Many thanks,

Kate

Kate Empson, Trainee Clinical Psychologist, Lancaster University

Telephone Number: (University provided mobile phone number)

Faculty of Health & Medicine

Division of Health Research

Furness College

Lancaster University

Lancaster, Lancashire

LA14YG

Supervisor details

Prof. B Sellwood

Appendix 4-B

Participant Information Sheet (Hard Copy)

Emotions in carers of people with long-term mental health difficulties

My name is Kate Empson and I am conducting this research as a student in the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

This study is about people who provide care for a friend or relative with a long-term mental health difficulty. Specifically, the study hopes to explore emotional reactions and whether certain attitudes help carers' experiences of these. We are aiming to identify specific aspects of carers' experiences that services could help them with.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to read and sign a consent form. You will then be asked to complete a questionnaire. This should not take any longer than 15-20 minutes to complete. This can then be returned to the principal investigator in the stamped addressed envelope. Once you have finished the questionnaire, you have completed the study. You will not be asked to participate in any follow-up studies.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Even if you agree to take part, you can withdraw your consent at any point while you complete the questionnaire. Once the completed questionnaire has been returned to the principal investigator, it will not be possible to withdraw consent.

Will my data be Identifiable?

No. Your responses are anonymous, meaning that data cannot be traced back to you, and the data collected for this study will be stored securely. The raw responses will be stored on a password protected, secure platform, and completed questionnaires will be kept in a locked cabinet.

What will happen to the results?

The results will be summarised and reported as a Thesis and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no known risks to taking part in the research, though you will be asked questions on topics that you may find distressing. However, you are free to leave the study at any time should you become upset.

ETHICS

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. However, your answers will help us to improve future care and support for clients, their families and friends.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the principal investigator:



Details of organisations offering support

Samaritans

Tel: 116 113 (freephone) Email: jo@samaritans.org

SANE

Tel: 0300 304 7000

<u>Mind</u>

Telephone: 0300 123 3393

Text: 86463

Rethink Advice and Information Service

Telephone: 0300 5000 927

Please note these details will be repeated at the end of the study, however if any questions raise significant distress you are advised to contact your GP for support, or discuss them with someone you trust.

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Roger Pickup Tel:
Associate Dean for Research Email:
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet

Appendix 4-C

Participant Information Sheet (Online Copy)

Emotions in carers of people with long-term mental health difficulties

My name is Kate Empson and I am conducting this research as a student in the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

This study is about people who provide care for a friend or relative with a long-term mental health difficulty. Specifically, the study hopes to explore emotional reactions and whether certain attitudes help carers' experiences of these. We are aiming to identify specific aspects of carers' experiences that services could help them with.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to read an online consent form. You will then be asked to complete a questionnaire. This should not take any longer than 15-20 minutes to complete. This must be completed in a single setting; if you were to close the webpage then answers completed to that point would be lost. Once you have finished the questionnaire, you have completed the study. You will not be asked to participate in any follow-up studies.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Even if you agree to take part, you can withdraw your consent at any point while you complete the questionnaire. After this time, it will not be possible to withdraw consent.

Will my data be Identifiable?

No. Your responses are anonymous, meaning that data cannot be traced back to you, and the data collected for this study will be stored securely. The raw responses will be stored on a password protected, secure platform.

What will happen to the results?

The results will be summarised and reported as a Thesis and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no known risks to taking part in the research, though you will be asked questions on topics that you may find distressing. However, you are free to leave the study at any time should you become upset.

ETHICS

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. However, your answers will help us to improve future care and support for clients, their families and friends.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the principal investigator:

Kate Empson,

Details of organisations offering support

Samaritans

Tel: 116 113 (freephone) Email: jo@samaritans.org

SANE

Tel: 0300 304 7000

Mind

Telephone: 0300 123 3393

Text: 86463

Rethink Advice and Information Service

Telephone: 0300 5000 927

Please note these details will be repeated at the end of the study, however if any questions raise significant distress you are advised to contact your GP for support, or discuss them with someone you trust.

