Obsessive-Compulsive Disorder in children and adolescents: parental understanding, accommodation, coping and distress

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Abstract

Parental accommodation of pediatric OCD is common and is associated with negative affect in parents. Qualitative accounts of caring for a child with OCD are limited and no studies have assessed differences between mothers and fathers in accommodation, coping and distress. The current study used a mixed methods approach to understand parental accommodation, negative affect and coping. Forty-one mothers and 29 fathers of 43 children with OCD were asked to write narratives about their understanding and management of OCD and to complete measures of accommodation, coping, and distress. Symptom accommodation was high with almost half of the parents watching the child complete rituals or waiting for the child on a daily basis. Analysis of parental narratives indicated a distressing struggle between engaging in and resisting accommodation in order to manage their own and their child's anger and distress. T-tests and correlation analysis indicated that accommodation did not differ significantly between mothers and fathers but was more strongly associated with negative affect in mothers. Analyses indicated that mothers reported using all types of coping strategy more often than fathers, particularly escape-avoidance, taking responsibility and using social support. Escape-avoidance coping was positively correlated with accommodation and negative affect in both mothers and fathers. Interventions that target parental constructions of OCD and their behavioural and emotional responses to it may assist in reducing the occurrence of accommodation, avoidant coping and parental distress.

Keywords: OCD; children; parents; accommodation; distress; coping

Introduction

Obsessive-compulsive Disorder (OCD) is a condition marked by the occurrence of persistent negative intrusive thoughts (obsessions) and overt or covert neutralizing strategies (compulsions) aimed at reducing distress or nullifying threat. OCD is potentially a debilitating condition that can cause marked distress and disruption to social, familial and academic functioning (Allsopp & Verdyn, 1990). OCD can occur throughout the lifespan, but typically first emerges in childhood and adolescence (Geller, et al., 1998). Epidemiological studies estimate a lifetime prevalence of pediatric OCD of up to 4% (Keeley, Storch, Dhungana & Geffken, 2007).

Parents tend to find OCD symptoms in their child distressing to observe (Amir, Freshman & Foa, 2000; Cooper, 1996; Peris et al., 2008) and so it is unsurprising that a number of studies indicate high rates of symptom accommodation (e.g. participating in rituals, providing reassurance, changing family routines) amongst parents of children with OCD in an effort to reduce the child's distress and the parents' own emotional reactions towards it (Allsopp & Verdyn, 1990; Peris et al., 2008; Shafran, Ralph, & Tallis, 1995; Storch et al., 2007). Family members are also motivated to engage in accommodation in order to avoid angry reactions from the relative with OCD if they do not accommodate and to reduce the duration of compulsive activity (Calvocoressi et al., 1999). Accommodation, therefore, is both a response to the impact of OCD on the child, and of the child's distress and emotional responses on the parent and the family. However, accommodation hinders therapeutic potential because it directly contradicts exposure-based approaches to treatment which aim to facilitate habituation to the anxiety provoked by obsessions through preventing compulsive activity and avoidance. These are aims which accommodation behaviors, such as providing reassurance, impede. A number of authors highlight the detrimental effect of accommodation and emphasize the need for families to be involved in pediatric OCD treatment to avoid counter-therapeutic effects (Amir et al., 2000; Peris et al, 2008; Storch et

al., 2007). Accommodation has been shown to be positively related to OCD severity (Peris et al., 2008; Stewart et al., 2008; Storch et al., 2007) and to parent-rated child functional impairment (Storch et al., 2007), although cross-sectional designs preclude causal inferences. However, Merlo, Lehmkuhl, Geffken & Storch (2009) showed that reductions in family accommodation, achieved through family-based cognitive-behavioural therapy, were associated with positive response to treatment in the affected relative.

It is evident then that parents find themselves in a bind that is likely to affect their wellbeing: they report symptom accommodation to be distressing (Amir, et al., 2000; Cooper, 1996; Peris et al., 2008), do not believe it is helpful (Calvocoressi et al., 1999) and yet often face aggressive outbursts or distress from their child when they refuse to accommodate (Storch et al., 2007). Accommodation is positively correlated with relatives' anxiety and depression (Amir et al., 2000) and can affect family relationships in that the burden imposed, either by engaging in accommodation or attempting to resist it, can lead to feelings of blame towards the child (Peris et al. 2008).

From the foregoing discussion, it is evident that parents not only need to cope with the impact of OCD on their child but they also need to manage the personal and familial consequences of engaging in accommodation or resisting it. Enquiring about relatives' coping in relation to OCD, therefore, will encompass how they cope with the consequences of OCD, including accommodation. Although several aspects of OCD in a family member are likely to lead to appraisals of threat and challenge, coping strategy use amongst relatives has received very little attention in the OCD literature to date (Geffken et al, 2006). Lazarus and Folkman (1984) defined coping as "changing cognitive and behavioural efforts to manage external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p141). Lazarus and Folkman (1984) drew a distinction between 'problem-focused coping', which incorporates processes directed at addressing the situation

causing stress, such as developing a plan of action; and ‘emotion-focused coping’ which incorporates processes that aim to regulate emotions associated with the stressful situation, such as avoidance and seeking social support. Lazarus and Folkman did not conceptualize that these processes were used independently of each other or that one type is more superior to the other, arguing instead that their context of use was important. Congruent with this, Austenfeld and Stanton (2004) caution against the use of ‘emotion-focused processes’ as a broad categorization since this encompasses a range of diverse strategies; instead, it is conceptually clearer to focus on discrete processes (e.g. seeking social support, denial).

