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Socio-emotional aspects, assessment and response to a carers' skills intervention in adolescent anorexia nervosa

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SOCIO-EMOTIONAL ASPECTS, ASSESSMENT AND RESPONSE TO A CARERS' SKILLS INTERVENTION IN ADOLESCENT ANOREXIA NERVOSA

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ABSTRACT

Background: Socio-emotional difficulties in anorexia nervosa (AN) and distress-related caregiver responses to the illness are both thought to play a role in illness maintenance according to the cognitive-interpersonal maintenance model of AN. **Aims:** The first main aim of this thesis is use multimodal measures to extend the evidence for socio-emotional difficulties (Autism Spectrum Disorder-like (ASD) traits and facial emotion expression) in treatment-seeking adolescents with AN. The second main aim is to establish the caregiving burden (distress and time spent caregiving) for families and interpersonal behaviour patterns associated with illness maintenance, and provide further scale validation for measuring these aspects. The third main aim is to examine whether the augmentation of treatment as usual with a carer skills intervention to target these interpersonal behaviours is of benefit. **Method:** Three experimental designs were employed. Socio-emotional difficulties, caregiver burden and behaviours, and longitudinal response to a carer skills intervention were examined within the context of a multi-site pragmatic randomised controlled trial (n=149 AN adolescents, n=226 carers). An experimental medicine paradigm was used to assess evoked facial emotion expression in 17 further AN adolescents and similar-age healthy controls. Cross-sectional data from 268 AN carers was used for further validation of two caregiving measures. **Results:** The main findings provide empirical support to show socio-emotional difficulties in adolescent AN consistent with previous findings, high levels of caregiving burden, and maladaptive patterns of distress interdependence that can be modified by augmenting treatment with a carer skills intervention. Further validation of two scales to measure aspects of these modifiable behaviours was also obtained. **Conclusions:** The research findings provide empirical support for the cognitive-interpersonal maintenance model of eating disorders in adolescent AN. The possible benefit of augmenting treatment of adolescent AN with a carer skills intervention to modify interpersonal behaviours has been demonstrated.

ACKNOWLEDGEMENTS

I would like to express my special appreciation and thanks to my supervisors Prof Janet Treasure who has generously provided inspiration and shared with me her enthusiasm and expertise throughout my PhD, and Dr Kate Tchanturia whose input and encouragement has been valued. I wold also like to thank Dr Will Mandy for his supervision and Prof Ulrike Schmidt, Prof Iain Campbell, and Gill Todd for their kind encouragement always. A special thank you is to all members of the EDU, especially my close colleagues in the basement: Dr Rebecca Hibbs, Dr Valentina Cardi, Dr Liz Goddard, and Rob Turton, and EDU legends: Dr Caitlin O'Hara, Katie Lang, Dr Jess McClelland, Maria Kekic, and Sam Lloyd who have helped make this experience what is has been. My PhD scholarship from The Psychiatry Research Trust is also gratefully acknowledged, as is funding for the ECHO trial by the National Institute for Health Research and the enormous support from all collaborating sites and participating families. A final thank you is to my friends, family, and housemates for their patience and support throughout, and particularly towards the final stage of, my PhD.

COMMON ABBREVIATIONS USED

AN	anorexia nervosa
AQ	autism quotient
ASD	autism spectrum disorder
BMI	body mass index
BN	bulimia nervosa
d.	cohen’s d. (effect size)
DASS-21	depression, anxiety, and stress scales (21-item version)
DSM	the diagnostic and statistical manual of mental disorders
ECHO	experienced carers helping others
ED	eating disorders
EDNOS	eating disorder not otherwise specified
ES	effect size
FBT	family based therapy
ICD	the international statistical classification of diseases and related health problems
M	mean
NHS	national health service
NICE	the national institute for health and care excellence
OCD	obsessive compulsive disorder
OCPD	obsessive–compulsive personality disorder
p.	critical value of statistical significance
SD	standard deviation
SPSS	statistical package for the social sciences
TAU	treatment as usual
UK	united kingdom

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LIST OF PUBLICATIONS ASSOCIATED WITH THESIS

Cardi, V., Corfield, F., Leppanen, J., Rhind, C., Deriziotis, S., Hadjimichalis, A., Hibbs, R., Micali, N., & Treasure, J. (2015, *in press*). Emotional processing, recognition, empathy and evoked facial expression in Eating Disorders: An experimental study to map deficits in social cognition. *PloS One.*

Hibbs, R., Magill, N., Goddard, E., Rhind, C., Raenker, S., Macdonald, P., Todd, G., Arcelus, J., Morgan, J., Beecham, J., Schmidt, U., Landau, S., & Treasure, J. (2015). Clinical effectiveness of a skills training intervention for caregivers in improving patient and caregiver health following in-patient treatment for severe anorexia nervosa: pragmatic randomised controlled trial. *B J Psych Open, 0*, 1-11. doi: 10.1192/bjpo.bp.115.000273.

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Treasure, J., Rhind, C., Macdonald, P., & Todd, G. (2015). Collaborative Care: The New Maudsley Model. *Eat Disord, 23*(4), 366-76.

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spectrum traits in adolescents with anorexia nervosa and their parents. *Molecular Autism, 5*(1): 56. doi: 10.1186/2040-2392-5-56.

Rhind, C., Hibbs, R., Goddard, E., Schmidt, U., Micali, N., Gowers, S., Beecham, J., Macdonald, P., Todd, G., Tchanturia, K., & Treasure, J. (2014). Experienced Carers Helping Others (ECHO): protocol for a pilot randomised controlled trial to examine a psycho-educational intervention for adolescents with anorexia nervosa and their carers. *Eur Eat Disord Rev, 22*(4), 267-77.

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Macdonald, P., Rhind, C., Hibbs, R., Goddard, E., Raenker, S., Todd, G., Schmidt, U., & Treasure, J. (2014). Carers' assessment, skills and information sharing (CASIS) trial: a qualitative study of the experiential perspective of caregivers and patients. *Eur Eat Disord Rev, 22*(6), 430-8.

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LIST OF PRESENTATIONS ASSOCIATED WITH THESIS

Rhind, C. An Examination of Autism Spectrum Traits in Adolescents with Anorexia Nervosa and Their Parents. Paper presentation at the International Conference for Eating Disorders 2015, Academy for Eating Disorders. May 2015, Boston: USA.

Rhind, C. Empirical Examination of Risk and Resilience Factors in the Cognitive-Interpersonal Maintenance Model of Adolescent Anorexia Nervosa. Paper presentation at the International Conference for Eating Disorders 2015, Academy for Eating Disorders. May 2015, Boston: USA.

Treasure, J. & Rhind, C. Transitions in Different Stages of Eating Disorder. Keynote presentation at the Royal College of Psychiatrists Eating Disorders Psychiatry Faculty Annual Conference; 2014, London, UK.

Rhind, C. Experienced Carers Helping Others (ECHO): a pilot RCT to examine a skills-sharing intervention for adolescents with anorexia nervosa and their caregivers. Paper presentation at the London Eating Disorders Conference; 2015, London: UK.

Rhind, C. An Examination of Autism Spectrum Traits in Adolescents with Anorexia Nervosa and Their Parents. Paper presentation at the London Eating Disorders Conference; 2015, London: UK.

Rhind, C. Empirical Examination of Risk and Resilience Factors in the Cognitive-Interpersonal Maintenance Model of Adolescent Anorexia Nervosa. Paper presentation at the London Eating Disorders Conference; 2015, London: UK.

Rhind, C. Experienced Carers Helping Others (ECHO): A pragmatic three-arm multicentre parallel group pilot randomised controlled trial to examine a psycho-educational intervention. Oral presentation at the Annual Palliative Care and Psychological Medicine PhD Symposium, KCL.

Rhind, C. & Todd, G. Using Motivational Interviewing to manage eating disorders symptoms. Workshop at the Eating Disorders International Conference; 2014, London, UK.

Rhind, C. & Hibbs, R. Experienced Carers Helping Others: a self-help intervention for carers of someone with anorexia nervosa. Presentation at the Mental Health Research Network (MHRN) SUNLOWS seminar; 2013, London: UK.

Rhind, C. Experienced Carers Helping Others: a self-help intervention for carers of someone with anorexia nervosa. Presentation at Talking Eating Disorders Conference 2013, Liverpool: UK.

DECLARATION OF CANDIDATE’S ROLE

Chapter 1: Introduction

All work is candidate’s own.

Chapter 2: An examination of autism spectrum traits in adolescents with anorexia nervosa and their parents

The data for this study was collected as part of the Experienced Carers Helping Others (ECHO) randomised controlled trial. Janet Treasure (JT), Ulrike Schmidt (US), Nadia Micali (NM), Simon Gowers (SG), Pamela Macdonald (PM), and Elizabeth Goddard (EG) made substantial contribution to the conception and design of the ECHO trial which was jointly co-ordinated (including all recruitment and data collection) by the candidate and Rebecca Hibbs (RH). The candidate and Elena Bonfioli (EB) were the main contributors to the data entry and data analysis was completed by the candidate. NM was the clinician who assigned autism spectrum disorder diagnoses relating to this study and Robert Goodman (developer of the instrument used) and JT made substantial contribution to data interpretation. The candidate was the main contributor to writing this chapter/paper and all authors JT, US, NM, SG, PM, EG, RH, EB, and Kate Tchanturia (KT) revised it critically for important intellectual content and provided final approval for this chapter as a manuscript for publication (Rhind et al., 2014).

Chapter 3: An exploratory study of evoked facial affect in adolescent females

The candidate was the main contributor to the design, data collection, data analysis, interpretation and write-up of this chapter/paper. Will Mandy (WM), KT, and JT revised the chapter/paper critically for important intellectual content and provided final approval for this chapter as a manuscript for publication (Rhind et al., 2014).

Chapter 4: Confirmatory factor analysis for two questionnaires of caregiving in eating disorders

Data for this study was collected as part of the CASIS trial (protocol avaliable: Goddard et al., 2012) for which EG, Simone Raenker (SR), PM, GT, JB, Ulrike Naumann (UN), Eva-Maria Bonin, US, Sabine Landau (SL), and JT made substantial contribution to the conception and design. The CASIS trial was run by the Eating Disorders Unit at King's College London mainly by EG and SR and data collection was supported in the final stages jointly by the candidate and RH. The candidate, RH and JT made substantial contribution to the conception and design of the study (chapter 4) and data analysis was completed together by the candidate, RH and King's College London statistician Hannah Sallis (HS) who also made substantial contribution to the interpretation. The candidate and RH *jointly* co-authored this chapter/paper which is included in both the candidate and RH's PhD thesis (RH PhD completed 03/2014). All authors RH, HS, EG, SR, Agnes Ayton (AA), Bryony Bamford (BB), Jon Arcelus (JA), Nicky Boughton (NB), Frances Connan (FC), Ken Goss (KG), Bert Lazlo (BL), John Morgan (JM), Kim Moore (KM), David Robertson (DR), Christa Schreiber-Kounine (SK), Sonu Sharma (SS), Linette Whitehead (LW), Hubert Lacey (HL), US, and JT revised the chapter/paper critically for important intellectual content and provided final approval for this chapter as a manuscript for publication (Hibbs, Rhind, et al., 2014).

Chapter 5: The Objective and Subjective Caregiving Burden and Caregiving Behaviours of Parents of Adolescents with Anorexia Nervosa

All data for this study was collected as part of the ECHO trial (candidate's role already described). The candidate and JT made substantial contribution to the conception and design of the study. The candidate was the main contributor for the primary data analysis of this study and statisticians Laura Salerno (LS) and Gianluca Lo Coco (GLC) made substantial contribution to the mediation analysis and interpretation. The candidate was the main contributor to writing this chapter/paper and all authors JT, US, NM, SG, PM, EG, RH, KT, LS, and GLC revised the chapter/paper critically for important intellectual content and provided final approval for this chapter as a manuscript for publication (Rhind et al., 2015, under review).

Chapter 6: Experienced carers helping others (ECHO): Protocol for a pilot randomised controlled trial to examine a psycho-educational intervention for adolescents with anorexia nervosa and their carers

The candidate was the main contributor for writing this chapter/paper describing the methodology of the ECHO trial for which JT, US, NM, SG, PM, and EG made substantial contribution to the design. JT, US, NM, SG, PM, EG, RH, Jennifer Beecham (JB), and KT revised the chapter/paper critically for important intellectual content and provided final approval for this chapter as a manuscript for publication (Rhind et al., 2015).

Chapter 7: A longitudinal examination of dyadic distress patterns following a skills intervention for carers of adolescents with anorexia nervosa

All data for this study was collected as part of the ECHO trial (candidate’s role already described). The candidate and JT, made substantial contribution to the conception and design of the study. The candidate, LS, and GLC made substantial contribution to the data analysis and interpretation with JT. The candidate was the main contributor to writing this chapter/paper and all authors JT, US, NM, SG, PM, EG, RH, KT, LS, and GLC revised the chapter/paper critically for important intellectual content and provided final approval for this chapter as a manuscript for publication (Rhind et al., 2015, under review).

Chapter 8: Discussion

All work is candidate’s own.

THESIS MAP

Chapter 1: The first chapter provides the background for the present thesis and an overview of the project aims and hypotheses.

Chapter 2: This published chapter presents a multimodal examination of autism spectrum disorder-like traits in adolescents with anorexia nervosa and their parents.

Chapter 3*:* This published chapter presents the first experimental assessment of evoked facial emotion expression in adolescents with anorexia nervosa.

Chapter 4: This published chapter presents a confirmatory factor analysis of two measures of care giving in eating disorders.

Chapter 5: This chapter (article under review) presents an examination of caregiving burden, accommodating and enabling behaviours, and expressed emotion in adolescent anorexia nervosa.

Chapter 6: This published chapter describes the theoretical rational and protocol for a pilot randomised controlled trial to explore the Experienced Carers Helping Others (ECHO) intervention for the first time in carers of adolescents with anorexia nervosa.

Chapter 7: This chapter (article under review) presents an examination of changes in carer/patient dyadic distress patterns over time in adolescent anorexia nervosa as an outcome of the ECHO intervention.

Chapter 8: This chapter synthesises and discusses findings in the present thesis, highlighting the key strengths, limitations, and clinical implications. Future research suggestions and an overall conclusion are made.

CHAPTER 1.

INTRODUCTION

1.1 Chapter aims

The aim of this chapter is to present the background for the research aims of the present thesis. This chapter is presented in six broad sections: The first section provides an overall introduction to eating disorders (EDs), mainly anorexia nervosa (AN), and introduces theoretical models of illness maintenance pertinent to this thesis. The second section highlights the role of socio-emotional processing in AN (risk and maintenance) using current evidence and highlights gaps in the literature. The third section describes the caregiving burden related to this group, emphasising the impact of altered aspects of socio-emotional functioning in AN within the context of an interpersonal maintenance model of illness. The fourth section introduces methods of assessing these difficulties (between self and others) and the benefit of using multimodal and multi-informant methods. The fifth section provides an overview of current treatment approaches and response, and introduces guidance for parents (or other carers) as a treatment supplement that may ameliorate problematic interpersonal patterns that are thought to hinder recovery, and the current evidence base for this approach. The final section outlines the research aims and hypotheses of the present thesis and an overview of the studies conducted to address these.

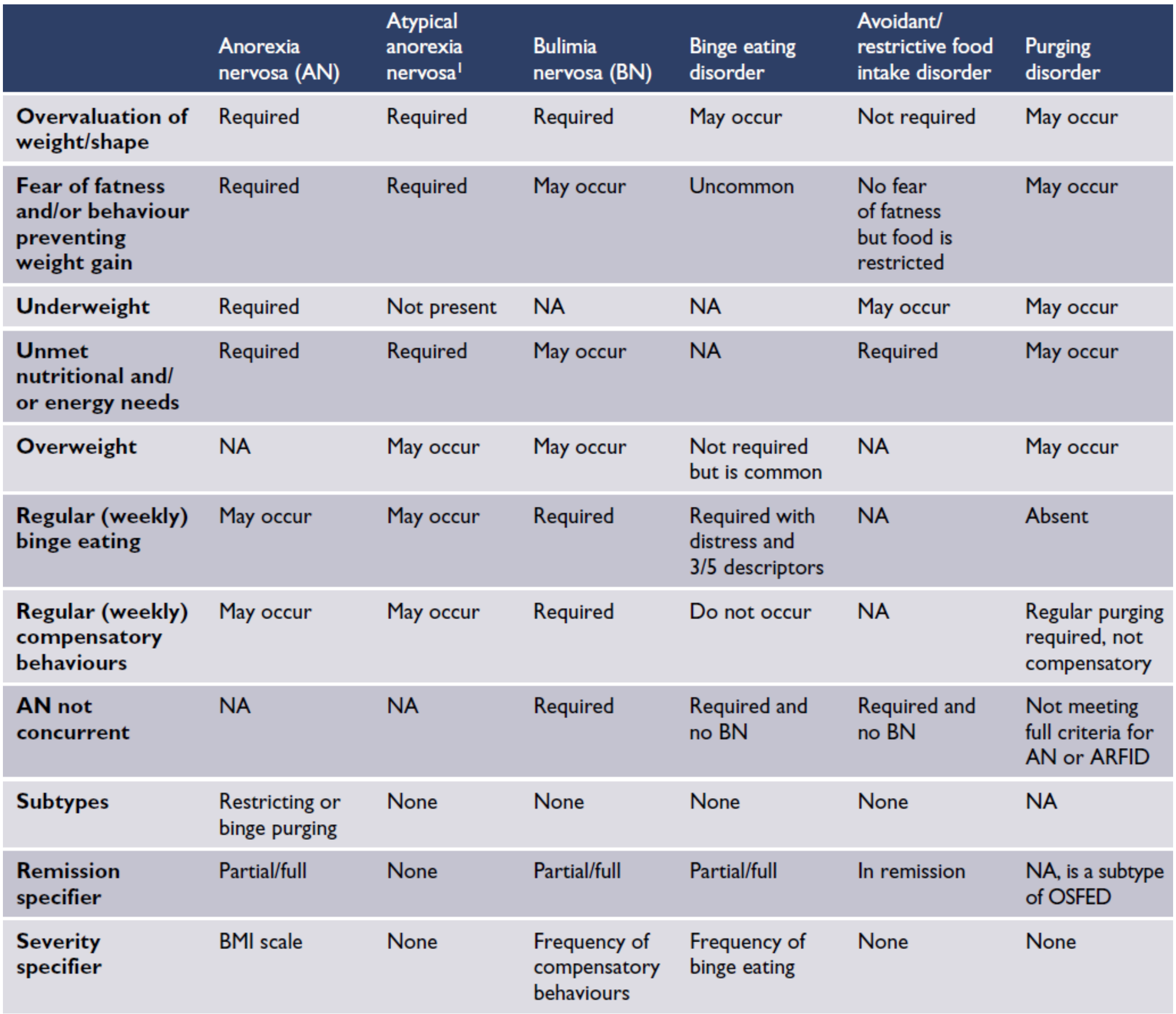
1.2 Eating disorders: an overview

1.2.1 General description of eating disorders

EDs are characterised by disturbances of eating behaviours and a core psychopathology centred on food, eating and body image concerns. Early reports of AN in various forms have been reported cross-culturally and date back to the 1600s (Silverman, 1983). Since the original appearance of AN in the medical literature in the late 19th century (e.g. Gull, 1874; Lasegue, 1873; Pearce, 2004), the relevance of social and emotional difficulties in its origin has been discussed: In 1873 Charles Lasegue noted that AN occurs in young women who *"suffers from some emotions she avows or conceals"* (cited in Vandereycken & van Deth, 1990). Additional insights into predisposing and precipitating socio-emotional factors for EDs emerged a century later: Hilda Bruch, in her writings of AN in the mid-20th Century stated that women with AN *"suffer from definite deficits in the way in which they interpret human relationships and think of their own role in life"* (Bruch, 1977). By the 20th century bulimia nervosa (BN) and binge eating disorder (BED) were also described, although only AN and BN were acknowledged as a diagnosable psychiatric illness in the Diagnostic and Statistical Manual of Mental Disorders third edition (APA, 1980). The subsequent DSM edition (APA, 1994) introduced ED not otherwise specified (EDNOS) to capture subthreshold presentations of AN and BN and broader ED presentations less clearly understood at the time. Given the heterogeneity of EDs, it is unsurprising that by 2009 the 'catch it all' diagnosis EDNOS became the most common of the ED diagnostic categories (Call, Walsh, & Attia, 2013; Thomas, Vartanian, & Brownell, 2009), accounting for approximately 50-60% of ED (Fairburn & Bohn, 2005; Treasure, Claudino, & Zucker, 2010). EDs have since been extensively researched and facilitated the development of more accurate diagnostic criteria in the current DSM-5 (APA, 2013) for their diagnosis and treatment. Most notably, by relaxing the criteria of AN and BN in the DSM-5, including BED as a primary ED classification, the DSM-5 aimed to eliminate the use of EDNOS as an 'overflow' diagnostic group with limited clinical utility. Rather, Other Specified Eating Disorders (OSFED) is a more clearly defined classification for broader and/or milder but specific ED presentations. Four other ED classifications are also included in the DSM-5 and summarised in Table 1. The World Health Organisation's International Statistical Classification of Disease and Related Health Problems' (ICD-10; WHO, 1992) ICD-10 criteria for EDs have also commonly been used in research and clinically over the past 20 years, and the Great Ormond Street (GOSH) ED criteria used, particularly co-opted as a more developmentally sensitive diagnostic tool for childhood ED cases (Bravender et al., 2010; Nicholls, Chater, & Lask, 2000). Therefore, caution should be taken when synthesising and cross-generalising evidence of individuals diagnosed with AN across the different diagnostic tools and versions (e.g. DSM-IV to 5). Most notably, a proportion of individuals diagnosed with DSM-IV EDNOS-AN subtype would meet current DSM-5 criteria for AN. Because both AN and AN-like (subthreshold) presentations are under investigation in the present thesis, the differences in criteria between AN and related presentations across diagnostic tools is of less concern.

1.2.2 Diagnostic criteria

The DSM-5 characterises AN by three essential features; (i) persistent energy intake restriction, (ii) intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain, and (iii) a disturbance in self-perceived weight or shape, according to the Diagnostic and Statistical Manual for Mental Disorders (DSM-5) (APA, 2013). Two subtypes are recognised by DSM-5, restricting AN or binge-eating/purging AN, distinguished by presentations in which weight loss is accomplished primarily through dieting, fasting, and/or excessive exercise (restricting type) compared to presentations where the individual has engaged in recurrent episodes of binge eating or purging behaviour. AN is further classified by severity, based, for adults, on current body mass index (BMI; kg/m^2), ranging from mild (BMI ≥ 17), moderate (BMI 16-16.99), severe (BMI 15-15.99) to extreme (BMI < 15) and for children and adolescents, by corresponding BMI centiles. Subthreshold AN presentations (e.g. where all the criteria for AN are met, except that despite significant weight loss, the individual's weight is within or above the normal range) are classified within OSFED as atypical AN.



	Anorexia nervosa (AN)	Atypical anorexia nervosa[1]	Bulimia nervosa (BN)	Binge eating disorder	Avoidant/ restrictive food intake disorder	Purging disorder
Overvaluation of weight/shape	Required	Required	Required	May occur	Not required	May occur
Fear of fatness and/or behaviour preventing weight gain	Required	Required	May occur	Uncommon	No fear of fatness but food is restricted	May occur
Underweight	Required	Not present	NA	NA	May occur	May occur
Unmet nutritional and/ or energy needs	Required	Required	May occur	NA	Required	May occur
Overweight	NA	May occur	May occur	Not required but is common	NA	May occur
Regular (weekly) binge eating	May occur	May occur	Required	Required with distress and 3/5 descriptors	NA	Absent
Regular (weekly) compensatory behaviours	May occur	May occur	Required	Do not occur	NA	Regular purging required, not compensatory
AN not concurrent	NA	NA	Required	Required and no BN	Required and no BN	Not meeting full criteria for AN or ARFID
Subtypes	Restricting or binge purging	None	None	None	None	NA
Remission specifier	Partial/full	None	Partial/full	Partial/full	In remission	NA, is a subtype of OSFED
Severity specifier	BMI scale	None	Frequency of compensatory behaviours	Frequency of binge eating	None	None

Table 1. Comparative clinical features of DSM-5 ED diagnostic groups (from Hay et al., 2014).

As displayed in Table 1, BN shares some features of AN (e.g. overvalued ideas about shape and weight). However, essential features to receive a diagnosis of BN include recurrent episodes of binge eating followed by inappropriate behaviours such as self-induced vomiting to avoid weight gain. The frequency of these behaviours needing to occur in order to qualify for a diagnosis of BN has been reduced in DSM-5 to on average, at least once per/week for three months. Weight loss through these methods is usually ineffective, therefore unlike AN, individuals with BN tend to be within the normal weight or overweight range (BMI ≥ 18.5 and < 30 in adults, equivalent for young people), although there may be severe medical complications (e.g. fluid and electrolyte disturbances) that can carry serious consequences. For subthreshold presentations (i.e. when all of the criteria for BN are met, except that the binge eating and inappropriate compensatory behaviours occur, on average, less than once a week and/or for less than three months), the OSFED classification low frequency BN is assigned. Alternatively, for presentations in which binge-eating episodes (of similar frequency to BN) caused marked distress however are not associated with inappropriate compensatory behaviours, the BED classification is assigned. The four remaining ED classifications included in DSM-5 share less in common with AN (see Table 1) and their description is therefore beyond the scope of the present thesis.

The diagnosis of an ED can be unstable (Eddy et al., 2008). Reportedly, less than one third retain a consistent ED diagnosis during a 30-month follow-up (Milos, Spindler, Schnyder, & Fairburn, 2005). Diagnostic cross-over is common between AN subtypes (Eddy et al., 2002), and between ED types. The most common crossover is from AN to BN and reported to occur in 20-50% of individuals (Bulik, Sullivan, Fear, & Pickering, 1997; Eckert, Halmi, Marchi, Grove, & Crosby, 1995; Strober, Freeman, & Morrell, 1997), although the reverse (i.e. BN to AN) is much less common (Keel & Mitchell, 1997). The diagnostic instability of EDs supports the notion that there are shared underlying mechanisms, or transdiagnostic traits (e.g. Fairburn & Harrison, 2003). That some enduring personality traits appear linked to specific types of eating behaviours whereas others are more general (Karwautz, Rabe-Hesketh, Collier, & Treasure, 2002), provides support for this approach. For example, whereas novelty-seeking personality is linked specifically to those who show disinhibited eating behaviours (Vervaet, Van Heeringen, & Audenaert, 2004), constrained eating, as seen in restricting AN, is linked to compulsivity. The evidence suggests there is considerable heterogeneity in transdiagnostic traits in AN but there is likely to be ED subgroups characterised by distinct profiles (Ribasés et al., 2004). For example, Renwick and colleagues (2015) found that neuro- and social-cognitive clustering highlighted distinct profiles in adults with AN, with a subset showing ASD-like features (Renwick et al., 2015). Therefore, considering both transdiagnostic traits and categorical diagnosis is likely to be important for predicting outcomes and in guiding the development of specific treatment that target aetiological and maintenance factors of AN.

1.2.3 Psychiatric comorbidity

In addition to diagnostic instability, EDs are associated with high levels of psychiatric comorbidity (Jacobi, Hayward, De Zwaan, Kraemer, & Agras, 2004). The most common of which are anxiety disorders including obsessive-compulsive disorder (OCD) and major depressive disorder (Braun, Sunday, & Halmi, 1994; Hudson, Hiripi, Pope Jr, & Kessler, 2007; Milos, Spindler, Buddeberg, & Crameri, 2003; Steinhausen, 2002; Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011; Swinbourne & Touyz, 2007; Von Lojewski, Boyd, Abraham, & Russell, 2012), and this of true of both adolescent and adult AN. Substance misuse disorders (Mann et al., 2014) and personality disorder (Godt, 2008) may also co-occur in less than 25% of individuals with AN. Furthermore, autism spectrum disorder (ASD) is over-represented in AN (Gillberg, 1992; Huke, Turk, Saeidi, Kent, & Morgan, 2013; McKnight & Boughton, 2009; Treasure, 2013; Zucker et al., 2007), with several studies reporting an approximate 20% lifetime prevalence of ASD in AN (Råstam et al., 2013; Wentz, Gillberg, Anckarsater, Gillberg, & Rastam, 2009). Given similarities between the highly comorbid conditions AN, ASD, and OCD (e.g. need for sameness/compulsivity, rigidity, obsessionality), examination into transdiagnostic traits and the study of endophenotypes, thought to provide clues to subserving neurocognitive processes, has recently been the subject of much examination across the research fields (e.g. Baron-Cohen et al., 2013; Hambrook, Tchanturia, Schmidt, Russell, & Treasure, 2008; Koch et al., 2015; Mandy & Tchanturia, 2015; Oldershaw, Treasure, Hambrook, Tchanturia, & Schmidt, 2011; Renwick et al., 2015; Tchanturia et al., 2013; Zucker et al., 2007).

1.2.4 Epidemiology

AN typically onsets during adolescence or young adulthood (Currin, Schmidt, Treasure, & Jick, 2005; Micali, Hagberg, Petersen, & Treasure, 2013). It is the third most common chronic disorder affecting adolescent girls (Steinhausen et al., 2002). It rarely begins before puberty or after age 40, but cases of both early and late onset have been described. The onset is often associated with a stressful life event, often a transition, such as leaving home for university. Incidence rates of AN vary across studies, for example, from reports of 4.7 cases per 100,000 population per year (Currin et al., 2005) to 8 cases per 100,000 per year (Hoek & Van Hoeken, 2003), and as high as 17.5 per 100,000 per year in 10 to 19-year-olds based on a UK general practise registry in the early 1990s (Turnbull, Ward, Treasure, Jick, & Derby, 1996). Although few suggest that the incidence of ED is increasing (Keel & Klump, 2003), and there is some concern about increasing numbers of childhood cases, generally incidence rates have been reported to be relatively stable over the past decades (Currin et al., 2005; Hoek & Van Hoeken, 2003), with some increase in the high risk group of 15-19 year old girls (Smink, Van Hoeken, & Hoek, 2013), that may reflect improved case detection rather than a true increase in incidence. On the other hand, Nicholls and Yi (2012) argue that true incidence is likely underestimated because a) detection is based on self- or clinician-report, and both of which are subject to under-reporting, particularly because of the covert nature and/or lack of insight associated with AN (Reid, Williams, & Hammersley, 2010); and b) not all cases reach primary care (Keski-Rahkonen et al., 2007).

An average prevalence rate for AN of 0.3% has been reported for young females (Hoek & Van Hoeken, 2003), although the DSM-5 estimates the 12-month prevalence of AN among young females as approximately 0.4%. Less is known about prevalence of AN among males; Although men with EDs are more likely to be underdiagnosed, misdiagnosed, and under-referred, EDs are much less common in men with clinical populations generally reflecting approximately a 10:1 female-to-male ratio (Jacobi et al., 2004), although this ratio narrows in children with early-onset EDs (Nicholls, Lynn, & Viner, 2011; Peebles, Wilson, & Lock, 2006). Others have estimated the lifetime prevalence of AN at 0.9% for women, and 0.3% for men (Hudson et al., 2007); and a more recent review reports similar rates in AN ranging from 1.2-2.2% (Smink et al., 2013). Although EDs have previously been characterised as culture-bound syndromes, specific to Caucasian subjects in Western industrialised societies (Keel & Klump, 2003), recent studies demonstrated the occurrence of EDs and abnormal eating behaviours in non-Western countries and among ethnic minorities (Eddy, Hennessey, & Thompson-Brenner, 2007; Lee, Ng, Kwok, & Fung, 2010; Marques et al., 2011).

The course and outcome of EDs like AN are highly variable and there may be complications from malnutrition and compensatory behaviours including growth retardation, osteoporosis, infertility, changes in brain structure (Katzman, 2005) and cognitive impairment (Hatch et al., 2010; K. Lang et al., 2015). These complications are greatest during early adolescence due to disruption of critical periods of physical, psychological and social development (Golden et al., 2003; Katzman, 2005). Although, evidence suggests that the onset of an ED during adolescence (i.e. typical onset) is associated with a better prognosis than onset during adulthood (Fisher, 2003). Outcomes for AN are poorer than other ED classifications. The ED course is often protracted (5 years on average) and the behavioural expressions of AN tend to change with increasing age of the patient and duration of the disorder (Fairburn & Cooper, 2011), and young cases tend to improve with time (Halvorsen, Andersen, & Heyerdahl, 2004; Nicholls et al., 2011; Steinhausen, 2002). Although more promising outcomes are associated with longer follow-up periods in community samples, with recovery rates of 34% reported in short-term studies vs. 73% in longer-term studies (Steinhausen, 2002), a sizeable proportion suffer a chronic course of illness. It has been estimated that between 10-20% (Keski-Rahkonen et al., 2007; Steinhausen, 2002, 2009; Zipfel, Löwe, Reas, Deter, & Herzog, 2000) to as high as 50% (Støving, Andries, Brixen, Bilenberg, & Hørder, 2011) of cases remain chronically ill. For this reason, this subgroup of patients have been acknowledged and defined by the term severe and enduring AN (SEED-AN; Robinson, 2014), although studies differ in their definition. The minimum criteria for this term is suggested as three years and most often the term applied by illness course over six or seven years (Touyz et al., 2013). Although some have highlighted that the duration of illness does not necessarily predict quality of life in AN (Bamford & Sly, 2010), patients with severe and enduring AN are associated with repeated hospital admissions, heavy burden on health and public sectors, and considerable strain on carers and families (Arcelus, Mitchell, Wales, & Nielsen, 2011; Steinhausen, 2002).

Although there is a lack of consensus regarding what constitutes ED recovery (Dawson, Rhodes, & Touyz, 2014), full remission is defined in the DSM-5 as an individual no longer fulfilling diagnostic criteria for AN for a sustained period of time and partial remission defined when body weight has been restored, but other criteria are still met. The lack of agreement in defining recovery between studies (Couturier & Lock, 2006) contributes to difficulties in determining useful outcomes measures for research and clinical practise. In exploring what constitutes recovery in adolescent AN, Couturier and Lock concluded that both weight and psychological symptoms appear to be important; although definitions of recovery may be dependent on specific goals of a particular study or treatment (Couturier & Lock, 2006). Broader assessment of psychological distress or psycho-social and interpersonal functioning may provide useful indicators for future ED symptom improvement and recovery.

All EDs have an elevated risk of mortality. The mortality rate is greatest for AN at up to 18 times greater than in non-affected females aged 15-24 years (Steinhausen, Boyadjieva, Griogoroiu-Serbanescu, & Neumärker, 2003) and, particularly in the context of severe and enduring AN, is reported by some to have the highest mortality rate across all psychiatric illnesses (Arcelus et al., 2011; Harris & Barraclough, 1998). The mortality level is reported between 10-20% (Berkman, Lohr, & Bulik, 2007; Harris & Barraclough, 1998; Zipfel et al., 2000) and death most commonly results from medical complications associated with the disorder (e.g. heart failure) or from suicide. In a meta-analysis across 36 studies published between 1966-2010 that included mortality rates EDs, Arcelus and colleagues found that suicide accounted for one in five deaths (Arcelus et al., 2011).

1.2.5 Risk factors for anorexia nervosa

A risk factor is defined as *"a variable that has been shown to prospectively predict some subsequent pathological outcome. Temporal precedence can be established by showing that a variable predicts subsequent onset of a disorder among initially disorder-free individuals (for dichotomous outcomes) or growth in symptoms controlling for initial* *symptom levels (for continuous outcomes)"* (Stice, 2002, p. 825). Significant attempts have been made to identify factors that contribute to risk and maintenance of EDs like AN. Although relatively little is still clearly understood, a number of multi-faced factors from within a biopsychosocial framework incorporating socio-cultural, biological, and psychological factors are evidently pertinent in elevating risk for the development of AN (Mitchison & Hay, 2014; Smink et al., 2013; Stice, 2002). The strongest socio-demographic risk factors understood for AN are being female (Jacobi et al., 2004) and being from a culture where the 'thin ideal' prevails, particularly those with high levels of exposure to environments that value body shape or body fat (e.g. modelling, dance, swimming). There is also an increased genetic heritability and frequency of a family history in AN. The estimated twin-based heritability of AN ranges from 33-88% (Bulik et al., 2006; Bulik, Sullivan, Wade, & Kendler, 2000; Bulik et al., 2010; Klump, Miller, Keel, McGue, & Iacono, 2001; Kortegaard, Hoerder, Joergensen, Gillberg, & Kyvik, 2001; Wade, Bulik, Neale, & Kendler, 2000). It is likely that multiple genes of a small effect are involved in elevated 'psychiatric risk' and the pathogenesis of AN (Sullivan, Daly, & O'Donovan, 2012). Higher-quality fully powered studies (e.g. the AN Genetics Initiative (ANGI) and the AN25K Challenge) are necessary to advance our understanding of the genetic risk profile associated with AN.

Furthermore, biological risk factors for AN have been examined in both human and animal research, and these identify a number of environmental triggers (e.g. perinatal events; Favaro, Tenconi, & Santonastaso, 2006) that induce alterations across the hypothalamic–pituitary–adrenal (HPA) ('stress system') and appetite regulation system, as well as alterations in the intestinal microbiota (Kleiman, Carroll, Tarantino, & Bulik, 2015) that contribute to a combination of down-regulation of appetite and the lean phenotype (Hebebrand & Remschmidt, 1995) associated with AN. Other biological risk factors relate to alterations in the dopaminergic response system, that may predispose an individual to higher reward from starvation, exercising, and lower food and social reward, and alterations in Oxytocin (Kim, Kim, Kim, & Treasure, 2014), although the extent to which these alterations are activated by starvation is unclear. It has been suggested that the a unique biological make-up may contribute to the adaptive functions associated with self-starvation in AN (e.g. a ‘soothing’, reduce social threat), which may help to explain the valued nature of starvation in the disorder and subsequent low motivation to change (Vitousek, Watson, & Wilson, 1998). This is in line with Paul Gilbert’s evolutionary approach to psychopathology, suggesting that psychiatric symptoms are *‘often related to the activation of defence mechanisms’*, which have evolved in response to social threats to key biosocial goals of evolutionary relevance (Gilbert, 1997, 1998a, 1998b, 2001a, 2001b). Therefore, as highlighted by Schmidt and Treasure (2006) self-starvation in AN may be understood as a manoeuvre with complex defensive functioning and with the effect of reducing harm and social threat.

Environmental triggers (e.g. perinatal events) have also been proposed to predispose an individual to a temperament style characterised by anxiousness and shyness (Troop, Allan, Serpell, & Treasure, 2008; Troop, Allan, Treasure, & Katzman, 2003) and an insecure attachment style (Ward et al., 2001) and relate to psychological factors in AN. For instance, people with AN are more likely to report social anxiety (Swinbourne et al., 2012) and an impoverished social network before the onset of the illness (Fairburn, Cooper, Doll, & Welch, 1999; Karwautz et al., 2001), fewer social activities (Krug et al., 2012), and less social support (Kim, Heo, Kang, Song, & Treasure, 2010). And these are thought to relate to the temperamental characteristics such as shyness, inhibition, and internalising problems (Adambegan et al., 2012). Further psychological factors implicated in risk for the development of AN include weight concern in formulative developmental years and specific personality traits, most notably low self-esteem (Keel & Forney, 2013; Stoeber, Otto, & Dalbert, 2009), high levels of clinical perfectionism (Bardone-Cone et al., 2007), and a neuropsychological profile characterised by low cognitive flexibility (poor set-shifting) and a detail-focused (weak central coherence) thinking style (Roberts, Tchanturia, Stahl, Southgate, & Treasure, 2007) that has also been observed in first degree relatives (Tenconi et al., 2010). The neuropsychological profile for adolescents with AN is less clear, although the results of a recent review suggest weak central coherence is present at this earlier stage of illness (precedence for detail, difficulty seeing the bigger picture) (Lang, Lopez, Stahl, Tchanturia, & Treasure, 2014).

Although a number of multi-faceted factors are implicated in the aetiology of AN, it is difficult to disentangle those which predate illness onset and are strictly causal from those that may be exacerbated in the acute phase of an ED, in part, due to the secondary effects of starvation on the brain, first described by Keys in 1950 (Keys, Brozek, & Henschel, 1950). Analogous to other psychiatric conditions, Shafran and de Silva suggested that the focus on specific models of illness maintenance (rather than descriptions of the development of the disorder) is likely to generate more advances in treatment (Shafran & de Silva, 2003). This shift has since been seen, with the development of theoretical models that integrate both causal and maintaining factors for AN and emerging empirical evidence to support and further refine their theoretical underpinnings.

1.2.6 Theoretical models of maintenance in anorexia nervosa

A maintaining illness factor is defined as *'a factor that predicts symptom persistence over time versus remission among initially symptomatic individuals [...]. If an experimental increase or decrease in a factor among initially symptomatic individuals results in symptom expression or suppression, respectively, it may be referred to as a causal maintenance factor'* (Stice, 2002, p. 826). A number of models with different degrees of specificity for AN and empirical support have been developed. Three theoretical models of illness maintenance that are particularly pertinent to the present thesis, in terms of acknowledging the role of altered socio-emotional processing and the interpersonal 'knock-on' effect.

The first model (see Figure 1) is a multi-factorial neurodevelopmental theoretical model of EDs developed by Connan and colleagues (2003) integrates genetics, early attachment style and perinatal factors, the stress response system, personality traits, and socio-emotional processes in the aetiology of AN (Connan, Campbell, Katzman, Lightman, & Treasure, 2003). In this model, it is theorized firstly that genetic risk, previously described (i.e. perinatal stressors (Favaro et al., 2006; Favaro, Tenconi, & Santonastaso, 2008) and attachment experience (Ward et al., 2001) contribute to a biological susceptibility to chronic stress and hypothalamic-pituitary-adrenal (HPA) axis dysregulation. This model proposes that social-communicative and emotional processing difficulties, coupled with perfectionist tendencies and rigid coping styles (Anderluh, Tchanturia, Rabe-Hesketh, & Treasure, 2003) that are characteristic of AN, facilitate chronic stress which predisposes an individual to the development of AN (Connan et al., 2003). An overactive serotonergic system and HPA axis are biological mechanisms that contribute to a hyper-sensitive stress response and hormonal changes around the time of puberty may trigger a set of responses that precipitate AN. A failure to up-regulate activity of the adrenocorticotrophic hormone secretagogue, arginine vasopressine (AVP) and persistent over activity of the corticotrophin releasing hormone (CRH) modulates an over-sensitive stress response and may have subsequent effects on appetite and weight loss. Both psychological (e.g. feelings of safety and pseudo-control) and biological (e.g. starvation) may serve to maintain symptoms. Therefore, this model posits that stress response and socio-emotional processes are central to the aetiology and maintenance of AN.

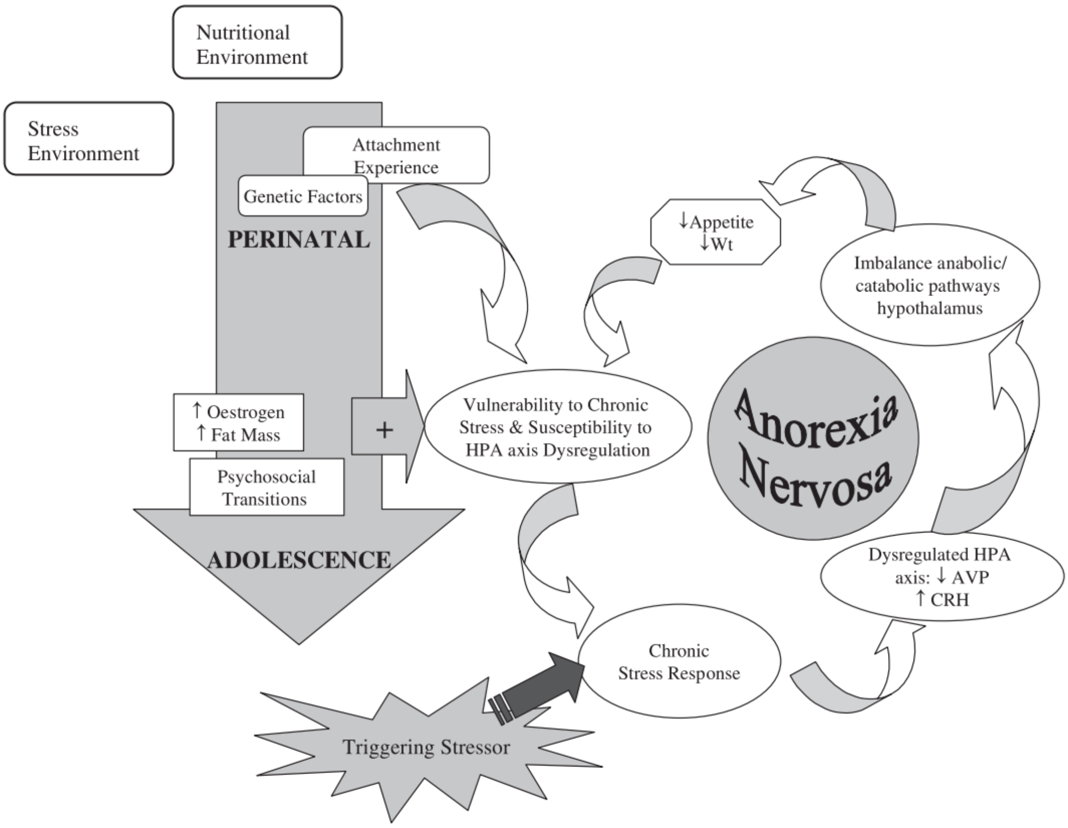


Figure 1: A neurodevelopmental model of AN (from Connan et al., 2003)

A three phase model of social emotional functioning in EDs (Treasure, Corfield, & Cardi, 2012) has since been proposed (see Figure 2), building on the before mentioned neurodevelopmental model and integrating both intra- and inter-personal factors. Phase 1 of this model suggests that environmental triggers (e.g. perinatal events), as already described (‘risk factors’), predispose an individual to a temperament (e.g. shyness, shame proneness, social comparison; Troop et al., 2008; Troop et al., 2003) and attachment style (eg. insecure; Ward et al., 2001) which affects socio-emotional development and functioning (e.g. harm avoidance, childhood anxiety; Favaro et al., 2008). Phase 2 highlights the effects of the illness on social attention, emotion recognition, and regulation (Cardi, Matteo, Corfield, & Treasure, 2013; Oldershaw, Hambrook, et al., 2011). These socio-emotional difficulties may be caused or exacerbated by the illness state. The third phase focuses on the role of interpersonal relationships on the maintenance of illness. The reciprocal interaction between parent and proband, which will be influenced by multiple genetic, trait and state effects, can exacerbate illness symptoms (Goddard et al., 2011; Treasure et al., 2008).

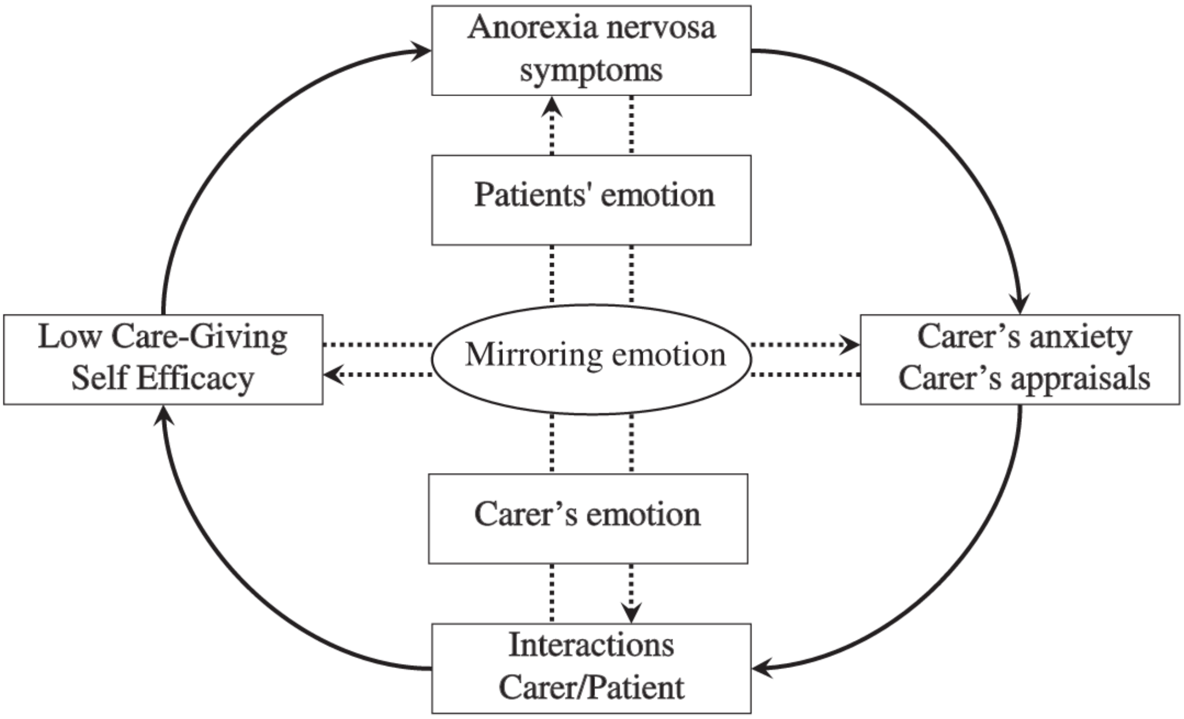


Figure 2. Three-phase model of interpersonal maintenance in AN (from Treasure et al., 2012)

The cognitive-interpersonal maintenance model of EDs (see Figure 3) provides another conceptualisation of risk and maintenance in EDs that integrates intra- and interpersonal factors and emphasises the role of socio-emotional functioning and specific behaviours in close others that contribute to the vicious cycle of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). In this model, four key components are theorized as maintaining (illustrated in Figure 1): (i) the ‘thinking style’ component includes perfectionistic traits, OCPD, and a neuropsychological profile characterised by poor set-shifting and weak central coherence that manifests as rigid thinking and detail focus; (ii) the ‘emotional and relational style’ component describes an anxious and avoidant temperament style in AN that manifests as shyness, aloofness and difficulties with peers; (iii) the ‘pro anorexia’ component describes valued aspects of the illness that have been described in detail in the literature (e.g. Vitousek et al., 1998), acknowledging the possible adaptive functionality of starvation in moderating negative affect for the individual, for example through activation of the ‘drive’ system and/or defence mechanisms to reduce social threat, as already described (Gilbert, 1997, 1998a, 1998b, 2001a, 2001b); and (iv) the 'response of close others' component proposes that maladaptive patterns of interaction with others that develop in response to the manifestation of AN play a role in illness maintenance. The two primary interpersonal behaviours that are described are expressed emotion and accommodating and/or enabling behaviours. These are described later in section 1.4 EDs and the impact on others.

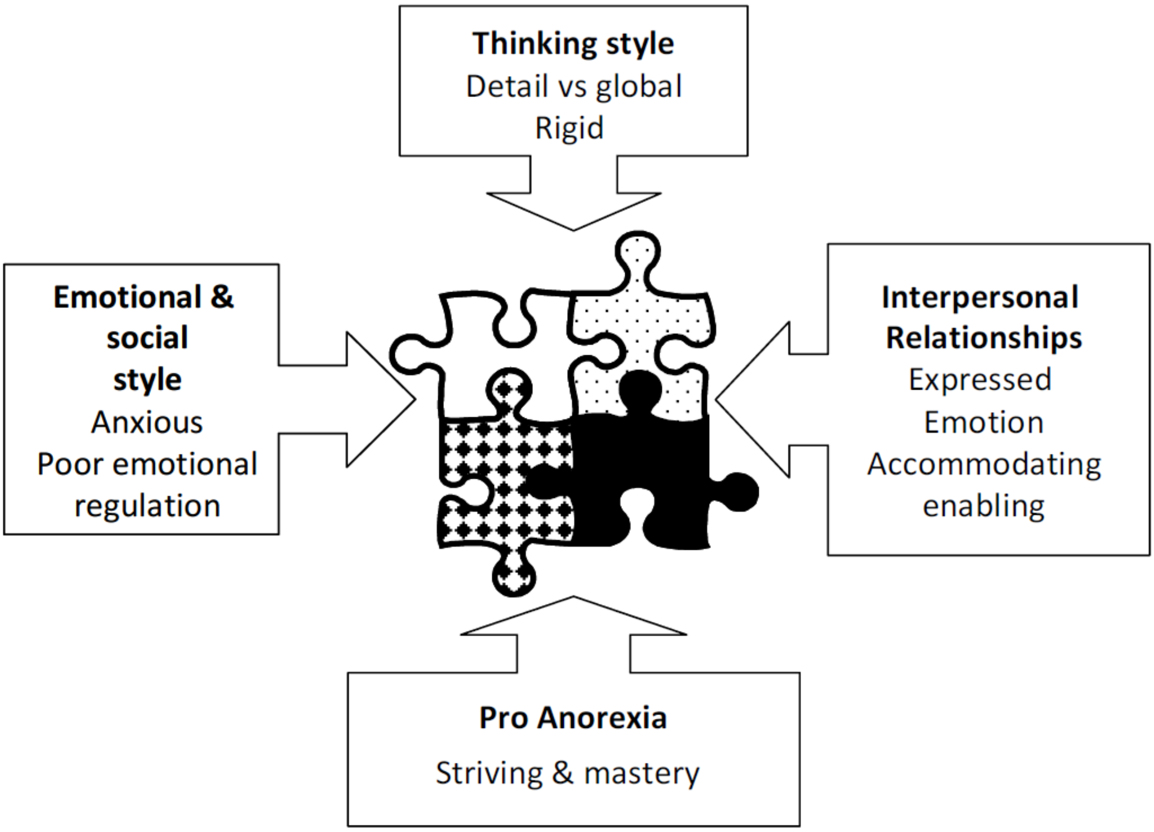


Figure 1. The cognitive-interpersonal maintenance model of EDs *(Treasure & Schmidt, 2013)*

1.3 Socio-emotional processing in anorexia nervosa

Social and emotional factors in the origin of AN have been discussed since the original appearance of AN in the medical literature. These early insights are supported by current theoretical model of illness maintenance (Connan et al., 2003; Treasure et al., 2012; Treasure & Schmidt, 2013) that emphasize the importance of social and emotional difficulties as maintenance factors, and contemporary evidence suggesting significant and wide-ranging impairments in socio-emotional functioning in AN, some of which fall within the autism realm (e.g. reviews; Caglar-Nazali et al., 2014; Huke et al., 2013; Oldershaw, Hambrook, et al., 2011; Treasure, 2013). The fact that premorbid social and emotional difficulties are reported, often manifesting as friendship difficulties (e.g. fewer friends, low social interaction; Doris, Westwood, Mandy, & Tchanturia, 2014; Krug et al., 2012), that some aspects of altered socio-emotional persist following recovery, and a large population study (the Avon Longitudinal Study of Parents and Children; ALSPAC) has revealed differences in social cognition between children identified as high vs. low risk for EDs (Kothari, Rosinska, Treasure, & Micali, 2014), implicate this disturbance at the 'trait' level. In particular, given the overlap with in these difficulties with ASD (e.g. aloofness, low empathy, poor flexibility), it has been thought that mapping AN onto the broad phenotype of ASD, where emotional and social-cognitive features are well-characterised, may help guide further enquiry into endophenotypes in AN (Zucker et al., 2007). It is thought that endophenotypes serve as a clue to underlying neurocognitive mechanisms, and therefore establishing these can provide direction for targeted aetiological treatments. Specifically, Gottesman and Gould have defined endophenotypes as something that (i) is associated with illness in the population; (ii) is heritable; (iii) is primarily state-independent (manifests in an individual whether or not illness is active); (iv) within families, co-segregates with illness; and (v) the endophenotype found in affected family members is found in nonaffected family members at a higher rate than in the general population (Gottesman & Gould, 2003). Because of the phenotypic overlap between AN and ASD (e.g. 40% of adolescents fulfilling criteria for the broad ASD phenotype (Baron-Cohen et al., 2013), and reports of elevated ASD-like traits in relatives (e.g. OCP-traits, alexithymia; Anderluh et al., 2003; Lilenfeld et al., 1998), there has been some discussion in the literature over whether AN may be considered a female manifestation of ASD, and with food, shape and weight as a topic of special interest (Oldershaw, Treasure, et al., 2011). However, mixed findings in the literature when comparing AN and ASD (e.g. psychometric study (Courty et al., 2013) and insufficient evidence to examine the developmental trajectory, suggests that further exploration of transdiagnostic similarities is required.