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Roger Pickup Tel:
Associate Dean for Research Email:
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet

Appendix 4-D

Recruitment Poster



We would like to invite you to take part in our research!

The research will explore emotions in carers of people with a long-term mental health difficulty.

We are recruiting people who provide care to a friend or relative with a mental health condition, and would like to understand your experience.

Please go to the link below for further information about the study and to take part:

http://www.lancaster.ac.uk/shm/study/doctoral_s tudy/dclinpsy/research/kateempson/



Please contact Kate Empson, Trainee Clinical Psychologist - k.empson@lancaster.ac.uk,

information, if known.

Appendix 4-E

Demographic Information Sheet

The following questions ask for some demographic information about you and the person you care for. Please leave any questions you do not wish to answer blank.

<u>Ab</u>	About you:	
1)	What is your age?	
2)	What is your gender?	
3)	How would you describe your current employment status (for example, in full-time employment, part-time employment, in full-time education)?	
4)	How are you related to the person you provide care for (for example, mother, brother)?	
5)	How long have you provided care to this person for, in years?	
6)	On average, how many hours per week do you provide face to face care for the person (please do not include time spent asleep)?	
Ab	out the person you provide care for:	
7)	How old is the person that you provide care for?	
8)	What is their gender?	
9)	What is their current employment status (for example, in full-time employment, part-time employment, in full-time education)?	
10)	What is the nature of their mental health issue/diagnosis?	
11)	How long have they been diagnosed with/experienced a mental health issue?	
12)	Do they have any other physical or mental health issues? If yes, please provide further	

Appendix 4-F

Consent Form (Online Copy)

By proceeding to the survey you confirm that:

- You have read the information sheet and understand what is expected of you within this study
- You confirm that you understand that any responses/information you give will remain anonymous
- Your participation is voluntary
- You consent for the information you provide to be discussed with my supervisor at Lancaster University
- You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished
- By clicking on this link, you consent to taking part in the current study.

Appendix 4-G

Consent Form (Hard Copy)

Emotions in carers of people with long-term mental health difficulties

We are asking if you would like to take part in a research project. This study is about people who provide care for a friend or relative with a long-term mental health difficulty. Specifically, the study hopes to explore emotional reactions and whether certain attitudes help carers' experiences of these. We are aiming to identify specific aspects of carers' experiences that services could help them with.

Before you consent to participate in the study, we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form, please speak to the principal investigator, Kate Empson.

I confirm that I have read the information sheet and fully understand what is expected of me within this study.	
I confirm that I have had the opportunity to ask any questions and to have them answered.	
I understand that my participation is entirely voluntary and that I am free to withdraw at any time up until I have completed the survey, without my/my friend or relative's medical care or legal rights being affected. I understand that once I have completed the survey, it will not be possible to withdraw my data.	
I understand that my responses are anonymous, and I consent for this data to be used for the purposes of research outlined in the participant information sheet.	
I consent to take part in the above study	
Name of Participant:	
Signature:	
Date:	
Name of Researcher:	
Signature:	
Date:	

Appendix 4-H

Debrief sheet (online and hard copy)

Thank you very much for taking part in this study. Many people who care for someone with a long-term mental health problem feel under great pressure. This in turn can affect how they help the person they care for. We are trying to discover whether particular emotions are related to levels of care and whether certain attitudes about oneself (self-compassion) protect against some of these negative emotions. For example, family members or other carers can feel guilty, but actually have not done things to feel guilty about. When people feel self-compassionate they are more likely to forgive themselves for perceived difficulties in the way that they might if it were someone else. If we find that self-compassion is important, then it should be something that people supporting carers should attend to.

If you have any questions or concerns about the study, please contact the principal investigator. The contact details are as follows:

Principal Investigator: Kate Empson,

Research Supervisor: Professor Bill Sellwood,

Please also find below details of relevant organisations that offer support:

Samaritans

Telephone: 116 113 (Free from UK landlines and mobiles)

Email: jo@samaritans.org

SANE

Telephone: 0300 304 7000

Mind

Telephone: 0300 123 3393

Text: 86463

Rethink Advice and Information Service

Telephone: 0300 5000 927