In a sample of sixty-seven primary caregivers/spouses of children and adults with OCD, Geffken et al. (2006) found that active coping (i.e. strategies aimed at changing the problem) was inversely correlated with depression as was degree of social support utilized. Further, family accommodation and denial/disengagement coping were positively correlated with depression and with each other. In a questionnaire study of parents of children with OCD, children with other anxiety disorders, and non-clinical children, Derisley, Libby, Clark and Reynolds (2005) found that the OCD group parents reported significantly greater avoidant coping than parents of non-clinical children although the OCD group parents did not differ from parents of children with other anxiety disorders. This latter finding would suggest that avoidant coping may be a function of parental distress rather than child diagnostic status given that the mental health of the parents of children with OCD and other anxiety disorders was significantly poorer than the mental health of parents of non-clinical children. In a similar vein, accommodation has been found to be significantly and positively correlated with relatives’ own level of obsessive-compulsiveness, raising the question of whether accommodation is an extension of the caregivers’ own symptoms (Calvocoressi et al., 1999; Peris et al., 2008).

Taken together, the above studies suggest that symptom accommodation is part of the parental experience of a child's OCD, that it occurs frequently within the families of children with OCD, and that it is a process that is associated with cognitive dissonance and distress in parents. Few studies have assessed the coping strategies used by parents and how they relate to parental distress. Additionally, if accommodation is used as a way to manage parental distress from witnessing OCD and distress in their child, then it is reasonable to propose that it may be related to more emotion-focused ways of coping, such as denial/ disengagement and avoidance. The current study utilizes a mixed-methods approach to understand how parents construe, accommodate and cope with OCD symptoms in their children. The extant literature on family accommodation in OCD primarily utilizes quantitative assessments of the extent to which accommodation occurs. Such studies are helpful in showing correlations between accommodation and symptom and family variables. However, they provide only a partial picture of the experience of caring for a child with OCD and managing the tension to accommodate symptoms. Additionally, studies have not illuminated how responses might differ between mothers and fathers. This seems crucial given the importance of the family context in pediatric OCD treatment.

We examined the experiences of mothers and fathers caring for a child with OCD in a number of ways. Through thematic analysis of narratives written by parents, we sought to discover how they understand their child's condition, how they respond to it, and how they experience caring for their child. Using computerized linguistic analysis, we further sought to assess the emotional and cognitive features of these narratives, and whether there were quantifiable differences in the content of mothers' and fathers' narratives. Additionally, we sought to establish levels of distress, symptom accommodation and coping processes in parents and whether mothers and fathers differed on these variables. Previous literature led us to hypothesize that level of accommodation would be positively correlated with parental

anxiety, depression and stress. We also hypothesized that emotion-focused coping strategies, such as avoidance, would be positively correlated with depression and with family accommodation. Given the lack of literature on parental differences in distress, accommodation and coping process use in OCD, directional hypotheses were not formulated for these analyses

Method

Design

A cross-sectional design using mixed methodology was implemented. Parents were invited to hand-write or type two narratives, one describing what it is like to care for a child with OCD and the other describing how they understand their child's disorder. Parents were not given any restriction on the length of the narratives and were advised to take as long as they needed. The specific questions used to focus each narrative were: What is it like to care for a child with OCD? How do you understand your child's difficulties? These written narratives were subjected to thematic analysis (Braun and Clarke, 2006). The narratives were also analyzed using the Linguistic Inquiry and Word Count (LIWC; Pennebaker & Francis, 2007), to explore parents' emotional and cognitive word usage in written text. The LIWC also allowed us to make a gender comparison for emotional and cognitive word usage. Parents also completed standardized measures to assess their levels of stress, depression and anxiety, coping strategies and accommodation of obsessive-compulsive symptoms.

Recruitment

Parents of children with OCD were recruited from two sources: from a UK National Health Service (NHS) child and adolescent specialist clinic for pediatric OCD, and from a UK OCD charity. All children referred to the specialist clinic are assessed by clinicians with expertise in the diagnosis and treatment of pediatric OCD. Diagnosis in the clinic is made using ICD-10 criteria. Parents were identified and initially approached by clinicians in the

specialist service. Interested parents then received an information sheet and consent form from the research team. To recruit parents from the OCD charity, an advertisement was placed in the charity newsletter and on its website. Interested parents contacted the research team direct. Parents were included in the study if they were currently living with a child with a primary diagnosis of OCD who was aged 18 years or younger. Only parents with verbal English language skills could be included due to the demands of the writing task.

Participants

The parents of 43 children with OCD participated. For 34 of these children, parents were recruited from the OCD clinic and so had a clinician confirmed diagnosis of OCD. Parents of the remaining 9 children were recruited from the OCD charity and we were not able to confirm diagnosis beyond parent report. For this reason, parallel analyses were performed on the full sample and the OCD clinic sample separately. The children (51% male) ranged in age from 9 to 18 years ($M = 14.88$, $SD = 2.32$). The mean age of onset of OCD was 10.90 years ($SD = 3.67$) and the mean duration 39.67 months ($SD = 36.81$). Pre-treatment indicators of severity of obsessions and compulsions and general functioning were available only for those children treated within the specialist OCD clinic ($n=34$). Their obsessions and compulsions severity score at intake, measured using the clinician-rated Children's Yale Brown Obsessive-Compulsive Scale (CY-BOCS; Scahill et al., 1997), was 25.16 ($SD = 5.69$) indicating a moderate level of severity. The mean pre-treatment level of functioning for these children, measured using the Children's Global Assessment Scale (CGAS; Shaffer et al., 1983) was 49.96 ($SD = 12.01$) indicating moderate impairment in most areas or severe impairment in one area.

The sample of parents totalled 71, comprising 42 out of 70 mothers recruited (62%) and 29 out of 61 fathers (50%) recruited. The total sample included 27 couples, 20 recruited from the OCD clinic and 7 from the OCD charity. Table 1 shows the characteristics of the

sample. Fathers were significantly older than mothers in this sample: $t(69) = 2.52, p = .014$, 95% CI [-5.8, -.69], $d = .60$.

INSERT TABLE 1 ABOUT HERE

Measures

In addition to the writing task, each parent completed a series of standardized measures as described below.

