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Obsessive Compulsive Disorder in Children and Young People:
Experiences of Children with OCD and the Involvement of
Families in Treatment

By
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A thesis submitted in partial fulfilment of the requirements for the degree of
Doctor of Clinical Psychology

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DECLARATION

This thesis was carried out under the supervision of Dr Eve Knight, Consultant Clinical Psychologist and Dr Lisa Summerhill, Clinical Psychologist. Apart from the collaboration with the above people this thesis is my own work. This thesis has not been submitted for a degree at another university. The authorship of the papers will be shared with the above named individuals. The thesis has been written for submission to the following journals (see Appendix A for Notes for Contributors). Any deviation from the journal word limits was for the purpose of thesis submission and will be adhered to for journal publication.

Chapter One: How Does Family Work Facilitate the Cognitive Behavioural Treatment of Children with Obsessive Compulsive Disorder? A Review of the Evidence. *Clinical Psychology Review*. (7974 words)

Chapter Two: The Experiences of Children and Young People with Obsessive Compulsive Disorder: Perceptions of Living with the Diagnosis. *The Journal of Child Psychology and Psychiatry* (8806 words)

Chapter Three: Conflict in the Perspective of OCD: Phenomenology, Systemic Network and Psychological Treatment. *Clinical Psychology Forum* (3188 words)

Overall word count: (Excluding tables and references): 19,968 words

SUMMARY

This research thesis has examined the way in which family involvement in childhood Obsessive Compulsive Disorder (OCD) facilitates treatment and the experiences of children in living with their diagnosis of OCD.

Chapter one is a literature review of eleven empirical studies of the effectiveness of CBT with family involvement. The review highlights the variety in the way families are involved in CBT treatment and suggests that there is a trend towards higher rates of improvement in symptom severity for treatments that involve families separate family sessions away from the child, and a potentially higher improvement for treatments that utilise a mixture of joint child-family sessions in addition to separate family sessions.

Chapter two is an empirical study of the experiences of seven children in living with their diagnosis of OCD. A qualitative methodology utilising Interpretative Phenomenological Analysis revealed three main areas of importance; the power and control of OCD, the associated emotional consequences and the role of relationships in OCD and in treatment. Clinical implications and areas for future research are discussed alongside methodological limitations.

Chapter three is a reflective account of the research thesis as a whole; methodological and clinical issues arising from the research are discussed along with personal reflections of personal and professional development.

Chapter One

How Does Family Work Facilitate the Cognitive Behavioural
Treatment of Children with Obsessive Compulsive Disorder?

A Review of the Evidence

Word Count (excluding titles, tables and references): 7974

Paper prepared for submission to Clinical Psychology Review
(see Appendix A for notes to contributors)

ABSTRACT

Obsessive Compulsive Disorder (OCD) is a debilitating condition for children and young people; impacting on their social, academic and personal development. Given the nature of such difficulties it is not surprising that the families of children with OCD are also impacted upon by this condition. Their attempts to understand and support their child's difficulties in their daily coping with symptoms can result in OCD becoming a family problem. Cognitive Behavioural Therapy (CBT) is advocated as an effective treatment for young people with Obsessive Compulsive Disorder and the involvement of families in treatment is recommended (Department of Health, 2005).

Previous reviews have highlighted that the involvement of families has been conducted in a wide variety of ways but there has been limited systematic evaluation about the way in which family involvement may facilitate the treatment of children with OCD. The present review critically evaluates the existing empirical evidence for family involvement in the CBT treatment of childhood OCD. A range of different family approaches have been utilised in treatment but this review highlights a potential trend towards greater improvement in symptom severity from treatments that involve families in a combination of separate family sessions in addition to joint child-family sessions. Methodological limitations of the literature are considered alongside areas for future research.

1.0 INTRODUCTION

1.1 Mental Health of Children and Young People

A survey by the Office of National Statistics (2004) carried out on behalf of the Department of Health and the Scottish Executive states that one in ten young people aged 5 to 16 years had a clinically diagnosed mental disorder as defined by ICD-10 (World Health Organisation, 1992). The proportion of emotional disorders (anxiety or depression) was 4%, whilst 6% had a conduct disorder, 2% had a hyperkinetic disorder, 1% had a less common disorder such as autism, tics, eating disorders and selective mutism, and 2% had more than one type of disorder.

1.2 Obsessive Compulsive Disorder in Children and Young People

Obsessive Compulsive Disorder (OCD) is an anxiety disorder seen in adults and children, characterised by the presence of obsessions and / or compulsions. Obsessions are defined as “persistent ideas, thoughts, impulses, or images that are experienced as intrusive and inappropriate and that cause marked anxiety or distress”. Compulsions are defined as “repetitive behaviours or mental acts, the goal of which is to prevent or reduce anxiety or distress, not provide pleasure or gratification” (American Psychiatric Association, 1994, p.418). The compulsions tend to obey strict

rules, yet the association between the compulsion and the act they intend to neutralise are not connected in a realistic way or are excessive in nature (Carr, 2004).

The variation in the content or character of the obsessions and compulsions is diverse. Common obsessions are fear of harm to others such as loved ones, blasphemous thoughts, worries of contamination and urges relating to the need for exactness or symmetry. Common compulsions are excessive washing and cleaning, repeated checking, ordering behaviour such as symmetry and straightening and mental acts such as counting or the need to think specific thoughts (Swedo, Rapoport, Leonard, Lenane & Cheslow, 1989). Whilst there are similarities in the nature of obsessive and compulsive characteristics between children and adults with OCD, a key difference in the diagnosis of OCD in young people, in comparison to the adult population, is that young people are not required to recognise the obsessions or compulsions as unreasonable or excessive (Carr, 2004).

1.2.1 Prevalence

OCD was once thought to be rare in young people (Barrett & Healey, 2003; Freeman et al., 2003; Heyman, 2005). Estimations of prevalence of OCD in people aged 18 years or less is generally estimated to be between 0.5 to 2% (Heyman, 2005; Leonard, et al., 2001; Rapoport, et al., 2000). The British

nationwide survey of child mental health reported rates of 0.25% in those aged 5 to 15 years (Heyman et al., 2001 in Presta, et al., 2003) yet when subsyndromal cases are included (Presta, et al., 2003) prevalence rates were reported to be up to 12% (Maina, et al., 1999 in Presta, et al., 2003). Indeed, some of the behaviours seen such as ordering and symmetry can be seen as part of the normal developmental pattern for children.

Examination of the adult population estimates that up to 50% of adults referred with OCD remembered the onset of their symptoms to be in childhood yet did not access treatment at this stage (Heyman, 2005). It is clear that further understanding of OCD in young people is needed to ensure that effective early intervention is sought and utilised, thus potentially minimising adverse consequences seen in adulthood.

2.0 THE ROLE OF THE FAMILY IN CHILDHOOD OCD

The family may play an important part in childhood OCD for children are highly dependent on their families relative to adults and are immersed within a family context. During this time they are undergoing cognitive, social and personal identity development; in which the family plays a key role. It is no surprise that the role of the family has been studied as a way to understand possible reasons for OCD development and maintenance. The following

section will briefly describe the way in which family involvement in childhood OCD may occur in order to help set the context of the present review.

2.1 Medical Causes

It is suggested that there is an inherited vulnerability to OCD and genetics play a role (Hudziak et al., 2004). The Johns Hopkins Family Study (Nedstadt et al., 2001) found higher rates of OCD and depressive disorder in the relatives of people with OCD compared with relatives of people without OCD; suggesting that OCD may have a genetic component. Other family studies have supported this conclusion (see Turner 2006, for a review).

2.2 Characteristics of Families of Children with OCD

In addition to a potential genetic contribution to OCD morbidity, the family environment is suggested to influence the development and maintenance of OCD through social learning and role modelling. The role of the family has been demonstrated to have a bidirectional influence on childhood OCD, in that families affect, and are affected by, the child's OCD (March, 1995).

2.3 Family Involvement in Symptomatology

Research has suggested that families of children with OCD may be characterised by 'high expressed emotion', (i.e. high levels of criticism and over-involvement) (Hibbs, et al., 1991) and that children with OCD perceive low levels of emotional support, warmth and closeness in comparison to "non-clinic" children (Valleni-Basile et al., 1995). Furthermore, it is suggested that the families of children with OCD make less use of positive problem solving, encourage avoidance of potentially difficult situations and are less likely to promote the independence of their children (Barrett, Shortt & Healy, 2002). Maternal over-control in families with anxious children was related to the mother's own anxiety and was characterised by interactions that were less warm and positive, less granting of autonomy and catastrophising in comparison to non-anxious mothers (Whaley, Pinto & Sigman, 1999).

Families often become involved in childhood OCD obsessions and compulsions in an attempt to restore family harmony, reduce child distress and to stop the child from engaging in symptomatic behaviour (Waters & Barrett, 2000). This may take the form of direct involvement with compulsive behaviours by assisting with or interrupting their completion or indirect involvement by altering family functioning and routines to accommodate obsessive-compulsive symptomatology (Cooper, 1996). Typical concerns for families are the involvement of family members in the accommodation of

compulsions, the difficulty experienced by family members in dealing with obsessions that are sexual or aggressive in nature, and disagreements over the best way to manage OCD within the family (March, 1995).

Van-Noppen, Steketee, and Pato (1997) suggest that families may respond on a continuum from accommodating (directly assisting and over-involved in symptomatology) to antagonistic (critical, hostile and refusing involvement). Waters (2000) suggests that while Van-Noppen et al.'s (1997) model is simplistic some family members may be divided in their stance with some members accommodating and some antagonising and that either position constitutes involvement in symptomatology.

2.4 Impact of OCD on Families

Family accommodation and participation in childhood compulsions are associated with increased anxiety and depression in family members (Amir, Freshman & Foa, 2000) and increases in the affected child's compulsions are related to increased critical comments and rejecting attitudes from family members (Amir et al., 2000).

Given the impact that OCD can have upon a family it is not surprising that children may attempt to conceal their symptoms from their family (Rapoport et al., 2000) and that family members may attempt to cope with

stigmatisation by attempting to conceal the patient's symptoms (Stengler-Wenzke, Trosbasch, Dietrich & Angermeyer, 2004). As highlighted, families can be involved in the causation, development and maintenance of OCD in children and everyone in the family system can be affected. Therefore, family involvement in treatment is worthy of consideration.

3.0 TREATMENT FOR OBSESSIVE COMPULSIVE DISORDER

3.1 Cognitive Behaviour Therapy

Obsessive Compulsive Disorder (OCD) has received an increased amount of research within the last 20 years. OCD was previously thought to be puzzling and severely chronic, and interventions failed to produce good outcomes in the short or long term. However, more recent advances have highlighted numerous developments in the understanding of OCD in adults that have been adapted to aid understanding of OCD in children and young people.

Historically, behavioural treatment of OCD in the adult and child population was the treatment of choice and led to the advocacy of exposure and response prevention (ERP) as a key component of the treatment of OCD. Further research has led to the development of the Cognitive Theory of OCD (Salkovskis & Kirk, 1989) and as a result has led to the development of Cognitive Behavioural Therapy as the most widely accepted choice for

treatment in adults and children based on research and clinical outcomes. However, unlike the adult population, there is limited research examining the efficacy of CBT for young people with OCD.

The National Institute for Clinical Excellence (Department of Health, 2005) guidelines recommend Cognitive Behavioural Therapy (to include ERP) as the treatment of choice for children and adolescents with OCD with moderate to severe functional impairment. Given what has been hypothesised about the involvement of family factors in the development, maintenance and impact on the family of childhood OCD, it is appropriate that the NICE guidelines recommend that treatment also involves the family or carers in some form of family therapy and that treatment is adapted to suit the developmental age of the child. The guidelines state that group or individual formats should be offered depending upon the preference of the child or young person and their family or carers.

Given the effect of childhood OCD on the family, the role that the family may take in response to OCD symptomatology and the impact this may have on the family and developing child, it is not surprising that OCD is seen as a family problem. Consequently, it is clear to see that it is important for treatment for childhood OCD to involve families and to do this it is important to understand the role that family work can take within cognitive behavioural treatment for young people.

3.2 What is known about Involving Families in Treatment?

There have been a number of review papers and meta-analyses to date that evaluate the effectiveness of CBT with children and adolescents with OCD (Barrett, Farrell, Pina, Peris & Piacentini, 2008; Freeman et al., 2007; Renshaw 2005; Freeman, 2003; Diamond & Josephson, 2005; Turner 2006). This literature has reviewed the efficacy of CBT across both group and individual delivery formats and family involvement ranged from a family-focused CBT approach in which the family work had an equal emphasis as working with the child, through to other CBT approaches in which the family may have a more distant ad-hoc involvement in the treatment. Whilst the involvement of families is a common component of CBT treatment for childhood OCD, and a number of CBT efficacy studies have included family involvement as part of the treatment (see Barrett et al., 2008 and Freeman et al., 2007 for a review) there has been limited specific evaluation of the importance of the role of family involvement in CBT. Consequently, we know little about the best way to involve families in CBT treatment for childhood OCD.

Barrett et al. (2008) conducted a comprehensive review of the CBT literature for the treatment of childhood OCD that included studies across various delivery modalities; group CBT and individual CBT and identified the level of family component within the studies. Barrett et al. evaluated the treatment

studies for methodological rigour based on classification criteria for 'well-established', 'probably efficacious', 'possibly efficacious', and 'experimental' treatments (based on criteria suggested by Chambless et al., 1998, Chambless et al., 1996; and Chambless & Hollon, 1998; cited in Barrett et al., 2008). The authors suggested that based on their evaluation of the data both family-focused individual CBT and family-focused group CBT can be considered 'possibly efficacious' treatments, and that the highest effect sizes of CBT reported in the study are from a study with what the authors describe as 'the highest dose' of family involvement in CBT. This suggests that to achieve the highest level of success families must be substantially involved.

The benefit of family involvement is supported by the findings from a meta-analysis by Freeman et al. (2007) who examined the effectiveness of CBT for children with OCD delivered in various formats; individual CBT, group CBT and CBT with a family component to the treatment, family CBT. Freeman et al. (2008) reported that individual CBT and family CBT had the greatest effect sizes (1.77 and 1.88 respectively) whereas group CBT was 0.76.

So in summary, the evaluation of family work in the treatment of childhood OCD has been demonstrated as 'possibly efficacious' (Barrett et al, 2008; Freeman et al., 2007). The review literature has evaluated the use of CBT in the treatment of childhood OCD and highlighted the variation and open-ended nature of the way in which families may be involved in treatment and

the difficulty this presents in enabling rigorous examination of the utility and efficacy of involving families in the treatment of childhood OCD (Renshaw, 2005; Diamond & Josephson, 2005; Turner, 2006; Barrett et al., 2008). Other childhood OCD CBT treatment review papers have been conducted but provided limited focus on the involvement of families in treatment (Freeman et al., 2003; Abramowitz, Whiteside & Deacon, 2005; O’Kearney, Anstey & von Sanden, 2006).

4.0 AIMS OF REVIEW

The NICE guidelines recommend some form of family therapy plus CBT as the treatment of choice for childhood OCD. It has been demonstrated that family-focused CBT treatment is ‘possibly efficacious’ (Barrett et al., 2008) but the considerable variation in the way families have been involved in CBT treatment has prevented systematic evaluation of its efficacy.

Therefore, in order to make recommendations for future clinical practice and systematic evaluation it would be useful to:

- Understand the way in which families have been involved in the CBT treatment of young people with OCD
- Critically evaluate what we know so far about the way in which family involvement facilitates CBT treatment

- Identify areas that guide clinical practice and the direction of future research

5.0 SEARCH STRATEGY

Papers were searched for using Psychinfo, Medline, ScienceDirect and the Cochrane Reviews database. Search terms used in this search were Obsessive, Compulsive, OCD, Cognitive, Behavior, Behaviour, Behavioral, Behavioural, CBT, ERP, Family, Parent, Parental, Parents, Sibling, Therapy, Treatment, Intervention'. All of these terms were cross referenced with the terms of Child, Children, Pediatric, Paediatric, Early Onset, Juvenile, Young People, Young Person, and Adolescent. After identifying papers that met the search criteria the papers were then searched individually for further references cited within the paper.

5.1 Inclusion Criteria

Research studies that used CBT with family involvement in the treatment of childhood OCD were included in this review. This includes randomised controlled trials, pilot studies and naturalistic studies. Only papers written within the past ten years have been included in this review. Included papers were those in which the sample had a primary diagnosis of OCD and for a number of papers this included additional co-morbid secondary diagnoses.

5.2 Exclusion Criteria

Unpublished studies, dissertation abstracts, non-English language studies were excluded. Papers that reported inclusion of a sample whose OCD aetiology may be associated with 'pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections' (PANDAS), (Swedo, et al., 1998) were excluded. Whilst the evidence for PANDAS is mixed it may represent a different classification entity (Moretti, Passquini, Mandarelli, Tarsitani & Biondi, 2008) and its inclusion in treatment studies may confound results. Additionally, one paper was excluded for it included tic-related OCD (Himle, Fischer, Van Etten, Janeck & Hanna, 2003) which is commonly thought to represent a different sub-type of OCD (Leckman et al., 2000) and may have therefore confounded the results.

6.0 REVIEW OF STUDIES

The literature search revealed eleven studies that utilised family involvement in the treatment of childhood OCD. The review will involve the division of the available studies into two categories; 1) studies that involved families in treatment by conducting 'joint' child-family sessions only and 2) studies that involved families in 'separate' family sessions away from the child in addition to 'joint' child-family sessions. There were no studies that had entirely separate family involvement.

