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Functional Impairment in South African Children and Adolescents
with Obsessive-Compulsive Disorder

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A dissertation submitted in fulfillment of the requirements for the award of the degree of Master
of Social Science (MSocSc) in Psychology

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COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

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1 June 2009

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ABSTRACT

This research aimed to increase current understanding of functional impairment in children and adolescents with Obsessive-Compulsive Disorder (OCD). Twenty-six South African children and adolescents with OCD participated in the study. The Schedule for Affective Disorders and Schizophrenia for School-Age Children-Present and Lifetime Version (KSADS-PL), the Mini International Neuropsychiatric Interview For Children and Adolescents Version 5 (MINIKID5.0), the Children's Global Assessment Scale (CGAS), the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) and the Child Obsessive-Compulsive Impact Scale-Revised (COIS-R) were used to assess the children's and adolescent's past and current psychopathology, OCD symptom severity and OCD-related functional impairment.

Findings suggest that most of the children (88.46%) in this study had one or more comorbid disorders. Parents and children agreed on very few of the rating items common to the COIS-R-P and COIS-R-C. Parents, however, consistently reported higher rates of significant problems than did their children. Correlations between the various instruments revealed that parents are more accurate than their children in rating their child's global impairment and OCD-specific impairment. Therefore, collateral information from parents is vital for the clinician to accurately assess and fully understand the child's OCD-related functional impairment. Moreover, the number of comorbid disorders, and whether the child had ADHD or not, did not impact on the COIS-R total scores, suggesting that the COIS-R is a useful measure to assess OCD-specific impairment. Parents and children both reported that the most significant domain of impairment is the school domain. Moreover, parents reported that the most significant functional problem is

“concentrating on his/her work” and children reported that the most significant functional problem is “getting good grades.”

Findings from studies such as this help clinicians to have a better understanding of childhood OCD-related functional impairment, which helps them to accurately diagnose and treat children with OCD.

Keywords: Obsessive-Compulsive Disorder; children; adolescents; functional impairment; diagnosis; treatment

INTRODUCTION

Obsessive-Compulsive Disorder (OCD) can be a devastating psychiatric illness that impairs a child's development across multiple domains (Piacentini, Bergman, Keller, & McCracken, 2003; Valderhaug & Ivarsson, 2005; Warner & Pottick, 2006). Recent studies have reported that children/adolescents with OCD from the United States of America and from Norway and Sweden are functionally impaired in home, academic, and social domains. Interestingly, Scandinavian individuals mainly reported impairments in the home domain, whereas American children and adolescents reported more impairment in the home and school/academic domain compared to the social domain (Piacentini, Bergman, Keller, & McCracken, 2003: Author; Valderhaug & Ivarsson, 2005). The extant research therefore suggests that functional impairments due to OCD may differ across cultures. These cross-cultural differences are important, as research also suggests that, in childhood and adolescence, functional impairment has critical implications for the diagnosis and treatment of OCD (Angold, Costello, Farmer, Burns, & Erkanli, 1999; Kramer, et al., 2004; Valderhaug & Ivarsson, 2005). In particular, these differences need to be considered when formulating treatment plans to adequately address pertinent areas of functional impairment in an individual within a specific cultural context. Given that the nature and extent of functional impairments in South African children and adolescents with OCD are not yet known, a study focusing on such impairments is necessary in order to stimulate future research into diagnosis and treatment of OCD-afflicted youth in this country.

LITERATURE REVIEW

OCD: Epidemiology, Etiology, Clinical Presentation, and Treatment

Although the current research specifically examines the functional impairment of South African children and adolescents with OCD, it is useful to first describe the broad profile of OCD (with particular reference to childhood OCD research where possible) to understand the context into which this study fits and the subsequent implications thereof.

The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000) describes obsessions as consistent thoughts, images, impulses or ideas that cause an individual anguish. Compulsions, in contrast, are repeated behaviours or mental acts that most times result from obsessions and therefore are often used to reduce the unease and worry caused by those obsessions. (See Appendix A for the complete diagnostic criteria according to the DSM-IV-TR.)