Coping. The Ways of Coping Questionnaire (WOCQ; Folkman & Lazarus, 1988) is a 66-item questionnaire that assesses the frequency of cognitive and behavioural strategies that individuals use to cope with the demands of a stressful situation, rated here in relation to the child's OCD. Fifty of these items are used to assess eight subtypes of coping (the remaining 16 items are distractors). Respondents rate statements on a 4-point Likert scale ranging from 0 (*the strategy is not used*) to 3 (*the strategy is used a great deal*). The eight subscales assessed are: confrontive coping (assertive efforts to alter the situation), distancing (minimizing the situation or detaching oneself from it), self-controlling (efforts to regulate feeling and action), seeking social support, accepting responsibility (for one's part in the situation and attempts at restorative action), escape-avoidance (efforts to escape or avoid the situation), planful problem solving (problem-focused efforts to change the situation) and positive reappraisal (attempting to give positive meaning to the situation). Folkman and Lazarus (1988) reported Cronbach's alpha coefficients ranging from .61 to .79.

Negative affect. The Depression Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995) is a 42-item self-report questionnaire measuring depression, anxiety and stress over the past week on a 4-point Likert scale from 0 (*did not apply to me at all*) to 3 (*applied to me very much, or most of the time*). Test-retest reliability coefficients reported by Brown, Korotitsch, Chorpita and Barlow (1997) were: depression .71; anxiety .79; and, stress

.81. Lovibond and Lovibond (1995) reported Cronbach's alpha coefficients of: depression .91; anxiety .84; and, stress .90.

Accommodation. The Family Accommodation Scale (FAS; Calvocoressi, et al., 1999) is a 12-item clinician administered assessment of relatives' report of accommodation of obsessive-compulsive symptoms over the previous week including items on providing reassurance, modifying routines, and participating in rituals. In the present study, we employed this measure as a self-report tool. For each item, parents were required to rate the frequency with which they engaged in each of the symptom accommodations on a 5-point Likert scale from 0 (*not at all*) to 4 (*every day*) for 8 of the items, and from 0 (*not at all*) to 4 (*extreme*) for the other 4 items. Calvocoressi et al. (1999) reported a Cronbach's alpha coefficient of .82.

Procedure

The study was reviewed and granted a favourable ethical opinion by a UK National Health Service Research Ethics Committee. Interested parents were sent an information sheet and consent form in the post. The information sheet outlined the nature of the study and the possibility that the writing task might bring up painful feelings. Once parents had returned a signed consent form, the measures along with instructions for the writing task were posted to them with a pre-paid reply envelope. Parents were reminded that they could withdraw from the study. All parents were sent a summary of the findings at the end of the study.

Analytic procedures

Thematic Analysis. Thematic analysis is a method for extracting and organizing themes from open-ended data. Parents' written narratives were analyzed using the guidelines provided by Braun and Clarke (2006). Each text was read several times following which codes (i.e. a summary statement representing a unit of meaning) were developed across the

entire data set. These codes were then organized into themes on the basis of conceptual similarity. These initial themes were then refined (for example, initial themes that clearly overlapped were combined into a single theme). Final themes were then checked against the whole data set to ensure they were an adequate representation of it.

Computerized Text Analysis. The written narratives were also analyzed using the Linguistic Inquiry Word Count (LIWC) program. This program analyses text on a word-by-word basis against predetermined linguistic dimensions. One of these dimensions relates to psychological processes including positive and negative emotions and cognitive procedures such as causation and inhibition. The LIWC calculates the percentage of words used in each dimension within a piece of text. Mean reference values were published by Pennebaker and Francis (2007) for writing about emotional topics; these index values are referred to in the current study.

Analysis of Standardized Measures. A combination of parametric and non-parametric analyses was employed due to data and residual distribution considerations. Initial analyses revealed no differences between parents who stated they were single/separated/divorced ($n=11$) with those who indicated they were married ($n=57$) on the main study variables. Therefore the sample was treated as one group for the purpose of the analyses except where analyses by parent gender were conducted. Two-tailed tests were used throughout. A priori alpha level for significance testing was set at the .05 level. In analyses, sample sizes differ due to some participants not completing all of the measures.

Analyses by Parent Gender. Analyses by gender are given for the whole sample (42 mothers and 29 fathers) and by couple ($n=27$). Analyses are conducted by couple because this analysis controls for severity of OCD, age and sex of child, service contact and therapeutic model. Hence, these analyses can indicate whether differences between mothers and fathers exist in the context of parenting the same child.

Results

Thematic Analysis

The analysis of the written narratives is presented within four overall themes below representing: parents' attempts to make sense of OCD; the power of OCD; the impact of OCD; and, their engagement with OCD. Each theme is summarized and then representative extracts from the narratives are presented in order to evidence the theme.

Parents' attempts to make sense of OCD. Parents struggled to make sense of OCD. Analysis of their narratives revealed competing constructions of this disorder. Most parents viewed OCD as an illness that was external to, and separate from, their child. Some parents wrote that they could deal more effectively with OCD symptoms if they construed OCD as a condition that their child had little control over. At the same time, parents expressed their incomprehension of a condition that appeared so irrational to them. Some narratives revealed a struggle in differentiating behaviors related to OCD from normative adolescent behaviors. Some parents viewed obsessions as normal worries that had got out of hand. As such, the narratives represented OCD as a normative, understandable process that had become maladaptive and as an illness that had assailed their child. A key way that parents seemed to deal with their uncertainty about OCD was to increase their knowledge of it. By understanding OCD, parents hoped they would be able to learn how to deal with it and feel less helpless. However, some parents remained perplexed about what might have caused their child's OCD and blamed themselves for not having noticed the problem early on.

"I managed to deal with it better when I disassociated OCD from my child and treated it as an unwanted 'guest' that was not welcome" (Mother).

"It can at times be very frustrating as I, who do not suffer with OCD, cannot understand why my daughter requires constant reassurance" (Father).