Each category of family involvement will be reviewed which will involve a critical review of the studies to illustrate the amount of family involvement in the treatment, the way in which the families were involved and the study findings. Secondly, a critical evaluation of the way in which the involvement of families facilitates CBT treatment will be conducted; to consider the impact of such involvement on OCD symptom severity and where applicable, on family outcome measures. Methodological limitations of the literature will be presented and, lastly, recommendations for clinical practice will be made on how best to involve families in OCD treatment and to highlight gaps in our understanding for future research.

The majority of studies utilise parents in treatment whereas some studies also invite siblings and so the term family involvement will be used to describe this involvement overall.

6.1 Family Involvement: Joint Child-Family Sessions

Of the eleven studies there were six that utilised joint child-family sessions in CBT treatment for childhood OCD. Table 1 presents a breakdown of the studies, illustrating the amount and nature of family involvement in the treatment. This ranged from minimal joint involvement; with families attending a small number of joint sessions or just the last part of all sessions through to maximum joint involvement with parents attending all sessions.

Table 1: Studies that use joint family-child sessions

STUDY	SAMPLE	AMOUNT OF FAMILY INVOLVEMENT	NATURE OF FAMILY INVOLVEMENT	FINDINGS (CY-BOCS scores reported unless otherwise stated)
Minimal Joint Family Sessions:				
1. Piacentini, Bergman, Jacobs, McCracken, Kretchman (2002)	N=42 5 to 17 yrs CBT	No. sessions and breakdown not specifically documented Some joint child + parent sessions at start of treatment	<u>Family Involvement:</u> -assessment of OCD, psychoeducation, development of symptom hierarchy and behavioural reward system, concrete rewards replaced with family praise, (family involvement varied with developmental age of child) -Discriminating OCD from non-OCD behaviours, facilitate familial withdrawal from rituals, foster a more relaxed home environment and minimise family conflicts about OCD symptomatology	<u>Symptom Severity</u> 46.2% reduction (NIMH-Global) $p < 0.001$ (CBT) no significant difference between CBT and CBT+ drug Severity of obsessions and OCD-related academic impairment associated with poorer outcome F/U: no data
2. POTS (2004)	N=112 7 to 17 yrs 28 CBT (28) x drug (28) x CBT + drug (28) x placebo drug (28)	<u>14 sessions:</u> 11 x child 3 x child + parent therapists flexible to additional family involvement one between visit and ten min telephone contact scheduled for wks 3 to 12	-Psychoeducation (content of remaining parent + child sessions not stated) -flexibility to accommodate the developmental stage of the child and to address maladaptive parent-child interactions resulting from the child's OCD	<u>Symptom Severity</u> 46.15% reduction (CBT), 29.79% (drug), 52.94% (CBT+ drug), 14.68% (placebo) CBT+ drug superior to CBT ($p=0.008$) <u>Remission</u> (CY-BOCS score above or equal to 10) no significant difference between CBT (39.3%) and CBT+ drug (53.6%) F/U: no data
Maximum Joint Family Sessions:				
3. Thienemann, Martin, Cregger, Thompson & Dyer-Friedman (2001)	13 to 17 yr N=18 GCBT	<u>14 sessions:</u> 12 x child 12 x child + parent (15min) 1 x child + parent + sibling 1 x family ending During the child sessions the parents wait together in a conference room (activity of parents not monitored)	<u>Parent Involvement:</u> -Parents attended final 15min of each session during which time the group topics were reviewed, homework plans were reiterated and question time for parents <u>Family Involvement:</u> -One session included parents and siblings: family roles around OCD, joint decision making about parents' participation in OCD rituals	<u>Symptom Severity</u> 25% reduction ($p < 0.001$) Significant reductions in child anxiety (MASC), depression (CDI) and general behaviour problems (CBCL) No change in parents' stress (PSI) F/U: no data

STUDY	SAMPLE	AMOUNT OF FAMILY INVOLVEMENT	NATURE OF FAMILY INVOLVEMENT	FINDINGS (CY-BOCS scores reported unless otherwise stated)
4. Benazon, Ager & Rosenberg (2002)	N=16 8 to 18 years CBT	<u>12 sessions:</u> 8 x child 8 x child + parent (10min) 4 x child + parent (60min)	<u>Parental Involvement:</u> -Parents encouraged to become co-therapists for child at home using ERP -Children trained in a cognitive behavioural technique and then taught this to parents two sessions later	<u>Symptom Severity</u> 47.65% reduction (p=0.0001) 55.95% reduction (NIMH-Global) (p<0.0001) 44% asymptomatic (NIMH-Global) significant reduction in HAM-A <u>F/U:</u> no data
5. Asbahr, Castillo, Ito, De Oliveira Latorre, Moreira & Lotufo-Neto (2005)	N=40 9 to 17yrs GCBT (20) x drug (20)	<u>12 sessions:</u> 11 x child 11 x child + parent (15min) 1 x child + parent + sibling	<u>Family Involvement:</u> -Family taught about family roles in OCD and how parents may participate in rituals <u>Parent Involvement:</u> -Parents invited to last 15min of session to review topics to be covered in next session, to confirm homework arrangements and for time for questions for clarification	<u>Symptom Severity</u> (estimated from graphical data) 53.85% reduction (CBT) vs. 50% reduction (drug) significant improvement, but not between groups <u>9mth F/U:</u> 5% relapse (CBT) vs. 53% relapse (drug)
6. Storch, Geffken, Merlo, Mann, Duke, Munson, Adkins, Grabill, Murphy & Goodman (2007)	N=40 7 to 17 yrs weekly CBT (20) x daily CBT (20)	<u>14 sessions:</u> 14 x child + parent	-Parent inclusion to facilitate understanding of treatment principles -To assist with generalisation of treatment gains by enlisting parents as at-home 'coach' reduce parent accommodation of OCD -To encourage optimal effort during in-session exposures and homework assignments	<u>Symptom Severity</u> 63.32% reduction (daily CBT) vs. 49.61% reduction (weekly CBT) (both significant to p<0.001) <u>Remission</u> 75% (daily CBT) vs. 50% (weekly CBT) (significant difference between groups) <u>3mth F/U:</u> no group differences in remission status

CBCL: Child Behaviour Checklist (Achenbach & Edelbrock, 1983); CDI: Child Depression Inventory (Kovacs, 1992); COIS: Child Obsessive Compulsive Impact Scale (Piacentini, Bergman, Keller & McCracken, 2003); CY-BOCS: Child Yale-Brown Obsessive Compulsive Scale (Goodman, Price, Rasmussen et al., 1989a, 1989b; Scahill, McSwiggen-Hardin et al., 1997); ERP: exposure and response prevention; FAD: McMaster Family Assessment Device (Epstein, Baldwin & Bishop, 1983); FAS: Family Accommodation Scale for Obsessive Compulsive Disorder (Calvocoressi et al., 1995); FRT: family based relaxation therapy; F/U: follow-up; GCBFT: group cognitive behavioural family therapy; GCBT: group cognitive behavioural therapy; HAM: Hamilton Anxiety rating Scale (Hamilton, 1959; 1967); MAS: Multidimensional Anxiety Scale for Children, (March, 1997); NIMH-Global: National Institute for Mental Health-Global Obsessive Compulsive Scale (Insel, Hoover & Murphy, 1983); PSI: Parenting Stress Index (Abidin, 1995); W/L: waiting list

There were six studies that used joint child-family sessions, two studies reported minimal joint sessions in the treatment protocol and the remaining four studies utilised joint family sessions for every session; ranging from a part of the session to the entire session.

Of the four studies which utilised maximum joint child-family sessions, Storch et al. (2007) was the only study to involve parents for the full length of all child sessions. The authors achieved a 49.61% reduction in mean symptom severity (weekly CBT) and an even higher rate for daily CBT (63.32%), demonstrating effect sizes of 1.73 and 2.62 respectively. The reductions represented statistically significant change from pre- to post-treatment, with no statistical differences between weekly and daily CBT. Improvement gains were maintained at follow-up and remission rates for weekly and daily CBT were 50% and 75% respectively.

Storch et al. (2007) hypothesise that the higher rates demonstrated by daily CBT were due to daily sessions allowing closer monitoring of family dynamics and therapeutic compliance, facilitating frequent feedback on family behaviour (e.g. providing reassurance) and reducing family accommodation, however the authors provide no specific evaluation of this. It would be interesting to evaluate the impact of intensive family monitoring and feedback (e.g. daily phone contact) on weekly treatment formats to isolate

the effects of the intensive monitoring and feedback from the effects of receiving intensive sessions.

Achieving similar outcomes, the second study to use maximum joint family involvement was Benazon, Ager & Rosenberg, (2002) who involved parents in four joint child-parent sessions and parents attended the final 10 minutes of each child session. They demonstrated that CBT reduced symptom severity by 47.65% and showed a large effect of treatment (1.65). Additionally, 44.44% were asymptomatic at the end of treatment (NIMH-Global score of ≤ 2). The study lacks follow-up data so it is not possible to ascertain if the gains were maintained after treatment. Benazon, et al. (2002) used less family involvement than Storch et al. (2007) which allowed for more child-only sessions yet achieved a similar outcome; this may suggest that it is not necessary to include parents in all sessions.

The remaining two studies that used maximum joint child-family involvement were group CBT studies. Achieving the highest rates in the joint involvement category, Asbahr et al. (2005) evaluated the effectiveness of group CBT compared with drug treatment for 40 children aged 9 to 17 years. The treatment protocol utilised one family session (parent + sibling) and parents attended the final 15 minutes of each child session. The treatment protocol included psychoeducation on family roles in OCD. The study demonstrated

that treatment with group CBT and drug treatment achieved statistically significant improvement and did not differ in significance from each other.

Asbahr et al. (2005) provide graphical representation of their outcome data and so from this it was possible to estimate the outcome data and calculate the percentage rate of improvement in symptom severity to be 53.85% and 50% for group CBT and drug treatment, respectively. However, the lack of numerical data renders this an estimation. The population treated within this study were relatively severe compared to other studies and had not received psychological treatment previously which may have provided the opportunity for a greater reduction in symptom severity compared to other samples. However, if we take the data estimation as accurate then it suggests that involving families in a part of each group CBT treatment session may lead to high improvement rates.

In contrast, the other group CBT study (Thienemann, Martin, Cregger, Thompson & Dyer-Friedman, 2001), although utilising a maximum approach to joint involvement, found only a 25% reduction in symptom severity; the lowest in the joint category. Whilst constituting a statistically significant change from baseline, this is a lower rate than studies with a similar design. This difference between the group CBT studies reflects the mixed evidence base for group CBT outcome research (e.g. Barrett et al., 2008; Freeman et al., 2007) and may suggest that the participants in the group were not able to

obtain as much from the group as in other groups or in individual treatment. Thienemann et al. (2001) provided families with a conference room to wait in during the child sessions; however this time was not monitored or evaluated. It would have been useful to have evaluated the impact of this time on families and perhaps this may have impacted on the amount families used their time together in-session, which may suggest the lower improvement rates compared to other group CBT and individual treatments.

In comparison to the studies with maximum joint involvement, Piacentini, Bergman, Jacobs, McCracken & Kretchman, (2002) and The Pediatric OCD Treatment Study Team (2004) used minimal joint child-family sessions. Piacentini et al. (2002) stated they involved parents in initial sessions for assessment and psychoeducation and that additional involvement was provided for families where there was significant conflict or disruption from OCD; however the exact details were not reported. Piacentini et al. found that CBT is as effective as CBT plus medication with symptom severity reductions of 46.2% and 44.1% respectively.

However, the reduction was measured on the National Institute Mental Health-Global Obsessive Compulsive Scale (Insel, Hoover & Murphy, 1983) which limits comparison to the other studies within this review, of which use Child Yale-Brown Obsessive Compulsive Scale (Goodman, Price, Rasmussen, et al., 1989a, 1989b; Scahill, McSwiggen-Hardin et al., 1997).

There was no follow-up data to ascertain if gains were maintained. The authors state that four participants initiated drug treatment during the study and that behavioural rewards were not used with older participants. This differential medical and behavioural treatment of participants and additional family involvement for some families may have confounded the treatment results and limits the conclusions that can be drawn for it is not possible to isolate the effects of the various components on treatment outcome.

Lastly, the Pediatric Obsessive Compulsive Treatment Study (2004) utilised a randomised controlled trial with 112 children aged 7 to 17 years. They involved parents in treatment in three dedicated parent-child joint sessions and the authors stated that they were flexible additional parental involvement. The results indicated that the greatest improvement was for those treated with either, medication and CBT combined (52.94%) or CBT only (46.15%), both statistically significant gains but not differing from each other. This compares to a 29.74% reduction for those treated with medication only and 14.8% placebo.

Similar differences were demonstrated in remission status with medication and CBT combined, and CBT only, achieving the highest rates (53.6% and 39.3% respectively). They did not differ significantly but were both superior to placebo; however, CBT-only demonstrated similar results to medication only. The authors utilised an intent-to-treat analysis in which missing data was

substituted for by the last observation made, which may have affected the results and skewed the outcome. No follow-up data was collected so it is not clear if the gains were maintained after treatment.

Both of the minimum joint family-child involvement studies report using minimal joint sessions in the treatment protocol yet state that they were flexible to additional family involvement. So although the results suggest that minimal family involvement produces relatively high rates of improvement, the studies may have had more than minimal family involvement, being more similar to the four studies using maximum involvement and may explain the similarity in results.

6.2 Summary of Joint Child-Family Involvement

The review highlighted the variation in use of joint child-family sessions and perhaps accounts for the variation in treatment outcome. Whilst the variation across studies prevents statistical comparison, there may be a trend towards greater symptom improvement in treatment approaches that utilise a majority of joint child-family sessions compared with minimal joint child-family sessions and majority child-only sessions. The treatment protocols of two studies reported minimal joint sessions but reported that additional family involvement was provided and interestingly, whilst only one of the two had data for comparison, it reported similar results to those with maximum joint

involvement. The lowest improvement was that with maximum joint involvement but utilising a group CBT approach and provided informal un-monitored time for families to wait together with other families during child sessions. It is not clear whether this impacted on treatment outcome or reflects the mixed evidence for group CBT.

6.3 Family Involvement: Combination of Separate Sessions and Joint Child-Family Sessions

Of the eleven studies there were five studies that used a mixture of separate family sessions and joint child-family sessions in CBT treatment for childhood OCD. Table 2 presents a breakdown of the studies, illustrating the amount and nature of family involvement in the treatment. There was a range of family involvement ranging from minimal separate involvement and maximum joint involvement through to maximum separate involvement and minimal joint involvement, and one study with equal amounts of both.

Table 2: Studies that use a mixture of separate family involvement and joint family involvement

STUDY	SAMPLE DESIGN	AMOUNT OF FAMILY INVOLVEMENT	NATURE OF FAMILY INVOLVEMENT	FINDINGS (CY-BOCS scores reported unless otherwise stated)
Minimal Separate Sessions and Maximum Joint Sessions:				
7. Valderhaug, Larsson, Gotestam & Piacentini (2007)	8 to 17 yr N= 28 CBT	<u>12 sessions:</u> 10 x child (45min) 10 x child + child or parent only (15–30min) 2 x child + parent Parents of young children attended child sessions too	-Hierarchy of fears for ERP tasks -Parental feelings and attributes about child's OCD addressed -Parental feelings of blame (self or child), frustration and anger addressed -Focus on parental and family wellbeing and how to build support for both parent(s) and child	<u>Symptom Severity</u> 60.6% reduction ($p > 0.001$) <u>Remission Status</u> (CY-BOCS score below or equal to 9) 50% significant reductions in MASC, CDI, CBCL No change in PSI (maternal or paternal) <u>3mth and 6mth F/U:</u> significant improvement maintained
8. Freeman, Garcia, Coyne, Ale, Przeworski, Himle, Compton & Leonard (2008)	5 to 8 yr N=42 FCBT (22) x FRT (20)	<u>12 sessions:</u> 2 x parent 10 x child + parent	<u>Role of Parents:</u> -Coaches at home -To reduce accommodation -Exposure for parents in tolerating their child's distress during child's ERP -Address parental worries about child's diagnosis and prognosis -Family assessment of impact and logistics of participating in treatment <u>central parenting tools:</u> differential attention, modelling and scaffolding, parent and child to develop hierarchy for ERP and reward program to facilitate ERP	<u>Symptom Severity</u> 37.43% reduction (CBT) vs. 21.20% (relaxation therapy) (intent-to-treat analysis) 50.26% reduction (CBT) vs. 23.32% (relaxation therapy) (sample who completed treatment) <u>Remission Status</u> (CY-BOCS score of equal or below 12) 50% CBT vs. 20% RT <u>F/U:</u> No data
Maximum Separate and Minimal Joint Sessions:				
9. Waters, Barrett, & March (2000)	10 to 14 yr N=7 CBT	<u>14 sessions:</u> 10 x child 10 x parent (30min) 4 x child + parent	<u>Parental skills training</u> -differential reinforcement, -relaxation, parental anxiety management, -reduction of family accommodation -problem-solving skills	<u>Symptom Severity</u> 60% reduction ($p < 0.001$) <u>Remission Status</u> 86% diagnosis-free Reductions in family accommodation (FAS) No change in general functioning (FAD) <u>3mth F/U:</u> Improvements maintained

