

**The Effect of Visuospatial, Verbal and Somatic Tasks on  
the Post-Meal Experience of Hospitalised Patients with  
Eating Disorders**

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## **UCL Doctorate in Clinical Psychology**

### **Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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## Overview

This thesis is presented in three parts; the literature review, empirical paper and critical appraisal. The literature review considers the effectiveness and acceptability of interventions aimed at carers of people with eating disorders. Included studies described a variety of approaches to educate, and provide skills and emotional support to carers, although were generally of a poor methodological quality. Overall, the interventions led to improved carer outcomes, were considered helpful and there was some limited evidence to suggest beneficial client outcomes.

The empirical paper explores whether engaging in various tasks can help hospitalised patients with eating disorders to improve the experience of ‘feeling fat’ during the post-meal period. The tasks comprised of the game ‘Tetris’ (visuospatial), a general knowledge ‘Quiz’ (verbal) and translating ‘Braille’ (somatic), which were designed to reduce intrusive images, thoughts and bodily sensations. When compared to a control condition - ‘Sitting Quietly’, the tasks requiring activity were superior at improving negative affect and additional benefits were seen for all other indicators of the post-meal experience.

The critical appraisal discusses the rationale behind the literature review and empirical paper. Some of the methodological decisions are reviewed, such as choosing the tasks and the use of an online programme to deliver the trials. Dilemmas that arose whilst conducting the research are explored, such as recruitment difficulties, with suggestions for how the research could have been approached differently. The appraisal concludes with personal reflections developed over the course of the research process.

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## **Part 1: Literature Review**

**Are Interventions aimed at Carers of People with Eating Disorders Perceived to be Helpful and are they Effective?**

## **Abstract**

- Aims:** This review aims to examine whether interventions that are aimed solely at the carers of people with eating disorders are associated with improvements in carer wellbeing and client outcomes, and whether they are considered beneficial by the carer.
- Methods:** PsycINFO, Medline, Embase and ISI Web of Science were searched for articles published between January 2000 and September 2013. Eligible studies were experimental in design, reporting outcomes of interventions aimed at carers of people with eating disorders.
- Results:** Twenty studies were included within the review. Due to variations in methodology it was difficult to make comparisons between studies, however the interventions in general appeared to be useful at improving carers' wellbeing and there was some limited evidence to support improvements in client outcomes. Overall the interventions are considered by carers as useful and satisfaction ratings were generally high.
- Conclusion:** The evidence suggests that interventions for carers are helpful and effective, and are well received. Future research should tackle problems of poor methodological quality and insufficient power to improve the evidence base and to help raise the profile of carer interventions for eating disorders.

## **Introduction**

### **Impact of Eating Disorders on Carers**

Caring for someone with an eating disorder is known to be highly stressful (Kyriacou, Treasure, & Schmidt, 2008a; Treasure et al., 2001; Zabala, Macdonald, & Treasure, 2009) and the level of burden is reported to be comparable to that of schizophrenia (Graap et al., 2008a; Treasure et al., 2001). The level of stress is made more apparent when we consider that over 70% of anorexia nervosa carers meet the threshold for anxiety, whilst 38% meet the threshold for depression (Kyriacou et al., 2008a). Caring for someone with bulimia nervosa is similarly distressing (Winn, Perkins, Murray, Murphy, & Schmidt, 2004) and carers report experiencing powerful negative emotions such as helplessness, feeling unable to cope and feeling that they are ‘going mad’ (Perkins, Winn, Murray, Murphy, & Schmidt, 2004). Carer stress is likely to be maintained by the additional financial burden of eating disorders (Whitney et al., 2005), conflicts within the family unit (Highet, Thompson, & King, 2005) and carers feeling isolated and alone (Perkins et al., 2004), leading to an overall impairment in their quality of life (de la Rie, Van Furth, De Koning, Noordenbos, & Donker, 2005). Unsurprisingly, female carers tend to report greater anxiety, perhaps because they are usually the main carer, are more likely to be at home during the day and possibly also because they respond to the eating disorder with greater emotional intensity (Kyriacou et al., 2008a; Whitney et al., 2005). The impact of an eating disorder on those caring for them clearly needs to be considered when offering treatment, as it is possible that negative carer outcomes also impede

recovery of the eating disordered individual (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013).

### **Carers' Needs**

The Carers' Needs Assessment Measure (Haigh & Treasure, 2003) has found that carers have a high level of unmet needs particularly in relation to information about eating disorders as well as practical and emotional support, with no differences between anorexia nervosa and bulimia nervosa (Graap et al., 2005). This can leave carers feeling that they lack the necessary skills to support their loved one, only increasing their stress levels further. Carers have reported a desire for practical skills to help them manage the eating disorder, knowledge of how best to adapt the home environment, information about eating disorders, its prognosis and treatment, meeting other carers to reduce feelings of being alone and emotional support from professionals (Graap et al., 2008b; Haigh & Treasure, 2003; Surgenor, Rau, Snell, & Fear, 2000; Winn et al., 2004; Zucker, Ferriter, Best, & Brantley, 2005). From these studies, it appears that meeting the needs of carers will not only help reduce their levels of distress but will also assist them in improving the wellbeing of their loved one.

### **Carers' Influence on Eating Disorders**

Working with carers to support the treatment of their loved one is particularly important when considering their role in the maintenance of the eating disorder. Family members are considered highly significant within the cognitive-interpersonal



maintenance model of anorexia nervosa (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). The model describes how the family observe a physical difference in their loved one's appearance as they lose weight, which elicits their care and attention resulting in the family reorganising itself to try to support her. The illness then begins to dominate family life, families reorganise themselves to focus on the present and other aspects of family life are neglected as their attention focuses on the eating disorder (Eisler, 2005; Whitney & Eisler, 2005). However, if the person with anorexia nervosa is unwelcoming of this care (which is common, due to anorexia nervosa being highly valued as shown by Serpell, Treasure, Teasdale, and Sullivan, 1999) it can leave carers feeling helpless and to blame. This may be translated into high levels of expressed emotion, such as criticism, hostility and over-involvement possibly in an attempt to assert dominance for control (Greenley, 1986). A qualitative study also revealed that carers of people with anorexia nervosa often misinterpret the illness leading to criticism and hostility (Whitney et al., 2005). These negatively expressed emotions, within families, are linked to longer-term and poorer outcomes (Kyriacou, Treasure, & Schmidt, 2008b; Sepulveda et al., 2010) leading to increased carer burden and distress (Coomber & King, 2013) and the individual with anorexia nervosa distancing themselves from the family (Schmidt & Treasure, 2006). Families may also accommodate to their loved one's symptoms, to prevent conflicts and added stressors (Whitney & Eisler, 2005), which may result in enabling some of the core symptoms creating additional vicious cycles (Treasure & Schmidt, 2013).

## **Including Carers**

It appears possible that including carers in the treatment of eating disorders will help to reduce carers' overall distress and improve outcomes for their loved ones. The National Institute of Clinical Excellence guidelines for eating disorders (NICE, 2004) recommends that families are involved in both the assessment and treatment of their loved one, and that family interventions are the treatment of choice for adolescents, although the guidelines do not describe ways to support carers themselves. In addition, they recommend that inpatient care is reserved for exceptional cases only, which is important to consider as outpatients will undoubtedly have greater contact with their carer. Carers are motivated to want to help, although they often feel they lack the necessary skills to do so (Treasure & Schmidt, 2001), so it is unsurprising that a large body of evidence has been developed looking at the benefits of family interventions (see Downs and Blow, 2013 for a review). Family interventions appear to be more effective for improving eating disorder symptoms than individual interventions for children and adolescents with anorexia nervosa (Eisler, Le Grange & Asen, 2003).

Treasure and colleagues (Treasure, Whitaker, Whitney, & Schmidt, 2005) have developed a model of carers' coping with anorexia nervosa. The model considers a variety of factors that influence the ability for carers to cope (Figure 1). They report working with families to target each of these factors, for example through networking with other carers to help reduce stigma and breaking vicious cycles of interpersonal factors that maintain the stress of being a carer.

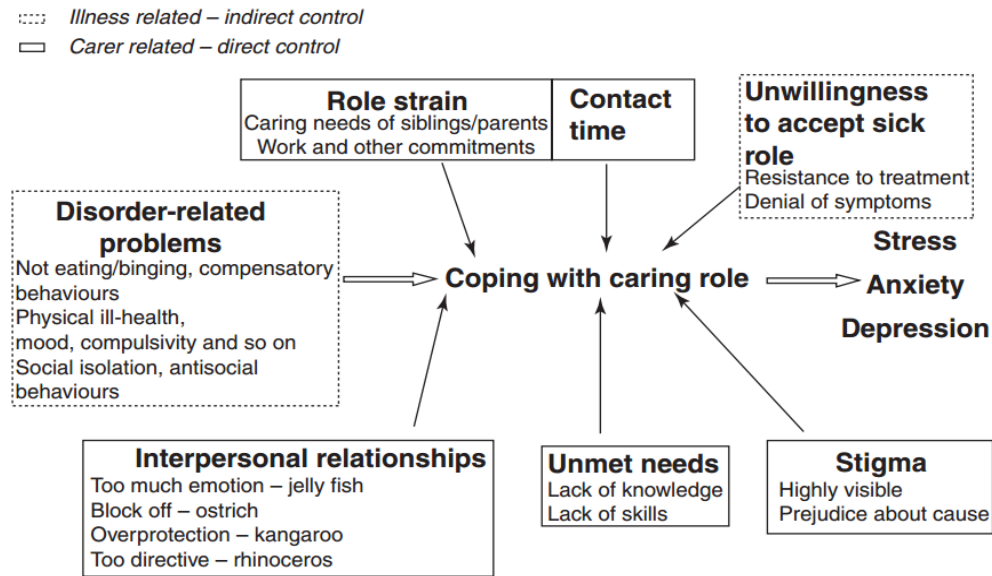


Figure 1. A model of carer strain and stress (Treasure et al., 2005).

### Interventions Aimed at Carers

Despite the evidence endorsing family interventions for eating disorders there is a clear need for interventions aimed solely at the carer for a number of reasons. Firstly, family therapy is very expensive, time consuming, stressful and complex so alternative interventions may need to be considered, particularly in non-specialist settings. Secondly, family interventions are not effective for all, with a third of clients not reaching 85% ideal body weight (Eisler, Le Grange & Asen, 2003) suggesting augmentations to these treatments may be beneficial. Thirdly, many people with eating disorders may be reluctant to be involved in treatment, perhaps due to a lack of insight or the highly valued nature of eating disorders. Where eating disordered individuals refuse treatment, carers still need support. Finally, family interventions involve improving client wellbeing but it is clear that carers need support to reduce their own levels of distress.

## **Current Reviews of the Literature**

A substantive review of quantitative literature looking at the effectiveness of family-based interventions for eating disorders over the past 25 years has recently been published (Downs & Blow, 2013). The studies they reviewed found that family interventions were effective for early onset anorexia nervosa in adolescents, but mixed results were found for both adult populations and sufferers of bulimia nervosa. A review of randomised controlled trials (RCTs) comparing family therapy with treatment as usual found some evidence to suggest that family therapy was more beneficial in the short term (Fisher, Hetrick, & Rushford, 2010). However, the authors express caution regarding these findings, due to the limited number of trials (N=13) and small sample sizes.

A special edition of the *Journal of Family Therapy* (Asen & Schmidt, 2005) reviewed a range of models of treatment that involve families of those with eating disorders including the 'Maudsley model', for adolescents with eating disorders of short duration. This intervention has recently been modified to include: multi-family therapy (several families receiving therapy together, see Dare and Eisler, 2000), conjoint family therapy (all family members included in the therapy at the same time) and separated family counselling (family members and their loved ones receive therapy separately see Eisler et al, 2000). In addition, they included a description of interventions aimed at carers, based on a carers model of distress previously mentioned (Treasure et al., 2005). A variety of ways of reducing carer stress were suggested, some of which may warrant interventions without the inclusion of the client. In fact, one intervention has been developed over the last 16 years, which involves training carers to become experts at managing their loved ones illness. The

collaborative care skills training workshops content and the processes involved are discussed in detail in one review (Treasure et al., 2007) and a number of the studies examining the effectiveness of these workshops will be considered within this review.

One review has specifically examined technology-enhanced interventions for eating disorders (Baurer & Moessner, 2013). They reviewed just two studies that offered technology interventions aimed at carers. One study found a benefit of an online cognitive behavioural therapy intervention for carers in reducing their anxiety and depression (Grover et al., 2011a), whilst a pilot study found reported benefits of an Internet-based chat support program as an adjunct to family-based therapy (Binford Hopf, Grange, Moessner, & Bauer, 2013). Both of these studies are included within this review.

## **Aims**

Research indicates a valuable role of family and carers in eating disorders, but no review has been conducted to assess the effectiveness of interventions aimed solely at the carer, without the involvement of the eating disorder sufferer. Therefore, a systematic review of the literature was conducted to determine the effectiveness of interventions aimed at the carers of people with eating disorders on carer wellbeing and client outcomes. The review will also consider carers appraisals of these interventions.

## **Method**

### **Search Strategy**

Using the search terms “eating disorders” AND “carer” AND “intervention” possible relevant articles were scanned to develop search terms. A computerised search was then conducted of PsycINFO, Medline, Embase, ISI Web of Science for articles published between January 2000 and 22<sup>nd</sup> September 2013.

The search terms were “eating disorder\*”, “anorexia nervosa”, “anorexia”, “bulimia nervosa”, “bulimia” and “disordered eating” AND “carer\*”, “caregiver\*”, “care giver\*”, “carer\* burden”, “parent\*”, “mother\*”, “father\*”, “relative\*” and “partner\*” AND “intervention\*”, “group intervention\*”, “support group\*”, “family intervention\*”, “family support”, “training”, “psychoeducation\*”, “psycho-education\*”, “self-help”, “online training”, “on-line training”, “parent\* support”, “carer\* support”, “coaching”, “parent-training”, “parent-to-parent” and “skill\* training”. In addition, MeSH terms were used in PsycINFO, Medline and Embase and limited to human articles. Truncation of terms was used to identify multiple endings and plurals in words, such as eating disorders and eating disordered.

Reference lists of all identified articles were also manually examined. All citations were transferred to Mendeley (<https://www.mendeley.com>).

## **Inclusion Criteria**

1. Studies reporting interventions aimed at carers; defined as anyone providing unpaid support to someone unable to cope without this help, which can include relatives, partners or friends (<https://www.carers.org>).
2. Carers supporting people with eating disorders; anorexia nervosa, bulimia nervosa and eating disorders not otherwise specified.
3. Study examines any intervention aimed at the carer, independent of the person with an eating disorder.
4. Experimental design looking at the effectiveness of a carer's intervention on outcomes for the carer and/or person with an eating disorder including satisfaction ratings of the intervention.
5. Published in English.
6. Published in a peer reviewed Journal.
7. Published between 1<sup>st</sup> January 2000 and 22<sup>nd</sup> September 2013.

## **Exclusion Criteria**

1. Carer interventions for alternative eating disorders such as; obesity; feeding and eating disorders of infancy or early childhood, e.g. pica; malnutrition; and loss of weight due to physical health problems, e.g. anorexia-cachexia.
2. Interventions aimed primarily at the person with an eating disorder and where they are actively involved e.g. conjoint, separated and multiple family therapy.

3. Study does not report on numerical outcomes of the intervention e.g. protocol papers, descriptions of interventions and solely qualitative analyses.
4. Studies that examine interventions designed to prevent eating disorders.

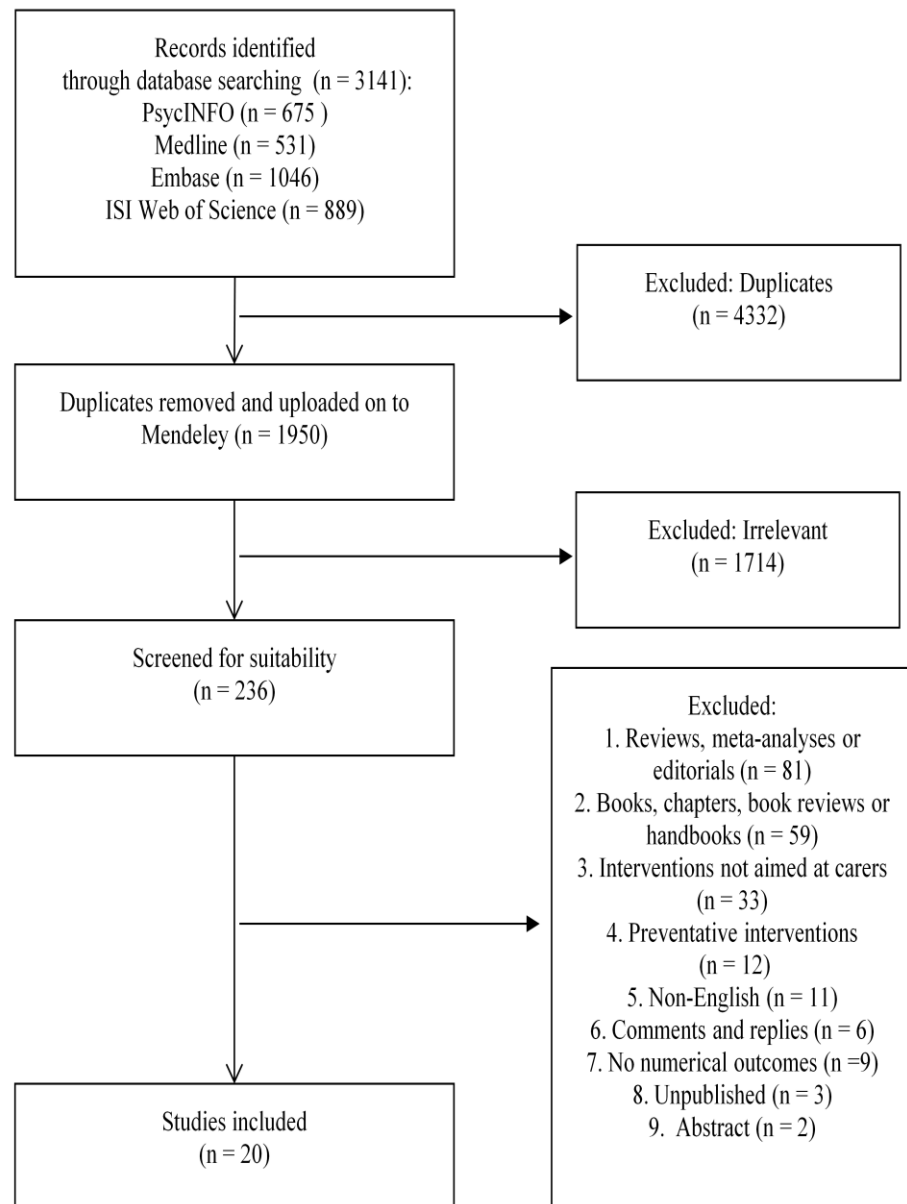
### **Studies Included in the Review**

Once duplicates were removed, a total of 1,950 studies were identified using the search terms. Using the inclusion and exclusion criteria the titles and abstracts were scanned to identify relevant studies. A total of 1,714 articles were immediately excluded as they were irrelevant to the study. A further 216 records were excluded following further examination of the text for the following reasons; identified as reviews, meta-analyses or editorials (n= 81); books, chapters, or handbooks (n= 59); the intervention was not aimed at the carer (n= 33); the intervention was designed for the prevention of eating disorders (n= 12); non-English (n= 11); comments and replies (n= six); no numerical outcome data reported (n= nine); unpublished (n= three); and abstracts (n= two).

One study (Leichner, Hall, & Calderon, 2005) was obtained after examining the reference lists but was later excluded as it was found to be a summary of an intervention for carers, with no quantitative data reported. One study sampled carers of people with eating disorders and people who were at risk of relapse (Grover et al., 2011b). The study was kept within the review as only one individual (3.7%) fell into this latter category. Another study included professionals as part of their sample of carers (Haltom, Ribeiro, & Potter, 2012). Paid or voluntary staff were not considered carers within this review, however it was deemed acceptable to include the study as



only ‘a few professionals’ made up the total sample of 81. In total 20 studies were included in the review. See Figure 2 for flowchart.



*Figure 2.* Flowchart of identified studies.

## **Results**

### **Quality Assessment**

Study quality was assessed using the adapted version of the Downs and Black rating sheet (Cahill, Barkham, & Stiles, 2010). This tool assesses quality of practice-based health interventions and points are awarded according to information provided by the study to allow for an unbiased evaluation, external validity, internal reliability and confounding factors. The final question was reworded to create a binary response. A score of 1 was given if the study conducted a power analysis and sampled a sufficient number of people to detect a clinically important effect. A score of 0 was given if either the study did not conduct a power analysis or if it did not sample a sufficient number of people. Table 1 reports the scores for each study under these four domains. The average quality rating was 18.0 out of a possible 32 points (SD: 5.0). Reporting was generally high at an average of 70%, however quality confounding biases were low at 14%.

