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Charlotte L. Wormald BA Hons MSc

INFLATED RESPONSIBILITY AND PERFECTIONISM IN CHILD AND ADOLESCENT
ANOREXIA NERVOSA

Section A: Research review: What are the psychological risk factors
associated with anorexia nervosa with co-morbid obsessive compulsive
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Summary of MRP

Section A. This paper presents a review of the literature that has investigated possible psychological risk factors underlying the presentation of anorexia nervosa (AN) with co-morbid obsessive compulsive disorder (OCD). This included theoretical research and two types of empirical studies (comparative studies and co-morbidity studies). These examined risk factors including personality development, family functioning, neuropsychological functioning, perfectionism, exercise behaviours and a cognitive biases. The review concludes that current research is too preliminary and limited by methodological issues to draw any firm conclusions.

Section B. This is a report of the pilot study investigating inflated responsibility (IR) and perfectionism in child and adolescent anorexia nervosa (AN). It also explored the relationship between child and parental IR. The empirical and theoretical background to the study is presented and a new theoretically-derived model for understanding IR in AN is proposed. Following this, the methodology is described. In total, 30 young people diagnosed with AN (which included diagnoses of AN and AN/EDNOS) and 32 of their parents participated. Children and adolescents with AN reported significantly higher levels of IR and perfectionism, compared to the published normed data. An interaction term of IR X perfectionism was a significant predictor of AN severity in the child and adolescent sample. Parents of children with AN reported higher levels of IR compared to healthy controls, but there was no relationship between child and parent IR. Further independent replication of these results is needed.

Section C. In this paper, critical reflection of the content and process of the research project is presented. Initial dissemination of the results is discussed and further research projects are described.

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SECTION A

Research review:

What are the psychological risk factors associated with anorexia nervosa and co-morbid obsessive compulsive disorder?

Inflated Responsibility and Perfectionism in Child and Adolescent Anorexia Nervosa

Abstract

Background: Research suggests that between 20-69% of people diagnosed with anorexia nervosa (AN) also have co-morbid obsessive compulsive disorder (OCD) or significant obsessive compulsive symptoms (OCS). People with this co-morbidity report higher levels of anxiety and depression and have a worse prognosis. Research has begun to identify possible psychological risk factors that may underlie this co-morbidity. The aim of this paper was to review this literature and critique the quality of the evidence.

Methodology: A systematic literature review incorporating predefined search terms and predetermined inclusion and exclusion criteria for population, outcome and study design was devised. Eleven electronic databases were searched and procedures to cross-reference the search and find unpublished literature were adopted. All returned studies were screened against the inclusion and exclusion criteria.

Results: Theoretical research and two types of empirical investigations (comparative studies and co-morbidity studies) have tried to determine what psychological constructs may underlie AN with co-morbid OCD or OCS. These examined risk factors including personality development, family functioning, neuropsychological functioning, perfectionism, exercise behaviours and a cognitive preoccupation with order and symmetry.

Conclusions: The current research is too preliminary and limited by methodological issues to draw any firm conclusions. Further research covering a range of individual and environmental factors is needed.

Introduction

Introduction to The Review

It is well established that individuals with anorexia nervosa (AN) frequently report psychological and psychiatric co-morbidities, with obsessive compulsive disorder (OCD) being the most common (Altman & Shankman, 2009; Halmi, 2009). This review will critique the literature regarding psychological risk factors that have been connected to AN with co-morbid OCD. Definitions and prevalence of both the individual disorders and their co-morbid presentation are reported in the introduction, because the cause rather than the nature of the co-morbidity is in question. This is followed by the review of the main theoretical and empirical arguments regarding possible psychological risk and vulnerability factors underlying the co-morbidity. Risk factors can be defined as variables related to an increased risk in developing a physical, psychological or psychiatric difficulty (Beglin, 1993). The evidence will be critiqued against pre-defined quality measures. Following this, research and clinical implications will be discussed.

Definition of Terms

Anorexia nervosa. Anorexia Nervosa is defined as a pattern of dysfunctional thoughts and behaviours regarding weight, body shape and eating that result in a persistent pursuit of low body weight, even when this poses clinical physiological risk (Diagnostic and Statistical Manual, 4th ed., text rev. (DSM-IV-TR); American Psychiatric Association (APA), 2000). The estimated prevalence of lifetime AN is approximately 0.5–0.9% and the estimated 12-

month prevalence is 0.3% (Favaro, Ferrara, & Santonastaso, 2004). The prevalence of AN in young people (under 18 years of age) is also estimated to be 0.3%, which some studies suggest is increasing (Halmi, 2009). The prognosis is currently poor: approximately a third of people recover, a third remain ill but make some improvement and manage to maintain some level of functioning, and a third do not recover and follow a chronic course of illness (Fisher, Hetrick & Rushford, 2010; Berkman, Lohr, & Bulik 2007).

The literature agrees that the 'causes' of AN are multi-factorial and can be considered within a bio-psycho-social model. Each individual will present with a unique combination of risk and maintaining factors, some of which are discussed below (Nunn, Lask & Frampton, 2011; Lask & Bryant-Waugh, 2013). Recent reviews have summarised the role of possible genetic and neurobiological variables that may contribute to the aetiology of AN and associated co-morbidity (Kaye, Wierenga, Bailer, Simmons & Bischoff-Grethe, 2013; Wade, Gordon, Medland, Bulik, Heath, Montgomery et al., 2013). AN is associated with high levels of co-morbidity, including depression, anxiety and personality difficulties (Bryant-Waugh & Lask, 2013).

Obsessive compulsive disorder. Obsessive Compulsive disorder (OCD) is defined by a pattern of intrusive and unwanted thoughts, impulses or images and/or compulsive behaviours (DSM-IV-TR; APA, 2000). The lifetime prevalence is estimated to be 2.3% and the 12-month prevalence of OCD is estimated to be 1.2% (Ruscio, Stein, Chiu, & Kessler, 2009). In approximately a third of cases people report an onset in childhood, and some risk factors are developmental

(Pauls, Alsobrook, Goodman, Rasmussen & Leckman, 1995). OCD can be conceptualised as a spectrum model, with people experiencing obsessive-compulsive symptoms (OCS) and traits (OCT), which may vary in severity depending on their environment and levels of stress (Gallop, 2009).

The Co-Morbidity of AN with OCD

There is a large body of evidence establishing a co-morbidity of OCD in individuals with AN (Altman & Shankman, 2009; Serpell, Livingstone, Neiderman & Lask, 2002; Godart, Flament, Perdereau & Jeammet, 2002; Milos, Spinder, Ruggiero, Klaghofer & Schnyder, 2001; Godart, Flament, Lecrubier, & Jeammet, 2000). While two studies did not find this relationship (Wu, 2008; Thiel, Züger, Jacoby & Schüssler, 1998), the majority of the research suggests there is a significant co-morbidity and 6.5-13% of adults with OCD have AN whereas 20-69% of adults with AN report clinically significant OCD and OC symptoms (OCS) (Swinbourne & Touyz, 2007; Godart et al., 2002; Serpell et al., 2002). The majority of the research, detailed above, is correlational. This limits understanding about the direction of the relationship and about aetiological factors that may lie beneath this co-morbidity.

Rationale and Aim

Individuals who have AN with co-morbid OCD are more likely to have a chronic and severe illness (Altman & Shankman, 2009, Halmi, 2009). They are more likely to experience higher levels of anxiety and depression compared to

individuals with AN without OCD or individuals with OCD alone (Altman & Shankman, 2009; Matsunaga, Kiriike, Iwasaki, Miyata, Yamagami & Kaye, 1999). Given the worse prognosis, understanding what might cause this co-morbidity may help inform assessment and treatments in clinical services. Recent reviews have explored the genetic and neurobiological risk factors (Kaye et al., 2013; Wade et al., 2013). Therefore, the aim is to critique the available evidence examining psychological factors that may underlie the co-morbidity. The quality of the associated evidence will influence whether any conclusions can be drawn.

Methodology

A systematic literature search was devised to answer the research question. The design of the search strategy was guided by the Cochrane handbook for systematic reviews (Higgins & Green, 2011). This determines that inclusion and exclusion parameters of population and outcome should be defined before commencing the search. The handbook also suggests that the most appropriate study design for answering the research question should also be pre-identified, although it remains within the author's discretion whether to include other study designs that may help to answer the research question (Higgins & Green, 2011).

The search strategy sought to include two types of studies to answer the research question. The first were *comparative* studies, which selected variables based on their theoretical connection to AN and OCD and then compared this variable between an AN and an OCD group. This offers a less direct but useful insight into possible shared risk or vulnerability factors (Beglin, 1993). The

second study type was co-morbidity studies. These directly tested potential risk factors in populations of individuals with AN and co-morbid OCD or OCS.

Population and Outcome Inclusion Criteria

Comparative studies were selected into the literature search if they:

- ! Compared a group of participants with AN to a group of participants with OCD or OCS
- ! Compared the two groups' functioning on the same theoretically derived outcome variable(s), which was being investigated as a possible risk factor

Co-morbidity studies were included if they recruited:

- ! Samples of participants who had been formally diagnosed with AN plus co-morbid OCD (AN+OCD) according to standardised criteria including DSM-IV-TR; DSM-IV and ICD-10 (World Health Organisation (WHO), 2008; APA, 2000)
- ! Samples of participants who had been diagnosed with AN who had significantly elevated obsessive compulsive symptoms and/or features (AN+OCS), which had been assessed using reliable and valid measures including self-report questionnaires and semi-structured interviews.
- ! Sub-clinical populations if they also used reliable and valid measures of AN and OCD.

Given the paucity of the literature and limitations of relying solely on categorical definitions, this dimensional model of symptoms was included. This is based on a spectrum model of symptoms ranging in severity from sub-clinical to more

extreme levels. This procedure had been established in similar published reviews (Young, Rhodes, Touyz & Hay, 2013). Please see Appendix 1 for the study design inclusion and exclusion criteria.

Population and Outcome Exclusion Criteria

All studies were excluded if they:

1. only recruited samples of people with AN without any features of OCD
2. only recruited samples of people with OCD without any features of AN
3. and/or did not compare an AN group to an OCD group.

Please see Appendix 1 for the full search strategy including terms, databases and limits. See Appendix 2 for quality criteria (Downs & Black, 1998).

Results

In total, six theoretical and 15 empirical studies met the inclusion criteria, which investigated psychological risk factors underlying AN with co-morbid OCD. The theoretical literature drew on statistical theory and personality development to hypothesise about the causality of the co-morbidity.

The empirical evidence can be split into comparative studies and co-morbidity studies (see Appendix 3 for the empirical study characteristics). The comparative studies identified potential risk factors that are theoretically relevant to both disorders and compared the prevalence of the risk factor between a sample with AN and a sample with OCD. These comparative studies examined the neuropsychological construct of conditional associative-learning,

family functioning, obsessional beliefs and thought preoccupations with order and symmetry.

Preoccupations with order and symmetry were also addressed by a co-morbidity study, which examines the prevalence of this thought preoccupation within a co-morbid sample using a case control design. Therefore, the discussion on preoccupation with order and symmetry acts as the bridge between the comparative studies and the co-morbidity studies in this review.

Perfectionism and excessive exercise are other risk factors that were tested by co-morbidity studies. Because theory can provide a context and understanding of the evidence, the theoretical arguments will be presented first, followed by the empirical evidence.

Theoretical Explanations of the Co-Morbidity

Chance. One possible hypothesis is that the co-morbidity happens by chance (Altman & Shankman, 2009). Some researchers calculated an estimate of the prevalence of AN with co-morbid OCD if it were due to chance (0.0036%) and compared this to the actual prevalence, estimated to be between 20-69% (Altman & Shankman, 2009). They concluded that there was no evidence that the co-morbidity happened by chance in the population.

Personality development. Another theory questions whether the overlap is attributable to personality factors (Halmi, Tozzi, Thornton, Crow,

Fichter, Kaplan, et al., 2005; Anderluh, Tchanturia, Rabe-Hesketh & Treasure, 2003; Serpell et al., 2002). This stems from the presence of shared personality traits across the two disorders (Anderluh et al., 2003; Halmi, Sunday, Strober, Kaplan, Woodside, Fichter, et al., 2000; Fairburn, Cooper, Doll & Welch, 1999). This theory hypothesises that individuals with AN and OCD may have atypical attachment styles and impaired emotional regulation and impulse control, which can lead to a problematic development of extreme levels of shared personality traits including compliance, persistence, perfectionism and being excessively cautious (Anderluh et al., 2003; Halmi et al., 2000). A strength of these theoretical studies is that they cite retrospective evidence to try and identify possible pre-morbid risk factors. However, these personality traits may not be exclusive to people with AN and OCD and there is not yet enough evidence regarding personality development to fully explain the co-morbidity of AN with OCD (Young et al., 2013; Serpell, et al., 2006; Serpell et al., 2001).

Empirical Investigations of the Co-Morbidity: Comparative studies

Family functioning. One study used Minuchin's theory of children's psychosomatic illness in families to hypothesise that similar difficulties with family functioning may cause people with AN to also develop OCD (Minuchin, Baker, Rosman, Liebman, Milman & Todd, 1975). This study used a between groups design to compare how young women (mean age 21, SD = 5.06 years) with OCD ($n = 17$), AN ($n = 15$), and bulimia nervosa (BN) ($n = 13$) reported their family functioning (Erol, Yazici & Toprak, 2007). The groups were matched for age, gender and education. The individual participants completed the Family

Assessment Device rating scale, adapted from the McMaster family assessment device (Epstein, Baldwin & Bishop, 1983) about their perceived family functioning. This scale covers seven domains including communication, problem-solving, emotional responses, emotional involvement, behavioural control and family roles. There were no group differences between the individuals with OCD, BN or AN for how they rated their families on any of the domains. Normed data was not reported, so it was not possible to tell whether all three groups reported elevated difficulties with family functioning, compared to healthy controls. No family members completed the measure, so the results may be subject to detection bias. The authors hypothesized that the lack of difference between the OCD and AN family functioning may be attributable to obsessive symptoms being present in both disorders (Erol et al., 2007) but the design was not sufficient to answer this question.

A further explanation of the results was that family dysfunction may be a consequence, rather than a cause of the individual's psychological difficulties, which is supported by similar research with families of people with AN (Gowers & North, 1999). It is not possible to conclude whether family functioning is a factor contributing to AN with co-morbid OCD, given that the literature search returned only one paper and there are methodological limitations within it. Further research is needed into the role of family functioning and to address the significant gaps in the literature regarding any other environmental risk factor that could be connected to AN with co-morbid OCD. Instead, the majority of the research has focused on individual factors, ranging from neuropsychological functioning to cognitive biases and preoccupations.

Neuropsychological factors: conditional associative learning (CAL).

CAL allows individuals to remember associations or responses to stimuli. One research group has tested the theory that individuals with AN and OCD will have deficits in CAL (Murphy, Nutzinger, Paul & Leplow, 2004). The authors compared ten participants with AN to ten with OCD and examined their CAL of threatening and neutral words. The researchers also recruited a healthy control group and controlled for age, depression, education, verbal ability, verbal and non-verbal memory, attention and planning. The participants were asked to learn associations between standardised words and arbitrary shapes in two paradigms: threat words (food, contamination and body shape related) and neutral words. The results showed that individuals with AN and OCD were significantly worse at learning associations in the neutral paradigm, compared to healthy controls. There were no group differences on the threat paradigm. The authors suggested that individuals with OCD and AN have an inherent CAL deficit, which is shown by their impaired performance on neutral paradigms. The reason why their performance is better on threat paradigms is thought to be because those with OCD and AN are already so hypervigilant to threat and punishment (Murphy, et al., 2004) that threat associations are learnt quickly and efficiently.

Independent replication is needed with larger sample sizes to test this preliminary finding and increase generalisability. Given the small sample size, there is a danger of a type one error, or finding an effect that is not really there. In addition it is unclear whether CAL deficits are unique to these disorders. The literature is too limited to draw any conclusions about CAL being a shared risk or vulnerability factor underlying the AN with OCD co-morbidity.