Current evidence suggests that while aspects of altered socio-emotional functioning in AN may relate to a trait (‘ASD-like’) disturbance, others may be the product of, or exacerbated by, the secondary effects (‘state effect’) of starvation on the brain (Keys et al., 1950). The nature of these secondary effects may mimic features of ASD (‘pseudo-ASD’). The secondary effects of prolonged period of starvation on the brain and illness over time (e.g. 'neuroprogression', habit-formation; Treasure, Stein, & Maguire, 2015; Walsh, 2013), and related alterations in brain structure in AN (Fonville, Giampietro, Williams, Simmons, & Tchanturia, 2014), may account for the more severe socio-emotional impairment associated with severe and enduring AN. On the other hand, an alternative interpretation is that a more severely impaired socio-emotional (‘ASD-like’) profile is a risk factor for illness chronicity (or ‘stuckness’ in treatment), particularly given that social impairment in AN has been associated with poorer prognosis (Keel, Dorer, Franko, Jackson, & Herzog, 2005; Råstam, Gillberg, & Wentz, 2003). Finally, it might be a combination of both.

Systematic reviews and meta-analyses (Caglar-Nazali et al., 2014; Oldershaw, Hambrook, et al., 2011; Treasure & Schmidt, 2013) have adopted and adapted frameworks (e.g. Ochsner’s social-emotional processing stream; Ochsner, 2008), developed in the ASD (or other disorders of social cognition, e.g. schizophrenia) field, in order to summarise and guide the systematic enquiry of altered socio-emotional functioning in AN. Broadly, these can be classified under five domains (or aspects) of socio-emotional functioning: (i) attentional mechanisms, (ii) understanding of the self, (iii) emotion recognition and interpretation of social signal, (iv) empathy, and (v) emotion expression. By classifying domains of socio-emotional functioning in AN, it may be easier to disentangle aspects that are likely ‘traits’ or ‘states’ in AN, and highlight where more evidence is needed, particularly given the potential utility in terms of predicting prognosis and developing targeted aetiological or early-intervention treatments.

1.3.1 Attentional mechanisms

The results of studies investigating attentional mechanisms in AN suggest that there is increased attention to social threat and decreased attention to social reward. Specifically, people with AN have been found to direct their gaze less at the face and eyes (Watson, Werling, Zucker, & Platt, 2010) and display attentional biases towards negative facial expressions such as anger (Cserjési, Vermeulen, Lénárd, & Luminet, 2011; Harrison, Sullivan, Tchanturia, & Treasure, 2010; Harrison, Tchanturia, & Treasure, 2010) to social dominance with a large effect size (Caglar-Nazali et al., 2014) and criticism (Cardi, Di Matteo, Gilbert, & Treasure, 2014) but not towards positive facial expressions such as happiness and compassion (Cardi et al., 2013). Although less is known about attentional mechanisms in adolescent AN, findings that these disturbances persist following recovery, albeit in an attenuated form, support the notion that this aspect of socio-emotional functioning relates to an underlying trait that is exacerbated in acute phase AN.

1.3.2 Understanding the self

Difficulties in identifying feelings have proven to be an important prognostic factor in AN (Speranza, Loas, Wallier, & Corcos, 2007). Alexithymia is the most widely studied concept in terms of the perception and understanding of self. Characteristics of alexithymia, particularly a difficulty distinguishing emotional states from bodily sensations, have been noted in patients with AN (Andersen, 1983; Garner & Garfinkel, 1982) and elevated scores, typically with a large effect size (Caglar-Nazali et al., 2014). These difficulties are also found in adolescents with AN (Lulé et al., 2014; Zonnevijlle-Bender, van Goozen, Cohen-Kettenis, van Elburg, & van Engeland, 2002; Zonnevylle-Bender, Van Goozen, Cohen-Kettenis, Van Elburg, & Van Engeland, 2004). Although alexithymia has been conceptualized as both a clinical state (secondary alexithymia) and as a more stable aspect of personality functioning (Horton, Gewirtz, & Kreutter, 1992; Parker, Bagby, & Taylor, 1991) particularly in the restricting subtype (Sexton, Sunday, Hurt, & Halmi, 1998), findings of elevated alexithymia in sisters of someone with an ED

(Rozenstein, Latzer, Stein, & Eviatar, 2011) implicate this facet of socio-emotional functioning as a trait disturbance.

1.3.3 Emotion recognition & Interpretation of social signal

Accurate reading of the emotions and intentions of others is considered a core facet of effective social communication, and people with AN also show difficulties in this domain. In particular, difficulties have been observed in recognising facial emotions (e.g. Harrison, Sullivan, et al., 2010; Oldershaw, Hambrook, et al., 2011; Russell, Schmidt, Doherty, Young, & Tchanturia, 2009) and interpreting emotional meaning, typically with a negative interpretation bias – often interpreting criticism or rejection from ambiguous social situation tasks (Kucharska-Pietura, Nikolaou, Masiak, & Treasure, 2004; Oldershaw, Hambrook, Tchanturia, Treasure, & Schmidt, 2010; Zucker et al., 2013), although less is known about emotion recognition and interpretation in adolescent AN. Misinterpretation of facial expressions of emotion, and a tendency to attribute negative valence to nonemotional faces, is also reported in high functioning adults with ASD (Eack, Mazefsky, & Minshew, 2015). However, in AN, difficulty with emotion recognition is less marked following recovery (Oldershaw et al., 2010), suggesting that this aspect may be exacerbated by acute phase AN.

1.3.4 Empathy

The ability to understand the mental processes of others is considered the most sophisticated aspect of social communication, and is a core defining feature of ASD. Low empathy in childhood and the later development of AN was the first suggestion of a link between AN and ASD, made by Gillberg in his report of ‘disorders of empathy’ (Gillberg, 1992). Low empathy in AN has been confirmed by the results of a large meta-analysis, albeit with an overall small effect size relative to controls across studies (Caglar-Nazali et al., 2014). Less is known about empathy in the recovered state and in adolescent AN.

1.3.5 Emotion expression

The ability to facially signal emotional state is considered a core facet of social and emotional competence (Schmidt & Cohn, 2001; Shariff & Tracy, 2009), and one that benefits both signaller and receiver (Fridlund, 1994; Schneider, Hempel, & Lynch, 2013). It is theorized that emotion is expressed as a means of regulating emotion (e.g. facial feedback theory, William James, 1884; review (Adelmann & Zajonc, 1989) and signalling emotional states to others, in order to facilitate effective communication, and elicit social support (Clark & Brissette, 2000; Fridlund, 1994; Susskind et al., 2008). Furthermore, several recent studies have also linked facial expressivity with the ability recognise emotion in others. For example, preventing individuals from producing emotion expressions (e.g. by chewing gum, biting down on a pen, clenching their teeth, or through use of Botox) interferes with accuracy in emotion recognition tasks (Neal & Chartrand, 2011; Oberman, Winkielman, & Ramachandran, 2007; Stel & Van Knippenberg, 2008).

As well as beneficial for the expresser, emotion expressions are also used by the receiver, as important cues for self-regulation (Salovey & Mayer, 1989), to understand (and therefore empathise with) the others' emotion experience (Horstmann, 2003), and to assess others' attitudes (Hess, Kappas, & Scherer, 1988). Specifically, it thought that automatic facial mimicry, as broadly linked with the construct of mirror neurons and mirror systems in neuroscience (e.g. Gallese, 2007; Keysers & Gazzola, 2007), helps a perceiver internally simulate and re-experience an emotion that corresponds to the perceived expression, thereby aiding the processes of recognition and interpretation (Niedenthal, 2007; Niedenthal, Mermillod, Maringer, & Hess, 2010; Ponari, Conson, D'Amico, Grossi, & Trojano, 2012). Therefore, facial expressions influence both regulatory efforts and evaluative judgements of both signallers and receivers, and the impact of altered emotion expressivity has been well-documented across the literature. For instance, emotion suppression has been associated with problematic relationships (Butler et al., 2003; English, John, Srivastava, & Gross, 2012; Gross & John, 2003) and social difficulties in people with depression (Berenbaum & Oltmanns, 1992), schizophrenia (Kring & Neale, 1996), and facial paralysis (VanSwearingen, Cohn, &

Bajaj-Luthra, 1999). In AN, difficulties with emotional expression have been found to be predictive of poor treatment outcome (Speranza et al., 2007); it is thought that reduced emotion expression may impact social networks (e.g. fewer friends) that hinders the use of social support (Doris et al., 2014) and contributes to illness maintenance (Treasure & Schmidt, 2013).

Despite the role of emotion expression for emotion regulation and evaluative judgements for both signallers and receivers, only few empirical studies have recently examined facial expressivity in AN, none of which have included adolescents. The evidence so far shows that women with AN display less emotion expressivity than controls, despite reporting no differences in subjective emotion experience (i.e. inward/outward emotion expression incongruence), and also display fewer expressions of frustration while playing a video game (Claes et al., 2012; Davies, Schmidt, Stahl, & Tchanturia, 2011). Reduced facial affect persists in recovery but is less marked (Davies, Schmidt, & Tchanturia, 2013). Empirical findings are consistent with self-reports of emotion inhibition due to beliefs and perceived negative consequences associated with emotion expression in AN (Forbush & Watson, 2006; Geller, Cockell, & Goldner, 2000; Ioannou & Fox, 2009; Jansch, Harmer, & Cooper, 2009; Lawson, Emanuelli, Sines, & Waller, 2008; Wildes, Ringham, & Marcus, 2010). However, the extent to which reduced emotion expression in AN is an effortful act remains unclear. Effortful emotion suppression (i.e. when used as a strategy to decrease the experience of unwanted emotion) may in fact increase emotion experience (Butler et al., 2003; Gross & John, 2003), increase physiological activation in a manner consistent with the emotion being suppressed (e.g. fear, disgust; Colby, Lanzetta, & Kleck, 1977; Gross, 1998; Gross & Levenson, 1993; Lanzetta, Cartwright-Smith, & Eleck, 1976; Notarius & Levenson, 1979), and have unintended cognitive (e.g. impaired memory; Egloff, Schmukle, Burns, & Schwerdtfeger, 2006) and interpersonal consequences (e.g. decreased liking; Butler et al., 2003).

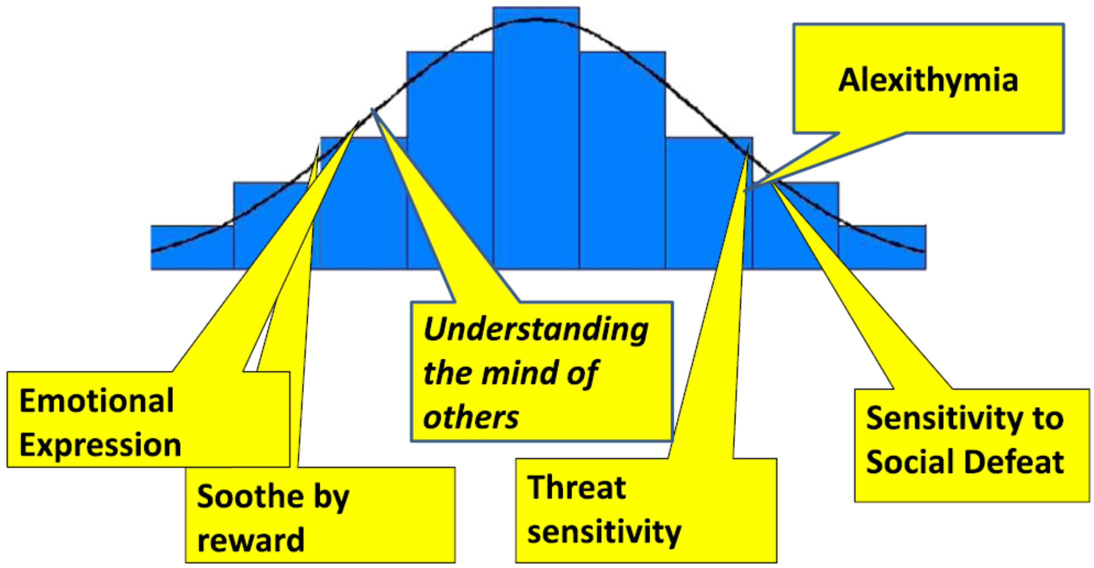


Figure 4. A diagrammatic representation of social and emotional processing traits in AN. Those that are mainly present in the acute starved state are shown in italics (from Treasure & Schmidt, 2013)

1.3.6 Summary

Overall, the findings suggest that the socio-emotional disturbance of patients with AN is pervasive and encompasses almost every aspect of one’s social capabilities and encompass domains from other psychiatric disturbances (see Figure 4). Thus, the social problems of patients with AN is likely to relate to elevated anxiety, difficulties in the autistic realm (reduced non-verbal communication and avoidance of communication, alexithymia, and difficulties in understanding how others think and feel, and difficulties related to one’s self-perception. Most of these disturbances in other psychiatric disorders are considered an early premorbid condition, potentially predisposing to the relevant disturbance. Still, the considerable effects of malnutrition and erratic consummatory patterns in AN preclude any definite conclusions about the generalisation of the influence of maladaptive social relationships on increasing the risk to AN. Furthermore, there are clear gaps in the evidence base to fully integrate and understand whether these difficulties may be best understood as ASD traits (‘subthreshold ASD’) or possible, a female manifestation of ASD. In particular, very little is currently known about altered socio-emotional processing in adolescent AN. Because adolescence is both the period during which AN typically develops (Currin et al., 2005) and a rapid developmental period of social cognition (Blakemore, 2012) and emotion regulation (Opitz, Gross, & Urry, 2012), examination of socio-emotional difficulties within this group is essential for furthering our understanding of these disturbances in AN.

1.4 Anorexia nervosa: The impact on others

1.4.1 The caregiving role

Current clinical evidence suggests that EDs have a considerable impact on affected families' lives, who typically assume a caregiving role. "Carers" are defined by criteria of the Princess Royal Trust (www.carers.org) as someone who provides unpaid help and support to a parent, child, partner, relative, friend or neighbour, who could not manage without their help. Caring for an individual with an ED is burdensome (Raenker et al., 2013) and has found to be comparable to that experienced by carers of people with schizophrenia (Santonastaso, Saccon, & Favaro, 1996). The caregiving role is associated with high levels of distress, higher than that reported in carers of people with psychosis (Treasure et al., 2001), poor physical health, and poor quality of life (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014). The caregiving role can be "virtuous" but in particular, families of someone with an ED are often characterised by fraught and distressing patterns of interpersonal interaction (Haigh & Treasure, 2003; Perkins, Winn, Murray, Murphy, & Schmidt, 2004; Whitney et al., 2005; Winn, Perkins, Murray, Murphy, & Schmidt, 2004; Winn et al., 2007).

The unique challenge to carers of someone with AN may related to the highly visible nature of AN, that arouses strong emotions (ranging from fear and despair to horror and disgust, particularly when emaciation is severe), combined with the extent to which the person with AN values and 'defends' their undernourished state (Schmidt & Treasure, 2006; Vitousek et al., 1998). Altered socio-emotional functioning (e.g. low empathy, reduced emotion expression) may further add to the frustration. Emotion inhibition has been associated with stress and arousal in carers (Butler et al., 2003). For instance, a child with AN’s relatively expressionless (‘blank’) face may appear aloof, disinterested, uncaring of the needs of their distressed parent. And this seeming lack of interest or empathy may subsequently be met with hostility. Furthermore, the ‘uncanny valley’ phenomenon of robot-human interaction demonstrates how expressivity that is not in line with that expected from another may appear somewhat ‘mechanical’ (i.e. low in empathy or human connectedness). This mismatch between expected and expressed emotion has been shown to evoke high levels of arousal and even disgust in others (e.g. Mori, 2012). However, as highlighted in the literature, emotion expression in AN may not reflect internal state. And through reduced emotion expression in the person with AN, opportunities for empathy and warmth from others may be lost (Adolphs, 2006; Carr, Iacoboni, Dubeau, Mazziotta, & Lenzi, 2005; Decety & Grèzes, 2006; Guéguen, Martin, & Meineri, 2011; Stel, Van Baaren, & Vonk, 2008). Furthermore, anxiety is understood to be mirrored (e.g. ‘emotion contagion’; Laird et al., 1994), and this may serve as particularly problematic within the context of altered emotion expressivity. For instance, anxiety may be mirrored by the person with AN, and rather than outwardly displayed to provide instant and meaningful feedback to the receiver, may be ‘internalised’ and expressed as worsening ED symptoms, that further elicit anxiety in others, and so the cycle persists; and with a cascade effect. On the other hand, facial mimicry plays an important role in emotion contagion (Laird et al., 1994). Therefore, reduced expression (and related reduced facial mimicry), may in fact serve as protective of emotion contagion for the person with AN. In this way, it is possible to consider reduced emotion expression from self-starvation in AN as a possible adaptive manoeuvre for harm avoidance and reducing social threat, in line with Paul Gilbert’s evolutionary model of psychiatric illness and the valued nature of AN (Vitousek et al., 1998).

Through a complex vicious cycle of distress in response to the manifestation of AN, two common patterns of behaviour have been widely described to develop in families, and are theorized to contribute to illness maintenance and inadvertently hinder recovery (Treasure & Schmidt, 2013). These are high levels of expression emotion, and accommodating and enabling behaviours (see Figure 5).

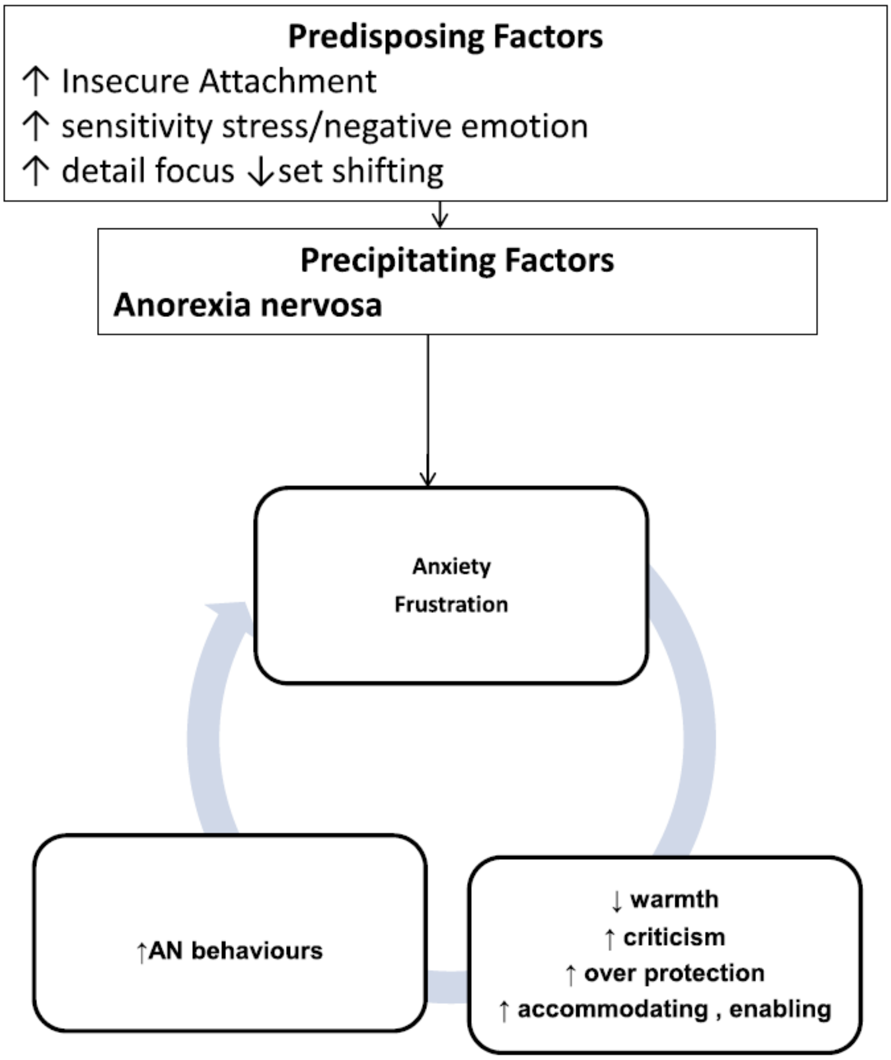


Figure 5. An interpersonal perpetuating cycle: Diagrammatic formulation of carers involvement within the maintenance of an ED (from Treasure & Schmidt, 2013).

1.4.2 The cycle of expressed emotion

Expressed emotion was the first behaviour considered in the interpersonal component of the cognitive-interpersonal model of ED (Schmidt & Treasure, 2006). The concept of caregivers’ expressed emotion has been of interest in psychiatry because overprotection, criticism, and hostility influence the course of and reliably predict relapse of many psychiatric disorders (e.g. schizophrenia; Butzlaff & Hooley, 1998). Expressed emotion is defined as interpersonal communication that comprises critical comments (e.g. derogatory remarks), hostility (criticism or rejection), and over-involvement. The additional difficulty for EDs, is the combination of expressed emotion that carers are susceptible to developing as previously described, and patients' hypersensitivity to social threat, as previously described. Therefore, these sorts of interactions may be perceived as progressively threatening to the patient, and reinforce the dependable safe nature of AN; and so the cycle continues.

A recent systematic review (Zabala, Macdonald, & Treasure, 2009) found high levels of carer expressed emotion, such as criticism and overprotection in families of someone with an ED, and these have been shown to be directly related to caregiver distress (Duclos et al., 2014; Hoste, Labuschagne, Lock, & Le Grange, 2012; Kyriacou, Treasure, & Schmidt, 2008). Although high levels of expressed emotion have been reported at 30% of adolescent AN families (Duclos et al., 2014; Le Grange, Hoste, Lock, & Bryson, 2011), the prevalence seems to increase with longer illness duration and a more severe clinical profile (Sepulveda et al., 2010). High levels of expressed emotion have been associated with poorer ED outcomes; Whereas warmth (conceptualised as a positive construct within the expressed emotion literature) has been associated with positive outcomes in adolescent AN (Le Grange et al., 2011), mothers' critical comments have been found to account for 28-34% of adolescent ED outcomes in one study (Van Furth et al., 1996). In a recent study, whereas paternal criticism predicted lesser improvement in ED psychopathology at end of treatment, maternal predicted less improvement in general family functioning and family communication at the end of treatment (Rienecke, Accurso, Lock, & Le Grange, 2015). These findings suggest that maternal and paternal expressed emotion may differentially impact treatment outcome and should be directly attended to in clinical settings. The authors of this latter study concluded that more research is needed to further explore ways in which parental expressed emotion can be effectively modified in treatment in adolescent AN.

1.4.3 The cycle of accommodating and enabling

Accommodating and enabling the ED forms the second pattern of behaviour considered in the interpersonal component of the cognitive-interpersonal model of EDs and were added to the model later (Treasure & Schmidt, 2013). Accommodating and/or enabling refers to an overprotective caring style that accepts difficult symptoms and behaviours in an attempt to alleviate distress and avoid conflict (Sepulveda, Kyriacou, & Treasure, 2009). Often families can become organized around the needs of the person with AN, and engage in behaviours which inadvertently serve to reinforce or fail to discourage symptoms or behaviours. For example, symptomatic behaviours may be reinforced or go unchecked (accommodating) and negative consequences may be ignored or removed (enabling) (Sepulveda et al., 2009). Families have been known to obey ED rules and safety behaviours such as high control over family food and meal rituals (accommodating), and to clear up kitchen or bathroom mess related to binge/purging behaviours (enabling). (Treasure, 2010). Unchallenged, the ED can quickly dominate family routines, at the cost of the needs of other family members (de la Rie, van Furth, de Koning, Noordenbos, & Donker, 2005; Highet, Thompson, & King, 2005; Kyriacou et al., 2008; Sepulveda et al., 2009). Evidence suggests that carers with greater contact with the person for whom they care, and carers with their own history of eating difficulties are at greater risk of engaging in accommodating behaviours (Goddard, Macdonald, & Treasure, 2013), although to date, accommodating in EDs is relatively under-researched. It is thought that these allowances gradually reinforce and endorse ED symptoms, as well as preventing the person with the ED from living through the consequences of their ED behaviours, and therefore removing opportunities for them to naturally deter. While accommodating and enabling behaviours are natural and understandable reactions to the ED, carer responses (both conflict and over protection) are theorized to contribute to greater carer distress and potentially serve to inadvertently maintain the ED symptoms (Treasure & Schmidt, 2013). Although more empirical evidence with well-validated measures is required to provide support to this aspect of the maintenance model, accommodating behaviours in families of young people with OCD is well-characterised and has been show to play an important role in the patients' response to treatment (Ferrão et al., 2006; Steketee & Van Noppen, 2003; Storch et al., 2008). More research is needed to further explore accommodating behaviours in adolescent AN families and ways in which this pattern of behaviour can be effectively modified in treatment.

1.4.4 Shared traits

In Treasure and Schmidt’s (2013) update of the cognitive-interpersonal maintenance model of AN, they acknowledge there may be shared OCPD and anxiety traits in the family member of someone with AN, which become more pronounced in the face of the symptoms of AN. These may contribute to higher levels of distress, expressed emotion and accommodating and enabling behaviours (see Figure 5) that may further perpetuate the cycle.

1.5 Multimodal assessment in anorexia nervosa and caregiving

A multimodal assessment can contribute to a more complete understanding of the complexity and multi-faceted nature of AN and the family, and therefore facilitate further theoretical refinement of models of illness maintenance with utility for developing targeted interventions. The use of multimodal assessment in AN has been demonstrated (e.g. Balottin, Nacinovich, Bomba, & Mannarini, 2014; Naab et al., 2013; Rome et al., 2003), however, this approach has been under-utilized in the EDs field. Multimodal assessment can be understood as a *general framework* which has to be specified for the concrete assessment of an individual or groups of individuals. It is generally understood that human behaviour and experiences have to be recorded in a multimodal way encompassing different perspectives and describing the patient on different dimensions (e.g. clinical symptoms, social/global functioning, family/environmental factors) with the aim to structure information and obtain a more adequate representation of the complexity of the clinical picture and to gather information about the patient which is relevant to treatment (Fernandez-Ballesteros, 2003). Specifically, a multimodal approach is generally required for complex intervention evaluation in order to cope with the complexity of psychiatric illness like AN and interpersonal processes studied and to account for the variance as to the degree of exactness in study databases and across different services as well as functional ranges. Furthermore, because a multimodal approach includes different perspective, the risk of investigator-dependent rating bias and self-report bias is reduced. For instance, self-report measures are subject to bias including central tendency and social desirability. On the level of observer-rating scales, problems may arise from relatively ‘inexperienced’ scales with insufficient validation, leading to response sets like generosity error or error of leniency.

Discrepancies in the literature that suggest a possible ever-estimation of the levels of ASD in AN have been attributed to ineffective assessment measures, and a problem of construct validity (Hiller & Pellicano, 2013). Subsequently, a call for more robust and comprehensive measures has been made (Mandy & Tchanturia, 2015). Multi-informant assessment includes self-rating from the patient as well as observer-rating, often from a clinician, parent, or teacher. Therefore, multi-informant and developmental assessment approaches (e.g. Developmental and Wellbeing Assessment; Goodman, Ford, Richards, Gatward, & Meltzer, 2000) may be particularly useful for acquiring information from across the developmental trajectory (e.g. ‘red flags’ for ASD-like patterns in early development), and therefore allowing robust assessment of premorbid difficulties rather than those relating to ‘state effects’ of acute phase AN. Furthermore, integrating experimental data using paradigms that integrate self-report with behavioural information (e.g. evoked emotion expression; Davies et al., 2011) is another way to provide a more complete understanding of the complexity of socio-emotional difficulties in AN with research and clinical utility.

Given the relevance of family functioning in AN in terms of carers’ wellbeing and prognosis of the person for whom they care, multi-informant and ecologically valid assessment of carers’ needs is important, and well-validated (‘experienced’) measures necessary for use in research and treatment. For example, the Brief Dyadic Scale of Expressed Emotion has been developed in order to capture both the patient and carers’ perspectives of dyadic patterns of interaction (Medina-Pradas, Navarro, López, Grau, & Obiols, 2011), and this is likely to provide a more well-rounded clinical picture than one perspective alone. In addition to triangulation across informants and experimental data, well-validated instruments that are sensitive to change are important for brief assessment, e.g. of caregivers’ needs, that can be utilised for brief regular monitoring or in pre-/post-intervention designs. The Accommodating and Enabling Scale for EDs (Sepulveda et al., 2009) and ED-symptom impact scale (Sepulveda, Whitney, Hankins, & Treasure, 2008) are two recently developed scales that notably require further validation to confirm the conceptual underlying framework for use in assessing needs and response to targeted treatments. Furthermore, very few and often small studies in the ED literature have examined the objective caregiving burden (e.g. pilot study; Santonastaso et al., 1996) and other interpersonal behaviours related to adolescent AN using structured clinical interview methods and well-validated scales that can be replicated across studies, with most focussing on the caregiving burden associated with severe and/or enduring AN (Raenker et al., 2013) or using descriptive methods.

1.6 Treatment of anorexia nervosa

Historically, the treatment of AN has focused on remediating the eating and weight symptoms through inpatient care. Although weight and medical stabilisation remains a key treatment goal, current treatment guidelines in the UK (NICE, 2004) and internationally (e.g. Hay et al., 2014) now endorse, as general principles, a least-restrictive (i.e. outpatient treatment in the first instance), multidisciplinary (encompassing medical, dietetic, and psychological interventions), approach to treatment that is person-centred, recovery-oriented care, and involves the family (and significant others). Most notably, the case for early intervention and phase-specific intervention in AN is particularly strong. Furthermore, because people with AN are often ambivalent about treatment, leading them to commonly deny that there is a problem and subsequently resist, refuse or feign compliance (Nesbitt & Uprichard, 2009), motivational enhancement approaches are endorsed (NICE, 2004). Although the increased availability of empirically investigated treatments and systematic reviews has facilitated more specific guidelines, particularly for adolescent AN, the evidence base is still relatively limited. As a result, a ‘best available evidence’ (i.e. evidence-led and practise-based, rather than evidence-based) approach is taken, and as a result, treatments tend to vary considerably across services, that can be challenging when integrating and interpreting results from studies across services (i.e. heterogeneity in what ‘treatment as usual’ constitutes) and the use of ‘treatment as usual’ as a control condition in pragmatic randomised controlled trials.

1.6.1 Treatment of adult and severe/enduring anorexia nervosa

Insufficient evidence exists to facilitate high-grade evidence-based recommendations for specific treatment of adult AN. However, ‘best available’ treatments include cognitive behavioural therapy (CBT), specialist supportive clinical management (SSCM), the Maudsley model of AN treatment for adults (MANTRA) (Schmidt et al., 2015), motivational-based therapies, and family therapies (e.g. Fisher, 2003; Hay et al., 2014; NICE, 2004). However, treatment response for this group is generally poor, and a substantial proportion develop a chronic course of illness (Keski-Rahkonen et al., 2007; Steinhausen, 2002, 2009; Støving et al., 2011; Zipfel et al., 2000) associated with repeated hospital admissions (Hjern, Lindberg, & Lindblad, 2006), which, according to the results of an economic study in the UK, are associated with a two-year average cost of £34,500 per AN individual (Byford et al., 2007). In response to poor treatment response, novel approaches have been developed that target the cognitive, social, and emotional factors (see Figure 4) (Treasure, Cardi, Leppanen, & Turton, 2015) theorized to maintain illness (Treasure & Schmidt, 2013). For instance, the severe and enduring AN group are over-represented by ASD-like traits of poor set-shifting and weak central coherence, that are theorized to contribute to ‘stuckness’ in treatment. Cognitive Remediation Therapy targets these neuropsychological inefficiencies and aims to ameliorate one aspect that may maintain symptoms (Tchanturia, Lounes, & Holttum, 2014). Although the efficacy is currently unknown, these novel approaches offer potential for this otherwise ‘treatment-resistant’ group. Furthermore, although these difficulties are associated with secondary effects of illness over time, as previously mentioned, aspects of this more severe profile (e.g. ASD traits) may be present early on in illness onset and relate to a risk factor for illness chronicity. Therefore further examination of these emotional and social-cognitive factors is necessary to understand whether these novel approaches may serve utility for early intervention in AN.

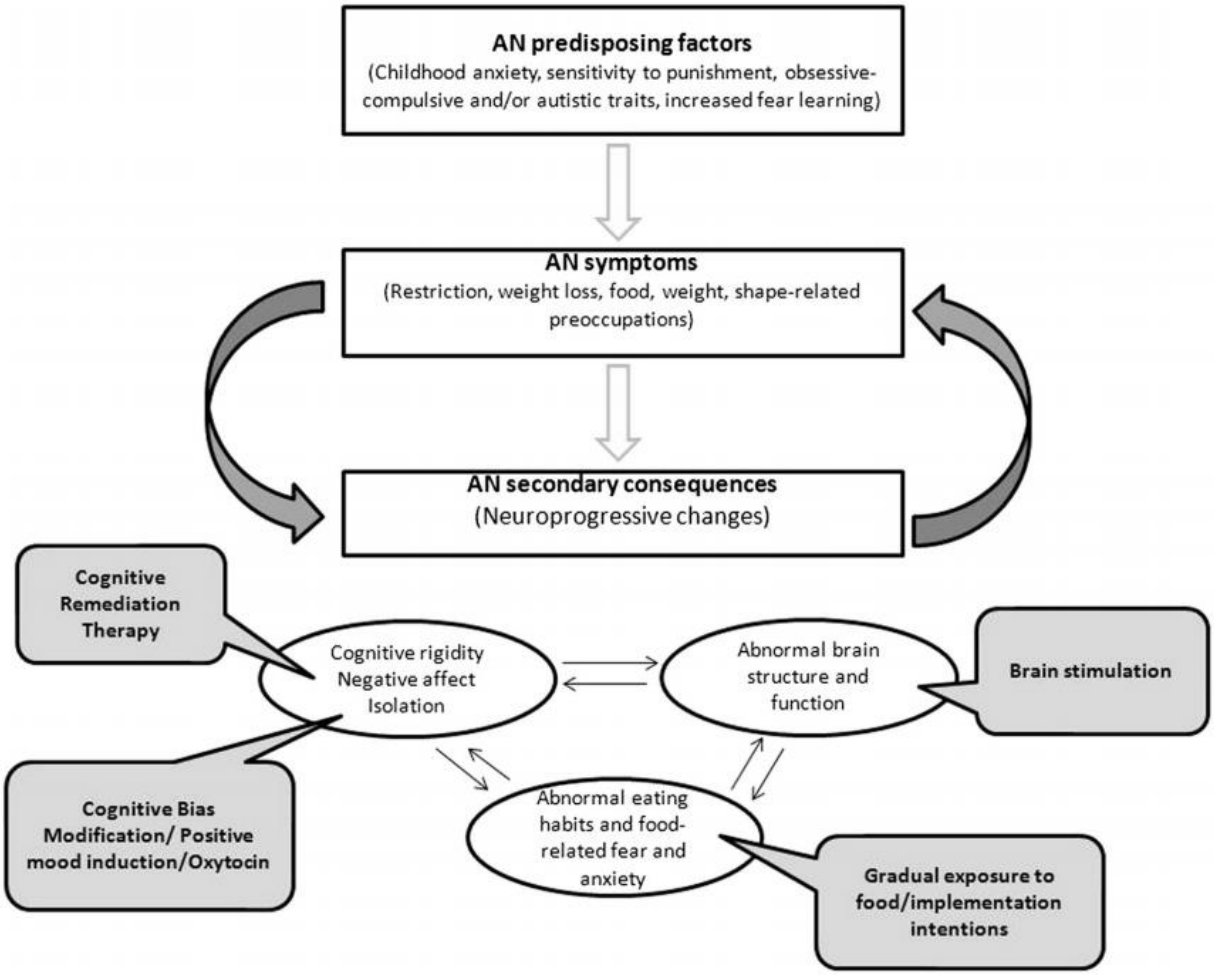


Figure 6: The development of novel interventions for severe/enduring AN (from Treasure, Cardi, et al., 2015).

1.6.2 Treatment of adolescent anorexia nervosa

Evidence for the effectiveness of treatment for adolescent AN is more established and as already highlighted, the prognosis more promising with early intervention (Treasure, Stein, et al., 2015). Family therapy is the most well-studied treatment for adolescents with AN (e.g. randomised controlled trials: Ball & Mitchell, 2004; Crisp et al., 1991; Eisler et al., 2000; Godart et al., 2012; Gowers et al., 2007; Le Grange, Eisler, Dare, & Russell, 1992; Lock, Agras, Bryson, & Kraemer, 2005; Lock et al., 2010; Rhodes, Baillee, Brown, & Madden, 2008; Robin, Siegel, & Moye, 1995; Robin et al., 1999; Russell, Szmukler, Dare, & Eisler, 1987) and is the only specific treatment for AN partially endorsed by NICE (a grade B recommendation). A 2010 Cochrane review further concluded that family therapy is the most effective form of intervention in the early phase of illness (Fisher, Hetrick, & Rushford, 2010), albeit with the caveat that many studies in AN have methodological limitations, especially problems of power due to small sample sizes. Furthermore, the dose or nature of family inclusion in treatment is not specified as the evidence relating to this is still relatively inconclusive (e.g. Eisler et al., 2000; Le Grange et al., 1992; Lock et al., 2005; Rhodes et al., 2008).

The most well studied form of family therapy is Family Based Treatment (FBT), devised by Gerald Russell and colleagues at the Maudsley Hospital in the 1970s. FBT is atheoretical and agnostic in stance towards the pathogenesis of AN, and instead is based on the principle that parents have within themselves the skills to facilitate their child's recovery. In this approach, anxiety is increased as a technique to mobilise parents who are then empowered with full responsibility for restoring their child's eating behaviour (Lock & Le Grange, 2013). Although this approach can be effective if delivered in the early (less than 3 years; Russell et al., 1987) phase of AN (Fisher et al., 2010; Lock et al., 2010; Stiles-Shields, Hoste, Doyle, & Le Grange, 2012) response diminishes over time, and a sizeable proportion of patients show poor treatment response (Asen, 2002). Furthermore, this approach is not acceptable to all families, some of whom. request information and help with their role, most notably practical and emotional help in managing the ED symptoms (Haigh & Treasure, 2003). In particular, research suggests that high levels of OCD, OCPD or autism traits are associated with poor treatment response and outcome (Crane, Roberts, & Treasure, 2007). Furthermore, most research using FBT have measured patient outcomes only and the impact on carers is unknown, and the mechanisms underlying change poorly understood.

Other types of interventions that involve the family have also been developed and have demonstrated efficacy. For example, 'separated family therapy', in which the patient is seen individually and the parents are seen in parallel (Le Grange et al., 1992), is particularly helpful for families with high levels of expressed emotion (Eisler et al., 2000). A further adaptation is multifamily therapy (Asen, 2002), in which several families are seen as a group, and has also produced similar outcomes to that as FBT (Eisler, 2005). However, this format can be demanding on family time and because of the group format, can be somewhat inflexible.

Access to treatment is one of the key barriers to early detection and intervention in AN. A recent report by Beat, the leading charity for EDs in the UK, found that respondents on average experience a 15-month wait between recognising ED symptoms and starting treatment (BEAT, 2015). The benefit of programme-lead approaches, such as self-help and guided self-help in terms of accessibility has recently been highlighted by Fairburn and Patel (see Figure 7), and supported by evidence. The results of several systematic reviews and meta-analyses have found comparable effects of self-help vs traditional face-to-face treatments for depression and anxiety (e.g. Andrews, Cuijpers, Craske, McEvoy, & Titov, 2010; Cuijpers, Donker, Van Straten, Li, & Andersson, 2010; Haug, Nordgreen, Öst, & Havik, 2012), and have highlighted advantages in terms of acceptability and a practical alternative for those who otherwise may not receive care in a timely manner. Furthermore, the addition of guidance to self-help programmes (e.g. by a telephone or 'e-therapist') has proven advantageous for minimising potential problems with treatment adherence in self-help programmes (e.g. Newman, Szkodny, Llera, & Przeworski, 2011).

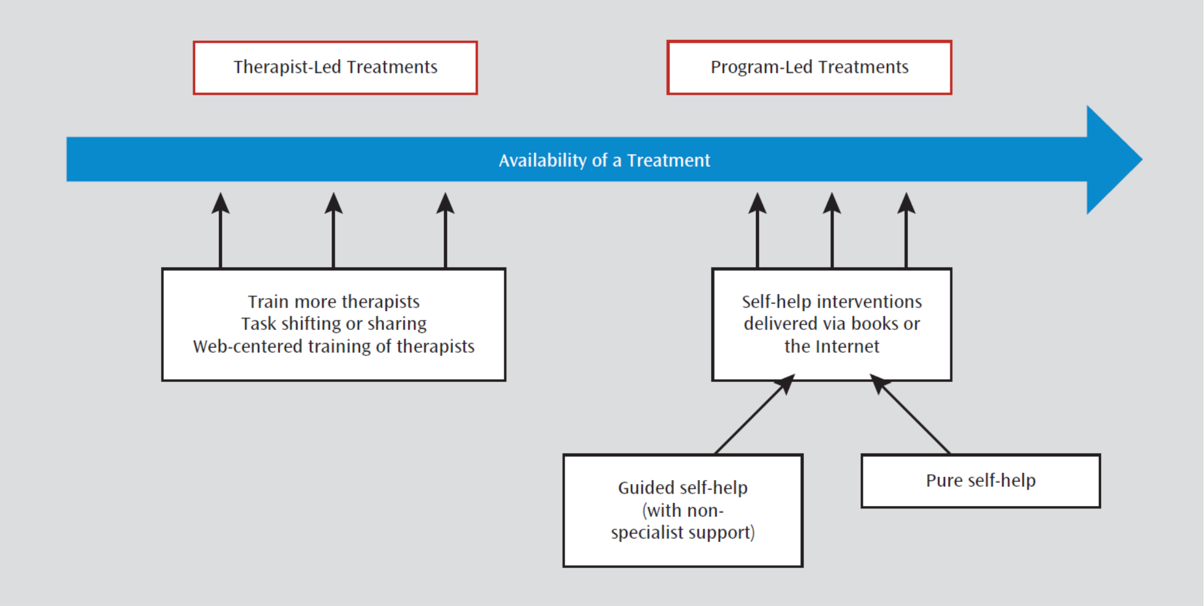


Figure 7. Forms of Treatment Delivery and Their Influence on the Availability of a Psychological Treatment (from Fairburn & Patel, 2014).

1.6.3 Guidance for carers

The 'New Maudsley Collaborative Care Approach' (Treasure, Rhind, Macdonald, & Todd, 2015; Treasure, Smith, & Crane, 2007) was developed through an iterative process of co-production with patients, carers and experts in the field to match carers' needs and ameliorate interpersonal maintaining factors in AN (Treasure & Schmidt, 2013), and derived from the success of carer interventions on outcomes for carers of individuals with dementia (Gallagher-Thompson & Coon, 2007; Schulze & Rössler, 2005), depression (Reinares et al., 2004) and psychosis (Cheng & Chan, 2005; Szmukler et al., 2003). Unlike FBT, this approach is theory-driven and similar to interventions from other areas of mental health associated with high levels of caregiving burden, this model involves (a) coping with the caregiving role, and (b) managing caregiving behaviours towards the person with AN. Treasure and colleagues' (2015) carer coping model for ED (see Figure 8) is based on the standard stress coping model that suggests there is inevitably stress from the caregiving role, related to objective burden (i.e. time spent caregiving) and subjective burden (i.e. psychological distress related to the role), as well as protective factors for coping (e.g. emotion regulation and management skills, social support). In the proposed carer coping model in EDs, the balance between coping and distress, combined with illness factors (e.g. level of patient distress), relates to risk (or resilience) for developing problematic behaviours in response to the illness (e.g. expressed emotion, accommodating) that may hinder recovery (Treasure & Schmidt, 2013). Therefore, contrast to FBT (aims to increase parental anxiety in order to mobilise them), reducing carer anxiety and distress is central to the New Maudsley Method, in order to optimise coping and adaptive caregiver behaviours in response to the illness. Similarly to FBT, parents are empowered with responsibility, however, in line with Paul Gilbert's compassion-focussed therapy model (Gilbert, 2009), this is encouraged via the 'compassionate system' (i.e. self-care/soothing, social support/social safeness, reduce distress/increase contentment) rather than the 'threat system' which is typically the default in situations of high stress and arousal. Gilbert’s compassionate approach was developed particularly for people who experience high levels of shame and self-criticism, and therefore, may be particularly suited to parents of young people with an ED who often blame themselves (Cottee-Lane, Pistrang, & Bryant-Waugh, 2004), compounded by an historic literature blaming parents for ‘causing’ their child’s ED (e.g older theories viewing AN as a maladaptive attempt to be separated from an overinvolved family; Minuchin, Rosman, & Baker, 1978), and worsened by feelings of inadequacy when parents ‘fail’ to feed their undernourished child using the parenting methods they know best, and in ordinary (i.e. not pathological) circumstances, may suffice. Therefore, approaches that accept carers (e.g. parents) as experts and as genuine partners in care where information-sharing and skills training is appropriate, the New Maudsley Collaborative Care Approach is in line with recommendations for approaches that addresses parents’ needs in a way that does not enhance their sense of guilt but does reinforce their responsibility (e.g. Nicholls, 1999). Furthermore, as self-compassion has been suggested as a possible active ingredient in AN recovery (Kelly, Carter, & Borairi, 2014), role-modelling more compassionate styles of coping (e.g. soothing/affiliative system) to the person with AN may provide a beneficial ‘knock-on’ effect.

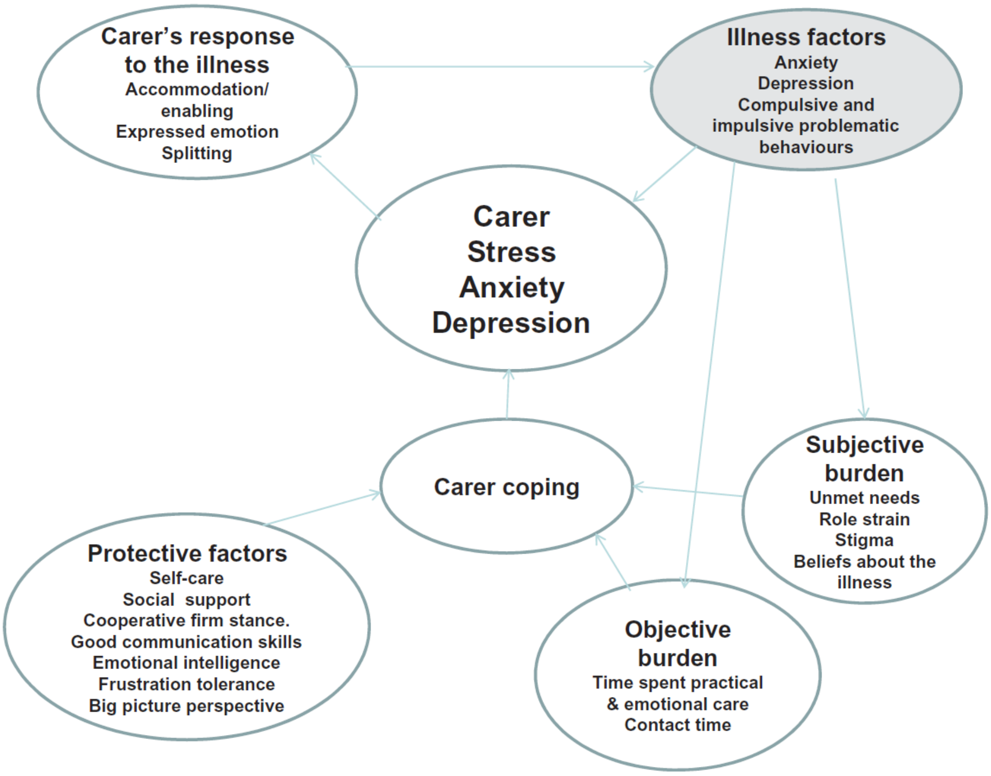


Figure 8: Model of carer coping and the interpersonal maintenance component from the cognitive-interpersonal model of AN (from Treasure, Rhind, et al., 2015).

1.6.4 Evidence base

A recent systematic review and meta-analysis has summarised the efficacy of carer interventions based on (or similar to) the New Maudsley Model (Hibbs, Rhind, Leppanen, & Treasure, 2014), that has been delivered as workshops (Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008; Whitney, Murphy, et al., 2012), and more recently as web-based materials (Grover et al., 2011), or workbooks/DVDs (Goddard et al., 2011; Hibbs, Magill, et al., 2015), in line with Fairburn & Patel's (2014) recommendations for programme-lead treatments to enhance accessibility. The results of the meta-analysis showed most interventions developed for optimising carer coping, of which some also targeted specific caregiver behaviours (expressed emotion, accommodating), produced a moderate sized reduction in carer distress and a small-to-moderate reduction in carer burden and expressed emotion, and these changes were maintained at follow-up (R. Hibbs et al., 2014). Furthermore, they have been reported to be feasible and acceptable (Pépin & King, 2013; Whitney, Currin, Murray, & Treasure; Whitney, Murphy, et al., 2012) and successful in terms of targeting the processes that maintain illness such as reduced expressed emotion (Sepulveda et al., 2010). Moreover, the patients themselves reported positive benefits (Goddard, Macdonald, et al., 2013). Specifically, a carer self-help (with or without guidance) form of the intervention that is low in delivery cost and highly disseminable called ‘Expert Carers Helping Others’ (ECHO) produced small improvements in psychopathology following inpatient treatment in severe and/or enduring AN (Hibbs, Magill, et al., 2015). In line with the need for early-intervention, and pilot data in support of the benefit of interventions to address parents’ (or other carers’) needs in the early stage (Nicholls & Yi, 2012), the subsequent trial (chapters 7 and 8 of the present thesis) was developed to examine the use of ECHO delivered as self-help (with or without guidance) in adolescent AN.

1.7 Thesis aims

The main aim of this thesis is use multi-modal and multi-informant measures to extend the evidence for socio-emotional difficulties in adolescents with AN and to establish the caregiving burden related to this group. The second main aim is to examine whether a carer intervention delivered to parents that focuses on sharing skills to manage these interpersonal difficulties more effectively ameliorates maladaptive interpersonal patterns of distress. Five main hypotheses were tested in this thesis:

Table 2. Aims, hypotheses, and related study/chapter

Aim	Hypothesis	Study (Chapter)
Examine aspects of socio-emotional functioning in AN	(i) Relative to the population norms, it is hypothesized that adolescents with AN would (a) have elevated levels of ASD traits, (b) be more likely to meet diagnostic criteria for ASD, and (c) these traits would be elevated in their parents.	Study 1 (Chapter 2)
	(ii) It is hypothesized that using an experimental paradigm, adolescents with AN would display less evoked positive and	Study 2 (Chapter 3)

	negative facial affect to positive and negative emotion stimuli than similar-age healthy controls, despite reporting no differences in subjective emotion experience.	
Examine caregiving in adolescent AN	(iii) It is hypothesized that the factor structure of two measures of caregiving behaviours (Eating Disorder Symptom Impact Scale, and the Accommodating and Enabling Scale for Eating Disorders) will be confirmed in a larger cohort of primary and secondary carers of individuals with AN and therefore provide further validation for the use of these scales in assessing aspects of caregiving in AN.	Study 3 (Chapter 4)
	(iv) It is hypothesized that (a) high levels of objective burden would be associated with high levels of subjective burden (psychological distress), (b) maladaptive caregiving interpersonal behaviours (high levels of accommodating and/or expressed emotion, low levels of carers' skills) would be associated with greater subjective burden, and (c) the levels of these interpersonal behaviours would mediate the relationship between objective and subjective burden.	Study 4 (Chapter 5)
Examine response to a carer intervention in adolescent AN	(v) It is hypothesized that (a) for patients and carers, intake (pre-treatment) levels of distress would be positively associated with distress at end of treatment; and (b) patients' intake levels of distress would predict carers' level of distress at end of treatment (i.e. distress interdependence) for the group receiving usual ED treatment only, whereas carer/patient distress interdependence would not be evident in the group augmented with the ECHO intervention.	Study 5 (Chapter 7)

CHAPTER 2.

STUDY 1: AN EXAMINATION OF AUTISM SPECTRUM TRAITS IN ADOLESCENTS WITH ANOREXIA NERVOSA AND THEIR PARENTS

Publication

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An examination of autism spectrum traits in adolescents with anorexia nervosa and their parents

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Abstract

Background: There may be a link between anorexia nervosa and autism spectrum disorders. The aims of this study were to examine whether adolescents with anorexia nervosa have autism spectrum and/or obsessive-compulsive traits, how many would meet diagnostic criteria for autism spectrum disorder, and whether these traits are shared by parents.

Methods: A total of 150 adolescents receiving outpatient treatment for anorexia nervosa or subthreshold anorexia nervosa and their parents completed the autism spectrum disorder and eating disorder sections of the Development and Well-being Assessment. Patients also completed the Children Yale-Brown Obsessive-Compulsive Scale and other measures of psychiatric morbidity, and parents completed the short Autism Quotient and Obsessive-Compulsive Inventory Revised.

Results: Adolescents with anorexia nervosa had a below average social aptitude (19% below cut-off) and high levels of peer relationship problems (39% above cut-off) and obsessive-compulsive symptoms (56% above cut-off). Six cases (4%, all females) were assigned a possible (n = 5) or definite (n = 1) diagnosis of autism spectrum disorder. Parental levels of autism spectrum and obsessive-compulsive traits were within the normal range.

Conclusions: This study suggests that adolescents with anorexia nervosa have elevated levels of autism spectrum traits, obsessive-compulsive symptoms, and a small proportion fulfil diagnostic criteria for a probable autism spectrum disorder. These traits did not appear to be familial. This comorbidity has been associated with a poorer prognosis. Therefore, adaptation of treatment for this subgroup may be warranted.

Trial registration: Controlled-trials.com: ISRCTN83003225. Registered on 29 September 2011.

Keywords: Anorexia nervosa, Eating disorder, Autism spectrum disorder, Obsessive-compulsive disorder, Traits, Social aptitude, Adolescents, Parents, Development, Well-being assessment

Background

An association between low empathy during development and the later development of an eating disorder (ED) was suggested by Gillberg in 1992 [1]. He proposed that individuals with autism spectrum disorders (ASD) and those with anorexia nervosa (AN) may share traits, some of which might be familial [1]. Evidence summarized in recent reviews provides support for this hypothesis, suggesting that there may be a shared liability between AN and ASD [2-4]. For example, both disorders have a similar profile of neuropsychological function (problems with set shifting, central coherence, and social cognition) and behavioral traits such as social problems, and obsessive-compulsive features such as rigidity and attention to detail [2-4], although the neuropsychological profile of adolescents with AN is less clear (for an example see Lang *et al.* [5]).