Studies have reported somewhat different prevalence rates for OCD in children and adolescents (see Table 1; Brynska & Wolanczyk, 2005; Diler & Avci, 2002; Heyman, et al., 2003; Karno, Golding, Sorenson, & Burnam, 1988; Rapoport, et al., 2000; Zohar, 1999). Interestingly, a recent epidemiological study conducted in the United Kingdom reported that OCD prevalence increases exponentially with age. The study found, for example, that there was a prevalence of 0.21% in the 11-12-year-old age group, compared to a prevalence of 0.63% in the 13-15-year-old-age group (Heyman et al., 2003).

Table 1
Prevalence Rates of OCD in Children and Adolescents

Study Identification	Country	Sample Size	Prevalence (%)	Age range
Zohar (1999)	Israel	861	2.3	16-17
Rapoport et al. (2000)	United States	1285	1.72	9-17
Diler & Avci (2002)	Turkey	1739	2.7	-
Heyman et al. (2003)	United Kingdom	10438	0.25	5-15
Brynska & Wolanczyk (2005)	Poland	3100	0.38	13-14

The etiology of OCD is multifactorial. For instance, a large body of research has indicated that the disorder has a neurobiological basis. Although theoretical models have proposed that OCD is characterized by functional and structural abnormalities in orbitofronto-striatal circuits, a recent meta-analysis of functional MRI studies revealed that there are abnormalities in the orbitofronto-striatal circuit and in related limbic structures (e.g., amygdala), as well as in more lateral frontal and parietal areas of the brain (Menzies et al., 2008).

In addition to neurobiology, other factors may also play a role in the development of OCD. For example, childhood trauma is an environmental risk factor for the development of OCD (Cromer, Schmidt, & Murphy, 2007; Gothelf, Aharonovsky, Horesh, Carty, & Apter, 2004; Vasconcelos, et al., 2007). For example, a recent study showed that children with OCD had a greater number of life events that had a negative impact on their lives, than healthy controls, the year before their OCD began (Gothelf et al., 2004). For instance, Lochner et al. (2002) used the Childhood Trauma Questionnaire (a self-report measure that assesses presence and degree of physical, emotional and sexual abuse, as well as physical and emotional neglect; (Bernstein et al., 1994) and found that females with OCD ($n = 74$; mean age = 36.1 years) reported a greater

severity of childhood trauma than female controls ($n = 31$; mean age = 21.5 years) ($p = 0.001$). Additionally, features of posttraumatic stress disorder (PTSD) may co-occur with OCD, and it has been suggested that a diagnosis of PTSD increases the risk of one being diagnosed with OCD (Brown, Campbell, Lehman, Grisham, & Mancill, 2001).

Furthermore some researchers (e.g., Swedo, 2002) have proposed that OCD can be caused by streptococcal infection (i.e., pediatric autoimmune neuropsychiatric disorder associated with streptococcal infection (PANDAS)). This is because a higher prevalence of OCD has been found among people with Sydenham's chorea (e.g., Swedo, Rapoport, & Cheslow, 1989). A study with OCD probands (i.e., first-degree relatives of OCD children) found that the rates of tic disorders and OCD are higher in the probands of children with PANDAS than they are in the rest of society (Lougee, Perlmutter, Nicolson, Garver, & Swedo, 2000). This may indicate that these children most likely had a genetic vulnerability to OCD and that an environmental trigger, such as a streptococcal infection, led to the development of OCD symptomatology. With regard to the actual mechanism of this environmental trigger, some researchers have proposed that the group A beta-hemolytic streptococcal bacteria activates antibodies that cross-react with the basal ganglia of a genetically vulnerable child, which results in the child developing OCD (Garvey, Giedd, & Swedo, 1998). Future research will determine the extent to which genetic vulnerabilities play a role in PANDAS.

Many researchers have argued that OCD has a genetic basis, and several recent meta-analyses have done much to advance the knowledge of the genetics of OCD. One of those recent reviews concluded that there has been much progress in OCD genetics research, but that a single gene or

single genetic model may not best describe the features of OCD transmission (Grisham et al., 2008).