STUDY	SAMPLE DESIGN	AMOUNT OF FAMILY INVOLVEMENT	NATURE OF FAMILY INVOLVEMENT	FINDINGS (CY-BOCS scores reported unless otherwise stated)
10. Barrett, Healy-Farrell & March (2004)	7 to 17 yrs N=77 CBFT (24) x GCBFT (29) x W/L (24)	<u>14 sessions:</u> 11 x child (50min) 11 x parent (30min) 11 x child + parent (10min) 3 sibling sessions: 1 x sibling 1 x parent + sibling 1 x child + sibling 2 x family booster sessions	<u>Parent involvement:</u> -psychoeducation, problem-solving skills, and strategies to reduce parental involvement in the child's symptoms, along with encouraging family support of home-based exposure and response prevention tasks. -Parents were encouraged to discuss session content with partners not present. <u>Family involvement:</u> -review of progress and booster sessions -coping strategies encouraged to be practiced as a family on a daily basis	<u>Symptom Severity</u> 65% reduction CBT, 61% GCBT 6mth F/U: gains maintained 18mth F/U: (of 90% of active treatment groups) 70% CBT, 84% GCBT diagnosis free
Equal amount of separate and joint sessions:				
11. Martin & Thienemann (2005)	8 to 14 yrs N=14 GCBT	<u>14 sessions:</u> 12 x child (60min) 12 x parent (60min) 12 x child + parent (30min) 2 x child + parent + sibling	-parents learn same CBT / ERP skills as child -cognitive: externalising OCD, constructive self talk, cognitive restructuring, cultivating detachment. - <u>30min joint</u> : review of topics and homework setting - <u>Two joint sessions</u> : 1)psychoeducation, 2)family roles in OCD (child, sibling and parent attendance) Individualised support to families session 9	<u>Symptom Severity</u> 24.76% reduction Significant reductions in COIS-P, CDI, CBCL No significant change in COIS-C, MASC-P, MASC-C F/U: no data

CBCL: Child Behaviour Checklist (Achenbach & Edelbrock, 1983); CDI: Child Depression Inventory (Kovacs, 1992); COIS: Child Obsessive Compulsive Impact Scale (Piacentini, Bergman, Keller & McCracken, 2003); CY-BOCS: Child Yale-Brown Obsessive Compulsive Scale (Goodman, Price, Rasmussen et al., 1989a, 1989b; Scahill, McSwiggen-Hardin et al., 1997); ERP: exposure and response prevention; FAD: McMaster Family Assessment Device (Epstein, Baldwin & Bishop, 1983); FAS: Family Accommodation Scale for Obsessive Compulsive Disorder (Calvocoressi et al., 1995); FRT: family based relaxation therapy; F/U: follow-up; GCBFT: group cognitive behavioural family therapy; GCBT: group cognitive behavioural therapy; MASC: Multidimensional Anxiety Scale for Children, (March, 1997); NIMH-Global: National Institute for Mental Health-Global Obsessive Compulsive Scale (Insel, Hoover & Murphy, 1983); PSI: Parenting Stress Index (Abidin, 1995); W/L: waiting list

There were five studies that used a mixture of separate and joint child-family sessions. Two studies reported using minimal separate involvement and maximum joint involvement, two used maximum separate involvement and minimum joint involvement and the fifth used equal amounts of both.

Two studies used maximum separate involvement and minimum joint involvement (Waters & Barrett, 2000 and Barrett, Healy-Farrell & March, 2004). Firstly, Waters & Barrett (2000) scheduled the majority of treatment sessions as separate child and separate parent sessions and demonstrated a large improvement in symptom severity (60%) over the course of treatment, with 6 of 7 (86%) children achieving clinical remission. There was a significant reduction in child anxiety and family accommodation to OCD demands but no differences in parental reports of family functioning. Such significant improvement in symptom severity was not evidenced on a measure of general functioning and symptom impairment (Children's Global Assessment Scale, (Schaffer, Gould, Brasic, Ambrosini, Fisher, Bird, & Aluwahlia, 1983) and there was no follow-up data to ascertain the durability of such improvements over time. Additionally, the sample was small and so difficult to draw firm conclusions from but the study suggests that maximum separate family sessions may maximise treatment outcome.

In the second study using maximum separate involvement and minimum joint involvement, Barrett, Healy-Farrell & March (2004) found similar high rates of

improvement in symptom severity (65%, CBT and 61% group CBT), using a larger sample than Waters and Barrett (2000). The majority of treatment sessions enabled a separate component for both child and parent and comprised of a joint review at the end. Additionally, this study scheduled sessions to include siblings. The separate parent-only sessions enabled parents to work in a group format with other parents and centred on psychoeducation, skills training to enable problem solving, reduction in family participation of child's OCD symptomatology and to support parents to encourage family support of home-based exposure and response prevention tasks. The study reported clinically and statistically significant reductions in diagnostic status and symptom severity for children with OCD in both active CBT conditions compared to waiting list.

Additionally, Barrett et al. (2004) demonstrated a significant reduction in family accommodation to OCD demands and in the associated distress. A significant reduction in depression and anxiety was demonstrated across active conditions and waiting list, indicating that any intervention can have a positive impact including assessment and waiting list only.

Both the Barrett et al. and Waters and Barrett (2000) studies utilising the maximum separate involvement and minimum joint involvement demonstrated equally high rates of reduction in symptom severity after treatment. This suggests that maximum separate involvement with some joint

child-family involvement may maximise treatment outcome. However, a study that demonstrated a similarly high rate of improvement was one of the two studies that used minimum separate and maximum joint involvement (Valderhaug, Larsson, Gotestam & Piacentini, 2007 and Freeman et al., 2008). Valderhaug et al. (2007) demonstrated high rates of improvement (60.6%) that were comparable to Waters and Barrett (2000). However, the rates of remission were lower (50%) but defined a stricter criterion for remission status than other studies, potentially artificially reducing the number entering remission status compared to other studies.

Valderhaug et al. found significant reductions in anxiety and depression in children with OCD following treatment but no change in parental stress levels. The parental component of the study enabled parents to discuss issues that may be inappropriate for discussion in the presence of the child (e.g. parental feelings of blame of self or child, frustration, anger). Facilitation of such issues may have provided parents with support they could not have had without separate sessions. The authors did not evaluate the outcome of such sessions for parents and so it is not possible to conclude the effect of this on treatment outcome.

However, despite being classified as a minimum separate involvement study based on the treatment protocol, Valderhaug provided opportunity for parental feelings of blame (of self or child), frustration and anger to be

discussed, presumably in separate sessions rather than in front of the child with OCD and a focus on family wellbeing and support was provided. Although not evaluated by the authors, the nature of such involvement may have addressed important difficulties for parents and may have impacted positively on treatment outcome.

In contrast to this is the second study that used minimum separate and maximum joint involvement. Freeman et al. (2008) found that children's symptom severity improved by 37.43% over the course of treatment and 50% entered clinical remission status. However, no follow-up data was gathered to ascertain if the gains were maintained after treatment. It is possible that Freeman et al. (2008) did not achieve such high rates of improvement as the other studies using a mixture of separate and joint sessions because of the young age of the sample in comparison to other studies (5 to 8 years). Whilst there is limited evidence for the use of CBT in younger children it is generally thought to be less effective for the age group in this sample.

Further research could clarify if the use of an older sample could produce similar improvement rates to Valderhaug. Also, the joint CBT sessions were less cognitively advanced and adapted to suit the understanding of young children and it is not clear how this impacts on the family's opportunity for learning about the treatment. However, the authors state that joint sessions allowed parents to tolerate their own distress in observing and supporting

their children to tolerate the distress associated with ERP tasks. Whilst this was not specifically evaluated this may be an important feature of joint child-family sessions for treatment outcome. Also, it is not clear whether the opportunity for family learning is reduced as the role that families play is potentially taken up with supporting the understanding of the child.

Lastly, the final study used equal amount of separate and joint involvement and found the lowest rate of improvement across all studies. Martin and Thienemann (2005) conducted a group CBT study and scheduled separate parent and child sessions in addition to joint sessions each week and also included a small number of joint sessions to include siblings. Despite such high involvement from families the study demonstrated an overall improvement in symptoms of 24.75% which represented statistically significant improvement of symptom severity over the course of treatment, but was less successful than other studies in this review.

Whilst this may suggest that an equal mixture of both separate and joint sessions is not the most effective, it is noteworthy that the two lowest improvement rates were demonstrated by group CBT studies; with Martin and Thienemann (2005) demonstrating similar results to Thienemann. Again this may reflect the limitation of the group treatment format in preventing maximisation of treatment outcome, potentially from preventing as much

individualised support for children or families as other group CBT studies or individual studies.

6.4 Summary of Combined Separate Family Involvement and Joint Child-Family Involvement

So overall, similar to the findings of the joint child-family involvement, the utilisation of a mixture of joint and separate family involvement demonstrated a variation in outcome, perhaps reflected by the variation in treatment design across studies. Again, the variation in treatment design prevents statistical comparison but there may be a slight trend towards the highest rates of improvement for those utilising maximum separate involvement with some joint involvement.

Comparison of this category of studies utilising both separate and joint involvement indicated higher rates of improvement overall compared with the category of studies utilising only joint child-family involvement.

7.0 DISCUSSION

7.1 Summary of Findings

The findings of the review indicate that all the studies demonstrated significant improvement in symptom severity after CBT treatment with some family involvement, some studies demonstrating larger improvements than others. There was a wide variation in the way in which families were involved in treatment and this prevented systematic and statistical comparison. However, whilst the available evidence has not specifically aimed to evaluate the contribution of family involvement to treatment, division of the treatment studies into the amount of family involvement may allow for a comparison across treatment designs to highlight potential trends in outcomes.

In summary, there appears to be high rates of improvement in symptom severity for studies that use a mixture of both joint child-family sessions and separate family sessions. Further still, those rates may be maximised in treatments that use a majority of separate sessions with some joint child-family sessions. Whilst it is not possible to isolate the effects of family involvement on treatment outcome, from other treatment effects; the review has also highlighted the differences in roles for family involvement, some of which are more suited to joint involvement and some to separate involvement.

Whilst not a feature of all studies utilising separate family involvement, time for families separate from child sessions may allow for parental issues to be addressed or may provide opportunity for additional learning not possible in joint sessions. Additionally, joint sessions may provide families with the opportunity to observe the clinical practitioner in-session and learn the skills necessary to support children to engage in treatment tasks at home and to tolerate their own distress in encouraging their child to engage in activities that may be distressing.

7.2 Methodological Limitations and Recommendations for Future Research

The reviewed studies highlighted a variation in the amount and role of family involvement in childhood OCD treatment. These include family members acting as co-therapists to support exposure and response prevention tasks in-session and at home, as an implementer of behavioural reward programmes for younger children, as an aide to support the developmental ability of the child in remembering homework tasks and to increase effort. In addition they offer the opportunity for families to learn to change their own behaviour patterns in response to the child's OCD, and family members as 'clients' in their own right addressing family well-being issues and receiving support for the impact of the child's OCD on their own functioning.

Such variation in methodology meant it was difficult to compare across studies and draw firm conclusions about the relative contribution of family involvement to the treatment outcome. Furthermore, none of the studies aimed to evaluate the contribution of family involvement relative to non-family involvement and so it is not possible to isolate the effects of family involvement from other treatment effects.

Future research could evaluate the contribution of family involvement by controlling variables such as the amount of family involvement (number of sessions), the nature of such involvement (joint, separate, mixture of both) and the role for families in treatment (e.g. child-focused, co-therapist role, family-focused role where the whole family are seen as in receipt of treatment) and comparing such variables on treatment outcome and in comparison to treatment with minimal or no family involvement. Ultimately, statistical comparison of a number of randomised controlled trials using meta-analysis would be ideal to draw firm conclusions about the effect of family involvement on treatment.

In addition to the variation in the design of family involvement in treatment, the review highlighted the variation in the definition of who constitutes 'family'; with some studies using only parents and others including siblings. Further research could evaluate the impact of involving parents in addition to siblings, grandparents and other significant family members. Additionally, the

involvement of the wider system in such treatment studies, such as key teachers, friends and general peer group may provide additional insights in how to support the generalisation of such treatment effects outside of the family.

In order to understand more fully the systemic context within which the child with OCD lives, research with a qualitative methodology may enable a perspective on family members' experiences of having a family member with OCD, and the family's experience of being involved in treatment. This may highlight the experiences of parents and siblings and may consider potential differences between the experiences of those prior to such treatment relative to those who have completed treatment.

The present review highlighted further variation in treatment design across studies. The majority of studies utilised an individual CBT design whilst some studies delivered CBT treatment in group format. Group CBT may have provided additional confounding variables that effected treatment outcome, such as peer group support and normalisation for the child with OCD and for those parents or siblings that were involved in treatment using a group CBT design. The evidence for the use of group CBT in childhood OCD treatment is mixed and as yet little is known about how group CBT impacts on the family's ability to engage in therapy in such a format. Given the additional clinical time required to provide separate family treatment in addition to the

traditional individualised CBT treatment for children, a group CBT approach comprising the families of children with OCD may be a cost effective way to address additional family issues and utilise the peer support from other families. Further research is needed to examine the benefits of such an approach and the effectiveness on symptom severity and also on family functioning, coping and support.

The research sample across studies varied in age, diagnostic severity, previous treatment experience, medication use and diagnostic comorbidity. In some studies there was a lack of information of sample characteristics such as the average age of onset and duration of OCD. Such variation creates differences within the baseline characteristics of the samples and may confound the treatment outcomes, rendering comparison between studies difficult. Future research to control such variables is needed before firm conclusions can be made about the effectiveness of treatment and may clarify the variation in outcome across some studies.

The review highlighted variation in the outcome measures used to assess symptom severity and other secondary measures of family functioning and impact of OCD. Whilst the CY-BOCS (Goodman, Price, Rasmussen et al., 1989a; 1989b) was the most widely used measure of symptom severity, this was not used consistently across studies and so prevents comparison with other studies. Additionally, there was some variation in classification of

remission status in terms of measures used and the cut-off scores. As above, this increases the difficulty in comparing across studies and future research would benefit from remaining consistent in outcome measure assessment to allow for comparison in meta-analytic reviews.

In order to evaluate wider treatment effects, further research could evaluate the impact of family involvement that may capture change in family coping and functioning, quality of life measures for the child and family members (impact on school, family and other relationships) and emotional well-being (self esteem, self-concept) in addition to the more frequently utilised symptom severity measures and secondary mental health measures (anxiety, depression, stress).

Consideration of cognitive change in families may provide further insight into the effect of CBT treatment. CBT treatment for childhood OCD has been adapted from the adult literature using the Cognitive Theory of OCD (Salkovskis & Kirk, 1989) and tends to neglect to consider children within the systemic context. The role of the family in the maintenance of both adult and childhood OCD at a cognitive behavioural level is evident within the model but specific consideration of cognitive styles of the family system and any cognitive change across treatment is more limited. Additionally, it may be interesting to consider the role of involving family members in CBT treatment and the impact on the cognitive formulation structures of family members (e.g. parental and sibling cognitions / schemas) and how this relates to the

success of children achieving the ability to reformulate their cognitive appraisal of the world and ultimately OCD.

Finally, given the variability in methodology across studies, the percentage reduction in symptom severity was used to compare across studies. This is only one way of evaluating effectiveness and what may have been more useful would have been the clinical significance of change and the percentage of those achieving an asymptomatic diagnostic status or falling below the clinical range. However, not all studies reported such data and so it was not possible to compare the studies on this level.

7.3 Clinical Implications

This review has examined the research literature to describe the way in which families have been involved in CBT treatment for childhood OCD. It then followed with a critical evaluation of the way in which family involvement facilitates CBT treatment and the impact this has on families.

A review of studies suggests that there are various ways to involve families in CBT treatment and that such involvement could be divided into separate family involvement, joint family-child involvement and a combination of joint and separate. Whilst all studies seemed to emphasise the importance of the family receiving psychoeducation about OCD and in the majority of studies,

learning the same CBT skills to help the child challenge and cope with OCD; additional potential benefits arose as a function of the nature of the way families were involved in treatment.

Sessions that provided parents and / or siblings with separate time from the child with OCD provided an opportunity to family members to obtain support for their anxieties, concerns, difficulties, guilt and blame (of self and / or the child with OCD) from trained professionals and from other parents and / or siblings. Whereas sessions that facilitated joint family involvement seemed to provide an opportunity for families to observe the child begin to engage in ERP tasks in-session and to enable family members to tolerate their own anxieties around facilitating the child to engage in ERP, tolerate the resulting distress and make sense of the experiment in a CBT framework.

Furthermore, whilst the child and family are expected to engage in attempting to change their behaviour, the family member attending the treatment sessions is implicitly expected to translate this understanding and rationale to the other family members. Maximum attendance in family sessions may enable family members to feel more immersed in the treatment and have the opportunity to gain the confidence in their knowledge to disseminate this to other family members who did not attend. More understanding is needed to know how best to support family members in taking such a role and the impact this role has on them.

The review has highlighted the need to understand who best to involve in treatment and who constitutes family. Furthermore, this extends to the consideration of addressing potential differences between parents and other family members in their response to the child's OCD and potential difficulties in engaging family members that may be considered to fall within the style of relating termed 'high emotional expression' such as critical comments, emotional over involvement and hostility, implicated in families of children with OCD (Leonard et al., 1993; Hibbs et al., 1991; Przeworski et al., 1999). Such family members may be difficult to engage but may be important to the outcome of treatment. Similarly, with family members who are deemed 'over-protective' or resistant to taking a role in supporting ERP tasks, additional support to foster understanding of the importance of such a component in treatment may require further separate involvement away from the child with OCD. It may be useful to consider the systemic family therapy literature in order to address such concerns.