Several studies have used the autism quotient (AQ), a self-report measure of autism spectrum traits, in people

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with AN and have found higher than normal scores [6,7]. A study using the AQ and measures of systemizing and empathizing traits concluded that over 40% of adolescents with AN fulfilled the criteria for the broad autistic phenotype [8]. Another study found that 26% of adults with AN scored above the cut-off score on the short AQ [9]. In a large population study using parent report, 23% of children with restrictive eating problems also screened positive for ASD [10]. These studies suggest that there are shared traits between AN and ASD.

One problem in establishing the association between these conditions is that it can be difficult to make the diagnosis of ASD in women. Their clinical presentation differs from that typically seen in men, as summarized in a recent review [11]. Parents endorse different items for girls with ASD (such as 'avoids demands', 'very determined', and 'careless with physical appearance and dress') using a scale adapted to capture the female phenotype of ASD [12]. Furthermore, females present with more lifetime sensory problems [13]. It is thought that females with autism spectrum traits may be more likely to focus on eating or shape and weight issues as a topic of special interest.

People with EDs and their family members have higher levels of obsessive-compulsive personality traits [14,15]. Behavioral traits, such as attention to detail and rigidity, are part of this personality profile and are common to those with EDs and ASD [2-4]. For example, the perceptual style of weak central coherence characterized by precedence for detail processing and/or difficulties with integrating global information is present in all three disorders [16-18]. A compulsivity phenotype may account for some of the common variance between these co-morbid conditions [19].

The aims of this study were to examine this dimensional approach to diagnosis by assessing whether adolescents with AN have autism spectrum and obsessive-compulsive traits, to establish the prevalence of ASD amongst this patient group, and whether these traits are shared by parents. It was hypothesized that (1) adolescents with AN would have higher levels of autism spectrum (poorer social aptitude skills and greater peer difficulties) and obsessive-compulsive traits, relative to population norms; (2) a higher proportion of adolescents with AN would fulfil diagnostic criteria for ASD than female healthy population norms, using the Development And Well-being Assessment (DAWBA) [20]; and (3) parents of adolescents with AN would have higher levels of autism spectrum and obsessive-compulsive traits, relative to population norms.

Methods

Participants

Adolescents newly referred for outpatient treatment with a primary diagnosis of AN or ED Not Otherwise Specified AN subtype (EDNOS-AN) and their parents completed a battery of assessments as part of a randomized controlled trial (Experienced Carers Helping Others (ECHO, trial registration: ISRCTN83003225)). Participants were recruited from 38 National Health Service (NHS) England outpatient services, providing an ecologically relevant sample representative of current United Kingdom practice. ED diagnoses were made by a clinician at the local recruitment site, according to the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) criteria [21]. An age range of 13 to 21 years was chosen to represent an adolescent sample; up until brain development comes to completion (early twenties) [22] and usually whilst in full-time education. This is also consistent with previous similar adolescent trials [23]. Main ethics approval was granted by the Northwick Park Hospital Ethics Committee (approval number: 11/H0724/4) and site-specific ethics and governance approval granted on all participating sites (please see Acknowledgements). Written assent was collected for all patients and informed consent from their parents or guardians and all other participating carers was collected prior to entering the study in accordance with ethical guidelines. The methodology is described in detail elsewhere [24]. Only participants who completed the DAWBA and their parents were included in the present study. The final sample consisted of 150 adolescents (92% of total recruited) receiving treatment for AN (75%) or EDNOS-AN (25%) and their parents (n = 207). No differences were found between the participants included in the present study and the 163 patients and 224 parents recruited on clinical (body mass index (BMI), lowest BMI, and illness duration) and demographic variables (gender, employment, and marital status) with the exception of parental age which was greater in the sample included (data not shown).

Patient measures

Standard demographic and clinical information were completed as self-report by patients (validated by clinicians) and their parents.

The developmental and well-being assessment

The DAWBA [20] is a well-validated and extensively used measure in epidemiological studies that is designed to generate a DSM-IV and an International Statistical Classification of Diseases and Related Health Problems (ICD-10) psychiatric diagnosis for childhood and adolescent psychiatric disorders. The ASD section is used as a diagnostic measure in population-based prevalence studies of ASD [25,26]. In the present study, parents (informants) and patients (self-report) complete the ASD and ED sections of the computerized DAWBA which includes interview questions (each with screening questions) and skip rules.

Parents report on their child's development (language, routines, play, and social ability) and complete the Social Aptitudes Scale (SAS) [27], both designed to capture 'traits' rather than 'state' effects. The SAS is designed to tap the sorts of social aptitudes that require a good ability to read social and emotional cues rapidly in complex situations in order to guide socially skilled behaviour. Parents rate their child from 'a lot worse than average' to 'a lot better than average', relative to other children of the same age, across 10 items. Low scores index a substantially raised risk of ASDs. The SAS has been well-validated and demonstrated good psychometric properties: data from a large epidemiological study of young people in the United Kingdom produced a mean score of 24.57 (SD = 6.26, n = 7768) with higher scores for females (mean = 25.33, SD = 6.14, n = 3764). A cut-off score of 16 or less is associated with good screening properties for the diagnosis of ASD [27]. Age-transformed aptitude scores with a mean of 50 and standard deviation of 10 have been developed [27]. Cronbach's α coefficient (α) for responses to the SAS in the present study was 0.90.

The DAWBA generates six diagnostic probability bands (ranging from <0.1 to >70% likelihood) and a summary of structured and open-ended interview data, triangulated across informants by a trained experienced clinician (NM), who assigned a diagnosis ('yes', 'possible', or 'no') according to DSM-IV and ICD-10 criteria.

Parents and the individuals themselves also completed the Strengths and Difficulties Questionnaire (SDQ) [28] which consists of 25 items that assess behaviour problems, hyperactivity, emotional symptoms, peer problems, and pro-social skills. The sum of the first four subscale scores forms a total difficulties score, with higher scores indicating greater difficulties. Ratings of child distress and the impact of difficulties on social capital form a total impact score. Social skills can be inferred from the pro-social and peer relationship subscales. Good psychometric properties are reported for the SDQ. Normative data from a large epidemiological study [29] are available online with cut-off points; specifically, peer difficulties scores of 0 to 2 may be classified as normal, a score of 3 as 'borderline', and scores of 4 to 10 as 'abnormal'. In the current study, Cronbach's α for responses to the SDQ symptom domains was 0.83 (informant) and 0.82 (self-report).

The children's Yale-Brown obsessive-compulsive scale

Obsessive-compulsive traits in patients were assessed using the self-report Children's Yale-Brown Obsessive-Compulsive Scale (CY-BOCS-SR) [30]. Higher scores indicate higher symptom severity (score range 0 to 40) and scores of 16 and over are used as a cut-off for clinically significant obsessive-compulsive disorder. Cronbach's α for responses to the CY-BOCS-SR in the current study was 0.71.

The short evaluation of eating disorders

The Short Evaluation of EDs (SEED) [31] was completed by self-report to assess ED symptom severity. Responses are scored using an algorithm including weight and key symptoms and computed a total AN and Bulimia Nervosa (BN) symptom severity index (score range 0 to 3; higher score indicating severity). Cronbach's α for the SEED in this study was 0.72.

Clinical impairment assessment 3.0

Psychosocial impairments related to the ED features over the past 28 days were also assessed using the Clinical Impairment Assessment (CIA) [32]. A global score is calculated with higher scores indicating greater severity of impairment. Cronbach's α for the CIA in this study was 0.94.

The depression, stress and anxiety scale

The Depression, Stress and Anxiety Scale (DASS-21) [33] was used as a self-report measure of current mood state. Cronbach's α for the DASS-21 was 0.94.

Parent measures

The short autism quotient

Autism spectrum traits in parents were assessed using the Short Autism Quotient (AQ-10) [34]. Healthy adults produced a mean score of 2.77 (SD = 2.00) and a cut-off point of 6 is indicative of ASD [34]. Cronbach's α for the AQ-10 in this study was 0.56.

The obsessive-compulsive inventory

Obsessive-compulsive traits in parents were measured using the Obsessive-Compulsive Inventory (OCI-R) [35]. A cut-off point of 21 is indicative of clinically significant obsessive-compulsive disorder. Cronbach's α for the OCI-R in this study was 0.88.

Data analysis

Data were analyzed using IBM SPSS Statistics for Windows, Version 21.0: Armonk, New York. Descriptive statistics summarized means and standard deviations for patient and parent scores on all measures. Independent samples t-tests were used for group comparisons: social aptitude scores in present study sample versus population mean; patients who did versus did not receive a diagnosis for ASD; and mothers versus fathers. Cohen's d was used to calculate effect sizes. Spearman's correlations were used to measure associations between patients autism spectrum and obsessive-compulsive traits, and their current ED clinical characteristics, and parental traits, applying a Bonferroni-corrected α (0.05 out of 13, α = 0.004) to correct for multiple comparisons.

Results

The patient sample was 91% female, 96% Caucasian, and 91% were living with their parents. The age ranged from 13 to 21 years (mean = 16.90, SD = 2.13) and 83.6% were within three years of illness onset. The majority of patients (69%) had received no prior treatment for their ED. One patient in the sample reported having received a diagnosis of ASD. Other clinical information is displayed in Table 1. The mother (mean age = 48 years, SD = 4.82) was involved in the study for 95% of patients and the father for 42% (mean age = 51 years, SD = 5.06).

Psychometric assessment of adolescents with anorexia nervosa

Social aptitude scores (mean = 22.87, SD = 8.16) were lower than the healthy population norm (see legend, Table 2; t = 3.03, $p = 0.002$, d = −0.23), particularly for females (mean = 22.71, SD = 8.35; t = 4.51, $p < 0.001$, d = −0.36). Scores fell within the clinically significant range for 18.8% of patients. They were not significantly correlated with clinical characteristics (BMI, illness duration, AN symptom severity, BN symptom severity, ED clinical impairment, depression, anxiety, or stress scores; data not shown).

For both categories of rater (informant (I) and self-report (SR)) completing the SDQ, the highest levels of difficulties relative to norms were in the emotional (I: d = 2.07, SR: d = 1.73) and peer domains (I: d = 0.76, SR: d = 0.94). Peer difficulties were 'abnormal' for 38.5% of patients, and 'borderline' for a further 12.9%. Informants only reported lower than average levels of pro-social skills (I: d = −0.75, SR: d = −0.05), particularly for females (I: d = −0.89, SR: d = −0.37). The individuals themselves reported higher than average levels of hyperactivity (SR: d = 0.62) and a smaller effect was reported by informants (I: d = 0.32). Informants rated a moderate level of conduct problems (I: d = 0.52, SR: d = 0.05).

Scores for obsessive-compulsive symptoms (CY-BOCS-SR) were within the clinically significant range for obsessive-compulsive disorder in 56.4% of the sample. Scores were significantly correlated with duration of illness (Spearman's correlation coefficient (r_s) = 0.26, $p < 0.001$), BN symptom severity ($r_s = 0.34$, $p < 0.001$), ED clinical impairment ($r_s = 0.51$, $p < 0.001$), depression ($r_s = 0.42$, $p < 0.001$) and anxiety ($r_s = 0.45$, $p < 0.001$), but not with BMI, lowest BMI or AN symptom severity.

Diagnostic assessment of autism spectrum disorder

Compared with normative data, more AN females were assigned to the higher diagnostic probability bands of the DAWBA (10.9% AN versus 1.2% norms at level 2 (>3% likelihood of ASD) and 2.5% AN versus 0.3% norms at level 3 (>15% likelihood of ASD)).

Six individuals (4%, all female) were assigned a possible (n = 5) or definite (n = 1) diagnosis of ASD by the clinical

Table 1 Sociodemographic and clinical characteristics

	Females (N = 137) Mean (SD, range)/n (valid %)	Males (N = 13) Mean (SD, range)/n (valid %)	Total (N = 150) Mean (SD, range)/n (valid %)	ASD subset (N = 6, all females) Mean (SD, range)/n (valid %)
Age (years)	16.86 (2.11, 12.42-21.57)	17.31 (2.37, 13.20-21.53)	16.90 (2.13, 12.42-21.57)	17.09 (1.95, 15.27-20.21)
Illness duration (months)	22.83 (23.60, 2.00-110.00)	20.58 (11.26, 4.00-39.00)	22.64 (22.79, 2.00-110.00)	19.00 (15.45, 4.00-49.00)
BMI	16.81 (2.17, 12.38-24.20)	17.16 (2.44, 13.00-21.60)	16.84 (2.19, 12.38-24.20)	16.45 (2.25, 14.30-20.50)
Weight-for-height (%)[a]	82.50 (11.58, 55.07-122.97)	84.77 (15.78, 65.19-106.14)	82.65 (11.82, 55.07-122.97)	79.93 (10.94, 65.98-92.70)
Lowest BMI	15.45 (2.29, 11.40-23.60)	15.22 (2.63, 12.00-18.30)	15.43 (2.30, 11.40-23.60)	14.56 (1.20, 13.10-16.40)
Previous hospital admission				
0	120 (92.3%)	11 (91.7%)	131 (92.3%)	5 (100%)
1	9 (6.9%)	1 (8.3%)	10 (7.0%)	0
2	1 (0.8%)	0	1 (0.7%)	0
Missing	7 (5.1%)	1 (7.7%)	8 (5.3%)	1 (16.7%)
DAWBA ED diagnosis[b]				
AN	82 (59.9%)	5 (38.5%)	87 (58.0%)	3 (50.0%)
EDNOS	49 (35.8%)	7 (53.8%)	56 (37.3%)	3 (50.0%)
BN	1 (0.7%)	0	1 (0.7%)	0
Possible	1 (0.7%)	0	1 (0.7%)	0
No	4 (2.9%)	1 (7.7%)	5 (3.3%)	0

[a] Age standardized weight-for-height (participants aged <20 years (n = 126) only are reported), according to Great Ormond Street Hospital for Children criteria.
[b] Clinical rating using the DAWBA (DSM-IV and ICD-10 criteria).
Abbreviations: AN, Anorexia Nervosa; ASD, Autism spectrum disorder; BMI, Body Mass Index; BN, Bulimia Nervosa; DAWBA, Development and Well-being Assessment; ED, Eating Disorder; EDNOS, Eating Disorder Not Otherwise Specified.

Table 2 Patient psychiatric symptomatology and comorbidity

	All females (N = 137) Mean (SD)	All males (N = 13) Mean (SD)	Total (N = 150) Mean (SD)	ASD subset (N = 6, all females) Mean (SD)
CY-BOCS total	16.95 (8.79)	13.58 (8.34)	16.63 (8.77)	16.00 (9.82)
SAS[a]	22.71 (8.35)	24.70 (5.29)	22.87 (8.16)	7.00 (2.37)
SAS T-score[a]	45.50 (12.01)	48.00 (7.23)	45.70 (11.69)	23.50 (2.34)
SDQ Peer problems[b]				
Self-report	3.14 (2.05)	3.00 (1.55)	3.13 (2.01)	4.60 (2.88)
Informant	2.95 (2.19)	3.36 (2.16)	2.98 (2.18)	5.67 (1.75)
SDQ Pro-social skills[c]				
Self-report	7.93 (1.70)	7.82 (1.66)	7.92 (1.69)	7.20 (0.84)
Informant	7.08 (2.29)	7.64 (2.20)	7.13 (2.28)	4.50 (1.98)
SDQ Emotional				
Self-report	6.63 (2.35)	6.91 (2.34)	6.65 (2.34)	6.40 (2.97)
Informant	6.59 (2.45)	5.82 (2.27)	6.52 (2.44)	8.00 (1.10)
SDQ Conduct				
Self-report	2.34 (1.70)	1.73 (1.35)	2.29 (1.68)	2.80 (1.64)
Informant	2.42 (1.74)	2.27 (2.37)	2.41 (1.79)	3.00 (2.37)
SDQ Hyperactivity				
Self-report	5.14 (2.29)	5.27 (1.95)	5.16 (2.16)	5.80 (2.39)
Informant	4.00 (2.30)	3.64 (1.86)	3.97 (2.26)	4.67 (2.51)
SDQ Total difficulties				
Self-report	17.24 (6.17)	16.91 (4.66)	17.22 (6.04)	19.60 (7.13)
Informant	15.96 (6.48)	15.09 (6.28)	15.89 (6.44)	21.33 (5.50)
SDQ Impact				
Self-report	4.40 (3.36)	3.73 (4.65)	4.34 (3.46)	4.40 (3.65)
Informant	3.99 (3.14)	3.82 (3.25)	3.98 (3.14)	7.17 (0.75)
ASD probability band[d,e]				
<0.1%	102 (85.7%)	10 (91.9%)	112 (86.2%)	1 (16.7%)
Approx. ~ 3%	13 (10.9%)	1 (9.1%)	14 (10.8%)	4 (66.7%)
Approx. 15%	3 (2.5%)	0	3 (2.3%)	1 (16.7%)
Approx. 50%	1 (0.8%)	0	1 (0.8%)	0
Missing	18 (13.1%)	2 (15.4%)	20 (13.3%)	0
Diagnosis ASD[e]				
Possible	5 (3.6%)	0	5 (3.3%)	5 (83.3%)
Yes	1 (0.7%)	0	1 (0.7%)	1 (16.7%)

[a] Lower scores indicate poor social aptitude (cut-off score 16 or less). British (age 11 to 14 years) healthy population mean = 24.57 (SD = 6.26), females only mean = 25.33 (SD = 6.14), males only mean = 23.81 (SD = 6.38). SAS Age-Transformed-score mean = 50 (SD = 10) [27].

[b] British (age 11 to 14 years) healthy population informant-rated mean = 1.5 (SD = 1.7), self-report mean = 1.5 (SD = 1.4) [29].

[c] British (age 11 to 14 years) healthy population informant-rated mean = 8.6 (SD = 1.6), self-report mean = 8.0 (SD = 1.7) [29].

[d] British (age 11 to 14 years) healthy population females (F) and males (M) selecting those with no intellectual disability ASD band <0.1% = 98.3% (F), 95.7% (M); ASD band approximately 3% = 1.2% (F), 2.1% (M); ASD band approximately 15% = 0.3% (F), 1.4% (M); ASD band approximately 50% = 0.2% (F), 0.4% (M).

[e] Valid percentages presented.

[e] Clinical rating using the DAWBA (DSM-IV and ICD-10 criteria).

Abbreviations: SAS, Social Aptitude Scale; SDQ, Strengths and Difficulties Questionnaire; ASD, Autism Spectrum Disorder.

rater. Clinical and psychometric features of these cases are displayed in Table 2. Informant-rated scores for total difficulties ($d = 0.95$) and impact ($d = 1.47$) were higher for this subgroup.

Parental autism spectrum and obsessive-compulsive traits

Levels of autism spectrum and obsessive-compulsive traits in parents of adolescents with AN were within the normal range (Table 3). Only 2.2% of parents ($n = 2$

Table 3 Parental traits

	All parents			Parents of ASD subset only		
	Mothers (N = 143)	**Fathers (N = 64)**	**Total (N = 207)**	**Mothers (N = 6)**	**Fathers (N = 6)**	**Total (N = 12)**
AQ-10	1.95 (1.52)	2.81 (1.84)	2.20 (1.66)	1.80 (1.10)	2.67 (1.53)	2.13 (1.25)
OCI-R	8.85 (9.06)	7.50 (7.23)	8.47 (8.59)	14.00 (9.43)	6.33 (4.04)	11.13 (8.44)

Means and SD displayed; Abbreviations: ASD, Autism spectrum disorder; AQ-10, Autism Quotient; OCI-R, the Obsessive-Compulsive Inventory Revised.

(3.1%) fathers, n = 2 (1.4%) mothers) scored within the clinically significant range suggestive of ASD. Fathers produced higher scores than mothers ($t = -3.32$, $p = 0.001$, $d = 0.51$). Scores for obsessive-compulsive traits (OCI-R) were within the clinically significant range for 7.9% of parents.

There were no significant differences in autism spectrum traits (AQ-10) between parents of those assigned an ASD diagnosis compared with those who were not.

Correlations between autism spectrum and obsessive-compulsive traits

Table 4 presents the correlations between autism spectrum (social aptitude and SDQ peer problems, and pro-social behaviors) and obsessive-compulsive traits (CY-BOCS-SR) in patients and in mothers and fathers (AQ-10 and OCI-R). Patient autism spectrum traits (social aptitude, peer difficulties, and pro-social behaviors) and obsessive-compulsive traits were not significantly correlated. Parental autism spectrum (AQ-10) and obsessive-compulsive traits (OCI-R) were significantly correlated for mothers only. Parental traits were not correlated with autism spectrum or obsessive-compulsive scores in patients.

Discussion

The first aim of this study was to examine whether adolescents with AN have traits suggestive of ASD. We confirmed our first hypothesis in that we found that poor social aptitude skills and peer difficulties were more prevalent in the AN patients than in healthy population norms. We also found high co-morbid obsessive-compulsive traits in the patient group. We found that six (4%) patients met the diagnostic criteria for a possible or definite ASD. However, we failed to confirm our hypothesis that the parents of the patient group would have higher than normal levels of autism spectrum and obsessive-compulsive traits.

The prevalence of autism spectrum traits (low social aptitude (18.8%) and peer difficulties) is similar to the approximate 20% of the cohort of adolescent cases of AN who were thought to have social communication difficulties reported by Gillberg [1] and the 23% of children with restrictive eating problems who also screened positive for ASD [10]. It is lower than the 40% of adolescents fulfilling the Baron Cohen's criteria for the broad autistic phenotype [8]. The different populations, screening, and diagnostic procedures used in these studies may account for this variance.

The prevalence of diagnostically defined cases (4%) is lower than the proportion (23%) of adult patients with a severe and enduring ED who were considered to have ASD [36]. In part this may relate to the use of the DAWBA as a developmentally based diagnostic measure; however, given the poor prognosis of this group [37], it might be expected that a greater proportion of cases with ASD will be found in cohorts with a severe and enduring illness.

The six individuals with possible and definite ASD had a similar clinical profile to the group as a whole. However, informant ratings suggested that this subgroup had greater overall difficulties. However, given the small number, group comparisons are underpowered and these descriptors are therefore unreliable.

The problems in social functioning are consistent with the previous literature. Patients with EDs particularly those with AN retrospectively report social difficulties in childhood [38]. In a longitudinal study, social problems at age eight were strongly predictive of ED onset at age 14 [39]. Furthermore, a recent systematic review has documented the wide range of difficulties within the social cognition domain [40]. Although there may be ‘state’ effects of AN on neuropsychological functioning, the lack of association between social aptitude and current AN features is more indicative of a trait level of disturbance. The level of other forms of comorbidity in this group (obsessive-compulsive disorder traits, negative affect and some Attention Deficit/ Hyperactivity Disorder symptoms) is similar to that in the literature [41-43].

We did not find that the parents of patients with EDs had high levels of autism spectrum traits themselves. Parents of people with ASD have been found to have high autism quotient scores [44,45], mainly in the social and communication domains [46,47], suggesting that there is a broad familial ASD phenotype. However, this finding is less robust in mothers of people with ASD [48]. The small number of cases and the different instruments used makes the interpretation of possible cross-generational traits versus possible ‘state’ effects of AN difficult.

Strengths and limitations

One of the strengths of this study was the use of the DAWBA as an assessment measure that has been widely

Table 4 Correlations between autism spectrum disorder and obsessive-compulsive disorder traits in female patients and their parents

	Patient variables									Parent variables			
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**
1. Social aptitude	-												
2. Peer problems[a]	−0.27	-											
3. Peer problems[b]	−0.40**	0.60**	-										
4. Pro-social skills[a]	0.17	−0.35**	−0.15	-									
5. Pro-social skills[b]	0.58**	−0.18	−0.38**	0.18	-								
6. Emotion difficulties[a]	−0.19	0.38**	0.27	−0.17	−0.09	-							
7. Emotions difficulties[b]	−0.29*	0.23*	0.53**	0.03	−0.32**	0.34**	-						
8. CY-BOCS-SR	−0.05	0.16	0.20*	−0.13	−0.09	0.32*	0.18	-					
9. ASD Diagnostic Band	−0.45**	0.31*	0.40**	−0.13	−0.27*	0.32*	0.32**	0.19	-				
10. Mother AQ-10	−0.11	0.15	0.20	0.03	−0.01	0.18	0.05	0.06	0.19	-			
11. Father AQ-10	−0.13	0.32	0.33	0.22	−0.11	−0.06	0.17	−0.14	0.09	−0.23	-		
12. Mother OCI-R	−0.20	0.19	0.21	−0.14	−0.09	0.15	0.24	0.07	0.24	0.32**	0.14	-	
13. Father OCI-R	−0.35	0.25	0.29	0.05	−0.39	0.13	0.26	−0.02	−0.01	0.04	0.31	−0.01	-

Spearman's correlation coefficient (r_s) applying a Bonferroni-corrected alpha ($\alpha = 0.004$); Abbreviations: AQ-10, Autism Quotient; ASD, Autism spectrum disorder; CY-BOCS-SR, Children's Yale-Brown Obsessions and Compulsions Symptom Scale Revised; OCD, Obsessive-compulsive disorder; OCI-R, the Obsessive-Compulsive Inventory Revised.

[a] Strength and Difficulties Questionnaire by self-report.

[b] Strength and Difficulties Questionnaire by informant.

*p <0.003, **p <0.001.

employed in epidemiological studies of child and adolescent psychiatry, with healthy population norms available for comparison. Furthermore, because the DAWBA is framed developmentally and collects self-report and informant perspectives, it is less reliant on current symptoms or impairment ('state' effects of AN). Another strength of this study is the inclusion of both child and parent data. Nevertheless, several limitations must be noted; we used instruments that measured obsessive-compulsive disorder behaviors and it would have been preferable to have included instruments to measure traits associated with compulsivity, an over-controlled temperament, and obsessive-compulsive personality. Additionally, the internal consistency of the AQ-10 was poor and caution must be taken when interpreting these results. It would have been preferable to have also screened the participants themselves with the AQ-10. The possibility that the DAWBA is less diagnostically sensitive than an in-depth face-to-face clinician examination must also be considered. Given that the DAWBA assigned fewer AN and overall ED diagnoses in a sample of clinically diagnosed and treatment-seeking AN and EDNOS-AN patients, it is possible that the DAWBA provides a relatively conservative diagnostic tool. Furthermore, the patient previously diagnosed with ASD prior to entering the study was assigned a 'probable' (rather than 'definite') diagnosis using the DAWBA in the present study. It is therefore possible that the prevalence of ASD in AN may be higher than that reported in this study. Finally, the data presented do not represent all treatment-seeking patients, but only the group who consented to be involved in a study that involves their parents. It is possible that the sample is therefore biased towards patients with parents who were more actively involved in their child's care.

Clinical implications

We have found that a small number of adolescent AN cases are possibly comorbid with ASD. We have also found evidence of transdiagnostic traits such as social communication and emotional problems. These may be associated with ASD, the over-controlled temperament [49], and obsessive-compulsive personality [50] in adolescents with EDs. Treatment adaptations to target these difficulties may be beneficial.

Conclusions

Approximately one fifth of adolescents with AN have obsessive-compulsive traits and problems in peer relationships and social functioning. A much smaller proportion (4%) fulfil the diagnostic criteria for a probable ASD. It will be of interest in the future to establish the prognosis of this subgroup and whether these traits moderate the response to standard treatment, as suggested by Crane *et al.* [51].

Abbreviations

AN: Anorexia Nervosa; AQ: Autism Quotient; ASD: Autism Spectrum Disorder; BMI: Body Mass Index; BN: Bulimia Nervosa; CIA: Clinical Impairment Assessment; CY-BOCS-SR: Children's Yale-Brown Obsessive-Compulsive Scale Self-Report; DASS: Depression Anxiety Stress Scales; DAWBA: Development and Well-being Assessment; DSM-IV: Diagnostic and Statistical Manual of Mental Disorders; ED: Eating Disorder; I: Informant; ICD-10: International Statistical Classification of Diseases and Related Health Problems; OCD: Obsessive-Compulsive Disorder; OCI-R: Obsessive-Compulsive Inventory Revised; SAS: Social Aptitude Scale; SD: Standard Deviation; SDQ: Strengths and Difficulties Questionnaire; SEED: Short Examination of Eating Disorders; SR: Self-Report.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

CR was a project coordinator for the Experienced Carers Helping Others (ECHO) study and carried out data collection, statistical analysis and drafted the manuscript. EB prepared data for analysis. RH was a project coordinator for ECHO, involved in the setup of the ECHO study, carried out data collection and critical appraisal of the manuscript content. EG, PM, SG, and US were involved in the design and setup of the study and contributed to the interpretation of data and critical appraisal of the manuscript content. SG was also Principal Investigator at one of the study recruitment sites. KT contributed to the interpretation of data and critical appraisal of the manuscript content. NM conducted the Development and Well-being Assessment clinician ratings, supervised statistical analysis, contributed to interpretation of data and was involved in revising the manuscript critically for important intellectual content. JT conceived of the study, participated in its design and coordination, contributed to the interpretation of results, and was involved in drafting of the manuscript and revising it critically for important intellectual content. All authors read and approved the final manuscript.

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CHAPTER 3.

STUDY 2: AN EXPLORATORY STUDY OF EVOKED FACIAL AFFECT IN ADOLESCENT FEMALES

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Brief report

An exploratory study of evoked facial affect in adolescent females with anorexia nervosa

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ABSTRACT

The aim of this exploratory study was to investigate facial affect in adolescent females with anorexia nervosa (AN). Evoked facial affect was recorded whilst AN and control participants ($n=34$) viewed emotional films. Significantly less facial affect was found in AN adolescents, despite reporting no differences in subjective emotion experience. These findings correspond with previous studies in adults with AN. Altered facial affect may impair interpersonal functioning and contribute to illness maintenance.

1. Introduction

Recent models of anorexia nervosa (AN) have emphasised the importance of social and emotional difficulties as maintenance factors (Treasure et al., 2012; Treasure and Schmidt, 2013). A comprehensive systematic review and meta-analysis has shown disturbances across the core facets of socio-emotional processing in AN, including attenuated facial affect (Caglar-Nazali et al., 2014). Only four studies published to-date have empirically assessed facial affect in eating disorders, all of which focused on adult patients (Claes, Jiménez-Murcia, Santamaría et al., 2012; Davies et al., 2011, 2013; Tarrega et al., 2014).

Despite reporting no differences in subjective emotion experience, women with AN were less facially expressive of positive and negative emotions compared to healthy controls (HC) while watching emotionally salient films (Davies et al., 2011). Attenuated facial affect was less marked in the recovered state (Davies et al., 2013). Furthermore, women with an eating disorder showed significantly less facial expressions of anger/frustration than HC while playing a therapeutic video game (Claes et al., 2012). Less facial expressions of anger/frustration but more expressions of joy were found in women with acute bulimia nervosa relative to HC and recovered patients in a follow-up study (Tarrega et al., 2014).

Findings from the self-report literature are consistent with experimental data; women with AN describe inhibiting the expression of positive (Jansch et al., 2009; Wildes et al. 2010) and negative emotions due to perceived negative consequences (Geller et al., 2000; Ioannou and Fox, 2009).

The ability to facially signal emotional state is considered a core facet of social and emotional competance (Schmidt and Cohn, 2001; Shariff and Tracy, 2009). Suppression is associated with problematic relationships (Butler et al., 2003; English et al., 2012; Gross and John, 2003), limited number of friends that may hinder the use of social support, and inadvertently contribute to illness maintenance (Doris et al., 2014; Treasure and Schmidt, 2013).

It is as yet unknown whether facial affect, in response to salient emotional content, is attenuated in adolescents with AN. Because adolescence is both the period during which AN typically develops (Currin et al., 2005) and a rapid developmental period of social cognition (Blakemore, 2012) and emotion regulation (Opitz et al., 2012), examination of facial affect in this group is essential for further discussions of these disturbances in AN. Inconsistencies between adult and adolescent findings in other facets of social processing in AN have emerged (e.g. Nandrino et al., 2006). State changes relating to the secondary consequences of prolonged starvation on the brain or a general deterioration in brain function from illness over

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time (“neuroprogression”), may account for the more severe impairment observed in adult patients (Fonville et al., 2014). Therefore, investigation of facial affect in adolescent AN is warranted.

1.1. Aims and hypotheses

It is hypothesised that, relative to HC, adolescent females with AN will show less evoked positive and negative facial expression during both positive and negative film stimuli, despite no differences in subjective experience of positive and negative affect.

2. Method

2.1. Participants

Participants were 17 consecutively referred inpatients with a primary diagnosis of AN restricting type according to DSM-IV criteria (APA, 1994) and 17 HC. Sample size power calculation was based on Davies et al. (2011) main finding of a large effect size (*d.*=1.1). Inclusion criteria were females aged 13–18 years, and for HC, weight-for-height within the normal range (BMI 18.5–25) and no personal/family history of an eating disorder. Inclusion age was selected to represent an adolescent sample consistent with previous studies in social cognition (e.g. Mills et al., 2014). Exclusion criteria for both groups were poor literacy, nonfluent English, or a history of head injury.

AN adolescents were recruited from an inpatient eating disorder service (January–June 2012) and HC from an independent school in the same region of the UK, and selected to not differ in age and education. Demographic and clinical characteristics are presented in Table 1. For the AN group, BMI at the time of testing ranged from 13.4 to 20.2, and 50% had BMI ≥ 17.5. Written consent was obtained for all participants and their parents prior to participation and ethical approval granted by the UCL Research Ethics Committee (3649/001).

2.2. Experimental stimuli

Stimuli were positive (‘The Bare Necessities’ from Disney's ‘Jungle Book’) and negative (‘the death of Mufasa’ from Disney's ‘Lion King’) film clips validated to evoke congruent positive and negative states in young people (von Leupoldt et al., 2007). A ‘neutral’ clip (ocean wave simulation) was included for baseline assessment. Film clips were matched on duration, sound, and picture motion, and presented in a fixed order of neutral, pleasant, neutral, unpleasant, and neutral to minimise ‘carry over’ effects (Ekman et al., 1990) and in line with previous similar studies (Davies et al., 2011, 2013).

2.3. Measuring facial affect

As in previous similar studies, recordings of the participants were coded using the Facial Expression Coding System (FACES; Kring and Sloan, 1991). FACES assesses global dimensions of positive and negative affect and frequency of expression (positive/negative valence) was used as the prime index of expressivity.

2.4. Materials

Demographic and clinical information was collected by self-report questionnaire for HC and from clinical notes for the AN group. The Centre for Epidemiological Studies Depression Scale for Children (Faulstich et al., 1986) and the Revised Children's Manifest Anxiety Scale (Reynolds and Richmond, 1978), were used to assess depressive and anxiety symptomatology and the Two Sub-test Version of the Wechsler Abbreviated Scale of Intelligence (Wechsler, 1999) used to assess IQ as a potential confound. The Positive and Negative Affect Scale for Children (PANAS-C; Laurent et al., 1999) was used to assess current state positive and negative affect during presentation of film clips. Across measures used in this study, Cronbach's alpha coefficient ranged 0.83–0.96.

Table 1
Between group comparison for demographic and clinical characteristics and descriptive data for facial affect and affective ratings.

	Between group comparisons for demographic and clinical characteristics					
	AN	HC	Test Statistic MW[a]	*p*-value		
	n=16	*n*=17				
Age	14.75 (1.65)	14.41 (S.D.=1.28)	131.00	0.879		
Years education	9.75 (1.65)	9.41 (1.28)	131.00	0.873		
Ethnicity						
White British/other	15 (93.8%)	16 (94.1)	N/A	N/A		
Black/Black British	1 (6.3%)	0	N/A	N/A		
Asian/Asian British	0	1 (5.9%)	N/A	N/A		
BMI[1] on admission	14.23 (1.92)	N/A	N/A	N/A		
Age of onset	13.13 (1.41)	N/A	N/A	N/A		
Illness duration[2]	20.63 (15.12)	N/A	N/A	N/A		
BMI[1]	17.03 (2.40)	19.97 (1.10)	41.50	< 0.001**		
Depression[3]	42.19 (8.35)	14.00 (8.63)	5.00	< 0.001**		
Anxiety[4]	21.88 (4.49)	8.65 (5.58)	11.50	< 0.001**		
IQ[5]	107.25 (11.31)	121.12 (9.66)	51.50	0.002*		
	Descriptive data for facial affect, affective ratings, and looking away					
	Positive film		Negative film		Neutral film	
	AN	HC	AN	HC	AN	HC
	n=16	*n*=17	*n*=16	*n*=17	*n*=16	*n*=17
Positive expressivity[6]	1.56 (2.20)	6.82 (3.71)	0.13 (0.34)	0.18 (0.53)	0.06 (0.25)	0.53 (1.07)
Negative expressivity[6]	1.31 (1.35)	4.35 (2.23)	1.31 (1.35)	4.35 (2.23)	0.38 (1.03)	0.65 (1.28)
Positive affect	22.38 (11.12)	28.29 (10.24)	7.31 (4.91)	8.94 (5.17)	9.13 (8.47)	13.24 (9.55)
Negative affect	22.13 (11.93)	21.35 (13.67)	22.13 (11.93)	21.35 (13.67)	7.06 (4.58)	2.88 (3.97)

Unadjusted means with standard deviations or frequency (%) are presented (one outlier in AN group excluded).

[a] MW-test statistics for Mann–Whitney U non-normally distributed data, Exact Sig. (2-tailed) is reported.

* $p < 0.05$.

** $p < 0.001$.

[1] Body Mass Index (BMI; Weight/Height^2).

[2] Measured in months.

[3] The Centre for Epidemoiological Studies Depression Scale for Children.

[4] The Revised Children’s Manifest Anxiety.

[5] The Two Sub-test Wechsler Abbreviated Scale of Intelligence.

[6] Frequency measurement.

2.5. Procedure

Participants took part in the study upon completion of consent forms and discussion with the researcher (C.R.). Time point within inpatient admission was not controlled. Level of weight restoration and exposure to the inpatient treatment programme therefore varied between AN participants. In the experimental session, participants completed assessment measures and were then presented with salient emotional film clips and their faces recorded. Participants were instructed to "allow themselves to get into the story", and completed the PANAS-C following each film clip. A researcher (C.R.) was present with participants throughout the experimental session.

2.6. Data analysis

Analyses were carried out using SPSS version 20. Mann–Whitney U tests were used for between group comparisons on demographic and clinical characteristics (Table 1). Frequency of facial expressions (positive, negative), and affective ratings (positive, negative) were analysed separately as dependent variables in separate two (group: AN, HC) × three (film: positive, neutral, negative) ANOVAs with repeated measurements. The Huynh–Feldt correction was applied in cases of violated sphericity assumptions (Mauchy's $W < 0.001$). Bonferroni-corrected univariate pairwise comparisons were performed to follow up significant main effects. Depression, anxiety, and IQ were included as covariates together (ANCOVAs) to assess for significant changes in main effects. Spearman's Rho analyses assessed correlations between facial expressivity and demographic (age) and other variables (BMI, BMI on admission, illness duration, anxiety, depression and IQ scores) separately for the AN group and HC.

3. Results

Descriptive data for facial expressivity and affective ratings are displayed in Table 1. The Studentized Residual detected one outlier that was excluded from analysis.

3.1. Positive facial affect

For positive expressivity, there was a significant main effect for Group [$F(1, 31)=24.44$, $p.<0.001$] and Film [$F(1.13, 34.99)=52.85$, $p<0.001$]. The response pattern to films differed between the groups [Group × Film: $F(1.13, 34.99)=21.06$, $p.<0.001$]. Pairwise comparisons confirmed that the AN group showed significantly less positive expression than HC in response to the positive film ($p.<0.001$, $d.=-1.7$).

When controlling for the effects of depressive symptomatology, anxiety symptomatology and IQ together, the main effect for Group [$F(1, 28)=28.20$, $p.<0.001$] and the Group × Film interaction [$F(1.27, 35.66)=24.95$, $p.<0.001$] remained significant. Pairwise comparisons confirmed that the AN group showed significantly less positive expression than HC in response to the positive film ($p.<0.001$, $d.=-1.8$). The main effect for Film was no longer significant [$F(1.27, 35.66)=0.178$, $p=0.736$].

3.2. Negative facial affect

For negative expressivity, there was a significant main effect for Group [$F(1, 31)=8.94$, $p.=0.005$] and Film [$F(1.79, 55.46)=46.82$, $p.<0.001$]. The response pattern to films differed between the groups [Group × Film: $F(1.79, 55.46)=19.03$, $p.<0.001$]. Pairwise comparisons confirmed that the AN group showed significantly less negative expression than HC in response to the negative film ($p.<0.001$, $d.=-1.6$).

When controlling for the effects of depressive symptomatology, anxiety symptomatology and IQ together, the Group × Film interaction [$F(2.00, 55.98)=11.62$, $p.<0.001$] remained significant. Pairwise comparisons confirmed that the AN group showed significantly less negative expression than HC in response to the negative film ($p.=0.004$, $d.=-1.4$). However the main effects for Group [$F(1, 28)=2.02$, $p.=0.166$] and Film [$F(2.00, 55.98)=0.977$, $p.=0.38$] were no longer significant.

3.3. Subjective emotion experience

For positive affect, there was a significant main effect for Film [$F(2, 62)=82.44$, $p.<0.001$]. However there was no significant main effect for Group [$F(1, 31)=2.43$, $p.=0.13$] and no significant Group × Film interaction [$F(2, 62)=1.13$, $p.=0.33$). When controlling for the effects of depressive symptomatology, anxiety symptomatology and IQ together, there was no longer a significant main effect for Film [$F(2, 56)=1.63$, $p.=0.20$], Group [$F(1, 28)=0.75$, $p.=0.79$] and no significant Group × Film interaction [$F(2, 56)=0.48$, $p.=0.62$].

Similarly, for negative affect, there was a significant main effect for Film [$F(1.30, 40.24)=80.97$, $p.<0.001$] and no significant main effect for Group [$F(1, 31)=1.28$, $p.=0.27$] and no significant Group × Film interaction [$F(1.30, 40.24)=0.53$, $p.=0.52$). When controlling for the effects of depressive symptomatology, anxiety symptomatology and IQ together, there was no longer a significant main effect for Film [$F(1.45, 40.63)=2.54$, $p.=0.11$], Group [$F(1, 28)=1.05$, $p.=0.31$] and no significant Group × Film interaction [$F(1.45, 40.63)=0.04$, $p.=0.92$].

3.4. Correlations between facial affect and demographic and clinical variables

For the AN group and HC there were no significant correlations between facial expressivity and other variables: age, IQ, BMI, anxiety or depression symptomatology, BMI on admission (AN only) and length of illness (AN only).

4. Discussion

This is the first study to experimentally assess facial emotion expression in adolescent females with AN. The main hypothesis for this study was confirmed as, adolescent females with AN showed less positive facial affect during positive and negative film clips and less negative facial affect during negative film stimuli, after controlling depression, anxiety and IQ. However, adolescent females with AN did not show less negative facial affect during the incongruent positive evoking film. Reduction in positive and negative facial affect was greatest for congruent positive and negative film stimuli, with large effect sizes ($d.=-1.7$ and $d.=-1.6$, respectively).

The main findings of this study are consistent with existing empirical findings of reduced facial affect in female adults with AN (Claes et al., 2012; Davies et al., 2011), and with self-report findings that people with AN do not express themselves (Geller et al., 2000). However, that adolescents with AN only showed reduced negative facial affect to congruent emotion stimuli (negative films), is consistent with findings from recovered (Davies et al., 2013) but not acute AN (Davies et al., 2011). It is possible that the mechanisms underlying these disturbances differ for positive and negative facial affect.

Recent studies suggest that a subgroup of individuals with AN have elevated levels of autistic traits, which may contribute to the onset and maintenance of their eating disorder (Baron-Cohen et al., 2013; Huke et al., 2013; Tchanturia et al., 2013). Limited facial expression of emotion is a core, diagnostic feature of ASD (Lord, et al., 2000). As such it will be interesting to investigate whether the reduced facial affect observed in the current study is part of a broader complex of autistic symptoms in AN, encompassing impaired social reciprocity, communication difficulties and inflexibility (Doris et al., 2014; Tchanturia et al., 2013).

4.1. Limitations and strengths

Limitations to the present study were a) the lack of a psychiatric control group; b) controlling for habituation to film stimuli; c) small sample size. There may have been insufficient power to detect associations between facial expressivity and clinical parameters and results should be interpreted with caution; and d) inclusion of an inpatient sample of adolescent females with AN; findings may not generalise to milder presentations of AN or to males.

Strengths of this study were the use of an ecologically valid approach for evoking emotional responses, and having controlled for the effects of depression, anxiety and IQ in analysis.

4.2. Clinical implications

Treatment of eating disorders remains challenging and experimental studies of this type can inform novel interventions. Facial expression of emotions can impact on therapeutic process and quality of the communication. There are attempts to translate experimental findings in adult inpatients to treatment intervention (Tchanturia et al., 2013). Given the similar disturbances in facial affect found in adolescent female inpatients in the present study, a similar treatment intervention that is developmentally adapted may be beneficial for the younger age group.

4.3. Conclusion

This exploratory experimental study has found adolescent females with AN have attenuated facial affect in response to emotional stimuli, in keeping with findings from adult AN studies. Altered facial affect may impair interpersonal functioning and contribute to illness maintenance.

Conflict of interest

None.

Role of funding source

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CHAPTER 4.

STUDY 3: CONFIRMATORY FACTOR ANALYSIS FOR TWO QUESTIONNAIRES OF CAREGIVING IN EATING DISORDERS

Publication

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Confirmatory factor analysis for two questionnaires of caregiving in eating disorders

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Objective: Caring for someone diagnosed with an eating disorder (ED) is associated with a high level of burden and psychological distress which can inadvertently contribute to the maintenance of the illness. The Eating Disorders Symptom Impact Scale (EDSIS) and Accommodation and Enabling Scale for Eating Disorders (AESED) are self-report scales to assess elements of caregiving theorised to contribute to the maintenance of an ED. Further validation and confirmation of the factor structures for these scales are necessary for rigorous evaluation of complex interventions which target these modifiable elements of caregiving. Method: EDSIS and AESED data from 268 carers of people with anorexia nervosa (AN), recruited from consecutive admissions to 15 UK inpatient or day patient hospital units, were subjected to confirmatory factor analysis to test model fit by applying the existing factor structures: (a) four-factor structure for the EDSIS and (b) five-factor structure for the AESED. Results: Confirmatory factor analytic results support the existing four-factor and five-factor structures for the EDSIS and the AESED, respectively. Discussion: The present findings provide further validation of the EDSIS and the AESED as tools to assess modifiable elements of caregiving for someone with an ED.

Keywords: caregiving; eating disorders; confirmatory factor analysis; burden; accommodation and enabling

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Introduction

Caring for a loved one diagnosed with an eating disorder (ED) is associated with a high level of burden and psychological distress (Dimitropoulos, Carter, Schachter, & Woodside, 2008; Treasure et al., 2008; Zabala, MacDonald, & Treasure, 2009). The interpersonal maintenance model, which can be applied trans-diagnostically, describes a causal chain whereby high levels of carer unmet needs (Graap et al., 2008; Haigh & Treasure, 2003) deplete coping resources (Coomber & King, 2012) and contribute to carer anxiety and depression. In turn, carers exhibit high expressed emotion (e.g. emotional over-involvement, criticism and hostility) and ineffective strategies in managing symptoms (e.g. accommodating and enabling behaviours). These responses may inadvertently allow the ED to flourish (Treasure & Schmidt, 2013). A vicious cycle is set in motion whereby carer anxiety is mirrored by the sufferer which in turn exacerbates illness symptoms (Goddard, Salerno, et al., 2013). Empirical testing is essential for rigorous complex intervention evaluation and for further refinement of the underpinning theoretical framework. The interpersonal maintenance model provides a theoretical basis for interventions which can target modifiable elements of caregiving. Skills-based approaches involving psycho-education and problem-solving skills groups for families of people with anorexia nervosa (AN) have reduced family distress and emotional over-involvement and have led to an improvement in the ED behaviours (Holtkamp, Herpertz-Dahlmann, Vloet, & Hagenah, 2005; Sepulveda, Lopez, MacDonald, & Treasure, 2008; Uehara, Kawashima, Goto, Tasaki, & Someya, 2001; Vandereycken & Louwies, 2005; Whitney et al., 2012; Zucker, Ferriter, Best, & Brantley, 2005). Self-management tools for carers (book and DVDs) (Treasure, Smith, & Crane, 2007) that specifically target maintaining factors reduced carer distress, expressed emotion and accommodating and enabling behaviours (Goddard, MacDonald, Sepulveda, et al., 2011). For further rigorous evaluation of interventions which target response to illness, outlined by the interpersonal maintenance model, well-validated scales which measure modifiable elements of caregiving are necessary.

The Eating Disorders Symptom Impact Scale (EDSIS) (Sepulveda, Whitney, Hankins, & Treasure, 2008) was developed to measure the range of symptoms (namely nutrition, guilt, social isolation and dysregulated behaviour) which have a direct impact on carers of people with EDs. The Accommodation and Enabling Scale for Eating Disorders (AESED) (Sepulveda, Kyraciou, & Treasure, 2009) measures caregivers' behaviours which inadvertently serve to reinforce or fail to discourage symptoms or behaviours. For example, symptomatic behaviours such as high control over family food and meal rituals may go unchecked (accommodating) and negative consequences of behaviour (e.g. clearing up bathroom mess following a purge) are not applied (enabling) (Sepulveda et al., 2009).

Both scales have demonstrated satisfactory psychometric properties in their initial validation in a community sample of carers, with EDSIS factors and AESED subscales explaining 58.5% and 60.1% of the variance in carer distress, respectively. Good reliability was reported for the EDSIS (Cronbach's alpha ranging from 0.84 to 0.90) and the AESED (Cronbach's alpha ranging from 0.77 to 0.92). Moreover, moderate correlations were found with specific elements hypothesised to contribute to illness maintenance included in other measures associated with caregiving such as the Experience of Caregiving Inventory (Szmukler et al., 1996), the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and the Levels of Expressed Emotion (LEE) (Cole & Kazarian, 1988).

The original four-factor structure of the EDSIS has been used in carer intervention outcome studies (Goddard, MacDonald, Sepulveda, et al., 2011; Grover, Naumann, et al., 2011; Grover, Williams, et al., 2011; Hoyle, Slater, Williams, Schmidt, & Wade, 2013; Pepin & King, 2013; Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008) as has the original five-factor structure of the AESED (Goddard, MacDonald, Sepulveda, et al., 2011). However, a six-factor structure for the EDSIS has since been proposed within an Australian sample of carers of someone with an ED (Coomber & King, 2013). In their sample, AN carers reported significantly lower level binge-purge impacts compared with bulimia nervosa (BN) carers, and a significantly higher level of mealtime difficulties than BN carers. Given the broad and complex range of symptoms and behaviours associated across EDs and their severity, and the associated different manifestations of caregiver burden and response to illness, further research examining the factor structure of the EDSIS and AESED in a single and stable diagnosis cohort is warranted.

The aim of the present study then, is to use confirmatory factor analysis (CFA) to investigate how well the factor structure of the EDSIS and AESED fits data from a sample of 268 carers of people with severe and enduring AN admitted for hospital treatment. The size of the sample should enable robust reassessment of scales, including possible item exclusion and factor structure examination for overall and subscale scores.

Method

Design

Data were collected as part of the baseline assessment of a multi-centre randomised controlled trial evaluating a skills-based intervention for carers of someone with AN (Carer, Assessment, Skills and Information Sharing (CASIS)) (Goddard, Raenker, et al., 2013). Ethical approval was granted by the Royal Free Hospital Ethics Committee (CREC ref no. 08/H0720/41).

Sample

Carers ($n = 268$) of people diagnosed with AN were recruited as part of the CASIS study. Patients admitted to 15 UK inpatient or day patient units with a primary diagnosis of AN or Eating disorder not otherwise specified with anorexic symptoms (EDNOS-AN) were offered the opportunity to participate in the research and at least one carer, identified by the patient, had to participate for the family to be included in the study. The final sample consisted of 144 mothers, 81 fathers and 28 partners (Table 1). There were also eight siblings, five friends and two "other relatives" in the sample. The majority of carers were white (95.8%), employed (63.9%) and parents of the sufferer (83.9%). Most mothers and partners described themselves as primary carers (97.2% and 92.9%, respectively), whereas the majority of fathers described themselves as secondary carers (92.6%). Definition of primary and secondary carer was subjective but was related to the level of dependence by the patient and number of hours of contact. The patients were all admitted to National Health Service (NHS) specialist ED services at the time of data collection and written consent to contact their carers was obtained from them by clinicians or clinical studies officer. After receiving the patients' consent, carers were contacted by the researchers and written consent was obtained. Inclusion criteria for participants required individuals to be fluent in English and able to provide consent. Patients had to have a primary diagnosis of AN or EDNOS-AN and have at least one carer consent to participate in the project. Patients were excluded if they or their carers were taking part in another treatment study. Both patients and carers had to be aged 12 years or older and participants with an identified severe comorbidity (e.g. severe learning disability and psychosis) were also excluded. All participants (patients and carers) completed self-report assessments by post at admission to the treatment hospital.

The Eating Disorders Symptom Impact Scale (Sepulveda, Whitney, et al., 2008)

The EDSIS is a 24-item self-report measure of caregiving burden in EDs. The scale is tailored to a population of ED carers and comprises subjective and objective burden. The scale has high internal consistency (Cronbach's alpha = 0.91) across four subscales managing nutritional

Table 1. Demographic and clinical data of carers and service users.

Variable	Service user ($n = 178$) M (SD)	Carer Mother ($n = 144$) M (SD)	 Father ($n = 81$) M (SD)	 Partner ($n = 28$) M (SD)
Age[a]	26.0 (9.0)	53.3 (7.3)	54.9 (8.6)	39.3 (12.1)
	N (%)	*N* (%)	*N* (%)	*N* (%)
Gender				
Female	169 (94.9)	144 (100)	0	2 (7.1)
Male	9 (5.1)	0	81 (100)	26 (92.9)
Education				
No qualification	9 (5.2)	13 (9.3)	4 (5.1)	2 (7.1)
O/A-levels	89 (51.4)	48 (34.3)	25 (31.7)	9 (32.1)
University/higher degree	73 (42.2)	64 (45.7)	37 (46.8)	17 (60.7)
Other	2 (1.2)	15 (10.7)	13 (16.5)	0
Missing	5	4	2	0
Employment				
Paid employed – full-time	16 (9.2)	41 (28.9)	52 (65.8)	16 (59.3)
Paid employed – part-time	10 (5.7)	44 (31.0)	3 (3.8)	5 (18.5)
Homemaker/unemployed/sick/retired	95 (54.6)	57 (40.1)	24 (30.4)	4 (14.8)
Student	53 (30.5)	0	0	2 (7.4)
Missing	4	2	2	1
Marital status				
Married/living together	35 (20.3)	111 (77.6)	72 (91.1)	22 (78.6)
Single/divorced/widowed	137 (79.7)	32 (22.4)	7 (8.9)	6 (21.4)
Missing	6	1	2	0
Carer type				
Primary carer	–	140 (97.2)	6 (7.4)	26 (92.9)
Secondary carer	–	4 (2.8)	75 (92.6)	2 (7.1)
Living with patient prior to hospitalisation				
Yes	–	95 (66.4)	50 (62.5)	22 (78.6)
No	–	48 (33.6)	30 (37.5)	6 (21.4)
Missing	–	1	1	0

Notes: M, mean and SD, standard deviation.

[a] 1 service user with missing age.

situations, guilt, dealing with dysregulated behaviours and social isolation. Scores are obtained on a five-point Likert scale. Higher scores indicate higher caregiving burden and more negative appraisal of caregiving.