“I still struggle to know what is truly OCD and what is his unwillingness or even ‘teenage rebellion’ to try and change the current situation” (Mother).

“Understanding that it is OCD has been helpful for him and us. It’s not bad behaviour, or silly, it’s a condition that’s understood and needs treatment” (Father).

Power of OCD. Parents expressed feelings of helplessness in the face of OCD. Helplessness was often accompanied by feelings of frustration at the situation, the irrationality of the behaviors, and the inability to intervene. In some mothers, but no fathers, this feeling of extreme powerlessness was expressed via the hope for a magical cure. Perceived inability to control the situation was pervasive across parents’ narratives, with OCD described as being in total control of their child and also of them as parents. Some parents likened the power of OCD as being in the grip of an addiction or being possessed by an inhuman source. Parents’ accounts expressed pain over the loss of their child to OCD. For many parents, the perceived power of OCD resulted in hopelessness regarding the possibility of change. However, feelings of hopelessness were not universal. Some parents, particularly mothers, believed that their child would be able to overcome OCD. For some, hope was an important way of coping. Some parents’ accounts did indicate some degree of agency in their child or, at least, recognized that OCD was part of their child. Generally, however, parents found the expression of OCD was unpredictable which they found extremely difficult to live with.

“It’s almost like watching your child taken over by an alien” (Mother)

“All in all it looks as though there is no end to this” (Father).

“It makes me feel I have lost my child forever” (Mother).

“I feel she can achieve this aim. She will see that she can do other things too. I know she can recover” (Mother).

“He makes us prisoners in our own home” (Father).

Impact of OCD. Parents described far-ranging and enduring impacts on individual family members and the whole family system, including their marital relationship and their ability to support their other children. The impact of OCD on the child was described as pervasive, affecting their educational potential, emotional well-being and social connections. Several mothers described their child's embarrassment about the condition and their demands that the OCD be kept a secret. Parents described the experience of caring for a child with OCD as challenging, demanding, time-consuming and relentless, particularly when they got involved in lengthy rituals. Fathers more commonly expressed concern about whether their child could have an independent future and the potential implications for themselves. Mothers in particular expressed the impact on their own physical and emotional well-being and described feeling overwhelmed and emotionally exhausted. Several fathers expressed significant concerns about the impact on their wives. Some mothers were unable to work outside of the family home because their child was unable to attend school regularly and because they feared leaving a child who may become distressed. As a consequence, they described feeling socially isolated. Mothers' feelings of loneliness and isolation also arose from them perceiving a lack of understanding and knowledge of OCD in others. Just as they described their child's embarrassment, mothers wrote of their own embarrassment about their child's condition, thus limiting their ability to confide in others. They were aware that their child's behaviors might seem bizarre to others, as indeed they seemed to the mothers themselves. A related worry was that others would view them as bad parents who were unable to control and discipline their child. Again, this reflects parents' own uncertainty regarding how much of their child's behavior might be attributed to OCD or explained as adolescent 'bad behavior'.

"The OCD has taken hold of her everyday life and everything she does is affected by it"

(Father).

“[He] also insists that I now keep his condition as secret as possible because he just doesn’t want others to know about it because he is embarrassed” (Mother).

“When you worry about whether your child will be able to look after himself when he is older or whether you will have to care for him for the rest of his life, then it is very stressful” (Father).

“OCD is very likely to spoil your own relationship with your child” (Mother).

“When your other children feel left out and have ‘normal’ issues of their own and you don’t seem to have the energy left to help them as much as you might, it’s not great” (Father). :

“Family life has been completely changed as a result” (Father).

Engagement with OCD. Evident in parents’ accounts was the tension between becoming involved in the child’s symptoms and resisting them. Parents described their efforts to resist accommodating obsessive-compulsive behaviors to help their child overcome OCD, and their struggle to not be drawn into the OCD in an effort to reduce their child’s distress or avoid angry outbursts. When parents did give in to avoid the possible consequences of not accommodating, many felt guilty. Several parents, particularly mothers, wrote about their attempts to decrease their child’s suffering either by becoming actively involved in their child’s OCD or trying to distract the child from their symptoms. Some parents expressed fear of aggressive outbursts if they did not accommodate and the effect that this has on the whole family. For some parents, avoidance of the situation perhaps provided a partial answer to dilemmas regarding accommodation. Some parents tried to avoid being at home or engaging with their affected child.

“I’ve been told not to feed OCD, as [her] mother that is a very hurtful and difficult thing to do. I try but sometimes I give into it. I know it’s not really helping when I do” (Mother).

“For me it is a dilemma - trying to help resist the OCD behaviour results in aggression yet going with the OCD seems to result in it getting worse in the longer run. I usually have to give in to become part of the OCD behaviour” (Father).

“Sometimes I let the hand washing go by not saying anything to avoid confrontation but then feel guilty for not saying anything because I am letting her down” (Father).

“When coming home from work I sometimes rather not ask how she is” (Mother).

Quantitative Analyses

Linguistic Inquiry Word Count (LIWC). Forty-one mothers and 28 fathers provided a written narrative. One father wrote just four words and so his text was not included in the analysis. The other narratives varied in length considerably with the shortest being 62 words and the longest being 1665 words. The sample mean word length was 555.62 ($SD = 403.15$). Mothers' letters were significantly longer than fathers' ($M = 644.27$, $SD = 420.48$ and $M = 425.82$, $SD = 343.52$ words respectively): $t(67) = 2.27$, $p = .026$, 95% CI [26.96, 409.92], $d = .56$. Analysis of the data for couples using a paired-samples t-test ($N = 25$) again indicated that mothers ($M = 699.08$, $SD = 407.60$) wrote significantly more words than fathers ($M = 377.80$, $SD = 280.60$): $t(24) = 4.11$, $p < .001$, 95% CI [160.15, 482.40], $d = .91$. The results of the analysis of the LIWC are presented in Table 2. Parents' narratives included a high proportion of emotion words, particularly negative emotions. The proportion of negative emotion and anxiety words in the texts of both mothers and fathers were considerably higher than the reported reference norms for emotional writing given by Pennebaker and Francis (2007), whilst the proportion of positive emotion words was smaller than the reference values. Independent-samples t-tests were used to compare word usage between mothers and fathers. There was a significant difference between mothers and fathers only in their use of tentative words: $t(67) = -2.25$, $p = .027$, 95% CI [-1.18, -.07], $d = .54$ with

fathers using a greater proportion of these words than mothers. P-values for all other comparisons were $>.15$. When a paired analysis was conducted with the couples data, the results were similar with a significant difference detected only for use of tentative words: $t(24) = -2.58, p = .016, 95\% \text{ CI } [-1.35, -.15], d = .62$.