Table 1

*Assessment of Methodological Quality*

Study	Reporting (Out of 11)	External Validity (Out of 11)	Internal Reliability (Out of 5)	Internal Reliability- Confounding Bias (Out of 5)	Total (Out of 32)
Abbate-Daga et al. (2013)	9	9	3	1	22
Binford Hopf et al. (2013)	11	7	4	0	22
Cairns et al. (2007)	4	6	2	0	12
Carlton & Pyle. (2007)	8	7	2	1	18
Gísladóttir & Svavarsdóttir. (2011)	8	8	4	0	20
Goddard et al. (2011)	10	6	4	4	24
Grover et al. (2011a)	10	7	5	3	25
Grover et al. (2011b)	10	7	4	0	21
Haltom et al. (2012)	5	1	1	0	7
Holtkamp et al. (2005)	2	6	2	0	10
Hoyle, et al. (2013)	7	0	5	2	14
Pasold et al. (2010)	6	9	3	0	20
Pépin & King. (2013)	10	9	4	0	23
Rhodes et al. (2008)	8	6	5	2	21
Sepulveda et al. (2008a)	5	6	3	0	14
Sepulveda et al. (2008b)	10	7	4	0	21
Sepulveda et al. (2008c)	8	4	3	0	15
Sepulveda et al. (2010)	9	7	3	0	19
Uehara et al. (2001)	9	6	3	1	19
Zucker et al. (2006)	5	5	2	0	12
Mean	7.7	6.2	3.3	0.7	18.0

## **Description of Studies**

All of the studies included within the review aimed to determine either the effectiveness or acceptability of an intervention for carers of people with eating disorders, with the exception of one study which aimed to test whether a new measure was sensitive to change following a carers' intervention (Sepulveda, Whitney, Hankins, & Treasure, 2008). The interventions described within the studies comprised of; psychoeducation and skills training groups, which often included an element of emotional support (N=11); individual counselling sessions (N= one); psychoeducation and training DVD and/or manuals (N= four); online chat groups (N= one); online psychoeducation and training modules (N= two); and a veteran carer reflective session (N= one). All of the studies used convenience samples and only three studies compared the intervention to a control group. The majority of studies either aimed the intervention solely at parents or did not describe the relationship of the carer to their loved one. A few studies included other family members and friends who were considered carers. The means for the carers age were reported in nine studies and ranged from 44.9- 53.3 (total mean= 50.4). The carers were mostly female (52-93% in thirteen studies where the carers gender was reported and couples were assumed to be heterosexual unless stated otherwise) caring for mainly female care recipients (80-100% female in nine studies where the clients gender was reported), who were a combination of adolescents and adults (N=11 studies). Six studies included solely adolescent care recipients (18 or under). The clients within the studies were diagnosed with anorexia nervosa, bulimia nervosa or eating disorders not otherwise specified, except three studies which only included anorexia nervosa (Binford Hopf et al., 2013; Hoyle, Slater, Willimas, Schmidt, &

Wade, 2013; Rhodes, Bailee, Brown, & Madden, 2008). Carers completed a variety of outcome measures to assess changes in variables such as family functioning, carer distress, carer burden, coping abilities and expressed emotion. Twelve studies included a measure of carers' satisfaction regarding the intervention. Three studies included outcome measures for care recipients assessing changes in medical and behavioural outcomes of their eating disorder. Table 2 summarises the included studies.

## **Interventions**

The majority of the study authors were aware of the importance of providing information about eating disorders to carers, many of which also involved teaching skills, strategies and adaptive coping responses to assist them in the caring of their loved one. Six studies within the review considered the effectiveness of 'The Collaborative Care Skills Training Workshops' also known as 'Expert Carers Helping Others' (Goddard et al., 2011; Pépin & King, 2013; Sepulveda, Lopez, Macdonald, & Treasure, 2008a; Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008b; Sepulveda, Whitney, Hankins, & Treasure, 2008c; Sepulveda, et al., 2010). In these workshops, carers are trained in strategies that help in the caring of their loved one and are based on the Maudsley model of the maintenance of eating disorders (Treasure et al., 2007) and a model of carer coping (Treasure et al., 2005). They involve carers developing skills in communication, emotional intelligence and reducing expressed emotion. The workshops are delivered via six sessions each lasting two hours, over a three month period, followed by an additional session three months later. Carers are also provided with a written manual. Whilst most of the

studies using this programme were carried out in the originating centre, one study examined how effective the workshops were when delivered to 15 carers in Australia by therapists who had received two days of training (Pépin & King, 2013). The workshops were also transferred on to a set of five DVDs and offered to carers along with three telephone coaching sessions (Sepulveda et al., 2008a). The benefit of additional telephone sessions along with the DVDs was evaluated in a further RCT (Goddard et al., 2011).

A number of other studies report developing psychoeducation and training groups to support carers. One of these groups consists of five monthly sessions lasting two hours each with a combination of lectures to provide information about eating disorders and adaptive strategies, as well as discussions to offer support (Uehara et al., 2001). Four separate groups were run over two years involving between five and twelve family members. This study then influenced a team in Iceland to develop a similar intervention (Gisladottir & Svavarsdottir, 2011). The intervention involved four weekly sessions covering eating disorders symptoms and treatment, supportive conversations about the impact of the illness on the family, validating emotions and encouraging more adaptive beliefs as well as homework tasks between sessions.

Table 2

*Characteristics of Included Studies*

Study	Sample	Intervention	Measure(s)	Main Findings
Abbate-Daga et al. (2013)	N Carers (of N clients) 166 (87) Relationship Parents Carers' Age Unknown Carers' Gender (%F) 52.4% Client's Age (Range) 21.7 (15-30) Client's Gender (%F) 100 Diagnosis AN-R (36.4%) AN-BP (20.5%) BN (23.9%) EDNOS (19.2%) Country Italy	Eight weekly parent counselling sessions, each lasting 60 minutes. An additional informative group two weeks before. Aim: to help parents cope more effectively by promoting more adaptive coping responses.	Carers: -Clinician evaluation of coping abilities Clients: -EDI-2	Parents with improved coping resources had daughters with a lower frequency of bingeing and purging than those who had not improved.
Binford Hopf et al. (2013)	N Carers (of N clients) 13 (10) Relationship Parents Carers' Age 44.9 Carers' Gender (%F) 76.9 Client's Age (Range) 13.3 (9-17) Client's Gender (%F) 80 Diagnosis AN (100%) Country USA	Fifteen virtual online chat sessions, 90 minutes duration. All were involved in family therapy at various stages of treatment. Aim: to encourage and support parents, including discussing helpful strategies.	Carers: -ECI -EDSIS -Before and chat session questionnaires <sup>a</sup> -Programme evaluation <sup>a</sup>	The programme was rated highly as parents felt more able to cope. Parents stated that they would recommend the sessions to others.
Cairns et al. (2007)	N Carers (of N clients) 40 (40) Relationship Parents/caregivers Carers' Age Unknown Carers' Gender (%F) Unknown Client's Age (Range) 13-18 (unknown) Client's Gender (%F) Unknown Diagnosis AN (65%) BN (2%), EDNOS (33%) Country Canada	Meal support training via a DVD and manual. Aim: to introduce meal support and help caregivers understand their loved ones feelings at meal times, whilst offering meal support strategies.	Carers: -Evaluation questionnaire <sup>a</sup>	Meal support training was found to be informative.

Carlton & Pyle. (2007)	N Carers (of N clients)	Intervention: 29 Control: 53 (unknown)	Parent Education and Support Program (PESP) involving a guide, an open parent support group and weekly open medical question and answer session. Aim: to provide information and emotional support developed from focus groups evaluating carers needs.	Carers: -Evaluation questionnaire <sup>a</sup>	Parents who were offered the PESP felt more educated and prepared than parents who were not offered the PESP.
	Relationship	Parents			
	Carers' Age	Unknown			
	Carers' Gender (%F)	Unknown			
	Client's Age (Range)	14.2 (10-17)			
	Client's Gender (%F)	89			
	Diagnosis	AN (58.5%) EDNOS (41.5%)			
	Country	USA			
Gísladóttir & Svavarsdóttir . (2011)	N Carers (of N clients)	21(14)	Education and support intervention involving lectures and group discussions. Three groups that ran weekly for four sessions. Aim: to improve understanding and provide support to assist the client's recovery.	Carers: -LEE -FQ -ABOS -Satisfaction questionnaire <sup>a</sup>	The intervention led to improvements in understanding of the illness and satisfaction ratings were high.
	Relationship	Parents, partners & siblings >18			
	Carers' Age (Mean)	Unknown			
	Carers' Gender (%F)	Unknown			
	Client's Age (Range)	21 (15-31)			
	Client's Gender (%F)	100			
	Diagnosis	AN (19%) BN (57%) Unspecified (10%) Unknown (14%)			
	Country	Iceland			
Goddard et al. (2011)	N Carers (of N clients)	ECHO: 80 ECHOc: 73 (153)	Self-help intervention: expert carers helping others (ECHO) compared to guided self-help (ECHOc). ECHO: book and five DVDs. ECHOc: an additional three telephone coaching sessions. Aim: self-help targeted at reducing maintaining factors proposed within a cognitive interpersonal maintenance model of eating disorders.	Carers: -HADS -GHQ-12 -ECI -EDSIS -FQ -CSE -AESED -GEDF -EatBeh -Evaluation questionnaire <sup>a</sup>	Both conditions led to improvements in carers' distress and all other factors.
	Relationship	Carers			
	Carers' Age	49.6			
	Carers' Gender (%F)	88.9			
	Client's Age (Range)	20.85 (unknown)			
	Client's Gender (%F)	95.4			
	Diagnosis	AN (79.7%) BN (7.8%) EDNOS (3.2%) Unknown (9.3%)			
	Country	UK			



Grover et al. (2011a)	N Carers (of N clients)	<p>           OAO: 33            Beat: 30 (63)            Carers            48.2            79.4            20.4 (12-44)            Unknown            AN-R (60.3%)            AN- BP (17.5%)            EDNOS (20.6 %)            Unknown (1.6%)            UK         </p>	<p>           Overcoming Anorexia Online (OAO) web intervention compared to Beat (usual support from a patient and carers organization). Eight weekly online modules with additional weekly 20 minute guidance from therapist via phone or email.            Aim: cognitive behavioural intervention to provide information, promote self-monitoring and skills training to manage the illness.         </p>	<p>           Carers:            -HADS            -ECI            -EDSIS            -LEE            -AESED            -Feedback questionnaire<sup>a</sup> </p>	OAO led to improvements in carers' distress and expressed emotion compared to carers in the control condition.
Grover et al. (2011b)	N Carers (of N clients)	<p>           27 (27)            Carers            50            63.0            28 (14-55)            Unknown            AN-R (70.4%)            AN- BP (18.5%)            EDNOS (7.4%)            Risk of relapse (3.7%)            UK         </p>	<p>           Piloting nine educational workbooks (based on OAO). Carers also received 20 minutes weekly email or telephone therapist support.            Aim: cognitive behavioural intervention to provide information and suggest skills in managing the illness.         </p>	<p>           Carers:            -HADS            -ECI            -EDSIS            -LEE            -FMSS            -SPSI-R         </p>	The intervention led to an improvement in carers' distress, expressed emotion and positive experiences in caregiving, maintained at 10-12 week follow-up.
Haltom et al. (2012)	N Carers (of N clients)	<p>           81 (unknown)            Carers and a few professionals            Unknown            Unknown            Unknown            Unknown            Eating disorders            USA         </p>	<p>           Parent Partner Program consisted of lectures, slides, group discussion and questions and answer discussions. Two sessions lasting three hours each.            Aim: to provide skills, knowledge and support to help manage the illness.         </p>	<p>           Carers:            -Evaluation questionnaire<sup>a</sup> </p>	100% of carers found the intervention helpful and improvements were made according to the evaluation questionnaire.

Holtkamp et al. (2005)	N Carers (of N clients) Relationship Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis Country	115 (unknown) Parents Unknown Unknown Unknown Unknown AN, BN & EDNOS Germany	Five psychoeducation sessions lasting 90 minutes each. Aim: to increase the parents understanding of eating disorders.	Carers: -Evaluation questionnaire <sup>a</sup>	The majority of carers rated the intervention as helpful.
Hoyle et al. (2013)	N Carers (of N clients) Relationship Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis Country	OAO= 18 OAOg = 17 (unknown) Carers Unknown 89 Unknown Unknown AN (100%) UK & Australia	Seven weekly modules of OAO via the web. This intervention was compared to OAO with additional email or telephone guidance (OAOg). Aim: cognitive behavioural intervention to provide information, promote self-monitoring and skills training to manage the illness.	Carers: -LEE -GHQ-28 -SF-36 -DASS -EDSIS -ECI Clients: -LEE	The intervention led to improvements in carer intrusiveness and negative experiences of care giving.
Pasold et al. (2010)	N Carers (of N clients) Relationship Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis Country	54 (unknown) Parent/guardian's Unknown 85.2 20 (13-26) Unknown Unknown USA	Weekly, open, parent support group. Aim: education and discussion of personal experiences with no specific agenda.	Carers: -PSSED <sup>a</sup>	Carers reported greater understanding of the illness and found the intervention supportive. Greater attendance related to greater satisfaction with treatment.

Pépin & King. (2013)	N Carers (of N clients) Relationship Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis  Country	15 (11) Parents 51 73.3 20.13 (unknown) 91 AN (64%) BN (18%) AN and BN (9%) Unknown (9%) Australia	Six weekly Collaborative Care Skills Training Workshops lasting 2.5 hours each.  Aim: introduction to the maintenance model of eating disorders and the model of carer coping. Teaching carers a variety of strategies.	Carers: -Brief Cope -EDSIS -GHQ-12 -FQ -Evaluation questionnaire <sup>a</sup>	The intervention led to a reduction in a number of factors believed to maintain the illness, maintained at 8 weeks follow-up.
Rhodes et al. (2008)	N Carers (of N clients) Relationship Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis Country	34 (20) Parents Unknown Unknown 14 (12-16) Unknown AN (100%) Australia	RCT to compare family therapy with an additional parent-to-parent consultation in the presence of a therapist between sessions three and five, lasting one hour.  Aim: to provide hope, listen to others experiences and reduce feelings of isolation.	Carers: -PVA -DASS	The additional consultation led to a small increase in rate of weight restoration.
Sepulveda et al. (2008a)	N Carers (of N clients) Relationship Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis  Country	14 (14) Carers 52.1 81.3 17.2 (14-27) 93 AN (78.6%) BN (14.3%) Unknown (7.1%) UK	Five skills based training DVDs (based on the Collaborative Care Skills Workshops) and three 30 minute telephone coaching sessions.  Aim: for carers to reflect on their role in the maintenance of the illness, reduce medical risk and elicit change through learning strategies.	Carers: -GHQ-12 -HADS -ECI -FQ -Acceptability questionnaires <sup>a</sup>	High satisfaction ratings were reported across the DVDs, whereas there was no reported reduction in distress and depression.

Sepulveda et al. (2008b)	N Carers (of N clients) Relationship  Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis  Country	28 (28) Parents, partners & siblings 52.7 82.1 22.7 (15-33) 100 AN (79%) BN (21%) UK	Six sessions of The Collaborative Care Skills Workshops lasting two hours each. In addition, carers are provided with a written manual and a follow up session three months after the intervention. Aim: to help moderate expressed emotion and teach motivational interviewing to improve communication and readiness to change.	Carers: -GHQ-12 -ECI -EDSIS -Acceptability questionnaire <sup>a</sup>	The intervention led to improvements in carer distress and negative experiences of care giving, and was considered highly valuable.
Sepulveda et al. (2008c)	N Carers (of N clients) Relationship  Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis Country	57 (57) Parents, sisters & friends 51.4 93.0 Unknown Unknown Unknown UK	As Sepulveda et al. (2008b)	Carers: -EDSIS -GHQ-12 -ECI Client: -CGAS	The workshops led to improvements on the overall and guilt subscale of the EDSIS. Negative aspects of care giving, carer distress and patient's functioning all improved.
Sepulveda et al. (2010)	N Carers (of N clients) Relationship Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis  Country	47 (47) Carers 53.3 91.5 21.5 (9-43) 93.5 AN (77.8%) BN (22.2%) UK	As Sepulveda et al. (2008b)	Carers: -FMSS -GHQ-12 -ECI	The intervention led to a reduction in the number of carers with high expressed emotion, maintained at 3 month follow up. Carer distress and caregiving burden also improved.

Uehara et al. (2001)	N Carers (of N clients) Relationship Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis  Country	28 (26) Mother, father, grandmother & siblings Unknown 92.3 20.1 (12-33) Unknown AN (69.2%) BN (26.9%) EDNOS (3.8%) Japan	Once a month psychoeducation groups. Five sessions in total lasting two hours each involving lectures and group discussions. Aim: psychoeducation aimed at reducing expressed emotion through problem solving and solution-focussed approaches.	Carers: -FMSS -POMS -ABOS Clients: -EDES -GAF	The number of family members with high expressed emotion tended to decrease. Secondary outcome measures all improved.
Zucker et al. (2006)	N Carers (of N clients) Relationship Carers' Age Carers' Gender (%F) Client's Age (Range) Client's Gender (%F) Diagnosis  Country	16 <sup>b</sup> (16) Parents Unknown Unknown 16 (13-18) Unknown AN (56%) BN (19%) EDNOS (25%) USA	Group Parent Training Program. 16-session group treatment, weekly 90 minutes. Aim: manage the eating disorder with strategies whilst also offering social support.	Carers: -Treatment satisfaction questionnaire <sup>a</sup>	Parents reported that the intervention helped; teach them how to manage the illness, improve their parenting and would recommend the group to others.

*Note.* Only measures relevant to this review are included. ABOS= Anorectic Behaviour Observation Scale; AESED= The Accommodation and Enabling Scale for Eating Disorders; CSE= The Revised Scale for Caregiving Self-Efficacy; ECI= The Experience of Caregiving Inventory; EDES= Eating Disorder Evaluation Scale; EDI-2= Eating Disorder Inventory 2; EDSIS= The Eating Disorder Symptom Impact Scale; FMSS= Five-Minute Speech Sample; FQ= The Family Questionnaire; DASS= Depression Anxiety and Stress Scale; GAF= Global Assessment of Function; GEDF= Global Eating Disorder Functioning; GHQ-12/GHQ-28= General Health Questionnaire; HADS= Hospital Anxiety and Depression Scale; LEE= Level of Expressed Emotion Scale; POMS= Profile of Mood States; PSSSED= The Parent Satisfaction Survey of Eating Disorders Parent Support Group; PVA= The Parent versus Anorexia Scale; SF-36= The Medical Outcome Study Short Form Scale; SPSI-R= Social Problem-Solving Inventory- Revised. Diagnosis: AN= Anorexia Nervosa; AN-R= Anorexia Nervosa, restrictive subtype; AN-BP= Anorexia Nervosa, binge/purge subtype; BN= Bulimia Nervosa; EDNOS= Eating Disorder Not Otherwise Specified.

<sup>a</sup>In-house questionnaire developed for the study.

<sup>b</sup>In nine families, partners would alternate attendance.

Group psychoeducation was offered to parents over five sessions lasting 90 minutes with the aim of improving parents understanding of eating disorders as well as strategies for relapse prevention (Holtkamp et al., 2005). Another program, The Parent Partner Program™ involves two sessions of three hours each to provide skills, knowledge and support to parents based on the idea that all families have strengths to be drawn upon (Haltom et al., 2012). The program involves lectures, video clips, discussions and question and answer sessions with the facilitators. One parent training intervention was based on ideas from Dialectical Behaviour Therapy such as training parents with skills to perform effective solutions in the context of mindfulness (Zucker, Marcus, & Bulik, 2006). Parents met weekly for 16 sessions lasting 90 minutes each with seven to twelve people attending each time.

Two studies describe more flexible group interventions, where the groups are held weekly and carers can attend as often as they wish. One of these open groups was aimed at parents of outpatients (Pasold, Boateng, & Portilla, 2010). The groups had no specific agenda but were a place for parents to discuss their experiences, where they were provided with information on a variety of aspects of eating disorders and guidance on how to support their loved one at home. The second study described holding focus groups for 20 parents of previously admitted adolescent eating disorder patients to determine the need for a parent support group (Carlton & Pyle, 2007). Parents reported not understanding the treatment process for their loved one and felt they lacked the necessary skills to support them once they returned home. The focus groups led to the development of the ‘Parent Education and Support Program’. The program included an information text on risks of eating disorders and treatment options, a weekly parent support group to share their experiences of caring for someone with an eating disorder and a weekly medical question and answer

session group, which included topics on eating disorder risks and the meaning of eating disorder diagnoses. Parents could attend the groups as often as they wanted to and these were attended by one to seven people at a time. Distance Learning to help improve skills for carers has been considered by a number of other authors within the review. Three studies used the ‘Overcoming Anorexia Online’ (OAO) intervention developed by professionals, a carer and a recovered sufferer of anorexia nervosa, that offers information and suggested skills to help manage their loved one’s illness along with weekly email or telephone therapist support based on a cognitive behavioural approach (Grover et al., 2011a; Grover et al., 2011b; Hoyle et al., 2013). The intervention involves eight weekly online modules and weekly therapist guidance via email or telephone. Another study considered the effectiveness of DVDs for meal support training (Cairns et al., 2007). The DVD, along with a manual, was developed in collaboration with families in recognition of the overwhelming nature of meal times for families of the eating disordered. The intervention aimed to help carers to understand the feelings of their loved ones and suggestions of helpful and unhelpful strategies at mealtimes. The DVD also included interviews with parents and a recovered client.

A unique medium for offering carer support was explored in one study (Binford Hopf et al., 2013). This study considered the helpfulness of an online chat support group for parents of adolescent anorexia nervosa sufferers involved in various stages of family based therapy. Two to five parents met online for 15 sessions, lasting 90 minutes each. The group aimed to encourage and support parents through the treatment, offer a space for parents to share their emotions and discussions on strategies that might be helpful in caring for their child.