7.4 Recommendations for Service Providers

The present review has highlighted the trend towards greater symptom improvement in treatments that provide separate family sessions compared to those utilising joint sessions only. Furthermore, studies using a mixture of both joint and separate sessions potentially demonstrated the largest impact on treatment outcome and showed clinical and statistically significant

change. A mixture of approaches may enable families to enhance their ability to act as co-therapists to support the child to generalise treatment effects at home through joint sessions and to address additional systemic, family coping and functioning issues through separate sessions.

Whilst conducting separate family sessions may potentially lead to an increased cost in clinical time, the gains of involving families in such a way may enable longer term effects and address wider issues not possible through solely joint sessions. A way to address this issue may be to conduct group CBT for the families of children with OCD which may reduce the cost on clinical time and provide additional group effects such as normalisation and peer support for families of children with OCD.

8.0 SUMMARY AND CONCLUSION

The present review has been conducted to evaluate the effect of the involvement of families in CBT treatment for childhood OCD. Whilst the NICE guidelines advocate the involvement of families in treatment, there has been little systematic review of the impact of involving families. The present review has considered the available empirical evidence and structured the studies that involve families in treatment in terms of studies that utilise joint child-family sessions and those that use both joint child-family sessions and separate family sessions away from the child. There were no studies that

used solely separate family sessions. The review findings suggest that whilst all studies demonstrated clinically significant change in symptom severity, studies that utilised a mixture of separate and joint child-family sessions demonstrated the highest improvement overall. The findings are discussed in light of methodological considerations and recommendations for future research are highlighted. The clinical implications of the findings and recommendations for service providers are discussed.

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Chapter Two

The Experiences of Children and Young People with Obsessive
Compulsive Disorder: Perceptions of Living with the Diagnosis

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ABSTRACT

Psychological research into Obsessive Compulsive Disorder (OCD) in children and young people has developed from the adult OCD literature and has enabled insights into our understanding of the aetiology, treatment and prognosis for children and young people. However, there is a lack of research exploring the perspective of children in their experience of living with a diagnosis of OCD. Therefore, this paper aims to understand the experiences of children and young people in living and coping with Obsessive Compulsive Disorder (OCD) and engaging in psychological treatment. Utilising a qualitative approach to offer a psychological interpretation on children's experiences of OCD, this paper will discuss three major themes found across the experiences of seven children aged 11 to 15 years. Three major themes were identified which were; "control", "the emotional consequences of OCD" and "OCD and relationships". Clinical implications, methodological limitations and recommendations for future research are discussed.

10.0 INTRODUCTION

10.1 Obsessive Compulsive Disorder in Children and Young People

Obsessive Compulsive Disorder (OCD) is an anxiety disorder seen in adults and children, characterised by the presence of obsessions and / or compulsions. Obsessions are defined as “persistent ideas, thoughts, impulses, or images that are experienced as intrusive and inappropriate and that cause marked anxiety or distress”. Compulsions are defined as “repetitive behaviours or mental acts, the goal of which is to prevent or reduce anxiety or distress, not provide pleasure or gratification” (American Psychiatric Association, 1994, p.418). The compulsions tend to obey strict rules, yet the association between the compulsion and the act they intend to neutralise are not connected in a realistic way or are excessive in nature (Carr, 2004).

10.2 The Impact of Obsessive Compulsive Disorder on Children and Young People

For young people with Obsessive Compulsive Disorder (OCD), the content of the young person’s obsessions can result in significant distress. Belief in the likelihood of a severe fearful outcome such as death, damnation or permanent separation from a loved one is not uncommon. The content of the

obsession can often violate the core values of the young person or can relate to age appropriate developmental fears (Leonard et al., 2001) such as sexual and religious fears in adolescents or separation from parents in younger children.

As with adults, the tendency for young people to overestimate their responsibility in the prevention of harm can lead the young person to become extremely preoccupied with their compulsions which become elaborate and time consuming. This can impact on the immediate daily functioning of the young person in simple daily tasks such as washing, dressing and eating. The debilitating and ongoing nature of OCD has a significant impact on the development and general functioning of the young person over time at school, home and with their peers. (Freeman, Choate-Summers, Moore, Garcia, Sapyta, Leonard and Franklin, 2007). The impact of OCD on a young person can lead to significant negative affect, mostly anxiety but children may also report guilt, sadness and anger (Turner, 2006).

Children with OCD may have impairments in academic performance (Freeman et al., 2003; Thomsen, 2000; Piacentini, Bergman, Keller & McCracken, 2003) associated with difficulties concentrating or from frequent school absence. Difficulties in social development resulting in social withdrawal, difficulty sustaining friendships and rejection from peers all contribute to added distress for the young person.

The family life of young people with OCD can be affected by increased stress within the household; with feelings of guilt, blame and frustration (Barrett, Shortt & Healy, 2002; Steketee & Van Noppen, 2003; Cooper, 1996). Studies examining the dynamics within the families of a young person with OCD highlight parents with reduced confidence in their child's ability, reduced use of positive problem solving and less allowing of their child's autonomy. Also, the young people with OCD demonstrated less confidence, showed less warmth to their parents and were less likely to use positive problem solving (Barrett et al., 2002).

High "expressed emotion" such as critical comments, emotional over involvement and hostility are implicated as factors in families with a young person with OCD (Leonard et al., 1993; Hibbs et al., 1991; Przeworski et al., 1999). Whilst it is unclear whether such family dynamics are causal factors it is likely that they may be maintenance factors if not at least additional stressors. Involvement from adults and siblings in the young person's compulsions is not uncommon (Piacentini, Bergman, Keller & McCracken, 2003; Derisley, Libby, Clark & Reynolds, 2005) and can lead to the development of OCD as a 'family illness' (Wagner, 2003).

Piacentini et al., (2003) examined the impact of OCD on young people over three domains; school / academic, home / family and social functioning. Their findings are consistent with previous adult research and highlight an adverse

impact of OCD on everyday functioning. Specifically, they found 85% and 88%, of young people and parents, respectively, reported a significant problem in at least one domain of functioning, whilst 44% and 46% of young people and parents, respectively, reported at least one significant problem in each of the domains of functioning.

In the same study, Piacentini et al., (2003) demonstrated differences between the reports of parents and young people's views of the impact of their difficulties. Using the Child OCD Impact Scale (Piacentini & Jaffer, 1999), the authors found that parents reported higher prevalence of impaired functioning than young people for 33% of items, whilst young people reported higher rates than parents on 13% of items. The differences in the views of young people centered on those aspects most hidden from the parent such as mental compulsions and incidents in which the parents were not usually present. This highlights the importance of listening to the views of young people so that valuable information is not neglected.

The literature highlights the negative impact that OCD has on young people in their immediate daily functioning and the long term impact on development; academically and socially. However, whilst this has provided researchers and clinicians with a further understanding of those factors we deem relevant to furthering our work with young people, the literature neglects the perspective of the young person in their lived experience of

OCD. Therefore, we may be missing information about what young people deem relevant and important in their experience of OCD.

10.3 Coping in Young People with Obsessive Compulsive Disorder

The distressing and chronic nature of OCD in young people and the delay in accessing help common to many young people means that many develop their own ways of coping with their difficulties. Some attempts to cope may ultimately worsen their difficulties, in that it becomes a necessary part of their compulsions, such as reassurance seeking, enlisting the help from other people in completing compulsions, and cognitive strategies such as thought suppression.

Other methods of coping may help the young person cope with difficulties in daily functioning such as attempts to distract themselves through other activities (Swedo, Rapoport, Leonard et al., 1989). Young people are usually considered to have good insight into their condition (Heyman, 2005), yet may deny knowledge of the reason they perform their compulsions (Robinson, 1998). Whilst it is possible that such denial may arise as a result of children's lack of awareness, it is possible that denial may be due to secrecy as a way of coping with embarrassment (Leonard, Lenane & Swedo, 1993, Rapoport et al., 2000) or wishing not to appear 'different'. This highlights the level of coping that young people have to attempt to develop so that they may deal

with the primary impact of the disorder and the secondary impact on their social and emotional wellbeing.

Despite the delay in accessing help in dealing with OCD, young people can learn to cope and manage their symptoms through psychological intervention. However, there is a lack of information exploring how young people do this. The literature suggests that young people attempt to develop ways to cope with their difficulties and are able to successfully utilise psychological interventions but little is known about their experience of this process. A study (O'Neill, 1999) that explored the experience of a female adult aged 32 years with OCD who was diagnosed at the age of 20 years, revealed that her sense of self and her identity were highly linked with her experience of OCD. This would have important implications for young people who are still developing their sense of self and identity yet, due to limited research into the experiences of young people, little is known about how the identity and sense of self is affected by OCD.

O'Neill (1999) focused on the way in which the client described her experience and the interpretation of her understanding of herself and OCD. Whilst this would be a useful process to explore with young people, the capacity of a young person for such self reflection may be limited due to their level of cognitive maturity. However, as O'Neill (1999) demonstrated, the way in which the person describes their experience can provide useful insights

into their understanding and coping and most importantly this insight will come from the person in their lived experience.

An informative and insightful attempt to explore the experience of a young person with OCD is a book written by a young person with OCD (Wells, 2006). It discusses the impact of OCD, coping and experience of medical and psychological intervention. Whilst this is unique in its illustration of the lived experience of a young person with OCD, it would be useful to explore the views of a number of young people with a variety of demographic variables. Additionally, the aim of the book was an informal and informative account of a young person's experience of OCD which is likely to have been edited for publication. Whilst Wells (2006) facilitates the opportunity for the views of a young person to be heard, if the information had been subjected to a thorough qualitative analysis this should minimise the impact of the researcher's bias in interpretation.

10.4 Children and Young People's Experiences of Obsessive Compulsive Disorder

Understanding of OCD in young people is continually developing with adaptations from the understanding of OCD in adults and through new research with young people. Quantitative studies further illustrate specific domains of deficit in development and highlight the impact of OCD on young

people. However, whilst the quantitative studies use information gathered from the young person and those who know them, this is largely gathered using structured questionnaires. Little is known about the experience of the young person from their perspective and in their own words. Furthermore, little is known about the psychological interpretation of their experiences both in understanding OCD and of receiving psychological treatment.

11.0 RATIONALE FOR STUDY

Whilst the literature on OCD in young people consistently describes it as a debilitating condition, there appears to be a lack of research investigating how this is experienced by young people. Mostly, the literature in this area focuses on the phenomenology of OCD as observed by others rather than the experience from the perspective of the young person. Largely, this is gathered through quantitative methods or relies on the accounts of professionals' views of the experiences of young people with OCD. To the knowledge of the author, there are no studies that explore the perspective of the young person in their lived experience of OCD. Specifically, there is limited research examining the experiences of young people with OCD in their attempts to understand and cope with OCD. The present study aims to provide the first psychological interpretation of the experiences of young people with OCD.

The value of qualitative research in enabling important insights into the subjective experience of people with mental health problems has been demonstrated in informing further research and clinical practice (Nicolson, 1992, 1995 as cited in O'Neill, 1999). Therefore, the present study may enable new insights into the views and experiences of young people that may inform research and clinical application such as assessment, intervention and long term outcome. Despite the useful implications of research in this area, this has not been examined in young people with OCD.

11.1 Aims of Study

Given the lack of research in this area the present study aims to further understanding by exploring the experiences of children and young people with Obsessive Compulsive Disorder. Specifically, the aims are:

- to explore young people's experiences of OCD within a psychological framework
- to increase understanding to guide clinical practice

12.0 METHODOLOGY

12.1 Participants

The sample consisted of seven young people aged 11 to 15 years (mean = 13.4) referred to a Child and Adolescent Mental Health Service (CAMHS) for difficulties with Obsessive Compulsive Disorder. Six participants were female and all of a white British ethnicity.

All participants were recruited from one Child and Adolescent Mental Health Service. All were referred for treatment for OCD; six participants had received group CBT and one participant had received individual CBT. The inclusion criteria for participation in the study were primary diagnosis of Obsessive Compulsive Disorder as per the DSM-IV criteria (APA, 1994) and aged between 11 and 17 years. Participants were excluded if they had a learning disability of the severity that they were unable to communicate their views or understand the requirements of participating in the study.

12.2 Design

The present study used qualitative research methodology in which semi-structured interviews were conducted with all participants. The interviews explored the experiences of children and young people in living and coping

with Obsessive Compulsive Disorder. The qualitative methodology of Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2003) was used to guide the data collection and analysis.

A qualitative design using a semi-structured interview is the most appropriate method for this study, for it values the subjectivity of human experience and will allow for a rich exploration of the perceptions of young people with Obsessive Compulsive Disorder. It does not require quantified or tightly defined hypotheses and so provides the opportunity for a more complete understanding of the topic area. This open and exploratory approach was particularly important considering the lack of previous research in this area.

12.3 Measures: Semi-Structured Interview

The interview schedule (see Appendix G) was designed based on recommendations by Smith and Osborn (2003). Questions were developed in conjunction with clinicians experienced within the research area and aimed to capture a wide range of areas that OCD may impact upon, based upon the relevant literature. The interview schedule was used flexibly to facilitate the participant to determine the direction of the interview and specific questions were asked in response to the material raised by the participant.

12.4 Procedure

12.4.1 Ethical Approval

Ethical approval for the study was granted by Coventry University Ethics Committee, NRES and Coventry Research and Development Department (see Appendix B)

12.4.2 Recruitment

Clinicians within the CAMHS team identified and contacted (see Appendix D) potential participants in line with the inclusion criteria for the study and obtained verbal consent for the researcher to send a participant information sheet to participants (see Appendix D). Additionally, as all participants were aged less than 16 years, an additional information sheet was sent to their parents (Appendix D). In line with The British Psychological Society's Code of Conduct (BPS, 2006; section 1.3), as participants were aged less than 16 years their parents were asked for written informed consent and the participants were asked for written assent. Participants were made aware that the interview will be tape-recorded when asked to give informed consent (see Appendix E).

The interviews lasted for one hour with breaks where needed. They were conducted in the participant's home or in a private room at CAMHS. The choice of location was considered with the participants and based on the best way to enable the participant to have a private space to speak freely. Participants were provided with the opportunity to make further comments, discuss emerging issues or ask questions at the end of the interview. They were debriefed using information provided in the debrief leaflet (see Appendix F) which contained the details of people or services they can contact if they become distressed after the interview. The tape recorded interviews were transcribed verbatim and any identifying information was removed (see Appendix H for example transcript).

12.5 Data Analysis

12.5.1 Qualitative Data Analysis

The transcripts were analysed to capture the experiences of children and young people with Obsessive Compulsive Disorder in living and coping with their diagnosis and receiving psychological intervention. The aim was to develop a psychological understanding of the meaning of their perceptions and experiences.

Interpretative Phenomenological Analysis (IPA) was used to analyse the data. This approach was chosen for it aims to explore the meaning of an experience for an individual from their perspective and the aspects of that experience that they hold to be important. (Smith & Osbourn, 2003). It is concerned with the capture of the quality and texture of individual experience and therefore it is useful for a topic area with limited research, where the emphasis is on model building rather than model testing.

IPA derives its data from texts and so is suited to the analysis of the transcripts of semi-structured interviews. It emphasises the importance of open ended and non-directive questions to limit the impact of the researcher's perspective on the data collection, therefore increasing the understanding of the individual's perspective on their experience.

The participant's transcript was read through by the researcher and the data analysed in accordance with IPA guidelines (Smith & Osbourn, 2003) (see Table 3. for IPA guidelines and Appendix H for a sample transcript with an illustration of data coding). This involved the interpretation of the data into themes and super-ordinate concepts referenced to the transcript text (see Table 4 for summary of identified themes).

12.5.1 Position of the Researcher

The researcher who conducted the analysis is a trainee clinical psychologist with a preference for psychodynamic working. This may have meant that the researcher had a particular interest in thinking about the data analysis from such a perspective and focusing on the underlying nature of conflicts within the internal world of the participants and the way in which they impact on relationships. However, a process of data triangulation was conducted which involved the repetition of the steps of the IPA guidelines (see Table 3) by the research team and other professionals familiar with IPA to check validity of coding. This should have minimised any bias or over emphasis towards a particular theoretical or overly personal perspective.

Table 3: Guidelines for Using Interpretative Phenomenological Analysis

(adapted from Smith & Osborn, 2003)

Step	Description of Process
Step one:	The first transcript is read a number of times and notes are made in the left margin commenting on significant or interesting comments expressed by the participant
Step two:	The transcript is re-read and potential themes which capture the essence of ideas spoken by the participants are documented in the right hand margin
Step three:	The emergent themes from step two are listed chronologically. Relationships between themes are examined and connections between themes are tentatively sought
Step four:	<p>Themes are clustered and superordinate themes are identified for each cluster</p> <p>The interpretative resources of the researcher are utilised, alongside continuous checking to ensure the list of themes and clusters identified are internally consistent and justified by the raw data from the transcripts</p> <p>A table to illustrate the cluster of themes and superordinate themes is produced</p>
Step five:	<p>Steps one to four are repeated with subsequent interview transcripts. Themes from transcript one can be used as a guide, or alternatively the process can be started from scratch with each transcript</p> <p>The process is cyclical, whereby previous transcripts are re-read and ideas are modified in light of emergent ideas from the other transcripts</p>
Step six:	A final table of superordinate themes is created. Themes to focus upon are selected not only on prevalence within the transcripts, but also the richness of text which highlight the theme and those which illuminate other aspects of the participant's account

13.0 FINDINGS

Three superordinate themes were identified from the data analysis: “Control”, “Emotional consequences of OCD” and “OCD and relationships”. The themes along with their subordinate themes are shown in table 2. Superordinate themes, along with their subordinate themes are described and illustrated with quotations from the interviews (*in italics*). The source of the quotation is identified by the participant’s research identification number, followed by page and line numbers of the transcript.