INSERT TABLE 2 ABOUT HERE

Descriptive and scale statistics for standardized measures. Parents recruited from the OCD specialist clinic and the charity did not differ significantly in accommodation, coping or negative affect. Consequently, they were treated as one sample in all analyses. Table 3 presents the sample means and standard deviations for the measures used in the study along with the sample Cronbach's alpha for each scale. The FAS interview items, utilised as a self-report scale in the current study, show high internal reliability as do the three DASS scales. Internal reliability of the WOCQ scales is more variable with the Distancing scale evidencing the lowest reliability for the full sample and for the mother and father subsamples. The Confrontive Coping and Self-Controlling scales were deemed to evidence unacceptably low reliability in the subsample of mothers and, as a consequence, were not utilised in further analyses. In this sample, coping process use was generally low with item means reflecting points between the 'not used' and 'used somewhat' anchors on the rating scale.

INSERT TABLE 3 ABOUT HERE

Rates of accommodation are shown in Table 4 below. The most common accommodations reported by parents were waiting for the child to complete compulsions (45% did this daily), watching the child complete rituals (43%), providing reassurance (37%) and refraining from doing or saying things because of the child's OCD (35%). Almost a

quarter of the sample reported extreme disruption or modification to their work or family routine as a result of accommodating.

INSERT TABLE 4 ABOUT HERE

Most mothers and fathers scored in the normal to mild range on the DASS scales and, generally, mothers' and fathers' means are more similar to the norm community sample than the clinical sample except for the depression score in mothers which is more similar to the clinical sample mean (Table 5). Notably, 26% of mothers scored as moderately depressed and 14% as extremely severely depressed. The proportion of extremely severely depressed mothers was similar in the specialist clinic and charity recruited groups.

INSERT TABLE 5 ABOUT HERE

Depression, anxiety and stress. Due to the presence of extreme scores on the DASS scales, Mann-Whitney tests were conducted to compare levels of anxiety, stress and depression between mothers and fathers in the full sample. Mothers ($Mdn = 3$, $Range = 0-37$, $N=42$) reported significantly more anxiety than fathers ($Mdn = 1$, $Range = 0-29$, $N=28$): $z = 2.10$, $p = .035$, 95% CI $[0, 3]$, $r = .25$. Mothers ($Mdn = 13.5$, $Range = 0-42$, $N=42$) reported significantly more stress than fathers ($Mdn = 6.5$, $Range = 0-39$, $N=28$): $z = 1.95$, $p = .05$, 95% CI $[0, 9]$, $r = .23$. Mothers ($Mdn = 11$, $Range = 0-35$, $N=42$) and fathers ($Mdn = 3$, $Range = 0-29$, $N=28$) did not differ significantly in depression: $z = 1.47$, $p = .14$, 95% CI $[-1, 9]$, $r = .17$.

The analysis was repeated with 25 mother-father pairs utilizing a Wilcoxon test. In this analysis, the only significant difference between mothers ($Mdn = 15$, $Range = 0-42$) and fathers ($Mdn = 6$, $Range = 0-39$) was in stress scores: $z = 2.81$, $p = .003$, 95% CI $[-8.5, -2.0]$, $r = .56$.

Symptom accommodation. Analysis of the full sample utilizing an independent samples t-test indicated that mothers ($M = 23.17$, $SD = 12.81$, $N=41$) and fathers ($M = 18.86$, $SD = 12.80$, $N=29$) did not differ significantly on total level of symptom accommodation: $t(68) = 1.38$, $p=.17$, 95% CI $[-1.89, 10.51]$, $d = .33$. When the analysis was repeated on the mother-father paired data utilizing a related samples t-test, the difference between mothers ($M=23.00$, $SD=12.67$) and fathers ($M=18.78$, $SD=12.06$) on total symptom accommodation was not significant: $t(26) = 1.83$, $p=.078$, 95% CI $[-.51, 8.96]$, $d = .34$.

As hypothesised, total accommodation was positively and strongly correlated with stress: $r_s = .57$, $p<.001$, 95% CI $[.31,.74]$, depression: $r_s =.71$, $p<.001$, 95% CI $[.51,.83]$, and anxiety: $r_s =.48$, $p=.001$, 95% CI $[.20,.68]$ in mothers ($N=41$). In contrast, the analysis indicated weaker and non-significant associations between total accommodation and stress: $r_s =.33$, $p=.078$, 95% CI $[.04,.62]$, depression: $r_s =.33$, $p=.079$, 95% CI $[.04,.62]$ and anxiety: $r_s =.03$, $p=.888$, 95% CI $[-.34,.39]$ in fathers ($N=28$).

Coping processes. Overall, mothers endorsed strategy use more frequently than fathers (Table 6). Coping scale scores in the full sample were positively skewed so these data were logarithmically transformed. Independent t-tests indicated that mothers used social support, accepting responsibility and escape-avoidance significantly more often than fathers.