Only one study within the review offered individual face to face family support via parent counselling (Abbate-Daga et al., 2013). The counselling involved eight weekly sessions lasting an hour with an aim to help parents adopt more adaptive coping responses and improve communication through an understanding of the mechanisms which maintain the illness, helping to also improve family relationships.

Finally, a RCT was conducted to determine the effectiveness of an additional parent-to-parent session during the standard Maudsley model of family therapy (Rhodes et al., 2008). This session involved parents meeting with another parent who had been through the process of helping in the recovery of their loved one suffering with anorexia nervosa. They met in the presence of a therapist between sessions three and five of the family therapy. The therapist conducted the interview with the veteran parent, followed by the carer asking questions at the end. The session lasted 60 minutes and was described as being an intense emotional experience, helping to reduce feelings of isolation and offering hope that they too could reach the goal of recovery (Rhodes, Brown, & Madden, 2009).

## **Outcome Measures**

The outcome measures used within the studies are detailed within Appendix A. In addition, a number of studies included questionnaires designed for the purpose of the study to evaluate carers views of the usefulness, acceptability and helpfulness of the intervention (Binford Hopf et al., 2013; Cairns et al., 2007; Carlton & Pyle, 2007; Gisladdottir & Svavarsdottir, 2011; Goddard et al., 2011; Grover et al., 2011a; Haltom et al., 2012; Holtkamp et al., 2005; Pasold et al., 2010; Pépin & King, 2013;



Sepulveda et al., 2008a; Sepulveda et al., 2008b). One study also used their own measures to assess eating behaviours and global functioning of the care recipient (Goddard et al., 2011).

## **Effectiveness of the Interventions**

The following is a summary of the literature in relation to how effective the interventions are at improving carer wellbeing and client outcomes. Mechanisms by which the interventions might bring about changes in these outcomes will then be discussed including; caregiving burden, coping abilities and illness maintaining factors. Carers' appraisals of the interventions will then be explored followed by a synthesis of the findings.

### **Carers' wellbeing.**

#### ***Collaborative care skills training workshops.***

Out of the six studies using the collaborative care skills training workshops, the four with the greatest sample sizes found that the intervention led to significant improvements in carer distress as measured by the GHQ-12 (Goddard et al., 2011; Sepulveda et al., 2008a; Sepulveda et al., 2008b; Sepulveda et al., 2010) or the HADS (Goddard et al., 2011). The study using the same intervention on an Australian sample found a non significant improvement in wellbeing, as measured by the GHQ-12, however, those scoring above the cut-off for moderate psychological distress reduced, from 57% before the intervention, to 40% after the intervention and this was maintained at 8 week follow up (Pépin & King, 2013). The DVD version of

this intervention was piloted on 16 carers. Of the 14 who completed the study their wellbeing improved following the intervention, but there was only a trend towards significance ( $p = .08$ ) (Sepulveda et al., 2008a).

### ***Overcoming anorexia online.***

A RCT comparing OAO to a control group (usual support from Beat; an eating disorders charity for clients and carers) found that OAO led to significant benefits in anxiety and depression as measured by the HADS, which was maintained at six month follow up (Grover et al., 2011a). However, only 58% of the intervention group and 37% of the control group completed post intervention measures, possibly due to the minimal direct contact with carers. A small study then piloted OAO as off-line workbooks. A significant reduction in carer distress was observed, as measured by the HADS, which was maintained at 12 week follow up (Grover et al., 2011b). A further RCT compared OAO with and without additional guidance, in the form of weekly email or telephone therapist support, for carers of people with anorexia nervosa. No significant improvements were observed on the DASS or GHQ-28 for either group (Hoyle et al., 2013). This finding may reflect the shorter time (seven weeks as opposed to two to four months) carers had to practice the skills and guidance being provided by a less experienced therapist than in previous evaluations of the same intervention (Grover et al., 2011a; Grover et al., 2011b) or may be related to poor external validity, as this study scored 0/11 on the assessment of methodological quality.

### ***Psychoeducation groups.***

Five monthly psychoeducation groups aimed at reducing expressed emotion helped improve carer distress, as measured by the POMS, although differences were not significant (Uehara et al., 2001).

In summary, all of the studies measuring carers' wellbeing, except one (Hoyle et al., 2013), found improvements following a carer intervention, with the majority reporting a significant improvement.

### **Client outcomes.**

The impact of the carer intervention on outcomes for their loved one was measured in seven studies. Global functioning of the client was observed to improve significantly following carer workshops (Sepulveda et al., 2008c). The same intervention transferred to a DVD format assessed the care recipients' behaviours associated with eating disorders, such as restricting food intake and secretive eating, as measured by the carer, before and after the intervention. Surprisingly, carers who received no telephone coaching sessions reported that their loved ones had significantly greater improvements in eating behaviours than carers who did receive telephone coaching sessions (Goddard et al., 2011). In addition, carers' reports of their loved ones functioning improved following the intervention, and continued to improve at 3 month follow up (Goddard et al., 2011). Group psychoeducation led to a significant improvement in observations of clients eating behaviours and non significant improvements in bulimic-like behaviour and hyperactivity (Gisladdottir & Svavarsdottir, 2011). A similar group (Uehara et al., 2001) also lead to

improvements in the clients eating behaviours, as rated by their family member, along with levels of global functioning as rated by staff.

In Abbate-Daga and colleagues (Abbate-Daga et al., 2013) study, parents with improved coping responses following counselling had daughters with a lower frequency of bingeing and purging than those who had not improved.

Hoyle and colleagues found that OAO led to no significant improvements on a medical outcome measure (Hoyle et al., 2013), whilst percentage ideal body weight did not differ whether parents received a consultation from a veteran parent or not (Rhodes et al., 2008).

In summary, carer interventions for eating disorders appear to have some benefits on client outcomes in terms of improvements in their global functioning and reported eating behaviours. However, there is not yet sufficient evidence to support the impact of carer interventions on clinical outcomes for care recipients.

### **Caregiving burden.**

The EDSIS was validated and found to be sensitive to change following the collaborative care skills training workshops with similar improvements to the ECI negative (Goddard et al., 2011; Sepulveda et al., 2008b; Sepulveda et al., 2008c; Sepulveda et al., 2010) and a non significant improvement in the DVD adaptation of the workshops (Sepulveda et al., 2008a). The same was observed for the off-line and on-line adaptation to OAO intervention, irrespective of whether or not carers received additional telephone coaching sessions, (Grover et al., 2011a; Hoyle et al., 2013). However, no significant changes were observed in the EDSIS and ECI negative when an RCT compared the same intervention to a control group (Grover et

al., 2011a). The authors suggest this was due to a small sample size and large dropout rate resulting in a lack of power to detect change.

In Binford Hopf and colleagues' study (Binford Hopf et al., 2013), the online chat support groups led to a significant change significant changes in the starvation subscale and total score of the EDSIS and in only the stigma subscale of ECI negative. Only one of the studies using the ECI (Grover et al., 2011b) found a significant improvement on positive aspects of caregiving following the intervention, however levels decreased back to pre-intervention levels at follow up.

In summary, a number of studies have found improvements in carers' perceptions of the impact of their loved ones eating disorders following a carer intervention, however, only one study showed significant improvements in positive aspects of caregiving.

### **Coping abilities.**

Relatively few studies aimed to measure abilities to cope with caring for their loved one's illness. Of those that did, changes in coping styles and carers' self-efficacy were examined using various measures. The collaborative care skills training workshops studies in Australia found carers used significantly more adaptive coping strategies following the intervention, maintained these at follow up, and there was a trend towards a reduction in maladaptive coping strategies (Pépin & King, 2013). A DVD version of this intervention found care giving self-efficacy significantly improved (Goddard et al., 2011). However, no changes were observed in social problem-solving skills following the offline OAO (Grover et al., 2011b). A parent-to-parent consultation did not bring about any significant change on parental

efficacy, described as the parents' ability to take control of the illness at home to help their child in the recovery process (Rhodes et al., 2008). This is unsurprising given the brief nature of the intervention, which involved carers listening and reflecting to a veteran carers' story.

In summary, carer interventions appeared to have mixed results on the effect of carers' coping abilities and self-efficacy in coping results were varied. It is possible that this is due to the variety of measures used, measuring different constructs.

### **Illness maintaining factors.**

Carers' high levels of expressed emotion are considered to maintain the eating disorder (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013), so a number of interventions aimed to reduce these.

The studies exploring the effectiveness of the collaborative care skills training workshops revealed similar improvements on carer levels of expressed emotion. One study used the FMSS and found that 55% of carers had high levels of expressed emotion, which significantly dropped to 24% post intervention (Sepulveda et al., 2010). At follow up they found that 35% of carers had high expressed emotion which remained a significant change from baseline. The same Australian intervention found that the number of carers high in critical comments reduced over time, but this change was not significant. However, a significant improvement was found in carers reporting high levels of over-involvement.

A DVD adaptation of the collaborative carer skills training workshops found similar improvements in expressed emotion, maintained at three month follow up,

however, there was no further benefit of receiving additional telephone coaching (Goddard et al., 2011). Similarly, a monthly psychoeducation group in Japan found rates of high expressed emotion decreased significantly from 29% to 4% (Uehara et al., 2001). However, there were no significant improvements in carer and the care recipients ratings of levels of expressed emotion following OAO (Hoyle et al., 2013), although a trend reduction in LEE scores was observed when the intervention was compared to a control group (Grover et al., 2011a). The off-line version of this intervention found a baseline of 37% of carers who rated as high expressed emotion using the FMSS which dropped to 19% following the intervention (Grover et al., 2011b). In contrast, 50% of carers were assessed as having high expressed emotion according to the FQ at baseline which later increased to 66.7% following the intervention. There were also positive changes on the LEE and FQ following group psychoeducation, however only the subscale of 'understanding' showed significance (Gisladdottir & Svavarsdottir, 2011).

Accommodating and enabling behaviours that may further maintain the illness were measured by two studies within the review. Such behaviours were reduced following a DVD intervention aimed at reducing maintaining factors (Goddard et al., 2011), with no further benefit if carers received additional telephone coaching sessions. In contrast, a RCT found no difference between the intervention OAO and a control group on accommodating and enabling behaviours (Grover et al., 2011b).

In summary, carer behaviours believed to maintain eating disorders appeared to significantly reduce following a number of interventions; however this was not the case for OAO.

### **Carers' appraisal of the intervention.**

Of the studies which measured carers' appraisals of the interventions, scores were overall very high. The collaborative care skills training workshops were considered easy to understand and were rated 4.91/5 on a question of whether people would recommend the intervention to others (Pépin & King, 2013). The DVD adaptation was rated on average 8/10 on usefulness of the information and helping with their communication (Goddard et al., 2011).

Psychoeducation and training carer groups were on the whole reported as useful (Carlton & Pyle, 2007; Gisladottir & Svavarsdottir, 2011; Haltom et al., 2012; Holtkamp et al., 2005; Pasold et al., 2010; Zucker et al., 2006). In one study, 88% of carers reported that the information helped them to cope with their child's illness (Holtkamp et al., 2005). In addition, 93% of carers felt the material was understandable and 100% reported having an improved understanding of the treatment process. Of the carers taking part in this study, 98% reported that they would recommend the group to others. Similarly, significant changes were observed following the psychoeducation group in relation to carers' reported understanding of behaviours that maintain eating disorders, knowing what treatment involves and understanding their role in their loved one's recovery (Haltom et al., 2012). Pasold and colleagues (2010) study showed that greater frequency of attending the group was also associated with greater satisfaction with the intervention. Another found that 91% of carers strongly agreed that the group was essential for helping their child to improve and all believed that the group helped them to manage the eating disorder, that they had become a better parent and that they would recommend to others (Zucker et al., 2006). Online chat support sessions were similarly well recommended



(Binford Hopf et al., 2013). Parents found the sessions helped them to cope with their child's illness and implement family therapy more effectively. Meal support training was also deemed informative by parents (Cairns et al., 2007).

The majority of carers within the two Sepulveda studies also believed that the interventions had helped improved their stress levels (Sepulveda et al., 2008a; Sepulveda et al., 2008b).

## **Summary**

Interventions aimed solely at carers of people with eating disorders on the whole appear to improve carers' wellbeing. There were also some reported improvements in client functioning and eating behaviours, although no evidence was found to support improvements in client clinical outcomes. Overall carers reported positive views of the interventions although the way this data was collected may have inhibited them from being more critical.

Eating disorders lead to changes in interactions between family members as families reorganise themselves to try and support their loved one. Many of these changes are often considered problematic, such as high levels of expressed emotion and accommodating and enabling behaviours, as they have been shown to maintain the illness and lead to increased carer distress and impairments in client functioning (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013).

All of the interventions described within this review offer carers one or more of the following:

- Knowledge - psychoeducation and information about eating disorders; the risks, course and outcomes.

- Emotional Support - allowing carers to express their feelings in a supportive environment.
- Sharing experiences - to help carers know that they aren't alone.
- Skills - teaching carers adaptive techniques to help their loved one.

Interventions that offer knowledge about eating disorders are likely to empower carers so that they have the confidence and self-efficacy required to effectively support their loved one. An improvement in carers' self-efficacy may result in a reduction in the perceived burden of caring for their loved one and thus an improvement in the carer's wellbeing. Supportive interventions allow carers to express their emotions and are likely to help carers to cope more effectively with the impact of the eating disorders and reduce strong emotions within the home environment, linking to improvements in both the carers' wellbeing and improvements in outcomes for their loved ones.

Thirteen of the twenty studies involved interventions where the carers met other carers or veteran carers, and it is likely that some of the remaining interventions which involved DVDs, workbooks and online modules included stories from other carers. Hearing other carers' stories is likely to help reduce feelings of isolation, helping the carers to feel more confident and reduce the perceived burden, which in turn may help to improve their wellbeing (Hoyle et al., 2013). Many of the interventions also trained carers in skills either aimed at reducing maintaining behaviours (expressed emotion, accommodating and enabling behaviours) or general coping skills, such as problem-solving. Developing skills in adaptive behaviours is likely to reduce carer burden (Coomber & King, 2013, 2013) and improve carer wellbeing (Coomber & King, 2013). The review suggests some evidence that the

interventions can improve client outcomes, although it is possible that studies which measured client outcomes did not allow enough time for carers to practice skills. Therefore, a later follow up of client outcomes is recommended. Improving carer wellbeing is also likely to reinforce the use of adaptive responses as carers will feel more able to put some of their learned skills into practice. The model below has been developed to consider the mechanisms which may have brought about these changes in carer and client outcomes (Figure 3). It is worth noting that the associations between factors, including those that are empirically supported, cannot be assumed to be causal.

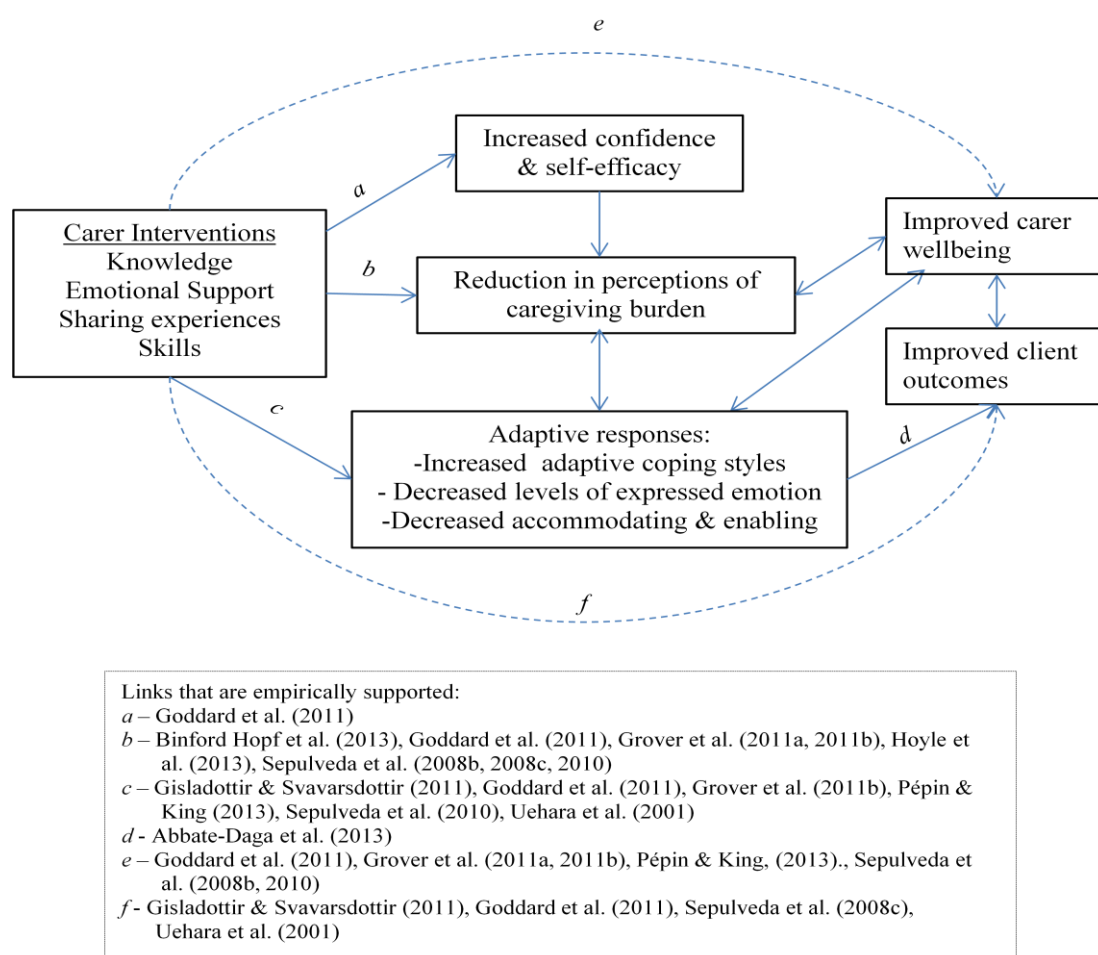


Figure 3. Proposed model of mechanisms of carer interventions for eating disorders.

Considering which interventions are likely to be more or less effective is beyond the scope of this current review, however it is likely that the most effective interventions include all of the core ingredients of offering knowledge, support, a space to share experiences as well as teaching skills aimed at improving coping and reducing behaviours known to maintain the illness.

## **Discussion**

The current review aimed to determine whether interventions for carers of people with eating disorders help to improve their wellbeing and outcomes for their loved ones, and consider their appraisals of these interventions. On the whole, the studies included within this review suggest that these interventions are useful at improving carer distress and some limited evidence to suggest that they can also positively impact on their loved one. In addition, carers appraise these interventions as helpful and agreed that they improved their skills and reduced their stress levels.

A variety of interventions have been described, however they all appear to offer at least some, if not all, of the following ingredients; knowledge of eating disorders, support, sharing experiences with other carers and learning new skills to help care for their loved one. These factors appear to increase carers' confidence and self-efficacy, reduce perceptions of carer burden, which in turn leads to more adaptive responses of reducing illness maintenance behaviours and putting new skills into practice. I propose that it is these mechanisms that lead to a reduction in carer distress and improvements in client outcomes. However, a number of studies found either no changes, possibly explained by poor methodological quality, or non-significant improvement, perhaps due to small sample sizes resulting in insufficient

power to detect effects. In addition, client outcomes were frequently rated by the carers so should be considered with caution as carers are likely to expect these outcomes to improve following the intervention, and may be inhibited in reporting less positive outcomes.

A number of limitations to this review need to be considered within the context of these results. Overall the studies included within the review were of low methodological quality, particularly due to small sample sizes and only two of the studies reported that they had conducted power analyses (Grover et al., 2011a; Grover et al., 2011b). The majority of studies either failed to report sampling methods or used convenience samples, limiting the ability to generalise their findings and the possibility that the samples are not representative of the whole eating disorders population. Only four of the studies included a control group (Carlton & Pyle, 2007; Goddard et al., 2011; Grover et al., 2011a; Rhodes et al., 2008). Studies lacking a control group fail to rule out alternative explanations for their findings, such as the effects of adjunctive treatments that carers and their loved ones may also have been receiving. The majority of studies reported carers who dropped out of the study, however only one study compared drop outs to completers (Abbate-Daga et al., 2013). It is likely that those that drop out of the study are more likely to have found the intervention unhelpful. In addition, none of the studies in the review examined differences between those who agreed to take part and those who did not. It is possible that those who agreed to take part were more motivated and engaged in the intervention, leading to improved scores. Five of the six studies using the collaborative care skills training workshops came from the site where the approach originated from, possibly leading to a bias from allegiance effects. Carers may also have felt pressured into rating interventions positively to the team who delivered it,

and it was unclear from the studies whether these measures were completed anonymously. In addition, a number of studies used more than one carer of the same client (e.g. mother and father) causing problems associated with a lack of independence. Finally, the majority of studies failed to fully describe their sample characteristics. A number of the studies did not report the relationship of the carer or the characteristics of the carers, such as age and gender. Most of the studies reported the age of their loved one, however just over half of the studies failed to report the clients' gender. It is also worth considering that several studies were missed from this review due to being written in a language other than English and limitations of databases providing all possible articles. In addition, studies reporting non-significant findings are less likely to be published due to publication bias, and therefore were not considered within this review.

A number of confounding variables were not controlled for, which was reflected in the low quality assessment ratings. Client factors including; diagnosis, age, inpatient vs. outpatients, gender and illness duration, as well as carer factors including; how they are related, age, gender, education and employment history, and amount of contact time all may have influenced results. For example, one study found that relatives who lived with their loved one had greater benefits from the carer intervention (Sepulveda et al., 2008a). In addition, greater adherence to the intervention led to improvements in expressed emotion, accommodating and enabling behaviours (Goddard et al., 2011).