However, the CAL deficit theory could explain why some individuals with AN and OCD may struggle with learning and feedback processing, which could underlie the need to continuously repeat stereotyped behaviours. It could also be linked to difficulties with changing established responses to stimuli, once they have been learned. This is consistent with the evidence suggesting that cognitive inflexibility, or, 'black and white thinking' is present in individuals with AN (Roberts, Tchanturia, Stahl, Southgate & Treasure, 2007) and OCD (OCCWG, 2003). This particular thinking bias has not been investigated in a study comparing people with AN and co-morbid OCD, but researchers have begun to explore whether other cognitive factors may be implicated in this presentation.

Shared obsessive beliefs. One study compared the presence of seven cognitive biases thought to be associated with OCD between groups of people with AN (n=120), OCD (n=248) and people who had recovered from AN (n=26) (Lavender, Shubert, deSilva & Treasure, 2011). They recruited the AN and recovered AN groups themselves and compared their performance on the obsessive belief questionnaire ((OBQ) OCCWG, 2003) to age and gender matched published norms for the other disorder groups. The OBQ measured belief in perfectionism, intolerance of uncertainty, over-estimation of threat, the importance of thoughts, responsibility and control of thoughts. A further questionnaire measured magical ideation (MI), which has been defined as a thinking bias which is beyond rational and culturally accepted laws of cause and effect (Einstein & Menzies, 2004). The AN group and OCD group reported similarly elevated belief in cognitive biases of responsibility, control of thoughts and importance of thoughts. The AN group was higher on perfectionism,

intolerance of uncertainty, over-estimation of threat and MI. A limitation is that the authors did not record co-morbidity in the AN group, so the elevated scores in the AN group may be due individuals meeting criteria for OCD or OCS. Also, the sample was self-referred, which increases the risk of selection bias. However, the inclusion of a recovered sample, which reported lower but clinically significant levels of all cognitive biases, suggests that these beliefs may act as trait risk factors. Further research is needed to replicate these results with a longitudinal design to examine causality.

A preoccupation with order and symmetry: comparative studies.

Some authors have questioned whether there is a unique set of intrusive thoughts that are specific to people with AN and co-morbid OCD and if so, whether this acts as a risk factor that 'causes' the co-morbidity. The first two studies adopted comparative studies to answer this question.

The first study recruited a group of female adults with AN ($n = 18$) and a group with OCD ($n = 16$) (Bastiani, Pigott, Rubenstein, Weltzin, & Kaye, 1996). The groups were matched for age and gender and participants completed a well-validated measure, the Yale Brown Obsessive Compulsive Scale (Y-BOCS; Goodman, Price, Rasmussen, Mazure, Fleischmann, Hill, Heninger & Charney, 1989a; 1989b). There were no differences between severity scores for the two diagnostic groups. The AN group endorsed intrusions regarding symmetry and order while the OCD group reported different intrusions about contamination and aggression, although this was not a statistically significant difference. These results have some support from a large community study, which found that

intrusions regarding order and symmetry were the strongest predictors of disordered eating scores (Roberts, 2006). However, the Bastiani et al., (1996) study was limited by the lack of a co-morbid group and the small homogenous sample, which limits generalisability of results.

A larger study using a clinical population contradicts these findings (Halmi, Sunday, Klump, Strober, Leckman, Fichter, Kaplan, et al., 2003). The authors compared 324 adults with AN to adults with OCS ($n = 112$) using the Y-BOCS. The groups were not matched for duration of illness and the OCD group was significantly older. The results suggested that the AN group reported a higher frequency of aggressive obsessions, not order and symmetry ones. Like the Bastiani et al., (1996) study, there were no statistically significant differences in severity between the AN group and the OCD group. The authors used interviewers who were blinded to diagnosis and had a large sample size, which decreases detection bias and increases generalisability of results. However, there were significant demographic differences between groups and all participants had been selected to be in the study by family members, which may have biased the sample.

Co-Morbidity Studies

The preoccupation with order and symmetry continued. One study adopted a case control design with three groups: AN only ($n = 21$), OCD only ($n = 23$) and AN+OCD ($n = 21$) in Japan (Matsunaga et al., 1999). The groups were matched for age, education, and illness onset. These participants completed the

Y-BOCS and any items connected to food and body issues were removed from the scoring. The results suggested that individuals with AN+OCD had statistically similar levels of severity to individuals with OCD only, like the two studies above. However, only the AN+OCD group reported obsessions regarding order, symmetry and exactness. In contrast, the OCD only group reported aggressive obsessions. The AN only group had sub-clinical scores on the YBOCS and did not endorse order and symmetry obsessions.

The design of this study reduces detection bias by reporting unique findings from individuals with AN+ OCD, compared to individuals with only one disorder. However the study authors were not blinded to diagnosis and conducted the interviews themselves, which could influence the objectivity of their data collection and increase the risk of detection bias.

Taking the comparative and co-morbidity studies together, three out of the four studies suggest that people with clinical and sub-clinical AN are more likely to endorse obsessions regarding order and symmetry over any others and that these obsessions are the strongest predictor of disordered eating. However, only one study found that people with AN+OCD have significantly more intrusions about order and symmetry, compared to people with just OCD (Matsunaga et al., 1999). This was the only study to compare a co-morbid group to 'single' disorder groups. The two studies that reported that the difference was not significant had not used a case control design. It is unclear whether the lack of significant findings is because of this study design. Therefore, given the contradictory results and the discrepancies in study design, it is not possible to

conclude whether preoccupations regarding order and symmetry are a unique risk factor for individuals with AN and co-morbid OCD.

Perfectionism. Following similar lines of investigation into cognitive risk factors, researchers have investigated whether the cognitive bias of perfectionism is a risk factor that underlies AN with co-morbid OCD (Egan, Wade & Shafran, 2011). Perfectionism is defined as the need to avoid negative circumstances and the theory suggests there are two different types: self-orientated and socially-prescribed, which convey the suggested locus of origin and control (Flett, Hewitt, Boucher, Davidson, & Munro, 2000).

One study tested the presence of perfectionism in adolescents with AN with co-morbid obsessive compulsive symptoms (AN+OCS) ($n = 25$) compared to an adolescent psychiatric control group ($n = 24$), using a cross-sectional questionnaire design. The participants were matched for age and gender and participants in the control group had mixed diagnoses of what the authors called conduct and affective problems (Cassidy, Allsopp & Williams, 1999). The AN+OCS group scored significantly higher on measures of perfectionism compared to the psychiatric control group. The authors argued that because they assessed the AN+OCS patients at the earliest point of their first eating disorder onset, the perfectionism symptoms could not simply be a consequence of having AN for a long time (Cassidy et al., 1999). However, this study presented very little demographic data so it was unclear whether differences in participant characteristics may have contributed to the increased perfectionism in the AN

+OCS group. In addition, the use of correlational design prevents any conclusions regarding causality being drawn.

However, another study evaluating the presence of perfectionism in an adolescent AN+OCS sample found contradictory results (Serpell, Hirani, Willoughby, Niederman & Lask, 2006). This study did not use a control group and asked 49 children and adolescents with AN+OCS to complete self-report measures of perfectionism symptoms. They found no relationship between perfectionism and levels of AN+ OCS. Over half of the AN+OCS group had OCS scores above the clinical cut-off, but the ones that had less severe OCS may have affected the statistical results. The authors also suggested that the lack of findings for perfectionism could have been due to their questionnaire, the multidimensional perfectionism measure (Hewitt, Flett, Turnbull-Donovan, & Mikail, 1991), which was not validated for a child and adolescent population. There may be risk of a selection bias because the participants were severely ill and a restricted range on the variables may have limited the ability to find a correlation. There is also a risk of detection bias as perfectionism constructs were being included in cognitive items on measures of OCS.

Further independent replication is needed to examine the role of perfectionism in AN+OCS. Given the inconsistent evidence for perfectionism detailed above, it is not possible to ascertain whether perfectionism is a risk factor underlying the co-morbidity of AN with OCD, or whether it also acts as a maintaining factor.

Excessive exercise. As well as exploring possible cognitive risk factors underlying the co-morbidity, there is a small body of research testing the role of shared behaviours in individuals with AN and OCD. Specifically, studies have tried to determine whether excessive exercise could explain the co-morbidity. Excessive exercise is defined as a behaviour pattern where individuals restrict their nutritional intake and combine this with a frequency and intensity of exercise that is considered 'hyper' activity. This prevents them from achieving or maintaining a healthy body weight and is harmful to their physical health (Casper, 2006; Davis, 1997).

Some preliminary research argued that individuals with AN+OCS reported significantly higher levels of excessive exercise compared to individuals with OCD alone or to individuals with AN without OC symptoms (AN-OCS) (Naylor, Mountford & Brown, 2011; Davis & Kaptein, 2006; Davis, Kaptein, Kaplan, Olmsted, & Woodside, 1998; Davis, Kennedy, Ralevski, Dionne, Brewer, Neitzert, et al., 1995). These studies used moderate sized clinical samples (n range 40 to 84) and measures with good psychometric properties, including the Y-BOCS. One prospective longitudinal study proposed that obsessive compulsive symptoms might predict excessive exercise in individuals with AN, rather than excessive exercise predicting AN+OCS (Davis & Kaptein, 2006). This would suggest excessive exercise could be a consequence rather than a cause of the co-morbidity.

However, several studies also reported that there were no differences in exercise levels between individuals with AN with or without OC symptoms (Shroff, Reba,

Thornton, Tozzi, Klump, Berrettini, et al., 2006; Anderluh, Tchanturia, Rabe-Hesketh, & Treasure, 2003). The latter study may be at risk of detection bias, as they used a retrospective design without informants, so reporting may have been affected by memory factors. All of the studies except one (Davis & Kaptein, 2006) used correlational designs, so it is not possible to draw conclusions about causality between variables. Most studies used different self-report measures to test OCS, which limits comparisons of results (see Appendix 3). Due to the contradictions between the studies and the methodological limitations, it is not possible to conclude whether excessive exercise is a risk factor that causes AN with co-morbid OCD.

Discussion

The scope of possible risk factors that may contribute to AN with co-morbid OCD is broad. Given that the causes of AN and OCD are multi-factorial, it is appropriate for the range of identified risk factors in the literature reviewed here to reflect this and address issues across neuropsychology, personality development, cognitions and behaviours. However, there are issues with both the content and the process of the research, which is trying to answer the question about what risk factors may cause AN with co-morbid OCD.

Issues with Content: Gaps in the Literature

There appear to be significant gaps in the literature regarding theoretical and empirical understanding of AN with co-morbid OCD. For example, the literature search did not return any studies discussing theoretical hypotheses from a

systemic or psychodynamic perspective. Some systemic (Eisler, 2005) and cognitive-analytic (Ryle & Kerr, 2002) interventions are suggested by the NICE guidelines (NICE, 2004) to address clinical presentations of AN so these theories may offer etiological insights into AN with co-morbid OCD.

As described in Appendix 1, broad and extensive literature searches were conducted and there was an expectation that studies exploring risk factors implicated in developing OCD or AN individually, such as attachment style, childhood abuse and physical health co-morbidity (Jacobi, Hayward, de Zwaan, Kraemer, & Agras, 2004) would be returned. However, to the author's knowledge these studies have not been conducted.

The Process of Research: Methodological Strengths and Limitations

Design. According to the quality criteria defined by Downs and Black (1998) most of the studies reviewed here successfully identified their hypotheses, outcome variables and provided adequate demographic data to convey the characteristics of the sample. The majority of studies evaluating risk factors used standardised measurements with excellent validity and reliability properties, which decreases detection bias (Downs & Black, 1998). Many of the studies looking at cognitive intrusions chose the same measure (Y-BOCS) in order to aid comparison of results, which is a further strength.

However, this measure involved retrospective recall in semi-structured interviews. Starvation effects on the brain can create a risk of reporting bias,

with a danger of over or under reporting due to memory and attention impairments (Altman & Shankman, 2009). There is also a phenomenon where individuals with moderate to severe AN may be ambivalent about their illness or even see their AN as beneficial. This phenomenon is associated with under-reporting on assessment measures in an effort to 'protect' their AN (Serpell, Teasdale, Troop & Treasure, 2004).

Key limitations were that the comparative study designs could not directly answer the research question (Downs & Black, 1998) and the co-morbidity studies lacked sufficient control groups. To explore the relationship between two frequently occurring co-morbid disorders, a case control design is needed with two 'pure' disorder groups, a co-morbid group and a healthy control group (Altman & Shankman, 2009). In addition, longitudinal retrospective or prospective designs are needed to determine whether risk factors exist as 'trait' and/or pre-morbid features.

Sample. 'Berkson's bias' (1946) suggests that individuals with more than one condition are more likely to be referred to services. Thus, clinical samples are more likely to include individuals with co-morbid presentations, for example AN with OCD. Most of the comparative and co-morbidity studies used clinical and inpatient samples. This creates a risk of sampling bias, because the co-morbidity prevalence and characteristics may be inflated as a result of recruiting from clinical populations (Altman & Shankman, 2009).

The majority of the studies reviewed here had small samples which increase the risk of making Type 2 errors, or report a lack of significant effect due to being underpowered (Downs & Black, 1998). Other studies selected their participants, which could increase the risk of bias, as it is not clear whether these individuals were 'cherry-picked' to be involved in the research. Collectively, this could decrease the external and internal validity of this research.

Sensitivity and Specificity. A strength of specificity is that some of the risk factors, including excessive exercise and a cognitive preoccupation with order and symmetry may be unique to individuals with AN and OCD, but this specificity has not been empirically tested. Other risk factors including personality development, difficult family functioning and CAL impairment may be relevant to individuals with a wide range of psychological and psychiatric disorders.

Clinical Implications

The lack of evidence for psychological risk factors, but relative wealth of evidence for genetic and biological risk factors (Kaye et al., 2013; Wade et al., 2013) may reflect a bias towards a medical model in the research literature. Clinical psychologists are in a position to make practice-research links and extend the preliminary body of psychological research.

The evidence regarding possible risk factors of personality development, neuropsychological differences, family functioning and cognitive biases in individuals with AN and co-morbid OCD could be used to expand detailed clinical

assessments across services. This information could also be used to inform possible interventions, both through highlighting possible cognitive biases that might act as blocks to therapy but also guiding clinicians to areas for specific work. For example, CAL impairment may be linked to perseverative and 'all or nothing' thinking styles.

The majority of the research was carried out with adult populations and the extrapolation of features and symptoms of adult AN with OCD to child populations is problematic. However, the perfectionism research was carried out in adolescent populations, which could alert clinicians working in child and adolescent services to the possibility of perfectionism being a risk and maintaining factor in the early-onset population (Bryant-Waugh & Lask, 2013). The fact that significant neuropsychological advancement occurs in the critical period in adolescence may be relevant to the possible development of impaired feedback processing and CAL deficits (Cicchetti, 2013). All of these factors could be addressed in assessment and treatments with children and adolescents.

Future Research

The current research focus on 'cognitions' and 'behaviours' in the field may reflect the cognitive and behavioural understanding of OCD, which is dominant in the NICE guidelines. Case reports, single case designs and mixed method quantitative and qualitative studies drawing on alternative therapeutic modalities, including psychodynamic and systemic theories, may offer valuable insights into possible causes of AN with co-morbid OCD.

Cognitive behavioural theory would suggest that the need to avoid a negative outcome is central to the thoughts and behaviours in both disorders. Within cognitive research, investigations into cognitive biases have begun. As well as the evidence investigating perfectionism and obsessive beliefs detailed above, there is preliminary research testing other cognitive biases in populations with AN, for example thought-action fusion (Roncero, Perpina & Garcia-Soriano, 2011; Coelho, Carter, McFarlane & Polivy, 2008; Shafran & Robinson, 2004; Radomsky, de Silva, Todd, Treasure & Murphy, 2002). Further research is needed to explore whether the remaining cognitive biases of OCD are relevant to an AN population and whether they are risk factors for the co-morbidity.