The Accommodation and Enabling Scale for Eating Disorders (Sepulveda et al., 2009)

The AESED is a 33-item self-report measure used to assess the degree of accommodating and enabling behaviours to the ED. A five-point Likert scale is used to yield a total score and subscale scores including: avoidance and modifying routine; reassurance seeking; meal ritual; control of family and turning a blind eye. This scale has good internal consistency (Cronbach's alpha = 0.76).

Statistical analysis

SPSS Version 18 and Amos Version 20 were used for the analysis. The characteristics of the sample were summarised and predictors of missing data were assessed. Due to the lack of independence between carers, logistic regression using a robust variance estimator was used to look at the distribution of missing data.

A CFA was carried out by applying the factor structure as described in the original papers detailing each questionnaire (Sepulveda et al., 2009; Sepulveda, Whitney, et al., 2008). In order to account for missing responses to items, a maximum likelihood approach to the analysis was used. This method does not delete cases or impute missing observations but estimates parameters and their standard errors directly from the available data (Kline, 2010).

Given that the sample consisted of both primary and secondary carers of the same sufferers and therefore not independent, CFA was not applied across the entire sample. Instead, carers were divided into groups according to the primary or secondary carer status and the factor model was applied to these groups separately to assess measurement invariance. The same analysis was run comparing male and female carers to check that the assessment of measurement invariance was not biased. The outcome was the same. Measurement invariance gauges whether scores in the two carer groups have the same meaning and can be fitted with the same factor structure (Kline, 2010). The stronger the measurement invariance, the more parameters are assumed to be equal in both primary and secondary carers. A weak invariance model builds on the simplest form of measurement invariance, configural invariance, in which only the number of factors and their associated indicators are assumed to be the same between groups, by constraining the unstandardised factor loadings to be equal in both groups. Constraining the means of the primary and secondary carers to be equal would constitute strong invariance. The strongest form of measurement invariance is that of strict invariance. Under this model, all parameters are assumed to be the same for both primary and secondary carers. That is, all carers are constrained to have an identical factor model specification with equal factor loadings, correlations, means and residual variances. Residual variance is the item variance not explained by the factor (Kline, 2010; Wu, Shen, & Bruno, 2007).

A chi-squared test was used to assess model fit and a non-significant result ($p > .05$) indicates a good model fit. When comparing between invariance models, the same threshold ($p > .05$) was used. Where the factors contained items which were highly correlated, or items that did not load on the latent variable, an additional exploratory analysis looked at removing some of these items in an attempt to improve the fit of the model. Where several items on the same factor had standardised regression weights of 0.80 or above, one or more of these were considered for removal from the model. The decision as to which item(s) to remove was based on expert opinion resulting from discussion among the study team.

The following measures were used to assess the model fit: the chi-square (χ^2) statistic and degrees of freedom (DF); relative χ^2 (normed chi-square = χ^2/DF) which is the chi-squared statistic divided by the DF of the model where values of less than 2.5 indicate a good model fit (Carmines & McIver, 1981); comparative fit index (CFI), which measures the proportion of covariation in the data that can be reproduced by a given model where values of greater than 0.9 represent a good model fit; and root mean square error of approximation (RMSEA), which is the discrepancy per DF. An excellent model fit is indicated by RMSEA values lower than 0.05 while a close model fit is suggested by values between 0.05 and 0.08 (Hoyle, 2011).

Results

There were missing data in response to both questionnaires. Eighty-seven percent of people returned complete data on all items of the EDSIS, and this was slightly lower for the AESED with 79% of respondents completing all items. In part, this was due to a printing error which resulted in missing responses to items 1–10 for a minority of carers ($n = 14$, 5% of sample). Secondary carers were less likely to complete the entire questionnaire in comparison to primary carers

(EDSIS: 1.7% vs. 5.7%, respectively, and AESED: 1.7% vs. 7.8%, respectively). This resulted in a final sample size of 260 for the EDSIS and 258 for the AESED.

The Cronbach's alpha for both scales was high. Reliability of each subscale of the AESED (avoidance and modifying routine = 0.89, reassurance seeking = 0.88, meal ritual = 0.89, control of family = 0.87 and turning a blind eye = 0.83) in addition to the overall reliability (alpha = 0.93) were high. The EDSIS also showed good reliability overall (alpha = 0.87) and for each of the subscales (nutrition = 0.83, guilt = 0.87, dysregulated behaviour = 0.73 and social isolation = 0.83).

Factor analysis – EDSIS

A four-factor structure had previously been suggested for this 24-item questionnaire (Sepulveda, Whitney, et al., 2008), with items corresponding to the following factors: nutrition (8 items), guilt (5 items), dysregulated behaviour (7 items) and social isolation (4 items).

Multiple group CFA was conducted between primary and secondary carers to assess measurement invariance. The model of configural invariance was shown to be an acceptable fit to the data (RMSEA = 0.070 (90% CI: 0.065–0.075); CFI = 0.77; Chi square/degree of freedom ratio = 2.30). However, a comparison with the weak invariance model showed this stronger form of measurement invariance to be the better fit to the data ($p = .608$). The weak invariance model again demonstrated an acceptable model fit (RMSEA = 0.068 (90% CI: 0.063, 0.073); CFI = 0.77; $\chi2 = 1156$ (DF = 518); $\chi2$/DF = 2.23). Comparison with both the strong and the strict invariance models did not show any improvement on the fit (both $p < .001$) and so the weak invariance model was retained.

Both unstandardised and standardised regression coefficients for this model are shown in Table 2, while between-factor covariances and correlations are reported in Table 3. Different standardised results are shown for primary and secondary carers; this is due to the fact that within the weak invariance model, equal variances have not been imposed on the two groups.

Within this model, most items were shown to correlate highly with their assigned factors, giving results similar to the original factor analysis. The exception to this was the dysregulated behaviour factor, for which three of the standardised regression coefficients were all found to be lower than 0.25. This suggests that these items (17, 19 and 20*)* did not contribute a great deal to the factor and that the model fit could potentially be improved by removing these items. However, since each of these items relate to different symptoms (missing food, plumbing problems and bad hygiene, respectively), after discussion with the study team it was decided that, on balance, these items would not be eliminated. Additionally, several items (6, 7 and 9*)* on the guilt factor were found to be highly correlated. After discussion among the study team, it was decided to remove item 7 ("Feeling that there could have been something that I should have done") given that the content of this item overlaps with, and is better elicited by, item 6 ("Feeling that I have let her/him down") and 9 ("Thinking about where I went wrong").

Although removing this item resulted in a very slight improvement of the model fit, the weak invariance model was still found to be the best fit to the data (RMSEA = 0.063 (90% CI: 0.056, 0.070); CFI = 0.82; $\chi2 = 719$ (DF = 350); $\chi2$/DF = 2.06).

Factor analysis – AESED

A five-factor model was previously suggested for this questionnaire consisting of 33 items (Sepulveda et al., 2009). The following factors were suggested: avoidance and modifying routine (10 items), reassurance seeking (8 items), meal ritual (7 items), control of family (4 items) and turning a blind eye (4 items).

Table 2. EDSIS questionnaire – weak invariance model, both unstandardised and standardised results are shown.

	Unstandardised estimate	S.E.	*p*	Standardised estimates Primary carers	 Secondary carers
Factor 1: Nutrition					
18. Did you spend a long period of time shopping for food	1.0	–	–	0.574	0.615
22. Did you check on her to ensure that she/he was ok	0.656	0.098	<.001	0.548	0.590
23. Did you notice or think about how the illness was affecting her/him physically	0.946	0.139	<.001	0.601	0.591
15. Were there arguments with other family members about how to handle mealtimes	1.095	0.141	<.001	0.632	0.695
24. Did you notice or think about how the illness was affecting her/him mentally	0.697	0.096	<.001	0.632	0.635
21. Did you have to turn up the heat due to her/him feeling cold	0.949	0.14	<.001	0.536	0.560
16. Were there arguments or tension during mealtimes	1.198	0.142	<.001	0.697	0.774
14. Did you experience difficulties preparing meals	1.263	0.148	<.001	0.722	0.683
Factor 2: Guilt					
8. Thinking that perhaps I was not strict enough	1.0	–	–	0.436	0.523
5. Feeling that I should have noticed it before it became so bad	1.471	0.205	<.001	0.670	0.718
9. Thinking about where I went wrong	1.621	0.208	<.001	0.833	0.862
7. Feeling that there could have been something I should have done	1.818	0.226	<.001	0.937	0.943
6. Feeling that I have let her/him down	1.835	0.232	<.001	0.880	0.941
Factor 3: Dysregulated behaviour					
11. Controlling/manipulative	1.0	–	–	0.853	0.742
20. Were there bad smells and poor hygiene in the bathroom	0.279	0.099	.005	0.210	0.186
17. Did food disappear from the cupboards	0.388	0.115	<.001	0.247	0.219
10. Physically and/or verbally aggressive	0.821	0.073	<.001	0.761	0.620
13. Out of control temper	0.769	0.072	<.001	0.702	0.705
12. Lying/stealing	0.563	0.058	<.001	0.643	0.565
19. Did you have difficulties with blocked drains, plumbing	0.249	0.08	.002	0.230	0.208
Factor 4: Social isolation					
3. Feeling unable to go out for evenings, weekends or on holiday	1.0	–	–	0.744	0.749
4. Cancelling or refusing plans to see friends or relations	0.930	0.081	<.001	0.758	0.763
2. Losing your friends	0.865	0.103	<.001	0.722	0.747
1. How your friends/relatives have stopped visiting	0.979	0.117	<.001	0.735	0.728

Note: Different standardised results are shown for primary and secondary carers since equal variances have not been imposed on the two groups.

Multiple group CFA was again carried out to assess measurement invariance between primary and secondary carers. In this instance, strict invariance was found to hold. In both primary and secondary carers the factor loadings, between-factor correlations, intercepts and residual variances can be assumed equal. The strict invariance model was found to be superior to the

Table 3. EDSIS – weak invariance model, both unstandardised (covariance) and standardised (correlation) results displayed.

			Covariance			Correlation	
			Estimate	S.E.	*p*	Primary carers	Secondary carers
Nutrition	<–>	Guilt	.110	.035	.002	.278	.235
Nutrition	<–>	Dysregulated behaviour	.226	.053	<.001	.367	.403
Nutrition	<–>	Social isolation	.273	.06	<.001	.459	.421
Social isolation	<–>	Guilt	.133	.039	<.001	.289	.286
Social isolation	<–>	Dysregulated behaviour	.283	.059	<.001	.396	.506
Guilt	<–>	Dysregulated behaviour	.154	.039	<.001	.323	.383

configural invariance ($p = .334$), weak invariance ($p = .120$) and strong invariance ($p = .169$) models. The strict invariance model was found to be an adequate fit to the data (RMSEA = 0.062 (90% CI: 0.059–0.066); CFI = 0.78; $\chi2 = 2197$ (DF = 1079); $\chi2$/DF = 2.04). Unstandardised and standardised regression coefficients are shown in Table 4 and between-factor covariances and correlations are shown in Table 5.

Within this model, most items again demonstrated a good level of association with their assigned factor and results were generally similar to those of the original factor analysis. Within four of the factors, there were several items which correlated very highly: meal ritual (15 and 16), control of family (2 and 3), reassurance seeking (5, 6 and 7) and turning a blind eye (22 and 23). After discussion among the study team, item 7 ("Does your relative engage any family member in repeated conversations asking for reassurance about whether she/he looks fat in certain clothes") was excluded from the model because it was thought to be made redundant by item 5 ("Does your relative engage any family member in repeated conversations asking for reassurance about whether she/he will get fat?"), whereas items 15, 16, 2, 3 and 6 were thought to relate to separate behaviours.

Using the new factor structure, strict invariance was once again found to hold. However, with the exclusion of just one item, the model fit remained very similar to that of the initial model specification (RMSEA = 0.061 (90% CI: 0.057, 0.065); CFI = 0.79; $\chi2 = 2006$ (DF = 1014); $\chi2$/DF = 1.98).

Discussion

The aim of the study was to reassess the factor structure of the EDSIS and AESED in a single and stable diagnosis cohort of carers. The size of the sample enables robust reassessment of scales, including possible item exclusion and factor structure examination for overall and subscale scores. Results from the CFA provide support for the validity of the existing four-factor structure for the EDSIS and the five-factor structure for the AESED for carers of a severe and enduring AN patient group. Multiple group CFA examined the stability of these factor structures across primary and secondary carers. Standards of weak invariance for the EDSIS and strict invariance for the AESED were achieved by supporting the robustness of the factor structure and the internal reliability for the items and subscales irrespective of the carer status. Exceptions were for a few highly correlated items on both scales and for items in the EDSIS which did not contribute significantly to the model. Reanalysis of the model fit omitting item 7 of the EDSIS and item 7 of the AESED very slightly improved the model fit in both cases. Due to sampling variation, there is always a chance that various items will not fit the data as well and since the original analysis found

Table 4. AESED questionnaire – strict invariance model, both unstandardised and standardised results are shown.

	Unstandardised Estimate	S.E.	*p*	Standardised estimate
Factor 1: Avoidance and modifying routine				
25. How often did you participate in behaviours related to your relative's compulsions over the last week	1.0	–	–	0.534
24. To what extent would you say that the relative with an ED controls family life and activities	0.521	0.074	<.001	0.576
26. How often did you assess your relative in avoiding things that might make him/her anxious	0.868	0.125	<.001	0.565
33. Has your relation become angry/abusive when you have not provided assistance	1.207	0.161	<.001	0.635
29. Have you modified your work schedule because of your relative's needs	1.062	0.151	<.001	0.578
32. Has your relative become distressed when you have not provided assistance	1.430	0.171	<.001	0.772
27. Have you avoided doing things, going places or being with people because of your relative's disorder	1.301	0.16	<.001	0.732
30. Have you modified your leisure activities because of your relative's needs	1.291	0.159	<.001	0.725
28. Have you modified your family routine because of your relative's symptoms	1.315	0.158	<.001	0.769
31. Has helping your relative in the previously mentioned ways caused you distress	1.313	0.156	<.001	0.784
Factor 2: Reassurance seeking				
8. Repeated conversations about ingredients and amounts in food preparation	1.0	–	–	0.730
10. Repeated conversations about self-harm	0.381	0.063	<.001	0.401
9. Repeated conversations about negative thoughts and feelings	0.989	0.088	<.001	0.740
18. Accommodation of routines of checking their body shape or weight	0.889	0.097	<.001	0.602
6. Repeated questioning whether it is safe or acceptable to eat certain foods	1.179	0.094	<.001	0.820
5. Repeated questioning about whether she will get fat	1.265	0.094	<.001	0.878
7. Repeated seeking of reassurance about whether she looks fat in certain clothes	1.215	0.094	<.001	0.843
17. Accommodation of the exercise routine of the relative with an ED	0.674	0.097	<.001	0.463
Factor 3: Meal Ritual				
13. Accommodating to what time food is eaten	1.0	–	–	0.543
19. Accommodating to how the house is cleaned and tidied	1.306	0.151	<.001	0.758
14. Accommodating to what place food is eaten in	1.063	0.142	<.001	0.597
16. Accommodating to how food is stored	1.491	0.157	<.001	0.913
11. Accommodating to what crockery is used	1.184	0.143	<.001	0.695
12. Accommodating to how crockery is cleaned	1.120	0.129	<.001	0.765
15. Accommodating to how the kitchen is cleaned	1.520	0.159	<.001	0.932
Factor 4: Control of Family				
1. Control choice of food that you buy	1.0	–	–	0.762
2. Control what family members do and for how long in the kitchen	1.144	0.092	<.001	0.799

(*Continued*)

Table 4. Continued.

	Unstandardised Estimate	S.E.	*p*	Standardised estimate
4. Control what other family members eat	1.065	0.09	<.001	0.766
3. Control cooking practice and ingredients used	1.213	0.09	<.001	0.868
Factor 5: Turning a blind eye				
21. Ignore if money is taken	1.0	–	–	0.530
22. Ignore kitchen left in a mess	3.296	0.386	<.001	0.891
20. Ignore food disappearing	2.652	0.348	<.001	0.690
23. Ignore bathroom left in a mess	3.326	0.392	<.001	0.871

these items to be important in the factor structure, and the model fit is only marginally improved by removing it in either case, the justification for removal is not enough to warrant revised versions of either questionnaire.

Although differences in the EDSIS overall and in subscale scores between primary and secondary carers have previously been reported (Sepulveda et al., 2012), the findings of the present study suggest that the EDSIS and the AESED are robust scales in measuring modifiable elements of caregiving across carers. Second, the present study provides the largest dataset of carers completing the EDSIS and the AESED available to date.

As already described, unmet carer needs can lead to high LEE and to accommodating and enabling behaviours which contribute to the maintenance of the illness and consequently poorer prognosis (Goddard, MacDonald, Sepulveda, et al., 2011). The examination of these elements of caregiving is essential to further the discussion of the cognitive interpersonal maintenance model (Treasure & Schmidt, 2013; Treasure, Sepulveda, et al., 2007) and for the development of carer interventions for which valid and reliable measures which are sensitive to change are crucial. There is evidence to suggest that elements of caregiving are modifiable following skills-based carer interventions with improved sufferer outcomes (Goddard, MacDonald, & Treasure, 2011) and the results of this study provide further validation of two measures as tools to assess these elements in a homogenous sample of carers of someone admitted for inpatient care with AN. From a clinical perspective, well-validated tools to assess caregiving enable robust assessment of the specific difficulties faced by ED carers and results from this study

Table 5. AESED questionnaire – strict invariance model, both unstandardised (covariance) and standardised (correlation) results displayed.

			Covariance			Correlation Estimate
			Estimate	S.E.	*p*	
Avoidance and modifying routine	<->	Control of family	.383	.07	<.001	.575
Avoidance and modifying routine	<->	Meal ritual	.259	.056	<.001	.466
Avoidance and modifying routine	<->	Turning a blind eye	.073	.019	<.001	.35
Avoidance and modifying routine	<->	Reassurance seeking	.322	.064	<.001	.476
Control of family	<->	Meal ritual	.364	.073	<.001	.463
Control of family	<->	Turning a blind eye	.080	.024	<.001	.271
Control of family	<->	Reassurance seeking	.426	.081	<.001	.445
Meal ritual	<->	Turning a blind eye	.038	.018	.037	.154
Meal ritual	<->	Reassurance seeking	.324	.07	<.001	.407
Reassurance seeking	<->	Turning a blind eye	.058	.023	.012	.192

and those of Coomber and King (2013), suggest that specific difficulties may be dependent on illness presentation and duration. This is important for caregiving interventions targeting relevant behaviours. We hope that this research will pave the way for interventions that have the potential to improve outcomes in severe and enduring AN at a small cost to the NHS.

Study limitations and recommendations for future research

The AESED is designed for carers who live with the sufferer. When this is not the case (e.g. during hospital admission), or the behaviour in question is not present, an item response "0" may reflect an absence of this behaviour rather than a true representation of levels of accommodating and enabling. Therefore caution should be taken when interpreting the questionnaire. Having said this, the carers in our sample completed the questionnaires when the patient was in the hospital (i.e. not at home) and the AESED was still valid according to the CFA.

The small percentage of missing data, particularly from the AESED, should be considered in interpreting the results. There were no systematic differences between completed and missing data groups on demographic variables, with the exception of primary/secondary carer status, with missing questionnaires more frequent among secondary carers.

Multiple group CFA examining the stability of the EDSIS and AESED factors across carers of adolescents compared with adult sufferers may provide direction for further refinement of the theoretical model of caregiving.

Conclusions

Overall, the present findings provide further validation of the EDSIS and the AESED as tools to assess modifiable elements of caregiving for someone with an ED.

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CHAPTER 5.

STUDY 4: THE OBJECTIVE AND SUBJECTIVE CAREGIVING BURDEN AND CAREGIVING BEHAVIOURS OF PARENTS OF ADOLESCENTS WITH ANOREXIA NERVOSA

Paper under review

Rhind, C, Salerno, L., Hibbs, R., Micali, N., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., Tchanturia, K., Lo Coco, G., & Treasure, J. (2015, *under review, Eur Eat Disord Rev*). The Objective and Subjective Caregiving Burden and Caregiving Behaviours of Parents of Adolescents with Anorexia Nervosa.

5.1 Abstract

Objective: To examine caregiving burden and levels of distress, accommodating behaviours, expressed emotion, and carers' skills, in parents of adolescents with AN. **Method:** A semi-structured interview assessed the objective burden (time spent across caregiving tasks) in parents (n=196) of adolescents (n=144) receiving outpatient treatment for AN. Subjective burden (carers' distress), accommodating, expressed emotion and carers' skills were measured by self-report. **Results:** Mothers, on average, spent 2.5h /day of care, mainly providing food and emotional support, compared to 1hr /day by fathers. The level of distress and accommodating behaviour was significantly lower in fathers than in mothers. Accommodating behaviours mediated the relationship between objective burden and subjective burden in mothers; whereas expressed emotion and carers' skills did not mediate this relationship for either parent. **Discussion:** The objective burden for most mothers is high. In order to reduce subjective burden, it may be helpful to target accommodating behaviours. **Trial Registration:** ISRCTN83003225 - Expert Carers Helping Others (ECHO).

5.2 Background

EDs develop in early adolescence at the time of transition from parental care to autonomous functioning. Most cases of AN present for treatment age 16 (Micali et al., 2013) and the median duration of illness is 6-7 years (Støving et al., 2011). Thus, the family of origin can be directly impacted by the illness over a protracted period. There is strong evidence that people in the early phase of the illness benefit from family based therapy (Lock, 2015). This is a form of treatment that prescribes active symptom management. Families are encouraged to be actively involved in providing direct care to support eating, requiring a great deal of time and effort from parents. Not all cases respond in a short period of time (Lock et al., 2005). For example, non-intact families or individuals with higher levels of obsessional features may require a longer period of treatment (Lock, Couturier, & Agras, 2006). Families with high levels of expressed emotion (criticism, in particular) do not respond as well to a conjoint approach and benefit more if the parents are seen separately (Eisler et al., 2000; Eisler, Simic, Russell, & Dare, 2007). Despite this active involvement of parents in providing support for adolescents and young adults, there has been very little research examining their experiences of caregiving.

The general caregiving experience in EDs has been summarised in systematic reviews (Anastasiadou et al., 2014; Zabala et al., 2009). Burden is high, quality of life is reduced and some parents have clinical levels of depression and anxiety. The emotional, physical, and social consequences associated with the caregiving role contribute to caregiving burden. Objective burden relates to the tasks involved in caring, such as providing meal support, and the time involved in completing these tasks (Bezance & Holliday, 2014). Given that parents are actively involved in meal support in the early phase of illness (particularly mothers who often provide this help), their objective burden might be expected to be substantial. However, to our knowledge this contribution to care has not been measured.

The subjective burden includes the level of psychological distress which is compounded by factors such as stigma, role strain and unmet needs for both information and other forms of support (Highet et al., 2005; McMaster, Beale, Hillege, & Nagy, 2004). Carers report high subjective burden, low sense of caregiving efficacy and high levels of unmet needs (Graap et al., 2008; Haigh & Treasure, 2003). Several factors are thought to contribute to this burden; one of which is the tendency of family members to adjust their behaviour to accommodate to the illness (Sepulveda et al., 2009). The Accommodation and Enabling Scale for Eating Disorders (AESED) has been developed to measure these behaviours. It contains five factors which measure various aspects of how the family reorganise their behaviours around the ED symptoms: avoidance and modifying routines, providing reassurance, accepting rituals around meals, turning a blind eye to unwanted behaviours and allowing family functioning to be controlled (Hibbs, Rhind, et al., 2015; R Hibbs et al., 2014). Longitudinal studies have found that maladaptive coping and high expressed emotion also contribute to burden (Coomber & King, 2012). Less adaptive caregiver responses to the illness have been associated with higher levels of ED severity (Goddard, Salerno, et al., 2013) and may also be related to comorbid obsessive-compulsive features and social communication difficulties that impact on family interpersonal functioning.

The Carer Skills (CASK) scale (Hibbs, Rhind, et al., 2015) has been recently developed to measure modifiable aspects of caregiver behaviour that, according to the New Maudsley Model, are hypothesized to be associated with outcomes (Treasure, Rhind, et al., 2015). It has six factors which include: Bigger Picture (the ability to take the long view and not get caught up in the details of the illness); Self-Care (strategies to improve carers' own mood and resilience); Biting-Your-Tongue (not getting caught up in nagging and bickering about the illness); Insight and Acceptance (the ability to recognise symptoms as part of the illness and to not personalise the behaviours; Emotional Intelligence (the ability to regulate emotional reactions, despite being provoked and to have empathy for the other); Frustration Tolerance (to be able to withhold getting drawn into conflict about aspects of the illness). Carers who naturally exhibit these styles of behaviour or adopt them after skills training may have reduced burden.

In summary, the caregiving role is associated with high and variable demands. In order to allow a more comprehensive understanding of the areas of caregiving burden at the early stage of illness, the current study presents data collected using an interview to assess objective caregiving burden, measured in terms of time spent with caregiving tasks. The overall aim was to explore the relationships between objective burden, subjective burden (psychological distress experienced by carers), skilful caregiving behaviours, and less adaptive behaviours (accommodating behaviours and expressed emotion), in parents of adolescents with AN. Furthermore, the relationship between objective and subjective burden and the mediating effect of these caregiving behaviours was examined. High levels of objective burden (time spent with care giving tasks) was expected to be associated with high subjective burden (psychological distress). We also hypothesized that high maladaptive caregiving behaviours, such as accommodating behaviours and expressed emotion and/or low carers' skills, would be associated with greater subjective burden. In addition, it was hypothesised that the level of these care giving behaviours would mediate the relationship between objective and subjective burden.

5.3 Method

5.3.1 Design

The cross-sectional data presented here were collected as part of the baseline assessment of a pragmatic three-arm multi-centre parallel group pilot randomized controlled trial comparing different intensities of a carers skill training intervention (Experienced Carers Helping Others; ECHO) (Rhind, Hibbs, et al., 2014). Consenting carers of patients who met the eligibility criteria were randomly allocated to receive treatment as usual (TAU) or TAU in addition ECHO (book and DVDs), or ECHOc, (book, DVDs and additional telephone coaching sessions). The sample (n = 144 patient/carer dyads) included adolescents (age 13-21 years) with AN or EDNOS–AN subtype, according to the DSM-

IV criteria (APA, 1994) as the diagnostic tool in use at the time of study recruitment. All patients would meet the DSM-5 criteria for AN or atypical AN (APA, 2013). Thirty eight ED outpatient National Health services across the UK recruited patients for the study. Ethics approval was granted by the Northwick Park Hospitals Ethics Committee (11/H0725/4). Site specific ethics and governance approval was granted on all participating sites and this study adopted by the Clinical Research Network.

Inclusion criteria required at least one carer (typically parent/s) to participate and, where possible, both parents were encouraged to take part. They were identified as 'carer' by the patient and needed to be currently living with the patient with the intention of living together for the following year. Other close carers were also encouraged to take part. "Carers" are defined by criteria of the Princess Royal Trust (www.carers.org) as someone who provides unpaid help and support to a parent, child partner, relative, friend or neighbour. The detailed protocol of the full study is available elsewhere (Rhind, Hibbs, et al., 2014).

5.3.2 Participants

This study cohort included all patients and parents recruited to the ECHO trial who had completed baseline data on the primary assessment for this study, the Care-ED measure of objective burden (described below). The final sample included 144 patients and their carers (n=196), of whom 135 were mothers, and 61 were fathers or step-fathers. Most mothers (97%) described themselves as the primary carer and fathers (90%) tended to describe themselves as the secondary carer, distinguished by amount of contact time with the child for whom they care.

5.3.3 Measures

Carers and patients provided standard demographic (age, ethnicity, marital/living/employment status, years in education, contact time with relative) and clinical information (illness duration, number of previous admissions, diagnosis, height and weight) by self-report as part of the baseline assessment of the larger trial. Patient diagnosis, number of previous admissions, height and weight information were validated by clinicians at the treating site. Both Body Mass Index (BMI) and age standardised weight-for-height percentage, using Great Ormond Street Hospital for Children criteria, version 4.22 UK, were calculated for each patient.

5.3.4 Objective burden

The Care giving demands in EDs (Care-ED) is a semi-structured telephone interview developed in order to capture the time families are spending with specific demands as part of their caregiving role (Raenker et al., 2013) and administered as part of the Client Service Receipt Inventory, linked to cost analysis of psychological interventions (Beecham & Knapp, 1999). Direct caregiving was measured in approximate hours per month across the four daily care giving categories: medical, food, practical related care, and emotional support. In this study, carers were asked to report on caregiving tasks during the one month prior to their relative’s referral to ED services.

5.3.5 Subjective burden

The Depression, Anxiety, and Stress Scale, DASS-21 (Lovibond & Lovibond, 1995) is a 21-item scale assessing depression, anxiety, and stress over the past week using a 4-point Likert Scale. The sum of the three subscales produces a total score for psychological distress. Cronbach’s α in the current sample was 0.96.

5.3.6 Carer response to the illness

The Accommodation and Enabling Scale for Eating Disorders (AESED) (Sepulveda et al., 2009) is a 33-item self-report measure used to assess the levels of accommodating to the ED symptoms that carers may engage in (e.g. “does your relative with an ED control the choices of food that you buy?”). A five-point Likert scale is used to measure behaviours as ranging from 0 (never) to 4 (every day) across subscales: avoidance and modifying routine; reassurance seeking; meal ritual; control of family; and turning a blind eye. The sum of subscale scores produces a total score. Cronbach's α in the current sample was 0.92.

The Family Questionnaire (FQ) (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002) is a 20-item self-report measure of expressed emotion in carers across two subscales: emotional over-involvement and criticism (e.g. "I have to insist that he/she behave differently"). Scores are given on a 4-point Likert scale ranging from 1 (never/very rarely) to 4 (very often). The sum of both subscales produced a total score of carer expressed emotion. Cronbach's α in the current sample was 0.87.

The Brief Dyadic Scale of Expressed Emotion (Medina-Pradas et al., 2011) is a 14-item scale completed by patients to measure their perspectives of levels of expressed emotion of their carers. Three subscales measure perceived criticism, perceived emotional involvement and perceived warmth using a 10-point Likert scale ranging from 1 to 10. The scale is completed separately for each carer taking part in the project. Cronbach's α in the current sample was 0.72.

5.3.7 Protective factors

The OSLO 3-item social support scale (Meltzer, 2003) is a measure of perceived social support covering support from family, friends and neighbourhood. Three items covering different fields of social support form a composite index of social support, ranging from 3-14. A score of 3-8 is considered "poor support", 9-11 is "moderate" and 12-14 is "strong support", with good predictive validity with respect to psychological distress (Meltzer, 2003). Cronbach's α in the current sample was 0.67.

The Carer Skills (CASK) (Hibbs, Rhind, et al., 2015) is a 27-item scale to measure carer skills specific to the support of a person with an ED across six factors: Bigger Picture, Self-Care, Biting-Your-Tongue, Insight and Acceptance, Emotional Intelligence, and Frustration Tolerance. Responses to items (e.g. "How confident are you that you can avoid getting drawn into arguments about the ED with X?") are given on a 10-point

Likert scale presented as percentages from 0% (never) to 100% (always). Cronbach's α in the current sample was 0.93.

5.3.8 Patient illness factors

Depression, Anxiety, and Stress Scale, DASS-21 (described above) was also completed by patients to measure distress. Cronbach's α in the current sample was 0.94.

The Children's Yale-Brown Obsessive Compulsive Scale Self Report (Piacentini, Langley, & Roblek, 2007) is a self-report measure of obsessive compulsive symptom severity. Higher scores indicate higher symptom severity (score range 0-40). Cronbach's α in the current sample was 0.90.

The Social Aptitude Scale (SAS) (Liddle, Batty, & Goodman, 2009) was completed by parents online as 'informants', reporting on their child's social development as part of a broader Developmental and Wellbeing Assessment (Goodman et al., 2000). The SAS is designed to tap the sorts of social aptitudes that require a good ability to read social and emotional cues rapidly in complex situations in order to guide socially skilled behaviour. Parents rate their child from "a lot worse than average" to "a lot better than average" relative to other children of the same age across 10 items (e.g. "Easy to chat with, even if it isn't on a topic that specially interests him/her"). Lower scores indicate poorer social aptitude and scores below 16 have been associated with good screening properties for a diagnosis of autism spectrum disorder (Liddle et al., 2009). Cronbach's α in the current sample was 0.90.

The Short Evaluation of Eating Disorders (SEED) (Bauer, Winn, Schmidt, & Kordy, 2005) is a brief measure of ED symptom severity completed as clinician interview or by self-report. It is scored by means of an algorithm including weight and key symptoms, and 10 items are scored using a 5-point Likert scale. A Total Severity Index score is produced separately for AN (ANTSI) and BN (BNTSI) symptoms (score range 0-3). Cronbach's α in the current sample was 0.71.

5.3.9 Data Analyses

Data were analysed using SPSS version 19. Descriptive statistics were used for reporting the means and standard deviations/medians and range for demographic, clinical and caregiving variables. Cronbach alpha (α) was computed for all scales to assess internal consistency.

Hierarchical Linear Modelling (HLM) was used to assess differences between mothers and fathers across the carer variables, relating to objective burden (time spent caregiving), subjective burden (distress), carer behaviours (accommodation, expressed emotion) and protective factors (social support, carer skills). HLM takes into account the correlations between the two parents, and were fitted using restricted maximum likelihood estimators. Spearman's correlations were conducted to test for correlations within mothers' caregiver variables and between caregiver and patient illness variables, applying a Bonferroni-corrected alpha (a = 0.005/10= 0.005).

Baron and Kenny's (1986) steps for mediation analysis were used to test the role of carer response to the illness (accommodation, expressed emotion) and protective factors (carers' skills) as mediators of the effect of objective burden (total time spent caregiving) on subjective burden (psychological distress experienced by carers): 1) the independent variable (total time spent caregiving) must be significantly related to the mediators (accommodation, expressed emotion and carers' skills); 2) the independent variable (total time spent caregiving) must be significantly related to the dependent variable (psychological distress); 3) the mediators (accommodation, expressed emotion and carers' skills) must be significantly related to the dependent variable (psychological distress); and 4) the relationship between the independent variable (total time spent caregiving) and the dependent variable (psychological distress) must be reduced when the mediators (accommodation, expressed emotion and carers' skills) are included in the regression equation. In addition to this procedure, the Sobel test was used to test the significance of indirect effect.

5.4 Results

5.4.1 Demographic and clinical information about the person with the ED

The majority (92%) of the sample were female with a mean age of 16 years (SD = 2.14). The majority described themselves as White British/Other (95%) and as single (85%). Mean number of years in education was 11.67 (SD = 2.03). Most were students (85%), with 8% in employment or other (7%, sick leave or unemployed). The majority (95%) of participants were living with their parent/s.

The majority of patients (79%) had an illness duration of less than three years with mean age of illness onset at 14 (SD = 1.96). They included n = 107 (74%) who fulfilled the criteria for AN and n = 37 (26%) who fulfilled the criteria for EDNOS-AN. Their mean age-adjusted weight-for-height percentage was 82.44 (SD = 11.27), BMI was 16.77 (SD = 2.16) and the majority (92%) had no prior hospital admissions related to their ED.

5.4.2 Demographic information about the carers

The mean age was 48 (SD = 4.9) for mothers and 50 (SD = 5.8) for fathers/step-fathers. The majority of mothers (72%) and fathers (91%) were married or living with their partner and described themselves as White British/Other (mothers 98%; fathers 94%). Most mothers (69%) and fathers (90%) were employed and both had a mean of 15 years in education. Eating/weight problems were reported in 31% of mothers and 17% of fathers. Approximately 75% of carers reported overall spending more than 21 hours per week in face-to face contact time with their child with an ED, and this was higher in mothers (80%) than fathers (68%). Up to seven hours per week in other contact (e.g. text, telephone) were also reported by 80% of carers, particularly by fathers (85%).

Table 1 Descriptive and inferential statistics comparing objective caregiving burden (time spent care giving within one month), distress, caregiver response to the illness and protective factors in mothers and fathers

	Mothers (n=135)	Fathers (n=61)	Total (n=196)	Group comparison (t)
Objective burden: Time spent caregiving (median/range)				
Medical	2.50 (0-260)	0 (0-30)	2.00 (0-260)	-2.250*
Food-related	30.00 (0-370)	2.50 (0-180)	15.00 (0-370)	-4.307***
Emotional	30.00 (0-644)	7.50 (0-360)	23.75 (0-644)	-2.934**
Practical	0 (0-120)	0 (0-180)	0 (0-180)	-.830
Total direct care	75.00 (0-693.50)	27.50 (0-570)	52.50 (0-693.50)	-4.137***
Subjective burden: distress (mean/SD)				
Depression	11.16 (9.97)	7.40 (7.76)	10.07 (9.52)	-3.335**
Anxiety	5.70 (7.46)	2.50 (4.07)	4.77 (6.80)	-4.005***
Stress	15.32 (9.32)	11.02 (8.12)	14.07 (9.18)	-3.380***
Total distress	32.18 (24.00)	20.91 (16.86)	28.90 (22.70)	-4.201***
Caregiver behaviours (mean/SD)				
Accommodating	52.16 (22.49)	44.11 (18.55)	49.70 (21.63)	-2.535*
FQ critical comments	20.01 (6.08)	20.17 (6.70)	20.06 (6.25)	.047
FQ Emotional Over-involvement	28.79 (4.77)	25.36 (4.64)	27.79 (4.97)	-4.987***
FQ total expressed emotion	48.80 (9.29)	45.53 (9.18)	47.85 (9.35)	-2.640**
Protective factors (mean/SD)				
OSLO-3 social support index	10.06 (2.40)	9.65 (2.09)	9.94 (2.32)	-1.274
Caregiver skills	176.27 (33.10)	179.00 (41.22)	177.06 (35.55)	.216

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

5.4.3 Objective burden: daily care giving tasks

Figure 1 illustrates the large variation in the time spent on different care giving tasks across the sample and between mothers (1a) and fathers (1b). Mothers tended to spend 2 - 5 times as long as fathers with caring tasks. Mothers spent a median of 2.5 hours per day on direct care (one hour per day providing emotional support and a further hour on food related support) and fathers spent approximately one hour per day. Less time was spent on medical and practical related care. Mothers' time spent on tasks was significantly higher in all the examined care activities except practical care (t= -2.250, t = -4.307, t= -2.934 and t = -4.137 for medical, food-related, emotional and total care, respectively).

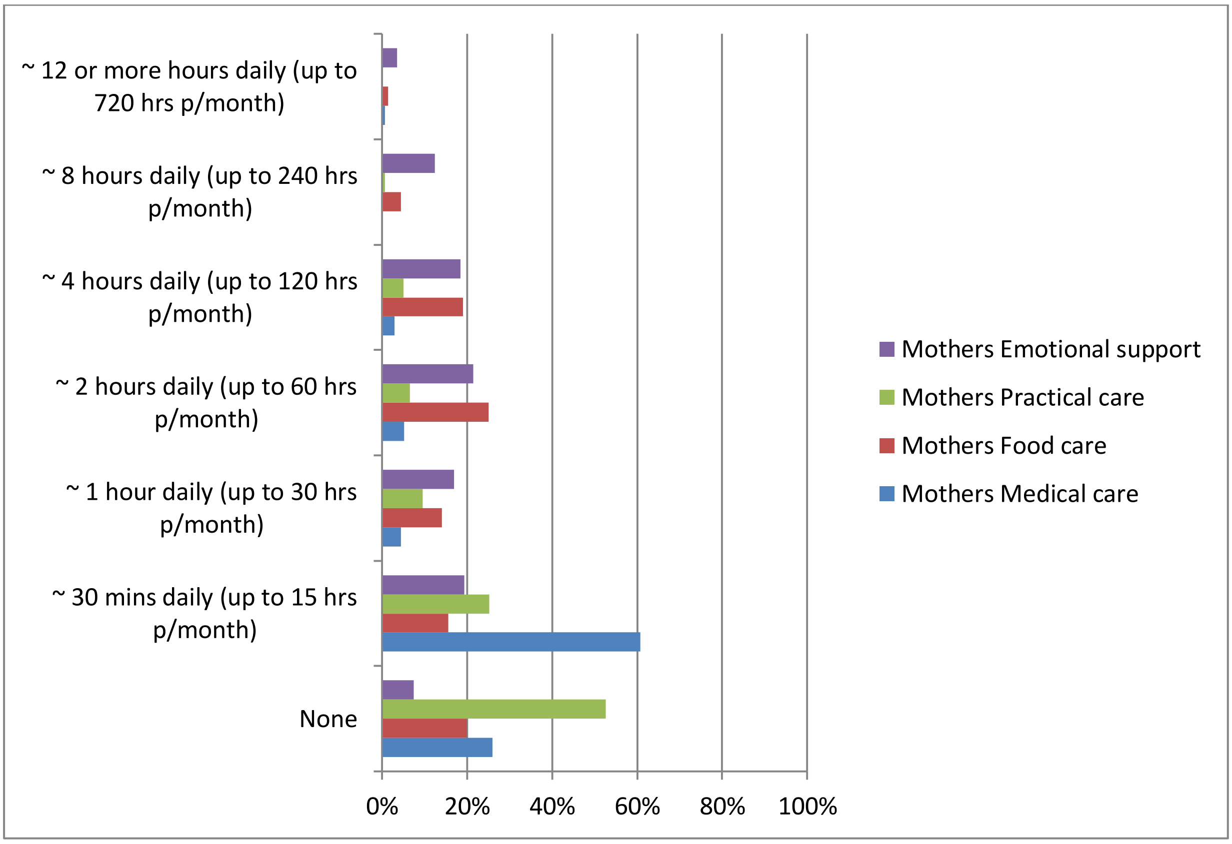


Figure 1a. Mothers' time spent caregiving

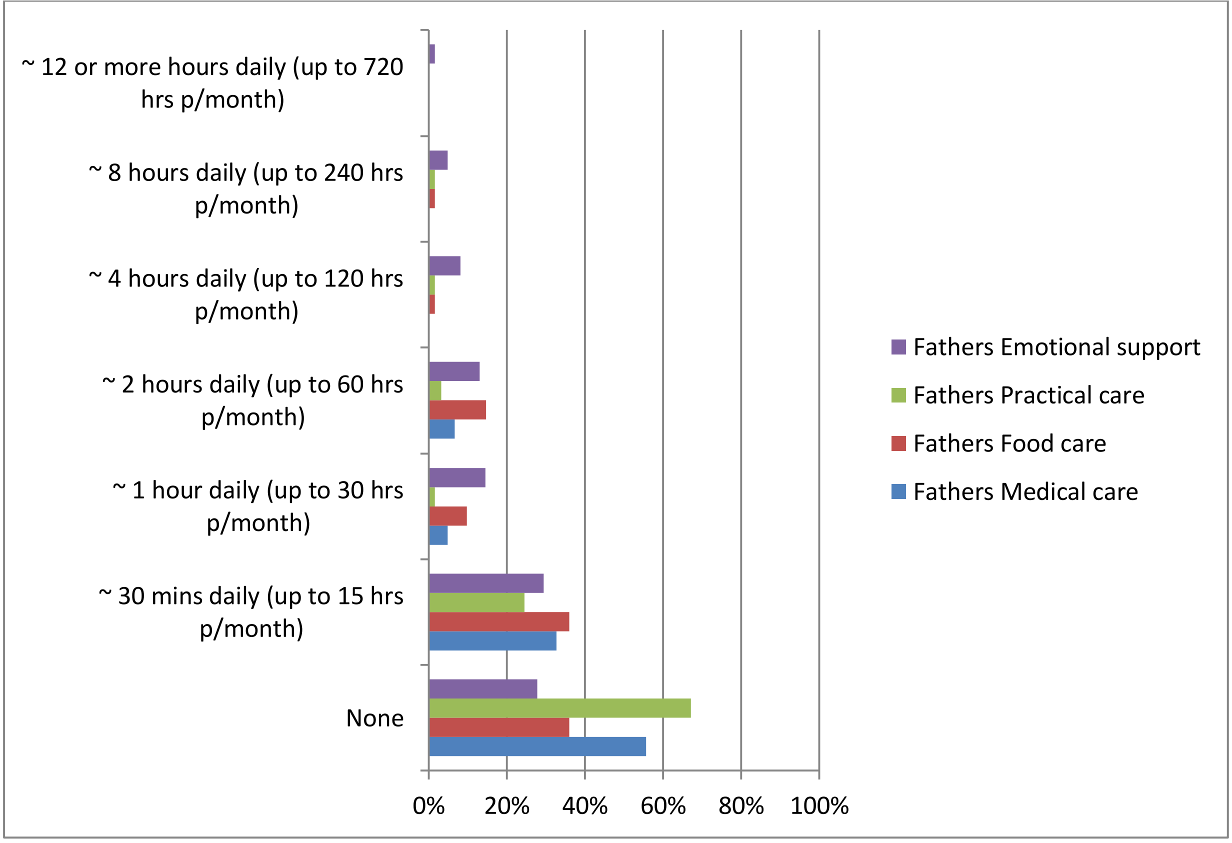


Figure 1b. Fathers' time spent caregiving

Figure 1. Distribution of time spent caregiving (objective burden) across key care giving tasks during one month

5.4.4 Subjective distress

Approximately one third of carers had moderate to severe levels of psychological distress (depression 30.8%, anxiety 17.6% and stress 25.6%). Levels of distress were significantly lower in fathers than mothers (t = -3.335, t = -4.005, t = -3.380 and t = -4.201 for depression, anxiety, stress and total DASS, respectively).

5.4.5 Care Giver Behaviours

The level of accommodating behaviour in fathers was lower than that seen in mothers (t = -2.535). Mothers also showed significantly higher emotional over-involvement (t = 4.987) and overall expressed emotion (t = -2.640) than fathers. However, mothers and fathers did not significantly differ in critical comments. Patients perceived their mothers as more overprotective (brief dyadic scale of expressed emotion – perceived emotional involvement: mothers M = 29.44, SD = 11.05; fathers M = 21.34, SD = 9.31; t = -7.316, p <.001) and warm (BDSEE - perceived warmth: mothers M = 34.12, SD = 6.13; fathers M = 31.16, SD = 7.08; t = -3.745, p < .001) than fathers. Patients perceived no significant differences between their two parents in critical comments (brief dyadic scale of expressed emotion - perceived criticism: mothers M = 17.46, SD = 8.96; fathers M = 18.51, SD = 8.77; t = .844, p = ns).

5.4.6 Protective factors: Social support and Carer Skills

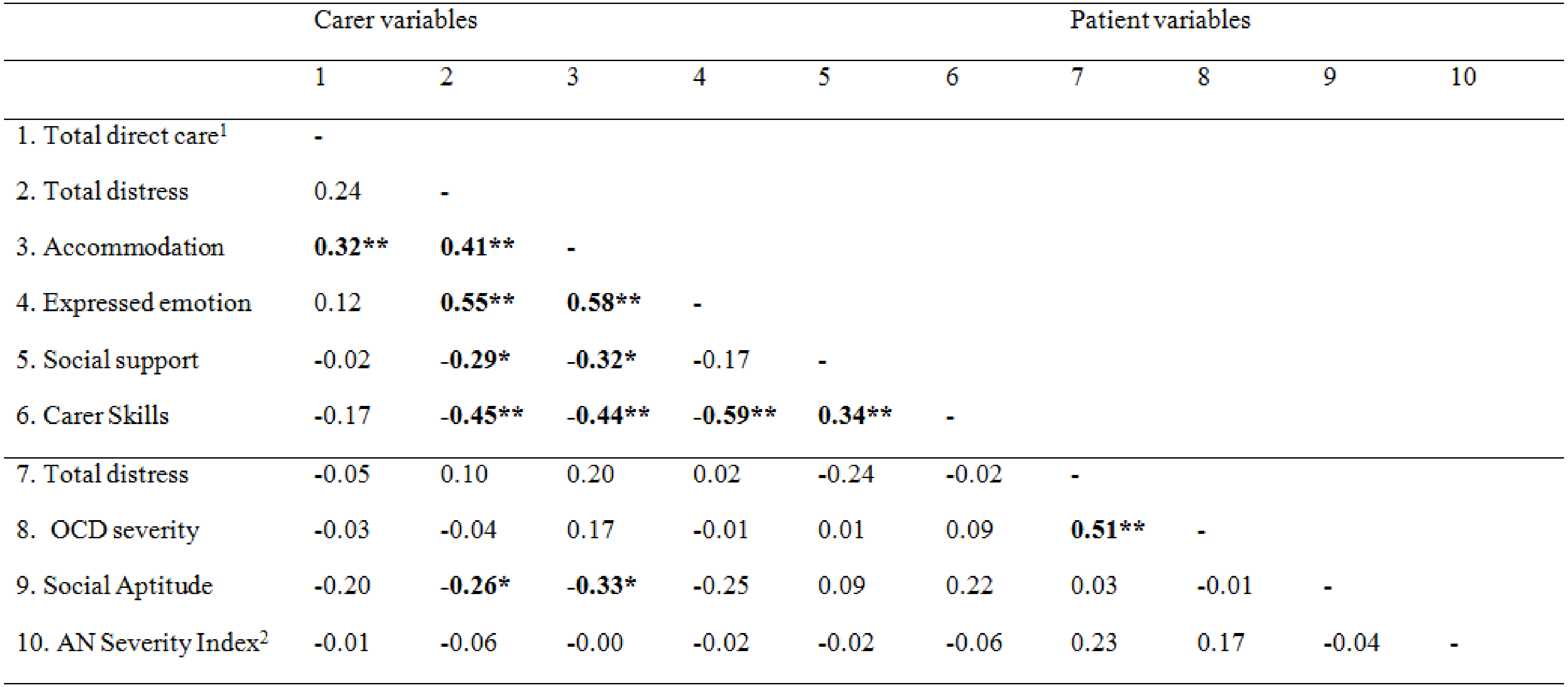
Mothers and fathers reported similar levels of perceived social support (mothers M = 10.06, SD = 2.40; fathers M = 9.65, SD = 2.09; t = -1.27, p = ns) which were within the moderate range. They also reported similar levels of carer skills (mothers M = 176.27, SD = 33.10; fathers M = 179.00, SD = 41.22; t = .22, p = ns).

5.4.7 Correlations between mothers' objective burden, subjective burden, response to the illness, protective factors and illness factors

Mothers' time spent caregiving was significantly correlated with their levels of accommodating behaviour (r_s = .32, p < .001). In turn, the level of accommodating behavior was significantly correlated with expressed emotion (r_s = .58, p < .001), carer distress (r_s = .41, p < .001), and negatively correlated with protective factors carer skills (r_s = -0.44, p < .001) and social support (r_s = -0.32, p < .005). Protective factors carers skills and social support were significantly correlated with each other (r_s = 0.34, p < .001).

Patient social aptitude was significantly negatively correlated with mothers' level of accommodating behaviour (r_s = -0.33, p < .005) and distress (r_s = -0.264, p < .005). Patient distress and severity of ED and obsessive-compulsive symptoms were not significantly correlated with mothers' caregiver variables.

Table 2: Correlations between mothers' objective burden, distress, response to the illness, protective factors, and illness factors



	Carer variables						Patient variables			
	1	2	3	4	5	6	7	8	9	10
1. Total direct care[1]	-									
2. Total distress	0.24	-								
3. Accommodation	**0.32****	**0.41****	-							
4. Expressed emotion	0.12	**0.55****	**0.58****	-						
5. Social support	-0.02	**-0.29***	**-0.32***	-0.17	-					
6. Carer Skills	-0.17	**-0.45****	**-0.44****	**-0.59****	**0.34****	-				
7. Total distress	-0.05	0.10	0.20	0.02	-0.24	-0.02	-			
8. OCD severity	-0.03	-0.04	0.17	-0.01	0.01	0.09	**0.51****	-		
9. Social Aptitude	-0.20	**-0.26***	**-0.33***	-0.25	0.09	0.22	0.03	-0.01	-	
10. AN Severity Index[2]	-0.01	-0.06	-0.00	-0.02	-0.02	-0.06	0.23	0.17	-0.04	-

Spearman's correlation coefficient (r_s) applying a Bonferroni-corrected alpha (a = 0.005/10= 0.005); [1]Time spent caregiving in hours p/month; [2]Anoreixa Nervosa Severity Index

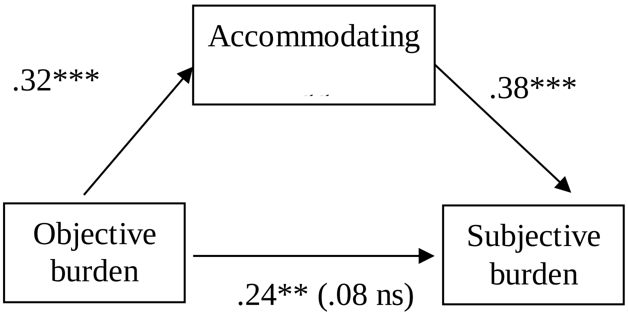
*** p < .005**

****p < .001**.

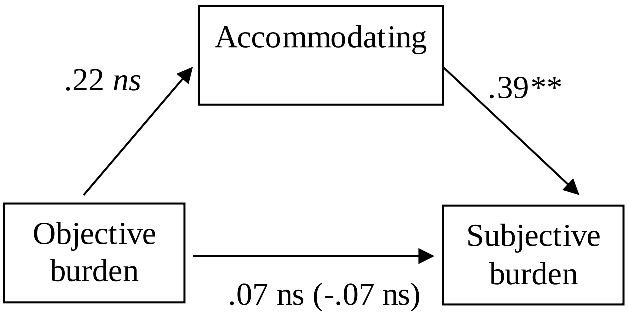
5.5 Mediation analyses

Three sets of regression were estimated to test the role of carers' response to the illness (accommodation and expressed emotion) and protective factors (carers' skills) as mediators of the effect of objective burden on subjective burden for both mothers and fathers.

Figures 2a and 2b summarise the results of the analyses with accommodation (AESED) as a mediator in mothers and fathers, respectively. In the first regression equation, total time spent caregiving (predictor) was significantly related to accommodation (mediator) for mothers only (β=.32). In the second regression equation, total time spent caregiving (predictor) was significantly associated with carers' distress (outcome) only for mothers (β=.24), indicating that high objective burden was associated with high mothers' distress. In equation 3, accommodation (mediator) was significantly related to carers distress (outcome) in mothers and fathers (β=.38, β=.39, respectively). Finally, in the fourth regression the relation between objective burden (total time spent caregiving) and carers' distress was no longer significant for mothers when accommodation was taken into account (β=.08). The Sobel test showed a significant coefficient for mothers (z-value = 2.61, p < .01).



2a - Results of regression analyses for accommodating behaviours (mothers).

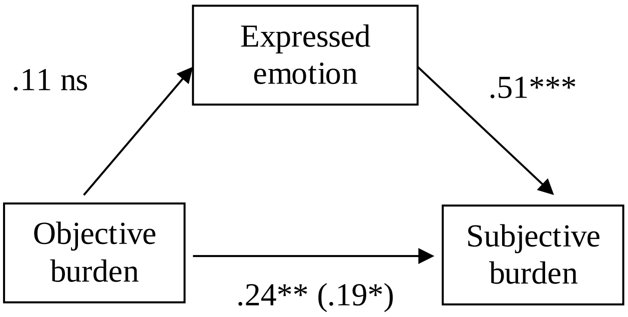


2b - Results of regression analyses for accommodation behaviours (fathers).