This review is of importance as it supports the cognitive-interpersonal maintenance model of anorexia nervosa (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013), as interventions aimed at educating and offering skills to carers to reduce behaviours that are considered to maintain the eating disorder, have led to

improvements in client outcomes. Considering carers' wellbeing is also important so that they can continue to support their loved one and not become unwell themselves. Therefore, it would appear that carer interventions are a useful adjunct to the treatment of eating disorders. Carer interventions should consider the core ingredients of helping carers to improve their knowledge and develop specific skills to reduce the maintenance of the eating disorder and improve their ability to cope, within an environment of offering emotional support and a chance to share experiences with one another.

Future research should consider improving the quality of the interventions and using control groups of carers who receive treatment as usual. In addition, studies should look at the impact on client outcomes, including eating disorder symptoms, and longer follow up periods, allowing time for carers to practice the skills they develop as a result of the intervention. In fact, research is currently underway that considers all of these factors, comparing ECHO with treatment as usual on carer distress and time until relapse post-discharge with a follow-up period of a year (Goddard et al., 2013). Further RCTs would help to support the use of carer interventions. It may also be worthwhile researching some of the direct links from the proposed model, such as whether improving adaptive responses directly improves carer wellbeing. Evidence should also compare group workshops, individual support and self-help in terms of outcomes for both the client and the carer whilst also determining optimal length of treatment. It would also be beneficial for research to focus on determining the most cost-effective approach of delivering these interventions to support their inclusion within guidelines for the treatment of eating disorders.

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## **Part 2: Empirical Paper**

### **The Effect of Visuospatial, Verbal and Somatic Tasks on the Post-Meal Experience of Hospitalised Patients with Eating Disorders**

## **Abstract**

- Aims:** This study compares the effects of various tasks on post-meal negative affect of hospitalised patients with eating disorders. Other investigated effects include positive affect, intrusive thoughts, intrusive images, difficulty in coping and perceived task helpfulness.
- Methods:** Twenty-two participants were recruited from an eating disorder inpatient ward, rehabilitation unit and day hospital and were randomised to one of four tasks for 15 minutes: the game ‘Tetris’ (visuospatial), a general knowledge ‘Quiz’ (verbal), ‘Braille’ translation (somatic) and ‘Sitting Quietly’ (control). Immediately following meals, over a two or four week period, participant’s accessed the tasks and pre-post questionnaires online.
- Results:** The visuospatial, verbal and somatic tasks had beneficial effects on all positive and negative indicators, when compared with a non active control condition. Visuospatial and somatic tasks were more effective at reducing intrusive imagery than the verbal task.
- Conclusions:** The results suggest that engaging activities can help hospitalised patients with eating disorders manage the difficult post-meal period.

## **Introduction**

### **The Post-Meal Experience**

Mealtimes can be an extremely anxiety provoking time for those with an eating disorder (American Psychiatric Association [APA], 2000) resulting in symptoms of both anxiety and depression (Lawson et al., 2013). Even just thinking about food has been shown to result in negative affect for people with anorexia nervosa and bulimia nervosa (Rawal, Williams, & Park, 2011; Shafran & Robinson, 2004; Shafran, Teachman, Kerry, & Rachman, 1999), and the sight of food can also elicit feelings of disgust and fear in women with abnormal eating attitudes (Harvey, Troop, Treasure, & Murphy, 2002). The time after meals can leave people feeling distressed as they consider the food they have just eaten (Shapiro et al., 2008). Post-meal anxiety levels have also been shown to correlate with body mass index (BMI), with lower BMI associated with the greatest anxiety (Robinson et al., 1983).

People with eating disorders can also feel physically uncomfortable during the post-meal period (Sharp & Freeman, 1993), due to delayed gastric emptying (Hadley & Walsh, 2003; Holt, Ford, Grant, & Heading, 1981). Some describe feeling physically sick and unable to fit more food in (Long, Wallis, Leung, & Meyer, 2012). These factors are likely to increase anxiety around mealtimes.

Due to the psychological and physiological experiences at mealtimes, it is not uncommon for patients to elicit unusual behaviours such as the concealment of their food and to experience a desire to compensate for eating, through purging and exercising (Tappe, Gerbery, Shide, Andersen, & Rolls, 1998). As the primary goal of eating disorder inpatient units is to help patients gain weight and improve their eating



behaviours, these unusual and compensatory behaviours require some degree of management (Geller, Williams, & Srikameswaran, 2001). Therefore, inpatients are frequently supervised and restricted in their activities following meals, which is likely to heighten their levels of distress and discomfort.

### **Current Post-Meal Interventions**

National Institute of Clinical Excellence (NICE, 2004) guidelines in the UK acknowledge that eating disorder services vary widely in their service delivery, with inpatient units having no standardised guidelines for how to implement mealtimes. Most rely on clinical judgement to determine how they should conduct mealtimes (Gowers et al., 2002). A study assessing mealtime practices in the UK found that almost half offered a post-meal activity (Long, Wallis, Leung, Arcelus, & Meyer, 2012). Activities varied between and within-units and included; individual supervision, community meetings, support groups and specific meal-related reflection.

Only two studies have put forward suggestions of specific activities that might be useful during the post-meal period, both of which have aimed to reduce anxiety. Breiner (2003) described positive feedback from service users and staff within an eating disorder unit when arts and crafts activities were used as post-meal distractions, such as fabric painting, bracelet making and sculptures. Unfortunately no formal evaluations were used in this research, limiting the validity of their findings.

Alternatively, relaxation techniques used after meals, such as progressive muscle relaxation, guided imagery and self-directed relaxation have shown to be

effective in reducing anxiety, feelings of fullness and thoughts about weight following meals (Shapiro et al., 2008). However, the treatment as usual group in this study, which involved choosing an activity of their choice such as reading, word puzzles or arts and crafts, also showed positive outcomes, which may reflect a similar benefit to relaxation. These exploratory and relatively descriptive studies provide some evidence for the benefit of engaging in activities during the post-meal period, although the evidence is limited due to poor methodological quality and lacking a theory driven approach. Reports from the clinical experience of staff within one inpatient unit confirm that distracting activities, such as puzzles and board games have helped children and adolescents with eating disorders delay difficult thoughts and urges during the post-meal period (Leichner, Standish, & Leichner, 2005).

### **Feeling Fat**

The underlying processes that underpin post-meal distress in people with eating disorders are not fully understood. What is known is that people with eating disorders repeatedly report feeling fat and disliking the feeling of fullness (Fairburn, 2008). They often equate the feeling of fullness with *being* fat (Fairburn, 2008) and serves as a diagnostic criteria for anorexia nervosa (APA, 2000). However, feeling fat is believed to be more than just a perception of being overweight (Tiggemann, 1996). Feeling fat has been associated with distress, bodily sensations and images (visual, auditory, olfactory, movement and tactile) and negative self-beliefs (Cooper, Deepak, Grocutt, & Bailey, 2007; Cooper, Todd & Turner, 2007). When describing the last experience of feeling fat typical thoughts reported by people include ‘I am fat’, ‘I am bloated’, ‘I am overweight’ with people with anorexia nervosa finding

these thoughts more distressing and more true than a group of dieters and a group of non-dieters (Cooper, Deepak, Grocutt, & Bailey, 2007). It is these automatic negative thoughts which are often challenged within cognitive therapy for eating disorders (Andersen, 2007). Visual images were similar among the groups and included imagining themselves walking down the street looking bigger than others, or imagining pictures of thin people. Bodily sensations were also similar among the groups and included the sensation of their blood slowing down or feeling their waistline pressing on their body.

One theory suggests that feeling fat results from a misinterpretation of particular emotions of depression, anxiety or guilt and bodily sensations of feeling full, bloated, sweaty (Fairburn, 2008; Murphy, Straebl, Cooper, & Fairburn, 2010). These sensations then lead the individual to develop cognitions, which they may perceive as reality – specifically, the feelings are misinterpreted as being or becoming fat. This is akin to thought-shape fusion, a cognitive distortion commonly associated with eating disorders where merely just thinking about food leads to the person thinking they are fat and feeling fat (Shafran et al., 1999). This process may be similar to what is seen in anxiety disorders in that a social phobic might misinterpret the bodily sensation of anxiety, imagine their cheeks are bright red and then believe that this is the case.

Considering this theory, it is possible that distress after mealtimes (the experience of feeling fat) is a result of misinterpreting bodily sensations, such as the stomach stretching, which leads to a variety of images such as an overly expanded stomach. This is then viewed as evidence for the feared catastrophe: rapid weight gain. Therefore, one possible way to reduce distress during the post-meal period may involve interrupting the processing of feeling fat either through interrupting intrusive

imagery, intrusive thoughts or somatic experiences. Studies within the Post-traumatic Stress Disorder (PTSD) literature have considered a similar approach of interrupting intrusive imagery to reduce later flashbacks and are discussed below.

### **Intrusive Imagery and Working Memory**

Intrusive imagery is a distressing and common feature of many mental disorders (Harvey, Watkins, Mansell, & Shafran, 2004). Intrusions are spontaneous and involuntary retrievals of real or imagined events (Brewin, Gregory, Lipton, & Burgess, 2010).

A working memory approach has been used to understand mental imagery (Baddeley & Andrade, 2000). The model consists of the central executive system which coordinates two subsystems: the visuospatial sketch pad storing visual and spatial information, and the phonological loop storing verbal and auditory information (Baddeley & Hitch, 1974). As these subsystems have limited capacity, concurrent modality specific processing, such as engaging in visual or verbal tasks has been shown to disrupt representations held in these associated systems (Baddeley & Andrade, 2000). For example, a tapping task, which loads on the visuospatial sketchpad, reduced the vividness of visual images of recently presented novel patterns. In the same study, a counting task, loading on the phonological loop, reduced vividness of auditory images (Baddeley & Andrade, 2000).

Trauma flashbacks are a type of intrusive memory common in PTSD. Eye movement desensitisation and reprocessing (EMD-R) has shown to help people with PTSD (Shapiro, 1989). One theory suggests that EMD-R reduces the vividness of distressing images by disrupting processing within the visuospatial sketchpad of

working memory (Andrade, Kavanagh, & Baddeley, 1997). To test this theory, healthy participants were asked to imagine distressing events whilst performing eye movement and spatial tapping tasks (Andrade et al., 1997). When engaging in these visuospatial tasks participants reported a reduction in distressing imagery and their emotional impact.

Brewin and colleagues, (Brewin, Dalgleish, & Joseph, 1996) proposed the dual-representation theory to explain the nature of trauma flashbacks in PTSD. They suggest that there are two memory systems in which trauma memories are processed, thereby creating two separate representations. The verbally accessible memory (VAM) system processes conscious trauma experiences that can be deliberately retrieved. These VAM memories only hold information that has consciously been attended to. Non-conscious memories are processed in the situationally accessible memory (SAM) system, which cannot be voluntarily accessed. The theory suggests that only external environmental reminders, or internal mental processes, trigger intrusive images of the trauma. Encoding into the VAM requires verbal processes whilst the SAM system involves visuospatial encoding.

Therefore, the dual-representation theory would predict that verbal tasks will interfere with verbal processing of traumatic memories, thus increasing intrusion frequency, whilst a visuospatial task will decrease intrusion frequency by interfering with the processing of visuospatial flashback memory consolidation (Brewin & Saunders, 2001). Studies using the trauma film paradigm have tested this prediction out.

The trauma film paradigm allows a prospective experiment to investigate how intrusions can be manipulated through cognitive mechanisms (Holmes & Bourne, 2008). Healthy participants watch a traumatic video and later record their

intrusive memories. Participants performing a visuospatial tapping task during the film reported significantly fewer intrusive memories than a non-task control condition (Brewin & Saunders, 2001; Holmes, Brewin, & Hennessy, 2004), whereas a verbal distraction task (counting backwards in threes) has shown to increase memory intrusions (Holmes et al., 2004). These findings support the dual-representation theory. In addition, a visuospatial task which involved participants making shapes from modelling clay, whilst watching a traumatic video, again led to a reduction in later intrusive memories of the film (Stuart, Holmes, & Brewin, 2006).

To prevent the development of PTSD flashbacks, a 'cognitive vaccine' has been proposed (Holmes, James, Coode-Bate, & Deerprouse, 2009). The researchers considered using a visuospatial task after the traumatic film, followed by participant recordings of later flashbacks. The computer game Tetris, in which players are required to rotate falling geometric shapes to form horizontal lines, was used as a good example of a fairly pure visuospatial task (Green & Bavelier, 2003). Holmes and colleagues (2009) used Tetris as a task that might compete for resources with trauma flashbacks, compared with a control condition, and asked participants to keep a diary of their flashbacks for one week. Those in the visuospatial condition reported significantly fewer flashbacks. A further study found that a verbal quiz appeared to increase flashbacks in the following week (Holmes, James, Kilford, & Deerprouse, 2010). They attributed their findings to the dual-representation theory, the verbal task prevented participants from verbally processing the trauma video. They also described their findings as evidence that the Tetris game was not simply a distraction of attention from the traumatic material.

Pearson and Sawyer (2011) showed traumatic images to participants and found that irregular tapping was equally as effective as the verbal task of generating

random numbers for reducing later intrusions. As only the more challenging (higher executive load) tasks significantly reduced intrusions they reported that the tasks created demand on the central executive component of working memory (Baddeley & Hitch, 1974). Their findings contradicted the results of Holmes and colleagues (Holmes et al., 2010), who found that a verbal task increased flashbacks. This may reflect a difference in their choice of verbal task, as generating numbers may not have loaded on the visuospatial component of working memory to the same extent as a verbal quiz; therefore only impacting on the central executive component.

### **Interrupting Processing of Feeling Fat**

The PTSD literature suggests that certain tasks affect processing of traumatic material and reduce intrusive imagery. Specifically the evidence suggests that visuospatial tasks reduce intrusive imagery whilst verbal tasks increase it, supporting the dual-representation theory (Holmes et al., 2009, 2010). However, some evidence also supports the view that tasks are simply a useful distraction which create demand on the central executive component of working memory (Pearson & Sawyer, 2011), limiting its capacity to process other information (Baddeley & Hitch, 1974).

On an eating disorder unit, mealtimes and the post-meal period are known to be particularly difficult times for patients, possibly because the experience of ‘feeling fat’ is at its greatest. It may be possible to interrupt the processing of feeling fat using a similar approach to that used within the PTSD literature, either using a visuospatial task that may interrupt processing of intrusive imagery, a verbal task to interrupt processing of intrusive thoughts or a somatic task, which may interrupt processing of

somatic experiences within the body. This may shed light on suitable activities to help with the difficult post-meal experiences within eating disorder units.

### **Aims and Hypotheses**

The primary aim of this study is to compare a control condition (sitting quietly) with visuospatial, verbal and somatic tasks on self reported negative affect, during the post-meal period, within an eating disorder unit. Secondary aims are to examine self-reported changes in positive affect and perceived post-task levels of intrusive thoughts, intrusive imagery, difficulty in coping, and helpfulness of the tasks. Perceived task enjoyment, difficulty and ability to focus will also be compared for each task and considered as potential moderators of negative affect.

The hypothesis is that all of the tasks will help with the post-meal experience compared to the control condition by reducing negative affect, increasing positive affect and improving levels of intrusive thoughts, intrusive imagery, difficulty in coping and task helpfulness. As this is a novel paradigm it is unknown whether one task will be more helpful than another. However this study may highlight mechanisms for ‘feeling fat’ by revealing whether one kind of task interrupts distressing post-meal processing more successfully than another and provide evidence of how best to clinically help patients during this difficult time.



## **Method**

### **Participants**

Participants were recruited from three hospital units within the same eating disorders service: an inpatient ward, a rehabilitation unit and the day hospital. Day patients at the rehabilitation unit were not invited to take part as they were only in the service to attend appointments and groups and were often not available at mealtimes. Participants were required to be between 18-65 years old and were excluded if they were unable to speak English fluently, had a moderate to severe learning disability, were on bed-rest or were imminently being discharged. Participants could have any diagnosis seen within the service (most commonly anorexia nervosa, and eating disorders not otherwise specified, but occasionally severe cases of bulimia nervosa). All eligible participants were invited to take part in the research, conducted between September 2013 and April 2014.

### **Setting**

The Eating Disorders unit comprises of; inpatient treatment, a stepped down residential facility, day hospital treatment and outpatient treatment. There are approximately 1,000 referrals and 650 patients in treatment a year. An audit of the service found that between 2006 and 2011 there were 278 inpatient admissions of whom 86% (240) had a primary diagnosis of anorexia nervosa, 6% (17) severe bulimia nervosa and 8% (21) with eating disorders not otherwise specified (Lawrence, Kyrtatos, Friddin, & Johnson-Sabine, 2011). Almost all admissions were

female (95%), the average age was 30 and the average body mass index (BMI) at admission was approximately 14.

During their stay, patients from the ward and rehabilitation unit are supervised eating three meals and two snacks a day, seven days a week, unless they are granted leave. Following meals, ward patients either attend therapy groups or are supervised for 30 minutes, in a communal room, where they are free to watch television or engage in activities such as reading and knitting. Patients within the rehabilitation unit are supervised less strictly following meals, and are free to return to their room, although a member of staff remains on site. Day hospital patients typically arrive at the hospital at 10am and leave between 3-4pm. They are only supervised eating lunch, after which they engage in a 30 minute informal group reflective discussion, facilitated by staff. Participants did not attend the group reflective discussion when taking part in the research.

## **Design**

This study is a within-subjects design. Following their meal (breakfast, lunch or dinner) whilst on the unit, participants were assigned to one of four tasks; either a visuospatial, verbal or somatic task, or a control condition. Each task lasted 15 minutes. Participants within the inpatient ward and rehabilitation unit completed each task three times, over a two-week period, and were free to choose whether they completed the task following breakfast, lunch or dinner. Day hospital participants, who could only complete the tasks following lunch, were given one month to complete the study. In total, participants completed 12 post-meal tasks.

So that participants could complete the study in their own time, an online programme was developed where participants' responses were submitted to an online password protected database.

## **Tasks**

The visuospatial and verbal tasks were similar to those used in studies conducted by Holmes and colleagues (Holmes et al., 2009, 2010), and only differed so that the tasks could be accessed online.

### **1. Visuospatial task - Tetris**

The visuospatial task required participants to play the computer game Tetris (<http://www.palmantics.com/games/tetris/>). This was a slightly different version to the one used in the Holmes and colleagues study (Holmes et al., 2009, 2010) so that the game could be played online and free from adverts. The scoring system and number of levels were the only differences between the two versions.

Participants were required to use the cursor keys to rotate falling geometric blocks with the aim of creating a complete horizontal row of blocks at the bottom of the screen. Following an accumulation of ten complete rows, the game progresses to the next level where the blocks fall faster until they reach level ten where they can progress no further. The game stops when the blocks reach the top of the screen. If this happened within 15 minutes, participants are asked to restart the game. Scores throughout the game were visible to participants only (see Appendix B for a screen shot of the game).

## **2. Verbal task – Quiz**

The verbal task involved participants completing a computerised general knowledge Quiz, designed specifically for the study. A spreadsheet of questions and answers were obtained online. The quiz used in the Holmes and colleagues study (Holmes et al., 2010) was only accessible offline. Essentially the games were identical except for the aesthetics of the programme design, with the one used in this study having a simple plain background with no animation or images, and the questions themselves were different, although on similar general knowledge topics. Participants were required to select one answer from four possible choices at a time on various general knowledge topics. Questions relating to food and drink were not included as they may have increased food and body-related experiences. Following each response, participants received feedback on whether they answered correctly, but were not given a total score at the end. Three separate quizzes were used for each session<sup>1</sup>, with over 700 questions in each (enough to ensure that participants would not finish the Quiz within 15 minutes). Participant responses and response times for each question were submitted to the online database (see Appendix C for a screen shot of the Quiz).

## **3. Somatic task - Braille**

The somatic task involved participants using their fingertips to translate a random list of Braille letters into letters of the English alphabet. An A4 sheet of up to 143 Braille letters were placed within a sealed box that participants could put their hand inside, so that they would be unable to see the Braille. The Braille letters were arranged using an online random letter generator. On top of the box was a key card

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<sup>1</sup> Throughout the empirical paper ‘session’ refers to one of the three occasions they completed the same task, whilst ‘trial’ refers to any one of the twelve occasions they completed the tasks.

so that participants were able to translate the letters. They were also provided with an answer sheet, which had a choice of three possible answers for each letter. A separate box and answer sheet were used for each session of the task, with a new randomisation of letters. Participants were not given feedback on how well they were doing, although they could see how many items they had completed and how many were remaining. If they completed the sheet within 15 minutes they were asked to check over their answers until the time elapsed (see Appendix D for photographs of the materials used in this task).

#### **4. Control – Sitting Quietly**

For this task participants were asked to remain seated, and not engage in any activities, such as talking to others or reading. However, if participants found it particularly difficult to cope with the post-meal experiences during this time then they could engage in any activity that they found helpful. At the end of the task the online programme asked participants a question as to whether they were able to sit quietly for the duration of the task, and if not they were asked to describe what they did instead.