Other future research possibilities concern the presence of other shared neuropsychological difficulties, including cognitive inflexibility and visuo-spatial processing. This would need to include longitudinal case control design, otherwise it would not be possible to know whether these neuropsychological difficulties are a cause or consequence of the co-morbidity.

Conclusion

The prevalence of AN with co-morbid OCD is a well-established and significant phenomenon. Individuals with this co-morbidity have a more chronic and severe level of illness (Altman & Shankman, 2009) and there is a large body of research establishing this overlap. Preliminary evidence has examined personality development, cognitive intrusions and biases, exercise behaviours and family functioning as possible risk factors underlying this co-morbidity. However,

extensive further research is needed to clarify the specificity of these and other environmental and individual risk factors.

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Section B

A pilot study investigating inflated responsibility (IR) in child and adolescent anorexia nervosa: Prevalence of IR, interaction with perfectionism and relationship with parental inflated responsibility.

Abstract

Objective: Theory suggests that cognitive biases in obsessive compulsive disorder (OCD) may occur in individuals with anorexia nervosa (AN) and anorexia nervosa /eating disorder not otherwise specified (AN/EDNOS), which may partly explain the large co-morbidity between the two disorders. The aim of the current study was to investigate the cognitive biases of inflated responsibility (IR) and perfectionism in children and adolescents who had been diagnosed with AN and AN/EDNOS. An additional aim was to investigate the relationship between IR and perfectionism and to test an interaction effect on AN severity. The relationship between young people and their parents' levels of inflated responsibility was also investigated.

Method: A cross-sectional multi-site pilot study using standardised questionnaires was conducted. Full ethical approval was gained and 30 young people diagnosed with AN and AN/EDNOS and 32 of their parents participated. This included 22 matched pairs of children and parents.

Results: Children and adolescents with AN and AN/EDNOS reported significantly higher levels of IR and perfectionism, compared to the published data for non-clinical norms. Self-orientated perfectionism was associated with frequency of IR thoughts. There was also a significant interaction effect: young people who had a higher frequency of IR thoughts and self-orientated perfectionism had lower BMIs. Parents reported higher levels of IR compared to the published non-clinical norms, but there was no relationship between child and parent IR.

Discussion: Further independent replication of these results is needed. IR and perfectionism should be considered in the assessment and treatment of child and adolescent AN and AN/EDNOS, both in individual and systemic interventions. This research also adds to the growing body of literature examining cognitive biases of OCD in an AN population, which may offer some insight into the overlap between the two disorders.

Introduction

Anorexia Nervosa in Children and Adolescents

Anorexia Nervosa is defined as a refusal to maintain weight at an appropriate level, defined by weight for age and height, and a negative preoccupation with body shape and weight (Diagnostic and Statistical Manual, 4th ed., text rev.;(DSM-IV-TR); American Psychiatric Association (APA), 2000). An individual at risk for AN may be born with an overactive anxiety arousal system and neuropsychological vulnerabilities in the context of developmental demands and adverse life events (Nunn, Lask & Frampton, 2011). A common diagnosis of eating disorders in young people is 'Anorexia Nervosa/Eating Disorder Not Otherwise Specified' (AN/EDNOS), which can relate to meeting almost all the criteria for AN, but may include some sub-clinical symptoms which may belong to another eating disorder.

It is well established that individuals with Anorexia Nervosa (AN) can experience a high rate of co-morbidity with both Axis-1 and Axis-2 disorders (Bryant-Waugh & Lask, 2013). One of the most common is the co-morbidity of AN with OCD. OCD is defined as a pattern of intrusive and unwanted thoughts, images or impulses that are ego-dystonic, or clash against individuals' sense of themselves (DSM-IV, 2000). Compulsive behaviours are often used to combat the perceived outcome of the thought and neutralise associated distress.

The prevalence range of AN with co-morbid OCD, or significant OC symptoms (OCS), is estimated to be between 20-69% (Serpell, Livingstone, Neiderman & Lask, 2002). The discrepancy in estimates has been attributed to researchers using different diagnostic criteria and assessment tools. Individuals with this co-morbidity are thought to have a

worse prognosis, are less responsive to treatment and have less positive outcomes (Altman & Shankman, 2009). Therefore, understanding features of OCD in people with AN and AN/EDNOS, with a view to developing treatments, is essential.

The Role of Cognitive Biases in AN and OCD

The need and ability to avoid a perceived negative outcome can be as dominant in AN as it can be in OCD. Cognitive behavioural theory of AN suggests that cognitions, assumptions and beliefs develop around the behaviours of restricting food intake and compulsive exercising (Fairburn, 2005). The theory suggests that the underlying function of these thoughts and behaviours is both the need and ability to avoid a negative outcome, i.e. feelings of disgust, self-loathing and anxiety. The negative cognitions and compensatory behaviours then become integral maintaining factors in AN and AN/EDNOS (Fairburn, Cooper & Shafran, 2003; Fairburn, Shafran & Cooper, 1999).

Researchers and clinicians have suggested that cognitive biases that are seen to be central in OCD (Obsessive Compulsive Cognitions Working Group (OCCWG) 1997, 2003) may also apply to individuals with AN (Lavender, Schubert, de Silva & Treasure, 2011; Shafran, 2003). The theory suggests that individuals with AN and OCD share similar cognitive biases, which may explain the cognitive component of the co-morbidity (Lavender et al., 2011; Shafran, 2003). So far, this has included initial research on perfectionism, thought-shape fusion and obsessional beliefs.

In OCD, perfectionism is defined as the need to avoid a negative outcome that can be either (or both) self-orientated or socially-prescribed (OCCWG, 2003; Flett, Hewitt,

Boucher, Davidson, & Munro, 2000). The theory of perfectionism in AN is that it could be both a developmental trait risk factor and a state construct, where it becomes connected to goals associated with weight, shape and eating (Southgate, Tchanturia, Collier & Treasure, 2008). This draws on the theory that individuals with perfectionism are more likely to set idealistic and unrealistic goals and continuously strive to achieve them (Flett et al., 2000). This is supported by some of the evidence that young people with AN may try to achieve these unrealistic weight and shape goals through restricting food and exercising, even when it is clinically dangerous to do so (Bryant-Waugh & Lask, 2013; Nicholson, 2013).

One theory of perfectionism in eating disorders suggests that 'clinical perfectionism' is a trans-diagnostic construct that can both inflate and sustain eating difficulties (Shafran, Cooper & Fairburn, 2003). The theory suggests that clinical perfectionism manifests itself both as cognitions regarding the need to avoid negative outcomes through accomplishing idealistic achievements, and as behaviours focused on striving for these goals (Egan, Wade & Shafran, 2011; Shafran et al., 2003). However, the findings for perfectionism in young people are mixed; some studies found a positive association between AN and perfectionism (Castro, Gila, Gual, Lahortiga, Saura & Toro, 2004; Cassidy, Allsopp & Williams, 1999) and one study found no significant association (Serpell, Hirani, Willoughby, Niederman & Lask, 2006). More research is needed to explore the relationship between perfectionism and AN.

Other literature exploring OCD cognitive biases in individuals with AN has examined the construct of thought-shape fusion, an adaptation of the OCD construct, 'thought-action fusion'. (Roncero, Perpina & Garcia-Soriano, 2011; Coelho, Carter, McFarlane & Polivy,

2008; Shafran & Robinson, 2004; Radomsky, de Silva, Todd, Treasure & Murphy, 2002).

Thought-action fusion is a thinking style where individuals believe that having an inappropriate thought is the ethical equivalent of acting out that thought; for example, having a thought about hurting somebody is as wrong as doing it (OCCWG, 2000). For people with AN, 'thought-shape fusion' has been defined as a belief where thinking about eating food is as morally unacceptable and as 'harmful' to one's body shape as eating it (Shafran & Robinson, 2004). This small body of literature offers some preliminary evidence that thought-shape fusion is a valid construct in AN.

A recent study compared the presence of shared cognitive biases by measuring seven obsessional beliefs in adults with AN and OCD (Lavender et al., 2011). The two groups reported similarly elevated levels of belief in responsibility, the need to control thoughts and the over-importance of thoughts. The AN group was higher on measures of perfectionism, intolerance of uncertainty, over-estimation of threat and magical ideation. The authors used a self-selecting sample, which may decrease generalisability of results. However, these studies collectively offer some preliminary evidence to suggest that cognitive biases thought to be associated with OCD may be relevant to individuals with AN.

A key limitation with the preliminary evidence investigating OCD cognitive biases in individuals with AN is that all of the research, with the exception of the perfectionism studies, has used adult samples. Given the high prevalence of AN in children and adolescents, the poor prognosis and the fact that cognitive biases may develop during childhood (Barrett & Healy, 2003) more research is needed to investigate cognitive biases in children and adolescents with AN.

Inflated Responsibility

Inflated responsibility (IR) is a well-established cognitive factor within OCD (Freeston, Rheaume & Ladoucer, 1996; Salkovskis, Rachman, Ladoucer, Freeston, Taylor, Kyrios et al., 1996). IR is defined as an individual's conviction that they have the power to bring about or prevent negative outcomes that are personally relevant and that the level of responsibility is too pervasive, too extreme and causes distress (Salkovskis, Shafran, Rachman & Freeman, 1999).

This theory suggests an individual will have an intrusive thought associated with a negative outcome and then make the appraisal that they have the power to cause or prevent this outcome. This will spark physiological symptoms of anxiety, which are then neutralised with a compulsive behaviour. This then enforces their belief that they have the power to prevent the negative outcome, which then maintains their inflated responsibility.

Preliminary research has reported a relationship between OCD and inflated responsibility in children (Matthews, Reynolds & Derisley, 2007; Libby, Reynolds, Derisley & Clark, 2004; Magusdottir & Smari, 2004). The results suggested that young people with OCD had significantly higher levels of IR, compared to anxious and control groups. The results also showed that IR had a significant positive association with OC symptoms (OCS) and was the most significant predictor of OCS. A recent review of the literature examining cognitive models of OCD in children and adolescents concluded that IR is a significant factor of OCD in children and that the effect sizes are consistently large (Reynolds & Reeves, 2008).

Cognitive theory proposes five developmental pathways that are hypothesized to promote inflated responsibility (Salkovskis et al., 1999). Two pathways suggest that inflated responsibility develops as a product of parenting and family environment (Salkovskis et al., 1999), with parents either placing excessive or inadequate levels of responsibility on the developing child. Two other theoretical pathways are concerned with children being indirectly or directly involved in an adverse life event and developing assumptions about their behaviour/thoughts, or lack of them, being responsible for the event. A final developmental pathway suggests IR is a product of strict and extremely moral parenting, which is linked to the development of perfectionism (Salkovskis et al., 1999). Given that some research shows that young people with AN are more likely to be perfectionist, it needs to be explored whether this population may also have IR.

Inflated Responsibility in AN

This theoretical model of inflated responsibility could offer some insight into the disordered eating of young people with AN. Anecdotal evidence suggests that when young people present in clinical settings they appear to be unable to take responsibility to eat appropriately and maintain a healthy body weight. In addition, young people report that if they eat, they are responsible for causing harm to themselves, because eating is associated with putting on weight and the subsequent negative consequences (B. Watkins, personal communication, September 10, 2011; L. Turner, personal communication, June 5, 2012). This could be understood using the theory of inflated responsibility, explained above. If a young person believes that they have the power to

cause harm to themselves by eating, they may also believe they have the power to prevent this harm, by not eating.

This paper proposes a possible model of IR in AN, displayed in figure one. When a young person with AN has an intrusion like 'I'm fat and ugly', the misappraisal of inflated responsibility will be 'I am responsible for making myself fat and ugly when I eat', so the cognitive distortion of inflated responsibility exaggerates the immediacy and the power of this threat. This distortion connects with an 'all or nothing' cognitive bias, so the misappraisal becomes either I eat nothing and stay thin or I eat and I get 'fat'. This belief may also connect with a perfectionist cognitive bias, where unrealistic goals about being as thin as possible are triggered.

The intrusive thoughts may trigger distress, which is neutralised by the safety behaviour of restricting food intake. The young person may then realise they have the power to prevent the negative outcome; so inflated responsibility becomes enforced in a maintenance cycle. Inflated responsibility distress is also managed by transferring the responsibility onto someone else, so they become responsible for harm. When a young person enters an inpatient ED unit, the safety behaviour of restricting is replaced by the safety behaviour of transferring the responsibility onto carers. This could be why young people continue to have disordered eating post-treatment, as they have not been handed back the responsibility for eating and so do not learn to manage the inflated responsibility distress. One study has reported the presence of IR in an adult AN sample (Lavender et al, 2011) but no research has tested IR in a child and adolescent AN sample.

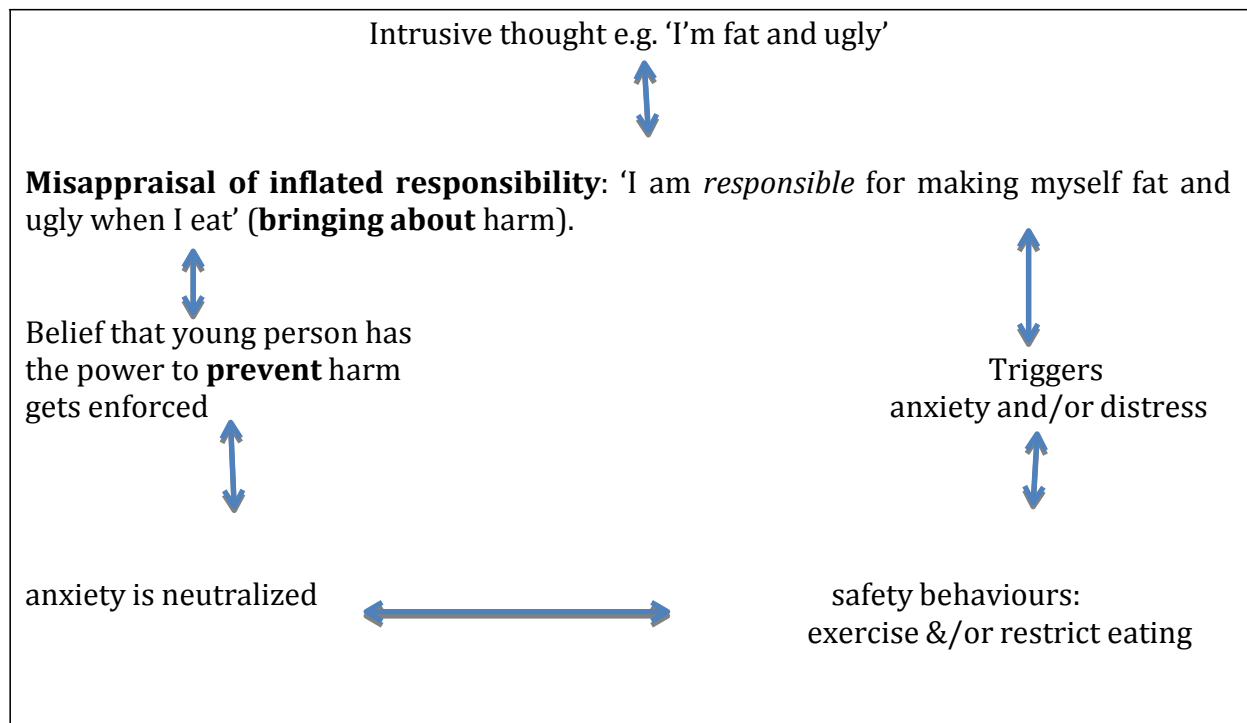


Figure 1. The proposed cognitive model of inflated responsibility in anorexia

nervosa.

The content of this model is adapted from the cognitive theory of AN (Fairburn et al., 2003), e.g. the thoughts about being 'fat and ugly' and the behaviours of restricting and exercising. The process of this model is adapted from the cognitive model of IR (Salkovsis et. Al., 2000), i.e. the intrusions about IR triggering distress and safety behaviours.

Study Aims

Hypotheses

Drawing on the model and cognitive theory of AN and IR explained above, the following hypotheses were made:

1. Young people with AN and AN/EDNOS would have significantly higher levels of self-orientated and socially-prescribed perfectionism, compared to norms for the general population.