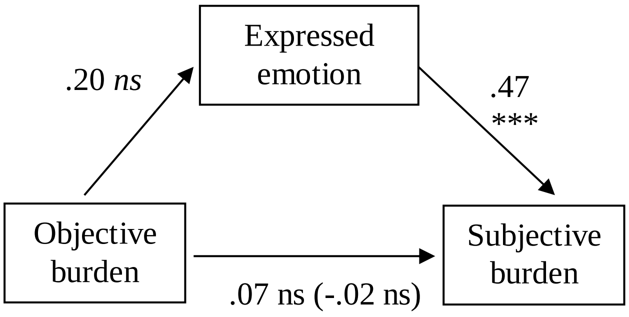
*The βs between parentheses indicate the effect of the predictor when the mediator is in the model. ns = not significant. ** p <.01, *** p <.001.*

Figure 2. Significant mediation in mothers only: Levels of carer accommodating as a mediator of the relationship between time spent caregiving and carer distress

Figures 3a and 3b summarize the results of the mediation analyses for expressed emotion as a mediator in mothers and fathers, respectively. In the first regression equation, objective burden (total time spent caregiving - predictor) was not significantly related to expressed emotion (mediator) in both groups. In the second regression equation, total time spent caregiving (predictor) was significantly associated with carers' distress (outcome) only for mothers (β=.24). In the third equation expressed emotion (mediator) was significantly related with carers' distress (outcome) in mothers and fathers (β=.51, β=.47, respectively). In the final equation, only the association between objective burden and subjective burden (carers' distress) for mothers was lower when expressed emotions was taken into account (β=.19).



3a - Results of regression analyses for expressed emotions (mothers).

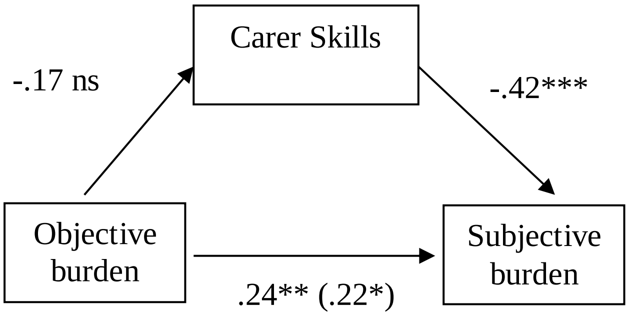


3b - Results of regression analyses for expressed emotions (fathers).

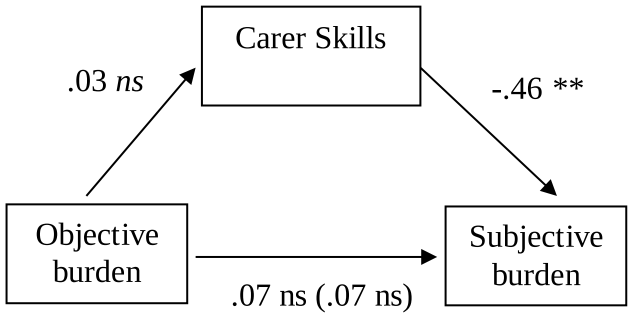
*The βs between parentheses indicate the effect of the predictor when the mediator is in the model. ns = not significant. * p<.05, ** p <.01, *** p <.001.*

Figure 3. No significant mediation in: Levels of carer expressed emotion as a mediator of the relationship between time spent caregiving and carer distress

Figures 4a and 4b summarize the results of the analyses for carer skills as a mediator in mothers and fathers, respectively. In the first regression equation, objective burden (total time spent caregiving - predictor) was not significantly related to carers' skills (mediator) in either group. In the second regression equation, total time spent caregiving (predictor) was significantly associated with carers' distress (outcome) only for mothers (β=.24). In the third equation carers' skills (mediator) were significantly related with carers' distress (outcome) both in mothers and fathers (β=-.42, β=-.46, respectively). In the final equation, the association between objective burden and subjective burden (carers' distress) for mothers was lower when carers' skills were taken into account (β=.22).



4a - Results of regression analyses for Carer Skills (mothers).



4b - Results of regression analyses for Carers Skills (fathers).

*The βs between parentheses indicate the effect of the predictor when the mediator is in the model. ns = not significant. * p<.05, ** p <.01, *** p <.001.*

Figure 4. No significant mediation in: Levels of Carers Skills as a mediator of the relationship between time spent caregiving and carer distress

These findings support the hypothesis that accommodation fully mediated the relationship between objective burden (total time spent caregiving) and subjective burden (carers' distress), for mothers only. However, expressed emotion and carer skills did not mediate the relationship between objective burden and subjective burden for either mothers or fathers.

5.6 Discussion

This study explored objective burden (time spent with care giving), subjective burden (psychological distress experienced by carers), protective factors (caregiving skills and social support) and less adaptive care giving behaviours (accommodating and/or enabling and high expressed emotion), in parents of adolescents with AN or EDNOS-AN referred for outpatient treatment. Approximately 75% of mothers and fathers had high levels of face-to-face contact time (>21 hours per week) with the person they were caring for, before referral to ED services. Most of their time was spent managing nutrition and providing emotional support. The direct time involved in providing care by mothers varied greatly but was approximately 2.5 h /day. This was mainly used for providing food and emotional support. Fathers provided on average 1hr /day and with a similar profile.

Overall, fathers spent 27.5 h/month, whereas mothers spent 75 h/month. The subjective burden was high, with approximately 30 per cent of the sample exhibiting moderate to severe levels of distress. The level of distress (particularly anxiety) was significantly lower in fathers than in mothers.

The level of skilful caregiving was similar between mothers and fathers. In terms of less adaptive care giving behaviours, the overall levels of expressed emotion were similar between mothers and fathers, although mothers were more over-protective. On the other hand, they were also perceived with more warmth than fathers. The level of accommodating behaviour was higher in mothers than in fathers, and was significantly correlated with poorer social aptitude in patients. Furthermore, the level of accommodating behaviour in mothers mediated the relationship between their objective burden (total time spent care giving) and subjective burden (carers' distress). However, neither expressed emotion nor carer' skills mediated the relationship between objective burden and subjective burden for either parent.

There were some similarities and also differences in the caregiving experience of parents in this study compared to that of carers of people at the severe and enduring stage of illness, which has previously been described (Raenker et al., 2013). The objective burden, in terms of time spent caregiving, was similar in both the late and early stages of AN. However, in the adolescent population approximately twice as much time was spent providing meal support and somewhat less on practical and emotional support. The level of carer distress was similar in both stages of illness.

Accommodating behaviours from mothers were higher in these adolescent cases than that seen in the carers of people with severe and enduring EDs. The qualitative nature of the stress that mothers, in particular, are under when their adolescent child has AN has previously been reported, describing a tendency for mothers to become 'enmeshed' (Bezance & Holliday, 2014). Accommodating behaviours are often used as a means of reducing distress or anger in the patient. However, this is at the cost of increasing the subjective burden in mothers. Furthermore, accommodating runs counter to the aims of exposure-based approaches, such as meal support interventions, preventing patients from processing the emotional responses to this feared task which is a necessary treatment mechanism (Foa & Kozak, 1986), and allowing the individual to avoid anxiety-provoking activities.

5.6.1 Limitations

The Care-ED interview retrospectively assessed the level of objective burden in carers in EDs and so the results are an approximation, to a degree. We only measured carer distress as a measure of subjective burden. Distress may be confounded by other factors and not be merely related to the caregiving experience. In order to minimise participant burden, we were not able to measure other important aspects of subjective distress, such as carer burden, coping, needs or self-efficacy. Finally, this study employed a cross-sectional design and therefore does not allow us to detect any causal relationship between the variables. Further analysis using longitudinal data will be beneficial to confirm the hypothesized direction of the relationship between variables.

5.6.2 Clinical implications

It is to be expected that carers in the early stage of AN provide more meal support, as this is regarded as a core part of family based treatment, which is now to be gold standard treatment. The high levels of accommodating behaviour, particularly in the mothers of adolescents, is also unsurprising, given that the level of accommodating behaviour is related to contact time, according to our previous work in patients with severe enduring illness (Goddard, Salerno, et al., 2013). In our work with families, we find that interventions focused on modifying accommodating behaviour can be an important leverage for change (Treasure, Rhind, et al., 2015). We suggest to parents that they first need to lead by example and change their own behaviour. Not only does this reduce a factor that contributes to subjective distress in carers but this also reduces avoidance of anxiety-provoking activities which may maintain the ED symptoms. Furthermore, carers taking steps to change their own behaviours, models behaviour change for the individual with an ED. As mothers' accommodating behaviour was correlated with poorer social aptitude in patients, this form of carer intervention might be particularly beneficial for the subgroup of patients with these transdiagnostic traits (Rhind, Bonfioli, et al., 2014).

5.6.3 Conclusion

These findings demonstrate the large amount of time spent (particularly by mothers), providing meal support for people in the early stage of AN. Mothers also have higher levels of accommodating behaviours and this contributes to their subjective distress and explains the relationship between time spent with caregiving and their subsequent distress. Supporting families in helping them reduce less adaptive behaviours, such as accommodation, may reduce subjective distress and help them cope with the caregiving role and also improve the outcome for the person with an ED.

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CHAPTER 6.

EXPERIENCED CARERS HELPING OTHERS (ECHO): PROTOCOL FOR A PILOT RANDOMISED CONTROLLED TRIAL TO EXAMINE A PSYCHO-EDUCATIONAL INTERVENTION FOR ADOLESCENTS WITH ANOREXIA NERVOSA AND THEIR CARERS

Publication

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RESEARCH ARTICLE

Experienced Carers Helping Others (ECHO): Protocol for a Pilot Randomised Controlled Trial to Examine a Psycho-educational Intervention for Adolescents with Anorexia Nervosa and Their Carers

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Abstract

Experienced Carers Helping Others (ECHO) is an intervention for carers of people with eating disorders. This paper describes the theoretical background and protocol of a pilot multicentre randomised controlled trial that will explore the use of two variants of ECHO for improving outcomes for adolescents with anorexia nervosa (AN) referred for outpatient care. Adolescent patients and their carers (typically parents and close others in a supportive role) will be recruited from 38 eating disorder outpatient services across the UK. Carers will be randomly allocated to receive 'ECHOc' guided self-help (in addition to treatment as usual), 'ECHO' self-help only (in addition to treatment as usual) or treatment as usual only. Primary outcomes are a summary measure of the Short Evaluation of Eating Disorders at 6- and 12-month follow-ups. Secondary outcomes are general psychiatric morbidity of AN patients and carer, carers' coping and behaviour, and change in healthcare use and costs at 6- and 12-month follow-ups. Therapist effects will be examined, and process evaluation of ECHOc will be completed. The findings from this pilot trial will be used in preparation for executing a definitive trial to determine the impact of the preferred variant of ECHO to improve treatment outcomes for AN. Copyright © 2014 John Wiley & Sons, Ltd and Eating Disorders Association.

Keywords
anorexia nervosa; Eating Disorder Not Otherwise Specified; outpatient; trial; treatment

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Background

Anorexia nervosa (AN) is a severe psychiatric illness with a protracted course (Stoving, Andries, Brixen, Bilenberg, & Horder, 2011; Wentz, Gillberg, Anckarsater, Gillberg, & Rastam, 2009) and associated with high healthcare costs (Krauth, Buser, & Vogel, 2002). The National Institute of Health and Clinical Excellence (NICE) guidelines recommend that most people with an eating disorder (ED) should be managed on an outpatient basis in the first instance (2004). The peak age of onset is in mid-adolescence (Currin, Schmidt, Treasure, & Jick, 2005; Micali, Hagberg, Petersen, & Treasure, 2013), and therefore, parents and close others usually take on a caregiving role. However, a meta-analysis of several aspects of carer functioning obtained from a systematic review concludes that carers find this role burdensome and distressing (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014; Zabala, Macdonald, & Treasure, 2009). Families request information and help with this role (Haigh & Treasure, 2003).

Family therapy is one way of involving families in treatment. To date, it is the most effective form of intervention in the early phase of the illness (less than 3 years duration), according to the results of a Cochrane (Fisher, Hetrick, & Rushford, 2010b), and later, systematic review (Couturier, Kimber, & Szatmari, 2013). However, this type of involvement is less effective in those with a longer duration of illness (Fisher, Hetrick, & Rushford, 2010a). Moreover, family therapy is not acceptable for all families. Other types of interventions that involve the family have been developed such as 'separated family therapy' in which the patient is seen individually and the parents are seen in parallel (Le Grange, Eisler, Dare, & Russell, 1992). This type of intervention was as effective as family therapy and was particularly helpful for families with high expressed emotion (Eisler et al., 2000). A further adaptation is multifamily therapy (Asen, 2002). In this form of therapy, several families are seen as a group for a week (9–5). Preliminary evidence suggests that this form of intervention is as effective as family therapy (Eisler, 2005). It is, however, demanding on family time and, because of the group format, can be somewhat inflexible.

Other approaches that have been used in working with families are based on a theoretical framework with the basic assumption that if carers are provided with skills and education to understand the 'enigma' of AN, then they can form part of the therapeutic team. We have undertaken a systematic review and meta-analysis of the literature relating to this type of intervention (Hibbs, Rhind, Leppanen, & Treasure, 2014). A variety of implicit and explicit theoretical maintenance models have been employed. Thus, there have been interventions based on a form of exposure model that teach carers how to give meal support (Cairns, Styles, & Leichner, 2007; Hildebrandt, Bacow, Greif, & Flores, 2014). Others teach specific skills to promote behaviour change in carers and the sufferer, such as motivational interviewing (MI) (Goddard, Macdonald, Sepulveda, et al., 2011) or cognitive behaviour therapy (Grover, Naumann, et al., 2011; Grover, Williams, et al., 2011). Some work on the possibility that the carers coping pattern is suboptimal leading to high carer anxiety (Pepin & King, 2013); in turn, anxiety is mirrored by the person with the ED and serves to escalate symptoms (Goddard, Macdonald, Sepulveda, et al., 2011). Others are based on a model that suggests that high expressed emotion such as criticism and overprotection may maintain ED behaviours (Butzlaff & Hooley, 1998; Treasure et al., 2008). Yet others suggest that accommodation and enabling behaviours serve to maintain ED behaviours (Sepulveda, Kyriacou, & Treasure, 2009; Treasure et al., 2008). Some of the models are complex and contain all of these features. The results of the meta-analysis of carer outcomes following these forms of parenting interventions show a moderate-sized reduction in carer burden and distress, expressed emotion and accommodating behaviours (Hibbs et al., 2014, submitted). However, very few high quality studies have examined the impact of interventions offered to carers on individuals with an ED themselves (e.g. Hibbs, 2014, in preparation; Whitney et al., 2012).

Experienced Carers Helping Others (ECHO) is a novel intervention for carers based on the cognitive interpersonal maintenance model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). One element of this model is that interpersonal factors (such as those described earlier) can develop within families and maintain the illness (Schmidt & Treasure, 2006; Treasure et al., 2008). Inadvertently, these may hinder recovery. Empirical evidence to support the model is emerging (e.g. Goddard, Macdonald, & Treasure, 2011; Goddard et al., 2013). The main difference of the ECHO intervention from family-based treatment is the premise that aspects of carers' behaviour may inadvertently maintain the disorder, whereas family-based treatment is atheoretical and considers that parents have within themselves the knowledge and skills to feed their child. For example, carers are taught to assess within themselves whether they might use accommodating and enabling behaviours and react to the ED symptoms with high expressed emotion. These are modifiable behaviours, and it is thought that carers may benefit from skills training in aspects of management of EDs that are used by professionals in specialised inpatient services. Thus, the skills of MI are taught both by example and theory as a means of providing calm and compassionate meal support and engaging intrinsic motivation to change (Treasure, Sepulveda, et al., 2007). Carers are also taught how to apply behaviour change principles (e.g. goal setting and contingency management). Furthermore, carers are taught about cognitive and emotional styles associated with EDs (Schmidt & Treasure, 2006) and how to promote balanced emotional regulation and a flexible, 'big picture' style of thinking. The cognitive interpersonal maintenance model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013) includes these individual vulnerabilities such as aspects of cognitive style that are thought to contribute to the maintenance of the illness. For example, in general, people with EDs have good cognitive abilities with superior attention to detail, but they sometimes show inefficiencies in set shifting (Lang, Stahl, Espie, Treasure, & Tchanturia, 2014; Lopez et al., 2008). These traits can manifest as an obsessive–compulsive personality that is associated with a poorer response to treatment (Crane, Roberts, & Treasure, 2007). These traits are also present in people with autistic spectrum disorders, and several studies have found that people with AN have high scores on the Autism Spectrum Questionnaire (Baron-Cohen et al., 2013; Hambrook, Tchanturia, Schmidt, Russell, & Treasure, 2008; Tchanturia et al., 2013). Individuals with AN with social and communication difficulties and autistic spectrum traits have been found to have a poorer prognosis (Anckarsater et al., 2012). First-degree relatives may share obsessive–compulsive personality traits (Lilenfeld, Wonderlich, Riso, Crosby, & Mitchell, 2006). These traits may make it difficult for both the patient and carer to have a flexible response to the development of ED symptoms and worsen the prognosis.

Another facet of the cognitive interpersonal maintenance model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013) is the pro AN beliefs and behaviours that can develop as a consequence of the illness (Serpell, Teasdale, Troop, & Treasure, 2004). It is possible that these can be particularly pronounced if other members of the family have their own ED problems. There is evidence that EDs are common in first-degree relatives of patients and that EDs run across generations (Kanakam, Krug, Raoult, Collier, & Treasure, 2013; Lilenfeld et al., 1998; Strober, Freeman, Lampert, Diamond, & Kaye, 2000). Furthermore, carers' own history of eating problems is associated with caregiver distress (Goddard et al., 2013). Therefore, a family history of an ED may moderate response to treatment.

The ECHO intervention

Experienced Carers Helping Others is a guided self-help skills training intervention developed to meet some of the complex unmet needs of carers. The intervention is theory-driven and combines psycho-education with skills training by ED specialists. Initially, the elements of ECHO were delivered in the form of workshops that were found to reduce carer distress (Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008) and expressed emotion (Sepulveda et al., 2010). These also produced positive effects for the patients themselves (Goddard, Macdonald, & Treasure, 2010). As a 'next step', the training materials were synthesised into a self-help intervention (book and set of DVDs) to enhance accessibility, reduce the delivery cost and aid dissemination. Carer coaches (individuals with personal or professional experience in caregiving for someone with an ED) were trained to act as telephone mentors in order to provide guidance in the implementation of the materials. The coaches were trained to use MI as a communication style and to use the model of carer stress and the interpersonal maintenance model as a template of behaviours for possible change. This was found to be a feasible and acceptable form of intervention (Goddard, Macdonald, Sepulveda, et al., 2011); however, the 'dose' of guidance given (three sessions for one carer) was insufficient to provide benefit. A more rigorous training programme with a manual to structure the sessions and an enhanced programme of supervision and monitoring was introduced to improve the quality assurance of the intervention. The duration of coaching was increased to 10 sessions per family. In a randomised controlled trial (RCT), this was used as an intervention to support carers of patients, with severe and enduring ED, admitted for inpatient care (see Goddard et al., 2012). Following the intervention, carer burden, time spent caregiving and unhelpful carer behaviours were reduced (Hibbs, 2014, in preparation). Furthermore, patient ED symptomatology and quality of life were significantly improved in the ECHO group. There were also shorter admissions, longer time to relapse and fewer readmissions in the ECHO group (although not statistically significant). Sharing skills and information with family members and other carers was therefore of benefit for patients and carers (Hibbs, 2014, in preparation). Given that patients at this stage of illness are resistant to most forms of treatment (Hay, Touyz, & Sud, 2012; Wonderlich et al., 2012), these improvements are encouraging (Hibbs et al., 2014). A common comment from carers was the wish to have had access to the intervention at an earlier stage of the illness (Macdonald et al., in prep.).

The current trial

The primary aim of the current study is to investigate the use of the ECHO intervention (guided and not guided) for adolescents with AN at an early stage of illness. This RCT compares three treatment conditions: (i) the ECHO intervention as guided self-help (ECHOc), in addition to treatment as usual (TAU); (ii) the ECHO intervention as self-help only (ECHO), in addition to TAU; and (iii) TAU. This design will explore the additional use of coaching (the 'guided' component of guided self-help) relative to providing self-help materials alone. For carers and patients, the primary hypotheses refer to outcomes at the 6- and 12-month follow-up time points.

Methods and design

Hypotheses

Primary hypotheses

1. At 6- and 12-month follow-ups, patients with carers allocated to the intervention arms (ECHO/ECHOc) will have a more rapid and stable reduction in AN symptoms compared with those in TAU alone, as measured by the Short Evaluation of ED (SEED).
2. At 6- and 12-month follow-ups, patients with carers allocated to the guided intervention (ECHOc) will have more rapid and stable reduction in AN symptoms compared with those in ECHO only (ECHO), as measured by the SEED.

Secondary hypotheses

3. The cost of support (societal and individual) will be lower for patients and carers in the ECHO/ECHOc arms than those in the TAU group at 6- and 12-month follow-ups.
4. Carers who receive ECHO/ECHOc will report a greater reduction in caregiving burden [objective (i.e. contact time and family expenditure related to AN) and subjective (i.e. distress)], and accommodation and enabling, compared with those with TAU at 6- and 12-month follow-ups.
5. A reduction in accommodation and enabling behaviours and caregiving burden will mediate outcomes for patients.
6. Obsessive–compulsive and autistic traits in patients and carers will moderate the effect of ECHO/ECHOc on carer and patient outcomes.
7. Parental attitude and behaviour towards food, weight and shape will moderate carer and patient outcomes.
8. ECHOc will be delivered to an acceptable level of competence, as measured by the Motivational Interviewing Treatment Integrity (MITI 3.1.1) (Moyers, Martin, Manuel, Miller, & Ernst, 2010).
9. There will be therapist effects (level of experience and carer coaches *versus* professional affiliation coaches) on the efficacy of ECHOc coaching intervention.

Research plan

Trial design

This is a pragmatic three-arm multicentre parallel group pilot RCT. The study design is shown in Figure 1. Consenting carers of patients who meet the eligibility criteria will be randomly allocated to receive ECHO (in addition to TAU), ECHOc (in addition to TAU) or TAU only. The delivery of ECHO and ECHOc is managed by the coordinating centre. Patients and their carers will be recruited from adolescent and ED National Health Services (NHS) providing ED specialist outpatient care to individuals with an ED aged 13–21 years inclusive across the UK. This evaluation will investigate ECHO and ECHOc in a pragmatic setting, reflective of outpatient care for ED in the UK. Data will be collected at baseline (referral to outpatient services) and follow-up time points (6 and 12 months).

Randomisation

Carers are randomly allocated to one of the three trial arms (ECHO, ECHOc or TAU) within 24 hours of completion of family baseline assessment. Randomisation is carried out using the King's Clinical Trials Unit's independent web-based system (King's College London, London, UK) and managed only by the two lead researchers (C. R. and R. H.). A database will hold the basic details required for randomisation [centre, severity of illness (weight/height, presence of compensatory behaviours and presence of previous hospital admissions), date of birth, initials and unique patient number]. Stratified randomisation using centre (3+) and illness severity (weight/height ratio) and minimisation with a random component is used. The first *n* cases (*n* will not be disclosed) are allocated randomly to further enhance allocation concealment. Randomisation can only be carried out by the lead researchers, and details are locked following group allocation. The stratification factors (study site, age and illness severity) will

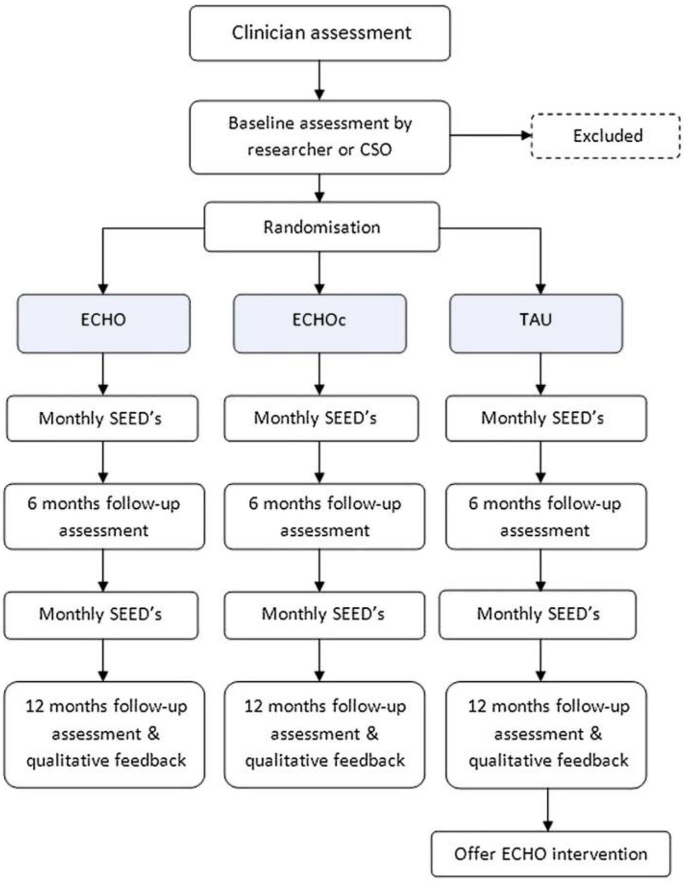

Figure 1. Study design. ECHO, Experienced Carers Helping Others; ECHOc, the ECHO intervention as guided self-help; TAU, treatment as usual; SEED, Short Evaluation of Eating Disorders; CSO, Clinical Studies Officer

be adjusted for in the analysis. All correspondence with carers on randomisation is by post. All coaches will be contacted simultaneously for each participant randomised, and families are allocated on a first-come-first-served basis. Information concerning participants will not be shared with the coaches prior to allocation.

Researcher blinding

This is a single blind study. The two lead researchers (C. R. and R. H.) are individually responsible for managing the randomisation of a selection of the participating sites and blind to the group allocation of those managed by the other. Assessment is coordinated so that researchers will only conduct interviews with those for whom they are blind to treatment allocation.

Participating sites

This project is a multicentred trial involving 38 UK ED services providing outpatient care for people aged 13–21 years inclusive. Seventeen of the sites are Child and Adolescent Mental Health Services (CAMHS), 13 are adult services and 8 have both CAMHS and adult teams recruiting. All sites are managed within the NHS (public sector).

Participants

Patients newly referred to an ED outpatient service, with a primary diagnosis of AN or ED not otherwise specified AN type (EDNOS-AN) according to the DSM-IV criteria (APA, 1994), and aged between 13 and 21 years are invited to participate. The DSM-IV was chosen as the diagnostic tool currently in use at the time of planning the trial. Age bounds were chosen to represent an adolescent sample up until brain development comes to completion (early twenties) (Keverne, 2004) and usually whilst in full-time education. This is also consistent with previous similar adolescent trials (Schmidt et al., 2007). At least one carer (typically parent/s) living with the patient currently and for the next year, identified by the patient, must participate for the family to be included in the study. Other close carers are encouraged to take part also. "Carers" are defined by criteria of the Princess Royal Trust (www.carers.org) as someone who provides unpaid help and support to a parent, child, partner, relative, friend or neighbour. Patients need to be fluent in English and are excluded if they or their carers are taking part in another treatment. Further exclusion criteria were severe comorbidity at time of admission (e.g. severe learning disability and psychosis). No formal sample size calculation was completed because this is a pilot RCT and will be used to obtain information on the likely effect size, variability and other aspects of outcome data for a future definitive trial sample size calculation. As achieved in the previous Carer Assessment, Skills and Information Sharing trial, we estimate that it is feasible to randomise 175 families over the planned 18-month recruitment phase.

Recruitment

Patients will be approached by clinical staff at the participating sites on initial assessment and given information about the study. Written assent will be collected for all patients and written and informed consent from their parents or guardians and all other participating carers. Clinical studies officers from the Mental Health Research Network (MHRN) support recruitment of patients and data on participant flow are collected according to Consolidated Standards of Reporting Trials recommendations (Moher et al., 2010). Participants are entered into a prize draw for taking part in the study. They are not reimbursed or paid for participation.

Treatment arms

Experienced Carers Helping Others

Participants allocated to ECHO will receive the self-help version of the intervention. This is offered as an additional resource to treatment offered by clinical teams and is not designed to replace any aspects of individual or family therapy. ECHO uses an educational and skills training approach and consists of self-help materials developed for parents, siblings, partners and other carers of someone with an ED. Materials are posted to carers and include a book co-authored by a professional, a carer and an individual with an ED (Treasure, Grainne, & Crane, 2007), a series of video clips that illustrate the principles described in the book (see Sepulveda, Lopez, Macdonald, & Treasure, 2008 for description of DVD content) and a short guide for carers as a further supplement to the book. ECHO utilises several strategies that have been identified as important for the success of behaviour change interventions (Michie, van Stralen, & West, 2011).

Coaching with ECHO (ECHOc)

In addition to the self-help materials, the ECHOc intervention package includes 10 telephone coaching sessions with 'experienced coaches' trained to deliver ECHOc. Coaching sessions will be allocated, where possible, between participating carers (e.g. mother and father). Participants will be contacted by the coach within two weeks of receiving the material by post. Coaches are asked to complete the sessions within a 5-month period. Calls can therefore be regular with a time lapse (e.g. two weeks) for carers to practise the skills. Calls are approximately 40 minutes in length, and carers receive a minimum of six calls (per family) to have completed the intervention.

Motivational interviewing (MI) is the primary therapeutic tool used to deliver the telephone coaching (Rollnick, Butler, Kinnersley, Gregory, & Mash, 2010). MI is defined as 'a collaborative, person-centred form of guiding to elicit and strengthen motivation to change' (Miller & Rollnick, 2009 p. 137). The spirit of MI is empathic, deferential and curious. Coaches are trained to promote change through recognition of ambivalence in the individual, reflective listening and eliciting change talk, as detailed in Table 1. Coaches utilise behaviour change principles such as those outlined in the NICE guidelines (2007), for example, setting of action plans (considering goals and obstacles) for commitment to behaviour change. Carers are also taught MI skills to initiate change with the person for whom they are caring.

Telephone coaches. The telephone coaches are 17 individuals with professional ($n = 7$) or lived (personal or carer) experience of ED. Inclusion criteria for coaches are people with lived or professional experience of ED with sufficient time and access for the training, supervision and coaching. Further inclusion criterion, but not a requirement, is previous participation in carer interventions and training in professions allied to medicine, or equivalent (psychology and counselling) or teaching. It is required that carer coaches' loved ones with an ED are stable or in a maintenance phase of the illness, and those with an ED personal history must describe

Table 1 Description of maintaining factors targeted by the intervention

Maintaining factors and how they are targeted in the carer skills interventions	
Anxiety, depression	Pleasant activity scheduling, social support. Emotion-focused therapy, compassion-focused therapy, self-care, self-nurturing
Guilt and shame	Education about illness Contact with other carers. Self-reflection regarding getting support for self, medication, counselling
Rigidity, compulsivity, preoccupation with detail, eating	Education and feedback. Remediation to ameliorate extreme traits
Misperceptions and misunderstanding of eating disorders	Education about illness Contact with other carers. Online support groups, websites. Skill-based Learning book
Enabling and accommodating to the illness	Functional analysis. Training in communication, and problem solving
Expressed emotion (criticism, hostility and overprotection)	Education about 'transference' issues. Education about expressed emotion animal models
Unhelpful communication	Motivational interviewing

themselves as recovered for at least two years. Exclusion criteria are having a family member with AN who remains acutely ill and English nonfluency.

Eleven coaches were recruited from the earlier RCT 'Carer Assessment, Skills and Information Sharing' (see Goddard et al., 2012), and the remaining coaches were recruited internally within the department as professionals and patient and public involvement members who expressed interest and met inclusion criteria. The telephone coaches are 17 individuals with professional ($n = 7$) or lived (personal or caregiving) experience of ED. Coaches were offered payment for their time, and running costs were reimbursed.

Treatment fidelity and quality assurance (ECHOc). All experienced coaches receive didactic training (eight face-to-face days) in MI and in the ECHO model based on the intervention book and DVDs. Experienced coaches are closely supervised with training cases (outside the study). They can only take on study participants once they have obtained a minimal level of competence as assessed by expert supervisors using the MITI 3.1.1 rating measures (Moyers et al., 2010). The coaching sessions are audio-taped, and sessions 3 and 7 are transcribed and coded using the MITI 3.1.1 to assess treatment integrity and fidelity. Feedback generated by the MITI 3.1 is also used for the purposes of supervision and ongoing training. Coaches may access further supervision on demand. The level of background experience of the experienced coaches varies, but the self-directed aspects of training allow for variable levels of practice and review. Coaches are required to give a brief overview of each session in a session record form for each family and complete the Positive and Negative Affect Scale (Watson, Clark, & Tellegen, 1988) twice per family (sessions 3 and 7) before and after the session.

Treatment as usual

The NICE guidelines have one Grade B and several Grade C recommendations for the treatment of AN in adolescents and young adults (2004). Accordingly, most people with AN should be managed on an outpatient basis with psychological treatment and physical monitoring provided by a healthcare professional competent to administer care and assess physical risk. NICE recommends this combination of treatment for at least 6 months duration, with more intensive forms of treatment to be considered in cases of significant deterioration, nonimprovement or in cases of physical risk. Weight restoration in an outpatient setting should aim for an average weekly weight gain of 0.5 kg, and for adolescents, family interventions that directly address the ED should be offered (grade B). Furthermore, when treating adolescents, family involvement should be encouraged because of the effects of AN on other family members. Meanwhile, individual appointments (separate from family members or carers) should be made available to the patient.

The treatments delivered at each centre differ, for example, the amount of contact time between patients and carers with professionals. The profile of each service is captured by Service Information Schedule (SIS) (detailed later). A variable describing the amount of direct carer-professional contact will be used as a covariate.

Those allocated to the TAU arm will be informed that they will have access to the intervention on completion of the study and given contact details for Beat, the leading UK ED charity.

Outcome measures

Participants (patients and carers) will complete assessments at baseline and over the course of 1 year by telephone interview and self-report by post or email. The assessments measure key outcomes and prognostic variables.

Patient assessments

1. Clinical and demographic information (baseline)
2. The SEED (Bauer, Winn, Schmidt, & Kordy, 2005) is a valid and reliable measure developed for the repeated measurement of ED symptoms over time. Regular monitoring allows identification of patterns of change and events during treatment (e.g. rapid response to treatment) that can contribute towards the further planning and development of complex interventions. The SEED assesses ED symptoms over the past week and can be completed as clinician interview or by self-report. Unlike the Eating Disorder Examination (Cooper & Fairburn, 1987), the SEED does not distinguish clearly between different aspects of attitudinal components; however, it provides a short measure that is quick to administer (5 minutes completion time) and sensitive to change. The SEED is scored by means of an algorithm including weight and key symptoms (baseline and monthly for 1 year).
3. The ED and Autistic Spectrum Sections of the (computerised version) Development and Well-being Assessment (DAWBA; www.dawba.com) (Goodman, Ford, Richards, Gatward, & Meltzer, 2000) are validated semi-structured assessments completed by an informant (primary caregiver) and the individual themselves. Preliminary clinical diagnoses [according to DSM-IV (APA, 1994), and ICD-10 (WHO, 2010)] are derived by an internal computer algorithm. An experienced clinical rater (N. M.) then reviews these, taking into account open-ended comments, and assigns a final diagnosis (baseline, 1 year).
4. The Social Aptitude Scale (Liddle, Batty, & Goodman, 2009) is a 10-item assessment instrument, completed by an informant, as part of the DAWBA. It measures skills in social understanding and behaviour. A cut-off score of 16 (lower scores indicate poorer social aptitude) is associated with sensitivity of 0.93 and specificity of 0.93 for the diagnosis of autism spectrum disorders. A modal score of 20 was found using data from a large epidemiologically based study of young people in the UK (http://www.dawba.com/SAS) (baseline, 1 year).
5. The Strengths and Difficulties Questionnaire is a well-validated 25-item questionnaire, completed by an informant and by the individual themselves, as part of the DAWBA. It is composed of five scales that assess behaviour problems, hyperactivity, emotional symptoms, peer problems and prosocial skills (Goodman, 2001). The sum of the first four subscale scores forms a total difficulties score. Ratings of child distress and the impact of difficulties on social capital form a total impact score. A follow-up version assesses change in difficulties, using a five-point Likert-type scale (www.sdqinfo.com) (baseline, 1 year).

6. The Clinical Impairment Assessment 3.0 (Bohn & Fairburn, 2008) is a 16-item scale to assess ED-related impairment on psychosocial functioning (baseline, 1 year).
7. The Depression, Stress and Anxiety Scale 21 (Lovibond & Lovibond, 1995) is a 21-item self-report measure of emotional symptoms (depression, anxiety and stress) validated in both clinical and nonclinical samples with good internal reliability (baseline, 6-months, 1 year).
8. The Children's Yale-Brown Obsessive–Compulsive Scale Self-report (Piacentini, Langley, & Roblek, 2007) measures presence and severity of obsessive–compulsive symptoms. It is a self-report version of the Gold Standard interview measure for obsessive–compulsive disorder (Scahill et al., 1997) (baseline).
9. The Brief Dyadic Scale of Expressed Emotion Patient Version (Medina-Pradas et al, unpublished) is a 14-item scale to measure patients' perspectives of levels of expressed emotion of their carers. Three subscales measure perceived criticism, perceived emotional involvement and perceived warmth. The scale is completed separately for each participating carer (baseline, 6 months).
10. The Treatment Satisfaction Questionnaire (Roots, Rowlands, & Gowers, 2009) is an established instrument rating prior expectation of, and motivation to participate in, treatment they have received (randomised or not) on a Likert scale. The measure includes an area for free expression about any aspect of the services they have received (baseline, 6 months).
11. The Client Service Receipt Inventory (CSRI) is a well-established interview method of data collection, linked to cost analysis (Beecham & Knapp, 1999). A brief version is developed for this study, to document each young person's use of specialist and generic health services and education or employment (baseline, 6 months and 1 year).

Carer assessments

1. Clinical and demographic information (baseline)
2. The Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995); see earlier discussion for details (baseline, 1 year)
3. The General Health Questionnaire 12 (Goldberg, 1972) is a well-validated 12-item measure assessing general well-being over the previous few weeks using a four-point Likert scale (baseline, 1 year).
4. The Family Questionnaire (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002) is a 20-item self-report measure of expressed emotion in carers. Scores are given on a four-point Likert scale and form two subscales: emotional over-involvement and criticism. Good internal consistency is reported (Wiedemann et al., 2002) (baseline, 6 months).
5. The Accommodation and Enabling Scale for EDs (Sepulveda et al., 2009) is a 33-item self-report measure including five subscales: avoidance and modifying routine, reassurance seeking, meal ritual, control of family and turning a blind eye. Internal consistency for the scale is good (baseline, 6 months).
6. The Autism Quotient 10 (Allison, Auyeung, & Baron-Cohen, 2012) is a 10-item self-report version of the original Autism Quotient instrument measuring social skills, attention switching, attention to detail, communication and imagination. A cut-off point of 6 is indicative of autistic spectrum disorder (baseline).
7. The Obsessive–Compulsive Inventory—Revised (Foa et al., 2002) is an 18-item self-report measure that assesses the frequency and associated distress of six obsessive–compulsive symptom domains and a cut-off point of 21 indicative of obsessive–compulsive disorder (baseline).
8. Family Meal Patterns (Neumark-Sztainer, Wall, Story, & Fulkerson, 2004) selected questions are included to assess attitudes to eating, weight or shape within the family and family eating patterns (baseline).
9. The Treatment Satisfaction Questionnaire (Roots et al., 2009), as discussed earlier (baseline, 6 months)
10. The CSRI (Beecham & Knapp, 1999), as discussed earlier. Also details additional expenses for them or their family as a consequence of AN (baseline, 6 months and 1 year).

Primary outcomes

The primary outcome is the rate of change of a summary symptom score measured at 6- and 12-month follow-up from the SEED. Weight data at assessment are obtained from the outpatient team and thereafter via a monthly telephone interview (SEED) with patients. In cases where patients themselves feel or are unable to complete the SEED, consent to contact a professional who regularly records their weight will be obtained.

Secondary outcomes

Secondary outcomes include general psychiatric morbidity of AN patients and carer, carers' coping and behaviour, and change in healthcare use and costs at 6 months (end of treatment) and 1 year (follow-up), between groups (ECHOc, ECHO and TAU). These include group difference in change from baseline in

- DAWBA diagnosis at 1 year
- Clinical Impairment Assessment scores in AN at 1 year
- health and social costs at 6 months and 1 year
- depression, anxiety and stress in AN and carers measured at 1 year
- expressed emotion (Family Questionnaire) and accommodation and enabling behaviours (Accommodation and Enabling Scale for EDs) at 6 months. Change in these scores as mediators of outcome for both carer and patient
- carer and patient obsessive–compulsive and autistic traits as moderators of outcome
- familial eating patterns and attitudes as moderators of outcome

Process evaluation

Acceptability of ECHOc will be assessed using a visual analogue scale completed by carers. The utilisation of ECHOc will be assessed using a self-report measure asking carers and coaches to rate the amount of the book read, DVDs watched and number of telephone sessions received. Carers will be asked to rate their coach across different dimensions and the utility of the intervention for specific areas of interest (e.g. responses to the ED, communication and own distress). We will examine how quality impacts on outcome, in order to determine how quality should be assessed and controlled in the definitive trial.

Economic evaluation

Service Information Schedule (SIS): The SIS is used to record details of staff grade and time use, travel and other expenses, materials (book, DVDs and recording devices) as well as training and supervision provided to telephone coaches. These data allow estimation of the unit cost of the ECHO intervention. Staff costs will include salary overheads.

The CSRI (Beecham & Knapp, 1999) is a well-established resource-use schedule. It has been specifically adapted for this evaluation, to record patients' and carers' service use over the 6 months prior to each interview, distinguishing service use related to AN and for other reasons. Out-of-pocket expenses, social security benefit receipt and absences from work or education are also recorded, as is reduced work productivity and the impact of AN on their daily routine.

Observed confounding variables

The following patient (P) and carer (C) variables will be included into statistical models as potential confounding variables:

- demographic information (P, C): self-report gender, age, marital status, education level and employment status
- ED history (C): a binary (yes/no) question about whether the carer has a history of difficulties with eating/shape/weight
- illness severity (P): duration of illness, lowest lifetime body mass index (BMI), comorbidity and number of previous hospital admissions due to their ED. Current BMI and whether they use vomiting as a compensatory behaviour will also be included (randomisation stratification). All will be entered as separate possible confounders
- treatment (P): centre of treatment will be coded.
- readiness to change (P): patients are asked to rate the importance of and confidence to change their ED on a Likert-type scale (0–10).
- contact time (P, C): amount of face-to-face and other contact and whether carer and patient are living together
- carer involvement (P, C): frequency of carer involvement in treatment and support received (e.g. carer support groups), number of carers involved and binary variable for whether both parents are involved (yes/no).

Statistical analysis plan

Outcome analysis

All main analyses will follow the 'intention to treat' principle; that is, patients will be analysed in the groups to which they were randomised irrespective of treatments received.

A summary approach will be taken. Because this is a pilot trial, we do not anticipate having sufficient numbers to use repeated measures models. The time trend in AN symptoms as measured by SEED over 12 months for each person will be estimated using an appropriate method, and effect sizes will be calculated; for instance, a linear regression model will be used if the trend is linear over time (we will explore other models if this is not the case). The parameter from these models that estimates the trend over time (i.e. the slope parameter) will be extracted for each person. The difference between the groups in the rate of change over time will then be examined by means of an analysis of variance test applied to these summary parameter data. Tukey's correction will be used to adjust for multiple statistical tests.

Economic evaluation

The number of contacts with healthcare services will be compared. In addition, a unit cost for each service will be estimated using a compendium of nationally applicable data (Curtis & Netten, 2008) or using an equivalent methodology, including that for the interventions. Costs per case will be calculated as the unit cost multiplied by the use made of each service over the 3 months prior to interview with repeat measures at 6 and 12 months. Costs of ECHOc will also be estimated to include training, supervision and number/duration of contacts with each carer.

Discussion

The aim of this pilot trial is to investigate the use of the ECHO intervention (guided and not guided) for adolescents with AN or EDNOS-AN at an early stage of illness referred for outpatient care. The intervention is based upon an interpersonal maintenance model of EDs (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013) and represents the next step in a series of experimental studies developing ECHO. This study will be the first to investigate the use of guided skills training for carers of adolescent sufferers, most of whom are at the early intervention stage (i.e. initial stage of the illness), by using quantitative measures for both patient and carer outcomes. The design of this intervention is novel, as the needs of family members themselves have not been taken into account in the field, despite the high levels of dependence and disability associated with AN.

Limitations and challenges

First, the necessity to involve both patients and carers may have a negative effect on the accrual rate. However, this is a novel aspect of the study, as the well-being and costs of care by parents of adolescents with AN have not been considered previously. We anticipate that the assessment procedure will seem burdensome at times, and we will accommodate participants' needs where possible (e.g. alternative reliable correspondence for weight data). We anticipate that the families who are allocated to TAU may be disappointed and may not adhere to follow-ups. We will strive to minimise this by offering carers the intervention materials on completion of the project and by sending regular newsletters and personalised reminders, birthday greetings and others. An additional difficulty with the design of the trial is the heterogeneity in treatment provision across treatment centres, and individuals and families will vary in their level of engagement in treatment programmes. This heterogeneity is acknowledged in the use of pragmatic trial design and a randomised procedure that stratifies by treatment centre. Furthermore, the record of services used on the CSRI will help identify any differences between the areas. The level of motivation, receipt of individual treatment and family involvement in treatment can be included in the analysis.

Training and support for telephone coaches is another challenge, as coaches are themselves volunteers and cannot commit to the level of training and supervision that other professionals may receive. In addition to the supervision offered in different formats (e.g. telephone, email and face to face) and quality control, we will share new developments through the website developed by P. M. www.thenewmaudsleyapproach.co.uk We will also provide annual conferences for carers (with special sessions for the carer coaches) to enable them to meet the team face to face and to also place their participation in the research into the larger context of research and development in this area. The carer coaches will also be invited to more specific training held at South London and Maudsley NHS Foundation Trust for professionals. Members of the research team will also accept invitations to talk about the study at the local recruitment sites.

Conclusion

This paper outlines the protocol for a project that will add to the small literature base on interventions for AN and EDNOS-AN, focusing on adolescents at the early stage of illness. We have outlined the components of the ECHO intervention and clearly stated the research methodology in accordance with recommendations that will improve reporting and replication of treatment evaluations (Glasziou, Meats, Heneghan, & Shepperd, 2008; Moher et al., 2010). We hope that the findings from this study will determine the parameters for, and be used to execute, a definitive trial. Overall, we hope to pave the way for more integrated and collaborative interventions that have the potential to improve outcome in AN and EDNOS-AN at a small cost to services.

Trial registration

ISRCTN83003225—ECHO

Ethics and governance

Main ethics approval has been granted by the Northwick Park Hospital Ethics Committee (11/H0724/4). Site-specific ethics and governance approval has been granted on all participating sites and this study adopted by the MHRN.

List of abbreviations

ED, eating disorders; AN, anorexia nervosa; EDNOS-AN, Eating Disorder Not Otherwise Specified, Anorexia Nervosa subtype; ECHO, Experienced Coaches Helping Others; RCT, randomised controlled trial; NICE, National Institute of Health and Clinical Excellence; MI, motivational interviewing.

Competing interests

J. T. is an author of the book used in the ECHO intervention (Treasure et al., 2007). R. H., C. R., E. G., P. M. and G. T. provided coaching in the ECHOc treatment arm.

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CHAPTER 7.

STUDY 5: A LONGITUDINAL EXAMINATION OF DYADIC DISTRESS PATTERNS FOLLOWING A SKILLS INTERVENTION FOR CARERS OF ADOLESCENTS WITH ANOREXIA NERVOSA

Paper under review

Rhind, C, Salerno, L., Hibbs, R., Micali, N., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., Tchanturia, K., Lo Coco, G., & Treasure, J. (2015, *under review, J of Affective Disorders*). A longitudinal examination of dyadic distress patterns following a skills intervention for carers of adolescents with anorexia nervosa.

7.1 Abstract

Background: Family interventions in AN have been developed to ameliorate maladaptive patterns of patient-carer interaction that can play a role in illness maintenance. The primary aim of this study is to examine the inter-relationship between baseline and post-treatment distress in dyads of carers and patients with AN in order to examine the interdependence between carers and patients. A secondary aim is to examine whether a carer skills intervention (Experienced Carer helping Others; ECHO) impacts on this inter-relationship. **Methods:** Dyads consisting of treatment-seeking adolescents with AN and their primary carer (n=149; mostly mothers), were randomised to receive a carer skills intervention (ECHO) in addition to treatment as usual (TAU) (n=99, 66%), or TAU alone (n=50, 34%), as part of a larger clinical trial. Carers and patients completed a standardised measure of psychological distress (DASS) at baseline and 12-months post-treatment. The Actor Partner Interdependence Model was used to examine longitudinal changes in interdependence by treatment group. **Results:** As expected, post-treatment levels of distress were related to baseline levels in both groups (actor effects). Carer distress at 12 months was related to patient distress at baseline for the TAU (partner effects), but not for the ECHO group. **Limitations:** These findings are limited to predominantly mother-offspring dyads and may not generalise to other relationships. **Conclusions:** The ECHO intervention which is designed to teach carers skills in illness management and emotion regulation may be an effective addition to TAU for ameliorating interdependence of distress in patients and their primary carers over time.

7.2 Introduction

AN develops in adolescence (Micali et al., 2013) and the prognosis is improved with early intervention (Treasure, Stein, et al., 2015). The evidence base concerning treatment for adolescents with AN indicates that involving the family is a key factor (Lock, 2015). Family based therapy has been studied most extensively (Lock, 2015). Family based therapy is not based on any underpinning theoretical framework; rather parents are empowered to manage the ED (Lock & Le Grange, 2013). Most research using family based treatment has only measured patient outcomes and the impact on carers is unknown.

Caring for an individual with an ED is burdensome (Raenker et al., 2013) and is associated with distress and a reduction in quality of life (Anastasiadou et al., 2014). The caregiving role can be "virtuous" as exemplified in family based therapy but "vicious" circles of interaction can develop whereby high expressed emotion, accommodation or collusion with the symptoms are elicited by the ED symptoms and serve to maintain the illness, as described in the cognitive interpersonal model (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). These less helpful forms of behaviours are often associated with high levels of distress and anxiety in both the patient and the parent (Goddard, Salerno, et al., 2013). Parent distress and burden can be reduced by interventions for parents (as described in a systematic review (R. Hibbs et al., 2014)). However not all of these interventions have targeted these "vicious" circles of interaction.

The carer skills intervention (Experienced Carer helping Others; ECHO) was specifically developed (Treasure et al., 2007) to target the interpersonal relationship patterns developed in the cognitive interpersonal model. One facet of the model is based on the premise of emotional contagion within families whereby observing the emotional expressions of another person causes an automatic tendency to share the person's experiences (Frith & Frith, 2006). Carers are therefore taught emotional regulation strategies so that they do not mirror the distress in their offspring (a potential "vicious" circle which escalates distress in the family). Carers are also taught how to reduce their own emotionally-driven behaviours such as overprotection and/or criticism and accommodation. There have, as yet, been no longitudinal studies that have examined whether this intervention does impact on the relationship between parent (or primary caregiver) and their offspring with AN.

Most studies about family involvement in the management of people with EDs have assessed changes in psychological distress of parents and/or patients. These approaches evaluate how the members of the dyads (patients and parents) change individually, but they do not capture if and how the dyads' inter-relationship have changed. To date, no studies have examined changes in mutual interdependence. This study uses the Actor–Partner Interdependence Model (APIM; Kashy & Kenny, 1999; Kenny, 1996) as a method for identifying relational changes. The APIM model has been used to examine mutual collaboration or influence by modelling the impact of one dyad member's ratings on the other member's ratings (partner effects). This model has been used in a variety of settings, including those where there is chronic illness in one family member, for example, spouses with chronic heart failure (Chung, Moser, Lennie, & Rayens, 2009; Vellone et al., 2014), children with asthma (Rayens & Svavarsdottir, 2003), cystic fibrosis (Driscoll, Schatschneider, McGinnity, & Modi, 2012) and elderly parents (Kim, Reed, Hayward, Kang, & Koenig, 2011).

The aim of this study was to examine the relationship over time between parent (or other primary carer) and ED patient distress levels, and whether this interaction could be improved with the augmentation of the ECHO intervention. We hypothesized that carers' initial distress would be positively related to their distress at the end of treatment in both of the two treatment conditions; and that patients' initial distress will be positively related to their distress at the end of treatment in both of the two treatment conditions (actor effects). Secondly, we predicted that, in the treatment as usual condition, patients' distress at baseline would predict carers' distress at time 2 (partner effect); whereas, for the carers given the ECHO intervention, no such relationship would be found, because one of the skills taught in the ECHO intervention was emotional regulation and a calm caregiving style; and therefore the partner effect would be ameliorated.

7.3 Methods

7.3.1 Design and Participants

This longitudinal study was a part of a multi-site randomized controlled trial examining the effect of a carer skills intervention (Experienced Carers Helping Others; ECHO) on the outcome of adolescents newly referred for specialist outpatient treatment for AN (Rhind, Hibbs, et al., 2014). Thirty eight ED outpatient services across the UK recruited patients (n=149) and up to three of their carers (n=226) for the study. Carers were identified as by the patient and needed to be currently living with the patient with the intention of living together for the following year. “Carers” are defined by criteria of the Princess Royal Trust (www.carers.org) as someone who provides unpaid help and support to a parent, child partner, relative, friend or neighbour. Carers were furthermore classified as primary, secondary or other, based on contact time spent providing support to their relative with an ED.

The collaborating sites included 17 Child and Adolescent Mental Health Services (CAMHS), 13 Adult Mental Health Services and eight offering both CAMHS and Adult teams. All sites were managed within the National Health Service (NHS) and are listed in the acknowledgements section. Ethics approval was granted by the Northwick Park Hospitals Ethics Committee (11/H0725/4). Site specific ethics and governance approval was granted on all participating sites and this study adopted by the Clinical Research Network.

Consenting carers of patients aged 13-21 years with a primary diagnosis of AN or EDNOS-AN, according to the DSM-IV criteria (APA, 1994) as the diagnostic tool in use at the time of study recruitment (all patients would meet the DSM-5 criteria for AN or atypical AN (APA, 2013)) were randomly allocated to receive treatment as usual (TAU) or TAU in addition to ECHO. For the purposes of the present study, all patients randomized to the clinical trial and their primary carers only (*n* = 149 carer/patient dyads, typically mother/offspring dyads), were included in the analysis. Participants were grouped according to the type of treatment they received: 99 (66%) dyads received the ECHO intervention and 50 (34%) dyads received TAU alone. See Table 1 for participants' demographics.

Table 1. Demographic and clinical characteristics of the sample.

	ECHO group (n = 99)	TAU group (n = 50)
	Mean (SD)/N (%)	Mean (SD)/N(%)
Patient		
Age	16.90 (2.17)	16.86 (2.06)
Female : Male	89 (90): 10 (10)	48 (96): 2 (4)
Ethnicity		
White British/Other White	93 (94)	47 (94)
Asian/Asian British/Other Asian	2 (2)	3 (6)
Mixed White and Black	3 (3)	0
African/Caribbean	1 (1)	0
Missing		
BMI on admission (kg/m²)	16.77 (2.33)	16.99 (2.03)
Weight for Height %	82.23 (11.88)	84.10 (10.16)
Primary diagnosis		
Anorexia nervosa	71 (72)	41 (82)
Atypical anorexia nervosa	28 (28)	9 (18)
Illness duration (months)	22.21 (22.37)	22.62 (22.61)
Primary Carers		
Age	48.17 (5.78)	48.52 (4.92)
Female : Male	92 (93): 7 (7)	50 (100): 0 (0)
Carer type		
Mother	90 (91)	49 (98)
Father	7 (7)	0
Grandmother	1 (1)	0
Sibling	1 (1)	1
# years in education	15.18 (2.71)	15.98 (5.03)
Employment status		
Full time	34 (34)	13 (26)
Part time	35 (35)	24 (48)
Unemployed / retired / sick leave / student	22 (22)	10 (20)
Other	8 (8)	3 (6)
Ethnicity		
White British/Other White	94 (94)	47 (94)
Asian/Asian British/Other Asian	2 (2)	1 (2)

	ECHO group (n = 99)	TAU group (n = 50)
Other ethnic group	0	1 (2)
Missing	3 (3)	1 (2)
Marital status		
Married / living together	72 (73)	38 (76)
Single/divorced /separated/widowed	27 (27)	12 (24)

7.3.2 Procedure

Following consent families were randomised to ECHO treatment or TAU. The ECHO materials and coaching were delivered from the research hub. There was no further interaction between the research hub and the contributing clinical sites where usual care was delivered. Follow up assessments included (computerised self-report instruments and structured interviews for both parent and patients).