#### **Piloting**

The Tetris, Quiz and Braille tasks were initially piloted on four people to help finalise their details. They were aged between 27 and 30, and all educated to degree level. Feedback that the Quiz questions were too hard resulted in the final version consisting of a series of about 80 easier questions to begin with. In addition, it was deemed more straightforward to use the keys 1-4 than to choose each answer with

the cursor. The Braille was initially put in an envelope, for participants to place their hand inside, however feedback suggested this was awkward. The sheet of Braille letters were therefore secured to the inside of a cardboard box file for easier access. The Braille task originally required the participant to translate each letter from the possible 26 letters of the alphabet; however, this design was deemed too difficult and frustrating. Therefore the score sheets were adjusted so that participants had a choice of three possible letters to choose from. Piloted individuals also reported easily losing their place and therefore, tactile markers (paper fasteners) were used to help participants differentiate each line of letters. The Tetris game was considered relatively easy compared to the other tasks, so following the initial pilot we requested participants start at Level 5.

Following these changes the tasks were then piloted on four additional people to ensure consistency in ratings of task enjoyment and difficulty. Those that were piloted were asked how much they enjoyed the task and how difficult they found the task using a Likert scale from 1, very slightly or not at all, to 5, extremely. Tasks were deemed similar enough if they did not vary by more than 2 points for each question. Table 1 shows that there was little variation in mean scores, so no further changes were made to the tasks.

Table 1

*Piloted Participants Ratings*

Measure	Tetris	Quiz	Braille
Enjoyment, mean	3.25	2.50	3.50
Difficulty, mean	2.25	3.50	3.25

## Measures

- Positive and Negative Affect Scale (PANAS)

The PANAS (Watson, Clark, & Tellegen, 1988) consists of 20 items of positive and negative affect. Each item requires the respondent to rate from very slightly or not at all (1) to extremely (5) of how much they are feeling each item at that very moment. To score the positive affect a total of 10 items are summed, with higher scores representing greater positive affect. Sample items include: interested, excited and strong. To score the negative affect, a total of 10 items are summed, with higher scores representing greater negative affect. Sample items include: distressed, upset and guilty. The PANAS was completed by participants immediately before and after each trial of the task to measure changes in affect. The measure has been validated among adult samples, with alpha coefficients ranging from 0.84 to 0.90 (Watson et al., 1988).

- Post-task questionnaire

A questionnaire was designed for the purpose of the study (see Appendix E). The questionnaire was presented online, following completion of the task and the post PANAS questionnaire. Using the same rating scale as the PANAS, participants were asked to measure the intensity of body and fatness related intrusions they experienced during the task ('intrusive thoughts' and 'intrusive images'), how difficult they found coping during the task ('difficulty coping') and how much they found the task helped with the post-meal experiences ('helpfulness'). They were also asked, using the same rating scale how much they enjoyed the task ('enjoyment'),

how difficult they found the task itself ('difficulty') and how much they were able to focus on the task ('focus').

- Eating Disorders Examination Questionnaire (EDE-Q)

The EDE-Q (Fairburn & Beglin, 1994) is a 28-item self-report questionnaire assessing eating disorder attitudes and behaviours. Questions require respondents to rate how often over the past four weeks they have had a particular attitude or engaged in a particular behaviour, for example 'Have you had a strong desire to lose weight?' and 'How dissatisfied have you been with your weight?' Means are calculated based on certain questions to create the following subscales: restraint, eating concern, weight and shape, with scores ranging from 0-6. A global score can be calculated by taking an average of the subscales. The EDE-Q has shown to have good internal consistency within a community sample, with an alpha coefficient of 0.9 for the total score (Peterson et al., 2007), good concurrent validity and acceptable criterion validity (Mond, Hay, Rodgers, Owen, & Beumont, 2004).

- Patient Health Questionnaire (PHQ-9)

The PHQ-9 is a self-report, 9-item measure of depression over the last two weeks (Kroenke, Spitzer, & Williams, 2001). Respondents rate how much each symptom is bothering them on a scale from not at all (0) to nearly every day (3). Example items include: 'Little interest or pleasure in doing things' and 'Feeling down, depressed or hopeless'. Each item is summed to give a total score. The PHQ-9 has been shown to have good reliability and validity (Kroenke et al., 2001).



- General Anxiety Disorder assessment (GAD-7)

The GAD-7 is a self-report, 7-item measure of anxiety over the last two weeks (Kroenke et al., 2007). Rating and scoring is the same as the PHQ-9. Example items include ‘Feeling nervous, anxious, or on edge’ and ‘Not being able to stop or control worrying’. It has been shown to be a reliable and valid measure of anxiety in the general population (Löwe et al., 2008).

## **Procedure**

All eligible participants were approached and invited to an initial one-to-one meeting, lasting approximately 30 minutes, to discuss the research. Posters were also displayed within each unit highlighting the nature of the research (see Appendix F). Those who expressed an interest were provided with an information sheet (see Appendix G). During the initial meeting, details of the study were discussed and there was an opportunity for participants to ask questions. Participants then completed a consent form (see Appendix H). A time was then arranged to meet again to practise the tasks. Following informed consent, information on participants’ demographic data (age, ethnicity, occupation, diagnosis, illness duration and current time at the unit), body mass index and routine clinical measures (EDE-Q, GAD-7 and PHQ-9) were taken from their records and the responsible clinician was informed of their participation in the study (see Appendix I for clinician information sheet and Appendix J for letter to clinician).

Participants accessed the online programme using a laptop and dongle (to access the internet). Participants without their own personal laptop or dongle were provided with one for the duration of the study. During the second meeting,

participants familiarised themselves with the online programme and practised completing the online questionnaires and tasks. This meeting lasted approximately half an hour. They were each given a folder that included instructions for the study (see Appendix K) and answers sheets for the Braille task (see Appendix D). Participants were reminded that they needed to complete the online programme on 12 separate occasions following their meals within a two week period (one month for day hospital participants).

Immediately following any of their meals whilst on the unit, when they had no other scheduled activity or appointments, participants accessed the online programme. Participants on the ward were required to complete the programme whilst in the supervised communal area and participants from the rehabilitation unit could use the lounge or their bedroom. Participants from the day hospital did not attend the informal group reflection so that they could participate in the study, usually in another room. The online programme began by asking which meal they had just eaten followed by the PANAS. At this point they were told whether they were randomised to the Tetris, Quiz, Braille or Sitting Quietly task. If they were randomised to the Braille task they were reminded to have the box and answer sheets ready in front of them. Both the Tetris and Quiz tasks were completed within the online programme. For the Braille task and Sitting Quietly task they were presented with a blank screen. They then completed the task that they were randomised to for 15 minutes. Each task included a count-down timer at the top of the screen and a brief alarm to signal the end of the task. The Tetris and Quiz tasks would then automatically stop. Participants then completed the PANAS again and the post-task questionnaire. Finally, participants had the option of reporting any problems they had encountered whilst completing the online programme via a comments box. Any

problems that were deemed to have a significant impact on the trial led to a removal of that trial's data from the analysis.

Participants on the ward or rehabilitation unit would repeat this procedure following any 12 meals (breakfast, lunch or dinner) of their choice, as long as they were on the unit and did not have any other scheduled activity, over a two week period. Participants at the day hospital repeated the procedure following any 12 of their lunches over a month. Participants' progress was reviewed up to twice a week, to ensure any difficulties were promptly resolved. In the event of participants on the ward or rehabilitation unit being unable to complete the study in two weeks, due to unforeseen circumstances (such as sickness) they were given the option to continue the study for up to two additional weeks.

## **Randomisation**

Participants were randomised to the tasks using the Latin Square method (Dénes, 1974). This ensured that each participant completed each task three times, in a random order. Furthermore, across participants, each task was equally likely to occur for each of the twelve trials.

## **Power Analysis**

This study used a quantitative within-subjects design. The primary focus was to determine the effect of various tasks on post-meal experiences, compared to a control condition. Therefore within-subjects paired sample t-tests comparing treatment to control conditions was used. An effect size of  $d=1.16$  was calculated from previous

literature (Holmes et al., 2010) using the same intervention. For 80% power to detect this effect at alpha of 0.05, a sample of 24 (8 per pairwise comparison) was required. This was calculated using G\*Power (Faul, Erdfelder, Lang & Buchner, 2007).

## **Statistical Analyses**

For the primary outcome (change in PANAS negative) and secondary outcomes (change in PANAS positive, intrusive thoughts, intrusive images, difficulty in coping and perceived helpfulness of the task) repeated measures ANOVAs were used, with within-subjects factors of task and session (either the 1<sup>st</sup>, 2<sup>nd</sup> or 3<sup>rd</sup> time they completed the task). In addition, a repeated measure ANOVA was also used when comparing task performance across the three sessions. Where the assumption of sphericity was violated the Greenhouse-Geisser correction was applied. Finally, a Pearson's correlation was applied when comparing PANAS negative with other outcome variables. Participants who completed fewer than 75% (9/12) of the trials were excluded from the study. Those who completed more than 75% but did not complete the study were included within the analysis.

## **Ethics**

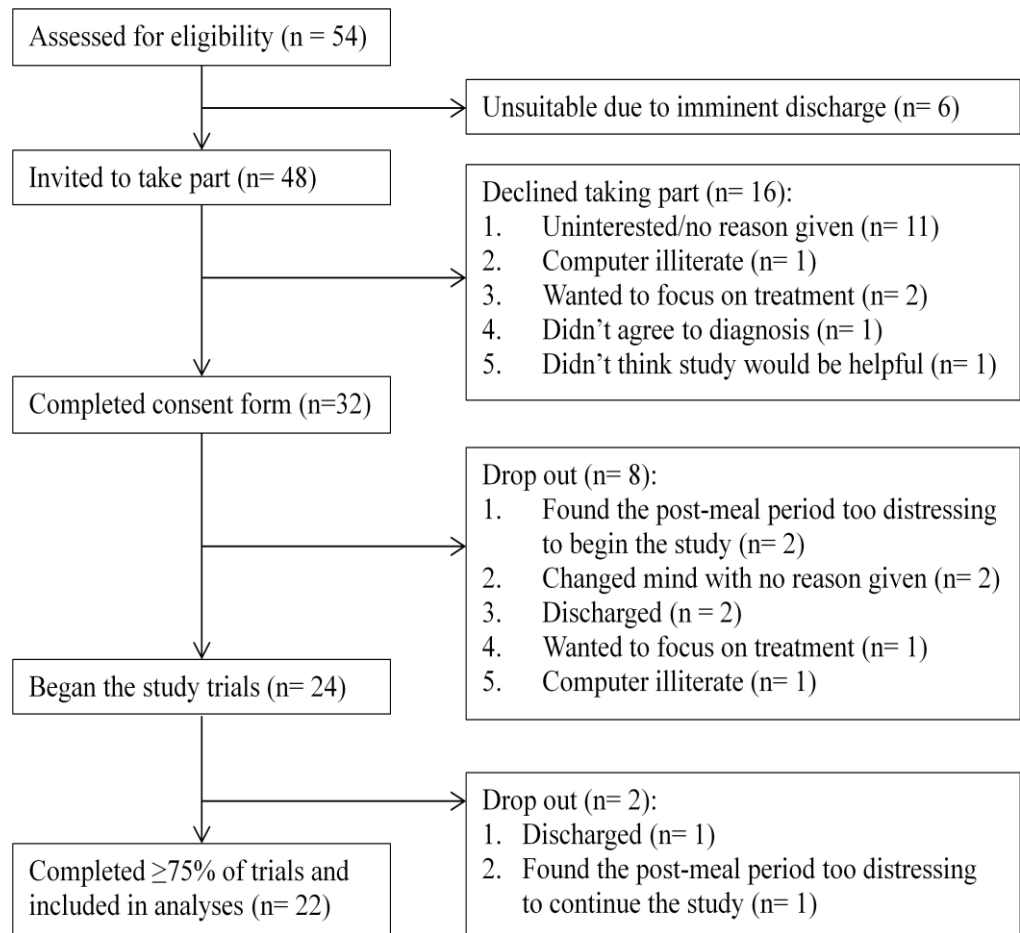
Participants were advised to seek support from staff if they found their levels of anxiety increased following tasks. During the control condition, participants were explicitly told that they could opt out of this task if they were feeling particularly anxious and engage in anything that might help them cope, including seeking support

from staff. Ethical approval was obtained from NRES Committee London – Harrow (Reference 13/LO/0800, see Appendix L for letter of approval).

## **Results**

### **Participant Flow**

The flow of participants through the study is shown in Figure 1. Of the 48 patients who were suitable and invited to take part in the study, 32 (67%) agreed and signed a consent form. Subsequently eight participants failed to begin the study, whilst two completed fewer than 75% of trials. This lead to 10 drop outs (31% of those who signed the consent form) versus 22 ‘completers’, who were included in subsequent analyses. Only two of the ‘completers’ were unable to complete all trials as one was discharged from the hospital before she could finish, and the other did not complete the final trial within the allocated time-frame. One of the participants had a naso-gastric feeding tube, and was administered meals via the tube at the same time as other patients on the unit ate their meals.



*Figure 1.* Flowchart of participants through the study.

## Clinical and Demographic Data

Clinical and demographic data on those who completed and those who dropped out of the study are described in Table 2. Two participants from the ‘completers’ group and one participant from the ‘drop out’ group did not complete the PHQ-9, GAD-7 and EDE-Q measures. There were no differences between these two groups for hospital unit, age, gender, diagnosis, BMI on admission to hospital, length of current stay in hospital at point of commencing the study, PHQ-9, GAD-7 and EDE-Q scores. However, there were differences between ‘completers’ and ‘drop outs’ in relation to ethnicity, employment status and duration of their illness. Those

who dropped out of the study were almost twice as likely to be White British, far more likely to be unemployed and to have had their diagnosis for over twice as long as those who remained in the study.

### **Data Removed from the Analyses**

Trials that were completed outside of mealtimes were removed from analyses. A window of two hours was allowed for participants to complete the study to accommodate for variations in meal-times on the units, i.e. breakfast trials needed to be completed between 8.30am-10.30am, lunch trials needed to be completed between 12.30pm-2.30pm and dinner trials needed to be completed between 6.00pm-8.00pm. This led to removal of three trials from two participants. In addition, one trial of one participant was removed due to reports that the Tetris game was not working. Participants were asked to describe any problems that affected their ability to complete the task. On six occasions participants reported delays in commencing the study due to needing to charge the laptop battery, or system updates. As there was no measure of how long these delays lasted for, these trials were kept within the analyses. No other problems were reported that were considered to significantly impair on the trial.

Table 2

*Demographic and Clinical Data*

Demographic	Completers (n= 22)	Drop Outs (n= 10)	<i>p</i> value
Unit (%)			
Inpatient	50.0	90.0	.07 <sup>a</sup>
Rehabilitation	36.4	0	
Day Hospital	13.6	10.0	
Age, years: mean (S.D.)	27.8 (10.1)	38.1 (15.0)	.12 <sup>b</sup>
Gender: % F	95.4	100	.49 <sup>a</sup>
Ethnicity (% WB)	41.0	80.0	.04 <sup>a</sup>
Employment status (%)			
Unemployed	9.1	70.0	.01 <sup>a</sup>
Student	50	10.0	
Non-professional/voluntary	18.2	20.0	
Professional	18.2	0	
Retired	4.5	0	
Diagnosis (%)			
AN-R	59.0	70.0	.84 <sup>a</sup>
AN-BP	27.3	20.0	
EDNOS	13.6	10.0	
BMI on admission: mean (S.D.)	15.3 (2.6)	13.7 (1.2)	.08 <sup>c</sup>
Duration of illness, years: mean (S.D.)	10.6 (10.8)	22.1 (14.0)	.04 <sup>b</sup>
Length of current stay in hospital <sup>d</sup> , days: mean (S.D.)	29.7 (52.1)	83.8 (147.5)	.15 <sup>b</sup>
PHQ: mean (S.D.)	18.3 (7.6)	16.6 (7.7)	.57 <sup>c</sup>
GAD: mean (S.D.)	13.4 (5.0)	13.6 (5.2)	.96 <sup>c</sup>
EDE-Q: mean (S.D.)			
Restraint	4.1 (1.8)	3.0 (2.7)	.22 <sup>c</sup>
Eating Concern	3.8 (1.5)	2.9 (1.7)	.14 <sup>c</sup>
Shape Concern	4.6 (1.4)	3.8 (1.0)	.17 <sup>c</sup>
Weight Concern	4.0 (1.6)	3.5 (1.4)	.33 <sup>c</sup>
Global	4.0 (1.3)	3.3 (1.4)	.16 <sup>c</sup>

*Note.* F= female; WB= White British; AN-R= Anorexia Nervosa, Restrictive subtype; AN-BP= Anorexia Nervosa, Binge Purge subtype; EDNOS= Eating Disorders Not Otherwise Specified; BMI= Body Mass Index.

<sup>a</sup> Categorical data was compared using Chi-squared statistical test. <sup>b</sup> Data meeting the assumptions for parametric tests was compared using independent samples *t*-test. <sup>c</sup> Data not meeting the assumptions for parametric tests was compared using Mann-Whitney U test. <sup>d</sup> Length of current stay calculated from admission into hospital until commencing the study.



## **Sitting Quietly**

Following the sitting quietly task, participants were asked via the online programme whether they were able to remain sitting quietly for the duration of the task. Participants reported that they were unable to remain sitting quietly for 20 (31%) of these sessions. For six sessions, participants did not comment on what alternate activity they were engaging in and for three sessions they described being interrupted by staff. For the remaining sessions, participants reported; reading or listening to the radio (N=4); using their mobile (N=2); going for a walk or stretching (N=2); knitting (N=1); talking to others in the room (N=1); packing things away (N=1). As there was no measure of how long they engaged in these alternate activities and because of the high proportion of sessions being contaminated, these sessions were kept within the analyses.

## **Task performance**

Performance data was obtained for the Quiz and Braille tasks. The means and standard deviations for all three sessions of participant performance on the Quiz and Braille tasks are shown in Table 3. One participant failed to return all the Braille response sheets and two participants failed to return the Braille sheet for session three, which led to some missing data.

The data suggests that participants were generally compliant with these tasks. For Quiz performance there was no main effect of session number on mean number of questions completed:  $F(2,42) = 1.18, p = .32$ , mean response time per question:  $F(1.49, 31.20) = 1.74, p = .20$  or mean percentage of questions correct:  $F(2, 42) =$

1.59,  $p = .22$ . However, there was a main effect of session number on mean number of letters translated for Braille performance:  $F(2,36) = 7.61$ ,  $p = .002$ . Pairwise comparisons, computed with a Bonferonni adjustment, revealed that there was a difference between session 1 and 3 only ( $p = .01$ ). There was no main effect of session number on percentage of correct responses:  $F(1.40, 25.15) = .35$ ,  $p = .63$ .

These findings suggest that as sessions progressed, participants improved in the number of Braille letters they translated, possibly representing a practice effect. However, no other variations in performance over sessions were found.

### **Mealtimes**

The number of trials completed at each meal time by task are summarised in Table 4. The trials completed at each meal time did not differ according to task:

$$\chi^2 (6, N = 257) = 11.89, p = .06$$

Table 3.

*Performance Results for Braille and Quiz*

	Session 1	Session 2	Session 3
Quiz			
Questions completed, n: mean (S.D.)	117.5 (22.6)	125.1 (24.2)	119.6 (29.9)
Response time per question, seconds: mean (S.D.)	5.8 (2.1)	5.3 (1.5)	6.0 (1.8)
Questions correct, %: mean (S.D.)	71.9 (8.6)	71.3 (9.9)	69.2 (9.0)
Braille			
Letters translated, n: mean (S.D.)	58.7 (38.2)	66.2 (42.0)	78.0 (44.1)
Correct responses, %: mean (S.D.)	92.0 (13.5)	88.5 (17.9)	88.6 (18.2)

Table 4

*Number of Trials Completed at each Meal Time*

	Tetris	Quiz	Braille	Sitting Quietly
Breakfast	10	11	21	18
Lunch	27	30	25	30
Dinner	29	23	19	14

## Outcomes

Mean baseline scores for PANAS negative and positive affect subscales did not differ between tasks:  $F(2.22, 46.63) = .66, p = .54$  and  $F(3, 63) = .67, p = .58$  respectively. Baseline and change over time of PANAS positive and negative scores along with post-task questionnaire subscales, averaged across the three sessions, are reported in Table 5. The baseline PANAS subscales are out of a total of 50 each. Positive change scores on the PANAS negative affect subscale represent an increase in negative affect over time, whilst positive change scores on the PANAS positive affect subscale represent an increase in positive affect over time. All other measures are rated from 0 (very slightly/ not at all) to 5 (extremely).