INSERT TABLE 6 ABOUT HERE

The analysis of coping processes by mother-father pairs ($n=24$) produced similar results to those found in the full sample. Mothers ($M=3.84$, $SD=3.44$) endorsed accepting responsibility significantly more often than fathers ($M=1.84$, $SD=2.35$): $t(24)=3.33$, $p=.003$, 95% CI $[.76, 3.23]$, $d=.67$. Mothers ($M=7.00$, $SD=4.58$) reported using escape-avoidance

significantly more often than fathers ($M=3.64$, $SD=4.26$): $t(24)=3.21$, $p=.004$, 95% CI [1.20, 5.51], $d=.75$. Mothers reporting using social support ($M=5.80$, $SD=4.37$) significantly more than fathers ($M=4.08$, $SD=3.76$): $t(24)=2.21$, $p=.036$, 95% CI [.11, 3.32], $d=.42$.

As hypothesized, there was a strong positive correlation between escape-avoidance coping and negative affect. For mothers ($N=38$) correlations were: with anxiety $r_s=.55$ ($p<.001$), with depression $r_s=.54$ ($p<.001$) and with stress $r_s=.67$ ($p<.001$). For fathers ($N=28$) escape-avoidance was significantly and positively correlated with anxiety ($r_s=.57$, $p=.002$) and stress ($r_s=.52$, $p=.006$). Additionally, for mothers taking responsibility was consistently correlated with negative affect: with anxiety $r_s=.46$ ($p=.003$), with depression $r_s=.36$ ($p=.025$), and with stress $r_s=.36$ ($p=.023$). In contrast, for fathers using distancing was consistently related to negative affect: with anxiety $r_s=.71$ ($p<.001$), with depression $r_s=.40$ ($p=.038$), and with stress $r_s=.64$ ($p<.001$).

As hypothesized, the use of escape-avoidance coping was positively correlated with level of accommodation in both mothers ($r=.58$, $p<.001$) and fathers ($r=.37$, $p=.047$). In addition, taking responsibility was positively correlated with accommodation in mothers ($r=.44$, $p=.006$). Distancing was positively correlated with accommodation in fathers ($r=.46$, $p=.013$).

Discussion

Previous research has found that parents of children with OCD experience increased levels of negative affect (Peris et al., 2008). This was evident in parents' narratives in the current study. The linguistic analysis indicated that parents in this sample used more negative emotion words, particularly anxiety words, in their writing than has been reported in the literature for emotional writing (Pennebaker & Francis, 2007). The narratives of mothers and fathers did not differ in emotional or cognitive content. In contrast, the analysis of

distress indices indicated that mothers reported significantly more stress and anxiety than fathers, but not depression. Mothers and fathers scored in the normal to mild range on these variables although a considerable proportion of mothers were moderately or severely depressed. These findings suggest that gender differences in the expression of negative affect vary as a function of mode of enquiry.

Like other studies, rates of accommodation in this sample were high with almost half of parents engaging in some form of accommodation on a daily basis. Mothers scored higher than fathers on accommodation although the effect size was modest and the difference non-significant. However, the sample size in this study was small and, given this is the first study comparing parents on accommodation, replication is needed. Qualitative analysis of written narratives illuminated the dissonance that these parents manage. Parents described the tension of not accommodating and, as found in other studies (e.g. Storch et al. 2007), were motivated to do so to reduce or manage the child's distress and anger. However, they experienced guilt for engaging in accommodation when they knew it to be counterproductive to their child's improvement, as has been found in other studies (e.g. Livingston-Van Noppen, Rasmussen, Eisen & McCartney, 1990; Shafran et al., 1995). Parents described how OCD had changed and restricted their family life and there was some element of blame towards the affected child when parents could not understand if the symptoms were part of adolescent bad behavior. The qualitative data support the suggestion made by Storch et al. (2007) that pediatric treatment strategies should include teaching parents strategies to resist accommodation in the face of the child's anger and distress. Some parents felt to blame for not recognizing the problems earlier. Keeley et al. (2007) point out that education and interventions with parents should encourage them to move beyond ideas about blame for OCD symptoms and to engage more with positive and adaptive behaviors that their children engage in. Some parents reported oscillating between accommodation and refusal or

antagonism. Similarly, Livingston-Van Noppen et al. (1990) found familial responses to OCD to fall along a continuum from consistent involvement and over-protectiveness to antagonism. Allsopp and Verduyn (1990) suggested that some families were split in their responses; one parent may be accommodating whereas the other antagonistic, and some parents may be oscillating in their responses. The latter has been associated with family conflict, which can be stressful for the person with OCD (Van Noppen, Steketee, & Pato, 1997; Stengler-Wenzke, Trosbach, Dietrich & Angermeyer, 2004). Some writers, most notably Guidano and Liotti (1983), theorize that ambivalent parenting might be a risk factor for the development and maintenance of obsessional states. As such, the assessment of contradictions in parental response to OCD seems important to intervention strategies.

As expected, accommodation was positively correlated with negative affect in parents although the effects sizes were stronger for mothers and correlations for fathers were non-significant. This may be due in part to fathers' generally low levels of negative affect on the standardized measures. Previous studies (Calvocoressi et al., 1999; Peris et al., 2008) have raised the question of whether symptom accommodation might arise as an extension of a relatives' own psychopathology. Although the results of this study do not suggest high levels of negative affect in this sample in general, we did not formally assess parental obsessive-compulsiveness or other forms of anxiety. However, the fact that mothers had higher distress scores and reported more accommodation might lend some support to this hypothesis. However, with a cross-sectional design, the causal direction cannot be inferred. Parents may accommodate more to manage their own distress or may be distressed as a result of accommodation. It is also possible that accommodation produces physical health implications that relate to the experience or amplification of distress.