2. Young people with AN and AN/EDNOS would have significantly higher levels of IR compared to norms for the general population
3. Child IR would be positively correlated with AN severity
4. The interaction between child IR and child perfectionism would account for a significant part of the variance on AN severity.
5. Parents would have higher levels of IR compared to the published adult norms
6. There would be a significant association, in either direction, between parent and child IR.

Method

A pilot study can be used to make the first attempt to examine hypotheses and test the chosen research methodology (Mylor & Blackmon, 2005). This pilot study used a cross-sectional multi-site questionnaire design.

Participants

Participants were outpatient child or adolescent and parent dyads, attending either a national specialist tier 4 eating disorders service or a borough wide, child and adolescent mental health service (CAMHS) specialist eating disorder service. All child and adolescent participants had been diagnosed with Anorexia Nervosa (AN) or AN/Eating Disorder- Not Otherwise Specified (AN/ED-NOS) according to DSM-IV (APA, 2000) by a multi-disciplinary specialist team. All participants were recruited consecutively between November 2012 and July 2013.

The inclusion criteria for the young people were: they had to be aged between eight and 18 years old, able to speak English and diagnosed with AN or AN/EDNOS in the past

twelve months, according to DSM-IV criteria. Young people with an acquired or traumatic brain injury and/or a diagnosis of a pervasive developmental disorder, or aged under eight were excluded from the study due to the possible cognitive difficulties completing the questionnaire. Inclusion criteria for the parents specified that they were able to speak English and were a parent or carer of a child that had been diagnosed with AN or AN/EDNOS in the past year.

Overall, 87 individuals were approached and 62 agreed to participate, which was a response rate of 71% and is comparable to other studies with similar designs (Maylor & Blackmon, 2005). There was also an 8% drop out rate of young people from the overall sample ($n=7$). These participants began the questionnaire and then stopped completing it, citing difficulties understanding the questionnaire ($n=2$) or reporting it did not apply to them ($n=5$).

Within the parents' sample, ten parents completed the study but their children refused: six cited being too distressed to participate and four reported that they were not interested. Within the young people's sample, eight young people completed the study but their parents declined, six saying that they did not think it was relevant to them and two reporting that they were not interested. It was not possible to analyse the demographics of the attrition sample because they withdrew their permission for any data to be collected. In total 32 parents and 30 young people were recruited into the study. This resulted in 22 matched pairs of 11 parent and child dyads.

The average age of the child sample was 14.87 years ($SD = 1.63$ years; range: 11 years - 18 years). The average age of the parent sample was 48.22 years ($SD = 5.18$ years; range:

28 years – 55 years). The average length of time involved in either eating disorder service was 8.45 months (SD = 9.22 months). Table 1 shows further demographic data.

Table 1

Demographic data of participants in the child and parent samples.

Demographics	Child Data (<i>n</i> = 30)	Parent Data (<i>n</i> = 32)
	Frequency	Frequency
Gender		
Male	0	8
Female	30	24
Ethnicity		
White British	27	30
Asian or Asian British	2	2
White Other (American)	1	0
Diagnosis		
Anorexia Nervosa	25	27*
AN/EDNOS	5	5*

**Parents reported their child's diagnosis of AN or AN/ED-NOS*

Procedure

Trained staff members in both clinical teams approached potential participants (young people and their parents together) and invited them to hear about the study. If they agreed, they were given an information sheet and the study was described in full.

Separate age-appropriate information sheets were used for children aged 12 years or less and for young people aged 13-18 years (see Appendix 4 for copies of all information sheets and consent forms). When parents and young people agreed to participate, young people signed a written informed assent form and parents signed a written informed

consent form. When children were aged 16 years or under, their parents also counter-signed their child's informed assent form. Participants were given a copy of their consent or assent forms and information sheets to keep. Participants then filled out the short research questionnaire while at the clinic, and returned their completed questionnaire to the team member who had recruited them.

Ethics

The study was approved by the national research ethics service's local research ethics committee and received full approval from the two NHS host trust research and development departments (see Appendix 5 for relevant documentation). Parents and young people were given the opportunity to ask any questions and were reminded that their data was anonymous and confidential. They were also assured that either choosing to participate or not would not affect their care in any way and they had a right to withdraw at any time. Both parents and their children were offered to de-brief after completing the questionnaire, in case the questions provoked any feelings of distress. See Appendix 6 for further ethical actions.

Measures

Demographic data were collected in the first part of the questionnaire, which included age in years, gender, ethnicity and approximate number of months since being referred to the service. Following clinical recommendation (E. Watkins, personal communication, November 5 2012) all questionnaires were adapted for attention or memory impairment due to possible starvation or anxiety effects. Specifically, alternating grey

and white lines were used for each item and a large and bold font was used, to make the questionnaire more visually engaging.

Inflated Responsibility. Young people completed the Child Responsibility Interpretations Questionnaire (CRIQ; Salkovskis & Williams, 2004). The first 11 items measure the frequency of responsibility interpretations, associated with intrusive thoughts, over the past week. An example item is '*Because these thoughts come from my own mind I must want to have them*'. The second 11 items measure the strength of belief in these same interpretations. In the frequency section, answers are rated on a Likert scale ranging from 0-4 where 0 denotes 'never had this idea' and 4 signifies 'always had this idea'. In the strength of belief section, answers are marked on a visual scale, which ranges from '0' to '100' percent, with '100' signifying 100% belief in the item statement. See Appendix 7 for a copy of the questionnaire. A total global score is not used, but the two sub-scales of frequency and belief are summed to give separate sub-scale scores. The questionnaire has good concurrent validity and high internal consistency along with normative data (Salkovskis & Williams, 2004). In this study, the internal consistency was excellent for the frequency scale (Cronbach's $\alpha = 0.93$) and the belief scale (Cronbach's $\alpha = 0.95$).

Parents completed the Responsibility Interpretations Questionnaire (RIQ; Salkovskis et al., 2000), which is a 22 item questionnaire designed to investigate appraisals of responsibility in adults. This questionnaire tests the frequency and belief in positive and negative responsibility interpretations over the past two weeks, which are associated with intrusive thoughts. The items are similar to the CRIQ, but more advanced language is used. See Appendix 8 for a copy of the parent RIQ. The questionnaire has good

concurrent and discriminant validity as well as good internal consistency statistics (Salkovskis et al., 2000). The internal consistency for this study was good for both the frequency scale (Cronbach's $\alpha = 0.87$) and for the belief scale (Cronbach's $\alpha = 0.85$). In both the child and parent responsibility questionnaires, higher scores denote higher levels of inflated responsibility.

Perfectionism. Children and adolescents completed the Child and Adolescent Perfectionism Scale (CAPS; Hewitt et al., 2000), which has 22 items investigating two sub-scales: self-oriented perfectionism (SOP) and socially prescribed perfectionism (SPP). The former construct relates to personally developed standards for perfection and the latter relates to idealistic goals that the individual believes are expected of them from family, friends and school. Three items are reversed and examples of questions for SOP include '*I feel that I have to do my best all the time*' and '*There are people in my life who expect me to be perfect*' for SPP. A higher score implies higher levels of perfectionism. This questionnaire has independent replication of concurrent validity and test-retest reliability over six months and one week (Castro et al., 2004) This questionnaire was used because it had been used to measure perfectionism in other studies with adolescents who have been diagnosed with AN (Castro et al., 2004, Cassidy et al., 1999) so was chosen to aid comparison of results. In this study, the internal consistency for the SOP scale was good (Cronbach's $\alpha = 0.70$) and the internal consistency for the SPP scale was excellent (Cronbach's $\alpha = 0.85$).

AN and AN/EDNOS Severity. There were two variables for AN and AN/EDNOS severity: one was the objective measurement of Body Mass Index (BMI) and the other was the self-report adolescent version of the Eating Disorder Examination-

Questionnaire, version 6.0 (EDE-Q 6.0; Fairburn & Beglin, 2008). BMI is a weight-to-height ratio, calculated by the individual's body mass divided by the square of their height in relation to their age (WHO, 2006). BMI has long-standing validity as a measure of clinical severity because it is a more objective clinician-rated observation and it is internationally recognised (Nicholson, 2013). Both measurements were collected routinely by the host services. The EDE-Q was completed on admission to the service as part of clinical outcome data. The BMI was recorded at admission and at six weekly reviews. Therefore the BMI measurement that was chronologically closest to completion of the research questionnaire was recorded as outcome data in this study.

The EDE-Q has 36 items that are measured on a 7 point Likert scale and includes the following subscales: Eating Concern; Shape Concern; Weight Concern; Dietary Restraint assessed over the past 28 days. A higher score reflects a more severe level of eating disorder difficulties. The EDE-Q has good concurrent and discriminant validity (Loeb, Brown & Goldstein, 2011). There is also evidence for good internal and test-retest reliability (Binford, Le Grange, & Jellar, 2005). In the county-wide host trust, the EDE-Q data was routinely collected, scored and entered onto a database as a total EDE-Q score. Following this, the paper versions were destroyed, meaning subscale data were not available. The ethics committee required that this host trust data were used for outcomes, rather than asking participants to repeat the completion of the EDE-Q in the study. This was to minimise cognitive and emotional load on the participants and because the EDE-Q has long-term stability of validity and reliability (Nicholson, 2013).

Control variables

The control variable was length of time in the service, which was measured as number of months and analysed as interval data. The length of time in the service could be an

indirect measure of how many interventions the young person and their parent had participated in. This was controlled for to try and partly mitigate treatment effects. The two host trusts routinely collected data on co-morbidity and none of the participants had been diagnosed with co-morbid depression or OCD.

Statistical Analyses

To the author's knowledge, all published studies examining inflated responsibility in children has reported large effect sizes (range $d = 0.75$ to 1.04) in both clinical anxiety and control populations (Reynolds & Reeves, 2008; Farrell & Barrett, 2006; Libby et al., 2004). Based on this, the following power calculation was made for a correlation and interaction analysis. A priori power analysis indicated that a sample size of 30 would be satisfactory to detect a significant interaction effect with a large effect size ($d > 0.75$), power of .80, and an alpha of .05 (Cohen, 1988).

All data were analysed using SPSS version 17. Exploratory analyses revealed that the data was normally distributed (see the Results section) and given the sample size ($n=30$) in each group, the central limit theorem applied (Rice, 1995). Therefore, parametric tests could be used.

One sample T-tests, Pearson's product correlations and a within-groups T tests were used to test the differences between the sample and the published normed data, to examine relationships between variables and to compare parent and child data respectively. To examine the third hypothesis, stepwise multiple regression was used. The two predictor variables of child IR and perfectionism were entered into the first step with the EDE-Q or BMI entered as the dependent variable. In the second step, these

four interaction terms were tested in separate regressions: SOP X Frequency, SOP X Belief, SPP X Frequency and SPP X Belief.

Results

Exploratory data analysis

Kolmogorov-Smirnov (KS), skewness and kurtosis figures were calculated to explore whether the data were normally distributed and all statistics were inside the ranges of a normally distributed population ($KS > 0.05$; $2.58 > \text{skewness} > -2.58$, $2.58 > \text{kurtosis} > -2.58$).

AN and AN/EDNOS severity

The young people's mean EDE-Q score was 4.58 (SD= 1.22; range 1.25-6) and mean BMI was 16.44 (SD = 2.45), shown in Figure 2. This is just above the clinical cut-off of 4 on the EDE-Q (Nicholson, 2013) but the range is extensive, suggesting a breadth of self-reported severity. In contrast, the mean BMI is well below the clinical cut off of 18.

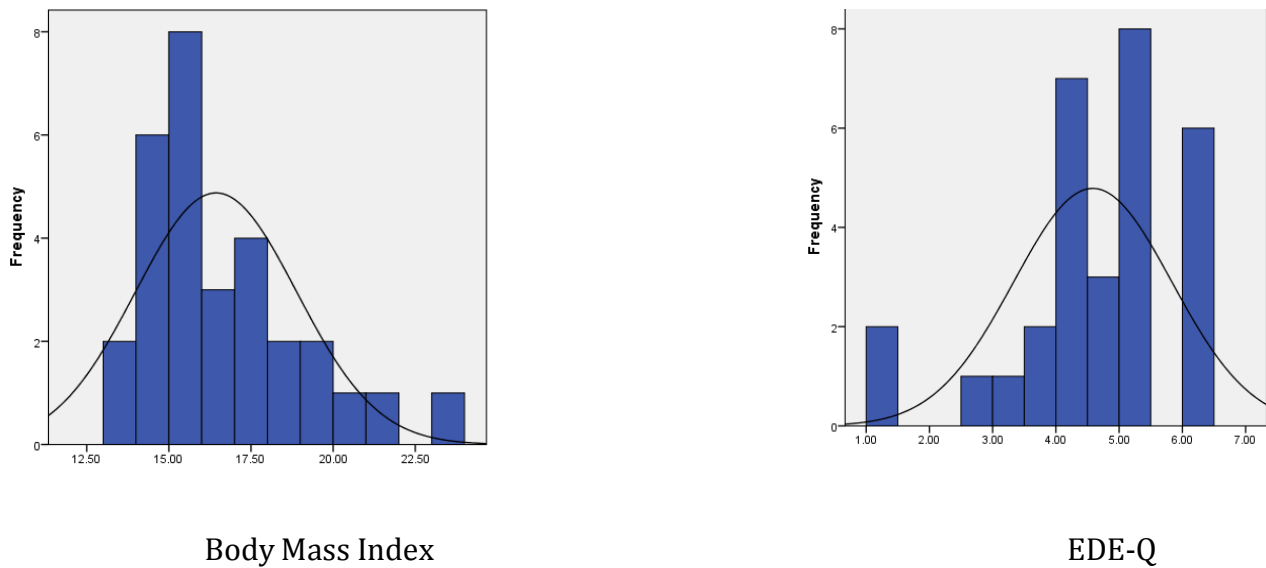


Figure 2. Sample distributions of BMI and EDE-Q.

Hypothesis 1 and 2

The first two hypotheses tested the presence of IR and perfectionism in young people with AN and AN/EDNOS. The IR subscales of frequency and belief, SOP and SPP were compared to the published normed data provided by the questionnaire authors (Salkovsis & Williams, 2004; Hewitt et al., 2000). Both normed samples were similar re age and ethnicity. All comparisons were statistically significant and showed that young people with AN and AN/EDNOS report significantly higher levels of IR and perfectionism, compared to the general population, which is shown in Table 2. All effect sizes were medium, with the exception of SOP, which produced a large effect size.

Table 2

Results of the comparisons between the clinical child participants in this sample and the published normed data.

Measure	Clinical Group Mean (SD)	Non-Clinical Comparison Data Mean (SD)	Mean Difference (SD)	<i>t</i> Statistic (df = 29)	Confidence Interval (95%)	Effect Size Cohen's <i>d</i>
IR FREQ	22.87 (13.10)	17.40 (NR)	5.47	2.29*	0.58- 10.36	0.42
IR Belief	608.40 (352.45)	451.70 (NR)	156.70	2.43*	25.09- 288.31	0.45
SOP	49.77 (7.96)	34.6 (NR)	15.17	10.43**	12.19- 18.14	1.91
SPP	29.70 (9.39)	25.90 (NR)	3.80	2.21*	0.29- 7.30	0.41

FREQ = Frequency, NR = not reported; SOP = Self-Orientated Perfectionism; SPP = Socially-Prescribed Perfectionism.

** $p < 0.05$; ** $p < 0.001$*

Hypothesis 3

The third hypothesis predicted a significant relationship between IR and AN and AN/EDNOS severity. In contrast to expectations, IR was not significantly related to EDE-Q score and the relationship did not approach significance for frequency ($r = 0.14$, $p = 0.48$) or belief ($r = 0.15$, $p = 0.43$). IR was not significantly related to BMI and the relationship did not approach significance for frequency ($r = -0.07$, $p = 0.71$) or belief ($r = -0.11$, $p = 0.56$). These relationships are depicted in Figure 3.