Table 5

## Outcome Measures Averaged Across Sessions

Measure	Tetris	Quiz	Braille	Sitting Quietly
Baseline PANAS negative: mean (S.D.)	24.18 (10.75)	24.94 (11.54)	24.35 (11.11)	25.19 (11.28)
Baseline PANAS positive: mean (S.D.)	16.24 (5.52)	16.73 (5.28)	16.32 (5.20)	15.95 (5.25)
PANAS negative change: mean (S.D.)	-2.19 (3.60)	-3.32 (2.72)	-4.09 (4.71)	.52 (2.95)
PANAS positive change: mean (S.D.)	2.53 (3.45)	1.08 (3.77)	2.38 (4.26)	-1.28 (3.24)
Intrusive thoughts: mean (S.D.)	2.23 (.94)	2.27 (1.14)	2.05 (.94)	3.39 (1.23)
Intrusive images: mean (S.D.)	1.73 (.79)	2.08 (1.09)	1.72 (.82)	2.98 (1.20)
Difficulty coping: mean (S.D.)	1.96 (.72)	2.24 (.90)	2.11 (.98)	3.43 (1.11)
Helpfulness: mean (S.D.)	2.84 (.86)	2.59 (.99)	2.75 (.99)	1.23 (.36)
Enjoyment: mean (S.D.)	2.85 (.97)	2.67 (1.09)	3.15 (1.16)	1.38 (.82)
Difficulty: mean (S.D.)	2.43 (.95)	2.08 (.73)	2.64 (.98)	3.24 (1.17)
Focus: mean (S.D.)	3.35 (.63)	3.02 (.95)	3.34 (.78)	2.21 (.92)

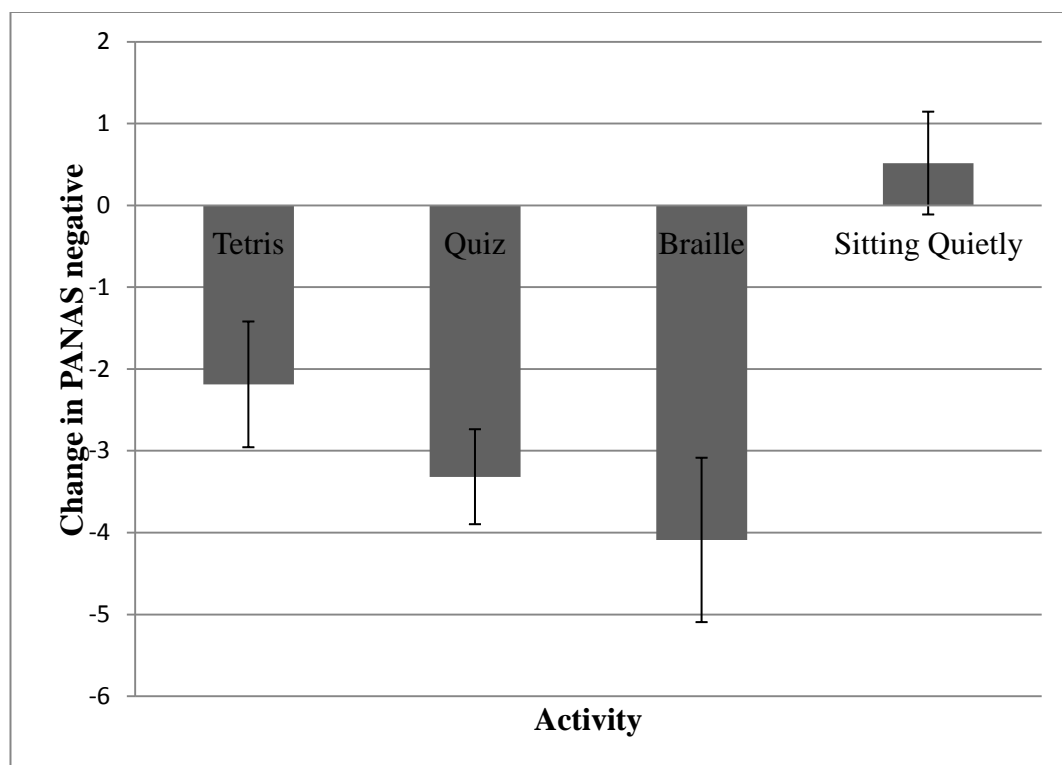
**PANAS Negative**

There was a main effect of task on change in PANAS negative subscale scores:  $F(3, 48) = 7.49$ ,  $p < .001$  (see Figure 2). Pairwise comparisons revealed that there was a difference between Sitting Quietly and: Tetris ( $p = .027$ ), Quiz ( $p = .01$ ) and Braille ( $p = .003$ ). There was also a trend towards a difference between Tetris

and Quiz ( $p = .06$ ), with the Quiz leading to greater improvements in negative affect. Tetris, Quiz and Braille led to a reduction in negative affect, whilst Sitting Quietly led to an increase in negative affect. No other differences were observed between Tetris, Quiz and Braille.

There was no main effect of session number on change in PANAS negative subscale scores:  $F(2, 32) = 1.92, p = .16$  and subsequently no interaction between task and session number:  $F(6, 96) = 17.41, p = .39$ .

This would suggest that doing an activity in the post-meal period helps to reduce negative affect, compared to no activity. Furthermore, this effect was not different between the three sessions or the three types of activities.



*Figure 2.* Change in PANAS negative scores across the four tasks. Error bars indicate standard error of the mean.

## **PANAS Positive**

There was also a main effect of task on change in PANAS positive subscale scores:  $F(3, 48) = 3.85, p = .02$ . Pairwise comparisons revealed that there was a difference between Sitting Quietly and: Tetris ( $p = .002$ ) and Braille ( $p = .02$ ). There was also a trend towards significance between Sitting Quietly and Quiz ( $p = .08$ ). No other differences were observed between Tetris, Quiz and Braille.

There was no main effect of session number on change in PANAS positive subscale scores:  $F(2, 32) = 2.48, p = .99$  and subsequently no interaction between task and session number:  $F(3.65, 58.33) = .744, p = .55$ .

This would suggest that doing an activity in the post-meal period helps to improve positive affect, compared to no activity.

## **Intrusive Thoughts**

There was a main effect of task on ratings of body and fatness related intrusive thoughts<sup>2</sup> during the post-meal period:  $F(1.95, 31.22) = 17.53, p < .001$ . Pairwise comparisons revealed that there was a difference between Sitting Quietly and: Tetris ( $p < .001$ ), Quiz ( $p = .001$ ) and Braille ( $p < .001$ ). Tetris, Quiz and Braille led to an increase in positive affect whilst sitting quietly led to a decrease in positive affect. There were no other differences between Tetris, Quiz and Braille.

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<sup>2</sup> Participants answered the following question related to intrusive thoughts (and images): ‘To what extent did you experience intrusive body and fatness related thoughts (images) during the activity?’ This was to ensure participants experience of quantity, intensity and duration were all captured within these questions.

There was no main effect of session number on change in scores for intrusive thoughts:  $F(2, 32) = 1.50, p = .24$  and subsequently no interaction between task and session number:  $F(6, 96) = 1.023, p = .42$ .

This would suggest that doing an activity in the post-meal period helps the experience of body and fatness related intrusive thoughts, compared to no activity.

### **Intrusive Images**

There was a main effect of task on ratings of body and fatness related intrusive images (see Footnote 3) during the post-meal period:  $F(1.71, 27.35) = 21.90, p < .001$ . Pairwise comparisons revealed that there was a difference between Sitting Quietly and: Tetris ( $p < .001$ ), Quiz ( $p = .002$ ) and Braille ( $p < .001$ ). In addition, there was also a difference between Quiz and Braille ( $p = .01$ ), and Quiz and Tetris ( $p = .002$ ). The Braille and Tetris tasks led to an improved experience of intrusive images than the Quiz task. No other differences were observed between Braille and Tetris.

There was no main effect of session number on scores for intrusive images:  $F(2, 32) = 2.38, p = .11$ , however there was an interaction between task and session number:  $F(6, 96) = 2.59, p = .02$ .

This would suggest that doing an activity in the post-meal period helps the experience of body and fatness related intrusive images, compared to no activity. This effect also varies across sessions. In addition, both the Braille and Tetris tasks appeared to be better at improving the experience of intrusive images than the Quiz.



## **Difficulty Coping**

There was a main effect of task on ratings of ‘difficulty coping’ during the post-meal period:  $F(3, 48) = 8.66, p < .001$ . Pairwise comparisons revealed that there was a difference between Sitting Quietly and: Tetris ( $p = .011$ ), Quiz ( $p < .001$ ) and Braille ( $p < .001$ ). No other differences were observed between Tetris, Quiz and Braille.

There was no main effect of session number on ratings of difficulty in coping subscale scores:  $F(2, 32) = 1.95, p = .16$  and subsequently no interaction between task and session number:  $F(6, 96) = .75, p = .31$ .

This would suggest that doing an activity in the post-meal period reduces perceived difficulty coping during the post-meal period, compared to no activity.

## **Helpfulness**

There was a main effect of task on ratings of ‘helpfulness’ of the task during the post-meal period:  $F(3, 48) = 10.82, p < .001$ . Pairwise comparisons revealed that there was a difference between Sitting Quietly and: Tetris ( $p < .001$ ), Quiz ( $p < .001$ ) and Braille ( $p < .001$ ). No differences were observed between Tetris, Quiz and Braille.

There was no main effect of session number on ratings of difficulty in coping subscale scores:  $F(2, 32) = 1.66, p = .21$  and subsequently no interaction between task and session number:  $F(6, 96) = 1.34, p = .25$ .

This would suggest that doing an activity in the post-meal period is perceived to be more helpful than engaging in no activity.

## Correlations

Scores on change in PANAS negative subscale were averaged across the three trials for each task. They were then correlated with ‘difficulty in coping’ and ‘helpfulness of task’ questions of the post task questionnaire to help determine if the measures were assessing similar constructs. The Pearson’s correlation coefficients and p-values for these correlations are reported in Table 6. There is a negative correlation between PANAS negative and ‘helpfulness of task’ for the Tetris task, in other words the more helpful people found Tetris the greater reduction in PANAS negative. However, no other correlations were observed, suggesting that these measures are assessing different constructs.

Table 6

*Correlations between PANAS negative and post task questionnaire across tasks.*

Measure	Tetris	Quiz	Braille	Sitting
Difficulty Coping	r = -.21 p = .35	r = -.23 p = .306	r = -.38 p = .08	r = .009 p = .97
Helpfulness	r = -.56 p = .007	r = -.31 p = .16	r = -.38 p = .08	r = .01 p = .97
Enjoyment	r = -.04 p = .85	r = -.32 p = .15	r = -.30 p = .18	r = -.05 p = .84
Difficulty	r = -.21 p = .35	r = -.13 p = .56	r = -.10 p = .65	r = .09 p = .69
Focus	r = .02 p = .93	r = .004 p = .99	r = -.04 p = .85	r = .18 p = .43

## Enjoyment, Difficulty and Focus

How much participants enjoyed the task, how difficult they found it and how much they were able to focus on the task were considered possible moderators of changes in negative affect. Therefore, the responses to these questions, as part of the post task questionnaire, were correlated with changes in PANAS negative (Table 6). No correlations were observed, and therefore these variables were not included within moderator analysis.

However, there was a main effect of task on ratings of enjoyment of the task during the post-meal period:  $F(3, 48) = 6.07, p = .001$ . Pairwise comparisons revealed that there were differences between Sitting Quietly and: Tetris ( $p = .002$ ), Quiz ( $p = .001$ ) and Braille ( $p = .003$ ). No differences were observed between Tetris, Quiz and Braille.

There was no main effect of session number on ratings of enjoyment:  $F(2, 32) = 3.21, p = .054$  and subsequently no interaction between task and session number:  $F(6, 96) = .828, p = .30$ .

This would suggest that doing an activity in the post-meal period is perceived as more enjoyable than engaging in no activity.

There was also a main effect of task on ratings of difficulty of the task during the post-meal period:  $F(3, 48) = 4.88, p = .005$ . Pairwise comparisons revealed that there were differences between: Sitting Quietly and Quiz ( $p = .003$ ); and Braille and Quiz ( $p = .021$ ). No other differences were observed between Sitting Quietly, Tetris, Quiz and Braille.

There was no main effect of session number on ratings of difficulty:  $F(2, 32) = 1.86, p = .17$  and subsequently no interaction between task and session number:  $F(3.56, 56.96) = 1.55, p = .17$ .

This would suggest that the Quiz was perceived as easier than Sitting Quietly and Braille.

There was also a main effect of task on ratings of ability to focus on the task during the post-meal period:  $F(3, 48) = 6.28, p = .001$ . Pairwise comparisons revealed that there were differences between Sitting Quietly and: Braille ( $p < .001$ ), Quiz ( $p = .02$ ) and Tetris ( $p = .001$ ). No other differences were observed between Tetris, Quiz and Braille.

There was also a main effect of session number on ratings of ability to focus:  $F(2, 32) = 3.44, p = .044$ . However, there was no interaction between task and session number:  $F(6, 96) = .12, p = .99$ .

This would suggest that Sitting Quietly was perceived as more difficult to focus on than any of the other tasks, but that ability to focus reduced over sessions.

## **Discussion**

The findings of this study show that engaging in an activity after meals helps to improve the post-meal experience for hospitalised patients with eating disorders. More specifically, a visuospatial, a verbal and a somatic task led to the following: reduced negative affect, increased positive affect (although only a trend in increased positive affect for the verbal task), improved experience of intrusive body and fatness related thoughts and imagery and improved perceived ability to cope. The tasks were

also considered more helpful than a control condition requiring no activity. These findings add to the scarce literature providing evidence of the benefit of post-meal activities for eating disorders, and are of practical use to patients and supporting services that incorporate mealtimes, in particular hospitals.

Theory suggests that feeling fat is a result of misinterpreting emotions and bodily sensations giving rise to intrusive thoughts and imagery (Fairburn, 2008; Murphy et al., 2010). One of the main ways the Tetris, Quiz and Braille may be improving the post-meal experience is by reducing feelings of fatness, through reducing the associated cognitions and emotions. The fact that Tetris, Quiz and Braille did not differ on all but one of the variables may suggest a number of possibilities relating to their involvement in the prevention of feeling fat. Firstly, it is plausible that Tetris, Quiz and Braille themselves acted simply as attentional distractions, creating demand on the central executive component of working memory (Baddeley & Hitch, 1974), limiting capacity to process information, as has been reported within the PTSD literature (Pearson & Sawyer, 2011). This could mean that neither visuospatial, verbal or somatic experiences are involved in the development of negative affect (feeling fat) or that one or more are involved but their relative contributions outweighed by the strength of the effect of general distraction on overall post meal cognitive processing. Alternatively, it is possible that feeling fat develops due to a combination of visuospatial, verbal and somatic experiences and these tasks created similar modality-specific interference. Comparing a task requiring a modality not hypothesised to be involved in the development of feeling fat, such as a task requiring auditory processing, but creating a similar level of attentional distraction, might help to differentiate these possibilities.

The findings suggest some evidence for task specific modality interference, as ratings of intrusive body and fatness related images differed between tasks. A visuospatial and somatic task led to improved experiences of intrusive imagery when compared with a verbal task. Despite being designed as a somatic task, translating Braille still requires a degree of visuospatial processing. Therefore, this would suggest that the development of intrusive images following meals can be inhibited by a visuospatial task, in line with the working memory model of limited capacity for visuospatial processing (Baddeley & Andrade, 2000). This finding also reflects evidence that visuospatial tasks, carried out by dieting and non-dieting women, help to reduce the vividness of food related images, which the authors report may help to treat people who have difficulties with food cravings (Kemps, Tiggemann, Woods, & Soekov, 2004).

One might expect that if visuospatial tasks helped with the experience of intrusive imagery there might also be an associated greater reduction in negative affect when compared to the Quiz, but the findings suggest no such effect. It is unlikely that this finding reflects a lack of relationship between body and fatness related images and distress for people with eating disorders, particularly as Sitting Quietly was not beneficial to the experience of intrusive imagery and was associated with an increase in negative affect. In addition, people with bulimia nervosa have been shown to experience significantly more negative and anxiety-provoking spontaneous imagery than controls (Somerville, Cooper, & Hackmann, 2007) and for psychological disorders in general, intrusive imagery is associated with strong emotions and often represents the individual's personal fears (Ottaviani & Beck, 1987; Wells & Hackmann, 1993). Alternatively, a lack of finding that the

visuospatial tasks led to a greater reduction in negative affect compared with the verbal task may simply be a result of insufficient power.

Ratings of how much participants enjoyed the tasks, how difficult they found them and how much they were able to focus on them were gathered to determine whether these factors might moderate changes in negative affect. However, none of these factors were found to correlate with negative affect and, therefore, could not be considered possible moderators. The lack of correlation between perceived difficulty of task and changes in negative affect is an interesting finding and corroborated by participants varied accounts of what factors within the tasks they found helpful. Some reported that tasks they found more difficult led to frustration and feeling like a failure and were considered unhelpful, whilst others described greater difficulty helping them to be more engaged, challenged and distracted, thus helping to improve the post-meal experience. However, participants described finding tasks they enjoyed and were engaged with as most helpful, which is contrary to the findings from the correlation analyses.

## **Limitations**

When reviewing the results of this study it is worth considering a number of possible limitations. Unfortunately the study failed to meet the number of participants necessary to have power to detect significant effects. Therefore, it is possible that potentially significant findings, such as differences in the impact of the different tasks, went undetected. In addition, although the sample that completed the study on the whole did not differ from those who dropped out of the study, data from those who refused to participate was not collected. Therefore, it is possible that the

sample is not entirely representative of all hospitalised people with eating disorders. However, this is likely to be less of a problem considering the high uptake of the research (67% agreed to take part).

Participants were required to independently complete the study, with little input from the researcher. This meant it was difficult to control for the length of time participants began each trial post-meal. Participants were instructed to begin the study immediately after their meal, but in some of the written comments, participants reported that they were unable to do the study immediately, and there was no option to record how long after the meal they began the study. Although attempts were made to minimise this limitation by removing trials that appeared to be outside of the mealtimes, this was a fairly large window of time to allow for variation in when the units might have the meals. A solution to this problem in future studies might be to ask participants to report the time they had completed their meal, and comparing this to the time the task started, which is recorded by the online programme. In addition, it was difficult to control how much people were adhering to the tasks and not completing other activities within the 15 minute time frame. However, the data on adherence to the Quiz and Braille tasks would suggest people were completing the tasks to the best of their abilities. However, there were variations in how people completed the control condition, with reports of completing other activities during this task. It is likely that participants were attempting to distract themselves from the difficult post-meal experience, as reflected in the increase in PANAS negative scores and decrease in PANAS positive scores following the task. Therefore, the control condition may reflect a more ecologically valid scenario, where patients engage in behaviours that help to occupy them when no activities are planned, particularly as



these types of activities are routinely observed within the units during the post-meal period.

Another limitation of the study was that there were key differences between the three units used to obtain participants. The inpatient ward, rehabilitation unit and day hospital all differed not only in terms of severity of illness but also how much participants were supervised following meals, levels of distraction and whether they could be on their own or not to complete the study. In addition, 90% of the drop outs were from the inpatient unit. Due to the sample size, the study would be underpowered to make comparisons between these three units. However, this limitation can also be seen as a strength in terms of generalisation.

### **Considerations for Future Research**

As previously alluded to, future research could compare tasks that interfere with different modalities that are not hypothesised to play a role in feeling fat to those that do. An example could be an auditory task, not requiring a verbal component that would be as distracting as other tasks. Since participants reported task related factors that helped to improve the post-meal experience, these factors could be manipulated, taking into consideration that what one individual finds as engaging or difficult might differ from another.

Although the post-meal experience for hospitalised patients with eating disorders is made more challenging due to patients being frequently supervised and restricted in activities, it is likely that the experience is difficult for non-hospitalised patients as well. Future research may want to consider outpatients, who may be able to shed light on their experiences of the post-meal period and how they manage this

time, but also developing evidence for tasks that might be helpful for this population. This would also help hospitalised patients, when thinking about their transition back to the community.

Hospital treatment for eating disorders rarely caters for people with bulimia nervosa and no one with this diagnosis was within the three units at the time of recruitment. Therefore, any future community research would want to consider this population who might experience the post-meal period differently. In addition, it would be useful to compare restricting and binge subtypes of anorexia nervosa, particularly as they are likely to have different experiences of the post-meal period.

### **Clinical Implications**

This research would suggest that doing structured activities helps to improve the experience of the post-meal period. Improving patients' ability to manage this time has the potential of improving their engagement to hospital treatment and improving clinical outcomes. In practice, it might be worth exploring individually with patients the activities that they find enjoyable, challenging and which they feel motivated to engage in, as it is likely that the choice of activity is also down to the preference of the individual. In addition, although there was no main effect of session number on both the positive and negative indicators it is possible that with repeated engagement in the same activity, patients may habituate to the activities, lessening their effects. Patients should therefore consider a variety of activities that they can alternate over time. Clinical experience would suggest that the majority of patients have access to a mobile phone, tablet computer or personal laptop during their stay in hospital. Games and applications that already exist and can be downloaded on to

these devices may provide a cheap and straightforward gateway into providing access to cognitively demanding activities. In addition, online ‘crowd sourcing’ projects (where the general public are invited to voluntarily take part in tasks proposed by individuals and organizations online) might be a useful way for patients to distract themselves, whilst also doing something fulfilling leading to a sense of achievement. The specific types of activities most suited to people with eating disorders would benefit from further exploration, but the consistent finding within this research suggests that doing something structured and engaging is likely to be helpful.

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## **Part 3: Critical Appraisal**

## **Introduction**

This critical appraisal will firstly focus on the rationale for researching an inpatient eating disorders population and reviewing the literature on carer interventions. Secondly, decision-making for particular areas of the methodological design of the empirical paper will be considered. Thirdly, some of the dilemmas that I came across whilst conducting this research will be reviewed, how they were managed and possible steps for future research. Finally, I will conclude with some personal reflections developed over the course of the research process.

### **Rationale for Eating Disorders Research**

When I first began embarking on the difficult decision of choosing a research area, I reflected on past experiences that have absorbed my interests. Several years ago I worked as a nursing assistant on a mental health ward, where there was no input from psychological services. Many of the patients were frequently described by staff as difficult, challenging and felt that there was little hope for their future. Some patients had remained on the ward for considerable lengths of time, whilst others had repeat admissions. It was at this point that I became aware that I was emotionally drawn to working with complex clients. I felt a deep sense of empathy towards their vulnerability and a strong desire to help them using a more psychological approach. Subsequently, when I had the opportunity of working on placement within a mental health inpatient setting I saw the potential for psychology to make a difference.