Table 4: Identified superordinate and subordinate themes

Superordinate themes	Subordinate themes	Frequency
Control	Conflict: OCD vs. Societal Reality	N = 7/7
	The Power of OCD	N = 7/7
	The Battle: Regaining Control	N = 7/7
Emotional consequences of OCD	The Pressure of OCD	N = 6/7
	Self Image, Difference and Shame	N = 7/7
OCD and relationships	Disguising the Secret	N = 7/7
	Trusting and Relating to Others	N = 7/7
	Impact of Treatment on Relationships	N = 7/7

13.1 Superordinate Theme 1: Control

This cluster of themes was present across all of the accounts and comprised three components; conflict, the power of OCD and regaining control. Participants frequently refer to aspects of control when talking about their experiences of OCD. This involves the control that OCD has over their lives and how this interacts with societal demands during their day to day functioning, the perception of OCD as an external being that takes over and the power it has to do this. The participants describe the way in which they realised they needed to regain control over OCD, the barriers to obtaining such control and the influence of treatment and others in this battle.

13.1.1 Subordinate Theme 1: Conflict between OCD Reality and Societal Reality

A strong component across the accounts of participants was a conflict between two views of reality; the view of the world from the perspective of OCD compared to common-sense societal reality.

“well you just have to try and look at things logically, touching something three times isn’t going to make a difference yet you still believe it. You carry on doing it and know it’s a lie as well ... it makes you feel safe, it gives you that feeling after you have done a compulsion, you feel relaxed again it’s the only thing that calms you down but when you think about it really it’s the thing that winds you up in the first place. That’s it, really it makes you feel safe. It makes a lot of sense to you, it doesn’t to anyone else really, but it does to you” (P4; 128)

Participants were aware that in addition to making little sense to others, the behaviour that they were compelled to perform appeared trivial or stupid to others and conflicted with societal expectations. However, for the participant, the cost of performing the behaviour was outweighed by the potential benefit as seen from the perspective of OCD reality.

“that [compulsion] was noticeable ... and like I felt people were looking at me but it was like okay because I thought at least something bad won’t happen”
(P3; 101)

13.1.2 Subordinate Theme 2: The Power of OCD

Participants described that OCD had a power to control them with threats that played on their fears and insecurities; for most this involved fear of loss, harm or illness of significant others, but for some this was a loss of their own sense of self or personality. In addition to threats, OCD was associated with a promise of security, safety and protection for themselves or their loved ones if they comply. One participant described the alluring nature of complying with OCD demands for the promise of security in her future:

“it makes [the future] look lovely, but then I have to do something to make sure its lovely. I remember I had this routine with the towels in the bathroom. I had to touch them eight times and each touch I had to think of the sections in my life, say like being in college all happy, being married to having kids and all that. So basically I think about it and suddenly it disappears and then it’s like “well you’ve got to do this to make sure that will happen” (P4; 526)

Participants described OCD as an external being which they perceived as 'taking over' them; for some this was as a result of perceiving intrusive thoughts or physiological sensations as alien to the self.

“yeah kind of like someone took over as soon as I was doing my routines and after I was like ‘why did I have to do that’ and then as soon as it comes again its always thinking ‘I’m stupid’ for doing that but then as soon as it gets to it its like ‘you have to do it’ (P5; 233)

another participant described a character to the OCD identity:

“it’s like an evil leopard that speaks inside my head, even though I think ‘no I’m not going to do it’, [but] it just makes me do it ...well in an evil voice he will like go like ‘if you don’t do this you will get a migraine the next day’ ... like Darth Vader or something ... scary!” (P1; 611)

The power of OCD is demonstrated by this quote in which the participant talks about the persistence of OCD in convincing them to conduct the compulsion:

“the voice in your head, it’s telling you it’s alright and if you do this it will be okay but in the long run really it isn’t, and you should completely ignore it but

it's like it convinces, you convince yourself that you are doing the right thing and that it is going to keep everything safe but really its not" (P4; 78)

13.1.3 Subordinate Theme 3: The Fight to Regain Control

Participants described that they reached a point in which they could no longer cope with the demands of OCD and spoke of the way in which they attempted to fight against OCD to regain control; to resist its demands and ignore intrusive thoughts. Participants referred to a strength required to fight OCD. Many participants stated that experience of resisting or delaying response to compulsions gave participants more strength, confidence and self efficacy.

"when I was more weak I was more giving in to it more and just letting it take over me and taking over myself, but now I am more stronger against it so I can see what its doing and why its doing it" (P7; 229)

Participants described the strength to fight OCD that came from learning techniques to control it, particularly in gradual resistance or delay of response to conducting compulsions. This led to a sense of confidence and self efficacy:

“it’s helped a lot, as it’s gradually helped me to build more confidence and a bit more confidence to stop against it and push it away and make it less stronger than it was in myself ... like with the techniques that they use like putting it off or saying no to it, or thinking about whether would touching the table actually change anything at all or actually change the situation” (P7; 361)

The strength to battle OCD appeared to fluctuate and participants stated that tiredness, life events or stressors and boredom, led to a weakness in themselves in which they found it hard to control OCD. The unpredictable nature of the occurrence of intrusive thoughts was difficult for many participants to manage for it meant they had to remain on guard to be ready to control it at any time. This was especially difficult for those whose compulsions had become integrated with habitual daily activities, often performed without awareness. When attempting to control OCD one participant described the way in which OCD led them to feel guilty for wishing to stop:

“horrible, constantly makes me feel selfish and guilty. If I don’t want to do something [a compulsion] it’s like ‘stop being lazy, you know it doesn’t take long to touch something three times’ erm it makes me feel useless” (P4; 486)

Many participants felt they were more able to control OCD if they were expected to do so in a gradual manner. This appeared to enable participants to gain a sense of experience and confidence to tackle compulsions that they found more difficult:

P: "start with the little [compulsions] first because that's quite hard at first if you haven't done it before and after you have got stronger and got your armour on and everything then you can start doing like the [habitual] ones"

R: "you say armour?"

P: "yeah like you are strong!" (laughs)

R: "so how do you build this armour up?"

P: "by experience" (P7; 405)

When reflecting on her personal growth in confidence and experience in beating OCD, one participant describes how incomprehensible such a change seemed to her at the start of treatment. There is a real sense of personal achievement and personal mastery over OCD.

"yeah I feel like I can actually understand it more and I can actually calm it down myself, I couldn't think that before and sometimes I get so much into the OCD I feel like there is no hope for it and I couldn't calm it myself and then that's when I would try to get help from other people but really that

doesn't help as you have to do it yourself, [CAMHS] told me ... you have to have the fear inside, to defeat it" (P7; 437)

13.2 Superordinate Theme 2: The Emotional Consequences of OCD

Participants frequently referred to the emotional consequences of living with OCD. The main themes which arose were about the pressure associated with OCD and the impact on the persons' sense of self; particularly in feeling different from others and ashamed of themselves or their behaviour.

13.2.1 Subordinate Theme 4: The Pressure of OCD

The pressure of living with OCD was accompanied by frustration for all participants; in coping with the constant bombardment of fears and of attempting to cope with them in addition to the pressure of daily living. The pressure of engaging in OCD impacts on the amount of resources left for engaging in other activities in life.

"I got frustrated then I started crying and then I thought I got to do it all again, again, to make sure something, everything's alright" (P2; 5)

"I used to get really annoyed and stressed and fall out with my dad because he wasn't giving me the reassurance and that and then he used to stop me

asking my mum and that's what got me upset and that's when we used to have like, not talking ... really annoying, because I just wanted to do them. But everyone was like, 'stop, you can't' so..” (5; 17)

For some the experience of OCD led to depression:

“I think it is the stress on yourself like in your head and the feelings that it puts you through well at the time, making it harder until you actually calm it down. It's just like getting really annoyed and then physically and mentally exhausted and then you just don't want to do it anymore and that's what really puts you down” (P7; 101)

Two participants spoke about reaching a point in which they felt they did not want to live:

“I don't know, running away, or dying but it was just the worst point” (P5; 453)

13.2.2 Subordinate Theme 5: Self Image, Difference and Shame

Participants spoke about a process of emerging awareness of being different to others. This was often 'discovered' or labelled by the participants' parents and led to diagnosis, which seemed to confirm a sense of 'something is wrong'.

“I wasn’t acting like everyone else ... I didn’t see my mates doing the kind of stuff I did. Erm, I don’t think anyone was thinking the kind of thoughts I was thinking and stuff like that. And my mum said “we think there is something wrong and we need to take you to the doctor” and I thought there was something wrong with me then as well” (P3; 41)

The majority of participants perceived themselves as different and believed that others would judge them as different. Participants described a sense of embarrassment or shame at their behaviour:

“I like to keep it private ... because I’m embarrassed of it ... like the stuff that I do, I think its weird, it makes me a weirdo and stuff like that ... I have been told it doesn’t and I’m starting to believe it now but I’m still embarrassed by the stuff that I do” (P3; 199)

“everyone was like “why are you doing that” so I had to tell them. And then I lost a couple, a few, most of my friends. Quite a few of them thinking I was just stupid” (P4; 33)

13.3 Superordinate Theme 3: OCD and Relationships

The third superordinate theme evident across the accounts of participants was the way in which OCD impacted on relationships. The theme comprised of three subordinate themes; disguising a secret; trusting and relating to others; and the impact of treatment on relationships.

13.3.1 Subordinate Theme 7: Disguising a Secret

Participants' sense of difference and shame led to attempts to conceal their secret for they feared that others would not understand and would judge or reject them.

“well it's like embarrassing but I don't sometimes, sometimes I hide it so it just looks like its normal. So say like I have to move something again I will just pretend it's stuck, if you know what I mean, hiding an OCD into real life but really it's me getting stressed out” (p7; 73)

“I feel like I'm going a bit mad so it's like, 'cus I feel like if I do tell anyone about the leopard [the character of OCD] then literally they'll think I'm mad and (whispered) then I'll go proper mad” (P1; 679)

Participants' attempts to disguise this part of themselves led to a pressure of 'having a secret' and became a source of additional anxiety and pressure in itself:

"I worry about it at school, 'cus everyday I think what about if they found out what about if they found out" (P1; 723)

Whilst the majority of participants feared that judgement and rejection from others, a strong component across the participants' accounts was a sense that normal childhood relationships involved the sharing of secrets and withholding such secrets was a barrier to friendship. Participants were in conflict between a pressure to conceal and disclose OCD:

"everyone was like telling secrets and they were like "have you got a secret?" and that was the only secret I had. And because I had been best friends with them for a while I thought I could trust them but I couldn't" (P3; 161)

"if they are good friends they might understand a bit I think, because they always know I have a problem with school they would probably think I'm a bit stupid and that but I didn't want to risk saying that when I was at school, because I don't want to just lose friends when I go to school so just keep quiet about it" (P5; 345)

13.3.2 Subordinate Theme 8: Trusting and Relating to Others

Participants' sense that they were different, their fear of judgement and lack of understanding from others impacted on their relationships. For some participants this impacted on their ability to trust others such as their family, friends or professionals which for some led to a sense that autonomy and independence in coping with OCD was the best solution. However, other participants described a lack of trust in themselves and their decision making ability which resulted in a sense of dependence on others, particularly manifesting itself in family participation of compulsions.

One participant described a sense of self confidence from dealing with OCD autonomously:

"I don't want to show people but then sometimes I will show my friends because then they will stop me and call me away ...It doesn't really help that much it is best to do it on yourself because then you are self confident" (p7; 81)

The same participant described the experience of the withdrawal of reassurance from a family member:

“no one else can help you, they can help with like solutions and what you could do or try but you have to do it out of your own accord. I remember last year my dad... he just left me and gradually I thought “why am I actually doing this?” ... it started off gradually and then let go. Not like “I’m abandoning you” but gradually ... seeing for myself that nothing was going to happen” (P7; 153)

Other participants described a sense of depending on their family and frequently enlisted the help of others in their compulsions:

“OCD is always about my mum like I have to protect my mum so when she is at work I find it hard to make decisions even more and what drink I can have and everything, if she’s not in the house” (P4; 29)

OCD appeared to have a negative impact on participants’ confidence and trust in themselves:

“because of my OCD I don’t like making decisions for myself in case it is the wrong one. If I didn’t have OCD I would probably be able to make more decisions and be more confident in my own decisions” (P3; 473)

13.3.3 Subordinate Theme 9: The Impact of Treatment on Relationships

Whilst coping with OCD impacted on participants' ability to trust others or themselves; engaging in cognitive behavioural treatment for OCD changed the way participants behaved within their relationships, impacted on participants' ability to trust others and required participants to learn to trust professionals and the treatment.

Learning to trust in the treatment involved trust to confide in professionals:

"I felt nervous, I didn't know what to expect I didn't know what to think and I felt really really nervous and embarrassed, I completely opened up about my biggest secret to someone that I never met before, but once I had done it, it felt so much better" (P3: 495)

It also involved learning to trust in a new way of viewing the world; to abandon the perspective of OCD and trust the perspective of the professionals and the treatment:

"it was kind of bad when they were telling me stuff that I didn't know whether to believe or not because that was really like confused ... like telling me that something bad won't happen if I don't do it; that I didn't really believe them. I thought 'well I have been thinking this for so long you cant just come in and

say it's a lie' I have been thinking it so long because it's obviously true, but they are saying 'no its not' and I felt like they were lying to me as well ... I didn't listen to them for a while but then when I went there it started to make a lot of sense" (P3: 531)

Engaging in treatment meant a change in the behaviour from others and learning to trust the professionals:

"before I went to the group my mum used to say "nah it wont happen" but when we started going the OCD group the person she talks to said ... 'don't reassure him by saying it wont happen' because you will never know if it wont happen ... but if I said it now she will say 'no I'm not reassuring you' .. I used to ask her questions and now I don't, I don't ask anything at all ... it's like they can't get involved as it's down to me to stop it ... I was actually pretty scared at the start because I thought anything could happen now and I'm used to it now because I know that nothing is going to happen" (P2; 547)

One participant described the change in her self confidence and in her dependence on her mum after treatment:

"I'm more confident, I'm more independent because I used to depend on my mum all the time and I can now just sit on my own and I got more control

over, like when I'm out with my mates I can just ignore it and it makes me feel better" (P3; 591)

There was a sense that participants learned to become more independent but without being completely autonomous from the support around them:

"I feel independent but it's nice to know that if I ever feel like I can depend on someone then I can go to my mum" (P3: 611)

Another participant spoke about the way in which treatment allowed her behaviour to be more understood by her family:

"at the start and no-one understood it at that point, they just thought I was naughty at the start and then after going [to CAMHS], after a bit they were realising and ... CAMHS were taking them through it and telling me how to deal with it" (P5; 85)

Engagement in group CBT enabled participants the experience of learning to trust other children with OCD and to talk about their experiences without fear of judgement:

"I just like talking to people who have it. That makes me, there is one girl who is just like me in many ways. I don't know, and when she was saying about

some of the things she used to do and think, I couldn't help but smile because I was exactly the same" (P4; 602)

This positively impacted on participants' sense of self and difference and provided them with a sense that they were not alone.

"knowing that other people in the group has got the same problem. So it 'aint just me, as I used to think it was just me who got it, so I realised that it 'aint just me" (P2; 485)

14.0 DISCUSSION

14.1 Summary of Findings

14.1.1 Superordinate Theme One: Control

Participants described a conflict between their thoughts, feelings and behaviours relating to OCD and the expectations of societal norms. The conflicting OCD reality was hard for participants to control; it had a power to exploit their fears, provided a promise of protection from harm and required participants to gain an inner strength to fight it. Participants spoke about the ways in which they learned to control OCD and the influence of psychological treatment in this.

14.1.2 Superordinate Theme Two: The Emotional Consequences of OCD

Participants spoke about the range of emotional consequences of coping with OCD; the pressure associated with OCD, the associated stress, depression, and anger and the impact on the person's sense of self; particularly in feeling difference from others their experience of embarrassment and shame.

14.1.3 Superordinate Theme Three: OCD and Relationships

Participants described the way in which they coped with OCD by disguising it from others from fear of judgement. Participants described the way relationships impacted on, and were affected by, OCD; particularly in relation to trusting and depending on others and the impact of treatment on relationships.

14.2 Consideration of the Findings in the Context of the Literature

To the author's knowledge the findings of the present study represent the first phenomenological exploration into the experiences of children and young people with Obsessive Compulsive Disorder. The findings of the present study support the current literature and provide additional insights to current knowledge.

14.2.1 The Impact of Obsessive Compulsive Disorder on Children and Young People

Consistent with the literature, the present study's findings indicated that children commonly experienced fear of death or separation from loved ones and that the content of obsessions related to age appropriate developmental fears (Leonard et al., 2000) and often violated the core values of the young person (e.g. being a nice person, being liked). However, fears related to sexual or religious issues were not discussed by the participants in this study, possibly due to embarrassment.