Generally, the coping processes measured in this study were used infrequently by parents. This may either be because these processes are deemed ineffective in relation to

OCD in a child and so are not utilized, or that the items do not tap relevant aspects of coping in this context. Geffken et al. (2006) reported a positive correlation between denial/disengagement and depression in relatives. Similarly, escape-avoidance coping was positively correlated with negative affect in both mothers and fathers in the current study. Additionally, distancing was positively correlated with negative affect in fathers. In contrast, taking responsibility was positively correlated with negative affect in mothers. Again, a cross-sectional design means competing interpretations. For example, taking responsibility might prompt more accommodation or responsibility might arise as a way to manage the effects of accommodation. These data do support a common finding in the literature that emotion-focused coping processes are associated with negative affect. However, Austenfeld and Stanton (2004) argue that the consistent finding that emotion-focused processes are correlated with poorer well-being may be due to emotion-focused process measurement being confounded by items tapping distress and self-esteem. Additionally, for refractory problems, emotion-focused coping may be a better option than problem-focused coping (Lazarus, 1993).

In the current study, as hypothesized, escape-avoidance coping was positively correlated with accommodation in both mothers and fathers. One interpretation may be that accommodation is a form of emotion-focused coping given that part of its function is to help parents regulate their own affect in relation to their child's distress. However, this interpretation is tempered by the observation that not all emotion-focused processes were consistently related to accommodation in mothers and fathers. Future studies on coping and accommodation are required given the small number of studies in this area. Geffken et al. (2006) observe that clinicians can play a useful role in supporting more effective coping mechanisms by encouraging parents' sense of hopefulness. Including parents as co-therapists may help them to feel more confident in their ability to support their child in managing and

overcoming OCD, and decrease their helplessness, frustration and distress. Psycho-education coupled with cognitive-behavioural strategies may be important in modifying parents' attributions about their child's responsibility and control, and their own hopelessness and helplessness. Providing such an intervention in a group setting can offer peer support which may be important given that parents in this study described feeling socially isolated and alone with their experiences. A group, in which they could share their experiences and meet other parents and affected children, may not only decrease social isolation but also stigma.

In conclusion, the study strengths and limitations will be addressed. The current study is the first to both qualitatively and quantitatively analyse parental narratives about caring for a child with OCD. Although the sample size is small, reasonable levels of participation from both mothers and fathers meant that we were able to compare them on indices of accommodation, coping and distress. Utilizing varied forms of data collection and analysis allowed us to triangulate findings in order to provide a more comprehensive picture of symptom accommodation and distress in parents. The use of two different methods to analyse parents' narratives proved particularly important. The qualitative analysis appeared to indicate more detached accounts by fathers and highly emotional ones by mothers, perhaps the latter impression being contributed to by the fact that mothers wrote significantly longer letters than fathers. Quantitative analysis, however, indicated no differences between mothers and fathers in their emotional word usage. This indicates the importance mixing methods in order that interpretations of open-ended data are not influenced, for example, by narrative length or cultural expectations regarding gender differences in emotional expression. The separate focus on mothers' and fathers' experiences, accommodation and distress also provides some insight into caring across family systems and where there might be potential for an ambivalent response to the child's distress. However, there are number of limitations to the current study that need to be attended to in future studies. The sample size

is small and, as such, the conclusions that can be drawn and the generalizability of the findings must be circumspect. Some of the statistical analyses were underpowered and significant effects may not have been detected. The overall response rate was a little over fifty percent. There may have been differences in those who participated and those who decided not to in terms of their subjective experiences and distress. The sample was drawn from two different sources and we were unable to verify diagnostic status of children whose parents were recruited from the national OCD charity. Similar to much published OCD research, the sample was predominantly White and several were from families where both parents have had formal education beyond 16 years of age. Therefore, additional research is needed with more diverse samples. The amount of time spent with a child with OCD was not assessed, which may impact on parents' experiences, distress and accommodation. Additionally, we cannot be sure of the order in which parents completed the study materials. If they completed the measures of affect after completing the letter writing task then it is possible that we unwittingly introduced a non-systematic confound in the study. Affect scores of those parents completing the measures after the letter writing task might be different from those completing them before the letter writing task because the task may have produced short-term cognitive and emotional effects. Future studies should ensure that affect measures are completed prior to writing tasks. Although internal reliability coefficients for the measures used in the current sample were good, the FAS was not developed as a self-report tool and further data are required supporting the validity of delivering the items in this way. The confrontive coping and self-controlling subscales of the WOCQ showed unacceptably low internal reliability in the subsample of mothers such that these variables were not used in the analyses. Kieffer and MacDonald (2011) indicate that the reliability of WOCQ varies widely as a function of sample composition and underscore the importance of researchers estimating reliability within their own samples. Finally, measuring coping

processes as discrete elements risks inferring that these are stable ways in which an individual responds and also fails to see them in broader context. Future studies might focus on which aspects of the OCD experience are perceived as threats and challenges, their temporal stability, how parents respond to them, and how accommodation fits within this framework.

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Table 1: Sample characteristics

Characteristic	Mothers	Fathers
N approached/participated (response rate) OCD clinic	53/33 (62%)	47/22 (47%)
N approached/participated (response rate) OCD charity	17/9 (53%)	14/7 (50%)
Mean age (SD)	46.33 (5.35)	49.62 (5.44)
White ethnic group	95%	92.9%
Married	80%	89%
Education: to 16 years	23%	23%
to 18 years	13%	20%
to diploma	33%	4%
to higher	25%	44%
no response	6%	9%

Table 2: Emotional and cognitive word usage in parents' writing about pediatric OCD