7.3.3 Intervention

Treatment as usual

The National Institute of Health and Clinical Excellence (NICE) guidelines have one grade B and several Grade C recommendations for the treatment of AN in adolescents and young adults (NICE, 2004). Accordingly, most people with AN and atypical presentations should be managed on an outpatient basis with psychological treatment and physical monitoring provided by a health care professional competent to administer care and assess physical risk. NICE recommends this combination of treatment for at least six months duration, with more intensive forms of treatment to be considered in cases of significant deterioration, non-improvement or in cases of physical risk. Weight restoration in an outpatient setting should aim for an average weekly weight gain of 0.5kg and for adolescents, family interventions that directly address the ED should be offered (grade B). Furthermore, when treating adolescents, NICE guidelines endorse family involvement because of the effects of AN on other family members.

As would be expected for a pragmatic trial in EDs, ‘treatment as usual’ varied to some degree across the 38 collaborating sites included in the present study. However, that ‘treatment as usual’ accessed by patients in the present study sample was comparable between the two treatment groups (treatment as usual alone (TAU) vs TAU+ECHO intervention) as confirmed by no significant differences in tests of group comparison using Mann-Whitney U tests. During the 6-month period from ED outpatient referral, 80.59% of patients received some form of individual therapy (TAU=82%, ECHO=80%), 23.5% of the sample received family therapy (TAU=24%; ECHO=23%), and 33% received dietician counselling (TAU=22%; ECHO=38%). A further 44% of patients also reported visiting their General Practitioner during this time for reasons related to their ED (TAU=48%; ECHO=41%), 11% reported using self-help or telephone helplines (TAU=14%; ECHO=9%) and 34% of the patient sample also reported use of other services, such as the community psychiatric nurse, crisis intervention team, or occupational therapy (TAU=34%; ECHO=41%). During this 6-month period following outpatient referral, 21.5% of patients (TAU=18%; ECHO=23%,) were admitted to inpatient ED/general psychiatric services, 9% entered a daypatient ED programme (TAU=12%; ECHO=7%), and 15% accessed General Hospital (e.g. Emergency) services for medical reasons related to the ED (TAU=20%; ECHO=13%).

Carer skills intervention (Experienced Carers Helping Others; ECHO).

This included a book (Treasure et al., 2007) and DVDs and 50% of the sample (n=50) also received carer coaching. The content of the intervention has been summarised (Treasure, Rhind, et al., 2015) and includes teaching carers emotional self-management, how to restrain their own emotionally driven behaviours (high expressed emotion, including emotional over-involvement, and accommodating and enabling behaviours) and communication skills (the basic principles of motivational interviewing.

7.3.4 Measures

Carers and patients provided standard demographic (age, ethnicity, marital/living/employment status, years in education, contact time with relative) and clinical information (illness duration, number of previous admissions, diagnosis, height and weight) by self-report as part of the baseline assessment of the larger trial. Patient diagnosis, number of previous admissions, height and weight information were validated by clinicians at the treating site. Both Body Mass Index (BMI) and age standardised weight-for-height percentage, using Great Ormond Street Hospital for Children criteria, version 4.22 UK, were calculated for each patient.

The Depression, Anxiety, and Stress Scale (DASS-21; Lovibond & Lovibond, 1995) was used as an overall assessment measure of psychological distress in patients and carers at baseline (pre-treatment) and 12-month follow-up (post-treatment). The DASS is a 21-item measure assessing depression, anxiety, and stress over the past 7 days using a 4-point Likert Scale. The scores of these three subscales can be added to obtain a total score for psychological distress. Only the total score were considered in this study. This instrument has good psychometric qualities (e.g. Cronbach's alpha = .87 - .94; Antony, Cox, Enns, Bieling, & Swinson, 1998) and has good internal consistency in the present study (DASS at T0: Cronbach's α = .94 and .94 for patients and parents, respectively; DASS at T1: Cronbach's α = .96 and .95, for patients and parents, respectively).

7.3.5 Statistical Analyses

Data were acquired from questionnaires collected from both patients and carers at two time periods: T0 (baseline assessment, prior to treatment) and T1 (following one year of treatment). Descriptive statistics (mean and standard deviations) were examined. Assumptions for parametric data were evaluated and no positive skewed distributions were found. Paired samples t-tests were conducted on patients and carers' DASS to examine differences between T0 and T1 assessments.

The APIM model tested in this study is displayed in Figure 1. Mplus software version 6.12 was used to test the model in Figure 1. Because the path model examined is identified no model fitting statistics were generated. Using regression language to describe the relationships depicted in the figure there are two actor effects: (a) the effect of the parents' distress (depression, anxiety and stress) at T0 on their own distress at T1 and (b) the effect of the patients' distress at T0 on their own distress at T1. There are also two partner effects: (a) the effect of the parents' distress at T0 on their children's distress at T1 and the effect of the patients' distress at T0 on their parents' distress at T1. The APIM also models two within dyad correlations: the relationship between parents' and patients' distress at T0 and the relationship between parents' and patients' Time 1 scores. The distress dyadic correlations model the interdependence that results from members of a family sharing a common burdensome experience.

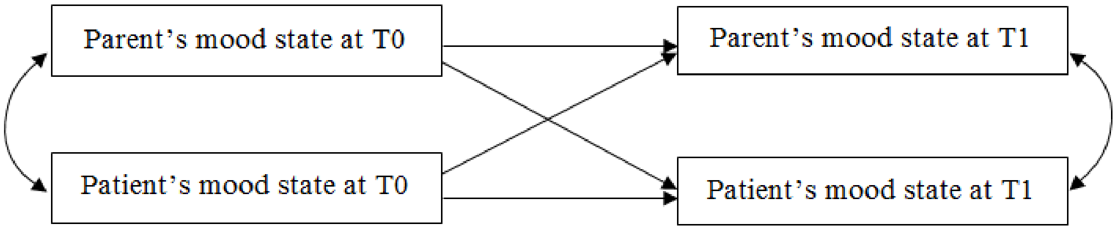

Figure 1. APIM for carers' and patients' mood state at intake and one-year follow-up

7.4 Results

7.4.1 Baseline Characteristics of Patient–carer Dyads

The clinical and socio-demographic characteristics of the patient group and their care givers are shown in Table 1. The patients were adolescents (average age 16.6 years) with a short duration of illness (22 months). The average BMI was 16.8 (age-adjusted weight-for-height 83%) and 75% fulfilled the criteria for ICD-10 AN and 25% for atypical AN. The majority (93%) of the primary carers were mothers, of whom 74% were married and

30% were in full time employment. Other primary carers included fathers (5%), siblings (1%), and grandparent (1%).

7.4.2 Carer and Patient Distress at baseline and 12 months follow up

The means and standard deviations for all of the variables examined in this study, separated for ECHO and TAU groups, are displayed in Table 2. Patients had high levels of distress at baseline (mean 67 (30)) and carers had low levels (mean 32 (28)). Patients' distress decreased over time to moderate levels in both the ECHO (t = 3.659 (df = 76), p< .001, ES = 0.38) and TAU (t = 3.381 (df = 31), p < .01, ES = 0.62) groups. Carers in the ECHO group had a small decrease (ES = 0.12) in DASS scores at T0 whereas in the TAU group there was a small increase (ES = -0.13) in DASS.

Table 2. Carer and patient distress (DASS) at intake (Time 0) and one year follow-up (Time 1) by treatment group.

	Time 0 M (SD)	Time 1 M (SD)	t	*p*	*d.*
ECHO group (n = 99)					
Carer distress	34.86 (26.88)	31.84 (24.62)	.784	.435	0.12
Patient distress	61.93 (31.24)	49.82 (31.82)	3.659	.000	0.38
TAU group (n = 50)					
Carer distress	29.28 (18.10)	32.46 (29.01)	-.589	.559	-0.13
Patient distress	72.20 (29.00)	52.92 (32.67)	3.381	.002	0.62

7.4.3 Actor–Partner Interdependence Model (APIM) Analyses

Actor Effects

The results of APIM approach are displayed in Table 3. For the TAU group patient and Carer's distress at baseline accounted for 36% and 23% of the variance in carer and patient's distress at T1, respectively (actor effects). For the TAU group, there were significant actor effects for both patients and carers. Specifically, carers' distress at baseline was a significant predictor of their own distress at Time 1 (β = .53, p < .001) and patients' distress at Time 0 was a significant predictor of their own distress at Time 1 (β = .46, p < .01). For the ECHO group patient and carer's distress at baseline accounted for 22% and 16% of the variance in carer and patient's distress at T1, respectively (actor effect). For the ECHO group also, there were significant actor effects for both patients and carers. Specifically, carers' distress at baseline was a significant predictor of their own distress at Time 1 (β = .42, p = <.001) and patient's distress at Time 0 was a significant predictor of their own distress at Time 1 (β = .41, p < .001).

Table 3. APIM analysis carers' and patients' distress at intake (Time 0) and 1 year follow-up (Time 1) by treatment group.

	Carer distress at Time 1				Patient distress at Time 1			
	b (β)	*SE*	*t*	*p*	*b (β)*	*SE*	*t*	*p*
ECHO group								
Carer distress at Time 0	.386 (.417)	.101	3.818	.000	-.012 (-.006)	.225	-.055	.956
Patient distress at Time 0	.119 (.148)	.084	1.420	.156	.759 (.407)	.207	3.664	.000
TAU group								
Carer distress at Time 0	.842 (.533)	.197	4.285	.000	.177 (.097)	.260	.682	.495
Patient distress at Time 0	.266 (.269)	.130	2.050	.040	.530 (.464)	.194	2.736	.006

Partner Effects

In the TAU group there was a significant partner effect between patient's distress at baseline and carer's distress at Time 1 (β = .27, p < .05). However in the ECHO group there were no partner effects for carers and patients.

7.5 Discussion

The aim of this study was to examine the relationship over time between the primary caregiver’s (typically mother) distress and that of the person with AN for whom they care (typically offspring). A secondary aim was to examine whether this interaction could be improved (i.e. reduce distress inter-dependence) with the augmentation of ECHO. We confirmed our first hypothesis in that we found that carers’ initial distress was positively related to their distress at the end of treatment in both of the two treatment conditions; and patients’ initial distress was positively related to their distress at the end of treatment in both of the two treatment conditions. We also confirmed our second hypothesis in that we found that carers who received the ECHO treatment were less impacted by patients’ initial levels of distress (i.e. no partner effects were found), whereas there were partner effects for the TAU group, as carers’ levels of distress at one year were related to the patient's initial level of distress. This suggests that the ECHO intervention, delivered in addition to TAU, was effective in ameliorating interdependence of distress over time.

There is evidence of interdependence between family members in chronic illness. In a study of families with elderly relatives a partner effect was found whereby caregiver's spirituality significantly influenced the elder's psychological well-being (Kim et al., 2011). However patients with chronic heart failure had poorer quality of life if their spouses had more depressive symptoms and high anxiety (Chung et al., 2009). Conversely better heart failure self-care was associated with better quality of life for their spouses (Vellone et al., 2014). The caregiving demands of a child with asthma had an impact on the perception of family adaptation by both parents (Rayens & Svavarsdottir, 2003). However to our knowledge this has been the first study which has examined the impact of an intervention targeting caregiving behaviours on these partner effects.

7.5.1 Limitations

We have only considered the interaction effect between the primary carer (predominantly mothers) and patient (typically offspring). Although up to three carers were invited to participate in the overall clinical trial, including fathers for 47% of patients, there were insufficient data to analyse other dyadic relationships. However, it would also be interesting to examine partner effects for fathers as anecdotally they can have an important impact. Furthermore, the patients included in this present study predominantly have a short illness course and a mild to moderate severity. Therefore these findings may be limited in the extent to which they can be generalized to more severe and chronic AN family dyads. Moreover, as inclusion criteria for the larger clinical trial required at least one carer to also participate, the present sample might be biased towards a sample with parents and other carers more actively involved in their care.

7.5.2 Clinical implications

These partner effects on distress suggest that the emotional regulation skills taught in the ECHO intervention had a beneficial effect in terms of breaking the vicious cycle of maintenance in which carers mirror the distress in their affected relative, which in turn leads to more distress in the patient, and other maladaptive caregiver responses (e.g. high levels of expressed emotion)/ These results validate the cognitive interpersonal maintenance model of AN as it suggests that a specific intervention targeting one of the maintaining factors can reduce carer distress (Treasure & Schmidt, 2013). Other family interventions that share skills in emotion regulation within an interpersonal context may also provide similar benefit.

7.5.3 Conclusion

Our findings suggest that Actor–Partner Interdependence Model of Analyses can be a useful method of examining the processes involved in family interventions. In the TAU group we found interdependence of distress between patients and primary carers (mostly mothers) over time. However, this mutual influence was not seen in the ECHO group. This suggests that skills taught in the ECHO intervention were having a positive effect in terms of breaking a positive feedback effect whereby parents mirror the distress in their offspring which in turn leads to more distress in the patient, as theorized in the interpersonal component of the cognitive interpersonal maintenance model of AN (Treasure & Schmidt, 2013).

7.6 Highlights

- We examined longitudinal dyadic distress patterns in adolescent AN
- We found interdependence between patient and primary carers’ distress
- A carer skills intervention (ECHO) ameliorated distress interdependence over time

Abbreviations: Actor-Partner Interdependence Model (APIM); Treatment as Usual (TAU); Experienced Carers Helping Others Intervention (ECHO); Depression, Anxiety and Stress Scales (DASS)

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CHAPTER 8.

DISCUSSION

8.1 Chapter aims

The aim of this chapter is to synthesise the study findings presented in this PhD thesis, to highlight their key strengths, limitations, and implications, and to make suggestions for future research. Finally, this chapter provides an overall conclusion of the present thesis.

8.2 Overview of research aims and findings

Socio-emotional difficulties in AN and distress-related caregiver responses to the illness are both theorized to play a role in illness maintenance. The first main aim of this thesis is use multimodal measures to extend the evidence for social communication difficulties (ASD-like traits and emotion expressivity) in treatment-seeking adolescents with AN. The second main aim is to establish the caregiving burden (distress and time spent caregiving) for families and the pattern of carer/patient interpersonal behaviour that are thought to play a role in illness maintenance. The third main aim is to examine whether the augmentation of treatment as usual with a carer skills intervention including skills to manage these interpersonal behaviours more effectively is of benefit. Five studies were conducted; their main aims and hypotheses are reiterated below and the key findings are summarised. An overall synthesis of the findings and discussion then follows.

8.2.1 Study 1 overview: An examination of autism spectrum traits in adolescents with anorexia nervosa and their parents

8.2.1.1 Study 1 main aims

The aims of this study were to use a multimodal assessment procedure to examine whether adolescents with AN have autism spectrum traits, to establish the prevalence of diagnostically relevant ASD amongst this patient group, and to examine whether ASD traits are elevated in their parents.

8.2.1.2 Study 1 hypotheses tested

It was hypothesised that (i) adolescents with AN would have higher levels of ASD-like traits (poorer social aptitude skills, greater peer difficulties, and obsessive-compulsive symptoms), relative to population norms; (ii) a higher proportion of these adolescents with AN would fulfil diagnostic criteria for ASD relative to healthy population norms, using the Development And Well-being Assessment (DAWBA); and (iii) parents of adolescents with AN would have higher levels of ASD-like traits (as measured by the short Autism Quotient (AQ-10) and the Obsessive-compulsive Inventory-Revised).

8.2.1.3 Study 1 main findings

- The hypothesis relating to higher levels of ASD-like traits was confirmed as adolescents with AN performed below average on social aptitude (of which 19% scored within clinical range indicative of ASD) and above average levels of peer difficulties relative to similar age population norms with small to large effect sizes (ES=-0.23 and ES=0.85 respectively). As expected, the cohort also showed elevated levels of obsessive-compulsive symptoms (56% of patients scoring within the range suggestive of clinical OCD).
- The hypothesis that there would be an increase in the prevalence of categorical ASD was also confirmed, as 4% of the cohort (n=6) met the diagnostic criteria for a (possible or definite) diagnosis of ASD, and this shows a small increase relative to the 1.1% prevalence of ASD in the UK normal population recently reported in a National Autistic Society research report (Mills & Kenyon, 2013).
- The hypothesis that ASD-like traits would also be elevated in the parents of this patient cohort was not confirmed, as parents' scores on the short Autism Quotient (AQ-10) and a measure of OCP-related traits fell within the normal range.
- The prevalence of increased ASD-like traits of clinical significance found in the present study is consistent with previous reports (e.g. Allen, Byrne, Forbes, & Oddy, 2009; Caglar-Nazali et al., 2014; Gillberg, 1992; Hambrook et al., 2008; Hughes et al., 2013; Krug et al., 2012; Nazar et al., 2008; Pooni, Ninteman, Bryant-Waugh, Nicholls, & Mandy, 2012; Råstam et al., 2003; Serpell, Hirani, Willoughby, Neiderman, & Lask, 2006; Tchanturia et al., 2013) although lower than the 40% rate of adolescents fulfilling the broad ASD phenotype reported by Baron-Cohen and colleagues (Baron-Cohen et al., 2013). Similarly, the small increase in ASD prevalence (4%) is lower than the previously reported 23% in individuals with severe AN hospitalised for treatment (e.g. Wentz et al., 2005); the

different measures used and severity and stage of AN are likely to account for some of these differences.

- Although previous studies have reported elevated ASD-like traits in parents of people with AN in the form of alexithymia and OCP traits (Anderluh et al., 2003; Lilenfeld et al., 1998), there are insufficient studies examining ASD traits in ED parents to meaningfully interpret the present study findings with regard to parental ASD traits.

8.2.1.4 Study 1 main strengths & limitations

- This is the first study to use the Developmental and Wellbeing Assessment (DAWBA) and inclusion of parents in the multimodal assessment of ASD-like traits and ASD prevalence in adolescent AN. As the DAWBA has been widely employed in large epidemiological studies in psychiatry, healthy population norms are available to draw meaningful comparisons, and because the DAWBA is developmentally based and involves triangulation of information across multiple informants (child and parent rating, computer algorithm, and overall clinician opinion) the results of the present study are more likely to be robust against the inflation of scores in ASD measures that has previously been noted and attributed to use of ineffective measures or inflated by the state effects (‘pseudo-ASD’) of acute phase AN (Mandy & Tchanturia, 2015). The findings of this study have been published in *Molecular Autism* and have already been cited in further discussions over the female manifestation of ASD and the AN/ASD overlap (Dudova, Kocourkova, & Koutek, 2015; Lai, Baron-Cohen, & Buxbaum, 2015).
- One of the main limitations of this study is the over-representation of mothers in the parent group and the choice of measures used to assess ASD-like traits. Although ASD traits are elevated in parents of people diagnosed with ASD using the Autism Quotient (Bishop et al., 2004; Kose et al., 2013; Mohammadi, Zarafshan, & Ghasempour, 2012; Ruta, Mazzone, Mazzone, Wheelwright, & Baron-Cohen, 2012) suggestive of a broad familial phenotype, this finding is less robust when examining mothers alone (Lau et al., 2013). It is possible that the short version of this measure designed as a ‘red flag’ for clinical ASD lacked

sensitivity in detecting ASD-traits in mothers of adolescents with AN, and a more thorough measure examining the broader ASD phenotype might have produced different results. For example, the Broad Autism Phenotype Questionnaire was developed to tap personality and language characteristics that reflect the phenotypic expression of the genetic liability to ASD in non-autistic relatives (Hurley, Losh, Parlier, Reznick, & Piven, 2007). The authors of this scale propose that these characteristics are milder but qualitatively similar to the defining features of ASD. Therefore, caution should be taken when interpreting the finding that ASD traits were not shared by parents in in the present study as the lack of findings may relate to ineffective measurement and more research is needed to draw firmer conclusions.

8.2.2 Study 2 overview: An exploratory study of evoked facial affect in adolescent females

8.2.2.1 Study 2 main aims

The aim of this exploratory study was to investigate for the first time facial affect in adolescent females with AN.

8.2.2.2 Study 2 hypotheses tested

It is hypothesized that, relative to healthy controls, adolescent females with AN will show less evoked positive and negative facial expression during both positive and negative film stimuli, despite no differences in subjective experience of positive and negative affect.

8.2.2.3 Study 2 main findings

- The hypothesis for this study was confirmed as adolescent females with AN displayed less positive facial affect during salient positive emotion stimuli (large effect size d.=-1.7) and less negative facial affect during salient negative emotion stimuli (large effect size d.=-1.6) than similar-age healthy controls (and after controlling for the effects of depression, anxiety and IQ) despite reporting no differences in subjective emotion experience.

- These findings are consistent with previous experimental findings in adults with severe and/or enduring AN also reporting reduced evoked positive and negative emotion in AN relative to healthy controls (also of large effect sizes) despite similar subjective emotion experience (Davies et al., 2011). These findings are in line with people with AN reporting that they do not express emotions (Geller et al., 2000).

8.2.2.4 Study 2 main strengths & limitations

- This is the first study to experimentally assess facial emotion expression in adolescent AN and therefore adds a significant contribution to the literature relating to altered socio-emotional functioning in AN. These findings have been published in *Psychiatry Research* and have already been cited in studies further exploring socio-emotional functioning in adolescent AN and the clinical implications (K. Lang et al., 2015; Tchanturia, Brown, & Fleming, 2015; Tchanturia, Dapelo, Harrison, & Hambrook, 2014; Tchanturia, Doris, Mountford, & Fleming, 2015).
- The main limitation of this study is the relatively small sample size and inclusion of a cohort of AN patients hospitalised for treatment. It is possible that the socio-emotional profile of this more severe inpatient group may relate to the effects of more severe starvation on the brain and/or a subgroup of patients at greater risk for illness chronicity. Therefore these findings may be limited in the extent to which they can be generalised to milder AN presentations.

8.2.3 Study 3 overview: Confirmatory factor analysis for two questionnaires of caregiving in eating disorders

8.2.3.1 Study 3 main aims

The aim of this study was to provide further validation of measures of caregiving in EDs by using confirmatory factor analysis (CFA) to investigate the factor structure of the Accommodating and Enabling Scale for Eating Disorders (Sepulveda et al., 2009) and the

Eating Disorder Symptom Impact Scale (Sepulveda, Whitney, et al., 2008) a relatively large sample of carers (n=268) of people with AN.

8.2.3.2 Hypotheses tested

It was hypothesized that the proposed four- and five-factor structures of the Eating Disorder Symptom Impact Scale and the Accommodating and Enabling Scale for Eating Disorders respectively will be confirmed in a larger cohort of carers of individuals with AN, and secondly, that the factor structures would be stable across primary and secondary carers.

8.2.3.3 Study 3 main findings

- The hypothesis for this study was confirmed as the results from the confirmatory factor analysis provide support for the validity of the existing four-factor structure for the Eating Disorder Symptom Impact Scale and the existing five-factor structure for the Accommodating and Enabling Scale for Eating Disorders for carers of AN patients, and demonstrate food reliability for these scales overall (Eating Disorder Symptom Impact Scale α = .87; Accommodating and Enabling Scale for Eating Disorders α =.93) and for their subscales (Eating Disorder Symptom Impact Scale α range .73 to .83; Accommodating and Enabling Scale for Eating Disorders α range .83 - .89).
- The second study hypothesis was also confirmed as multiple group confirmatory factor analysis showed that the factor structure of these scales is stable across both primary and secondary carers.
- The findings of this study corroborate those reported in the original scale development and validation (Sepulveda et al., 2009; Sepulveda, Whitney, et al., 2008).

8.2.3.4 Study 3 main strengths & limitations

- This study provides the largest validation of the Eating Disorder Symptom Impact Scale and Accommodating and Enabling Scale for Eating Disorders to-date and therefore provides robust validation for the use of these measures in assessing modifiable elements of caregiving for use in clinical settings (e.g. assessment of carer needs) and research (e.g. intervention evaluation). The findings of this study have been published in *Health Psychology and Behavioral Medicine* and have already been cited by a Spanish validation study of the Accommodating and Enabling Scale for Eating Disorder (Quiles Marcos, Quiles Sebastián, Pamies Aubalat, Sepúlveda García, & Treasure, 2015).

- The main limitation of this study is the inclusion of carers of adolescents and adults requiring hospital treatment (in- or day-patient), that limits the extent to which validation of these caregiving measures is relevant to their use at the earlier stage of illness and in milder AN presentations.

8.2.4 Study 4 overview: The Objective and Subjective Caregiving Burden and Caregiving Behaviours of Parents of Adolescents with Anorexia Nervosa

8.2.4.1 Study 4 main aims

The overall aim of this study was to explore the relationships between objective burden (time spent across care giving tasks), subjective burden (distress), skilful caregiving behaviours, less adaptive distress-related carer behaviours (accommodating behaviours and expressed emotion) theorised to play a role in illness maintenance and patient factors such as severity of ASD-like traits. A second aim was to use mediation analysis to investigate the relationships between caregiver burden and behaviours in response to the illness.

8.2.4.2 Study 4 hypotheses tested

It was hypothesised that (i) high levels of objective burden (time spent with care giving tasks) would be associated with high subjective burden (psychological distress); (ii) high levels of maladaptive caregiving behaviours (accommodating behaviours and expressed emotion and/or low carers' skills) would be associated with greater subjective burden; (iii) the level of maladaptive caregiving behaviours would mediate the relationship between objective and subjective burden.

8.2.4.3 Study 4 main findings

- Overall, mothers and fathers had high levels of objective caregiving burden (approximately 2.5h/day for mothers and 1hr/day for fathers, mostly spent managing nutrition and providing emotional support) and high levels of distress (approximately 30% of the sample within the moderate to severe clinical range). Distress and levels of accommodating were significantly higher in mothers than fathers and were significantly correlated with the level of ASD-like traits in the patients.
- The first hypothesis was confirmed in mothers only as their level of objective burden predicted their levels of distress (subjective burden).
- The second hypothesis was confirmed in full as levels of accommodating behaviour, expressed emotion, and carer skills predicted levels of distress (subjective burden) in mothers and fathers.
- The third hypothesis was confirmed in part as the level of accommodating behaviour in mothers mediated the relationship between their objective burden (total time spent care giving) and subjective burden (psychological distress). However, this was not true of fathers, and the level of expressed emotion and carer skills did not mediate the relationship between objective burden and subjective burden for either parent.
- The level of caregiving burden found in the present study is consistent with a previous similar study conducted in carers of severe and/or enduring AN (Raenker et al., 2013) and other studies reporting high levels of carer burden (Anastasiadou et al., 2014; Santonastaso et al., 1996; Treasure et al., 2001) fraught interpersonal patterns of behaviour (Haigh & Treasure, 2003; Perkins et al., 2004; Whitney et al., 2005; Winn et al., 2004) and specifically high levels of expressed emotion (Duclos et al., 2014; Le Grange et al., 2011; Sepulveda et al., 2010; Van Furth et al., 1996; Zabala et al., 2009) and accommodating (de la Rie et al., 2005; Goddard et al., 2011; Highet et al., 2005; Sepulveda et al., 2009) theorised to inadvertently maintain the illness and hinder recovery (Treasure & Schmidt, 2013).

8.2.4.4 Study 4 main strengths & limitations

- The study is the first to use multimodal assessment of caregiver burden, using clinical interview to ascertain objective caregiving burden (across specific care giving tasks), and self-report measures to assess distress, and ED-related caregiver behaviours in a relatively large (n=196) sample of carers of adolescent AN. This study is also the first to examine the mediating role of levels of accommodating on carers' distress.
- The main limitations of this study are the use of a cross-sectional design and over-representation of mothers in the parent sample. Therefore, the findings may not generalise to fathers of adolescents with AN, and the proposed direction of the relationships (e.g. objective burden 'predicts' subjective burden) is strictly theoretical based on the cognitive-interpersonal maintenance model of EDs (Treasure & Schmidt, 2013). Further analysis using longitudinal data is necessary to confirm the direction (which may be of a bi-directional nature).

8.2.5 Study 5 overview: A longitudinal examination of dyadic distress patterns following a skills intervention for carers of adolescents with anorexia nervosa

8.2.5.1 Study 5 main aims

The aim of this study was to use the Actor Partner Interdependence Model to examine carer/patient dyadic distress interdependence over time. The second main aim of this study was to examine whether the augmentation of a carer skills intervention (ECHO) to usual ED treatment would be beneficial for ameliorating dyadic distress interdependence.

8.2.5.2 Hypotheses tested

It was hypothesized that (i) for patients and carers, intake (pre-treatment) levels of distress would be positively associated with distress at end of treatment; and (ii) patients' intake levels of distress would predict carers' level of distress at end of treatment (i.e. distress interdependence) for the group receiving usual ED treatment only, whereas carer/patient distress interdependence would not be evident in the group augmented with the ECHO intervention.

8.2.5.3 Study 5 main findings

- The first hypothesis was confirmed as levels of distress in patients and carers were predictive of their levels of distress at end of treatment.
- The second hypothesis was also confirmed as carer/patient distress interdependence was evident in the group randomly allocated to receive usual treatment only (i.e. baseline patient distress predicted carer distress over time) but not in those receiving treatment augmented with the ECHO intervention.
- These findings are consistent with the interpersonal component of the maintenance model of AN (Treasure & Schmidt, 2013) and emerging evidence (Goddard et al., 2011; Goddard, Macdonald, et al., 2013; Hibbs, Magill, et al., 2015; R. Hibbs et al., 2014) showing that carer skills interventions are effective for breaking the vicious and perpetuating cycle of distress in EDs, within which maladaptive caregiver behaviours (accommodating, high levels of expressed emotion) are theorised to develop and inadvertently maintain patient distress and hinder ED recovery (Treasure & Schmidt, 2013).

8.2.5.4 Study 5 main strengths & limitations

- The main strength of this study is the inclusion of a relatively large sample of patients and carers (n=149 dyads) assessed longitudinally as part of a multi-site (n=38) pragmatic randomised controlled trial that is the first to evaluate the use of the ECHO intervention for adolescents with AN. These findings therefore offer a unique contribution to the ED literature.
- The main limitation of this study is the reliance on dyadic distress patterns as the primary outcome. Although improving negative family interactions related to distress and expressed emotion may improve the prognosis of the person with AN (Rienecke et al., 2015), further research is necessary to examine the specific impact of changes in dyadic distress patterns on other psychosocial and ED outcomes.

8.3 Synthesis of thesis findings

Overall the main findings of the research presented in this thesis provide empirical evidence to show that adolescents with AN have altered aspects of socio-emotional functioning (reduced emotion expressivity and elevated ASD traits) broadly within the ASD realm that is consistent with existing literature. Although the 'state effects' of acute phase AN cannot be ruled out entirely, these findings and those from the literature suggest that altered socio-emotional functioning in AN likely exists as a core disturbance (i.e. is present at illness onset) *and* is likely exacerbated by the secondary effects of starvation and illness over time (e.g. 'neuroprogression', habit-formation; Treasure, Stein, et al., 2015; Walsh, 2013), and this may account for the more severe profile associated with adults with severe and/or enduring AN (Treasure, Cardi, et al., 2015). Although these traits did not appear to be familial, it is possible that ineffective measurement contributed to null findings and caution should be taken when interpreting these results.

The findings of the present thesis also add the literature by providing empirical support for the interpersonal component of the cognitive-interpersonal maintenance model of EDs (Treasure & Schmidt, 2013) in adolescent AN and the benefit of carer skills interventions such as ECHO based on this model (R. Hibbs et al., 2014; Treasure, Rhind, et al., 2015). Specifically, the findings of the present thesis have used a randomised controlled trial design to prove the benefit of augmenting treatment as usual with ECHO, consistent with previous findings proving ECHO beneficial for carers and patients with severe and/or enduring AN for ED psychopathology, distress, and quality of life (Hibbs, Magill, et al., 2015). In this case, the benefit of ECHO for adolescent AN families was measured in terms of changes in dyadic distress interdependence over time (i.e. breaking the 'vicious cycle' of distress between carers and patients) using the Actor-Partner Interdependence model which emphasizes the bi-directionality of distress that is often overlooked. Furthermore, the findings of this thesis have shown that levels of accommodating behaviours are particularly high in carers of adolescents with AN (relative to carers of severe and/or enduring AN) and these levels mediate the relationship between objective burden and carer distress. Finally, the findings of this thesis have provided further validation for the use of the Accommodating and Enabling Scale for Eating Disorders and the Eating Disorder Symptom Impact Scale for measuring modifiable aspects of caregiving across primary and secondary carers (e.g. mothers and fathers) and that is sensitive to change and therefore suitable for pre-/post-intervention designs.

8.4 Strengths

The following discussion briefly discusses the global strengths of the research presented in this thesis as the specific strengths per study have already been highlighted.

8.4.1 Originality and clinical relevance of research

A general strength of the research presented in this thesis is its novelty and direct clinical utility. This research presents the first experimental assessment of facial emotion expression in adolescent AN, and unlike previous research, has employed multimodal methods of assessment for in-depth examination of socio-emotional difficulties in adolescent AN and the caregiving burden related to this group. This thesis also presents the first high-quality evaluation (i.e. pragmatic multi-site randomised controlled trial design) of a carer skills intervention applied to adolescent AN that represents a unique and major collaboration of ED services (n=38) across National Health England. This research has also highlighted for the first time using validated tools and a large sample that accommodating behaviours are particularly pertinent in families of adolescents with AN. In applying the Actor Partner Interdependence Model, this research has also demonstrated for the first time the bi-directionality of distress between carers and patients. The novelty of this research adds to the literature and specifically enables further theoretical refinement of the cognitive-interpersonal maintenance model of EDs with clinical implications.

8.4.2 Design & participant related

Another primary strength of this thesis is inclusion of a relatively large sample of treatment-seeking adolescents with AN and carers recruited from ED services throughout England with cross-sectional and longitudinal data. The cohort therefore provides a nationally representative sample of treatment-seeking adolescents with AN and of usual ED treatment reflexive of that provided by National Health Service England. The findings of the present thesis are therefore high in ecological validity and widely generalizable. The broad range of methodologies employed in this research (multimodal assessment, longitudinal data, and experimental assessment) that provides relatively robust empirical data facilitates a well-rounded and justified overall conclusion to this thesis.

8.5 Limitations

Whilst the limitations of the specific studies have already been highlighted in their respective chapter and study summary in this chapter, the global themes of importance relevant to this thesis as a whole are discussed below.

8.5.1 Participant related

The participants included in this thesis may be biased towards families who are actively involved in their child’s care. With the exception of study 2, patients and carers were recruited as part of a treatment study for carers and both needed to agree to take part to be included, and therefore a degree of interest and willingness to engage in family work may be over-represented by this group and not represent all treatment-seeking adolescents with AN and their carers.

Another participant-related limitation is that fathers and males with AN were particularly under-represented in this research. Differences in the caregiving role between mothers and fathers has been highlighted and recent findings have shown that while mothers’ expressed emotion was predictive of family functioning, fathers’ expressed emotion was predictive of ED outcomes in the patient (Rienecke et al., 2015). Furthermore, although the presentation of male AN is described as similar to that of female AN, there is very little research investigating socio-emotional impairments in males with AN. For example, all research investigating facial emotion expression in AN to-date has included females with EDs only. It has been shown that women smile more than men (Barr & Kleck, 1995; Briton & Hall, 1995) and generally “specialize” in expressions of happiness (Coats &

Feldman, 1996). Although studies are conceptually justified in examining these processes in males and females separately, they offer limited utility to the treatment of male AN. Therefore, the findings of this thesis that are mostly based on adolescent females with AN and carers who are predominantly mothers. Findings may be limited in the extent to which they can be generalised to adolescent males with AN and to carers who are fathers or close others (e.g. partners, siblings).

A final limitation of the participant group is the broad use of 'AN' and 'adolescents', both of which were not strictly defined. As previously noted, DSM-IV was the diagnostic tool currently in use at the time of recruitment for all the AN and EDNOS-AN participants in the present research, and the results have been generalised to current DSM-5 criteria for AN and atypical AN. Furthermore, given that ED diagnostic flux is common (Eddy et al., 2008; Milos et al., 2005), particularly with people with AN crossing over to BN within the first year of onset (Bulik et al., 1997; Eckert et al., 1995; Strober et al., 1997), a proportion of these participants may no longer meet criteria for AN. Furthermore, participants aged 13-21 years were recruited to represent an adolescent sample up until brain development comes to completion (early twenties) (Keverne, 2004) and usually whilst in full-time education, consistent with previous similar adolescent trials (e.g. Schmidt et al., 2007). However, a proportion of the group included young adults and caution should be taken when generalising these findings as strictly adolescents.

8.5.2 Design

An important consideration of the present research is that the benefit of ECHO has been proven for adolescent AN within the specific context of changes in dyadic distress; the benefit of ECHO for improving patient ED outcomes is not yet established and currently under investigation, as per trial protocol (Rhind, Hibbs, et al., 2014). The benefit for ED outcomes is hypothesized, based *conceptually* on the cognitive-interpersonal maintenance model of ED (Treasure & Schmidt, 2013) which is supported by empirical evidence showing that distress relates to less adaptive caregiver behaviours which in turn unfavourably impacts on ED course (Goddard, Salerno, et al., 2013); and based on empirical findings proving the benefit of ECHO on ED outcomes for patients with severe and/or enduring AN (Hibbs, Magill, et al., 2015). Another consideration of the choice of outcome (distress interdependence) of the present thesis is that distress may be confounded by other factors. Therefore, caution must be taken when interpreting these findings, and further examination of the benefit of ECHO on other outcomes is necessary to confirm the benefit of ECHO for adolescent AN.

The use of treatment as usual (TAU) as a ‘control’ for measuring the benefit of ECHO is another limitation derived when conducting a pragmatic trial. National guidelines endorse family therapy for adolescents although the definition is unspecified (variant and dose is not stated). Therefore, what constitutes TAU will have inevitably varied between the collaborating sites, as reflected by the commonly used phrase of a ‘postcode lottery’ when referring to service provision across National Health Service England. On the other hand, although the specific nature of treatment offered, waiting periods, and contact time with services will have varied, the results of study 5 showed that there were no significant differences in the proportion of the key service types between those randomly allocated to TAU alone versus those augmented with ECHO. This may be attributed to the randomisation procedure applied in this trial which stratified by site. Therefore, the problems of heterogeneity in including TAU in trial designs may not be too problematic when interpreting the findings of this thesis.

A final methodological limitation was the ineffective measurement of ASD-like traits in the parents of adolescents with AN. The lack of shared traits implied by the research in the present thesis therefore cannot be meaningfully interpreted.

8.6 Suggestions for future research

The work presented in this thesis has highlighted numerous avenues for future research to take. A number of suggestions and recommendations are discussed below.

In regards to furthering our understanding of altered socio-emotional processing in adolescent AN, an important aspect of future research will be examining these difficulties in the recovered state and in relatives. Examination of altered socio-emotional functioning in recovered AN is currently limited to adults with severe and/or enduring AN populations. As already described, this group is associated with a more complex profile and secondary symptoms that may not be present as part of the core AN psychopathology at the earlier stage AN. Further examination of these difficulties following recovery (e.g. weight-recovered following treatment) and in first degree relatives is likely to provide valuable evidence to add to the discussions over endophenotypes in AN. Furthermore, as noted, very little is currently understood about socio-emotional functioning in male AN. Given the differences in the gender ratio for AN (approximately 10 female: 1 male; Jacobi et al., 2004) and for ASD (currently reported at 2-3 male: 1 female; Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015; Mills & Kenyon, 2013), the overlap between ASD and AN, and discussions in the literature over gender in ASD (Lai, Baron-Cohen, et al., 2015) and AN as a possible female manifestation of ASD (e.g. Mandy & Tchanturia, 2015; Oldershaw, Treasure, et al., 2011), further establishing these difficulties in males is necessary and carries important research and clinical implications.

In relation to further establishing the caregiving role related to adolescent AN, studies including longitudinal data and larger samples of fathers are needed. The direction of the relationships between the aspects of caregiving (e.g study 3) were theory-driven based on cross-sectional data and causality can therefore not be inferred. Further examination of the relationship between the modifiable aspects of caregiving (e.g. burden, distress, and accommodating behaviours) using longitudinal data will enable the direction of these relationships to be confirmed (or altered). In addition, further examination of the caregiving role and related behaviours in fathers of adolescents with AN may be a useful next step with direct clinical implications.

A crucial next step for research will be proving the effectiveness of carer skills interventions (like ECHO) for ED patient outcomes. As already stated in the limitations section, response to ECHO in adolescent AN is currently restricted to improvements in distress independence. Examining the impact of ECHO on carer and patient psychosocial outcomes and patient ED symptoms will be an important next step. Further examining subgroups of patients (e.g. high ASD-like traits) and carers (e.g. high accommodating behaviours) for whom ECHO is particularly beneficial for will also be a valuable next step for research. Another avenue will be examining the benefit of ECHO for other ED presentations, including BN and childhood-onset EDs and examining which variant of ECHO (with or without guidance) is more acceptable and/or effective.

8.7 Clinical implications

8.7.1 Treatment of adolescent AN

The findings of the present thesis show that transdiagnostic traits such as socio-emotional difficulties are evident in a substantial proportion of adolescents at the early stage of AN. Socio-emotional difficulties may be associated with ASD and a small minority of adolescents with AN may be co-morbid with clinically relevant ASD. These transdiagnostic difficulties may also be associated with the over-controlled temperament (Schneider et al., 2013) and/or an obsessive-compulsive personality (Robbins, Gillan, Smith, de Wit, & Ersche, 2012). These transdiagnostic traits have been associated with a poorer prognosis and therefore treatment adaptations to target these may be beneficial for patient outcomes. Novel treatments have been developed for adults with severe and/or enduring AN that incorporate these difficulties (e.g. Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA); Schmidt et al., 2015) or target them directly (e.g. Cognitive Remediation and Emotion Skills Training (CREST); K. Tchanturia et al., 2015). Therefore adapting these for use in the treatment of adolescent AN may be beneficial, as may be other approaches designed to target the transdiagnostic traits (e.g. compulsivity phenotype) associated with the over-controlled temperament (e.g. radically Open-DBT; Lynch et al., 2013). However, as indicated by the research of the present thesis, these difficulties may not be present in all adolescent AN cases, and therefore effective assessment, which may benefit from multimodal methods, is important for targeted treatment.

8.7.2 Assessing carers' needs in adolescent AN

The research of the present thesis has highlighted the complex needs of carers of adolescents with AN (that may differ between mothers and fathers) that is often overlooked. Well-validated and quick to administer tools that assess the specific difficulties pertinent to carers of adolescents with AN may be of utility in clinical settings. The research of the present thesis provides further validation for the use of the Eating Disorder Symptom Impact Scale and the Accommodating and Enabling Scale for Eating Disorders (among others) as tools to assess burden and accommodating behaviours. Furthermore, given that social communication difficulties in adolescent AN has been shown to relate to caregiving burden in parents, an assessment that incorporates these difficulties may be of use for treatment planning in clinical settings.

8.7.3 Guidance for carers of adolescent AN

The findings of the present thesis have provided empirical support for the interpersonal component of the cognitive-interpersonal maintenance model (Treasure & Schmidt, 2013) at the early stage of adolescent AN for the first time. Therefore, these findings justify the use of parent/carer skills interventions that target these modifiable elements of caregiving in this group (e.g. Treasure, Rhind, et al., 2015). Most notably of clinical relevance, the present thesis findings have demonstrated for the first time the benefit of augmenting treatment with ECHO for improving interpersonal maintaining processes between carers and adolescents with AN. Although further examination of the benefit of ECHO is important, as an 'add-on' to treatment, it offers guidance for parents and other carers that is highly scalable, accessible and acceptable, and therefore may be feasibly implemented across National Health Service England and wider with low delivery cost and potential to benefit patient outcome.

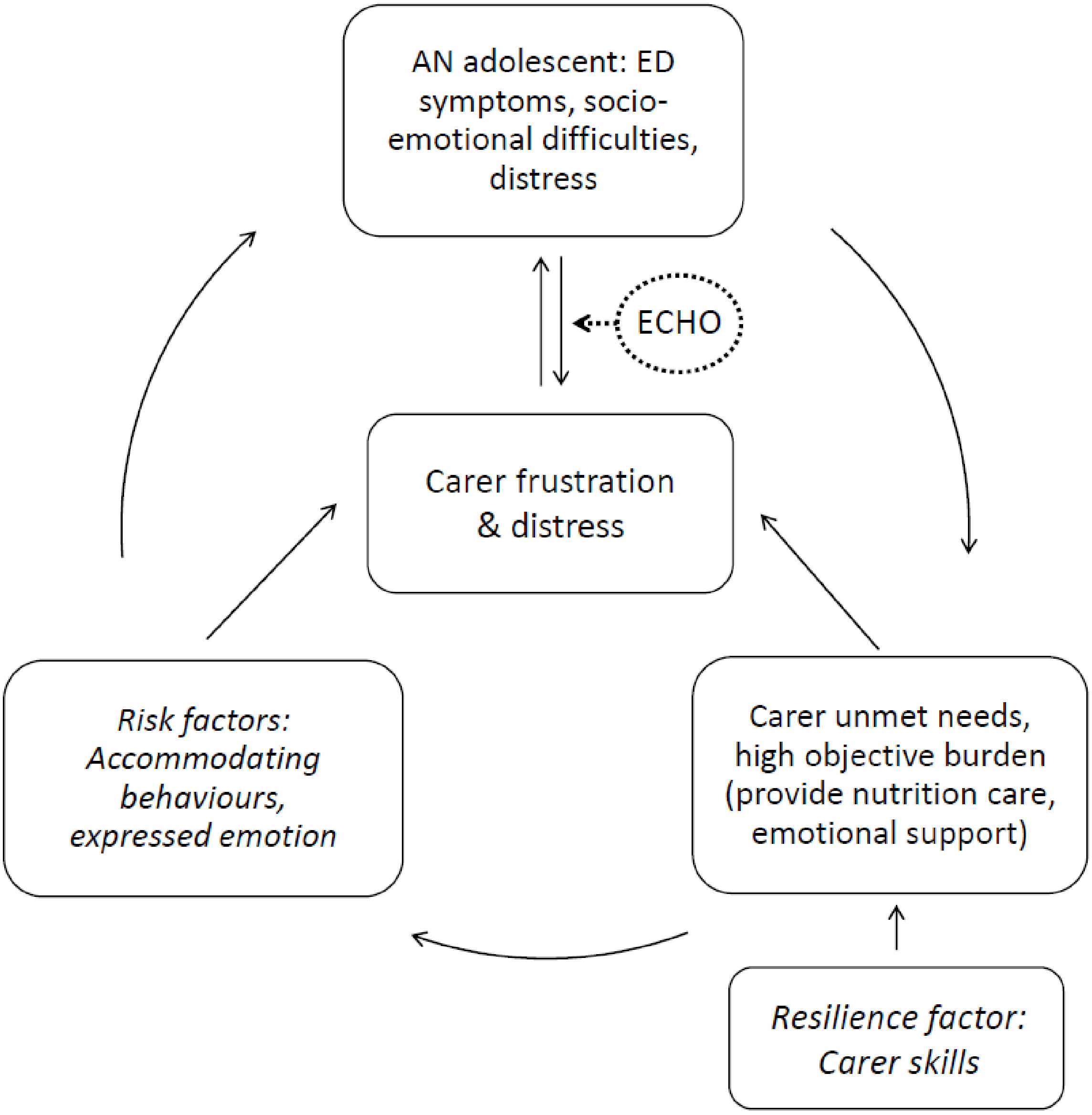

Figure 1. Diagrammatic formulation of carers' involvement within the maintenance of adolescent AN based on the present thesis research findings, highlighting the positive impact of ECHO for ameliorating carer/patient distress interdependence

8.8 Conclusion

Overall this thesis provides further evidence showing that adolescents with AN have socio-emotional difficulties and their carers (typically parents) have high levels of caregiving burden (objective burden and distress) and engage in patterns of behaviour (accommodating behaviours, expressed emotion) theorised to maintain illness. This thesis highlights the positive impact of augmenting usual adolescent AN treatment with a carer skills intervention (ECHO) for effectively modifying interpersonal maintaining processes which in turn may benefit patient outcomes.

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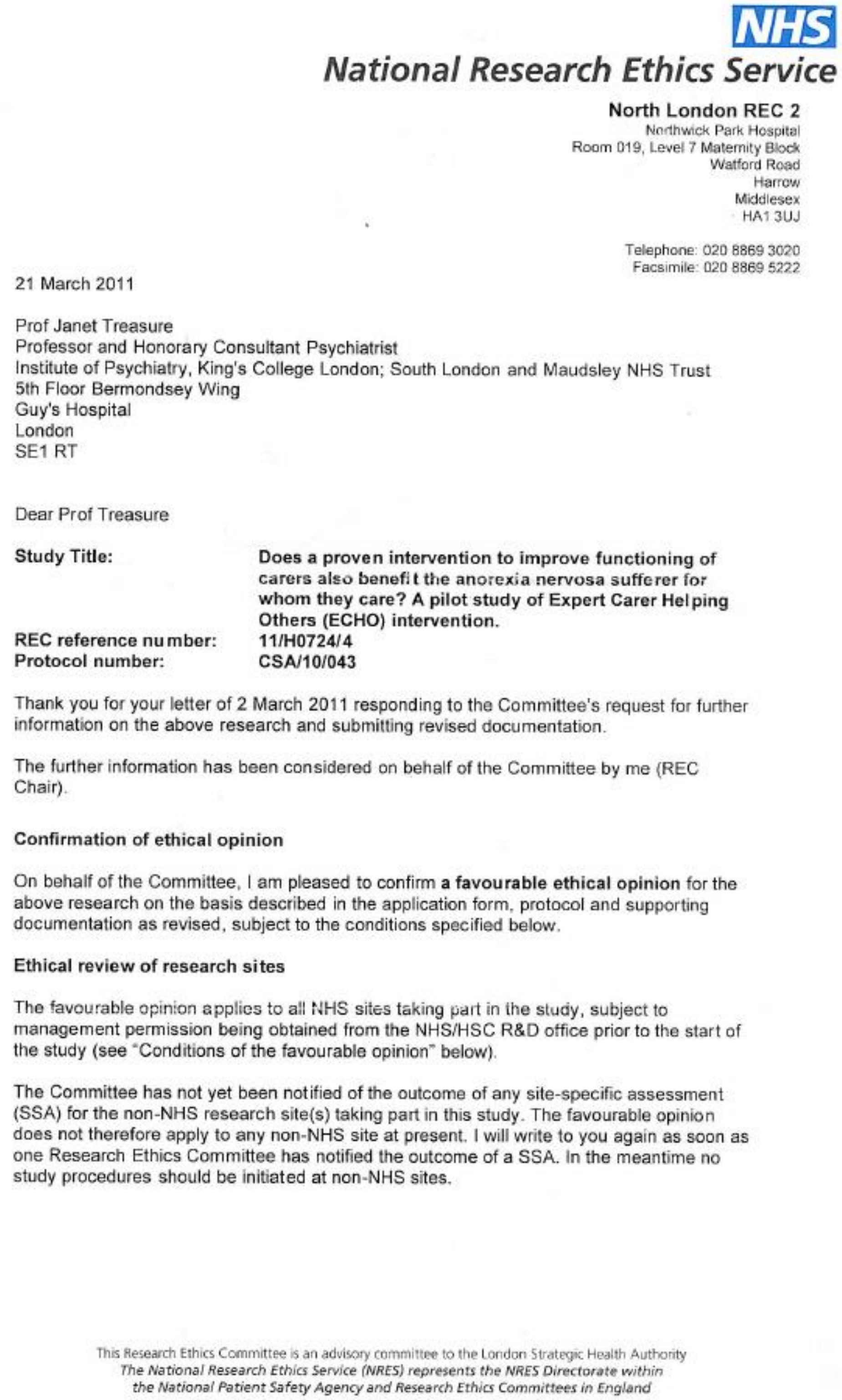
APPENDICES

Appendix A: Main ethical approval documents

Appendix A.1 Ethics approval relating to studies 1, 3, 4, and 5



NHS
National Research Ethics Service

North London REC 2
Northwick Park Hospital
Room 019, Level 7 Maternity Block
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Middlesex
HA1 3UJ

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21 March 2011

Prof Janet Treasure
Professor and Honorary Consultant Psychiatrist
Institute of Psychiatry, King's College London; South London and Maudsley NHS Trust
5th Floor Bermondsey Wing
Guy's Hospital
London
SE1 RT

Dear Prof Treasure

Study Title:	**Does a proven intervention to improve functioning of carers also benefit the anorexia nervosa sufferer for whom they care? A pilot study of Expert Carer Helping Others (ECHO) intervention.**
REC reference number:	**11/H0724/4**
Protocol number:	**CSA/10/043**

Thank you for your letter of 2 March 2011 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 me (REC Chair).