The impact of OCD on young people was consistent with previous findings (Freeman, Choates-Summers, Moore, Garcia, Saptya, Leonard and Franklin, 2007) in that children described the time consuming and preoccupying nature of OCD and the impact this had on their ability to complete tasks of everyday living such as getting dressed and going to school. Additionally, the findings suggested that the demands of OCD impacted on children's academic performance, school attendance (Freeman et al., 2003; Thomsen, 2000; Piacentini, Bergman, Keller & McCracken, 2003) and on their relationships with their peers. Although the impact of OCD on peer relationships is suggested in the literature, the strength of the secondary impact on the child's sense of self and identity has received limited attention in contrast to

the frequency and strength of impact with which it was referred to in the findings of the present study.

The findings indicated that the impact of OCD on family life was consistent with current literature; particularly with consideration of the 'high expressed emotion' (Leonard et al., 1993; Hibbs et al., 1991; Preworski et al., 1999) whereby children described overly accommodating through to overly critical or hostile responses towards their demands relating to OCD. The present study's findings suggested that some children were quite autonomous of others' help whilst others were quite dependent which may relate to the expectation of overly accommodating or the hostile or critical responses from family members. As currently discussed within the literature, it is unclear whether high expressed emotion responses are causal or reactive to OCD and similarly, it is not clear whether children's independent or dependent coping responses are causal or reactive to family responses.

The findings of the present study illustrated a sense of conflict within which the child with OCD lives in their attempts to understand the world. This involved a conflict between a common societal expectations and sense-making compared with an understanding of reality from the perspective of OCD. Living within such a conflict appeared to impact on children's self confidence and trust in both themselves and in others. Furthermore, the conflict led children to perceive themselves as different from others in which

they did not feel understood and feared judgement and rejection. Whilst the current literature acknowledges the impact of OCD on the self esteem and psychological functioning of children in terms of self esteem, anxiety and depression (Turner, 2006) it is not clear how such a conflict impacts on the child's sense of confidence, self esteem or identity.

14.2.2 Coping in Children and Young People with Obsessive Compulsive Disorder

Consistent with current literature, the findings of the present study indicated that children attempted to cope with OCD by enlisting the help of others in conducting compulsions and in reassurance seeking (Piacentini, Bergman, Keller & McCracken, 2003; Derisley, Libby, Clark & Reynolds, 2005). However, the findings indicated that 6 of the 7 children attempted to cope with OCD in an autonomous manner, potentially arising as a result of feeling different and not understood, whilst others were very dependent on significant others, potentially arising from a lack of confidence in their own sense of self and decision making.

The current literature on children's experiences of engaging in psychological treatment is limited and the present findings suggest that treatment impacted on children's sense of self, and their relationships with family members and peers. An important aspect of Cognitive Behavioural Therapy treatment for

OCD is the gradual reduction of OCD behaviours in order to enable children to test assumptions of the likelihood of anticipated consequences. The findings indicated that children found the gradual reduction of OCD behaviours enabled children to obtain a sense of mastery and self confidence to manage OCD and associated this with a sense of strength to control OCD. Additionally, children reported a change in their ability to trust in other people as a result of engaging in therapy.

Treatment required families to change their reassurance providing behaviour and their accommodation of compulsions. The findings suggested that children had good insight into OCD (Heyman, 2005) and the way in which others' behaviour may reinforce OCD (e.g. reassurance seeking and accommodation of compulsions) which appeared to have come from engaging in CBT treatment. However, the findings of the present study indicate that despite children's awareness of the need for change in family members' behaviour, such change in behaviour raised issues for some children that they were being abandoned or expected to deal with OCD on their own.

Engagement in treatment involves learning a psychological formulation of OCD and the findings of the present study suggested that this required children to learn a new perspective on the world and new rules for living their lives in order to deal with OCD. However, in addition to a sense of conflict

between OCD and societal reality, treatment itself appeared to become a third component of conflict in the way in which the children made sense of the world. The implications of such conflict are discussed later.

14.3 Clinical Implications

The sense of difference and shame was evident across the accounts of participants and impacted on participants' relationships, trusting others and their fears about engaging in treatment. Given the tendency for children with OCD to conceal symptomatology the impact of their engagement and 'sharing their secret' must be more fully considered and the potential for children to explore this in therapy may be useful. Additionally, engagement in treatment may enable children to have the opportunity to learn to trust in others and the experience of group treatment may further enhance self esteem and reduce the sense of difference and shame.

The impact of treatment as a third component of conflict in children's understanding of the world must be more fully considered when delivering psychoeducation, challenging assumptions, creating graded exposure hierarchies and in sharing rules of CBT treatment. In particular, a specific rule children often reported was that psychological treatment stated they must not seek reassurance from others about their OCD. Whilst this fits a cognitive behavioural framework, the rigidity within which the rule was

adhered to within the present sample may have left children and families without a means of knowing how to obtain or provide support and comfort to their child, within the boundaries of avoiding maintenance of OCD beliefs. This may be important considering the enormity of the emotional impact the majority of children experienced in their day to day lived experience of OCD and the tendency for some children to be very autonomous in their coping strategies. Furthermore, acknowledgement of the conflict of perspectives of OCD, society and treatment may enable validation of the confusing nature of living within conflicting views of the world and may enable children to have the space to explore the impact of this on their confidence and self esteem.

14.4 Methodological Limitations and Recommendations for Future Research

Secretiveness and disclosure were discussed frequently in the accounts of children and encompassed a lot of fears and additional stress in the lives of children attempting to cope with OCD. However, the interview schedule directly asked all participants about disclosure and so this may have accounted for its presence within the accounts of participants. However, the richness of information gathered from participants and the emotional impact this had on their lives suggests that this is an important issue for children

coping with OCD and suggests that it may have emerged within the accounts without prompting.

Whilst the present study provides an account of the lived experiences of children with OCD, the findings may not be generalisable to all children with OCD. The present sample engaged in CBT treatment at the same service and may represent the views of this specific cohort of children from this service. Repetition of the study with a different population of children may provide different views of treatment. Additionally, the age of participants suggests that the sample may be moving towards independence and peer group identification which may have influenced the amount of material raised about peer relations, a younger cohort may have revealed more family related issues rather than peers.

The participants within this study had all had experience of engaging in CBT for coping with OCD. Whilst this provided insights into the role of therapy in the experiences of children with OCD, it is possible that this may have influenced the accounts of participants compared to their experiences prior to treatment. Future research with children who have not had treatment before may provide more of an understanding of how children with OCD conceptualise the world and OCD at that time, which may illuminate our knowledge of the reasons that children get to the point of requiring engagement in such a powerful dynamic in the first place.

In order to increase validity of qualitative data analysis, it is often good practice to check the validity of the emerging themes against the transcript data with the participant. However, this was not conducted as part of the data analysis in this study for such a task may have been difficult for some participants given their age. The majority of the older participants had additional academic commitments that prevented their time for validity checking.

Whilst the independent nature of the research was emphasised clearly on numerous occasions, it is possible that some children may have felt less able to speak freely about their experiences of therapy due to the primary researcher's occupation within the NHS. However, analysis of the data appeared to demonstrate that participants spoke relatively freely about their experiences and many acknowledged the confidential nature of the interview.

The present study covered a wide range of issues as a result of talking to children about their experiences. It may have been useful to explore some of the topics in greater detail, but this would have increased the length of the time that participants had volunteered and so was deemed unnecessary in this study. Further research could explore in more depth the way in which OCD impacts on identity formation and the role of secretism and a sense of difference.

15.0 SUMMARY AND CONCLUSION

In summary the present study has enabled a psychological interpretation of the experiences of children and young people with OCD. Consistent with the literature, the findings highlighted the impact of OCD on children's daily functioning and relationships with others. Additionally, by exploring the perspective of children the present study has highlighted new areas for exploration in issues of control and conflict, emotional consequences of OCD and in particular self image and shame, and the impact of OCD on relationships and trust.

Clinical implications of the findings emphasised the need to consider children's fears of difference and their sense of not feeling understood in the context of accessing treatment and the role for treatment in enabling children to trust in others for support. Furthermore, children's experience of conflict of understanding of the world must be considered when offering a new psychological formulation of OCD. Whilst further research is needed to explore the issues within a wider population, such as younger children or a sample that is treatment naïve, this study provides a number of areas in which further research could explore, so that we are able to understand children's experiences more fully to inform their psychological treatment.

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Chapter Three

Conflict within OCD: Psychological Treatment and Personal Development

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(see Appendix A for notes to contributors)

17.0 INTRODUCTION

This paper is a reflective account that will consider some of the issues that have arisen from conducting research with children with Obsessive Compulsive Disorder (OCD); a literature review paper and a qualitative empirical research study. Methodological and clinical issues arising from the research will be discussed in the context of treatment for childhood OCD. This will be followed by reflecting on the impact that conducting the research has had on my personal and professional development as both a clinical psychologist and a clinical researcher.

18.0 OCD CONFLICTS AND PSYCHOLOGICAL TREATMENT

18.0.1 The Involvement of Families in Treatment

Family involvement is regarded as a crucial factor for understanding the development and maintenance of childhood OCD and central to the fears for most, if not all, of the children was a sense of fear of loss of their loved ones. Therefore the literature review aimed to examine the available evidence for the involvement of families in childhood OCD Cognitive Behavioural Therapy (CBT) treatment. The review highlighted the variety in the way in which families can be involved in the treatment of childhood OCD and suggested

that a mixture of joint and separate family sessions may be most beneficial for highest symptom improvement.

18.0.2 Who is the Client?

Traditionally, the child is seen as the client in receipt of the service and the family are involved in the treatment to a greater or lesser degree in order to support the child. However, within some CAMHS teams, services may have more of a systemic view to psychological difficulties and view the family as the client, without attributing the 'blame' for the psychological difficulty on any one member. Whilst listening to the research interview accounts I found myself considering such a role for many of the families and being aware of areas deemed important in family systems such as family conflict, hostility and over-protectiveness that are referred to as 'high expressed emotion' (Hibbs et al., 1991) that may benefit from more of a family-focused therapeutic approach.

During the evaluation of the research literature of the literature review paper I found myself more strongly of the opinion that the family should be seen as the client and that therapy should aim to address such wider systemic issues. Particularly, those of the judgements from family members as to who is to blame, the seriousness of the problem, and in working on supporting family

patterns of communication, and support that fosters trust and understanding within the family.

Furthermore, family involvement is paramount to the CBT treatment of childhood OCD for the treatment inevitably involves some form of change within the family context; most often in helping families to resist the temptation to reassure the child, and to resist the accommodation of their child's compulsions. It is important that families are fully involved in the treatment rationale and are engaged in the monitoring and feedback of treatment, for we cannot rely on children to relay this information to their families. Equally, we cannot expect families to be equipped to take on such a role and so it is essential that families are offered the support to take on such a challenge. This is especially important with consideration that many family members are likely to be very much part of the problem and so it is necessary to address such issues as blame (self, child or others), guilt, frustration, over-protectiveness and antagonistic communication to facilitate change within the family system.

18.1 The Wider Systemic Network

Whilst writing my literature paper I was immersed in considering the role of families in the treatment of childhood OCD. However, whilst families were important in the experiences of children with OCD, there was a large

emphasis placed on the role of the wider systemic context; mostly the peer group. I was struck by the frequency with which children referred to their peer group and the associated anxiety of managing such relationships whilst coping with OCD; particularly, this arose from managing feelings of difference and shame.

Such emphasis on the peer group may reflect the developmental level of the sample, as from the age of 12 children are looking to be more independent from their families and therefore their peers are the referential group, especially considering identity formation (Carr, 1999). The experiences of the research participants indicated that coping with OCD may impact on their ability to engage in peer relationships and therefore it is important that we understand more about how to support children through this.

Given the importance to children of the wider systemic context, it is necessary that treatment consider the role for school and peer involvement in treatment. It may be beneficial for staff members or relevant peers to attend psychoeducation sessions to understand about OCD but also to understand about the role of CBT treatment for OCD. Alternatively, treatment could enable discussion with the child and family on the best way to disseminate relevant information to the wider system and to consider the best way for the system to support the treatment.

18.2 Reflections on the Role of Psychological Therapy

18.2.1 A Consideration of CBT

An important theme that emerged from the empirical paper was that of control, in which a conflict between an understanding of reality from the perspective of OCD conflicted with a perspective of the world from general society. CBT treatment aims to modify dysfunctional beliefs and faulty appraisals of OCD obsessions (Clark, 2000); ultimately, it aims to eradicate belief in the probability of harm, their responsibility to prevent it and the power of OCD to influence this. Therefore, consideration of CBT within the theme of conflict may suggest that CBT aims to deconstruct and challenge belief in OCD reality.

However, the majority of the children interviewed reported that they believed that OCD would never disappear fully and some suggested that they gained this view from CAMHS clinicians. Such a perspective of the permanency of OCD may allow children to rest in the knowledge that they will not be required to fully 'give up' OCD but can continue to subscribe to their understanding of the world from the perspective of OCD, retaining the secondary gains associated with OCD, yet learn methods to keep it under control so as not to intrude so greatly with the expectations of society.

Ultimately, this may be undermining the goal of CBT in its aim to deconstruct and challenge OCD beliefs about reality.

Furthermore, when considering the struggle between the two opposing forces and the role that families, schools, clinicians and peers play in taking sides in the battle; CBT treatment may be another object in this battle, with views on the way the child should think about the world and therefore forcing the child to choose sides in a conflict. It is important that we as clinicians question how we involve ourselves in such a dynamic and minimise the confusion for children who are already experiencing emotional reactions to OCD and to their subscription to OCD in the context of society's conflicting perspective.

Whilst a belief in the permanency of OCD may impact on the motivation of children to fully challenge OCD's assumptions of the world, I was intrigued by the readiness for children to align themselves with the OCD reality in the face of what appears to me, as a person with a belief of reality outside of OCD's perspective, to be enormous evidence to its contrary. This left me wondering about, not what the dynamic consisted of or how to eradicate one side or not, but why this dynamic appeared in the first place and what this serves for the child. Perhaps the most important question is to consider why some children have become so drawn to accept the perspective of OCD reality, and to

consider the secondary gains of such a perspective for the child and understand what treatment is attempting to remove from such children.

18.2.3 A role for Psychodynamic Thinking?

Whilst CBT has provided a useful perspective in understanding childhood OCD, a Psychodynamic perspective may enable us to consider more fully the issues underlying the reasons why children choose to subscribe to OCD. Listening to the accounts of children I perceived OCD to be a manipulative friend; something that promises all the security in the world but comes with a high price. Also it was interesting to note the way in which OCD appeared to strike at the person's 'Achilles Heel' in its threats to keep them believing they need to be signed up to cope. What has led some children to sign up to such a deal and to be so dependent on it?

I found myself identifying a sense that the children needed to subscribe to a system that enabled them to feel a sense of power and control over that which is ultimately uncontrollable; loss of loved ones. Issues that also seemed important were that of independence vs. dependence, safety and containment. Also the sense of powerlessness and being 'taken over' by OCD may relate to children wishing to hand over a responsibility to an external being. It may be important to consider such variables in the context of some children's need for a secure structure to guide their world. My

thoughts were about attachment (Ainsworth & Bowlby, 1991) and also the need for a parental figure with rules and regulations, and with praise and punishment. The power of such a dynamic is important to consider before attempting to remove this dynamic and may enable an understanding of how best to support effective treatment, without treatment becoming another figure in the battle for control.

19.0 PERSONAL REFLECTIONS AND PROFESSIONAL DEVELOPMENT

19.1 Research Experiences Compared with Clinical Experiences

One of the research participants had a remarkable similarity to a child I had worked with in the past whose obsessions led the Psychiatric team within the department to perceive this child as potentially Psychotic, a diagnosis I disagreed with. The participant I interviewed as part of my research had similar content in obsessions to my previous client and also had similar goals in life that contrasted with the obsessions. Particularly, this related to the fear that they would be taken over by OCD and this would change their personality or they wouldn't be the same person. The account could be perceived as psychotic but upon listening to the story it was possible to understand why the experience was perceived in such a way by the child. Both the participant and my previous client had come to such a conclusion for this was how they perceived the physiological experience of anxiety

attacks. Interestingly, both children enjoyed acting and wished to become actors in the future, a role in which a person has to take on another persona.

After hearing the research participant's account it forced me to think of the way in which children may become misidentified as Psychotic if their experiences and understanding of the world from the perspective of OCD reality sound so far from societal reality. Whilst the potential for a diagnosis of Psychosis should not be overlooked, it may be useful to consider the way in which the conflict of realities as described by the participants in this empirical study may provide another way of viewing such a deviation in belief from reality.

19.2 My Position as a Clinical Psychologist

The challenges that children face when attempting to understand psychological problems and engage with clinical services in order to seek help was evident through the research process and I found myself enthused by listening to the experiences of children and the potential for change to a persons life by working with them at an early age. This experience concreted my decision about the passion I have for working with children and also families.

By listening to the views of children, I was able to consider how I may improve my practice as a clinician. In future I shall not underestimate the anxiety that children face when coming to see you for the first time and the requirement for them to build up trust with you. As a clinician, I think it is easy to become desensitised to how anxiety provoking it must be to discuss your innermost personal concerns with a stranger. The interviews led me to consider more fully children's fears of whether you will be strict or whether you will think they are the strangest case you have ever seen, and their fears of whether they will forget what they are supposed to say in sessions, as reported by some research participants.