LIWC word category	Reference values (emotional writing) ¹ Mean	Writing about child's OCD			
		All parents N=69 Mean (SD)	Mothers N = 41 Mean (SD)	Fathers N = 28 Mean (SD)	95% CI for the difference between parents
Affective processes	6.02	6.91 (1.66)	6.81 (1.29)	7.06 (2.12)	-1.07, .56
<i>Negative emotions</i>	2.67	4.27 (1.57)	4.23 (1.34)	4.33 (1.88)	-.87, .67
Anxiety	0.68	1.65 (1.26)	1.60 (0.82)	1.71 (1.73)	-.81, .60
Anger	0.66	.69 (.66)	0.65 (0.61)	0.75 (0.74)	-.42, .22
Sadness	0.63	.64 (.55)	0.71 (0.56)	0.53 (0.54)	-.08, .45
<i>Positive emotions</i>	3.28	2.62 (1.15)	2.53 (0.97)	2.77 (1.38)	-.80, .32
Cognitive Processes	19.66	20.19 (3.08)	20.34 (3.27)	19.97 (2.84)	-1.14, 1.89
<i>Insight (e.g. know)</i>	3.25	3.57 (1.25)	3.68 (1.31)	3.41 (1.14)	-.34, .88
<i>Causation (e.g. because)</i>	1.85	2.34 (1.17)	2.38 (1.13)	2.27 (1.25)	-.46, .69
<i>Discrepancy(e.g. should)</i>	2.13	1.81 (1.01)	1.92 (0.91)	1.63 (1.14)	-.20, .79
<i>Tentative (e.g. maybe)</i>	2.93	2.98 (1.17)	2.72 (1.04)	3.35 (1.26)	-1.18, -.07*
<i>Certainty (e.g. always)</i>	1.73	1.43 (.96)	1.45 (0.85)	1.41 (1.12)	-.43, .51
<i>Inhibition (e.g. block)</i>	0.46	.95 (.72)	0.89 (0.55)	1.04 (0.93)	-.54, .24

¹ Reference emotional writing values obtained from Pennebaker and Francis (2007)

*Significant difference between mothers and fathers

Table 3: Means, standard deviations and Cronbach's alpha coefficients for study scales

Scale	Total sample mean	N items	Alpha total sample (N)	Alpha mothers (N)	Alpha fathers (N)
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	(SD)*				
FAS Total	21.39 (12.89)	12	.92 (70)	.91 (41)	.92 (29)
DASS Anxiety	4.39 (7.48)	14	.94 (70)	.94 (42)	.93 (28)
DASS Depression	9.91 (10.23)	14	.95 (70)	.95 (42)	.95 (28)
DASS Stress	12.80 (10.65)	14	.95 (70)	.93 (42)	.97 (28)
WOCQ Planful problem-solving	.96 (.60)	6	.71 (66)	.68 (38)	.71 (28)
WOCQ Positive reappraisal	.67 (.60)	7	.78 (66)	.76 (38)	.81 (28)
WOCQ Distancing	.82 (.56)	6	.67 (66)	.67 (38)	.66 (28)
WOCQ Escape- avoidance	.73 (.58)	8	.75 (66)	.71 (38)	.78 (28)
WOCQ Accepting responsibility	.74 (.76)	4	.82 (66)	.83 (38)	.78 (28)
WOCQ Confrontive coping	.91 (.54)	6	.69 (66)	.60 (38)	.78 (28)
WOCQ Self- controlling	1.14 (.61)	7	.71 (66)	.56 (38)	.83 (28)
WOCQ Seeking social support	.90 (.69)	6	.76 (66)	.75 (38)	.72 (28)

FAS=Family Accommodation Scale; DASS=Depression Anxiety Stress Scale; WOCQ=Ways of Coping Questionnaire; *item means are given for the WOCQ scales

Table 4: Descriptive statistics for individual FAS items

FAS item	M	SD	Range	Daily (%)*
Providing reassurance to child	2.34	1.52	0-4	37
Watching child complete rituals	2.31	1.66	0-4	43
Waiting for the child	2.51	1.61	0-4	45
Refraining from saying/doing things	2.44	1.46	0-4	35
Participating in compulsions	1.19	1.62	0-4	20
Facilitating compulsions	1.37	1.62	0-4	22

Facilitating avoidance	1.01	1.45	0-4	14
Helping the child with simple tasks	2.19	1.28	0-4	21
	M	SD	Range	Extreme (%)**
Tolerated odd behaviour/disruption	1.83	1.49	0-4	22
Taking on the child's responsibilities	1.23	1.28	0-4	7
Modifying your personal routine	1.53	1.32	0-4	13
Modifying the family routine	1.43	1.34	0-4	13

*Proportion reporting engaging in the accommodation on a daily basis; **proportion reporting extreme disruption or modification (e.g. unable to work, tolerating extreme behaviour, disruption to all aspects of family routine).

Table 5: Descriptive statistics for depression, anxiety and stress in mothers and fathers

	Depression – N		Anxiety – N		Stress – N	
	Mothers	Fathers	Mothers	Fathers	Mothers	Fathers
Normal	20	19	35	25	21	21
Mild	4	3	1	-	9	1
Moderate	11	2	3	2	7	3
Severe	1	2	-	-	3	1
Extremely Severe	6	2	3	1	2	2
Sample Mean (SD)	11.45 (10.69)	7.61 (9.19)	5.24 (8.21)	3.11 (6.16)	14.40 (10.27)	10.39 (10.95)
Norm Mean (SD)*						
Community	6.34 (6.97)		4.7 (4.91)		10.11 (7.91)	
Clinical	10.65 (9.3)		10.90 (8.12)		21.1 (11.15)	

*Lovibond & Lovibond (1995)

Table 6: Differences between mothers and fathers in coping process use

Coping process	Mothers (N=38) Mean (SD)	Fathers (N=28) Mean (SD)	t(64)	p	d	95% CI for difference
Distancing	5.32 (3.48)	4.50 (3.29)	.74	.46	.24	-.09, .20
Social support	6.42 (4.34)	4.04 (3.60)	2.50	.015	.59	.04, .37
Responsibility	3.66 (3.33)	2.04 (2.36)	2.34	.022	.56	.02, .36
Escape-avoidance	7.11 (4.57)	4.14 (4.33)	2.76	.007	.66	.07, .44
Positive reappraisal	5.37 (4.37)	3.82 (3.96)	1.61	.11	.37	-.03, .34
Problem-solving	6.47 (3.74)	4.93 (3.39)	1.69	.09	.43	-.02, .26