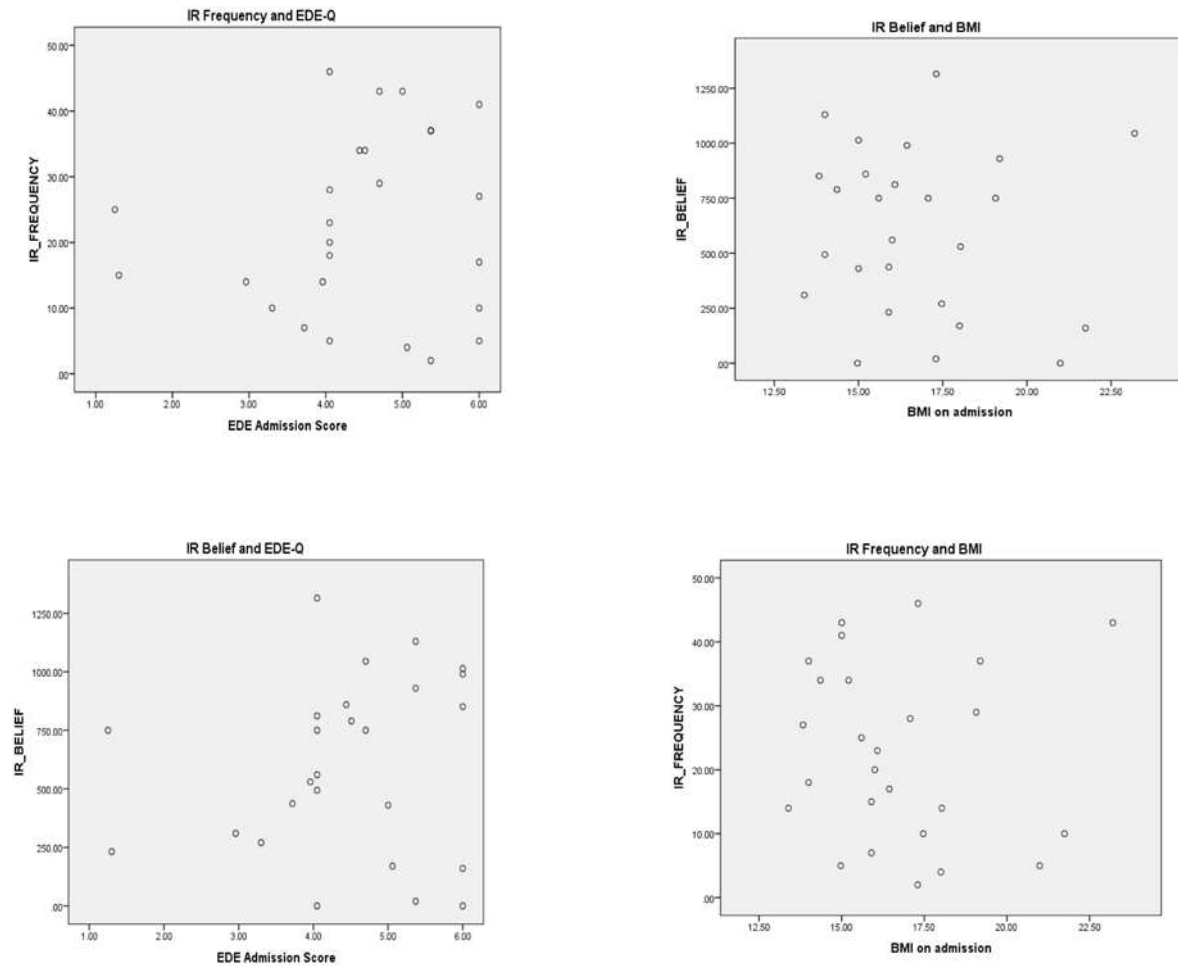


Figure 3.

Scatter graphs showing the non-significant relationships between IR and EDE-Q (above and below, left) and IR and BMI (above and below, right).

Hypothesis 4

A Relationship between Perfectionism, IR and severity

SOP was significantly and positively associated with frequency of IR thoughts ($r = 0.44$, $p = 0.01$). This is a moderate correlation, but could suggest that young people who report a higher frequency of thoughts about inflated responsibility may also report higher levels of self-orientated perfectionism. SOP was also significantly and positively associated with length of time in the service ($r = 0.43$, $p = 0.03$), suggesting that young people who

have more chronic presentations of AN or AN/ED-NOS may have higher levels of perfectionism. Apart from these findings, no other correlations between sub-scales on any of the variables were significant ($p > 0.05$).

The fourth hypothesis aimed to test whether an interaction between perfectionism and IR was a significant predictor of severity. When the more objective variable of BMI was used, the interaction of IR frequency X SOP was moderately significant (Multiple $R = 0.38$). Together, IR frequency X SOP accounted for 14% of the variation in BMI score (adjusted R^2). IR frequency negatively related to BMI: the regression coefficient was -0.75 (95% confidence interval (CI) = $-1.51, -0.01$). Since the confidence intervals included a negative value, the population regression coefficient for IR frequency will also be negative (IR frequency: $t = 2.02, p = 0.05$). The standardised regression coefficients suggest IR frequency (0.1 ± 0.402) is a stronger predictor than SOP (0.20 ± 0.79). However, these results suggest that individuals with higher levels of IR frequency and self-orientated perfectionism may have lower BMI scores.

IR frequency X SOP did not account for any significant variation in EDE-Q score (adjusted $R^2, p > 0.05$). There were no significant interaction effects for SOP with IR belief or for SPP with either IR frequency or IR belief on the EDE-Q or BMI. Thus, Hypothesis 3 was at least partially supported, in that the IR x SOP interaction was a significant predictor of eating disorder severity, as measured by BMI.

Hypothesis 5 and 6

The final two hypotheses examined the relationship between child and parent IR. First, a one sample T-Test was used to compare the IR subscale scores of negative frequency

and negative belief from the parent questionnaire with the published normed data (Salkovsis et al., 2000). Only the negative scale normed data was available in the questionnaire manual and the results are depicted in Table 3 below. The results suggest that parents of young people with AN and AN/EDNOS report significantly higher frequency of negative thoughts about inflated responsibility and significantly higher levels of belief in inflated responsibility, compared to the normed data. The effect sizes were large for both scales.

Table 3

Results of the comparisons between the parents of young people with AN and AN/ED-NOS in this sample and the published normed data.

Measure	Clinical Group Mean (SD)	Control Group Mean (SD)	Mean Difference	<i>t</i> Statistic (df = 31)	Confidence Interval (95%)	Effect Size Cohen's <i>d</i>
IR Frequency	14.87 (13.37)	0.67 (0.61)	14.20	5.92**	9.30- 19.10	1.0
IR Belief	447.87 (389.89)	15.76 (17.52)	431.61	6.06**	286.02- 577.19	1.11

** $p < 0.001$

In order to investigate whether there was any significant difference between child and parent levels of IR, the matched pair sample ($n=22$) was used. The child and parent IR questionnaires were both standardised and ask equivalent questions using age-appropriate language, so it was possible to compare them directly. The results of a within-groups t-test suggested there were no significant differences between child and

parent levels of IR frequency or belief, shown in Table 4. There were no significant correlations between levels of child and parent IR frequency and IR belief.

Table 4

Differences and relationships between parental and child IR in the matched pairs: frequency and belief subscales.

	Mean Difference between Parent and Child groups			Direction of Relationship	
	Mean Difference (SD)	Lower CI	Upper CI	<i>t</i> Value	<i>r</i> Value
Child IR Freq & Parent IR Freq	0.95	-9.95	11.86	0.18	0.11
Child IR Belief & Parent IR Belief	204.27	-33.87	442.42	1.78	0.01
(All results were non-significant, $p > 0.05$)					

Discussion

Summary of Results

The results of this study offer some preliminary evidence to suggest that young people with AN or AN/EDNOS and their parents report significantly higher levels of IR compared to the published normed data from a non-clinical population. This study has also added to the literature examining perfectionism in young people with AN and AN/EDNOS by supporting the results of self-orientated perfectionism (SOP) and socially prescribed perfectionism being present in this population. However, IR and perfectionism were not independently associated with severity of AN or AN/EDNOS on

the self-report measure of the EDE-Q or on the more objective measure of BMI. There was an interaction effect of IR and perfectionism, where young people with higher levels of IR frequency and SOP had lower BMI scores. There were no associations between child levels of IR frequency or belief with the negative levels of parent IR frequency and belief.

The possible meaning and strengths of the results detailed above will be discussed in relation to their respective hypotheses. Then the limitations of the results and the study as a whole will be presented. Following this, potential clinical and research implications that derive from this pilot study will be considered.

Perfectionism

Several studies have attempted to determine whether or not young people with AN and AN/EDNOS have significantly higher levels of perfectionism, compared to healthy controls and in comparison to young people with different mental health difficulties (Serpell et al., 2006; Castro et al., 2004; Cassidy et al., 1999). The findings of this study support the hypothesis that young people with AN and AN/EDNOS may have significantly higher levels of perfectionism, both self-orientated (SOP) and socially-prescribed (SPP); the effect sizes were large and medium respectively. This supports the preliminary body of literature suggesting that perfectionism is a factor in child and adolescent AN and AN/EDNOS (Castro et al., 2004; Cassidy et al., 1999). This finding is strengthened by the decision to use the same perfectionism questionnaire in this pilot that was used in both the Castro et al. (2004) and the Cassidy et al. (1999) studies, which aids comparison of results. The Castro et al. (2004) study did not find a significant effect

for SPP, so this study has extended the literature by reporting significant results for SPP in a child and adolescent AN and AN\ED-NOS population.

The elevated level of SPP may suggest that the young people in this study think their family, friends and teachers expect and demand them to be 'perfect'. One tentative explanation could be that parents of children with AN and AN/EDNOS have their own levels of perfectionism, as has been shown in some preliminary research (Woodside, Bulik, Halmi, Fichter, Kaplan, Berrettini, et al., 2002). There may be a developmental mirroring effect, where parents model perfectionism and their children copy it, in line with social learning theory (Bandura, 1977).

The young people may be drawn to friends who are similar (Muuss, 2006), with their own elements of perfectionism and the majority of participants in the young person sample attended private schools, where there may be a lot of pressure on them to succeed academically. These are cautious interpretations and further replication is needed before conclusions can be drawn.

The fact that SOP was positively associated with length of time in the service could suggest that individuals with more chronic presentations may be more perfectionistic. Also, if SOP appears to increase despite the length of time spent in the service increasing, this could mean that perfectionism continues to act as a risk and/or maintaining factor for AN and AN/EDNOS unless it is specifically addressed in treatment. This finding is consistent with the possibility that perfectionism is a risk and maintenance factor for AN and AN/EDNOS (Egan et al., 2011; Shafran et al., 2003). The

findings for raised SOP and SPP have potential clinical implications, which will be discussed below.

Inflated Responsibility

The results of this study also suggest that young people in this sample have significantly higher levels of IR compared to a similar aged non-clinical population. This was for both the frequency of thoughts about inflated responsibility and for levels of belief in these thoughts. This is the first empirical finding that supports the hypothesis that IR is present in young people with AN and AN-EDNOS. It is consistent with the existing preliminary literature, showing elevated levels of IR in adults with AN (Lavender et al., 2011).

These findings were discovered using the same standardised questionnaires that were employed in the studies looking at IR in children with anxiety and OCD (Matthews et al., 2007; Libby et al., 2004). Thus this study adds to this literature by providing preliminary evidence of IR in a new psychological domain. The participants belonged to either a national specialist clinic or a countywide eating disorder service, both within the NHS. This could increase the generalisability of these results to services across the UK by incorporating national, outpatient and community based service users.

The interaction of IR and Perfectionism on Severity

Severity is defined as the level of AN and AN/EDNOS psychopathology, depicted by a lower BMI score and/or a higher EDE-Q score. The results suggest that there was no relationship between IR and severity or between perfectionism and severity when

considered on their own, but an interaction term of perfectionism X IR was a significant predictor of BMI severity. This finding is consistent with the possibility that neither cognitive bias is sufficient to independently influence AN and AN/EDNOS severity, but if a young person has the two together, they may increase BMI severity. These findings are in line with the theoretical model presented earlier in the introduction to this study, which proposes that both perfectionism and IR may be important in understanding AN and AN/ED-NOS severity.

These findings are consistent with the existing preliminary literature, which has shown the influence of IR and perfectionism in OCD (Reynolds & Reeves, 2008; Ye, Rice & Stauch, 2008; Farrell & Barrett, 2006; Libby et al., 2004, Magusdottir & Smari, 2004) and the literature portraying a relationship between perfectionism and AN detailed above. Perfectionism has been identified as a trait factor and even a personality factor that is present in young people both before and after illness onset (Egan et al., 2011) so further research could determine whether IR acts as a trait and/or state factor in AN and AN/EDNOS.

The interaction effect was only found on the severity variable of BMI and not the EDE-Q, which could be attributable to limitations of the EDE-Q data in this study. The first is the fact that only total scores were available. The EDE-Q questionnaires were scored in routine clinical practice and then the total score was entered onto a clinic database. Following this, the paper copies were destroyed. Given that the EDE-Q data had already been collected, it was not deemed ethical to ask the participants to complete it again, as explained in the method section. This was especially relevant in the context of cognitive load theory (Paas, Renkel & Sweller, 2004), which suggests that people can have

difficulty processing information when both the amount of information and the effort to manage it increases. Therefore, it was not possible to extract the subscale data from the EDE-Q. It would have been helpful to have the scores of the three concern sub-scales, as these assess cognitions regarding weight, shape and eating. Given that IR is a cognitive construct, it would have been useful to assess whether there was a significant relationship between the cognitions regarding IR and the cognitions associated with concern about weight, shape and eating.

A different reason for the lack of findings for the EDE-Q may be due to reporting bias. It is a well known phenomenon that young people with AN can minimise their responses on self-report measures (Gale, Holliday, Troop, Serpell & Treasure, 2006; Serpell, Teasdale, Troop & Treasure, 2004). This may be a cognitive and conscious decision to 'protect' or hide the eating disorder and so offer inaccurate responses on the questionnaires. A further reason for under-reporting may be that at the stage of assessment and commencement of treatment, when they completed the EDE-Q, young people may be in a pre-contemplative stage (Miller & Rollnick, 2002) where they are consciously or even unconsciously unaware of the severity and range of their difficulties. It was for these reasons that the more objective severity measurement of BMI was collected.

The interaction effect suggested that when young people experience an increased frequency of intrusive inflated responsibility thoughts and endorse elevated levels of self-orientated perfectionism, they may be more likely to have a lower BMI. This is consistent with, but not exclusive to, a more severe presentation of AN and AN/EDNOS.

This relationship remains correlational rather than causal and further research is needed to replicate these results. However, the importance of this result resides in the novelty of these findings and their potential clinical implications. If young people with a lower BMI have a higher frequency of IR and SOP cognitions, these could be explored in assessments and addressed in interventions.

The Relationship between Child and Parent IR

The results suggested that parents of young people with AN and AN/EDNOS have significantly higher levels of IR compared to the normed adult population. However, an important caveat is that the IR questionnaire may have been detecting parents' general level of anxiety, guilt and/or sense of responsibility about their children's illness, rather than showing they have inflated responsibility per se.

The results suggested there was no relationship between child and parental IR and no mean difference between the child and parent groups in the matched pairs. This does not rule out the possibility that parents and children have similar and significantly elevated levels of IR and the lack of findings may be due to the study being underpowered. Even though the parent and child groups had the required sample size specified by the power calculation, there is no previous research comparing child and parent levels of IR, so the effect sizes may be smaller than expected. If this is the case, larger samples in each group will be needed to detect a relationship, if one exists.

Theoretical research suggests that IR is developmental (Salkovskis et al., 1999) i.e. parenting style influences how much responsibility children are expected to adopt,

which can be excessive or inadequate. The results of this study are too preliminary to support or challenge this developmental parenting theory. Further investigation is needed to explore how the young people in this sample developed the cognitive bias of IR.