The interview accounts led me to consider the way in which children may believe their homework task is relatively easy to understand whilst in-session but then how some reported becoming confused when expected to generalise this out at home. Also, some children reported having to explain the homework task to their parents when they were not sure they knew themselves. I found myself considering how I may use this to inform my own clinical practice and wondered about how to involve parents in this, perhaps children could be asked to summarise the learning from the day's session and present it to parents if and when they joined the end of the session. This would enable the child to synthesise what they had learned, identify any gaps or questions that could be addressed before the end of the session and would provide parents with an update and the opportunity to ask questions.

The insights from the interviews enabled me to realise that it is easy to lose sight of how hard engaging in CBT is for children to complete when balancing the demands of home life and school work. Previously I had been aware of the difficulties in getting children to complete homework and had considered this in terms of motivation, but listening to the accounts of the children I shall be more mindful of considering the therapeutic task in the context of other work the child has to complete. Also, I shall consider the role of families in homework completion for if families are not on board then this can conflict greatly. What came across from the interviews was a sense of children feeling low self esteem for their lack of success at controlling OCD. I shall be more mindful of this when a child comes to their session having not completed their homework task and consider the emotional impact of this on the child, especially within a participant group who has high standards for achievement and a sense of responsibility for themselves and those closest to them.

19.3 My Position as a Researcher

Initially the process of conducting an interview as a researcher felt in conflict to my role as a clinical psychologist and I found myself wanting to reflect on issues raised and to give something back to the child to support them with their OCD. I learned to be more comfortable in my role as a researcher and to enable myself to have a different relationship with the children, one in

which they were providing potentially useful insights to guide clinical practice, rather than being there for their own support.

I learned to allow participants to do more of the work and felt the need to jump in and rescue less. This is an important skill for my role as a clinical psychologist in working with clients in the therapy room. I found that by providing the participants with a chance to demonstrate their opinions and trusting in their ability to do so, I was rewarded with unique insights and it enabled me to grow in my own confidence in interviewing skills. Whilst I had been learning how to do this over the course of my three year training on clinical placements, I found that the urge was quite strong with this population. This may be due to my anxiety on taking a researcher role and also perhaps due to the anxiety of the children who I was interviewing.

Throughout most of the research process I found I enjoyed the opportunity to examine an area in depth and to question issues I hadn't considered before. I believe that the scientist-practitioner role of a clinical psychologist allows the research to be more fully informed by the context of the clinical world and too strengthens the practitioner's ability to be critical of the evidence for their own practice.

19.4 Transference from the Interview Data

I found the analysis process very interesting and felt that it fitted with my preference for an analytic style. Whilst analysing a participant's interview that described fears of contamination from food, I became very aware of contamination from raw meat whilst preparing food myself. I consider myself to be relatively unconcerned by worries of infection and contamination overall, but am more naturally inclined to be careful about contaminating food surfaces in the kitchen when preparing raw meat. On this occasion I noticed an exaggerated sense of awareness and extreme hypervigilance to contamination and frequently washed my hands.

Additionally, I noticed how I attempted to encourage my partner to ascribe to the same methods and felt concerned when he did not follow suit. I was aware of feelings of needing to take entire responsibility for the both of us and the feeling of not being believed or over-reacting. Furthermore, I was somewhat alarmed at having such thoughts for I hadn't experienced this before. I became very aware of the sense of a fear that I could be taken over from OCD and also a sense that once such thinking had entered my mind it would be very difficult to unlearn it.

This experience enlightened me to the fear that children have in such an external force that may take over and dominate their lives, and the impact

this can have on relationships. Thankfully, I have not had this experience again and find it interesting that it occurred only around the time of coding the data of a participant who was very concerned by contamination from meat. Psychodynamically, this is considered to be transference (Malan, 2001) that is invaluable in informing understanding of client's experiences, something I have become more able to utilise through working this way in clinical placements.

20.0 CONCLUSIONS AND SUMMARY

Conducting research with children with OCD has enabled me to more fully consider the experiences of children with OCD that may enable insights for future research and guide clinical practice. Additionally, in reviewing the literature of the childhood treatment of OCD and considering the effect of involving families in treatment has enabled me to see the importance of their involvement but also the difficulties in involving families. The experiences of children points towards a conflict between an OCD reality and societal reality and it may be important to consider the role of treatment within this context. My personal experience of working with children informed and is informed by this research process and I feel I have learned a lot about the experience of OCD and the role of treatment for children. I aim to take this learning forward to influence my future clinical practice and I hope to continue with research in this field in the future.

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APPENDICES

Appendix A: Notes for Contributors

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Manuscript processing

Refereeing

The *Journal* has a policy of anonymous peer review and the initial refereeing process seldom requires more than three months. Most manuscripts will require some revision by the authors before final acceptance. The Editorial decision on the suitability of a manuscript for publication is final.

Proofs

Proofs will be sent to the designated author only. These will be sent via email as a PDF file, and therefore a current email address must be provided with the manuscript. Only typographical or factual errors may be changed at proof stage. The publisher reserves the right to charge authors for correction of non-typographical errors.

Offprints

The designated author will receive a PDF file of their article. The designated author should undertake to forward copies of the PDF file to their co-authors.

Copyright

Exclusive Licence Form

Authors will be required to sign an Exclusive Licence Form (ELF) for all papers accepted for publication. Please note that signing the Exclusive Licence Form does not affect ownership of copyright in the material.

Advice for NIH authors

JCPP and Wiley-Blackwell will support NIH funded authors by posting the accepted version of articles by NIH grant-holders to PubMed Central upon acceptance by the journal. The accepted version is the version that

incorporates all amendments made during peer review, but prior to the publisher's copy-editing and typesetting. This accepted version will be made publicly available 12 months after publication. The NIH mandate applies to all articles based on research that has been wholly or partially funded by the NIH and that are accepted for publication on or after April 7, 2008. Please let the editorial office know that you are an NIH-funded author when you submit your article.

Alternatively, any author wishing to publish their article open access can do so using our author-pays Online Open service - please see details below.

Instructions to Authors for Clinical Psychology Forum

Guidelines for Contributors

Clinical Psychology Forum (CPF) welcomes contributions which are **original, innovative and of interest to the membership of the Division**. We aim to publish a variety of contributions ranging from personal reflections on clinical practice to critiques of current health policy, innovations in service development and audit and research studies. We also publish **correspondence** either regarding articles published within CPF or around issues of general interest to the membership.

Articles submitted to CPF will be sent to members of the editorial collective for refereeing. Reviewers will assess each contribution in relation to the manuscript's clarity and economy of expression, its critical and analytic stance, whether its original or innovative and, where appropriate, that methods and results are well described, methodological sound and any conclusions drawn are valid. Overall, articles must be relevant and of interest to the profession. The reviewer shall then communicate directly with the authors.

Articles of **1000-2500 words** including references are welcomed. If you feel an article longer than 2500 words is justified please state the reasons in an accompanying letter and these will be considered by the reviewer.

Please **e-mail one electronic copy and post one hard copy** of your contribution (details below). Please ensure that your **contact details, current employer and job role** are included in case the editors need to contact you.

When sending copy, make sure it is double spaced, in a reasonably sized font (no less than 11 point) and that all pages are numbered.

Give a 40-word summary (maximum) at the beginning of the paper.

Include the first names of all authors and give their affiliations, and remember to give a full postal address for correspondence.

Contributors are asked to use language which is **respectful and psychologically descriptive** rather than medical, and to **avoid using devaluing terminology**; i.e. avoid clustering terminology like 'the elderly' or medical jargon like 'patients'. In addition, language should conform to the Society's guidelines on non-sexist or discriminatory terminology. We acknowledge that language is context specific and that occasionally authors may wish to justify the use of particular terms commonly adopted within specific contexts. Please include any such qualifications within an accompanying footnote.

We reserve the right to shorten, amend and hold back copy if needed.

Include a word count at the end (including references).

Spell out all acronyms the first time they appear

Give references in the format set out in the Society Style Guide. This can be found on the Society's website. If a reference is cited in the text, please make sure it is in the list at the end.

Do not include tables and figures unless they are **essential** and save space or add to the article. All figures should be in black and white.

Ask readers to **request a copy** of your questionnaire from you rather than include the whole of it in the article.

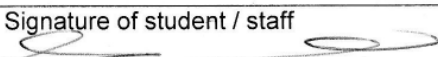
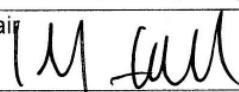
Please e-mail one copy of your completed article to Sue Maskrey and also post one to her:

Sue Maskrey, CPF Administrator, Clinical Psychology Unit, University of Sheffield, Sheffield S10 2TN

Appendix B:
Ethical Approval

COVENTRY UNIVERSITY ETHICS COMMITTEE (CU Ethics Form 1)

POSTGRADUATE STUDENT & STAFF APPLICATION FOR ETHICAL APPROVAL

Name Sarah Simmonds		E-mail simmonds@coventry.ac.uk		
Designation / Subject & Faculty Trainee Clinical Psychologist / Clinical Psychology				
Title of Study The Experiences of Children and Young People with Obsessive Compulsive Disorder				
1. Summary of proposal There is a lack of research examining the experiences of young people with obsessive compulsive disorder; instead most of the research centres on quantitative measurement of phenomenology or reports from professionals who have worked with young people with obsessive compulsive disorder. The proposed study intends to interview ten young people (aged 11 to 17 years) using semi-structured interviews on their experiences of living and coping with obsessive compulsive disorder. Interpretative Phenomenological Analysis will be applied to the data to examine the psychological interpretations of the experiences of young people. It is hoped that this will inform understand of obsessive compulsive disorder in young people to aid future research and clinical practice.				
2. Sample of participants Ten participants aged 11 to 17 years, with a diagnosis of Obsessive Compulsive Disorder, accessing a local Child and Adolescent Mental Health Service for treatment of their disorder. Exclusion criteria include participants with a learning disability such that will impact on their ability to communicate their experiences.				
3. Site/s location Child and Adolescent Mental Health Service, Kendall House, Gulson Hospital, Coventry, CV1 2SU				
<i>Tick / Cross. *Where answered 'NO', please give reasons on separate page.</i>			Yes	No*
4. Scientific background, design, method and conduct of the study.				
a) Have you given a justification for the research?			√	
b) Have you commented on the appropriateness of the design, the perceived benefits, risks and inconveniences to participants?			√	
5. Recruitment of participants. Have you provided a comprehensive account of the characteristics of the population including the process for obtaining access as well as the inclusion and exclusion criteria?				
			√	
6. Care and protection of research participants and researcher. Have you given an account of any interventions, situations and risks which have the potential to cause harm to the participants and researchers?				
			√	
7. Access, storage, security and protection of participants' confidentiality. Have you identified who will have access to the data and what measures have been taken to ensure confidentiality and compliance with the Data Protection Act?				
			√	
8. Informed Consent. Have you given a full description of the process for requesting and obtaining informed consent?				
			√	
9. Community considerations. Have you considered how this study will benefit the participants or the community from which they have been drawn?				
			√	
10. Participant information Sheet and consent form. Are these attached?				
			√	
11. Source of External Funding if any				
Signature of student / staff 		Address James Starley Building Priory Street, Coventry Uhi	Date 7/4/08.	
Signature of Supervisor Sarah Kent		Print Name SARAH KENT Internal Address (RESEARCH TUTOR) James Starley	Date 7/4/08	
Signature of Chair 		<input checked="" type="radio"/> Approved. <input type="radio"/> Approved with the conditions below:	Date 20/5/08	



National Research Ethics Service

Coventry Research Ethics Committee

2nd floor West Wing
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

11 July 2008

Telephone: 024 7696 7529
Facsimile: 024 7696 5033

Sarah Simmonds PhD student*
Trainee Clinical Psychologist
Coventry University
James Starley Building
Coventry
CV1 5FB

Dear Sarah Simmonds

Full title of study **The Experiences of Children and Young People with
Obsessive Compulsive Disorder: Perceptions of Living
with the Diagnosis**

REC reference number: **08/H1210/80**

Thank you for your letter of 02 July 2008, responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

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

Confirmation of ethical opinion

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

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of the favourable opinion

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

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

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority

*The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England*

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	AB	26 May 2008
Investigator CV	Sarah Simmonds	27 May 2008
Protocol	Version 1 appended by REC	27 May 2008
Covering Letter	S Simmonds	27 May 2008
Peer Review	Coventry University	21 May 2008
Interview Schedules/Topic Guides	Version 1	07 May 2008
Letter of invitation to participant	Version 1	07 April 2008
Participant Information Sheet Parent	Version 2	02 July 2008
Participant Information Sheet: Child includes Important Things about Taking Part and return slip	Version 1	07 April 2008
Participant Consent Form	Version 2	02 July 2008
Response to Request for Further Information	Letter S Simmonds	02 July 2008
Confirmation of Indemnity	Coventry University	27 May 2008
Statement from Prof I Marshall that he is the sponsor's representative		27 May 2008
Debrief Letter Thank you for taking part in the research project	Version 1	07 April 2008
CV academic supervisor	Dr Eve Knight	

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

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

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

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H1210/80**Please quote this number on all correspondence**

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

Yours sincerely



Mr Stephen Keay
Chairman

Email: pauline.pittaway@uhcw.nhs.uk

Enclosures: "After ethical review – guidance for researchers" SL- AR2

Copy to: *Professor Ian Marshall, Coventry University*
R&D office for Coventry & Warwickshire Partnership NHS Trust



West Midlands (South) Comprehensive Local Research Network (CLRN)
Fourth Floor Rotunda (ADA40017)
University Hospitals Coventry & Warwickshire NHS Trust
University Hospital
ifford Bridge Road
Coventry
CV2 2DX

4th July 2008

Sarah Simmonds
Trainee Clinical Psychologist
Coventry University
James Starley Building
Coventry
CV1 5FB

R&D Ref: PAR130608
REC Ref: 08/H1210/80

Dear Ms Simmonds

I am pleased to confirm that **Coventry & Warwickshire Partnership Trust** has reviewed your research study entitled 'The Experiences of Children and Young People with Obsessive Compulsive Disorder: Perceptions of Living with The Diagnosis', and give approval for you to conduct this research within the Trust on the condition that the Trust suffers no costs as a result of this study being undertaken. Your research has been entered into the Trust's research database.

Please reply to this letter confirming the expected start date and duration of the study. As part of the Research Governance Framework it is important that the PCT is notified as to the outcome of your research and as such we will request feedback once the research has finished along with details of dissemination of your findings. We may also request brief updates of your progress from time to time, dependent on duration of the study. Similarly, if at anytime details relating to the research project or researcher change, WM (South) CLRN must be informed.

If you have any further questions regarding this or other research you may wish to undertake in the Trust please feel free to contact me again. The Trust wishes you success with your research.

Yours sincerely

A handwritten signature in black ink that reads 'Luke Chaplin'.

Luke Chaplin

Appendix C:
Invitation Letter

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

THE UNIVERSITY OF
WARWICK



**Child and Adolescent Mental Health
Service Gulson Clinic
Gulson Road
Coventry
CV1 2SU
Tel: 024 7624 6330**

Dear (participant name, if over 16, or guardian name if participant under 16),

I am Dr Lisa Summerhill who is a Clinical Psychologist at CAMHS.

I am writing to you because you / your child have been selected to take part in an interview as part of a Doctorate in Clinical Psychology research project funded by Coventry University. The title of the research is "The Experiences of Children and Young People with Obsessive Compulsive Disorder".

I shall enclose some information about the project if you would like to read it. If you would like to find out more then please complete the reply slip enclosed so that Sarah can contact you. Or if you would like to speak to me then you can contact me at the CAMHS address at the top of the letter.

Yours sincerely,

Dr Lisa Summerhill
Child Clinical Psychologist

**The Experiences of Children and Young People with OCD / Covering
Letter to Parents / Participants aged over 16 Years / Version 1 / 7.4.2008**

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology

Professor Koen Lamberts BA BSc MSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

www.coventry.ac.uk

Appendix D:
Participant Information Pack: Child and Parent Versions

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702



Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

Participant Information Leaflet

“What is it like to have OCD when you are a young person?”

Many people have done research to help us know more about OCD, such as; what types of things people may find difficult, what they worry about and what things can make them feel better. Often what has happened in research is that the professionals don't ask the young person what they think about OCD. It is really important to find out what young people think, for you are the people who live with OCD everyday. This means that you may have ideas that may help the researchers understand more about OCD. The more we know about OCD the more we may be able to help.

Who am I?

I am Sarah Simmonds and I am a Trainee Clinical Psychologist. I have worked with young people before who have OCD and so I will understand what it is about.

What I would like?

I am really interested in hearing what you have to say about what you think it is like to have OCD. I hope to speak with about ten young people with OCD to get lots of ideas.

I am not trying to find out how many facts that you know about OCD but I would like to know about what OCD feels like for you, what things are difficult and what things are okay?

What will happen?

I would like to speak with you for an hour at the most with some breaks in between if we need it. It would be nice if we could speak on our own but if you would like someone with you such as you mum or dad then that is fine.

If there are some things that you are not sure about, that is okay and I will try and find something else that you find it easier to talk about. I want to make sure that you feel okay when you talk with me so that you feel able to speak to me without feeling worried.

The Experiences of Children and Young People with OCD / Participant Information Leaflet /
Version 1 / 7.4.2008 /

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology

Professor Koen Lamberts BA BSc MSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

www.coventry.ac.uk

How to get involved

With your mum or dad, read the yellow sheet about important things about taking part. Together fill in the reply slip and send to me. I will then contact you to arrange a time that would be best to speak with you. When we meet I will answer any questions and you can decide if you want to take part and how we will do it.