Confirmation of ethical opinion

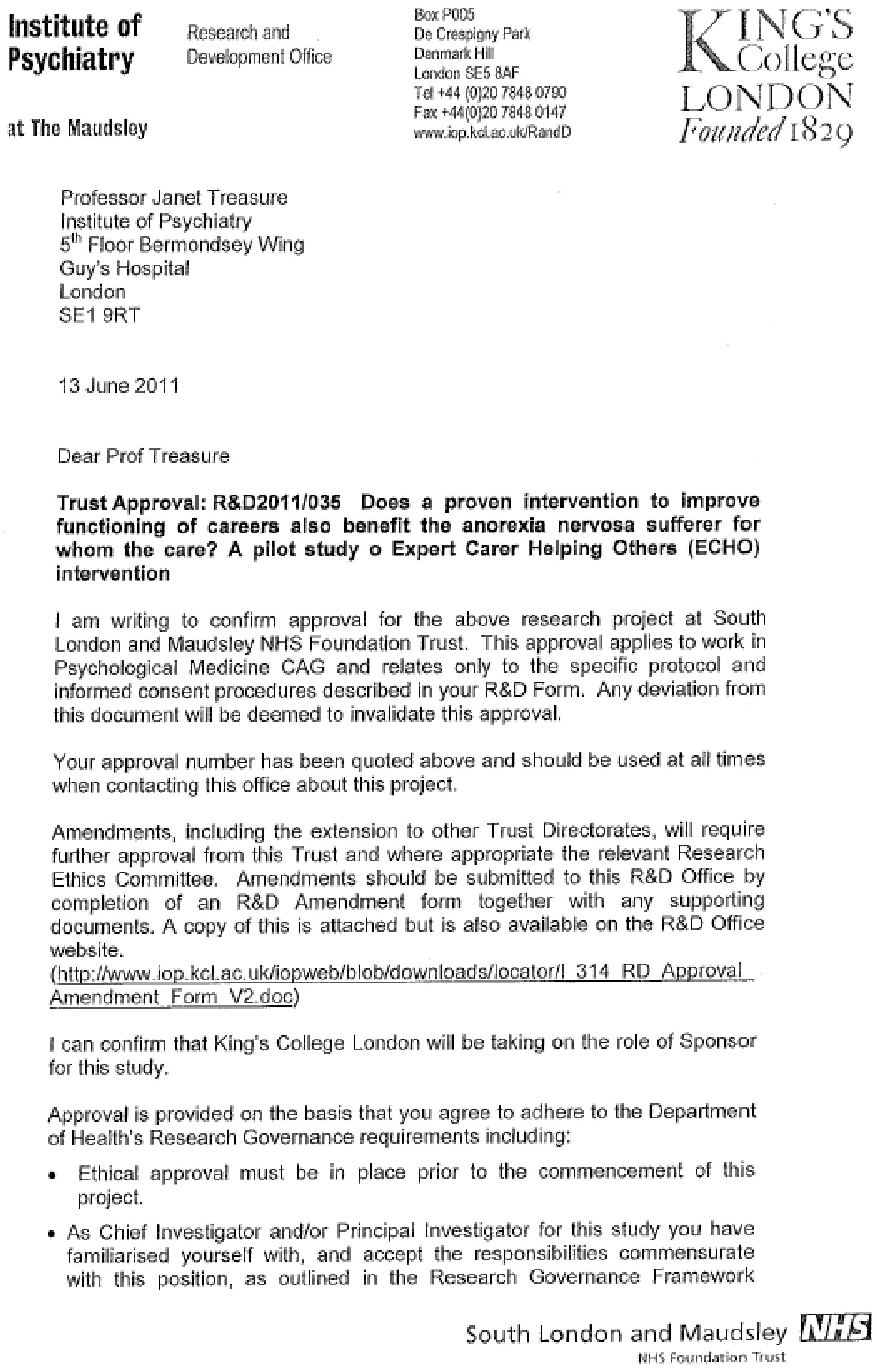
On behalf of the Committee, I am pleased to confirm **a favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

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

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. I will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

This Research Ethics Committee is an advisory committee to the London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England



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KING'S College LONDON Founded 1829

Professor Janet Treasure
Institute of Psychiatry
5th Floor Bermondsey Wing
Guy's Hospital
London
SE1 9RT

13 June 2011

Dear Prof Treasure

Trust Approval: R&D2011/035 Does a proven intervention to improve functioning of careers also benefit the anorexia nervosa sufferer for whom the care? A pilot study o Expert Carer Helping Others (ECHO) intervention

I am writing to confirm approval for the above research project at South London and Maudsley NHS Foundation Trust. This approval applies to work in Psychological Medicine CAG and relates only to the specific protocol and informed consent procedures described in your R&D Form. Any deviation from this document will be deemed to invalidate this approval.

Your approval number has been quoted above and should be used at all times when contacting this office about this project.

Amendments, including the extension to other Trust Directorates, will require further approval from this Trust and where appropriate the relevant Research Ethics Committee. Amendments should be submitted to this R&D Office by completion of an R&D Amendment form together with any supporting documents. A copy of this is attached but is also available on the R&D Office website.
(http://www.iop.kcl.ac.uk/iopweb/blob/downloads/locator/l_314_RD_Approval_Amendment_Form_V2.doc)

I can confirm that King's College London will be taking on the role of Sponsor for this study.

Approval is provided on the basis that you agree to adhere to the Department of Health's Research Governance requirements including:

- Ethical approval must be in place prior to the commencement of this project.
- As Chief Investigator and/or Principal Investigator for this study you have familiarised yourself with, and accept the responsibilities commensurate with this position, as outlined in the Research Governance Framework

- (http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4122427.pdf).

- Compliance with all policies and procedures of the Trust which relate to research, and with all relevant requirements of the Research Governance Framework. In particular the Trust Confidentiality Policy. http://www.iop.kcl.ac.uk/iopweb/blob/downloads/locator/l_313_SLaM_Confidentiality_Policy_v4.pdf
- Co-operating with the Trust R&D Office's regular monitoring and auditing of all approved research projects as required by the research governance framework, including complying with ad hoc requests for information.
- Informing the Trust's Health and Safety Coordinators and/or the Complaints Department or of any adverse events or complaints, from participants recruited from within this Trust, which occurs in relation to this study in line with Trust policies. Contact details are available from the R&D Office if required.
- Sending a copy of any reports or publications which result from this study to the Trust Departments involved in the study if requested.
- Honorary Contracts must be in place prior to patient contact for all relevant members of the research team. Advice on this will be provided by the R&D Office at the point of obtaining R&D approval and on an ongoing basis for new members of staff joining the research team.
- Sending a copy of the annual reports and end of project notification submitted to ethics.
- Your project has been adopted onto the NIHR Portfolio. There is a mandatory requirement that your study team provides monthly accrual (recruitment data as requests – completion of this is a condition of your continuation of R&D approval of this study.

Failure to abide by the above requirements may result in the withdrawal of the Trust's approval for this research.

If you wish to discuss any aspect of this research approval with the R&D Office, please contact Jenny Liebscher jennifer.liebscher@kcl.ac.uk in the first instance.

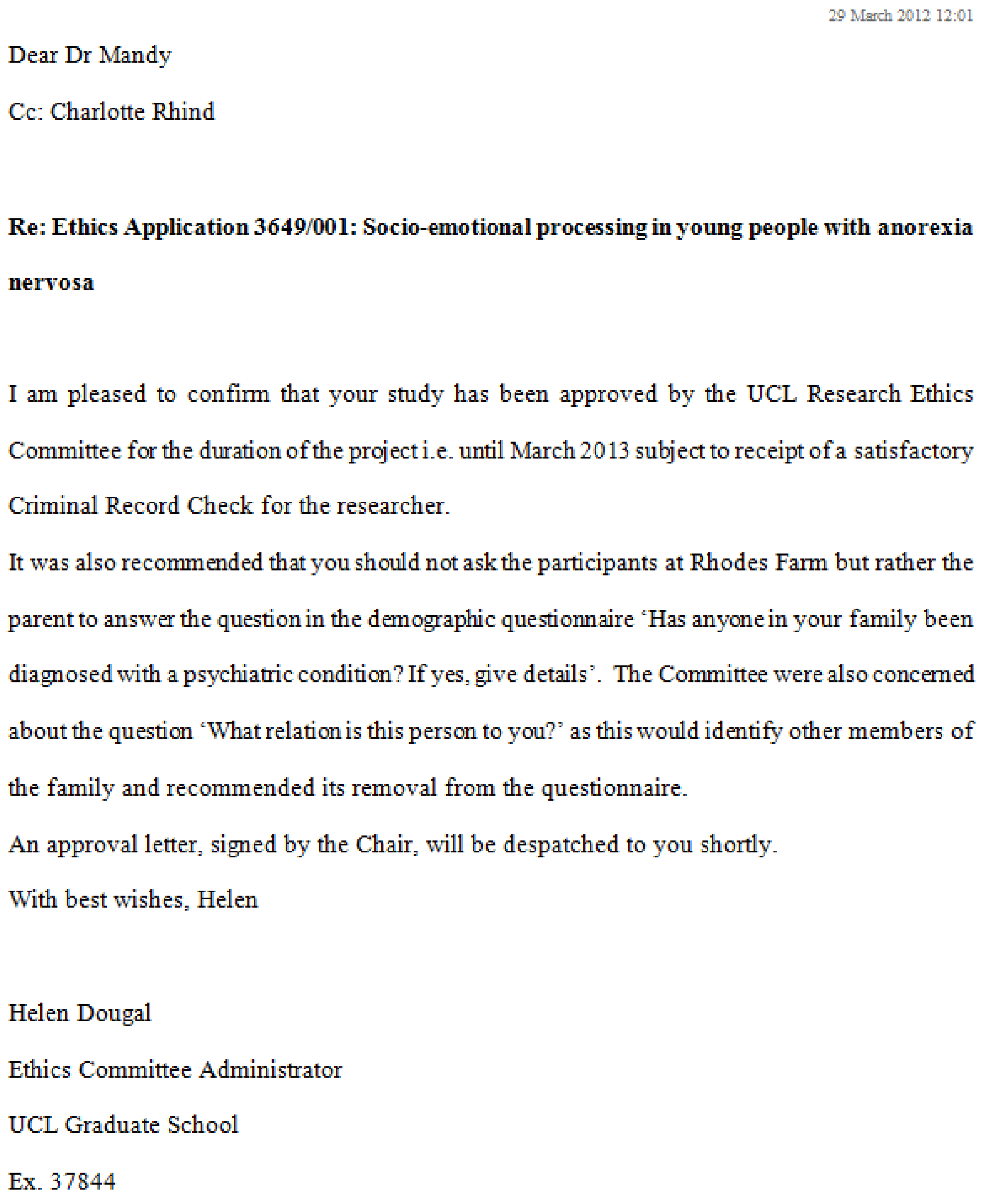
I wish you every success with this study.

Yours sincerely

Jenny Liebscher
R&D Governance and Delivery Manager
SLaM/IoP R&D Office

Enc. R&D Approval Amendment Form

Appendix A.2 Ethics approval relating to study 2



29 March 2012 12:01

Dear Dr Mandy

Cc: Charlotte Rhind

Re: Ethics Application 3649/001: Socio-emotional processing in young people with anorexia nervosa

I am pleased to confirm that your study has been approved by the UCL Research Ethics Committee for the duration of the project i.e. until March 2013 subject to receipt of a satisfactory Criminal Record Check for the researcher.

It was also recommended that you should not ask the participants at Rhodes Farm but rather the parent to answer the question in the demographic questionnaire ‘Has anyone in your family been diagnosed with a psychiatric condition? If yes, give details’. The Committee were also concerned about the question ‘What relation is this person to you?’ as this would identify other members of the family and recommended its removal from the questionnaire.

An approval letter, signed by the Chair, will be despatched to you shortly.

With best wishes, Helen

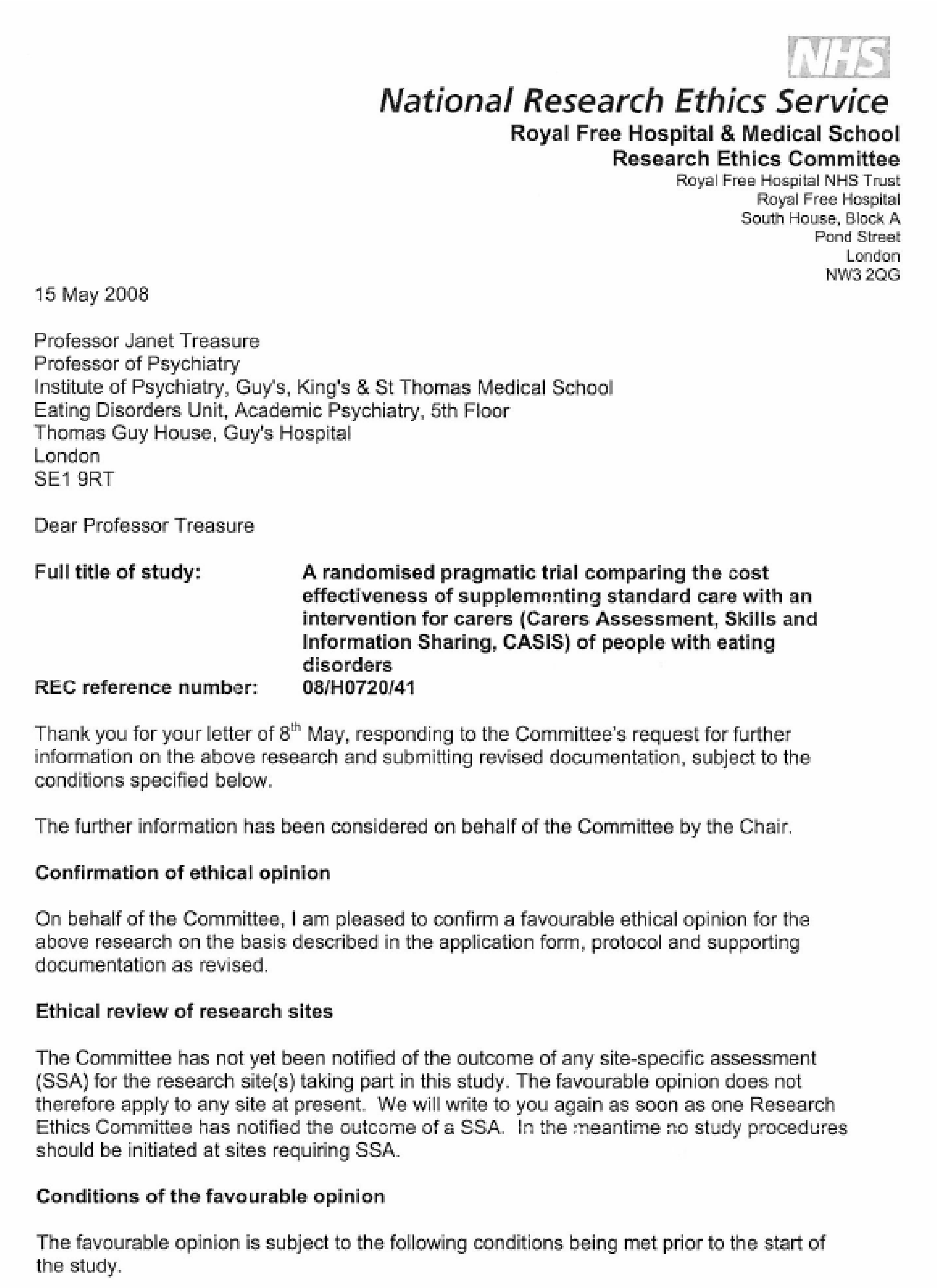
Helen Dougal

Ethics Committee Administrator

UCL Graduate School

Ex. 37844

Appendix A.3 Ethics approval relating to study 3



National Research Ethics Service
Royal Free Hospital & Medical School
Research Ethics Committee
Royal Free Hospital NHS Trust
Royal Free Hospital
South House, Block A
Pond Street
London
NW3 2QG

15 May 2008

Professor Janet Treasure
Professor of Psychiatry
Institute of Psychiatry, Guy's, King's & St Thomas Medical School
Eating Disorders Unit, Academic Psychiatry, 5th Floor
Thomas Guy House, Guy's Hospital
London
SE1 9RT

Dear Professor Treasure

Full title of study:	**A randomised pragmatic trial comparing the cost effectiveness of supplementing standard care with an intervention for carers (Carers Assessment, Skills and Information Sharing, CASIS) of people with eating disorders**
REC reference number:	**08/H0720/41**

Thank you for your letter of 8th May, responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

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

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.

Ethical review of research sites

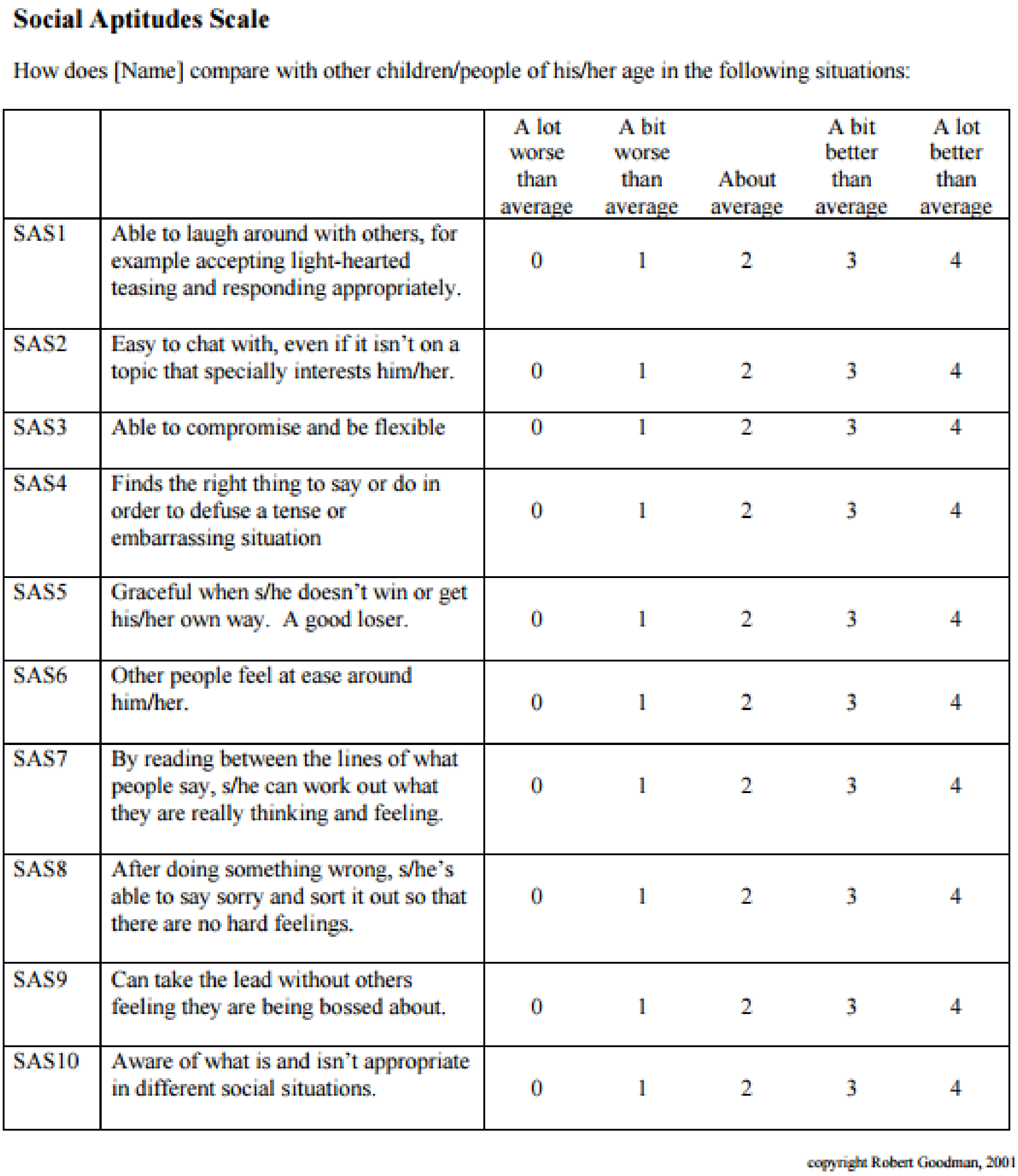
The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the research site(s) taking part in this study. The favourable opinion does not therefore apply to any site at present. We will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at sites requiring SSA.

Conditions of the favourable opinion

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

Appendix B: Main study materials

Appendix B.1 Main study materials relating to studies 1, 3, 4, and 5



Social Aptitudes Scale

How does [Name] compare with other children/people of his/her age in the following situations:

		A lot worse than average	A bit worse than average	About average	A bit better than average	A lot better than average
SAS1	Able to laugh around with others, for example accepting light-hearted teasing and responding appropriately.	0	1	2	3	4
SAS2	Easy to chat with, even if it isn't on a topic that specially interests him/her.	0	1	2	3	4
SAS3	Able to compromise and be flexible	0	1	2	3	4
SAS4	Finds the right thing to say or do in order to defuse a tense or embarrassing situation	0	1	2	3	4
SAS5	Graceful when s/he doesn't win or get his/her own way. A good loser.	0	1	2	3	4
SAS6	Other people feel at ease around him/her.	0	1	2	3	4
SAS7	By reading between the lines of what people say, s/he can work out what they are really thinking and feeling.	0	1	2	3	4
SAS8	After doing something wrong, s/he's able to say sorry and sort it out so that there are no hard feelings.	0	1	2	3	4
SAS9	Can take the lead without others feeling they are being bossed about.	0	1	2	3	4
SAS10	Aware of what is and isn't appropriate in different social situations.	0	1	2	3	4

Friendships Questionnaire

Fr1 What is [Name] like at making friends?

Finds it harder than average	About average	Finds it easier than average
0	1	2

Fr2 What is [Name] like at keeping the friends s/he has made?

Finds it harder than average	About average	Finds it easier than average
0	1	2

Fr3 At present, how many friends does s/he have that s/he fairly often spends time with, for example chatting, or doing things together, or going out as part of a group?

None	One	2-4	5-9	10+
0	1	2	3	4
↓ Next section			Fr4	

Fr4 Do [Name] and his/her friends have interests in common?

No	A little	A lot
0	1	2

Fr5 Do [Name] and his/her friends take part in joint activities such as playing sport together, playing computer games together, or shopping together?

No	A little	A lot
0	1	2

Fr6 If [Name] were very stressed or had some secret worry, do you think s/he'd be able to talk about this with a friend and tell the friend how s/he was feeling?

No	Perhaps	Definitely
0	1	2

Fr 7 By and large, do you approve of his/her friends?

No	A little	A lot
0	1	2

Fr8 Are many of his/her friends the sorts of children/young people who often get into trouble for bad behaviour?

Not at all	A few are like that	Many are like that	All are like that
0	1	2	3

Development Section

R1 Thinking about his/her school work and about his/her ability to reason things out, is s/he about average for his/her age, ahead, or behind?

Ahead	Average	Behind
0	1	2
R3		↓ R2

R2 At present, roughly what sort of age level is s/he at in his/her school work and ability to reason things out? (*Optional*: For example like an average [*insert an age 2 years younger than the child's chronological age]* year old?)

If under 12 month level, code as '0'

☐ years old

R3 Is his/her ability to use language – to say what s/he means and to understand what other people are saying – about average for his/her age, ahead or behind?

Ahead	Average	Behind
0	1	2
R6		↓ R4

R4 At present, roughly what sort of age level is s/he at in his/her use and understanding of language? (*Optional*: For example like an average [*insert an age 2 years younger than the child's chronological age]* year old?)

If under 12 month level, code as '0'

☐ years old

R5 Can s/he get round difficulties in explaining what s/he wants to say by other means, for example by using gestures, signs, facial expressions or acting things out?

No	A little	A lot
0	1	2

R6 Going back to his/her first **3 years** of life, was there anything that seriously worried you or anyone else about:

		No	Yes
a)	the way his/her speech developed?	0	1
b)	how s/he got on with people?	0	1
c)	the way his/her pretend or make-believe play developed?	0	1
d)	any odd rituals or unusual habits that were *very* hard to interrupt?	0	1
e)	his/her ability to learn and do new things – things such as puzzles or helping get dressed?	0	1

Only ask if R6a, R6b, R6c,R6d orR6e = 'Yes'

R7 Have the things that seriously worried you or someone else now cleared up completely?

Cleared up completely	Some continuing problems
0	1

Skip rule for the rest of this section

Only continue if SAS score is 12 or less, if R7 = 'Some continuing problems', or if the SDQ peer proble score is 2 or more points higher than the prosocial score. Otherwise go to next section.

If R6a = 'Yes' continue with R8, else skip to R10

R8 Could s/he use any real words other than 'mama' or 'dada' before the age of 2 years?
(*Baby words such as 'bikkie' for 'biscuit' do count. Exclude other words for mother or father)*

No	Yes
0	1

R9 After using single words, children go on to join them up into phrases or short sentences like 'Go park see ducks' or 'Mama give biscuits'.

Did [Name] join words together into phrases or short sentences before the age of 3 years?
(*Do not count set phrases like 'Thank you' or 'Night night' that the child uses as just one word*)

No	Yes
0	1

R10 Toddlers often communicate through physical gestures such as waving goodbye, pointing to things, blowing a kiss, or bringing a finger to their mouth and saying Shh!

When s/he was a toddler, did [Name] use these sorts of gestures as much as other children of the same age?

About the same / More	A little less	A lot less
0	1	2

R11 Some children like playing nursery games like Ring a Ring a Roses, Round and Round the Garden, Peekaboo or Peepo.

Did [Name] ever like these games?

No	A little	A lot
0	1	2

R12 Young children often try to share their enjoyment or interests or achievements, for example by pointing out something that they think you will enjoy seeing or find interesting.

As a toddler and young child, did [Name] want to share his/her enjoyment, interests or achievements with other people?

No	A little	A lot
0	1	2

R13 Some children spend a lot of their play time repeating the same action over and over again, for example spinning the wheels on a toy car, turning taps or light switches on and off, or opening and shutting doors.

Has this ever been true of him/her?

No	A little	A lot
0	1	2

R14 Children are sometimes very interested in unusual aspects of toys or other things. For example, rather than playing with a toy, they may spend their time sniffing it, or running their fingers over its surface, or holding it to their face to feel any vibration that it makes.

Has this ever been true of him/her?

No	A little	A lot
0	1	2

R15 Make-believe play is important to some children. This can include pretend games with other children – games such as cops and robbers, or mummies and daddies. Even when they are by themselves, children may act out stories with dolls, action men or make-believe objects.

If aged under 11: As a preschool child and more recently, has [Name] taken part in make-believe play?

If aged 11 or more: Thinking about when s/he was younger (say between 5 and 10), did [Name] take part in make-believe play?

No	A little	A lot
0	1	2

R16 *If aged under 11*: At present, can [Name] make allowances according to who s/he is playing with? For example, not being too rough when playing with younger children, and not being too bossy when playing with older children.

If aged 11 or more: When s/he was younger (say around 10), could [Name] make allowances according to who s/he was playing with? For example, not being too rough when playing with younger children, and not being too bossy when playing things with older children.

No	A little	A lot
0	1	2

R17 When s/he's with other children/teenagers, does s/he have difficulty taking turns, sharing or co-operating?

No	A little	A lot
0	1	2

R18 Some children/teenagers enjoy putting a lot of time into collecting things, or get a lot of pleasure out of focusing on just one topic, such as sport, cars or a particular pop group. In everyday language, we often say that these children/teenagers are 'obsessed' by their interest, but this is not an unpleasant obsession – this is something they like and usually enjoy talking about.

Has [Name] had any long-lasting obsessions of this sort?

No	A little	A lot
0	1	2
R24		↓ R19

R19 Obsessions may be about common or unusual topics. For example, it is fairly common for an 8 year old to be obsessed by dinosaurs, but it is unusual for an 8 year old to be obsessed by Victorian fireplaces, bar codes or street lamps.

Is or was the topic of his/her obsession unusual?

No	A little	A lot
0	1	2

R20 Does or did the obsession dominate his/her life?

No	A little	A lot
0	1	2

R21 Does or did it tend to dominate his/her conversation with other people?

No	A little	A lot
0	1	2

R22 Does or did it stop him/her doing other important things in his/her life, such as playing, studying or going out?

No	A little	A lot
0	1	2

R23 Please describe the obsession:

……

……

……

R24 Is [Name] able to start conversations with other people?

No	A little	A lot
0	1	2

R25 If other people start conversations with him/her, can [Name] keep the conversation going?

No	A little	A lot
0	1	2

R26 Is [Name] genuinely interested in chatting with other people in order to hear what they have to say about their experiences and interests – even if those interests are different from his/her own interests?

No	A little	A lot
0	1	2

R27 Some children/teenagers have trouble adjusting their language to suit different social occasions. For example they may speak too casually to a teacher or too formally to other children.

Does [Name] change the way s/he speaks according to whether it is a formal or informal situation?

No	A little	A lot
0	1	2

R28 It is relatively easy to tell what some children/teenagers are feeling by observing their facial expressions, their tone of voice and their body language. It is harder to tell with other children/teenagers, particularly if you don't know them very well.

Do most people have difficulty knowing what [Name] is feeling by observing his/her face, body language or tone of voice?

No	A little	A lot
0	1	2

R29 The other way round, children/teenagers vary in their ability to know what other people are feeling. Some children/ teenagers are good at recognising subtle clues in body language, facial expressions, or tone of voice. For example, they can immediately tell when their mother is starting to get a little cross, or when another child/teenager is feeling a bit embarrassed. Other children/teenagers find this much harder.

Does [Name] have difficulty recognising the clues in other people's facial expressions, body language and tone of voice?

No	A little	A lot
0	1	2

R30 When we're talking with someone face-to-face, eye contact is very important. It generally makes us feel uneasy, or as if there's something wrong, if the other person makes too little eye contact, or too much, or makes it at the wrong time.

Has [Name] ever been through a phase of making too little or too much eye contact, or making it in the wrong sort of way?

No	Perhaps	Definitely
0	1	2

R31 Many young children go through a phase of repeating what someone has just said to them. For example, if you said, "We'll be going home in a few minutes", they might parrot back "We'll be going home in a few minutes". Or they might echo back the last word, "minutes", in your tone of voice. Some young people do this a lot.

Has [Name] ever echoed or parroted speech in this way?

No	A little	A lot
0	1	2

R32 Some children/teenagers ask the same questions over and over again. For example, "When are we going to the park?" or "What's for dinner?" or "Are we going swimming this weekend?" They keep repeating these questions even though they've already been told the answers many times. The questions that are repeated may not be exactly the same from week to week.

Has [Name] ever tended to ask repetitive questions?

No	A little	A lot
0	1	2

R33 Another way in which young people repeat themselves is by using the same catch-phrase or cliché over and over again. For example, almost every sentence may begin "If you want my opinion …" or "Logically speaking …" Occasionally the phrase is appropriate, but it is used far more than is really needed.

Has [Name] ever filled his/her speech with these fairly empty catch-phrases or clichés?

No	A little	A lot
0	1	2

R34 Some children enjoy routines and want things to be the same every day. For example, they may want to eat the same food off the same plate while sitting in the same chair every single day. Or there may be very fixed routines for dressing or undressing.

Has [Name] ever had strong or unusual routines that s/he has insisted on because s/he enjoyed doing it that way?

No	A little	A lot
0	1	2
R36		↓ R35

R35 Please describe the routines

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

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

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

R36 Some children are easily upset by small changes in their routines. For example, they may be very upset by having to go to school a different way, by having to take a bath at a slightly different time, or by the furniture being moved around.

Has [Name] ever been easily upset by changes in routine?

No	A little	A lot
0	1	2

R37 Some preschool children go through a phase of flapping or waving their hands or arms up and down if they are excited or upset. Some continue doing this for years.

Since [Name] has been going to school, has s/he tended to flap his/her arms when excited or upset?

No	A little	A lot
0	1	2

R38 You have answered a lot of questions about his/her pattern of development – focusing particularly on language, play, routines and his/her ability to get along with other people.

Are you concerned at present about any of these aspects of his/her development?

No	A little	A lot
0	1	2
↓ Next section	*tick Development on the check list in M1 (p.55) and continue with* R39	

R39 Thinking about the last 12 months, have difficulties in any of the areas that we have covered resulted in him/her becoming upset or distressed?

Not at all	A little	A medium amount	A great deal
0	1	2	3

R40 Have difficulties with language, routines, play, or social ability interfered with...

	Not at all	A little	A medium amount	A great deal
a) how well s/he gets on with you and the rest of the family?	0	1	2	3
b) making and keeping friends?	0	1	2	3
c) learning or class work?	0	1	2	3
d) playing, hobbies, sports or other leisure activities?	0	1	2	3

R41 Have these difficulties put a burden on you or the family as a whole?

Not at all	A little	A medium amount	A great deal
0	1	2	3

R42 Some children's development is unusual from birth onwards. With hindsight, their parents realise that development was never quite normal. That's not always the case, though. Sometimes parents are sure that development was completely normal for a while and then there was a relatively sudden change.

Which was true for him/her?

Always there to some extent	Sudden change
0	1
↓	↓
Next section	R43

R43 How old was [Name] when this change happened?

If during the first 12 months, code as '0'

☐ years old

Section N Strengths

I have been asking you a lot of questions about his/her difficulties and problems. I now want to ask you about his/her good points or strengths.

N1	**Do the following descriptions apply to him/her?**	**No**	**A little**	**A lot**
a)	Generous	0	1	2
b)	Lively	0	1	2
c)	Keen to learn	0	1	2
d)	Affectionate	0	1	2
e)	Reliable and responsible	0	1	2
f)	Easy going	0	1	2
g)	Good fun, good sense of humour	0	1	2
h)	Interested in many things	0	1	2
i)	Caring, kind-hearted	0	1	2
j)	Bounces back quickly after setbacks	0	1	2
k)	Grateful, appreciative of what s/he gets	0	1	2
l)	Independent	0	1	2

N2	**What are the things s/he does that really please you?**	**No**	**A little**	**A lot**
a)	Helps around the home	0	1	2
b)	Gets on well with the rest of the family	0	1	2
c)	Does homework without needing to be reminded	0	1	2
d)	Creative activities: art, acting, music, making things	0	1	2
e)	Likes to be involved in family activities	0	1	2
f)	Takes care of his appearance	0	1	2
g)	Good at school work	0	1	2
h)	Polite	0	1	2
i)	Good at sport	0	1	2
j)	Keeps his/her bedroom tidy	0	1	2
k)	Good with friends	0	1	2
l)	Well behaved	0	1	2

N3 Does [Name] have any other good points you particularly want to mention?

………

Section N Strengths

I have been asking you a lot of questions about possible difficulties and problems. I now want to ask you about your good points or strengths.

N1	Do the following descriptions apply to you?	No	A little	A lot
a)	Generous	0	1	2
b)	Outgoing, sociable	0	1	2
c)	Nice personality	0	1	2
d)	Reliable and responsible	0	1	2
e)	Easy going	0	1	2
f)	Good fun, good sense of humour	0	1	2
g)	Caring, kind-hearted	0	1	2
h)	Independent	0	1	2

N2	What are the things you do that you are really proud of?	No	A little	A lot
a)	Good at sport	0	1	2
b)	Good with friends	0	1	2
c)	Helpful at home	0	1	2
d)	Good at music	0	1	2
e)	Well behaved	0	1	2
f)	Good with computers	0	1	2
g)	Good at drama, acting	0	1	2
h)	Raising money for charity, helping others	0	1	2
i)	Good at art, making things	0	1	2
j)	Polite	0	1	2
k)	Good at school work	0	1	2

N3 Do you have any other good points you particularly want to mention?

………

Baseline Questionnaire for Patients

This questionnaire is about you and your carers. A carer can be anyone who plays a supportive role in your life and in helping you manage the eating disorder, e.g. mum, dad, step parent, sister, brother, grandma, friend.

The information that you give us on this sheet will be treated as strictly confidential and will be used to help us understand how we can help those with an eating disorder and their carers. Please fill it as much of this questionnaire as you can.

If you need any help completing these questions, you can ask someone in your family or a friend to help, or you can call Liz Goddard on 02071881090 or email Elizabeth.Goddard@kcl.ac.uk to ask any questions.

Your contact details will be stored separately from your questionnaire responses. This will ensure the details you provide are kept confidential.

Please complete the following:
Name: ____
Address:____
____
____
____
Postcode: ________________
Tel (home):____________________________Tel (work):____________________________
Email: ____
Name of your carer/s
____
___What is your relationship to your carer/s taking part in this study?
____
___

Would you please give us the contact details of your GP? We need to inform the GP that you are taking part in this evaluation.

GP Name:
____

GP Address:
____

Who could we contact if we couldn't reach you (e.g. you might change address during the project)? We will only use these details if we need to send you a questionnaire, for example, and cannot get hold of you. This person will not be directly involved in the project

Alternative contact:
____
____
____

Thank you very much for your help.
Please complete the following questionnaire by reading each question carefully and answering every question as honestly as you can.

1. Section – Code and Date

1.1 Code (please put your initials) ☐

1.2 Today's Date _ _ / _ _ / _ _
DD MM YY

1.3 Date of assessment at Eating Disorders clinic _ _ / _ _ / _ _
DD MM YY

2. Site

Where are you attending your clinical assessment/receiving outpatient treatment?
(e.g. STEPS Avon and Wiltshire)

____

3. Demographic Questions

3.1 What is your date of birth: _ _ / _ _ / _ _
DD MM YY

3.2 What is your gender: ○ Female ○ Male

3.3 How old are you? __________years

3.4 What is the lowest weight you have ever been at your current height? _________ Kg

3.5 What is your diagnosis? (e.g. Anorexia nervosa) _______________________

3.6 In your view, how long have you had an eating disorder? _______years _______months

3.7 How old were you when you first developed an eating disorder? __________ years

3.8 Do you have a current diagnosis of anything other than an eating disorder. E.g. depression, OCD, self harm
○ Yes
○ No
If yes, please specify ____

3.9 Are you currently taking any medication?
○ Yes
○ No
If yes, please specify dosage, type and frequency**: ____________________________________**
____

3.10 How many times have you been admitted to hospital (inpatient or daypatient) because of your eating disorder in the past? Please specify whether they were specialist eating disorder units, general hospitals, general psychiatric hospitals, or A&E

Hospital type (e.g. ED specialist)	Length of stay	Age

If you need more space, please feel free to attach another sheet of paper.

3.11 Have you received treatment for your eating disorder in the past? If so, please give details below including type of treatment, length of treatment and your age when you started receiving it

Treatment type (e.g. ED outpatients)	**Length of treatment**	**Age**

3.12 Do you have any siblings?

○ Yes
○ No

If Yes, how many?

Older brother(s) ___________ Younger brother(s) ___________

Older sister(s) ___________ Younger sister(s) ___________

If you have a sister or a brother, are you a twin? ○ Yes ○ No

3.13 What is you current employment status?

○ Full time employed
○ Part time employed
○ Unemployed
○ Student
○ Retired
○ Sick leave
○ Housewife / -husband
○ Other

If other, please specify ____

3.14 If employed, what is your current or most recent occupation?

____

3.15 What is the highest level of education you have completed? (Tick one box)

○ No qualifications
○ O Level / GCSE
○ A Level / NVQ
○ BTEC
○ University degree
○ Postgraduate degree
○ Diploma

○ Other

If other, please specify ____

3.16 How many years of education have you received? _________________________years

3.17 Is your first language English?

○ Yes
○ No

3.18 What is your ethnicity?
○ White British
○ White Irish
○ Other White
○ Mixed White and Black Caribbean
○ Mixed White and Black African
○ Mixed White and Asian
○ Other Mixed
○ Asian or Asian British – Indian
○ Asian or Asian British – Pakistani
○ Asian or Asian British – Bangladeshi
○ Other Asian
○ Black or Black British – Caribbean
○ Black or Black British – African
○ Other Black
○ Chinese
○ Other ethic group

3.19 What is your marital status?
○ Single
○ Married
○ Living together
○ In a relationship, not living together
○ Divorced
○ Separated
○ Widowed

3.20 Do you have children?
○ Yes. If yes, how many? _______
○ No

3.21 If you have answered yes to question 3.22, please type in the ages of your children in the table.

Children	***1. child - age***	***2. child - age***	***3. child - age***	***4. child - age***	***5. child - age***
Daughter(s)					
Son(s)					

3.22 Who do you live with at the moment?
○ On my own
○ With parents
○ With friends / flatmates
○ With partner
○ University halls of residence
○ Supported/residential accommodation
○ Other ____

4. SEED

1. Present body weight in kg (when undressed) and height: __________kg __________cm

2. Are you afraid of becoming fat or gaining weight?

○	○	○	○	○
Not at all	Rarely	Sometimes	Frequently	Constantly

3. In what way do you perceive your body? (Please put a cross in the appropriate box where, between to poles, you see yourself.)

Much too thin	1 ○	2 ○	3 ○	4 ○	5 ○	Much too fat
Attractive	1 ○	2 ○	3 ○	4 ○	5 ○	Unattractive

Muscular	1 ○	2 ○	3 ○	4 ○	5 ○	Flabby
Feminine (for women)	1 ○	2 ○	3 ○	4 ○	5 ○	Lacking feminity
Masculine (for men)	1 ○	2 ○	3 ○	4 ○	5 ○	Lacking masculinity

4. How often on average did you use the below mentioned measures over the previous 4 weeks? (Please put a cross in each line.)

	Not at all	**Up to once a week**	**Twice or more a week**	**Daily**	**Several times a day**
	1	2	3	4	5
Vomiting	○	○	○	○	○
Laxatives	○	○	○	○	○
Diet / low calorie food	○	○	○	○	○
Excessive exercise	○	○	○	○	○

5 How often did you binge over the previous 4 weeks?

Not at all	**Up to once a week**	**Twice or more a week**	**Daily**	**Several times a day**
○	○	○	○	○

6. Have you missed your period over the previous 4 weeks?

○ no ○ yes ○ for male patients: n/a

7. Do you take the pill at present?

○ no ○ yes ○ for male patients: n/a

Questions about your carer

5.1 Who are your carer(s) to you? (You may tick more than one box)

She / He is my…

○ Mother
○ Father
○ Step-Mum
○ Step-Dad
○ Sibling
○ Other relative If other, please specify ________________________________

○ Friend
○ Other If other, please specify ______________________________________

5.2 Who do you consider to be your primary carer (carer 1)? (i.e. person you turn to first, spend the most time with, depend on the most) __________________

5.3 Who do you consider to be your secondary carer? (carer 2) (i.e. the person who you would turn to after your primary carer, even if they are fairly equal, spend less or slightly less time with than primary carer)_________________________

If you have asked a third carer to take part in this study, who is this carer (carer 3) to you?
____

For the next set of questions, please refer to the people you have named above as your "primary carer" (carer 1), "secondary carer" (carer 2) and, if applicable, your other carer (carer 3).

5.4 Do you currently live together with the carer(s)?

○ Carer 1 (primary carer) ○ Carer 2 (secondary carer) ○ Carer 3 ○ Carer 1 and 2
○ Carer 1 and 3 ○ Neither

5.5 Please think about CARER 1 (i.e. primary carer) for this question (tick one box for Face to Face and one for Other contact)

How many hours of FACE TO FACE contact each week		How many hours of OTHER contact with carer each week	
	0 – 7 hours / week		0 – 7 hours / week
	8 – 14 hours / week		8 – 14 hours / week
	15 – 21 hours / week		15 – 21 hours / week
	More than 21 hours / week		More than 21 hours / week
	Other		Other

If “Other”, please give details

____

5.6 Please think about CARER 2 (i.e. secondary carer) for this question (tick one box for Face to Face and one for Other contact)

How many hours of FACE TO FACE contact each week		How many hours of OTHER contact with carer each week	
	0 – 7 hours / week		0 – 7 hours / week
	8 – 14 hours / week		8 – 14 hours / week
	15 – 21 hours / week		15 – 21 hours / week
	More than 21 hours / week		More than 21 hours / week
	Other		Other

If “Other”, please give details

____

5.7 If applicable, please think about CARER 3 for this question (tick one box for Face to Face and one for Other contact)

How many hours of FACE TO FACE contact each week		How many hours of OTHER contact with carer each week	
	0 – 7 hours / week		0 – 7 hours / week
	8 – 14 hours / week		8 – 14 hours / week
	15 – 21 hours / week		15 – 21 hours / week
	More than 21 hours / week		More than 21 hours / week
	Other		Other

If “Other”, please give details

____

5.8 Please answer these next 3 questions thinking about your primary carer

a) How would you rate the communication between you and your primary carer?

I can’t talk to them								*I can talk openly*		
○	○	○	○	○	○	○	○	○	○	○
0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

b) Can you lean on and turn to your primary carer in times of difficulty?’

Never										*Always*
○	○	○	○	○	○	○	○	○	○	○
0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

c) Please rate how close your relationship is with your primary carer

I don’t feel close									*I feel very close*	
○	○	○	○	○	○	○	○	○	○	○
0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

5.9 Please answer these next 3 questions thinking about your secondary carer

a) How would you rate the communication between you and your secondary carer?

I can’t talk to them								*I can talk openly*		
○	○	○	○	○	○	○	○	○	○	○
0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

b) Can you lean on and turn to your secondary carer in times of difficulty?’

Never										*Always*
○	○	○	○	○	○	○	○	○	○	○
0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

c) Please rate the quality of your relationship you have with your secondary carer

I don’t feel close To them										*I feel very close*
○	○	○	○	○	○	○	○	○	○	○
0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Family Eating Patterns

We are interested to know more about different patterns of eating within families. We do not think that one thing causes an eating disorder (and are certainly not looking to blame any one person or thing) so please be honest when answering these questions. We are asking these questions because we think it is important that we figure out how we can support families in different ways.

Please think about the time BEFORE your eating disorder started when answering these questions.

1) Before your ED started, did any of the following influences act to change your eating patterns?

In the table below, please tick the appropriate box to indicate how much you have been influenced by each item:

	Not at all (0)	Slightly (1)	Moderately (2)	Very (3)	Extremely (4)
Family concerns about your weight/shape					
Family relationships					
Joint dieting with family member(s)					
Comments or jokes about your eating habits by family member(s)					
Comments or jokes about your weight/shape by family member(s)					

2) During your childhood, how many family members would be present at most meals?

Overall _______ Evening Meal _______

3) How often did you eat meals together as a family (children plus at least one parent/care-giver) before your eating disorder and once it had started, when you were living at home (please tick)?

	3 times a day (0)	1-2 times a day (1)	2-7 times a week (2)	Once a week or less (3)
Before ED				
After ED				

4) Before your ED started, did you usually eat meals at regular/set times of the day (tick one)?

☐ Yes ☐ No

5) Before the onset of your ED, did you usually have your first meal of the day before school/lessons started?

☐ Yes ☐ No

6) During your childhood, how much value was put on food by your mother and/or your father (tick as applicable)?

	An average amount or less value than most people (0)	More value than most people (1)	A lot more value than most people (2)
Mother			
Father			
Caregiver 3 (e.g. step parent) Please note_________________			

7) During your childhood, did anyone in the family pay specific attention to healthy eating, such that it had a profound (big) effect on the food that was eaten in your family (tick as appropriate)?

	Yes (1)	No (0)
Mother		
Father		
Sibling		
You		
Other household member/caregiver _________________		

8) Compared to your friends, did your parents have strict rules about the types of food you ate as a child?

☐ Yes ☐ No

9) If yes, how often did you follow these rules (tick one)?

☐ Never ☐ Occasionally ☐ Frequently ☐ Always

Brief Dyadic Scale of Expressed Emotoin

Please answer the following questions thinking about your *primary carer* (carer 1)

1. How critical is _______ of you?

Not at all critical	1	2	3	4	5	6	7	8	9	10	Very critical indeed

2. How warm is _______ towards you?

Not at all warm	1	2	3	4	5	6	7	8	9	10	Very warm indeed

3. How disapproving is _______ of what you do?

Not at all disapproving	1	2	3	4	5	6	7	8	9	10	Very disapproving indeed

4. How caring is _______ of you?

Not at all caring	1	2	3	4	5	6	7	8	9	10	Very caring indeed

5. How much do the things you do annoy _______?

Not at all	1	2	3	4	5	6	7	8	9	10	Very much indeed

6. How much does _______ like to spend time and do things with you?

Does not like at all	1	2	3	4	5	6	7	8	9	10	Like it very much indeed

7. Do you feel criticised by _______?

Not criticised at all	1	2	3	4	5	6	7	8	9	10	Very criticised indeed

8. Do you feel loved by _______?

Not loved at all	1	2	3	4	5	6	7	8	9	10	Very loved indeed

9. _______ does not let me do things on my own

Never					Sometimes					Always
1	2	3	4	5	6	7	8	9	10	

10. _______ meddles in my activities (my life and my affairs)

Never					Sometimes					Always
1	2	3	4	5	6	7	8	9	10	

11. _______ makes me feel like I am not capable of taking care of myself

Never					Sometimes					Always
1	2	3	4	5	6	7	8	9	10	

12. I feel controlled by _______

Never					Sometimes					Always
1	2	3	4	5	6	7	8	9	10	

13. _______ stresses out easily because of my problems

Never Sometimes Always
1 2 3 4 5 6 7 8 9 10

14. _______ cries easily when we talk about my things

Never Sometimes Always
1 2 3 4 5 6 7 8 9 10

Please answer the following questions thinking about your *secondary carer* (carer 2)

1. How critical is _______ of you?

Not at all critical 1 2 3 4 5 6 7 8 9 10 Very critical indeed

2. How warm is _______ towards you?

Not at all warm 1 2 3 4 5 6 7 8 9 10 Very warm indeed

3. How disapproving is _______ of what you do?

Not at all disapproving 1 2 3 4 5 6 7 8 9 10 Very disapproving indeed

4. How caring is _______ of you?

Not at all caring 1 2 3 4 5 6 7 8 9 10 Very caring indeed

5. How much do the things you do annoy _______?

Not at all 1 2 3 4 5 6 7 8 9 10 Very much indeed

6. How much does _______ like to spend time and do things with you?

Does not like at all 1 2 3 4 5 6 7 8 9 10 Like it very much indeed

7. Do you feel criticised by _______?

Not criticised at all 1 2 3 4 5 6 7 8 9 10 Very criticised indeed

8. Do you feel loved by _______?

Not loved at all 1 2 3 4 5 6 7 8 9 10 Very loved indeed

9. _______ does not let me do things on my own

Never Sometimes Always
1 2 3 4 5 6 7 8 9 10

10. _______ meddles in my activities (my life and my affairs)

Never Sometimes Always
1 2 3 4 5 6 7 8 9 10

11. _______ makes me feel like I am not capable of taking care of myself

Never Sometimes Always
1 2 3 4 5 6 7 8 9 10

12. I feel controlled by _______

Never Sometimes Always
1 2 3 4 5 6 7 8 9 10

13. _______ stresses out easily because of my problems

Never Sometimes Always

1 2 3 4 5 6 7 8 9 10

14. _______ cries easily when we talk about my things

Never Sometimes Always

1 2 3 4 5 6 7 8 9 10

Thoughts of change

INSTRUCTIONS: Please tick the number which best describes what you think.

6.1 Importance to change. Ask yourself the following questions: How important is it for you to change? What score would you give yourself out of 10?

Not at all *Very Much*

○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○

0 1 2 3 4 5 6 7 8 9 10

6.2 What are you desires, reasons and needs for change?

____

____

____

____

6.3 Ability to change. Ask yourself the following questions: How confident are you in your ability to change? What score would you give yourself out to 10?

Not at all *Very Much*

○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○

0 1 2 3 4 5 6 7 8 9 10

5. Questions about your treatment

7.1 Are you currently receiving treatment?

○ Yes ○ No

If yes, what sort of treatment is this?

____

If yes, how long have you been receiving this treatment? How often do you receive it?

____

____

7.2 How satisfied are you with the current treatment? (If no current treatment please consider the most recent one)

`○	○	○	○	○	○
Very satisfied	**Quite satisfied**	**unsure**	**Quite dissatisfied**	**Very dissatisfied**	**Never received treatment**

Treatment Satisfaction Questionnaire

7.3 Whose idea was it for you to be referred to your current outpatient treatment?

____

7.4 How willing were you to come along to the first appointment?

Not at all *Very willing*

○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○

0 1 2 3 4 5 6 7 8 9 10

Please tick one box for each question that best applies to you:-

1.	I fully agree with the referral ☐	I agree in part with the referral ☐	I do not agree much with the referral ☐	I do not agree at all with the referral ☐
2.	My eating problem is a major concern for me ☐	I'm quite concerned ☐	I'm hardly concerned ☐	I'm not concerned about my eating problem at all ☐
3.	My difficulties have developed only because of me ☐	My difficulties are mainly down to me, but other circumstances have also had an effect ☐	My difficulties are mainly due to circumstances, but I have had a part to play in how they have developed ☐	My difficulties are entirely due to circumstances out of my control ☐
4.	I want to tackle my eating problem now ☐	I want to tackle my eating problem soon ☐	My eating problem can wait a while ☐	I do not wish to tackle my eating problem now ☐
5.	If my eating problem is sorted, all my other difficulties will also be solved ☐	If my eating problem is sorted, then most of my other difficulties will also be better, although I may still have some problems ☐	If my eating problem is sorted, my other difficulties may be a little easier but they will remain ☐	Even if my eating problems are sorted, I will have other difficulties which will be just as bad as ever. ☐
6.	Any progress I make will be achieved by me ☐	Any progress I make will be achieved mainly by me ☐	Any progress I make will be mainly due to the efforts of others ☐	Someone needs to do something if I am to make progress ☐
7.	I am very optimistic that xSITEx will help me ☐	xSITEx may help me ☐	I doubt xSITEx will help much ☐	I do not think xSITEx will help at all ☐
8.	I am going to have a go at what is offered ☐	I will probably have a go at what is offered ☐	I probably will not accept what is offered ☐	I will not accept what is offered ☐
9.	I expect that in 6 months my life will be very different ☐	I expect that in 6 months my life will be somewhat different ☐	I expect that in 6 months time my life will be mostly the same as it is now ☐	In 6 months my life will be just the same as it is now. ☐

Depression, Anxiety & Stress Scales

INTRUCTIONS: *Please read each statement and tick a number 0, 1, 2 or 3 which indicates how much the statement applied to you* <u>*over the past week.*</u>
There are no right or wrong answers. Do not spend too much time on any statement.
The rating scale is as follows:
0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1.	I found it hard to wind down	○ ○ ○ ○ 0 1 2 3
2	I was aware of dryness of my mouth	○ ○ ○ ○ 0 1 2 3
3	I couldn't seem to experience any positive feeling at all	○ ○ ○ ○ 0 1 2 3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	○ ○ ○ ○ 0 1 2 3
5	I found it difficult to work up the initiative to do things	○ ○ ○ ○ 0 1 2 3
6	I tended to over-react to situations	○ ○ ○ ○ 0 1 2 3
7	I experienced trembling (eg, in the hands)	○ ○ ○ ○ 0 1 2 3
8	I felt that I was using a lot of nervous energy	○ ○ ○ ○ 0 1 2 3
9	I was worried about situations in which I might panic and make a fool of myself	○ ○ ○ ○ 0 1 2 3
10	I felt that I had nothing to look forward to	○ ○ ○ ○ 0 1 2 3
11	I found myself getting agitated	○ ○ ○ ○ 0 1 2 3
12	I found it difficult to relax	○ ○ ○ ○ 0 1 2 3
13	I felt down-hearted and blue	○ ○ ○ ○ 0 1 2 3
14	I was intolerant of anything that kept me from getting on with what I was doing	○ ○ ○ ○ 0 1 2 3
15	I felt I was close to panic	○ ○ ○ ○ 0 1 2 3
16	I was unable to become enthusiastic about anything	○ ○ ○ ○ 0 1 2 3
17	I felt I wasn't worth much as a person	○ ○ ○ ○ 0 1 2 3
18	I felt that I was rather touchy	○ ○ ○ ○ 0 1 2 3

19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	○ ○ ○ ○ 0 1 2 3
20	I felt scared without any good reason	○ ○ ○ ○ 0 1 2 3
21	I felt that life was meaningless	○ ○ ○ ○ 0 1 2 3

Children's Yale-Brown Obsessive Compulsive Inventory

INSTRUCTIONS: The following are a list of common obsessions and compulsions. We are interested in whether you have experienced any of these symptoms in the **last month**. For each symptom, please put a tick in the appropriate box on the left.

OBSESSIONS (thoughts you can't stop thinking about and are distressing)

	CONTAMINATION OBSESSIONS
	Concerns or disgust with bodily waste or secretions (e.g. urine, faeces, saliva)
	Concern with dirt or germs
	Excessive concern with environmental contaminants (asbestos, radiation, toxic waste)
	Excessive concern with household items (e.g. solvents, cleansers)
	Excessive concern with animals (eg. insects)
	Bothered by sticky substances or residues
	Concerned will get ill because of contaminant
	Concerned will get others ill by spreading contaminant (Aggressive)
	No concern with consequences of contamination other than how it might feel
	Other:
	AGGRESSIVE OBSESSIONS
	Fear might harm self
	Fear might harm others
	Violent or horrific images
	Fear of blurting out obscenities or insults
	Fear of doing something else embarrassing
	Fear will act on unwanted impulses (e.g. to stab friend)
	Fear will steal things
	Fear will harm others because not careful enough (e.g. Hit/run MVA)
	Fear will be responsible for something else terrible happening (e.g. fire/burglary)
	Other:
	SEXUAL OBSESSIONS
	Forbidden or perverse sexual thoughts, images or impulses
	Content involves children or incest
	Content involves homosexuality
	Sexual behaviour towards others (Aggressive)
	Other:

	HOARDING/SAVING OBSESSIONS (Distinguish from hobbies and concern with objects of monetary or sentimental value)
	Fear of losing things
	Fear of losing something symbolic
	Other:
	OBSESSION WITH NEED FOR SYMMETRY OR EXACTNESS
	Accompanied by magical thinking (e.g. concerned that mother will have accident unless things in the right place)
	Not accompanied by magical thinking
	Other:
	CHAPTER 9. MAGICAL THOUGHTS/SUPERSTITIOUS OBSESSIONS

	Lucky/unlucky numbers, colours, words
	Superstitious fears
	Other:
	SOMATIC OBSESSIONS
	Concerns with illness or disease
	Excessive concern with body part or aspect of appearance (e.g. dysmorphophobia)
	Other:
	RELIGIOUS OBSESSIONS (scrupulosity)
	Concerns with sacrilege and blasphemy
	Excess concern with right/wrong morality
	Other:
	MISCELLANEOUS OBSESSIONS
	Need to know or remember
	Fear of saying certain things
	Fear of not saying just the right thing
	Intrusive (non-violent) images
	Intrusive nonsense sounds, words or music
	Other:

The following questions refer to the above **obsessive thoughts**, especially those that you consider as most disabling.