The two other theoretical pathways concerning the development of IR suggest a possible causal link between the cognitive bias and experiencing childhood critical events. It is acknowledged that adverse life events (ALE)s are risk factors for AN and AN/EDNOS (Nunn, Lask & Frampton, 2011), so it may be that this sample experienced ALE's and this is connected to their IR. ALE's were not measured in this sample, but further research could address this question.

Limitations

The Validity and Reliability of the Questionnaires

The limitations of the EDE-Q data in this study were outlined above. A further possible limitation is with the IR questionnaire. This measure asked participants to identify their own intrusive thoughts and answer the questions in response to these thoughts. The participants were not asked to only think of thoughts regarding weight, shape and eating, as this would have violated the instructions of the standardised questionnaire. It may be that the young participants answered the questions in response to general thoughts about inflated responsibility, rather than IR specifically related to AN. This may be a limitation of the questionnaire and is a limitation of the study. To address this limitation, the next research stage would be to carry out a qualitative piece of research exploring how and why IR is relevant to young people with AN.

A key limitation across all the results is that some insignificant results may be due to a Type 2 error, where despite meeting the required sample size, the study does not have sufficient power to detect effects. A further issue is that correlation does not equal causation, so all of the findings here need independent replication with longitudinal designs. The latter are more suitable for assessing the direction of the relationship and possible causal effects.

Research Implications

The overall aim of this study was to examine whether IR and perfectionism were present in young people with AN and AN ED-NOS. The quantitative questionnaire design was able to answer this question and revealed that young people do show significantly higher levels of IR and perfectionism, compared to the published data from non-clinical samples. Maylor and Blackmon (2005) argue that the methodology of a pilot study can be evaluated following the data analysis stage. At this point, an alternative methodology can be chosen, which may be able to answer the research question, or remaining aspects of the research question, in a more suitable way (Maylor & Blackmon, 2005). To address this, a mixed methods design could be adopted next (Creswell & Plano-Clarke, 2007). A sequential explanatory model, where qualitative research follows quantitative findings could be useful. Group and/or individual interviews could be conducted with participants from this sample or belonging to the same clinics.

The aim of these interviews would be to address the following areas: given that IR and perfectionism were found to be significantly higher in this population compared to the normed data, questions could explore what IR and perfectionism mean to young people

with AN or AN/EDNOS and how they might impact on their experience of the illness. Interpreting the content of these interviews using thematic analysis may give some explanation of the results found in the current quantitative study.

A further area of research could be to develop an adapted questionnaire for IR in AN, which would require using an exploratory mixed methods design (Creswell & Plano-Clarke, 2007), where a quantitative questionnaire development study would follow the qualitative interview study, described above.

Clinical Implications

Given the results of elevated self-orientated and socially-prescribed perfectionism, an intervention that specifically addresses this construct may be useful. For example, CBT-E (Fairburn, 2005) expressly addresses perfectionism in adult populations, but this is not always addressed in child populations. If young people with AN and AN/EDNOS endorse the presence of IR and perfectionism it may be useful for clinicians to examine their presence when undertaking clinical assessments. It may also be important for clinicians to be aware that the interaction effect of having both IR and perfectionism together is particularly significant and could be associated with having a lower BMI.

If they are found to be present, the role of IR and perfectionism may be important factors to include in formulations, either as risk or maintaining factors. Therapeutic interventions used to address IR in OCD therapies may be useful to address IR in children and adolescents with AN and AN/EDNOS. If it appears that either IR and/or

perfectionism do appear to be related to eating disorder psychopathology, it would be useful to disseminate this as a published case study, which could add to the preliminary literature on IR in AN.

The evidence base for interventions for AN and AN/EDNOS suggests that family therapy can be an effective intervention (Fisher, Hetrick, & Rushford, 2010). Given that young people reported perceived perfectionism coming from their family, friends and school and that parents appeared to endorse high levels of IR, it could be important for the family therapy team to address the presence and role of both variables in the family system.

This may improve understanding of the development of IR and perfectionism and, if necessary, help to reconstruct the meaning and impact of IR and perfectionism in relation to the illness and within the family relationships (Eisler, 2005).

Conclusion

The results of this study suggest children and adolescents with AN and AN/EDNOS report significantly higher levels of IR and perfectionism compared to the normal population. Preliminary evidence of an interaction effect was found, where young people with higher levels of self-orientated perfectionism and a higher frequency of intrusive thoughts were found to have lower BMIs. There was no relationship between parent and child IR, even though parents reported significantly higher levels of IR compared to the normal population. Independent replication and exploration of these results are needed, but this pilot offers the first empirical evidence of IR in child and adolescent AN.

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SECTION C

Critical Appraisal Paper

Inflated Responsibility and Perfectionism in Child and Adolescent Anorexia Nervosa

What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

The overall topic was ‘why do young people with anorexia nervosa start eating when they come into hospital?’ This pilot study is attempting to answer one part of that question, by addressing possible beliefs concerned with disordered eating. An important set of skills I learned was how to ‘narrow’ a research idea down into a clear, measurable and realistic research question.

I learnt how to manage recruitment and ethical procedures at two sites simultaneously. I was not on placement at either site, so I had to manage the recruitment remotely. This meant learning how to plan ahead, monitor and adapt a systematic recruitment process. This included always ensuring that each on-site ethics and research management file was up to date, supplying resources and certifying that the recruitment procedure detailed in the ethics application was being adhered to by team members on both sites. I learnt to devise a management protocol for any ethical issues ahead of time, so if they arose, I would be prepared to manage it and have the relevant resources in place. Luckily, this was not necessary, but it was a valuable task I will adopt in future research projects.

An overarching skill was learning how to be consistent and thorough in maintaining the momentum of the project and addressing perpetual recruitment difficulties. The clinical teams at both recruitment sites were undergoing extensive re-structuring and cutbacks. Fewer people were being asked to manage too many cases, which were increasingly complex. The level of stress and burn out meant staff preferred people not asking them to do anything ‘extra’, which included agreeing to collect my data.

I had to develop my inter-personal professional communication skills to maintain relationships in the context of a highly stressed environment. I also had to use my study and annual leave to do the majority of data collection, in teams that had no time or space to focus on or prioritise my research. This also meant I learnt a lot of skills in managing chronic recruitment uncertainty and managing my anxiety due to feeling out of control of the circumstances.

Towards the end of the project I achieved a place on a British Council funded 'Erasmus Intensive Programme: Doctoral Studies in Research Methodologies' course in Turkey. The programme was an intense two weeks of attending lectures, round-table debates and workshops about research methodology. I was asked to present my project, adapting my presentation for the audience, who were from Turkey, Finland, Lithuania, Italy and the UK. The audience consisted of colleagues from philosophy, education, finance and linguistics backgrounds. Many of them had English as their third or fourth language and none of these colleagues were from a clinical psychology background. I had to learn presentation and communication skills that could be effective across different academic, language, social and cultural differences (See Appendix 9 for a copy of the presentation). I received very positive feedback and some colleagues thanked me for addressing, what they perceived to be, a highly emotive topic.

Learning how to protect 'research time' in the context of a very busy and demanding job will be something I need to develop. At times I felt very stressed and overwhelmed with trying to manage the project but my external supervisor reminded me that making space for research while working a busy clinical job is something that some clinical psychologists may have to keep negotiating. The statistical design and tests I used in this project were similar to the ones I used in my MSc thesis, so an objective will be to develop new statistical and interpretative skills to analyse data.

If you were able to do this project again, what would you do differently and why?

I would have tried to make sure that my supplementary placement happened on a research site. Being a member of staff at a recruitment site may have improved the rate of recruitment and reduced the stress of managing the study remotely. Being present may also have helped me develop good relationships with staff members and have better insight into team dynamics.

For example, the service manager initially suggested we put my research questionnaire in the assessment pack to discuss it with families when they first attended the clinic. This would have been beneficial in reducing selection bias and intervention effects, as all families would be approached at the beginning of their treatment. However, more senior members of the team were also conducting research and a month later, they decided to put

their research questionnaire in the same assessment pack as mine. The families then reported that there were too many questionnaires to complete. So the team decided that my research questionnaire would have to be removed. This resulted in my recruitment process being temporarily terminated. This team decision may have been partly connected to the fact that I was not a member of staff. If I could do it again, I would have started earlier and included my questionnaire in the assessment packs well before the other study began.

I would also have conducted a mini-pilot with one of the outcome variables, the EDE-Q questionnaire. Results from my study suggested this may not have been a valid or reliable measure in this sample, as it may have been subject to under-reporting, ambivalence or denial from the participants. In addition there was no relationship between the EDE-Q and any other variable. In the pilot, I would have collected my own EDE-Q data, which would allow me to analyse the cognitive and behavioural subscales in relation to my predictor variables. The cognitive subscale data may have been related to the cognitive biases of perfectionism and IR (Egan, Wade & Shafran, 2011). Alternatively, if the EDE-Q had continued to be invalid, despite having the raw scores and sub-scale data, I would have discussed this with my supervisors and identified an alternative outcome variable.

Another aspect I would do differently is to recruit a control sample in schools. Several attempts were made to do this anyway and I made an ethics application to the Salomon's ethics board to conduct the same study within a community population in schools. I received provisional approval from the ethics board but then was unable to recruit a school. I approached six different schools and they took an average of four months to consider my proposal and then inform me that they were unable to host the study. All the schools I approached reported being too busy and too 'burnt out' with their own restructuring and cutbacks. It seemed the difficulty I was experiencing in the NHS sites was being mirrored across the public sector in schools also. This made me realise the systemic nature of the challenges facing public sector agencies and also made me question the impact that this systemic stress may be having on the young people and their families.

As a consequence of doing this study, would you do anything differently in regard to making clinical recommendations or changing clinical practice, and why?

From my own clinical experience and through conducting research development meetings at both eating disorder clinics where I collected my data, the construct of responsibility seems to be a very important in child and adolescent anorexia nervosa. The role of inflated responsibility (IR) in AN may be as follows: young people report that if they eat, they are responsible for causing harm to themselves, because eating is associated with undesirable weight and body shape changes, which connect to the key formulations of being unlovable, rejected and/or out of control (Bryant-Waugh & Lask, 2013).

This project has provided some preliminary pilot data to suggest that there is an empirical foundation to these clinical hypotheses and discussions. I would make recommendations that clinicians undertaking assessments consider how responsibility is connected to healthy or disordered eating and beliefs about eating in young people with AN. If this were found to be relevant to the young person, I would recommend that this is included in the formulation. Given the positive association between self-orientated perfectionism and frequency of beliefs about IR, I would also recommend that perfectionism is addressed at assessment and treatment, if relevant. If IR and/or perfectionism were specifically addressed in treatment, I would suggest that the IR and perfectionism questionnaires are completed by the young person at the beginning and end of treatment. This way, clinicians can start to collect outcome data that may develop the preliminary understanding of IR in AN. Additionally, I would encourage clinicians to publish case reports if they have experience of working with young people with IR in AN, as case reports can offer valuable insight into clinical complexity.

I would advise staff working in inpatient and outpatient teams to be aware of who is taking responsibility for eating when they are supporting young people through meals. The theoretical model of IR suggests that people can transfer their sense of inflated responsibility onto other people, which temporarily allows them to relieve the belief that they are responsible for causing themselves harm. Clinical staff and parents of young people with AN explicitly state that they will take responsibility for the young person eating appropriately, as long as the young person eats. This appears to allow the young person to eat their meal. However, when the parents or staff member are absent, young people report that they are unable to take responsibility for eating again. There is a risk that if this is not specifically addressed, young people may be discharged from hospital with their weight and

shape goals achieved, but the maladaptive responsibility beliefs about eating may act as relapse factor.

If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

The first project would be a qualitative investigation of what IR means to young people with AN. This would be rooted in the fact that the pilot has suggested that this population reports significantly higher levels of IR, but the meaning, experience and impact of this is unclear. The project would be conducted using individual or group interviews and analysed using inductive thematic analysis (Boyatzis, 1998). Given the novelty of exploring IR in people with AN, inductive thematic analysis would be chosen to be as open as possible to any themes within the data, rather than using theoretically derived themes.

If IR was found to be a valid and relevant construct in the course and outcome of AN, an adapted IR questionnaire, focusing on responsibility thoughts and beliefs in connection to shape, weight and eating could be developed. Then the research project would focus on item design, content and factor analysis and pilots to test the new questionnaire's reliability and validity.

Two further qualitative projects adopting similar designs to the one explained above would also be conducted, one with parents of people with AN and one with clinical staff members, who support young people through meals. The aim of the parents project would be to discover whether IR is a familial trait, to see if parents endorse more or less belief in IR compared to their children and to test the developmental theories of IR. These developmental theories suggest that three possible causes of children acquiring IR are due to parenting styles, so it would be interesting to explore whether this applies in the AN population.

The aim of the staff members project would be to document and understand the discussions about inflated responsibility that may happen between staff and clients during meal times. Anecdotal evidence suggests that a lot of conversations about responsibility occur and it would be interesting to explore any relationships between staff and young people's beliefs about and levels of inflated responsibility at mealtimes.

References

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- Bryant-Waugh, R. & Lask, B. (2013). Overview of the eating disorders. In R. Bryant-Waugh & B. Lask (Eds.), *Eating disorders in childhood and adolescence (4th Edition)* (pp. 33-49). Hove: Routledge.
- Egan, S.J., Wade, T.D., & Shafran, R. (2011). Perfectionism as a transdiagnostic process: A clinical review. *Clinical Psychology Review, 31*, 203-212.

Section D

Appendices

Appendix One Search strategy

The following search strategy was informed by the Cochrane Handbook of Systematic Reviews of Interventions, version 5.1.0 (Higgins & Green, 2011). This review was not evaluating intervention research, but this handbook offers guidelines for all systematic reviews.

Aim of the Search Strategy

The search strategy was designed to detect all studies of people with AN and AN/ED-NOS in which OCD and its features had been measured and in which possible risk factors causing this co-morbidity had been investigated.

Electronic Searches

The following electronic databases were systematically searched between September to October 2012:

- ! APA PsycNet (present) - 4 (0)
- ! BioMed, (present) – 34 (4)
- ! Cochrane (1993-present) - 6 (4)
- ! EBSCO (present) - 94 (3)
- ! Ingenta Connect (present) - 48 (8)
- ! JSTOR, (present)- 22 (0)
- ! Medline, (1950-present) - 90 (8)
- ! Psychinfo, (1806-present) - 88 (18)
- ! SAGE (present) - 0
- ! SpringerOpen (present) – 1 (0)
- ! Web of Science (1864-present) – 81 (12)

The number in brackets denotes how many passed the initial selection stage, where abstracts only were checked.

Other Searches

A Google Scholar search and B-EAT eating disorders charity resources website was used to identify any unpublished literature and conference proceedings. The article reference lists from pertinent articles were also searched by hand to check for additional studies.

Search Terms

The following search terms were used:

- ! Anorexia Nervosa OR anorexia* OR anore* OR eating disorder* OR eating disorders OR Anorexia Nervosa [epidemiology]; Body Mass Index
- ! obsessiv* OR obsessive compulsiv* OR compulsiv* OR OCD OR Obsessive compulsive symptoms OR obsessive compulsive traits

Types of Research

Given the paucity of the literature, all types of research were included, which incorporated peer-reviewed and non peer reviewed articles, other journal articles, books and dissertation abstracts.

Reliability of the search

The literature search was repeated by an Assistant Psychologist at the host Trust to cross-reference the results and to check for any gaps in the search.

Results of Search Strategy

In total, the electronic search returned 419 papers. The abstract of each paper was screened to assess relevance. From this process, 362 papers were rejected as being inappropriate for the review. The remaining 57 papers were retrieved and the full text versions were checked against the inclusion and exclusion criteria (please see below). This resulted in 39 studies being excluded. The reference lists of

the remaining 18 studies were checked by hand and three more articles were identified through this method. Overall, this process resulted in 21 studies being included in the review. Please see figure 1 below for a flow-chart of this process.