Thank you – I look forward to hearing from you ☺

Important Things about Taking Part

- **You can decide when we stop talking – at anytime!**
- You can say you don't want to do it anymore – at any time!
- I can delete all of what we have said if you want me to – at anytime!

- **I will record what we say so that I can remember it.**
- I will keep the recording safe so that only I hear it.
- I will write down everything from the recording onto paper
- I will take out your name and anything that makes it obvious it is you
- I will then delete the recording and just keep the paper I have written on
- I will keep this safe too.

- **What you say is private and I will not tell people what you said**
- This means I will not tell people about what we talked about
- The only time I might speak to someone about what you said was if I was worried that you were not safe or that someone else was not safe.
- I might take parts of what you say and use it in the research without anyone knowing it was you

- **I will be speaking to other young people with OCD too.**
- I will think about all of the things that everyone has said about OCD
- I will put this all together to make the research
- I might write some things that you say in the research but I won't say your name or show that it is you.
- I can tell you about what I find if you would like?

If you decide you would like to speak to me then we can go through these important things again when we meet. You can ask any questions that you have then too. Then you can decide if you would like to take part or not.

Return Slip

Tick one of the sentences to tell me what you would like to do:

- I would **like** Sarah to contact me about taking part in the research
- I would **not like** Sarah to contact me about taking part in the research

Ask your mum or dad to help you with this part:

I would prefer to be contacted by:

- Telephone: _____ (enter phone number)
- Email: _____ (enter email address)
- Post: _____ (enter postal address)

Please can you reply to me within 14 days. Thank you for taking the time to read this.

Sarah Simmonds
Trainee Clinical Psychologist
Coventry University and the University of Warwick
School of Health and Social Sciences
Priory Street
Coventry
CV1 5FB

Tel: 02476 888328
Email: ocdresearch@yahoo.co.uk

All details obtained from those taking part in the research will remain strictly confidential and you can withdraw from the research at any time. This research is separate from your involvement with CAMHS and does not affect the service you receive at CAMHS.

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushman
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

THE UNIVERSITY OF
WARWICK



Information for Parents

The Experiences of Children and Young People with Obsessive Compulsive Disorder

I am writing to you because your child has been identified to take part in an interview as part of a Doctorate in Clinical Psychology research project funded by Coventry University.

What is the purpose of the research project?

The aim of the project is to speak with young people who have difficulties that some people would call Obsessive Compulsive Disorder or OCD. It is hoped that this will contribute to the knowledge base which informs practice for children and young people who suffer from the difficulties associated with having a diagnosis of OCD.

Why has my child been identified?

Your child has been identified by a clinician working at the Coventry Child and Adolescent Mental Health Services (CAMHS) because they are aged between 11 and 17 years old and they have a diagnosis of OCD. The research project aims to interview between 8 to 10 children about their experiences of OCD.

Does my child have to take part?

'No. It is up to you and your child to decide whether or not to take part. You and your child will be asked to give consent to participate before the research can commence. You are both free to withdraw from the research at any time and without giving a reason. Your decisions about this will not affect the standard of care your child will receive. Even once you have agreed to take part, you or your child can stop at any time; before, during or after the interview and can ask for everything you said to be removed from the study without giving a reason.

What does my child have to do if we agree to take part?

If you agree to take part in the research project then the researcher will ensure that you are happy with the explanations you have been given about the purpose and nature of the research project and ask to complete a consent form. Additionally, your child will be asked to sign an 'assent' form to, if they want to, to say they are happy to take part. You will have a copy of the signed consent /

The Experiences of Children and Young People with OCD / Parent / Participant Information 1
Leaflet / Version 2 / 2.7.2008 /

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology

Professor Koen Lamberts BA BSc MSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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assent forms for your own records, along with another copy of this information about the research project.

If your child agrees to take part then they will be asked to take part in one interview which is anticipated will be an hour long. The researcher is a Trainee Clinical Psychologist called Sarah Simmonds who would like to speak with your child about what it is like for your child to have OCD. She will have some questions to help your child talk about their experience. There are no right or wrong answers as the interview aims to capture your child's ideas and perspective on living with OCD. You can find out more about the project by meeting with Sarah before you decide if you want to take part. Her details are listed below.

The interview will include breaks as appropriate and will be tape recorded to ensure that your child's perspective is accurately recorded. The researcher is happy to conduct the interview at a time to suit you and your child best, in your home or, if you prefer it can be conducted in a private room at CAMHS. Any travel expenses will be covered by the researcher.

What will happen after the interview?

After the interview your child will be given the opportunity to ask any questions of the researcher. You and your child will be thanked for taking part and will not be required to do anything further. You will be given a debrief leaflet with details of who you can contact if you require further support following your participation in the research and an explanation of what will happen to your information.

What are the other possible disadvantages and risks of taking part?

Every effort will be made to encourage your child to feel comfortable in talking to the interviewer. The possible disadvantages associated with taking part are that for some people, talking about their experiences of OCD may lead them to feel upset during or after the interview. If your child becomes upset during the interview Sarah will stop the interview and manage the immediate issues. The interview will only continue if your child feels able to.

If your child becomes distressed as a result of the interview once it is finished then you can speak to your case manager at CAMHS or to Lisa Summerhill (Clinical Child Psychologist) at CAMHS. The phone number for CAMHS is 02476 246330.

What are the possible benefits of taking part?

The possible benefits for taking part are that your child will be provided with the opportunity to give their view on what it is like to live with OCD. It is important that research listens to the views of children and young people for they are the 'experts' in what OCD is like for them and it is possible that this may help researchers and clinicians to understand OCD better. This may then further understanding of how to help young people with OCD to cope with or even to overcome their difficulties.

What if there is a problem?

Any complaint about the way you or your child have been dealt with during the study or any possible harm you might suffer will be addressed.

In the event of a complaint relating to the NHS Trust, you should follow the usual NHS Trust complaints procedure. Should the complaint relate directly to the research, you are requested to inform the researcher, Sarah Simmonds, who will try to resolve the matter. Failing this, you may wish to contact the Coventry University Ethics Committee chair, Professor Ian Marshall, in writing at AB122, Coventry University, Priory Street, Coventry CV1 5FB, or by telephone on 024 7688 5293.

Will my child's taking part in the research project be kept confidential?

Yes. The audio recording and written transcript will be kept confidential and stored in a locked filing cabinet at CAMHS, that only the researcher can access. If your child discloses something of concern during the interview this will be reported to Lisa Summerhill (Clinical Child Psychologist) at CAMHS and research supervisor. This may involve consideration of how to take this further, calling upon Coventry and Warwickshire Partnership Trust Child Protection guidelines.

The final write up of the research paper for the Doctorate study and if applicable, the journal publication will not identify you or your child. Once the data has been used in the study it shall be stored safely and confidentially by Coventry University for five years. After this time it will be destroyed safely and confidentially.

Contact Details:

Sarah Simmonds (Trainee Clinical Psychologist), Doctorate Course in Clinical Psychology, Coventry University, James Starley Building, Priory Street, Coventry, CV1 5FB.

What will happen to the results of the research study?

The results of the study will be anonymised so that any information that may identify your child will be removed. The study will be written up into a research paper as part of a Doctorate in Clinical Psychology final year thesis project. It is hoped that the research paper will be published in a scientific peer reviewed journal. If so, you can request that you would like to see the research paper the researcher can help you to obtain a copy.

Who is organising and funding the research?

The research is funded by Coventry University and Warwick University and is organised by the research team. This comprises of:

- Sarah Simmonds (Trainee Clinical Psychologist / Researcher)
- Dr Eve Knight (Doctorate Course in Clinical Psychology Programme Director / Clinical Psychologist / Academic Research Supervisor for Sarah Simmonds)
- Dr Lisa Summerhill (Clinical Psychologist / Clinical Research Supervisor for Sarah Simmonds).

Who has reviewed the study?

The research study has undergone an academic review through Coventry University. Additionally, the study has been subjected to an ethical review by:

- Coventry University ethics committee
- National Patient Safety Agency: National Research Ethics Service
- NHS Coventry and Warwickshire Partnership Trust Research and Development Committee.

Appendix E:
Consent Form

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

THE UNIVERSITY OF
WARWICK



Participant Consent Form

This sheet is to help you to make a choice about whether you want to take part in the research. Ask your mum or dad to help if you with this choice. Please answer these questions and tick the boxes if you have done these things.

Have you read the yellow sheet?

Have you talked to your mum or dad about it?

Have you and your mum or dad read the information for parents sheet?

Have you had the time to ask me any questions that you may have?

Would you like to talk to me about your feelings about OCD?

I am happy for the interview to be tape recorded

If you answered all of the questions and ticked all of the boxes then please write your name in the space below to say you would like to take part in the research.

(Write your name here)

(Parent signature here)

The Experiences of Children and Young People with OCD / Participant Consent Form /
Version 2 / 2.7.2008 /

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology

Professor Koen Lamberts BA BSc MSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

Appendix F:
Debrief Letter

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

THE UNIVERSITY OF
WARWICK



Thank you for taking part in the research project!

I am really grateful that you came to speak to me about what it is like to have OCD. I hope that you found it okay to do.

I shall listen to the recording of the things we talked about and have a think about all of the things you said. I shall also do this with other people that I spoke to too.

Then I shall put all the things together and write a research paper on it. This means that I shall look very carefully at the different things that people said about OCD and how they live with it. I hope that I can find out some new ideas about what OCD is like and maybe some new ideas about what can make it easier.

I hope that the things that I find can help people with OCD and also like the people who help you at CAMHS.

When I have finished writing my research project I can send you some information saying what I found – if you want?

The Experiences of Children and Young People with OCD / Debrief Leaflet / Version 1 / 7.4.2008 /

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology

Professor Koen Lamberts BA BSc MSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

www.coventry.ac.uk

Remember:

If you feel upset after the interview and need someone to speak to then:

- Try to speak to your Mum or Dad
- You can also speak to a person at CAMHS (02476 246330)
Your main person to speak to is (Lisa Summerhill, Clinical Child Psychologist)
- You can speak to someone at Child Line if you want to speak to someone who doesn't know you. (0800 1111)

If after the interview you do not want me to use the things we talked about in the research project then that is absolutely fine. You will not get into trouble by saying this, you do not have to give any reason and I will not be upset with you. I only want to use the things you said if you think that is okay. Speak to your mum or dad and they will help you to let me know.

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Appendix G:
Interview Schedule

Interview Schedule

The beginning of the interview will attempt to engage with the participant in a way to understand the language they use to describe OCD so to remain concordant with their understanding of OCD. This may alter the way in which the questions are asked.

Why do you think you see someone at CAMHS / come here?

What is it like to have OCD?

- What is the worst thing about OCD?
- Is there anything good about OCD?

When do you think you first noticed OCD?

- Do you know when it started?
- Do you think anything caused it?

Have you told anyone about your OCD?

- Who have you told about your OCD?
- Why did you tell them?
- What do other people think about your OCD?
- Are there people you have not told?
- What might they think about it?

Is there anything different about people who don't have OCD?

Have you ever tried to speak to OCD?

- What have you said?
- What would you like to say to OCD?

What things have you learned about OCD?

- What do you think makes OCD worse / better / go away?

How does OCD make you feel about yourself?

- About your friends?
- About school?
- About your family?

How does OCD make you feel about your future?

- Do you think it may get better or go away?
- Do you think it may get worse?

What would life be like if OCD went away?

- Would anything be different?
- Would anything be the same?

Additional questions for participants who have received psychological intervention

Has anyone tried to help you with OCD?

- Help make you feel better?
- Help OCD feel easier to cope with / go away

What was it like seeing somebody to help you with OCD?

- What was the best thing about their help?
- Worst thing?
- Thing you will remember the most?
- What was the hardest
- What was the easiest?

Have you learned new ways of coping with OCD?

- What were the best / worst?

Do you feel any different about OCD since seeing someone to help you?

- Do you feel any different about yourself?

What is your life like now with OCD?

- Is it any different since getting some help?

Appendix H:
Example of Transcript with Line by Line Coding

01 Researcher (R): so what is it like to have OCD?

02

03 Participant (P): I don't think it is very nice because it really does affect your life and what you can do

☀ impact on life

04

05 R: Does it?

06

07 P: well in school I can do science but cause I'm quite scared I can't, like I start to cry in Science normally 'cus, 'cus in secondary school you use like dangerous chemicals and if you get it on your skins it burns or what ever, its not really helping the same like but it just means I was upset

☀ danger
☀ fear
☀ school
☀ upset

08

09 R: so what it is that you worry about at school?

10

11 P: Just I worry about if stuff gets out like, 'cus I told some people and some people knew from my old school that if someone starts spreading it then people are 'gonna act different. Like, like this one person I told he wouldn't go near me 'cus he thought he could catch it.

☀ keeping OCD secret
☀ others' judgement
☀ others' negative responses

☀ disclosure

12

13 R: Oh I see, so what did you think about it?

14

15 P: He just thought like you know like chicken pox you can catch it he just thought it was a bit like that

☀ others' misunderstanding

16

17 R: Oh I see so how did you feel about that?

18

19 P: I was well upset, so it's meant that some people
have found out about it

secret revealed
upset

20

21 R: And people have reacted in a funny way and have
been worried about actually catching it

22

23 P: Yeah

24

25 R: So what else it is like to then, then to have OCD?

26

27 P: It's a bit boring 'cus you get put on the spot I
think.... 'Cus teachers ask, all ask you questions
about it and you don't really want to talk about it at
school

others' curiosity
school
unwanted attention

28

29 R: I see.... So, so when might they do that?

30

31 P: Like, in science or if we are doing something that
includes dangerous or some kind of, there are
obviously a lot of people who [say] 'are you okay
doing it because of your OCD?' It's like, I don't like
talking about it, I like now [during interview], but, I
don't like talking about it any other place 'cus no one
understands it

keeping OCD secret
people dont understand
school
unwanted attention

32

33 R: So the teachers might ask you if you are alright,
and will they say anything in front of people or?

34

35 P: Yeah, yeah, like, Miss said erm I'll be able
because everyday 'that has been very good' and
because I joined in with science, for once, erm she
came over to me and she went "oh, this person faced
their fears" but she didn't, she wouldn't want me to go
into too much information, but see even that still like,
... and then everyone is asking me 'what, why why
why?'

disclosure
keeping OCD secret
others' curiosity
school
unwanted attention

36
37 R: So she had said that you had faced your fears, is
that right?

38
39 P: yeah and then everyone was wondering about
what it was

others' curiosity

40
41 R: oh I see, so she said that in front your

42
43 P: the whole class

44
45 R: Right, so how did you feel when that happened?

46
47 P: Embarrassed, 'cus no one else knew I had it

disclosure
Embarrassment

48
49 R: so sometimes at school it can be difficult and
teachers sometimes say things in front of the class

50
51 P: yeah

52
53 R: What do you think is the worst thing about OCD?

54

55 P: That you can't erm, get included in stuff, well you
can but you don't want to

☀ cant vs wont
☀ exclusion from activity

56

57 R: So what kinds of things?

58

59 P: It's all really about school to be honest, like before
I go to, if I go P.E. yeah, I don't want to do it in case I
get dirty hands and then they like 'cus on Mondays
we have it, as soon as we get to school, we aren't
allowed to wash our hands after

☀ school rules vs OCD rules

60

61 R: Oh right, so what does that mean for you?

62

63 P: I feel just, I don't want to touch anything else in
case like .. well I'll get ill or something

☀ feared consequences
☀ illness
☀ school rules vs OCD rules

64

65 R: Yeah, so P.E. is difficult then 'cus you like to wash
your hands afterwards

66

67 P: mmm but they wont let me

68 R: but you're not allowed?

69

70 P: your not allowed to, they are quite strict in like the..
you're not allowed to wash, go to toilet in lessons, you
not allowed to wash your hands. I was once because
I had been at the Science lab and using dangerous
things but that was it, she won't let me

☀ school rules vs OCD rules

71

72 R: So there are some things that you want to do. Do
you like P.E. or is it..?

73

74 P: Yeah I do, I enjoy it but it's harder

75

76 R: So there are some things that you might want to
be part of but you can't do for other reasons and you
might want to wash your hands afterwards but you
know you're not allowed, is that right?

77

78 R: is that one of the worst things about OCD then, it,
is that you can't take part in things?

79



80 P: Probably


81

82 R: So is there anything else that's really bad about
OCD?

83

84 P: I have to check if meat's cooked. Like, it's hard for
me to go to school and if I have school dinners I try to
not pick the meat. So, if it's meat, I normally have to
ask my mum. You know gammon's pink? Well, I
didn't know that (laughs) and I was like, I didn't like it,
so I was scared. I was fine the next day but again if I
have it again I'll do it again

 fear
 food contamination

 hindsight overcome by fears

85

86 R: So what were you scared about?

87

88 P: I guess food poisoning it's 'cus I've been really ill

 illness

before I don't want to do it again

89

90 R: So have been really ill before then?

91

92 P: Well kind of, and I'm scared like if I do do that, I'll get, I know it's a bit silly, I'll get a migraine, that's because I suffer from them, but I, I think in my imagination that they come from what I do

fear

awareness: not reality
responsibility

93

94 R: can u tell me more about that?

95

96 P: Erm like if I put, what are they called? Oh yeah, the sound on the remote on the TV, I have to turn it on an even number, so if I put it on odd I'll get a migraine the next day. Has to be an even number anyway, you know that isn't true but you know when, when it's the ... it comes to your mind

consequence -disobeying OCD
OCD rules

awareness: not reality