Genetic association studies of OCD (i.e., studies that attempt to compare single-locus alleles or genotype frequencies in OCD participants versus non-OCD participants) have directed their research to genes that are vital to the serotonergic and dopaminergic neurotransmitter systems (e.g., Camarena, Loyzaga, Aguilar, Weissbecker, & Nicolini, 2007; Denys, Van Nieuwerburgh, Deforce, & Westenberg, 2006; Saiz et al., 2008). The majority of these candidate genes have been chosen by examining animal models, clinical case observations and drug usefulness in treating OCD. With regards to the serotonergic system, the serotonin transporter, serotonin receptor types (2A, 2C, 1D β), and tryptophan hydroxylase have been examined. For instance, Bloch et al. (2008) examined the link between OCD and the long and short alleles of the serotonin transporter polymorphism in the promoter region (5-HTTLPR) of the SLC6A4 gene. Although their overall meta-analysis did not support the association between an OCD diagnosis and the long and short alleles of the serotonin transporter polymorphism in this region of that gene, their stratified meta-analysis suggested that there is a link between the long allele and OCD in family-association studies. In the dopaminergic system, dopamine receptors 2, 3 and 4, the dopamine transporter gene, monoamine oxidase A (MAOA), and catechol-O-methyltransferase (COMT) have been examined. Other candidates that have been investigated are genes encoding glutamate, glutamate ionotropic kainite receptors (1 and 3), GABA Type B receptor 1, brain-derived neurotropic factor, and myelin oligodendrocyte glycoprotein (Grisham, et al., 2008). However, a recent review indicated that findings from association studies have been inconsistent

thus far and future studies that consider OCD subtypes may be useful (Hemmings & Stein, 2006).

Another recent review examining twin, family and linkage genetic studies in OCD revealed that the disorder is familial and that this heritability is at least partially explained by genetic factors (Pauls, 2008). For instance, studies reviewed by Pauls (2008) showed that the rate of OCD is much higher among the relatives of those with the disorder than among the general population, and that particular vulnerable areas on the genome appear to be where OCD is implicated. However, no studies have been able to reach genome-wide significance.

In summary, genetic and environmental factors probably play complementary roles in OCD development (e.g., a functional polymorphism in the promoter area of SLC6A4 may mediate the risk for developing OCD after enduring a harrowing event; Grisham et al., 2008). It is, however, exceptionally difficult to design a study examining this gene x environment interaction. One of the principal challenges here is that OCD is a heterogeneous disorder (Ivarsson & Valderhaug, 2006). Therefore, different varieties of the OCD phenotype may have dissimilar etiologic pathways (Cavallini, Bella, Siliprandi, Malchiodi & Bellodi, 2002, as cited in Grisham et al., 2008), which means that there may be differences amongst genetic, neural, and neuropsychological correlates in OCD (Grisham et al., 2008). Thus, OCD subtypes (e.g., contamination and cleaning sub-type; Ivarsson & Valderhaug, 2006) may develop as a result of different gene x environment interactions, and so subtypes would need to be examined separately, as described above.

With regard to the kinds of cognitive contents (beliefs and appraisals) that are relevant to OCD, there has been disagreement amongst researchers, although it has been clear that cognitive contents and cognitive processes are significant in the etiology and maintenance of OCD. The Obsessive Compulsive Cognitions Working Group provided clarity on this issue (Obsessive Compulsive Cognitions Working Group, 1997). This group of researchers reached consensus that “intrusions”, “appraisals” and “assumptions” are relevant levels of cognition in OCD (p. 670). Furthermore, they agreed that specific domains of obsessive-compulsive beliefs are important in OCD: inflated responsibility; thought-action-fusion and other beliefs concerning the over-importance of the consequences of one’s thoughts; excessive concern about the importance of controlling one’s thoughts; overestimation of the probability and severity of threat; and intolerance for uncertainty. For example, people with OCD may perform compulsions in order to neutralize their unwanted thoughts and diminish distress that they are experiencing. The distress that they are experiencing results from their feelings of responsibility and accountability (Salkovskis, Shafran, Rachman, & Freeston, 1999).