General Selection Criteria

Studies had to be written in English and accessible either through a database, through an inter-library loan or by accessing the author directly. No limits were applied to age or gender of participants, severity or chronicity of their illness or presence of other co-morbidity. No limits were applied to publication date.

Population and Outcome Inclusion Criteria

Comparative studies were selected into the literature search if they:

- ! Compared a group of participants with AN to a group of participants with OCD
- ! Compared the two groups' functioning on the same theoretically derived outcome variable(s), which was being investigated as a possible vulnerability factor

Co-morbidity studies were included if they recruited:

- ! Samples of participants who had been formally diagnosed with AN plus co-morbid OCD (AN+OCD) according to standardised criteria including DSM-IV-TR; DSM-IV and ICD-10 (World Health Organisation (WHO), 2008; APA, 2000)
- ! Samples of participants who had been diagnosed with AN who had significantly elevated obsessive compulsive symptoms and/or features (AN+OCS), which had been assessed using reliable and valid measures including self-report questionnaires and semi-structured interviews.
- ! Sub-clinical populations if they also used reliable and valid measures of AN and OCD.

Study Design Inclusion Criteria

For the co-morbidity studies, case control designs would be most suited to answering the research question, where a group of people with AN+OCD (cases) were compared to controls: OCD only, AN only, and healthy controls.

For the comparative studies, cross-sectional or longitudinal between group clinical cohort designs or within group community designs were selected. Case reports and single case designs were also considered, as long as they met the population inclusion criteria.

Population, Outcome and Study Design Exclusion criteria

All studies were excluded if they:

- ! only recruited samples of people with AN without any features of OCD
- ! only recruited samples of people with OCD without any features of AN and/or did not compare an AN group to an OCD group.
- ! Only investigated interventions, treatment outcome and prognostic indicators.

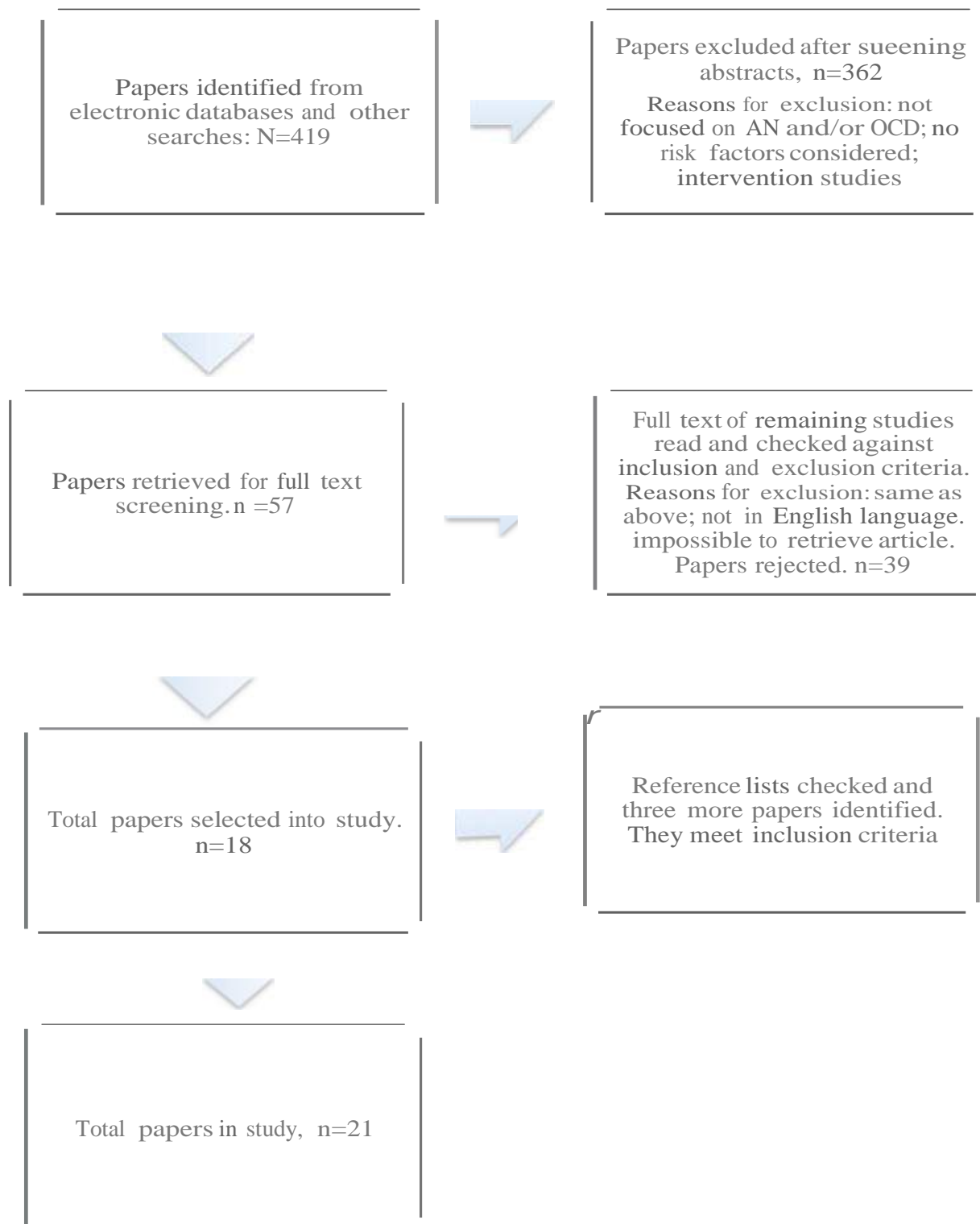


Figure 1. Flow chart showing selection of articles in search strategy.

Appendix 2 Quality Index of Included Studies

The items below were used to determine the quality of reviewed studies (Downs & Black, 1998)

1. Hypothesis clearly described
2. Main outcomes clearly described
3. Characteristics of patients described
4. Main findings clearly described
5. Estimates of random variability
6. Actual probability values used
7. Response rate clearly described
8. Patients – represent population
9. Patients prepared represent population
10. Staff, place and facilities
11. Data dredging
12. Statistical tests appropriate
13. Outcome measures valid/reliable
14. Adjustment for confounding
15. Sample size or power calculation

Appendix 3 Characteristics of the empirical studies included in this review.

Authors (Year) (Country)	Characteristic of Study; Sample Size	OCD Measures used*	Risk Factor Investigated	Child (age<12 years) adolescent (12-18 years) or adult sample (age>18 years)
Anderluh et al. (2009) (UK)	Co-morbidity; N=97	DSM-IV	Compulsive exercise and personality factors	Adult
Bastiani et al. (1996) (UK)	Comparative; N=34	Y-BOCS	Pre- occupation with order and symmetry	Adult
Cassidy et al. (1999) (UK)	Co-morbidity; N=49	MOCI, Leyton Obsessive Inventory (Cooper, 1970)	Perfectionism	Adolescent
Davis et al. (1998) (Canada)	Co-morbidity; N =26	MOCI	Compulsive exercise	Adult
Davis et al. (1995) (Canada)	Co-morbidity; N =46	Symptom Checklist-90 (SCL-90) (Derogatis,	Compulsive exercise	Adult

Rickels & Rock, 1976)				
Davis & Kaptein (2006) (Canada)	Co-morbidity; N = 50	OCI-R	Compulsive exercise	Adult
Erol, Yazici & Toprak (2007) (Turkey)	Comparative; N= 45	DSM-IV	Family Functioning	Adult
Halmi et al. (2003) (USA)	Comparative; N=436	Y-BOCS	Preoccupation with order and symmetry	Adult
Holtkamp et al. (2004) (Germany)	Co-morbidity; N =30	SCL-90	Compulsive exercise	Adolescent
Lavender et al. (2011) (UK)	Comparative; N = 499	OBQ (OCCWG,2001); Magical Ideation Scale (Eckblad & Chapman, 1983)	Magical Ideation, cognitive beliefs in OCD ^a	Adult, including a recovered AN group

Matsanuga et al. (1999) (Japan)	Co-morbidity; N = 65	Y-BOCS	Preoccupation with order and symmetry	Adult
Murphy et al. (2004) (Germany)	N = 48	Structured Interview for DSM-IV (SCID), YBOCS	Conditional-associative learning	Adult
Naylor et al. (2011) (UK)	Co-morbidity; N = 64	Y-BOCS	Compulsive exercise	Adult
Roberts (2006) (New Zealand)	Co-morbidity; N=141	OCI-R	Preoccupation with order and symmetry	Non-clinical adults
Serpell et al. (2006) (UK)	Co-morbidity N = 49	Y-BOCS (Child version)	Perfectionism	Child and adolescent
Shroff et al. (2006) (USA)	Co-morbidity; N = 431	Y-BOCS	Compulsive exercise	Adult

**All studies included participants who had been diagnosed with AN by DSM-IV or ICD-10 criteria by specialist teams. The co-morbidity studies included people with OCS and/or OCD, so all OCD measures used in all studies are listed here.*

^aThe OCD beliefs examined were intolerance of uncertainty, responsibility, perfectionism, over-importance of thought, over-estimation of threat and thought-action fusion.

- Derogatis, L.R., Rickels, K., & Rock, A.F. (1976). The SCL-90 and the MMPI: a step in the validation of a new self-report scale. *British Journal of Psychiatry*, 128(7), 280–289.
- Eckblad, M., & Chapman, L. (1983). Magical ideation as an indicator of schizotypy. *Journal of Consulting and Clinical Psychology*, 51, 215–225.
- Foa, E.B., Huppert, J.D., Leiberg, S., Langner, R., Kichic, R., Hajcak, G. (2002). The obsessive-compulsive inventory: development and validation of a short version. *Psychological Assessment: Journal of Consulting and Clinical Psychology*, 14, 485–496.

Appendix 4

Child and Parent Information Sheets, Consent Forms and Assent Forms

(Trust ID logos, version numbers, R&D codes, REC numbers and contact details have been removed to preserve confidentiality)

PARTICIPANT INFORMATION SHEET: YOUNG PEOPLE (8-12 YEARS)

Study title: The role of inflated responsibility in child and adolescent eating disorders: how common is it, what is the relationship with perfectionism and is it related to parental inflated responsibility?

Why is this project being done?

Research is a way we try to find answers to questions. We want to find out about thoughts about responsibility in children and young people who have anorexia nervosa.

Why have I been asked to take part?

You are being asked to take part, as we think young people here are in the best position to tell us about this.

Did anyone else check the study is ok to do?

Before any research is allowed to happen it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the [REDACTED] Ethics Committee

Do I have to take part?

No, it is completely up to you. It is your choice whether you want to join in or not. None of the information you give will be used to treat you or to tell anyone else about you. You will not be treated differently from other young people if you do not take part.

What will happen to me if I take part?

We will ask your parents to sign a consent to say they are happy for you to take part and we will ask you to sign a separate form if you are happy to take part. We will then ask you to fill out four forms, called questionnaires, for us. This should take about twenty minutes. These ask about your feelings and thoughts. You only need to do this once.

Might anything else about the research upset me?

One of the questionnaires asks you about ideas about your weight and shape, which might be uncomfortable. The other questionnaires are more general so should not cause you any distress.

What if something goes wrong?

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Will anyone else know I am doing this?

Everything you tell us will be confidential, which means that no-one else will know what you have said. No-one will be able to work out who you are by looking at your answers. We will let your GP (family doctor) know that you are taking part but will not tell them what you have said.

Will joining in help me?

If you like, your name will be put into a lucky dip to win a £50 book voucher, to say thank you. We cannot promise that the study will help you but the information we get might help treat young people with anorexia nervosa with better treatments in the future.

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What if I have questions about the Project?

Please contact [REDACTED] by email at [REDACTED] or by post at

[REDACTED]

INFORMATION SHEET FOR PARTICIPANTS: YOUNG PEOPLE (13-18 YEARS)

Study title: The role of inflated responsibility in child and adolescent eating disorders: how common is it, what is the relationship with perfectionism and is it related to parental inflated responsibility?

Name of researchers: [REDACTED]

You are being invited to be involved in this research study. We are interested in looking at thoughts about eating and responsibility that young people with anorexia nervosa might have.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what taking part will involve for you. Please take time to read through this sheet. Please ask me if anything is unclear or if you would like more information. Take as much time as you need to decide whether or not you wish to take part.

Thank you for reading this.

Why are we doing this research?

This study is to try and understand how thoughts and beliefs about responsibility might be connected to having a diagnosis of anorexia nervosa. This will help us understand more about what it is like to have anorexia nervosa and hopefully develop our treatments for it.

Why have I been invited to take part?

You are being invited to take part in this study, as we think young people in this unit are in a good position to tell us about this area. We need to ask about 30 young people so we can get a good idea of what this might be like for different people.

Do I have to take part?

No, it is up to you. We will ask you for your assent and ask you to sign a form saying you are happy to be involved. We will give you a copy of this information sheet and the assent form. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive.

What will happen to me if I take part?

We will ask your parents to sign a consent to say they are happy for you to take part if you are under 16 and we will ask you to sign a separate form if you are happy to take part.

We will then ask you to fill out four questionnaires for us. This should take approximately twenty minutes. The questionnaires ask about your experiences with your eating disorder and about more broad things including beliefs and thoughts that sometimes pop into your head. You only have to fill these questionnaires out one at a time. We will also ask you to tell us some general things about your background, but we will not ask for any details that could identify you. You will not need to meet with us again.

What if there is a problem or something goes wrong?

An experienced and qualified clinician will be available to talk to you if something goes wrong while you are completing the questionnaires. If this study has harmed you in any way you can contact [REDACTED] using the details below for further advice and information: [REDACTED]

What are the possible side effects of taking part?

One of the questionnaires asks you about ideas about your weight and shape, which might be uncomfortable. The other questionnaires are more general so should not cause you any distress.

Will anyone else know I am doing this?

Everything you tell us will be anonymised, which means that you cannot be identified from what you have said. No-one will be able to recognise you from any of the data we collect. We will write to your GP that you are involved in a research study, but we will not tell them what you have said. All of this anonymous research data will be stored as hard copy at Canterbury Christ Church University for 10 years.

What are the possible benefits of taking part?

If you wish, your name will be entered into a prize draw to win a £50 book voucher, to say thank you for completing the questionnaires. We cannot promise that the study will help you but the information we get might help treat young people with anorexia nervosa with better treatments in the future.

Who is organising and funding this research?

This research is being funded by Canterbury Christ Church University and is being organised by this hospital.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee to make sure that it is fair. Your project has been checked by the [REDACTED] Research Ethics Committee.

For more information please contact [REDACTED]
[REDACTED]

PARTICIPANT INFORMATION SHEET FOR PARENTS/GUARDIANS

Title of project: The role of inflated responsibility in child and adolescent eating disorders: how common is it, what is the relationship with perfectionism and is it related to parental inflated responsibility?

Chief Investigator: [REDACTED]
Principal Investigator: [REDACTED]

You and your child are being invited to be involved in this research study. We are interested in looking at thoughts about eating and responsibility that young people with anorexia nervosa might have.

Before you decide we would like you to understand why the research is being done and what it would involve for you and your child. One of our team will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 10 minutes. Talk to others if you wish and ask us if there is anything that is unclear. Thank you for reading this.

What is the purpose of the study?

We are interested in how beliefs and thoughts about responsibility are connected to having a diagnosis of anorexia nervosa. We are hoping to ask young people about this to understand a bit more about anorexia nervosa and how it might get maintained. This will then help us plan and design better treatments for young people.

Why have I been invited?

You and your child have been invited because your child is being seen at the [REDACTED] c. We are inviting other parents and children from [REDACTED] and also people from around the UK to get involved. We have invited families that represent a wide range of different backgrounds, to get a better understanding of what having anorexia nervosa might be like for different people. In total we need 80 parents and their children to take part.

Do I have to take part?

It is up to you to decide to join this study. We will describe the study and go through this information sheet. If you agree to take part, we will ask you to sign a consent form for you and your child, if they are under the age of 16. Your child will be asked to sign an assent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you and your child receive.

What will happen to me if I take part?