1. **How much of your time is occupied by obsessive thoughts? How frequently do the obsessive thoughts occur?** {Be sure to exclude ruminations and pre-occupations about everyday problems}

0 = None.
1 = Mild, less than 1hr/day or occasional intrusion.
2 = Moderate, 1-3hrs/day or frequent intrusion.
3 = Severe, greater than 3 and up to 8hrs/day or very frequent intrusion.
4 = Extreme, greater than 8hrs/day or near constant intrusion.

2. **How much do your obsessive thoughts interfere with your social or work/study functioning? Is there anything that you don't do because of them?** {If currently not working/studying, rate how much performance would be affected if you were employed/studying}.

0 = None.
1 = Mild, slight interference with social or occupational activities, but overall performance not impaired.
2 = Moderate, definite interference with social or occupational performance, but still manageable.
3 = Severe, causes substantial impairment in social or occupational performance.
4 = Extreme, incapacitating.

3. **How much distress do your obsessive thoughts cause you?**

0 = None.
1 = Mild, not too disturbing.
2 = Moderate, disturbing, but still manageable.
3 = Severe, very disturbing.
4 = Extreme, near constant and disabling distress.

4. **How much of an effort do you make to resist the obsessive thoughts? How often do you try to disregard or turn your attention away from these thoughts as they enter your mind?** {Only rate effort made to resist, not success or failure in actually controlling the obsessions}

0 = I make an effort to always resist, or the symptoms are so minimal that I don't need to actively resist.
1 = I try to resist most of the time.
2 = I make some effort to resist.
3 = I yield to all obsessions without attempting to control them, but I do so with some reluctance.
4 = I completely and willingly yield to all obsessions.

5. **How much control do you have over your obsessive thoughts?, How successful are you in stopping or diverting your obsessive thinking?, Can you dismiss them?**

0 = Complete control.
1 = Much control, usually able to stop or divert obsessions with some effort and concentration.
2 = Moderate control, sometimes able to stop or divert obsessions.
3 = Little control, rarely successful in stopping or dismissing obsessions, can only divert attention with difficulty.
4 = No control, experienced as completely involuntary, rarely able to even momentarily alter obsessive thinking.

COMPULSIONS (RITUALS or habits you can’t stop)

	CLEANING/WASHING COMPULSIONS
	Excessive or ritualised handwashing
	Excessive or ritualised showering, bathing toothbrushing, grooming or toilet routine
	Involves cleaning of household items or other inanimate objects
	Other measures to prevent or remove contact with contaminants
	Other; please describe:
	CHECKING COMPULSIONS
	Checking locks, stove, appliances, etc
	Checking that did not/will not harm others
	Checking that did not/will not harm self
	Checking that nothing terrible did/will happen
	Checking that did not make mistake
	Checking tied to somatic obsessions
	Other; please describe:
	REPEATING RITUALS
	Re-reading or re-writing
	Need to repeat routine activities (e.g. in/out door, up/down from chair)
	Other:
	COUNTING COMPULSIONS
	Objects, certain numbers, words, etc
	Other:
	ORDERING/ARRANGING COMPULSIONS
	Need for symmetry or evening up (e.g. lining items up in a certain way or specific patterns) etc.
	Other; please describe:
	HOARDING/COLLECTING COMPULSIONS (Distinguish from hobbies and concern with objects of monetary/sentimental value)
	E.g. carefully reads junk mail, piles up old newspapers, sorts through garbage, collects useless objects
	Difficulty throwing things away, saving bits of paper, string, etc
	Other; please describe:
	9.1 EXCESSIVE GAMES/SUPERSTITIOUS BEHAVIOURS (distinguish from age appropriate magical games)
	E.g. array of behaviour, such as stepping over certain spots on a floor, touching an object/self certain number of times as a routine game to avoid something bad from happening.
	Other; please describe:
	9.2 RITUALS INVOLVING OTHER PERSONS
	The need to involve another person (usually a parent) in ritual (e.g. asking a parent to repeatedly answer the same question, making mother perform certain meal time-rituals involving specific utensils)
	Other; please describe:
	MISCELLANEOUS COMPULSIONS
	Mental rituals (other than checking)
	Need to tell, ask, confess
	Measures (not checking) to prevent harm to self, harm to others, terrible consequences
	Ritualised eating behaviours
	Excessive list making
	Need to touch, tap, rub
	Need to do things (e.g. touch or arrange) until it feels just right
	Rituals involving blinking or staring
	Trichotillomania (hair pulling)
	Other self damaging or self mutilating behaviours
	Other; please describe:

The next five questions are about the above **compulsive behaviours**, or **rituals**, especially those that are most disabling/time consuming.

6. **How much time do you spend performing compulsive behaviours? How much longer than most people does it take to complete routine activities because of your rituals? How frequently do you perform compulsions?** {in most cases compulsions are observable behaviours (eg. hand washing) but some compulsions are covert (eg. silent checking)}.

0 = None.
1 = Mild, (I spend less than 1hr/day performing compulsions), or occasional performance of compulsive behaviours.
2 = Moderate, (I spend from 1-3 hrs/day performing compulsions), or frequent performance of compulsive behaviours.
3 = Severe, (I spend more and up to 8 hrs/day performing compulsions), or very frequent performance of compulsive behaviours.
4 = Extreme (I spend more than 8 hrs/day performing compulsions) or near constant performance of compulsive behaviours (too numerous too count).

7. **How much do your compulsive behaviours interfere with your social or work/study functioning? Is there anything that you don't do because of the compulsions?** {If currently not working/studying rate how much performance would be affected if you were employed/studying}

0 = None.
1 = Mild, slight interference with social or occupational activities, but overall performance not impaired.
2 = Moderate, definite interference with social or occupational performance, but still manageable.
3 = Severe, causes substantial impairment in social or occupational performance.
4 = Extreme, incapacitating.

8. **How would you feel if prevented from performing your compulsion(s)? How anxious would you become? How anxious do you get while performing compulsions until you are satisfied they are completed?**

0 = None.
1 = Mild, only slightly anxious if compulsions prevented, or only slight anxiety during performance of compulsions.
2 = Moderate, anxiety that would mount but remain manageable if compulsions prevented, or anxiety increases but remains manageable during performance of compulsions.
3 = Severe, prominent and very disturbing increase if compulsions interrupted, or prominent and very disturbing increase in anxiety during performance of compulsions.
4 = Extreme, incapacitating anxiety from any intervention aimed at modifying activity, or incapacitating anxiety develops during performance of compulsions.

9. **How much of an effort do you make to resist the compulsions?** {only rate effort made to resist, not success or failure in actually controlling the compulsions}

0 = I make an effort to always resist, or my symptoms are so minimal that I don’t need to actively resist.
1 = I try to resist most of the time.
2 = I make some effort to resist.
3 = I yield to almost all compulsions without attempting to control them, but I do so with some reluctance.
4 = I completely and willingly yield to all compulsions.

10. **How strong is the drive to perform the behaviour? How much control do you have over the compulsions?**

0 = Complete control.
1 = Much control, I experience pressure to perform behaviour but usually able to exercise voluntary control over it.
2 = Moderate control, strong pressure to perform behaviour, can control it only with difficulty.
3 = Little control, very strong drive to perform the behaviour, must be carried to completion, can only delay with difficulty.
4 = No control, drive to perform behaviour experienced as completely involuntary and overpowering, rarely able to even momentarily delay activity.

Clinical Impairment Assessment

INSTRUCTIONS: Please place and ‘X’ in the column which best describes how your eating habits, exercising or feelings about your eating, shape or weight have affected your life over the past four weeks (28 days). Thank you.

	Over the past 28 days, to what extent have your …eating habits …exercising Or feelings about your eating, shape or weight…	Not at all	A little	Quite a bit	A lot
1	…made it difficult to concentrate?				

2	…made you feel critical of yourself?				
3	…stopped you going out with others?				
4	…affected your work performance (if applicable)?				
5	…made you forgetful?				
6	…affected your ability to make everyday decisions?				
7	…interfered with meals with family or friends?				
8	…made you upset?				
9	…made you feel ashamed of yourself?				
10	…made it difficult to eat out with others?				
11	…made you feel guilty?				
12	…interfered with you doing things you used to enjoy?				
13	…made you absent-minded?				
14	…made you feel a failure?				
15	…interfered with your relationships with others?				
16	…made you worry?				

OSLO Social Support

INSTRUCTIONS: There are three questions about you experience your social relationships in terms of your immediate, personal experience. Please read and choose ONE of the following options for each question.

1	How many people are so close to you that you can count on them if you have serious personal problems?	None	1 or 2	3-5	More than 5	
2	How much concern do people show in what you are doing?	A lot of concern and interest	Some concern and interest	Uncertain	Little concern and interest	No concern and interest
3	How easy is it to get practical help if you should need it? Who from? ____________________	Very easy	Easy	Possible	Difficult	Very difficult

Carer skills

We are interested in some areas of your carer's behaviour. Please think about the questions in relation to your carer, and be as frank and honest as you can.

The statements below describe situations that are commonly are associated with eating disorders.

Please rate how often your carer carries out each item from 0 to 100 using the scale given below.

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

For example, a rating of 100 means that your carer would always perform the activity. For each scenario, please circle the number that you feel best reflects the likelihood of your carer's behaviour. You can choose any score between 0 and 100 (10, 20, 30, etc.)

Please make all your ratings based on what they would do TODAY as the person they are NOW rather than on the person they used to be or the person you would like them to be. **This is very important.**

If you feel some of the questions aren't applicable to you, try to rate how your carer would respond should the situation arise.

Thank you for taking the time to complete this questionnaire.

Does your carer…….

1. … Do things with you not related to the eating disorder, including things you enjoyed before the illness?

Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

Secondary carer (if applicable):
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

2. …Discuss and explain their own feelings about the eating disorder with you?

Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

---

3. …Discuss the eating disorder openly with *all* other immediate family members involved.

Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

---

4. … Avoid getting drawn into arguments about the eating disorder with you

Primary carer:
0 10 20 30 40 50 60 70 80 90
100

Almost never Occasionally Frequently Almost
Always
Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

__
5. … Take some time for themselves when they need a break?
Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always
Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always
6. …Keep doing the things that they enjoy whilst caring for you?
Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always
Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

___ ….. Engage you so that you think more positively about making changes?
Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always
Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

__
7. ……Keep hope that you will recover?
Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always
Secondary carer:

0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

8. ….. Step back and trust that you will cope with day to day challenges on your own?

Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

9. ….. Agree boundaries, plans or household rules in collaboration with you?

Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

10. …..Uphold boundaries/rules consistently in a compassionate tone, even when you are arguing with them?

Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

11. ….. Control the urge to argue against the eating disorder behaviours even though they believe their argument to be logical?

Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

---

12. ….. Have pleasant verbal interactions with you, not related to the eating disorder?

Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

13. … Intervene without criticism when you are engaging in eating disorder behaviour?

Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

---

14. ….. Avoid getting caught in repetitive conversations with you about food and eating?

Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

---

15. ….. Praise change or attempts at change by you even if the effects/results were less than they were hoping for?

Primary carer:
0 10 20 30 40 50 60 70 80 90
100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

---

16. ….. Resist constantly reminding/asking about agreed behaviour targets?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

17. ….. Talk and listen with you about difficult and complex emotions that you are feeling?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

---

18. ….. Control the urge to keep enquiring/checking on your behaviour even when they are very worried?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

---

19. ….. Resist relying solely on weight as a marker of how you are doing?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

---

20. ….. Keep their eye on your overall progress/bigger picture?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

21. ….Avoid getting caught in conversations with you about weight and shape?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

---

22. …..Separate you as a person from the illness?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

---

23. …. Reflect and understand the effect of their behaviour on you?

Primary carer:

0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always
Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always

24. ….. Accept that the eating disorder is not their fault?
Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always
Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost Always

25. ….Accept that the one cause or trigger for the eating disorder may not be the solution to recovery?
Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always
Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost Always

26. ….Talk about the eating disorder openly with people outside the immediate family?
Primary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost
Always
Secondary carer:
0 10 20 30 40 50 60 70 80 90
100
Almost never Occasionally Frequently Almost Always

27. …Understand what you think is positive about your eating disorder?
Primary carer:
0 10 20 30 40 50 60 70 80 90
100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

28. …Find time to spend with other members of the family?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

29. Manage their anxiety levels so that they don’t feel overwhelmed?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Is your carer…

30. …Reassured by even the smallest signs of improvement?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

31. …Understanding towards you even when they are angry or frustrated with you?

Primary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

Secondary carer:

0 10 20 30 40 50 60 70 80 90 100

Almost never Occasionally Frequently Almost Always

32. ….. Calm when dealing with difficult behaviours associated with the eating disorder?

Primary carer:
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always
Secondary carer:
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

Thank you very much for filling out the questionnaire!
We really appreciate your help.
The follow up questionnaires are not nearly as long!

BASELINE QUESTIONNAIRE FOR CARERS

This questionnaire is about you and the person who you are supporting with an eating disorder.

The information that you give us on this sheet will be treated as strictly confidential and will be used to help us understand how we can help those with an eating disorder and their carers. We are not investigating causes of eating disorders; we are trying to find out ways in which we can offer families support, and to identify where families or carers may need more support or information.

Please fill it as much of this questionnaire as you can. This first questionnaire is the longest – the next ones you receive (in 6 months, and 12 months) are *much* shorter.

Your contact details will be stored separately from your questionnaire responses. This will ensure the details you provide are kept confidential.

Please complete the following:

Name:…………………………………………………………………………………………………
…
Address:
………………………..……………………………………………………………………

Postcode:…………………

Tel (home):……………………..…………..………. Tel (work):………………………………………

Email:…………………………………… …………………………………
………………………

Name of the person you are caring for:
……………………………………………………………….
What is your relationship to your relative currently receiving treatment?
……………………………

Who could we contact if we cannot reach you (e.g. you might change address during the project)? We will only use these details if we need to send you a questionnaire, for example, and cannot get hold of you. This person will not be directly involved in the project.

Alternative contact:
____

____
Thank you very much for your help.

Please complete the following questionnaire by reading each question carefully and answering every question as honestly as you can.

Code and Date

1.1 Code (filled in by the research team) ☐

1.2 Today's Date
_ _ / _ _ / _ _
DD MM YY

Demographic Questions

1 Date of birth: _ _ / _ _ / _ _
DD MM YY

2 Gender: ○ Female ○ Male

3 Do you consider yourself to be the primary or secondary carer of the person you care for? (e.g. primary carer might be the person who spends the most time with X or is the person who is called upon first; a secondary carer may be someone who is still very involved but maybe doesn't spend quite as much time with X or perhaps sees them less frequently, for example)

○ Primary
○ Secondary
○ Other

3 What is your current employment status? (Tick one box)

○ Full time employed
○ Part time employed
○ Unemployed
○ Student
○ Retired
○ Sick leave
○ Housewife / -husband
○ Other
If other, please specify

____

4 What is the highest level of education you have completed? (Tick one box)

○ No qualifications
○ O Level / GCSE
○ A Level / NVQ
○ University degree
○ Postgraduate degree
○ Diploma / BTEC
○ Other
If other, please specify____

5 How many years of education have you received?

__________ years and __________ months

6 Is your first language English?

○ Yes
○ No

7 What is your ethnicity?
○ White British
○ White Irish
○ Other White
○ Mixed White and Black Caribbean
○ Mixed White and Black African

○ Mixed White and Asian
○ Other Mixed
○ Asian or Asian British – Indian
○ Asian or Asian British – Pakistani
○ Asian or Asian British – Bangladeshi
○ Other Asian
○ Black or Black British – Caribbean
○ Black or Black British – African
○ Other Black
○ Chinese
○ Other ethic group

8 What is your marital status?
○ Married
○ Living together
○ In a relationship but not living together
○ Single
○ Divorced
○ Separated
○ Widowed

9 Do you have children?
○ Yes
○ No

10 If yes, how many? _________

11 If you have answered yes to question 9, please type in the ages of your children in the table.

Children	***1. child - age***	***2. child - age***	***3. child - age***	***4. child - age***	***5. child - age***
Daughter(s)					
Son(s)					

12 Who do you live with for most of the time?
○ Self and children
○ Partner and children
○ On your own
○ With partner/spouse
○ With friends
○ With other family
○ Other ____

13 Does the person you care for live with you? (for most of the time, outside of term time)
○ Yes
○ No

Details about the person you are caring for

14 Please describe your relationship to the person you are caring for with the following options: (Tick one box)
She / He is my…
○ Spouse

○ Partner
○ Child
○ Sibling
○ Parent
○ Other relative
If other, please specify ______________________________________
○ Friend
○ Other

If other, please specify ____

15 What is her / his date of birth?

_ _ / _ _ / _ _
DD MM YY

16 What is her /his age?

__ __ years

17 What is her / his gender?

○ Female
○ Male

18 What is her / his marital status? (Tick one box)
○ Married
○ Living together
○ Single
○ In a relationship but not living together
○ Divorced
○ Separated
○ Widowed

19 We are interested to know what sort of an eating disorder the person you care for has/had. Please answer to all the behaviours and symptoms below that describe their eating difficulties:

○ Yes ***Severely underweight***

○ Yes ***Restricting food intake***

○ Yes ***Exercising excessively***

○ Yes ***Vomiting after meals***

○ Yes ***Missing menstrual periods for 3 months or more***

○ Yes ***Eating unusually large amounts of food in one sitting (binge eating)***

○ Yes ***Eating in secret***

○ Yes ***Stealing food/money in order to binge***

○ Yes ***Severely overweight***

Others? Please specify

____

20 Has the person that you care for ever been diagnosed with an eating disorder by a health professional?

○ Yes
○ No

If Yes, what was the diagnosis? (You may tick more than one if the eating disorder has changed over time)

☐ Anorexia nervosa
☐ Bulimia nervosa
☐ Binge eating disorder
☐ I don't know
☐ Other

If other, please specify

____

____

21 At what age was the person you care for first diagnosed with an eating disorder?

____

22 At what age did the person you care for start to experience eating difficulties?

____

23 While the person you care for is suffering from their eating disorder does she / he have any additional problems? Please answer to all the behaviours below. E.g. does she / he:

○ Yes ***Drink a lot of alcohol***

○ Yes ***Use illegal drugs***

○ Yes ***Use legal drugs (e.g. sleeping tablets) in excess of the recommended amount***

○ Yes ***Deliberately hurt themselves (e.g. by biting, cutting burning themselves***

○ Yes ***Steal (including food)***

○ Yes ***Gamble***

Others? Please specify

____

24 On average, how many hours of face to face contact do you have with the person you care for each week? (Tick one box)

○ 0 – 7 hours / week
○ 8 – 14 hours / week
○ 15 – 21 hours / week
○ More than 21 hours / week
○ Other

If other, please specify ____

25 On average, how many hours of other contact do you have with the person you care for each week? (e.g. telephone, text, email etc)

○ 0 – 7 hours / week
○ 8 – 14 hours / week
○ 15 – 21 hours / week
○ More than 21 hours / week

○ Other

If other, please specify ____

Other Information

6.1 Have you ever had a problem with eating or weight?

○ Yes
○ No

If Yes, please give brief details of your eating problem (e.g. anorexia, over-eating); and whether you have ever been diagnosed with an eating disorder:

____

6.2 Has anyone else in your family ever had a problem with eating or weight?

○ Yes
○ No

If Yes, please detail their relationship to you (e.g. mother or cousin); their eating problem (e.g. anorexia, over-eating); and whether they have ever been diagnosed with an eating disorder:

____

6.3 Have you or anyone in your family been diagnosed with any other psychiatric or mental illness? (e.g. depression)

○ Yes
○ No

If Yes, please give details

____

6.4 Is there anything else that you would like to add?

PRE-TREATMENT QUESTIONNAIRE

Please tick one box for each question that best applies to you:-

1.	I fully agree with the referral	I agree in part with the referral	I do not agree much with the referral	I do not agree at all with the referral
	☐	☐	☐	☐
2.	The eating problem of X is a major concern for me	I'm quite concerned	I'm hardly concerned	I'm not concerned about X's eating problem at all
	☐	☐	☐	☐

3.	His/her difficulties have developed only because of him/her	His/her difficulties are mainly down to him/her, but other circumstances have also had an effect	His/her difficulties are mainly due to circumstances, but s/he has had a part to play in how they have developed	His/her difficulties are entirely due to circumstances out of their control
	☐	☐	☐	☐
4.	I want him/her to tackle their eating problem now	I want him/her to tackle their eating problem soon	Their eating problem can wait a while	I do not wish for them to tackle their eating problem now
	☐	☐	☐	☐
5.	If their eating problem is sorted, all their other difficulties will also be solved	If their eating problem is sorted, then most of their other difficulties will also be better, although they may still have some problems	If their eating problem is sorted, their other difficulties may be a little easier but they will remain	Even if their eating problems are sorted, they will have other difficulties which will be just as bad as ever.
	☐	☐	☐	☐
6.	Any progress they make will be achieved by them	Any progress they make will be achieved mainly by them	Any progress they make will be mainly due to the efforts of others	Someone needs to do something if they are to make progress
	☐	☐	☐	☐
7.	I am very optimistic that xSITEx will help him/her	xSITEx may help him/her	I doubt xSITEx will help much	I do not think xSITEx will help at all
	☐	☐	☐	☐
8.	S/he / We are going to have a go at what is offered	S/he / We will probably have a go at what is offered	S/he / We probably will not accept what is offered	S/he / We will not accept what is offered
	☐	☐	☐	☐

8.	It is very important that I as a carer am offered support and information to help myself and him/her ☐	It is quite important that carers are offered support and information so that they can help ☐	I think carers can have some support but it’s mostly down to the individual ☐	I don’t think it is important for carers to be involved as they s/he has to do it on their own ☐
9.	I expect that in 6 months my life will be very different ☐	I expect that in 6 months my life will be somewhat different ☐	I expect that in 6 months time my life will be mostly the same as it is now ☐	In 6 months my life will be just the same as it is now. ☐

Depression, Anxiety, & Stress Scales

INTRUCTIONS: *Please read each statement and tick a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week.*
There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1.	I found it hard to wind down	○ ○ ○ ○ 0 1 2 3
2	I was aware of dryness of my mouth	○ ○ ○ ○ 0 1 2 3
3	I couldn't seem to experience any positive feeling at all	○ ○ ○ ○ 0 1 2 3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	○ ○ ○ ○ 0 1 2 3
5	I found it difficult to work up the initiative to do things	○ ○ ○ ○ 0 1 2 3
6	I tended to over-react to situations	○ ○ ○ ○ 0 1 2 3
7	I experienced trembling (eg, in the hands)	○ ○ ○ ○ 0 1 2 3
8	I felt that I was using a lot of nervous energy	○ ○ ○ ○ 0 1 2 3

9	I was worried about situations in which I might panic and make a fool of myself	○ ○ ○ ○ 0 1 2 3
10	I felt that I had nothing to look forward to	○ ○ ○ ○ 0 1 2 3
11	I found myself getting agitated	○ ○ ○ ○ 0 1 2 3
12	I found it difficult to relax	○ ○ ○ ○ 0 1 2 3
13	I felt down-hearted and blue	○ ○ ○ ○ 0 1 2 3
14	I was intolerant of anything that kept me from getting on with what I was doing	○ ○ ○ ○ 0 1 2 3
15	I felt I was close to panic	○ ○ ○ ○ 0 1 2 3
16	I was unable to become enthusiastic about anything	○ ○ ○ ○ 0 1 2 3
17	I felt I wasn't worth much as a person	○ ○ ○ ○ 0 1 2 3
18	I felt that I was rather touchy	○ ○ ○ ○ 0 1 2 3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	○ ○ ○ ○ 0 1 2 3
20	I felt scared without any good reason	○ ○ ○ ○ 0 1 2 3
21	I felt that life was meaningless	○ ○ ○ ○ 0 1 2 3

FAMILY QUESTIONNAIRE

***INSTRUCTIONS**: This questionnaire lists different ways in which families try to cope with everyday problems. For each item please indicate how often you have reacted to the person you care for in this way and tick the box which is most accurate from your point of view. There are no right or wrong responses. It is best to note the first response that comes to mind, and make only one response per question. Please think about how things have been on average over the past month.*

		Never / Very rarely	**Rarely**	**Often**	**Very often**
1	I tend to neglect myself because of him/her	○ 1	○ 2	○ 3	○ 4
2	I have to keep asking him/her to do things	○ 1	○ 2	○ 3	○ 4
3	I often think about what is to become of him/her	○ 1	○ 2	○ 3	○ 4

4	He/she irritates me	○ 1	○ 2	○ 3	○ 4
5	I keep thinking of the reasons for his/her illness	○ 1	○ 2	○ 3	○ 4
6	I have to try not to criticise him/her	○ 1	○ 2	○ 3	○ 4
7	I can't sleep because of him/her	○ 1	○ 2	○ 3	○ 4
8	It's hard for us to agree on things	○ 1	○ 2	○ 3	○ 4
9	When something about him/her bothers me, I keep it to myself	○ 1	○ 2	○ 3	○ 4
10	He/she does not appreciate what I do for him/her	○ 1	○ 2	○ 3	○ 4
11	I regard my own needs as less important	○ 1	○ 2	○ 3	○ 4
12	Her/she sometimes gets on my nerves	○ 1	○ 2	○ 3	○ 4
13	I am very worried about him/her	○ 1	○ 2	○ 3	○ 4
14	He/she does some things out of spite	○ 1	○ 2	○ 3	○ 4
15	I thought I would become ill myself	○ 1	○ 2	○ 3	○ 4
16	When he/she constantly wants something from me it annoys me	○ 1	○ 2	○ 3	○ 4
17	He/she is an important part of my life	○ 1	○ 2	○ 3	○ 4
18	I have to insist that he/she behave differently	○ 1	○ 2	○ 3	○ 4
19	I have given up important things in order to be able to help him/her	○ 1	○ 2	○ 3	○ 4
20	I am often angry with him/her	○ 1	○ 2	○ 3	○ 4

OSLO Social Support

INSTRUCTIONS: There are three questions about you experience your social relationships in terms of your immediate, personal experience. Please read and choose ONE of the following options for each question.

1	How many people are so close to you that you can count on them if you have serious personal problems?	None	1 or 2	3-5	More than 5	
2	How much concern do people show in what you are doing?	A lot of concern and interest	Some concern and interest	Uncertain	Little concern and interest	No concern and interest
3	How easy is it to get practical help should need it? Who from? ______________________________	Very easy	Easy	Possible	Difficult	Very difficult

Accommodating & Enabling Scale for Eating Disorders

12.1 INSTRUCTIONS*: The following items contain a number of statements that commonly apply to the family members who live with a relatives or friends with an eating disorder. We would like you to read each one and decide how often it has applied to your family members over the* ***<u>past one month</u>****. It is important to note that there are no right or wrong answers. Your first reaction will usually provide the best answer.*

Items -During the past <u>month</u> how often have you thought about:

12.3 Does your relative with eating disorder control…

		never	**rarely**	**some-times**	**often**	**every day**
1.	the choices of food that you buy?	○ 0	○ 1	○ 2	○ 3	○ 4
2.	what other family members do and for how long in the kitchen?	○ 0	○ 1	○ 2	○ 3	○ 4
3.	cooking practice and ingredients you use?	○ 0	○ 1	○ 2	○ 3	○ 4
4.	what other family members eat?	○ 0	○ 1	○ 2	○ 3	○ 4

12.4 Does your relative engage any family member in repeated conversations…

		never	**rarely**	**some-times**	**often**	**every day**
5.	asking for reassurance about whether she/he will get fat?	○ 0	○ 1	○ 2	○ 3	○ 4
6.	about whether it is safe or acceptable to eat a certain food?	○ 0	○ 1	○ 2	○ 3	○ 4
7.	asking for reassurance about whether she/he look fat in certain clothes?	○ 0	○ 1	○ 2	○ 3	○ 4
8.	their ingredients and amounts, possible substitutes for ingredients?	○ 0	○ 1	○ 2	○ 3	○ 4
9.	about negative thoughts and feelings	○ 0	○ 1	○ 2	○ 3	○ 4
10.	about self-harm	○ 0	○ 1	○ 2	○ 3	○ 4

12.5 Do any family members have to accommodate to the following:

11.	what crockery is used?	○ 0	○ 1	○ 2	○ 3	○ 4
12.	how crockery is cleaned?	○ 0	○ 1	○ 2	○ 3	○ 4
13.	what time food is eaten?	○ 0	○ 1	○ 2	○ 3	○ 4
14.	what place food is eaten?	○ 0	○ 1	○ 2	○ 3	○ 4
15.	how the kitchen is cleaned?	○ 0	○ 1	○ 2	○ 3	○ 4
16.	how food is stored?	○ 0	○ 1	○ 2	○ 3	○ 4

17.	the exercise routine of the relative with an ED?	○ 0	○ 1	○ 2	○ 3	○ 4
18.	your relative's checking their body shape or weight?	○ 0	○ 1	○ 2	○ 3	○ 4
19.	how the house is cleaned and tidied?	○ 0	○ 1	○ 2	○ 3	○ 4

12.6 Do you choose to ignore aspects of your relative's eating disorder that impinge your family's life in an effort to reconcile or make it tolerable for the rest of the family such as if…

		never	**rarely**	**some-times**	**often**	**every day**
20.	food disappears?	○ 0	○ 1	○ 2	○ 3	○ 4
21.	money is taken?	○ 0	○ 1	○ 2	○ 3	○ 4
22.	the kitchen is left a mess?	○ 0	○ 1	○ 2	○ 3	○ 4
23.	the bathroom is left a mess?	○ 0	○ 1	○ 2	○ 3	○ 4

24. In general, to what extent would you say that the relative with an eating disorders controls family life and activities?

None at All *About Half* *Completely*

○	○	○	○	○	○	○	○	○	○	○
0	1	2	3	4	5	6	7	8	9	10

		never	**rarely**	**some-times**	**often**	**every day**
25.	How often did you participate in behaviours related to the your relative's compulsions?	○ 0	○ 1	○ 2	○ 3	○ 4
26.	How often did you assist your relative in avoiding things that might make her/him more anxious?	○ 0	○ 1	○ 2	○ 3	○ 4

Items -During the past month how often have you thought about:

0 = no 1 = mild 2 = moderate 3 = severe 4 = extreme

		no	**mild**	**mode-rate**	**severe**	**extreme**
27.	Have you avoided doing things, going places, or being with people because of your relative's disorder?	○ 0	○ 1	○ 2	○ 3	○ 4
28.	Have you modified your family routine	○ 0	○ 1	○ 2	○ 3	○ 4

		no	**mild**	**moderate**	**severe**	**extreme**
	because of your relative's symptoms?					
29.	Have you modified your work schedule because of your relative's needs?	○ 0	○ 1	○ 2	○ 3	○ 4
30.	Have you modified your leisure activities because of your relative's needs?	○ 0	○ 1	○ 2	○ 3	○ 4
31.	Has helping your relative in the before mentioned ways cause you distress?	○ 0	○ 1	○ 2	○ 3	○ 4
32.	Has your relative with an eating disorder become distressed/anxious when you have not provided assistance?	○ 0	○ 1	○ 2	○ 3	○ 4
33.	Has your relative become angry/abusive when you have not provided assistance?	○ 0	○ 1	○ 2	○ 3	○ 4

The Caregiver Skills (The CASK)

We are interested in your thoughts on some areas of caregiving. Please be as frank and honest as you can.

The statements below describe situations that are commonly associated with eating disorders. For each situation please rate how confident you are that you could respond in the way described.

Rate your degree of confidence from 0 to 100 using the scale given below.

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

For example, a rating of 100 means that you are absolutely, 100% confident that you could perform the activity whenever you wished. For each scenario, please circle the number that you feel best reflects your confidence. You can choose any score between 0 and 100 (10, 20, 30, etc.)

Please make all your ratings based on what you could do THIS WEEK as the person you are NOW rather than on the person you used to be or the person you would like to be. This is very important.

If you feel some of the questions aren't applicable to you, try to rate how confident you would be should the situation arise.

The blank spaces refer to your loved one with an eating disorder. You do not need to fill in the gaps.

Thank you for taking the time to complete this questionnaire.

How confident are you that you can…….

1. …Keep doing the things that you enjoy whilst caring for ________?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

2. …Discuss and explain your own feelings about the eating disorder openly with _________?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

3. ….. Discuss the eating disorder openly with *all* other immediate family members involved?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

4. ….. Be understanding towards _______, even when you are angry or frustrated with them?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

5. ….. Avoid getting drawn into arguments about the eating disorder with _________?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

6. ….. Be calm when dealing with difficult behaviours associated with the eating disorder?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

7. ….. Take some time for yourself when you need a break?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

8. ….. Talk and listen with _________ about difficult and complex emotions that s/he is feeling?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

9. ….Be reassured by even the smallest signs of improvement?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

10. ….. Keep hope that _______ will recover?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

11. ….. Step back and trust that ____________ will cope with day to day challenges by themselves?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

12. …Agree boundaries, plans or household rules in collaboration with _________?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

13. …Uphold boundaries/rules consistently in a compassionate tone, even when ________ is arguing with you?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

14. … Control the urge to argue against the eating disorder behaviours, even though you believe your argument to be logical?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

15. ….. Have pleasant verbal interactions with ___________, not related to the eating disorder?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

16. ….. Control the urge to keep enquiring or checking on _______ ‘s behaviour even when you are very worried?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

17. ….. Praise change or attempts at change by _______ even if the effects/results were less than you were hoping for?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

18. ….. Resist constantly reminding/asking about agreed behaviour targets?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

19. ….. Avoid getting caught in repetitive conversations with _________about food and eating?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

20. ….. Keep your eye on ________’s overall progress/the bigger picture?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

21. ….. Resist relying solely on weight as a marker of how s/he is doing?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

22. …..Separate ___________ as a person from the illness?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

23. …. Reflect and understand the effect of your behaviour on __________?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

24. ….. Accept that the eating disorder is not your fault?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

25. ….. Accept that the one cause or trigger for the eating disorder may not be the solution to recovery?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

26. …Find time to spend with other members of the family?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

27. … Manage your anxiety levels so that you don't feel overwhelmed?
0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

Obsessive-compulsive Inventory-Revised

The following statements refer to experiences that many people have in their everyday lives. Circle the number that best describes HOW MUCH that experience has DISTRESSED or BOTHERED you during the PAST MONTH. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Not at all
1 Applied to me a little
2 Moderately
3 A lot
4 Extremely

1.	I have saved up so many things that they get in the way.	○ ○ ○ ○ ○ 0 1 2 3 4
2	I check things more often than necessary.	○ ○ ○ ○ ○ 0 1 2 3 4
3	I get upset if objects are not arranged properly.	○ ○ ○ ○ ○ 0 1 2 3 4
4	I feel compelled to count while I am doing things.	○ ○ ○ ○ ○ 0 1 2 3 4
5	I find it difficult to touch an object when I know it has been touched by strangers or other people.	○ ○ ○ ○ ○ 0 1 2 3 4
6	I find it difficult to control my own thoughts.	○ ○ ○ ○ ○ 0 1 2 3 4
7	I collect things I don't need.	○ ○ ○ ○ ○ 0 1 2 3 4

8	I repeatedly check doors, windows, drawers, etc.	○ ○ ○ ○ ○ 0 1 2 3 4
9	I get upset if others change the way I have arranged things.	○ ○ ○ ○ ○ 0 1 2 3 4
10	I feel I have to repeat certain numbers.	○ ○ ○ ○ ○ 0 1 2 3 4
11	I sometimes have to wash or clean myself simply because I feel contaminated.	○ ○ ○ ○ ○ 0 1 2 3 4
12	I am upset by unpleasant thoughts that come into my mind against my will.	○ ○ ○ ○ ○ 0 1 2 3 4
13	I avoid throwing things away because I am afraid I might need them later.	○ ○ ○ ○ ○ 0 1 2 3 4
14	I repeatedly check gas and water taps and light switches after turning them off.	○ ○ ○ ○ ○ 0 1 2 3 4
15	I need things to be arranged in a particular order.	○ ○ ○ ○ ○ 0 1 2 3 4
16	I feel that there are good and bad numbers.	○ ○ ○ ○ ○ 0 1 2 3 4
17	I wash my hands more often and longer than necessary.	○ ○ ○ ○ ○ 0 1 2 3 4
18	I frequently get nasty thoughts and have difficulty getting rid of them.	○ ○ ○ ○ ○ 0 1 2 3 4

Short Autism Quotient (AQ-10)

How to fill out the questionnaire
Below is a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it by ticking your answer.
DO NOT MISS ANY STATEMENT OUT.

	Definitely agree	Slightly agree	Slightly disagree	Definitely disagree
1. I often notice small sounds when others do not.				
2. When I'm reading a story, I find it difficult to work out the characters' intentions.				
3. I find it easy to 'read between the lines' when someone is talking to me.				
4. I usually concentrate more on the whole picture, rather than the small details.				
5. I know how to tell if someone listening to me is getting bored.				
6. I find it easy to do more than one thing at once.				
7. I find it easy to work out what someone is thinking or feeling just by looking at their face.				
8. If there is an interruption, I can switch back to what I was doing very quickly.				
9. I like to collect information about categories of things (e.g. types of cars, birds, trains, plants, etc.).				
10. I find it difficult to work out people's intentions.				

FAMILY EATING PATTERNS

Lastly, we are interested in different patterns of eating within families. All families (both ED and non ED) have their own unique family dynamics. In this case, we are looking at specific eating patterns in families where ED has become a problem. Please be assured that this is not about 'blame'. We are interested solely in learning as much as we can about eating patterns in families already fighting EDs. We are optimistic that this information will inform current research and help those groups most at risk. These groups may be other families or even future generations of your own family. Only families such as yourself can help us with this goal and we very much appreciate your support and insight in this area. Therefore, please answer these questions as honestly as possible.

When answering these questions, please think about the time BEFORE the onset of the eating disorder.

Before the onset of your loved one's eating disorder, how often did you think about wanting to be thinner?

Never	Rarely	Sometimes	Often	All the time
0	1	2	3	4

Before onset of the ED, how often did you try to lose weight?

Never	Rarely	Sometimes	Often	All the time
0	1	2	3	4

Before the onset of your loved one's eating disorder, how often did you think about wanting to be more toned or muscular?

Never	Rarely	Sometimes	Often	All the time
0	1	2	3	4

Before onset of the ED, how often did you try to change your weight so you were more muscular?

Never	Rarely	Sometimes	Often	All the time
0	1	2	3	4

Before ED, I ate anything I wanted, whenever I wanted

Never	Rarely	Sometimes	Often	All the time
0	1	2	3	4

Before ED, I paid a great deal of attention to changes in my figure

Never	Rarely	Sometimes	Often	All the time
0	1	2	3	4

Before ED, were you likely to buy low calorie foods?

Never	Rarely	Sometimes	Often	All the time
0	1	2	3	4

Before the onset of ED, how concerned were you about your child having to diet to maintain a desirable weight?

Unconcerned	A little concerned	Concerned	Fairly concerned	Very concerned
0	1	2	3	4

How concerned were you about your child becoming overweight?

Unconcerned	A little concerned	Concerned	Fairly concerned	Very concerned
0	1	2	3	4

Thank you for completing this questionnaire.
We greatly appreciate your help.
(Remember, the next ones aren't as long as this!)

Eating Disorder Symptom Impact Scale

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

Never	Rarely	Sometimes	Often	Nearly Always
0	1	2	3	4

-During the past month how often have you thought about:

1. How your friends/relatives have stopped visiting 0 1 2 3 4

2. Losing your friends 0 1 2 3 4

3. Feeling unable to go out for evenings, weekends or on holiday 0 1 2 3 4

4. Cancelling or refusing plans to see friends or relatives 0 1 2 3 4

5. Feeling that I should have noticed it before it became so bad 0 1 2 3 4

6. Feeling that I have let her/him down 0 1 2 3 4

7. Feeling that there could have been something that I should have done 0 1 2 3 4

8. Thinking that perhaps I wasn't strict enough 0 1 2 3 4

9. Thinking about where I went wrong 0 1 2 3 4

During the past month how often have you had difficulties with your loved one's behaviour:

10. Physically and/or verbally aggressive behaviour 0 1 2 3 4

11. Controlling/manipulative behaviour 0 1 2 3 4

12. Lying/stealing 0 1 2 3 4

13. Out of control temper 0 1 2 3 4

- ***When the sufferer was living with you at home during the past month, how often:***

(if the sufferer was not living at home with you during the past month, please refer to the last time she/he was living at home)

14. Did you experience difficulties preparing meals (i.e. making separate meals for family members, not having correct ingredients)? 0 1 2 3 4

15. Were there arguments with other family members about how to handle mealtimes? 0 1 2 3 4

16. Were there arguments or tension during mealtimes? 0 1 2 3 4

17. Did food disappear from the cupboards? 0 1 2 3 4

18. Did you spend long periods of time shopping for food? 0 1 2 3 4

19. Did you have difficulties with blocked drains, plumbing? 0 1 2 3 4

20. Were there bad smells and hygiene in the bathroom? 0 1 2 3 4

21. Did you have to turn up the heat due to her/him feeling cold? 0 1 2 3 4

22. Did you check on her/him to ensure that she/he was "*okay*"? 0 1 2 3 4

23. Did you notice or think about how the illness was affecting her/him physically (i.e. see her/him fall, faint, struggle up the stairs)? 0 1 2 3 4

24. Did you notice or think about how the illness was affecting her/him mentally? 0 1 2 3 4

CSRI-Carer Baseline

INSTRUCTIONS: In this questionnaire we ask you questions about your daily routine and the circumstances of your life. Some of the questions might sound intrusive and personal. The reason why we ask you these questions is the crucial importance of exploring the individual and family costs of illnesses. All the information you give us will be treated confidentially.

We will ask you about the following questions within a telephone interview; hence; **you don't have to fill out** this questionnaire but it is there for your guidance and can **make notes**. We will ask you some of these issues again at different stages of the study.

It would be appreciated if you could have a look at the questions before we conduct the interview to **prepare yourself**. Preparation might be important in the context of questions about the expenses you had within the last few months or the time it took you to provide care for your relative.

This majority of this interview focuses on the 6 months (24 weeks) **BEFORE your relative's initial or most recent assessment** with the outpatient service (where you heard about this study). Please think about that time period when answering the questions.

Background information

Name / code of carer: ______________________

Date of Interview: ______________________

Interviewer's name / code: ______________________

Are you the primary or secondary carer? Primary carer ☐ Secondary carer ☐

Relationship of patient to carer: ______________________

Gender of carer: Female ☐ Male ☐

DOB of carer: ☐☐ ☐☐ ☐☐
dd mm yy

Date of relative's assessment

The Care-ED time spent care giving

Please think about the month before your relative had their recent assessment (unless it was particularly untypical of the previous 6 months, for example you were on holiday. If this is the case, please choose a typical month before the initial assessment).

On average, on how many days did the following care giving behaviours / activities relate to you?

Each section relates to a certain category we found important in the context of providing care for someone with an eating disorder. The examples for each category are there for your guidance.

If you are employed / in volunteer work: Earlier in this questionnaire we have asked you whether you had to take time off work to provide care. Please indicate for every category if you took time off and on how many days.

Medical related care

→ e.g. going to hospital appointments, GP, counselling , therapy, giving medication …

Yes ☐ No ☐

If yes, on how many days did you provide this kind of care? ___________ days (max 30)

In total, how much time have you spent on these activities within the last month in hours?
______________ hours / month

If you took time off work, how many days in total?
_________days (or n/a)

Food related care

→ e.g. shopping, meal support / planning, cooking the meals …

Yes ☐ No ☐

If yes, on how many days did you provide this kind of care? ___________ days (max 30)

In total, how much time have you spent on these activities within the last month in hours?
______________ hours / month

If you took time off work, how many days in total?
_________days (or n/a)

Practical care related

→ e.g. help with cleaning, giving lifts …

Yes ☐ No ☐

If yes, on how many days did you provide this kind of care? ___________ days (max 30)

In total, how much time have you spent on these activities within the last month in hours?
______________ hours / month

If you took time off work, how many days in total?

________days (or n/a)

Giving your relative emotional support → e.g. reassurance, discussions, listening … Yes ☐ No ☐	***If yes, on how many days did you provide this kind of care?*** ___________ days (max 30) ***In total, how much time have you spent on these activities within the last month in hours?*** ______________ hours / month ***If you took time off work, how many days in total?*** ________days (or n/a)
Gathering information about eating disorders → e.g. reading eating disorder literature (books, internet etc.), finding out about local services and help / support … Yes ☐ No ☐	***If yes, on how many days did this behaviour / activity relate to you?*** ___________ days (max 30) ***In total, how much time have you spent on these activities within the last month in hours?*** ______________ hours / month ***If you took time off work, how many days in total?*** ________days (or n/a)
Communication with Professionals → (non eating disorder professionals) teacher, dentist, pharmacist Yes ☐ No ☐	***If yes, on how many days did this behaviour / activity relate to you?*** ___________ days (max 30) ***In total, how much time have you spent on these activities within the last month in hours?*** ______________ hours / month ***If you took time off work, how many days in total?*** ______days (or n/a)
Other (e.g. church, emotional support to partner or primary carer of relative) ___________________________ ___________________________ ___________________________	***If yes, on how many days did this behaviour / activity relate to you?*** ___________ days (max 30) ***In total, how much time have you spent on these activities within the last month in hours?*** ______________ hours / month ***If you took time off work, how many days in total?*** ____________days (or n/a)

12M Depression, Anxiety, and Stress Scales for Patients/Carers

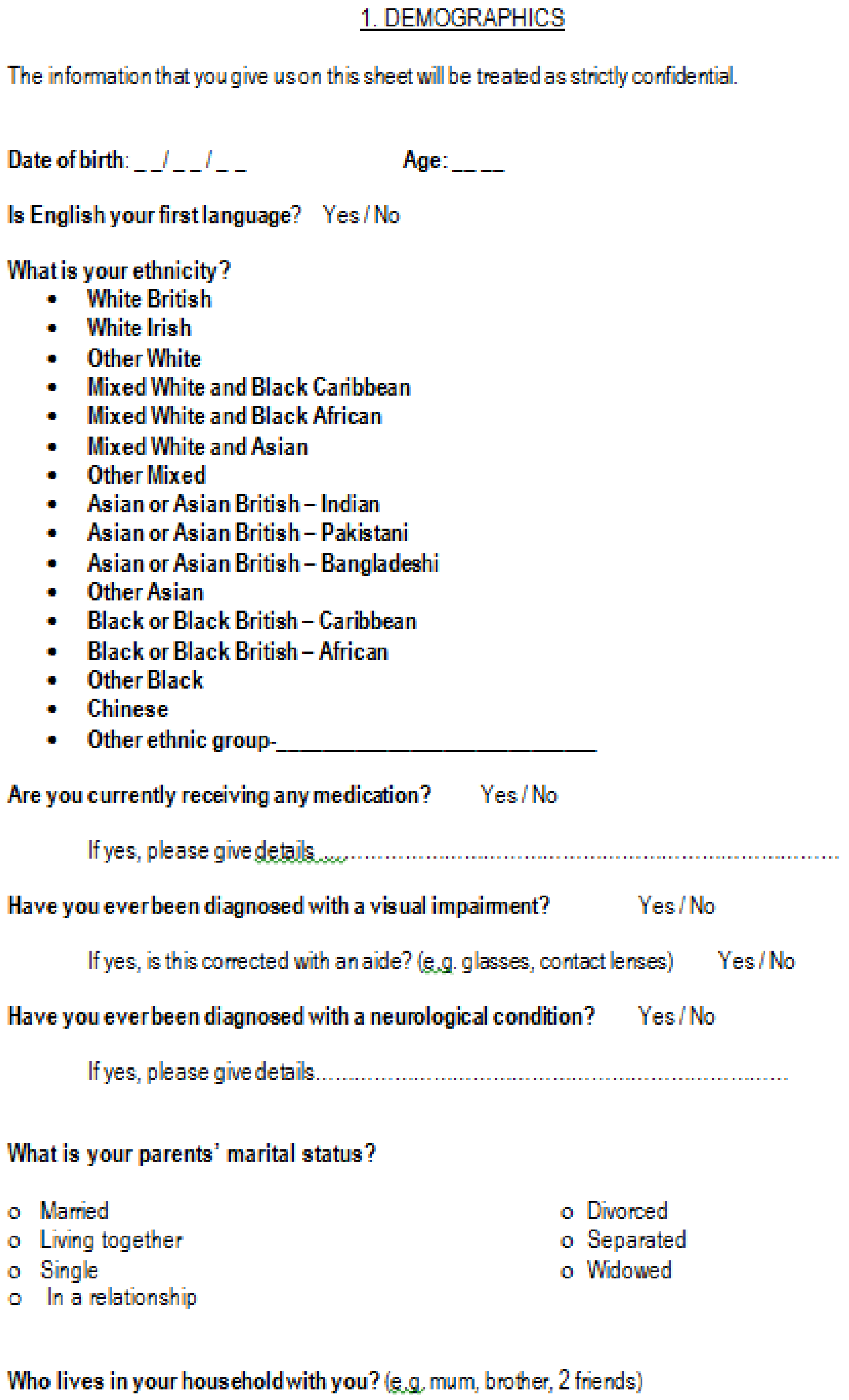
INTRUCTIONS: *Please read each statement and tick a number 0, 1, 2 or 3 which indicates how much the statement applied to you <u>over the past week.</u>*
There are no right or wrong answers. Do not spend too much time on any statement.
The rating scale is as follows:
0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1.	I found it hard to wind down	○ ○ ○ ○ 0 1 2 3
2	I was aware of dryness of my mouth	○ ○ ○ ○ 0 1 2 3
3	I couldn't seem to experience any positive feeling at all	○ ○ ○ ○ 0 1 2 3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	○ ○ ○ ○ 0 1 2 3
5	I found it difficult to work up the initiative to do things	○ ○ ○ ○ 0 1 2 3
6	I tended to over-react to situations	○ ○ ○ ○ 0 1 2 3
7	I experienced trembling (eg, in the hands)	○ ○ ○ ○ 0 1 2 3
8	I felt that I was using a lot of nervous energy	○ ○ ○ ○ 0 1 2 3
9	I was worried about situations in which I might panic and make a fool of myself	○ ○ ○ ○ 0 1 2 3
10	I felt that I had nothing to look forward to	○ ○ ○ ○ 0 1 2 3
11	I found myself getting agitated	○ ○ ○ ○ 0 1 2 3
12	I found it difficult to relax	○ ○ ○ ○ 0 1 2 3
13	I felt down-hearted and blue	○ ○ ○ ○ 0 1 2 3
14	I was intolerant of anything that kept me from getting on with what I was doing	○ ○ ○ ○ 0 1 2 3
15	I felt I was close to panic	○ ○ ○ ○ 0 1 2 3

16	I was unable to become enthusiastic about anything	○ ○ ○ ○ 0 1 2 3
17	I felt I wasn't worth much as a person	○ ○ ○ ○ 0 1 2 3
18	I felt that I was rather touchy	○ ○ ○ ○ 0 1 2 3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	○ ○ ○ ○ 0 1 2 3
20	I felt scared without any good reason	○ ○ ○ ○ 0 1 2 3
21	I felt that life was meaningless	○ ○ ○ ○ 0 1 2 3

Thank you very much for filling out this LAST questionnaire! We really appreciate your help.

Appendix B.2 Main study materials relating to study 2



1. DEMOGRAPHICS

The information that you give us on this sheet will be treated as strictly confidential.

Date of birth: _ _/_ _/_ _ **Age:** _ _ _

Is English your first language? Yes / No

What is your ethnicity?
- White British
- White Irish
- Other White
- Mixed White and Black Caribbean
- Mixed White and Black African
- Mixed White and Asian
- Other Mixed
- Asian or Asian British – Indian
- Asian or Asian British – Pakistani
- Asian or Asian British – Bangladeshi
- Other Asian
- Black or Black British – Caribbean
- Black or Black British – African
- Other Black
- Chinese
- Other ethnic group-___________________________

Are you currently receiving any medication? Yes / No

If yes, please give details…………………………………………………………………

Have you ever been diagnosed with a visual impairment? Yes / No

If yes, is this corrected with an aide? (e.g. glasses, contact lenses) Yes / No

Have you ever been diagnosed with a neurological condition? Yes / No

If yes, please give details……………………………………………………………

What is your parents' marital status?

- Married
- Living together
- Single
- In a relationship
- Divorced
- Separated
- Widowed

Who lives in your household with you? (e.g. mum, brother, 2 friends)

Instructions for Watching the Movie

- You are about to watch 5 shorts film clips (Films 1, 2, 3, 4, and 5), each lasting about 3 minutes
- Some of the films are repeated during the experiment
- Your job is to watch each film clip (starting with Film 1) in turn
- Please allow yourself to get involved in the film

Instructions for viewing the films:

1. Before you watch each film clip **PLEASE READ OUT LOUD THE FILM'S NAME (e.g. before pressing the play button for Film 1, please read out "Film 1", so the camera knows which film your are about to watch)**
2. Then press PLAY to watch each film clip all the way through one at a time
3. After watching each film clip press PAUSE to give yourself time to rate how you felt while watching the film clip on the rating sheet given.
4. On the rating sheets, there are lots of words about feelings a person may experience when watching a film. Please read each word and choose a rating for it on a scale of 1 to 5 (1= very slightly, 5 = extremely) for how strongly that word fits with how you felt while watching the film.
5. If you think you felt any other feelings that are not included in the list, please write it down and choose a rating for it at the bottom of the sheet where is says *"Did you feel any other emotion during the film clip?"*

While watching the films please:

- Do NOT rate the films (please wait until it has finished)
- Try and keep still so you don't go out of the camera shot
- Try not to talk

It is important that you follow these instructions for the study to work. A camera will be recording you during the experiment to see how you're completing the experiment.

Please feel free to ask if you have any questions.

THE RATING SHEET

PLEASE DO NOT RATE WHILE YOU ARE WATHING THE FILM CLIPS

How I felt

Not much or not at all 1	A little 2	Some 3	Quite a bit 4	A lot 5

Feelings	Film 1	Film 2	Film 3	Film 4	Film 5
Interested					
Sad					
Frightened					
Alert					
Excited					
Ashamed					
Upset					
Happy					
Strong					
Nervous					
Guilty					
Energetic					
Scared					
Calm					
Miserable					
Jittery					
Cheerful					
Active					
Proud					
Afraid					
Joyful					
Lonely					
Mad					
Fearless					
Disgusted					
Delighted					
Blue					
Daring					
Gloomy					
Lively					
Please write down, and give a rating for, any other emotion you may have experienced during the film clip					

Had you seen any of the films before? If so, which ones and how many times do you think you've seen them?

……