Eating disorders have an estimated 9.6 mortality ratio, the highest of all psychiatric illnesses (Nielsen et al., 1998), and suicide rates are worryingly high

(Franko & Keel, 2006). In addition, it is common for patients to be diagnosed with co-morbid psychiatric and physical health difficulties (Fairburn, 2008). I was not only drawn to research in the area of eating disorders because of the level of complexity and vulnerability, but also because I personally experienced the impact of an eating disorder when a close friend developed the illness. It was this experience that highlighted to me the power of an eating disorder and the struggle that ensues.

Through my clinical experiences I have become increasingly aware of patient dissatisfaction towards inpatient treatment. In fact, only half of people with eating disorders find inpatient treatment useful (Newton, Robinson & Hartley, 1993). Considering the government's view of a more patient-centred healthcare (Department of Health, 2001), it is important that the experiences of patients are considered, particularly when it is associated with improving clinical outcomes (Clinton, Björck, Sohlberg, & Norring, 2004; de la Rie, Noordenbos, Donker & van Furth, 2008). A qualitative study of inpatient mealtimes highlighted a variety of factors which patients report influence how they perceive the mealtime (Long, Wallis, Leung, & Meyer, 2012). This led to a number of recommendations of how to improve mealtimes based on patients' views. Therefore, I felt that this study would not only be useful in developing the theory of 'feeling fat' but would also be clinically relevant.

The move towards community rather than inpatient care provision for people with mental health problems has brought about an increased awareness of the importance of carer involvement (Worthington, Rooney, & Hannan, 2013). In contrast to caring for someone with a physical health problem, carers of people with mental health problems face additional challenges; the unpredictable nature of mental health problems, stigma (which could result in the carer feeling isolated as

they try to cope on their own), lack of information due to concerns about confidentiality, for some the fear of losing their loved one to suicide, and a lack of specialised respite support (Royal College of Psychiatrists, 2005). Greater awareness of the need for carer involvement has led to guidelines that recommend improving carer involvement, including carer assessments and interventions. For carers of people with eating disorders the National Institute of Clinical Excellence guidelines recommend that carers are offered information and education to support their involvement in the care of their loved one and that family interventions are the treatment of choice for adolescents with eating disorders (NICE, 2004). Since I had experience of running a carers' group intervention within a psychosis service and noted the benefits of group members sharing their experience with each other, I became curious of what similar interventions were available for carers of people with eating disorders. This led me to reviewing the literature on this area, with the aim of supporting their inclusion within guidelines for eating disorders.

### **Rationale for Methodological Choices within the Empirical Paper**

As the study design was based on a design used within the post traumatic stress disorder literature (Holmes, James, Kilford, & Deeprose, 2010), I was fortunate not to have to develop suitable visuospatial and verbal tasks. However, I included an additional somatic task within the design, which aimed to tap into body and fatness related physical sensations. When considering possible options, I tried to keep in mind the need to find a task that would be relatively straightforward for participants to understand, could be set up easily and be completed independently and had a game-like quality about it to ensure similarity with the other tasks. I



considered some of the motion control games that already exist on computers that involve using the body. However, these games would require a level of exercise that would be prohibited within an eating disorders unit. Another possibility was to consider the psychophysics field, which uses sensory perception tasks. Two possible tasks emerged following a brief review of the literature. One would involve distinguishing different temperatures or distances from various pointers touched on their skin. Although this task would be non-visual, it would have been difficult to set up, particularly as I was expecting participants to complete the study independently. The second option would involve participants differentiating different gradients of abrasive paper. I quickly disregarded this possibility when considering that participants would need to engage in the task for 15 minutes, as it would have been difficult to find enough variations in paper gradients to fill the time. Muscle relaxation was another alternative task considered, which would have been relatively easy to implement, but was felt to be too different from the other tasks that were likely to have been more difficult, more game-like and more active. Finally, I decided on developing a task involving the translation of Braille. The benefits of using this task was that it was cheap to develop, task instructions were straightforward, the task could be administered independently and it could be relatively easily adapted in relation to its level of difficulty and length of time. In addition, Braille tasks have been shown to involve the somatosensory systems of blind and sighted people (Sadato, 1998). Translating random letters, rather than words or sentences, was chosen to limit the verbal processing involved in the task. However, I was aware that there would still be a level of visuospatial processing (Sadato, 1998), and this was reflected in the empirical papers findings that the Braille

and Tetris tasks helped improve the experience of intrusive imagery when compared to the Quiz and control conditions.

Early on in the design of the study I decided to develop an online programme administered via a laptop to deliver the questionnaires and some of the task materials. The benefit of this approach was that it allowed more control over the data, which could be safely secured on a password-protected database, thus eliminating human error when transferring data to databases. In addition, all data were immediately uploaded to a central database when they were collected, rather than being stored locally on each participant's laptop. Participants were also forced to answer all of the questions before being able to move on, reducing the potential for incomplete data. In addition, this approach allowed participants to work on the study independently and removed any bias of an observer being present, known as the observers paradox. However, without the presence of a researcher during the trials it was difficult to control various factors that might also have influenced the results, such as length of time before commencing the study and engaging with other activities during the tasks. Future research should consider the use of smart phone technology as over half of the adult population now use a smart phone (Ofcom, 2013).

The post-meal period is known to be anxiety-provoking (Shapiro et al., 2008), but clinical experience suggests that other difficult emotions are elicited during this time. Therefore, the aim was to determine whether the tasks impacted on the whole experience of emotions and the Positive and Negative Affect Scale (PANAS) was felt to fit this purpose (Watson, Clark & Tellegen, 1988).

Positive and negative affect have been consistently shown as factors which describe how someone is feeling and incorporates a range of emotions (Watson &

Tellegen, 1985). Positive and negative affect are not considered opposites, but two distinctive dimensions. High positive affect represents enthusiasm and activity, whilst low positive affect represents lethargy and sadness. High negative affect represents distress and displeasure whilst low negative affect represents calmness and sensitivity. The PANAS, a measure of these two dimensions, was developed to be brief and easy to administer and has been found to have high internal consistency (Watson et al., 1988). In addition, the PANAS is sensitive to momentary mood fluctuations. Correlations between the Eating Disorders Examination (an interview of eating disorder pathology) and a self-report version, suggest that patients with eating disorders are able to accurately self-report their symptoms (Carter, Aime, & Mills, 2001; Wolk, Loeb, & Walsh, 2005).

### **Dilemmas**

Recruiting people with eating disorders is notoriously challenging particularly as many are reluctant to seek or accept treatment (Agras et al., 2004). This may be due to the highly valued nature of eating disorders (Serpell, Treasure, Teasdale, & Sullivan, 1999). Approximately only one new patient is admitted to the inpatient ward a week (Lawrence, Kyrtatos, Friddin, & Johnson-Sabine, 2011), so I was keen to go beyond the inpatient ward for recruitment. Initially I avoided recruiting from the day hospital and rehabilitation unit, where there are different procedures for carrying out mealtimes and post-meal supervision. However, when recruitment was slow I decided to recruit from these units. With more time and resources it would have been useful to gain ethical permission to recruit from units in other trusts. To try to boost uptake of the research, those who had declined the

research previously were asked at a later stage whether they had reconsidered. This led to one participant changing her mind, albeit I was conscious that when I was inviting participants to take part that I was coercion-free (Fulford & Howse, 1993; Hategan, Parthasarathi, Bourgeois, 2014). I was also mindful of the covert pressures arising from the unequal power relationship (Lidz et al, 1984). I noticed that when visiting the unit, I dressed more informally than my typical attire for work, possibly to try and reduce this power differential.

The drop-out rate for the study was 31%, which falls within a previously reported drop-out range of 13-66% for studies of participants with eating disorders (Agras et al., 2004). Once starting the study, the drop-out rate was even lower at just 8%. Perhaps this reflects a perfectionist trait, commonly described as a central feature of eating disorders (Bruch, 1973), helping motivate them to complete the study trials.

Financial incentives have been shown to be an important motivator for healthy volunteers to participate in research (Tishler & Bartholomae, 2002). Therefore, this was considered a possible way to improve the uptake of the study, but unfortunately I had no surplus funds to do so. I felt uncomfortable asking patients to complete the study, requiring a considerable amount of time and effort and with what felt like no return for them. However, after obtaining participants informal feedback after the study, I observed many found doing the study enjoyable and helpful, either because the tasks themselves improved their post-meal experience, because it inspired them to try new things or because they simply learnt the sorts of things that help them during this difficult time.

When developing the post-task questionnaire, a question I failed to include was rating participants' somatic experience post-meal. Thus, I was unable to

determine whether tasks could interrupt this experience differently. In addition, it might have been helpful to separate intrusive imagery into differential sensory modalities. Evidence suggests that modality specific tasks reduced vividness of distressing auditory and visual images (Kemps & Tiggemann, 2007). This would suggest that the visuospatial task would only interfere with intrusive visuospatial imagery as opposed to other sensory specific imagery.

### **Personal Reflections**

Over the course of this research I became struck by participants' personal accounts of how they experienced the post-meal period and which tasks they found helpful. It reminded me of the importance of an individualised and collaborative treatment approach, as everyone reported different preferences, abilities and coping strategies. In addition, giving patients with eating disorders choice has been shown to improve engagement (Vandereycken & Vansteenkiste, 2009). Considering what resources participants already had, I now wonder whether I missed an opportunity to involve service users in the development of this research. For example, a focus group may have helped determine the design of the research or piloting the tasks on patients might have given a more accurate reflection of how difficult and enjoyable they found the tasks. The secondary benefit of this approach might have been a greater uptake of the research.

I often felt like an intruder, when sporadically visiting the units to recruit participants and to follow up with people already taking part. Before commencing the study I had introduced myself at a staff meeting and hoped to meet with patients individually when inviting them to the research. However, not all of the staff

attended the meeting and I did not get an opportunity to meet with some of the patients, as they had often been invited to take part by the assistant psychologist. On reflection, I think that I would have felt more comfortable and would have engaged more of the staff and patients if I had been able to introduce myself to everyone individually. In addition, it might have been beneficial to have a photograph of myself on the research posters, something which could have been distributed amongst the team.

In addition, it was often very difficult to find times to meet with participants during their busy structured days. I was mindful that to be able to provide informed consent participants would need enough knowledge to make a decision but that their illness might impair their understanding (Fulford & Howse, 1993; Hategan et al., 2014). When I did manage to meet with participants, I often had limited time and I think it might have been more useful to meet participants in the evenings or weekends, when they would have more time and have felt less rushed.

Distraction is a common method in which to manage difficult experiences, and I have seen how distraction tasks can be beneficial as well as detrimental to people. Consequently, when I considered researching distraction tasks I felt pulled in two directions. On the one hand, I was aware that paying attention to difficult thoughts and feelings, and fusing with these can often leave people feeling worse. In this sense, distraction can be helpful by transferring attention to something less threatening (Hawton, Salkovskis, Kirk & Clark, 1989). On the other hand, distraction is also a form of avoidance that, in the long term, prevents people from being able to challenge negative thoughts and feelings, and can exacerbate problems. Therefore, I was also concerned that investigating distraction techniques could serve to prevent people with eating disorders from being able to confront their difficulties.

After listening to participants' accounts of how they experience the post-meal period I became aware of just how difficult the experience is. I observed that they commonly used their own distraction techniques, including reading and puzzles, and I realised it would be very difficult for patients to manage this event without applying some distraction. Sitting quietly was also reported as being difficult and almost impossible to carry out at this time. Therefore, in the short-term, distraction techniques are likely to be useful strategies in a hospital context, where the post-meal experience is known to be anxiety provoking (Shapiro et al., 2008). When returning to the community, distraction techniques may also help reduce compensatory behaviours, although this brings me back to the detriment of not confronting the problem. Perhaps over time patients can learn to find other strategies to manage these experiences, such as mindfulness and defusion techniques.

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## **Appendix A**

### **Outcome Measures used within the Literature Review**

## Client Outcome Measures

- **Eating Disorder Inventory 2 (EDI-2).** The EDI-2 is completed by the client as a measure of attitudes and behaviours towards eating and personality traits associated with eating disorders (Garner, 1991).
- **Anorectic Behaviour Observation Scale (ABOS).** The ABOS is a 30-item measure of eating behaviour completed by the carer, with yes, no or don't know responses. There are three subscales: 1. Concern with weight and food, and denial of the problem; 2. Bulimic-like behaviour; and 3. Hyperactivity (Vandereycken & Meermann, 1984).
- **The Medical Outcome Study Short Form Scale (SF-36).** The SF-36 consists of 36 items measuring the effect of health problems on factors including: physical, social, usual role, pain, distress and wellbeing, vitality and health perceptions (Ware & Sherbourne, 1992).
- **Eating Disorder Evaluation Scale (EDES).** The EDES is an objective evaluation of the severity of the eating disorder based on 15 items (Vanderlinden, Norre, & Vandereycken, 1995).
- **Global Assessment of Function (GAF).** The GAF is a global assessment of how an individual is functioning based on a score from 0-100. It corresponds to axis V of the DSM-IV-TR (American Psychiatric Association, 2000).
- **Global Eating Disorder Functioning (GEDF).** The GEDF has been adapted from the GAF to enable carers to rate their loved ones functioning on a scale of ten intervals from 1-100 (Goddard et al., 2011).

- **Children's Global Assessment (CGAS).** The CGAS is a global measure of child psychiatric illness and functioning using 10 Likert scales from 1-100, where 100 is the healthiest (Shaffer et al., 1983).

### **Carer Measures**

- **Hospital Anxiety and Depression Scale (HADS).** The HADS measures the presence of anxiety and depression over the previous week and consists of 14 items (Zigmond & Snaith, 1983).
- **General Health Questionnaire (GHQ).** The GHQ is a measure of general wellbeing over the last few weeks. There is a 12 item version (GHQ-12) (Goldberg, 1992) or a 28 item version (GHQ-28) (Goldberg & Williams, 1988).
- **Depression Anxiety and Stress Scale (DASS).** The DASS is a self-report 42 item measure of tension/stress, anxiety and depression (Lovibond & Lovibond, 1995).
- **Profile of Mood States (POMS).** The POMS is a list of 65 words/statements to describe people's feelings to measure their mood state over the previous week. Subscales consist of: anger; confusion; depression; fatigue; tension and vigour (McNaire, Lorr & Droppleman, 1971).
- **The Revised Scale for Caregiving Self-Efficacy (CSE).** The CSE measures caregiving self-efficacy on a 15-item self report scale (Steffen, McKibbin,, Zeiss, Gallagher-Thompson, & Bandura, 2002).

- **The Parent versus Anorexia Scale (PVA).** The PVA measures parental efficacy, the ability to take on a primary role of taking charge of the anorexia at home (Rhodes, Baillie, Brown, & Madden, 2005).
- **The Eating Disorder Symptom Impact Scale (EDSIS).** The EDSIS measures the impact of the eating disorder on families. There are 24 items which are completed by the carer, with four subscales; impact of starvation, guilt, social isolation and dysregulated behaviours (Sepulveda et al., 2008c).
- **The Experience of Caregiving Inventory (ECI).** The ECI measures caregiving burden and is divided into two subscales; positive and negative. ECI negative covers difficult behaviours, negative symptoms, stigma, problems with services, effects on family, the need to provide backup, dependency and loss. ECI positive covers positive personal experiences and good relationships (Szmukler et al., 1996).
- **The Family Questionnaire (FQ).** The FQ is a self-report measure of carers expressed emotion with 20 items. There are two subscales; criticism and emotional over-involvement (Wiedemann, Rayaki, Feinstein, & Hahlweg, 2002).
- **Level of Expressed Emotion Scale (LEE).** The LEE measures levels of expressed emotion and consists of four subscales: intrusiveness; emotional response (whether hostile or warm); understanding of the illness and tolerance/expectations. There are 60 true or false items (Cole & Kazarian, 1993).
- **Five-Minute Speech Sample (FMSS).** The FMSS is measure of levels of expressed emotion based on the content and tone of a five minute

conversation with the carer about their thoughts and feelings in relation to their loved one (Magaña et al., 1986).

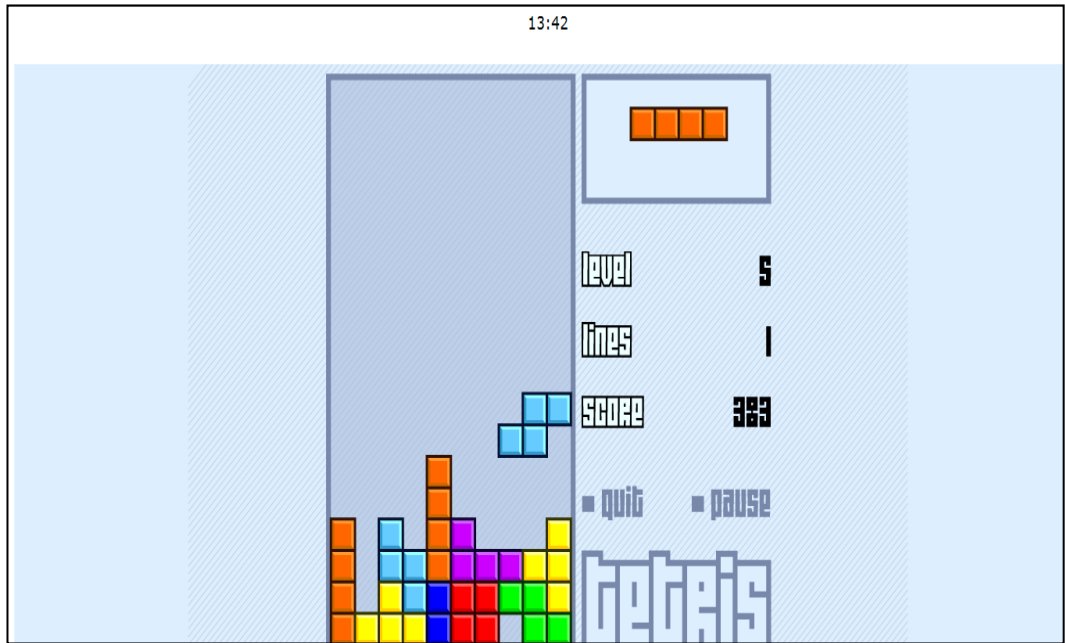
- **The Accommodation and Enabling Scale for Eating Disorders (AESED).** The AESED measures behaviours the caregiver may elicit that might accommodate the eating disorder. It is a 33 item Likert scale completed by the caregiver (Sepulveda, Kyriacou, & Treasure, 2009).
- **The Brief Cope.** This scale measures a variety of ways of coping with a particular situation. Fourteen subscales are divided into adaptive and maladaptive coping styles (Carver, Scheier, & Weintraub, 1989).
- **Social Problem-Solving Inventory- Revised (SPSI-R).** The SPSI-R measures perceptions of problem-solving skills under five subscales; positive problem orientation, negative problem orientation, rational problem solving, impulsivity/carelessness, and avoidance. There are 52 items to make up a total score (D’Zurilla, Nezu & Maydeu-Olivares, 1996).



## **Appendix B**

Screenshot of the Tetris Task

13:42



## **Appendix C**

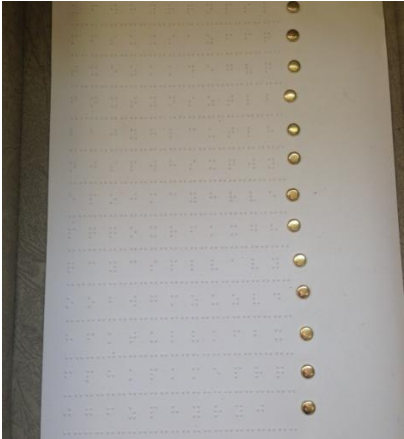
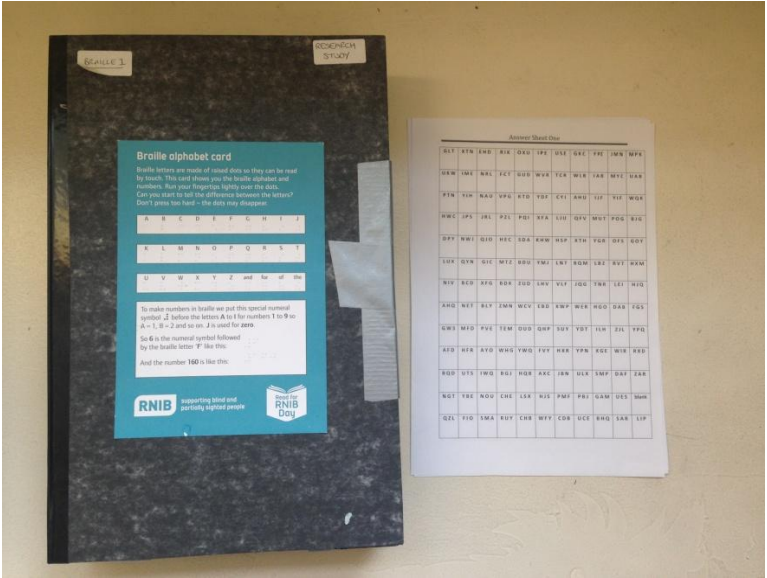
Screenshot of the Quiz Task

Which of these sports is the term Grand Slam associated with?