You will be asked for some background information about your gender and ethnicity. We will then ask you to complete a short questionnaire about thoughts and responsibility. This will be done when you come to the clinic or we can send these to you for you to fill in at home or online. Completing these questionnaires should take approximately ten minutes. We will only need to meet with you once.

What will happen to my child if they take part?

They will be asked to complete three questionnaires. One is about thoughts and ideas about responsibility, one is about attention to detail and one is about their eating patterns. We expect that this will take approximately twenty minutes.

Who Must We Exclude?

Unfortunately, we must ask you to not participate if you are not happy to sign the consent form. We will ask your child not to participate if she or he has significant learning disabilities or a developmental disorder because our questionnaires are not designed for children who might need a lot of extra help understanding what we are asking.

Will You Compensate Me for My Time?

Yes. To thank you and your child for taking the time to participate, we will offer to put your child's name in a prize draw for a £50 book or CD voucher.

What are the possible disadvantages and risks of taking part?

The risks involved in participating are minimal. If there are questions that you would not like to answer, you are free to not answer those questions. We will make sure your child understands that if there are questions he or she would not like to answer, then she or he does not have to answer them. We will make sure your child understands that she or he can stop taking part in the study at any time without it having any impact on them or their care.

What are the possible benefits of taking part?

We cannot promise that the study will help you but the information we get from this study may help us to improve our understanding of anorexia nervosa and improve treatments.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Everything you and your child tell us will remain completely confidential within the limits of the law. With your consent we will send a letter to your GP to notify them that you are involved in a research study, but they will not know what you have said.

We will give you a special identification number for the information you and your child give us, so it will be completely anonymous. No-one will be able to know what you have said. We will keep your contact details in a separate file, that no-one else involved in the study or the hospital will have access to. No-one outside the research team will have access to any personal or medical information about your child and you.

Your information will be stored on secure computers in locked offices and in locked filing cabinets. Your responses to our questions will remain completely confidential unless you tell us something to indicate that your own health and safety or your child's health and safety are currently in danger. We will then discuss this with you.

After the study has finished, a CD containing the anonymous questionnaire data will be kept in a locked filing cabinet in a specified office in Christ Church Canterbury University. This will be kept for 10 years. It will not be possible to identify you from this data.

What will happen if I don't want to carry on with the study?

If you decide to withdraw from the study, we will delete all records of the data you have given us.

What if there is a problem?

An experienced clinician will be available to help if any problems arise. We do not expect that completing the questionnaires will cause any problems.

Complaints

If you have a concern about any aspect of the study, you should ask to speak to the researchers who will do their best to answer your questions ([REDACTED]). If you remain unhappy and wish to complain formally, you can do this by contacting [REDACTED].

Harm

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for legal action for compensation against Christ Church Canterbury University but you may have to pay your legal costs.

What will happen to the results of the study?

It will not be possible to identify you in the results or in the report. The results will be used to form part of a doctoral thesis for a doctorate in Clinical Psychology at Christ Church Canterbury University. A report about the study will also be submitted to some journals that publish research into eating disorders. This report will also be presented at conferences about developing better treatments for eating disorders. If you wish, when the project has finished we will send you a letter describing the major findings and letting you know where the findings will be published.

Who is Organising and Funding the Research?

The study is being organized and funded as part of a doctorate at Christ Church Canterbury University. It is being organised in collaboration with [REDACTED].

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee to make sure that it is fair. Your project has been checked by [REDACTED] Research Ethics Committee.

What If I Have Questions about the Project?

Please contact [REDACTED] by email at [REDACTED] or by post at

[REDACTED]

Young Person – Assent Form (8-18 years)

(to be completed by young person and their parent if they are under 16 years of age)

Study title: The role of inflated responsibility in child and adolescent eating disorders: how common is it, what is the relationship with perfectionism and is it related to parental inflated responsibility?

Young person to circle all they agree with:

I understand it would not be possible to identify anyone from the reports on this study Yes/no

I know that I need not answer questions that I do not wish to Yes/no

Has somebody explained this project to you? Yes/no

Do you understand what this project is about? Yes/no

Have you asked all the questions you want? Yes/no

Have you had your questions answered in a way you understand? Yes/no

Are you happy to take part? Yes/no

If any &-%)#(%\$&(#\$A-02\$0(\$/01\$ _0-2!\$)&-!\$!O\$!&3#\$4&(!=\$ _0-2!\$%*;-\$/01(\$-& _#5\$
If you do want to take part, you can write your name below

Your name: _____

Date: _____
day/month/year

If you are under 16, your parent needs to sign it too:

Parent name _____ Sign _____

Date _____

The person who explained this project to you needs to sign it too:

Print name_____

Sign_____

Date_____

(Two copies: one for young person and one for research file)

PARENT/GUARDIAN CONSENT FORM

Title of project: The role of inflated responsibility in child and adolescent eating disorders: how common is it, what is the relationship with perfectionism and is it related to parental inflated responsibility?

Name of researchers: [REDACTED]

Please initial box:

1. I confirm that I have read and understood the information sheet dated 14/05/2012 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have them answered satisfactorily.

☐

2. I understand that my child's and my participation is voluntary and that either of us can withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

3. I understand that relevant sections my child's data collected during this study will be looked at by individuals from [REDACTED] and Christ Church Canterbury University, where it is relevant to my child and I taking part in this research. I give my permission for these individuals to have access to my child's and my data.

☐

4. I agree to my GP being informed of my participation in the study.

☐

5. I agree to take part in the above study and I agree that my child can take part in the above study.

☐

Name of parent

Date

Signature

Name of person taking consent

Date

Signature

(Two copies: one for parent and one for research file)

Appendix Five

Evidence of Ethical Approval from National Research Ethics Committee and Research Site Research and Development Departments

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Appendix 6 Further Ethical Actions

Anonymised data and a back-up copy were kept in a locked and secure filing cabinet on the main NHS site. A secure host trust memory stick was used to store an anonymised copy of the database. One copy of anonymised raw data will be kept by the academic supervisor for ten years, in line with the university policy. A separate database including participant codes and names only was kept separately on a second secure trust memory stick. Once a letter had been sent to a GP notifying them of their patient's involvement in the study, this data was destroyed.

Appendices Seven and Eight: Child and Parent Questionnaires

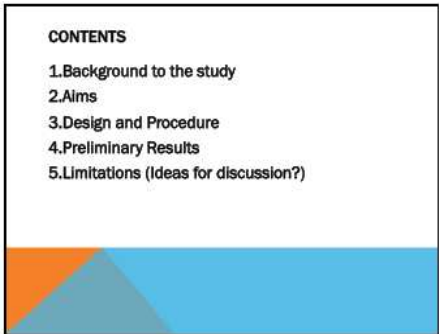
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Appendix 9

Slides of the study presentation given at the Erasmus Intensive Programme: Doctoral Studies in Research Methodology.

05/07/2013







DEFINITIONS: ANOREXIA NERVOSA

Figure 1: Anorexia Nervosa

- A. A refusal to maintain body weight at or above a minimally normal weight for age and height (e.g., weight loss leading to a maintenance of body weight less than 85% of that expected, or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).
- B. Intense fear of gaining weight or becoming fat, even though underweight.
- C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.

DSM-IV T-R DIAGNOSTIC CRITERIA (APA, 2000)

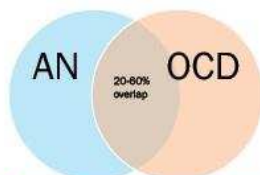
DEFINITIONS: OCD

Figure 2: Obsessive Compulsive Disorder

- A. Either obsessions or compulsions:
- (1) recurrent and persistent thoughts, impulses, or images that are experienced at some time during the disturbance, as intrusive and inappropriate and that cause marked anxiety or distress
 - (2) the thoughts, impulses, or images are not simply excessive worries about real life problems
 - (3) the person attempts to ignore or suppress such thoughts, impulses, or images, or to neutralize them with some other thought or action
 - (4) the person recognizes that the obsessional thoughts, impulses, or images are a product of his or her own mind (not imposed from without as in thought insertion)
- B. Repetitive behaviors (e.g., hand washing, checking, ordering) or mental acts (e.g., praying, counting, repeating words silently) that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly. (Other behaviours or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however, these behaviours or mental acts either are not connected to a realistic way with what they are designed to neutralize or prevent or are clearly excessive)

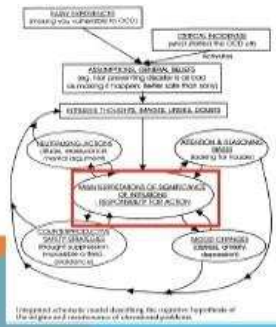
DSM-IV T-R DIAGNOSTIC CRITERIA (APA, 2000)

ANOREXIA NERVOSA IN CHILDREN

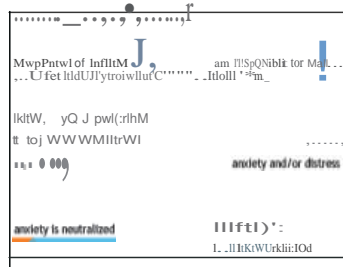


- In clinical and non-clinical populations (Altman & Shankman, 2009; Bryant-Waugh & Lask, 2007; Serpell et al., 2001).

COGNITIVE THEORY OF OCD: INFLATED RESPONSIBILITY

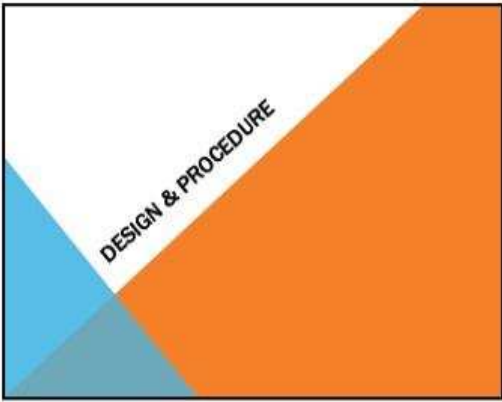


PROPOSED MODEL OF IR IN AN



AIMS OF THE STUDY

- To investigate the role of inflated responsibility in the maintenance of AN.
- To examine the role of inflated responsibility in the maintenance of AN.
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- To examine the role of inflated responsibility in the maintenance of AN.



HYPOTHESES

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DESIGN & PROCEDURE

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Rationale: correlation and regression models can examine relationships between
these continuous variables.

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DESIGN & PROCEDURE

1. Inclusion criteria
 - Participants need to be diagnosed with anorexia nervosa or anorexia nervosa not otherwise specified according to DSM-IV criteria.
 - Participants need to be older than 8 years and younger than 18 years and must not have been diagnosed with a developmental disorder.
2. Data analysis
 - Power calculation: desired power of 0.80, $\alpha = 0.05$, and a large effect size: required sample size of $n = 30$ in each group (Cohen, 1992).
 - Normally distributed: Pearson's Product (correlations) and T-Tests (differences between groups) or non-parametric equivalents if necessary.

MEASURES

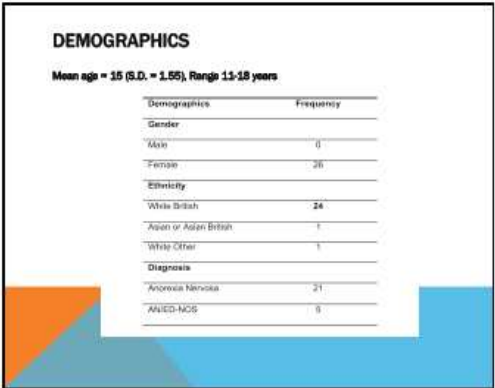
1. Child Response Interview Questionnaire (CRIQ; Salkovskis & Williams, 2004).
2. Parents completed the Response Interview Questionnaire (RIQ; Salkovskis et al., 2000).
3. Children and adolescents also completed the Child and Adolescent Perfectionism Scale (CAPS; Hewitt, Flett, Turnbull-Donovan, & Mikul, 1991).
4. The outcome variable of eating disorder psychopathology was measured using the child version of the Eating Disorder Examination-Questionnaire, version 6.0 (EDE-Q 6.0 (Fairburn & Beglin, 2008)) and the Body Mass Index (BMI) number.
5. Control variables: length of time in the service, depression, which was measured with either the Child Depression Inventory, version 2 (CDI-2; Kovacs, 2010) or the Beck Depression Inventory (BDI; Beck, Steer & Brown, 1996).

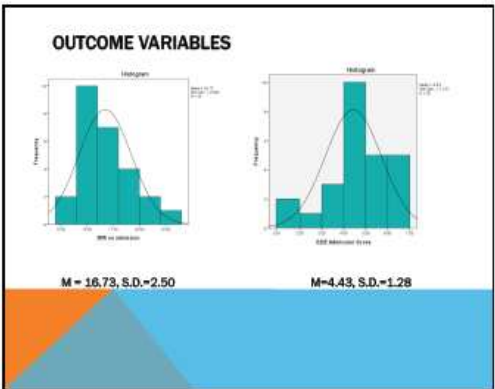
ETHICS

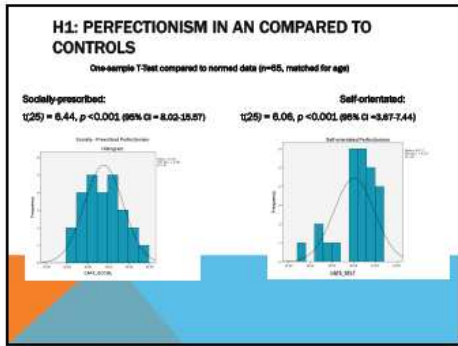
Ethics

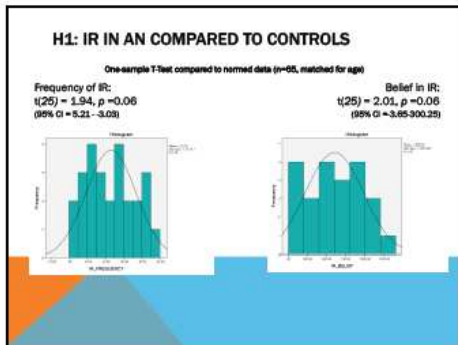
1. The study was approved by the National Research Ethics Service's local Research Ethics Committee and received full approval from the two NHS host trust Research and Development departments.
2. Parents and young people were given the opportunity to ask any questions and were reminded that the data was anonymous and confidential.
3. They were also assured that either choosing to participate or not would not affect their care in any way and they had a right to withdraw at any time.
4. Both parents and their children were offered to de-brief after completing the questionnaire, in case the questions provoked any feelings of distress.
5. Anonymised data and a back-up copy were kept in a locked and secure filing cabinet on the main NHS site.
6. A separate database including participant codes and names only was kept separately on a second secure trust memory stick.

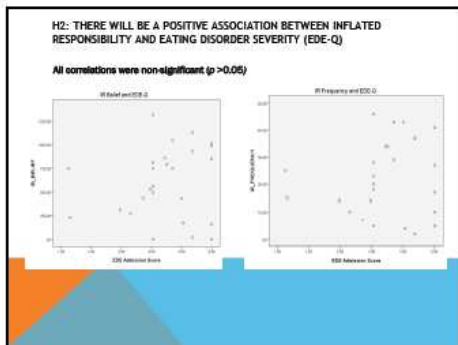






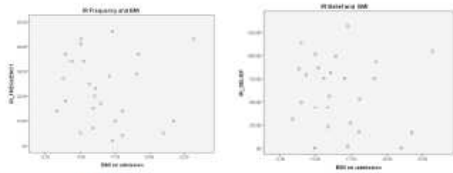






H2: THERE WILL BE A POSITIVE ASSOCIATION BETWEEN INFLATED RESPONSIBILITY AND EATING DISORDER SEVERITY (BMI)

All correlations were non-significant ($p > 0.05$)



LIMITATIONS.....

LIMITATIONS

1. Difficulties with the clinical population
2. Problems with the measures
3. Problems with team dynamics
4. Difficulties with the health system

Thanks for listening
Any questions?

Appendix 10 DECLARATION OF THE END OF A STUDY

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