1. Baseball
2. Cricket
3. Rugby
4. Tennis

## **Appendix D**

Photographs of the Materials used in the Braille task



## **Appendix E**

Screenshot of the Post-Task Questionnaire

Please answer the following questions.

	very slightly / not at all	a little	moderately	quite a bit	extremely
To what extent did you experience intrusive body and fatness related <b>thoughts</b> during the activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To what extent did you experience intrusive body and fatness related <b>images</b> during the activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How difficult did you find coping during the activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much did the activity help with post-meal experiences?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much did you enjoy the activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How difficult did you find the activity itself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To what extent were you able to focus on the activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Continue



**Appendix F**  
Recruitment Poster

## VOLUNTEERS NEEDED



We are researching how different activities might be able to help reduce anxiety following meals



We are recruiting:

- People with an eating disorder receiving treatment from Phoenix, Acacia House or the Russell Unit Day Hospital.
- We plan to recruit 24 people in total.

To participate, you must:

- Speak English fluently; be between 18 and 65 years old.
- Have the approval of your clinician.

You must not:

- Be on bed-rest.

If you are not sure if you meet the criteria, we are happy to discuss this with you further.

**Please contact:** Emily Griffiths, Trainee Clinical Psychologist  
By email: [ucjtegig@ucl.ac.uk](mailto:ucjtegig@ucl.ac.uk)

Or speak to staff on the unit who will let the researchers know your interest.  
Emily will then arrange to meet with you to discuss the study in more detail.

This study has been funded by the Research Department of Clinical, Educational & Health Psychology at UCL and has been approved by a Research Ethics Committee.

## **Appendix G**

### **Participant Information Sheet**

Department of Clinical,  
Educational & Health Psychology  
1-19 Torrington Place  
London  
WC1E 7HB

**Participant Information Sheet**

**Study title:** Effects on post-meal anxiety and cognitive processes amongst inpatients with eating disorders

**Investigators:**

Emily Griffiths (Trainee Clinical Psychologist)  
Dr Nicholas Hawkes (Clinical Psychologist)  
Dr Lucy Serpell (Clinical Psychologist)  
C/o Research Department of Clinical, Educational & Health Psychology, UCL, Gower Street,  
London. WC1E 6BT

We would like to invite you to take part in our research study which is looking at whether a number of activities, following meals, can help reduce anxiety in people with eating disorders. Before you decide whether to take part, we would like you to understand why the research is being done and what it could involve for you. One of our team will go through the information sheet with you and answer any questions you have. We suggest that this will take about 10 minutes.

Part 1 tells you the purpose of the study and what will happen if you take part

Part 2 gives you more detailed information about the conduct of the study

Please ask us if anything is not clear. Talk to others about the study if you wish.

**PART 1**

**What is the purpose of the study?**

The study's first aim is to see how a variety of activities affect how you feel and what you experience during the time following meals. The activities will involve a computer game (the game Tetris), a general knowledge quiz, and an activity requiring you to use your fingertips to work out a coded message.

The study may help eating disorder researchers find activities that are better suited to help people during what we understand can be an anxiety provoking time, the time straight after meals.

**Why have I been invited?**

This study is inviting people who are currently an inpatient at Phoenix Wing (inpatient ward), Acacia House (rehabilitation unit) or an outpatient at the Russell Unit Day Hospital.

#### Who can take part?

To be eligible to participate all participants must meet the following requirements:

- Be between 18 and 65 years old
- Be a patient at Phoenix Wing, Acacia House or Russell Unit Day Hospital.
- Speak English fluently
- Not be on bed-rest
- 

If you are not sure whether you meet these requirements, we are happy to discuss them further with you.

#### Do I have to take part?

No, you don't have to take part. It is up to you to decide if you want to join the study. We will describe the study and go through this information sheet with you. If you agree to take part, we will then ask you to sign a consent form. If you decide to take part you are still free to withdraw from the study at any time without giving a reason. This will not affect the standard of care you receive. However, if you do withdraw after providing the research team with some information about you, that information will be kept as part of the study.

#### What happens if I agree to take part?

If you agree to take part in the study, Emily Griffiths (Trainee Clinical Psychologist) will ask you to complete a consent form. Information on your demographics (diagnosis, date of birth, ethnicity and employment status), body mass index and routine clinical measures will then be obtained from your clinical records by Dr Nicholas Hawkes (Clinical Psychologist).

Emily will then arrange a time to meet to discuss the research and introduce you to the different activities, which will last approximately 30 minutes. You will then have some time to practice the activities and again ask any questions, which will last approximately 30 minutes. Emily will provide you with a laptop and dongle (to be able to access the online programme) for the duration of your time in the study, unless you have your own that you would prefer to use. If you do use a laptop and dongle that we provide we would ask that you keep it on the unit if you leave and you will be required to return it at the end of the study.

Following your meal (breakfast, lunch or dinner), when you have no other scheduled activity on the unit, we ask that you use the dongle to run an online programme on the laptop. The programme will ask you a series of questions, which will take approximately 5 minutes to complete. The programme will then randomly pick one of four activities, which you will complete for 15 minutes, and then you will be asked some more questions afterwards taking approximately 5 more minutes. In total the questionnaires and the activities will take approximately 25 minutes of your time, and then you are free to spend the rest of the time as you normally would. The activities are as follows:

1. Tetris- using the cursor keys you will need to rotate falling blocks to complete horizontal rows of blocks.
2. General Knowledge Quiz- a quiz where you will answer questions from a possible four choices on various topics including history, sport and geography.

3. Braille messages- you will be provided with sheets of Braille. During this activity you will use just your fingertips to work out a message in Braille and type your answers into the laptop programme.
4. Just sitting- you will remain sitting for the 15 minutes duration, if you can manage it. If you are finding it too difficult to remain just sitting you can do what you might normally do to cope during this time.

You will complete each of these activities three times. In total you will run the programme following 12 of your meals over two weeks. If you are unable to complete the study in this time, due to unforeseen circumstances, you will be asked whether you would like to continue the study for up to a further 2 weeks. Emily Griffiths (Trainee Clinical Psychologist) will be available for the first time you complete the programme and at least twice a week to check your progress and troubleshoot any difficulties you may be experiencing. We will then invite you to a one-to-one debrief meeting to discuss your experience of the study with Emily where you will be asked a series of open questions, which will last approximately 30 minutes. This meeting will take place in your bedroom, an interview room, the dining room or a group room. This meeting will be recorded on a Dictaphone so that we may be able to use short anonymised quotes in the writing up of this research. The recorded interviews will be transcribed and then the tapes will be destroyed.

You will be involved in the research for up to four weeks, which includes two weeks of using the online programme and time for practising the tasks and the meetings. However, if you are unable to complete the online programme within two weeks, we will ask whether you would like to continue to complete the programme over a maximum, additional two weeks. Taking part will not affect the length of your stay on the unit one way or the other. We understand that people do not always know for exactly how long they will be remaining as a patient. If you are discharged before the end of the study, you can stop participating then. To be able to recruit enough people in to the study, the research will continue until July 2014.

What are the possible disadvantages and risks of taking part?

There is a chance that you might feel more anxious by doing some of the activities. If this is the case we ask that you speak to staff on the unit who will be able to support you. In addition, some people can find completing questionnaires boring, however we have tried to make them as brief and as easy to complete as possible.

What are the possible benefits of taking part?

We are hoping that some of the activities might help to reduce your anxiety during what can be an anxious time and some people should find them fun to do. The information that we get from this study will also help to improve the treatment of people with eating disorders.

What happens when the research study stops?

When the research has ended if you have used a dongle and laptop we have provided you will need to return these to the research team and your usual care will continue.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2 of this information sheet.

Will my taking part in the study be kept confidential?

It is possible that patients and staff will know you are taking part because you might be using our laptop in a communal area, but they will not have access to any of your information and data. We will follow ethical and legal practice and all information about you will be handled in confidence. Confidentiality would be broken if a risk of harm to self or other is identified. The details are included in part 2 of this information sheet.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decisions.

PART 2
--------

What if relevant new information becomes available?

If this happens, the research team and/or your responsible clinician within the unit might consider you should withdraw from the study. He/she will explain the reasons and arrange for your care to continue.

What if there is a problem?

Every care will be taken in the course of this study. However in the unlikely event that you are injured by taking part, compensation may be available.

If you suspect that the injury is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with the research team, please make the claim in writing to Dr Lucy Serpell who is the Chief Investigator for the research and based at the Research Department of Clinical, Educational & Health Psychology, UCL, Gower Street, London, WC1E 6BT. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed, National Health Service or UCL complaints mechanisms are available to you. If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions (020 8442 6387) and can provide you with more information on complaints mechanisms.

If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints procedure. Details can be obtained from the Patient Advice and Liaison Service (PALS - [www.pals.nhs.uk](http://www.pals.nhs.uk)).

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against University College London and Barnet, Enfield and Haringey Mental Health NHS Trust, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?

It is possible that patients and staff will know you are taking part because you might be using our laptop in a communal area, but they will not have access to any of your information and data. All responses are treated as confidential. Once your testing session is complete, you will be given a unique participant number and will only be identifiable by this. All data will be collected and stored in accordance with the Data Protection Act 1998. Only researchers involved in the study will have access to the data and it will be stored securely at all times.

If you disclose any information that suggests serious risk of harm to self or others, confidentiality would need to be broken and the researcher is obliged to contact your allocated clinician and GP or other health professional and inform them. Where possible, this will always be discussed with you beforehand.

#### How will the data be collected and stored?

The task data will be collected through the online programme and stored on a password protected online database. The data will be stored alongside a participant code and therefore will be anonymous. Information collected from the debrief meeting will be stored in a locked filing cabinet. The Dictaphone will also be kept within the locked filing cabinet. The recorded interviews will be transcribed and then the tapes will be destroyed. The data is only accessible by the direct clinical care team and researchers who are authorised members of the research team.

Anonymised study data is kept securely for up to a maximum of 20 years and is then deleted or destroyed securely.

#### What will the data be used for?

The data will only be used to answer the research questions and will not be used for any other study.

#### What will happen to the results of the research study?

It is intended that the broad results of the study will be written up as a research paper and published by a journal, direct quotations from the post study meeting may be included but we will make sure that you cannot be identified from these. Individual participants will not be identified in any written report or publication.

We will summarise the findings of the study at a community meeting.

#### Involvement of your responsible clinician on the unit

After agreeing to take part in the study we will inform your clinician. At the end of the study they will also be given a summary of the overall research findings.

#### Who is funding the study?

The Research Department of Clinical, Educational and Health Psychology at University College London (UCL) have provided £250 towards the funding of this study.

#### Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by (name) Research Ethics Committee.

#### Further Information and Contact Details:

If you would like advice about whether to participate in this study, you may want to speak to one of your health care professionals.



If you would like further information about this study or would like to participate please contact Emily Griffiths, by emailing [ucjtejg@ucl.ac.uk](mailto:ucjtejg@ucl.ac.uk) or phoning 020 7794 0500 ext 38826. You will be provided with consent form to sign and a copy will be given to you to keep.

Thank you for taking the time to read this.

**Appendix H**  
Consent Form

Patient Identification Number:

### CONSENT FORM

**Title of Project:** Effects on post-meal anxiety and cognitive processes amongst inpatients with eating disorders

**Investigators:** Emily Griffiths (Trainee Clinical Psychologist)  
Nicholas Hawkes (Clinical Psychologist)  
Lucy Serpell (Clinical Psychologist)

Please initial  
all boxes

1. I confirm that I have read and understand the information sheet dated **24/06/2013** (Version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University College London, Barnet, Enfield & Haringey NHS Trust or from the regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to these records. ☐
4. I agree to have the debriefing interview audio-taped and that my anonymised verbatim quotes may be used in the writing up of this research. ☐
5. I agree to my responsible units clinician being informed of my participation in the study. ☐
6. I agree to take part in the above study. ☐

Consent form date of issue: 24/06/2013  
Consent form version number: Version 2.0

Page 1 of 1

## **Appendix I**

### **Clinician Information Sheet**

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Clinician Information Sheet

**Study title:** Effects on post-meal anxiety and cognitive processes amongst inpatients with eating disorders

**Investigators:**

Emily Griffiths (Trainee Clinical Psychologist)  
Dr Nicholas Hawkes (Clinical Psychologist)  
Dr Lucy Serpell (Clinical Psychologist)  
C/o Research Department of Clinical, Educational & Health Psychology, UCL, Gower Street,  
London. WC1E 6BT

**Study objectives**

To determine the effect of visuospatial, verbal and somatic activities following meals on anxiety and intensity of different types of intrusions.

**What will the study require the participant to do?**

The participant will attend an initial meeting to discuss the research. They will be provided with a laptop, or may use their own, and then have some time to practice the activities.

Following meals where they have no other scheduled activities on the unit they will run an online programme through the laptop. The programme will ask them a series of questions and will randomise them to one of four activities, which they will complete for 15 minutes, and then they will be asked some more questions afterwards. The questionnaires and the activities will take approximately 30 minutes of their time, and then they are free to spend the rest of the time as they normally would. The activities are as follows:

1. Visuospatial- a game of Tetris
2. Verbal - a general knowledge 'Pub Quiz'
3. Somatic- using fingertips alone to work out a Braille message.
4. Control- just sitting. If they are finding it too difficult to manage just sitting they can do what they might normally do to cope during this time.

They will complete each of these activities three times. In total they will run the programme following 12 of their meals over two weeks. If they are unable to complete all 12 within two weeks, due to unforeseen circumstances, they will be given the opportunity to continue for up to another 2 weeks. They will then be invited to a meeting to discuss their experience of the study with Emily Griffiths (Trainee Clinical Psychologist), which will last approximately 30 minutes.

**Number of participants**

We would like to recruit 24 patients from Phoenix, Acacia and the Russell Unit Day Hospital.

**How long do we have to recruit this number?**

9 months

**Who is suitable to take part?**

- Be between 18 and 65 years old
- Be a patient at Phoenix Wing, Acacia House or Russell Unit Day Hospital.
- Speak English fluently
- Not been diagnosed with a moderate-severe learning disability
- Not be on bed-rest.

**What are the benefits of participants taking part?**

We are hoping that some of the activities might help to reduce their anxiety some people should find them fun to do. The study may help eating disorder researchers find activities that are better suited to help people during what we understand can be an anxiety provoking time, the post-meal period.

**What are the possible disadvantages of participants taking part?**

There is a chance that participants might feel more anxious by doing some of the activities. If this is the case they will be advised to speak to staff on the unit. In addition, some people can find completing questionnaires boring, however we have tried to make them as easy to complete as possible.

## **Appendix J**

### Letter to Clinician

Clinician Letter

Department of Clinical,  
Educational & Health Psychology  
1-19 Torrington Place  
London  
WC1E 7HB  
Emily Griffiths  
Email: [uciteio@ucl.ac.uk](mailto:uciteio@ucl.ac.uk)  
Date

Dear (Name of Clinician)

Re: (patient name, date of birth)

I am writing to inform you that the above has kindly agreed to participate in a study exploring the effect of various activities on anxiety and intrusions during the post-meal period.

This will involve completing questionnaires and doing the following activities for 15 minutes, three times each over two weeks:

Visuospatial- a game of Tetris  
Verbal - a general knowledge quiz  
Somatic- using fingertips alone to work out a Braille message.  
Control- sitting quietly

The questionnaires and activities will be online that they will access using a dongle we provide on either their own personal laptop or one that we will provide them with for the duration of the study. Following this they will be invited to attend a qualitative debrief meeting lasting approximately 30 minutes.  
The study will run until July 2014 and we will send you a summary of the results then. Please find attached an information sheet for further details.

If you have any questions regarding this patient's participation or the study please do not hesitate to contact me.

Yours sincerely,

Emily Griffiths  
Trainee Clinical Psychologist



## **Appendix K**

### **Participant Instruction Sheet**

## Starting the online programme

- Please turn on your laptop and insert the dongle into your USB drive **immediately** following your meal.
- If you do not automatically connect to the internet Click 'Connect' on the O2 Connection Manager.
- Open your internet browser and click on the bookmark link entitled 'Study'.
- You should have the relevant box with the Braille inside and a score sheet to hand in case you are asked to complete the Braille task.
- Please turn on your speakers and turn up the volume.
- Read through all the questions carefully and answer them as accurately as you can.
- Please work as quickly but as accurately as you can for all the tasks.

## General Knowledge Quiz

- Please read each question carefully and choose one of the options by pressing 1, 2, 3 or 4 on your keyboard.
- Click the next button to proceed to the next question.
- If you answer correctly it will be highlighted in green. If you answer incorrectly the answer you selected will appear crossed out in red and the correct answer will be highlighted in green.
- Continue answering the quiz questions for a duration of 15 minutes. The quiz will automatically stop after 15 minutes.

## Tetris

Blocks of different shapes drop from the top of the screen into a box. As the blocks fall they can be rotated or moved horizontally so that every space in the box is filled. When a horizontal line is completed, that line is "destroyed" giving you more points and moving the rest of the placed pieces down by one square. If a line remains incomplete, another line must be finished above it. The more lines that stand incomplete, the higher the blocks above them stack, reducing the space in which falling shapes can be manipulated. Eventually the blocks reach the top of the screen and the game ends. If you clear 10 lines you will be moved up a level and the blocks will move faster.

- Click 'Play' and choose level 5 and then click 'OK'.
- Use the left and right cursors to move the blocks horizontally. The down cursor will move the block vertically down the screen faster and the up cursor will rotate the blocks.
- If the game ends during the 15 minutes click 'OK' (no need to enter your name), click 'Play', 'Play' again and 'OK' again, to start the game on level 5.
- The Tetris game will automatically stop after 15 minutes.
- NB: DO NOT click on 'Play full screen' in the bottom left hand corner.

## Braille

- Use one hand to feel the Braille letters inside the box and the other to write down your answers on the score sheet. It will be easier to keep your hand inside the box for the duration of the task so that you do not lose your place.
- Identify the paper fastener in the top left hand corner to mark where the start is.
- Then moving your fingers from left to right work out what letter the Braille is using your key card.
- There are 11 random letters in each line. Each Braille symbol represents a letter only (no words).
- On your score sheet circle the letter you think is correct.
- Move along to the next letter and so on until you reach the end of the line and then go to the line below.
- There are paper fasteners on the right hand side to differentiate each line in case you do lose your place.
- Keep going for 15 minutes when you will be notified by a noise on the online programme.

## Sitting quietly

- Please remain silent for the duration of the 15 minutes. Do not engage in any other activity other than sitting quietly.
- Try not to talk to anyone around you and if someone tries to talk to you simply tell them that you need to remain silent for the task and will talk to them later.
- If you are feeling very uncomfortable during this activity then you may engage with something you normally would do (e.g. reading or knitting) but please let us know what you did in the comment box at the end of the 15 minutes.
- After 15 minutes you will be alerted to the end of the task by a noise on the online programme.

## **Appendix L**

### **Ethical Approval Letter**

**NRES Committee London - Harrow**

Bristol Research Ethics Committee Centre  
Level 3, Block B  
Whitefriars  
Lewins Mead  
Bristol  
BS1 2NT  
Telephone: 01173 421383  
Facsimile: 01173 420455

28 June 2013

Dr Lucy Serpell  
Lecturer  
University College London  
1-19 Torrington Place  
London  
WC1E 7HB

Dear Dr Serpell

<b>Study title:</b>	<b>Effects on post-meal anxiety and cognitive processes amongst inpatients with eating disorders</b>
<b>REC reference:</b>	<b>13/LO/0800</b>
<b>IRAS project ID:</b>	<b>120506</b>

Thank you for your letter of 24 June 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

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

**Confirmation of ethical opinion**

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

**Ethical review of research sites**

**NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management

A Research Ethics Committee is a body set up by the Health Research Authority

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Non-NHS sites

#### Conditions of the favourable opinion

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

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

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

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

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

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

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

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

#### Approved documents

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

Document	Version	Date
Advertisement	2.0	24 June 2013
Evidence of Insurance or Indemnity		10 May 2013
GP/Consultant Information Sheets	Clinician Information Sheet, v1.0	17 April 2013
GP/Consultant Information Sheets	Clinician Letter, v1.0	17 April 2013
Interview Schedules/Topic Guides	Debrief Meeting Questions, v1.0	17 April 2013

Investigator CV	Emily Griffiths	10 May 2013
Investigator CV	Nicholas Hawkes	10 May 2013
Investigator CV	Lucy Serpell	10 May 2013
Letter from Sponsor	Trainee Indemnity	06 September 2009
Letter from Statistician	Statistician Review	04 March 2013
Other: Data Protection Registration		03 March 2013
Other: Screen Shot of Tetris	1.0	17 April 2013
Other: Screen Shot of Quiz	1.0	17 April 2013
Participant Consent Form	2.0	24 June 2013
Participant Information Sheet	2.0	24 June 2013
Protocol	1.0	17 April 2013
Questionnaire: EDE-Q 6.0		
Questionnaire: GAD-7		
Questionnaire: PANAS		
Questionnaire: PHQ-9		
Questionnaire: Visual Analogue Scales	1.0	03 March 2013
Questionnaire: Mealtime Experiences Measure	1.0	03 March 2013
REC application	120506	14 May 2013
Referees or other scientific critique report	Peer Review	14 October 2012
Response to Request for Further Information		24 June 2013
Summary/Synopsis	Flow Chart, v1.0	17 April 2013

#### Statement of compliance

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

#### After ethical review

##### Reporting requirements

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

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

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

Feedback

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

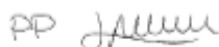
Further information is available at National Research Ethics Service website > After Review

13/LO/0800	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

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

Yours sincerely



Dr Jan Downer  
Chair

Email: [nrescommittee.london-harrow@nhs.net](mailto:nrescommittee.london-harrow@nhs.net)

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Clara Kalu  
Mrs Angela Williams