With regard to the treatment of OCD, two recent meta-analyses of randomized and quasi-randomized controlled trials suggested that cognitive-behavioural therapy (CBT) is an effective approach for children (O’Kearney, Anstey, & Von Sanden, 2006; Watson & Rees, 2008).

Although CBT and pharmacotherapy were both found to be effective, there was evidence that CBT is more effective than pharmacotherapy (Watson & Rees, 2008). One of these reviews confirmed that behaviour therapy (BT) and CBT may be more effective when administered in conjunction with medication (O’Kearney et al., 2006). Another meta-analysis of CBT trials in childhood OCD, this time not limited to randomized controlled trials, confirmed that CBT is an

effective treatment approach, with individual and family-based CBT being the most effective approaches (Freeman et al., 2007).

A major component of (C)BT for OCD is exposure and response prevention (ERP; O'Kearney et al., 2006). Exposure involves putting the patient in settings that provoke anxiety linked to his/her obsessions; response prevention involves prohibiting the patient from performing the ritualistic or compulsive behaviours that normally help to decrease anxiety (Storch, 2005). In other words, exposure and response prevention typically entails exposing the child to the situation that causes him/her to perform a compulsive behaviour and then stopping him/her from performing that compulsion. Moreover, because a child with OCD never feels normal anxiety reduction (i.e., always performs a compulsion to decrease their anxiety and distress), response prevention therefore requires a child to stop performing his/her compulsions so that their anxiety can decrease as a result of habituation instead. For example, a child that always wants to wash her hands after touching something that he/she thinks has germs on it will be prohibited from washing his/her hands. This prevention will, in turn, reduce his/her fear of germs. Consecutive exposures to the stimulus both decrease the rising anxiety that results from exposure to the stimulus and helps the patient's distress to more quickly dissipate in future exposures.

With specific regard to pediatric OCD, the disorder is usually first diagnosed in adolescence or young adulthood; in some cases, however, the first diagnosis may occur during childhood.¹

¹Developmentalists generally regard the word *childhood* as describing the period from birth until approximately 12 years old, and *adolescence* as spanning the period from 12 years old to about 20 years old (Shaffer, 2002). The functional impairments due to OCD occurring during both these life spans (i.e., childhood and adolescence) will be examined.

Although the clinical presentation of OCD in childhood is very similar to that in adulthood (e.g., both report multiple obsessions and compulsions and the same levels of depression) there are some differences (Farrell & Barrett, 2006; Mancebo et al., 2008). For example, in childhood and adolescent OCD more males than females are diagnosed, whereas in adult OCD there is a more equal sex distribution. Additionally, children more frequently have comorbid diagnoses of ADHD, Oppositional Defiant Disorder (ODD), Specific Phobia and Tics; and fewer mood, substance use and eating disorders. They also have fewer checking compulsions; have less pathological doubting; and have less trait anxiety. Children less frequently describe experiencing aggressive obsessions and mental rituals than adolescents and adults. However, adolescents differ from children and adults in that they describe more contamination obsessions and washing compulsions. Children also have less insight into their disorder than adolescents and adults.

Perhaps most importantly with regard to clinical presentation, OCD becomes more severe across the lifespan (Farrell & Barrett, 2006). In childhood OCD, there is “less anxiety, severity of obsessions and compulsions, avoidance, indecisiveness, pathological responsibility and social impairment, compared to adulthood” (Farrell & Barrett, 2006, p. 115). This fact points to the need to treat childhood OCD effectively so that it does not continue into adulthood.

In terms of specific symptoms of childhood OCD, a principal components analysis of 137 children with OCD demonstrated that four factors describe the features of childhood OCD: compulsions, sexual/aggressive obsessions, superstitions, and hoarding/ordering/somatic concerns (McKay et al., 2008). The researchers make clear that many of the items within the different symptom domains of the Children’s Yale-Brown Obsessive-Compulsive Scale (CY-

BOCS; Scahill et al., 1997) could be linked to more than one factor. This research demonstrates that in childhood, symptom domains are clearly not as fully developed as they are in adulthood OCD. Thus, it is evident that discrete OCD symptom dimensions may only develop later on in life.

Functional Impairment in Childhood/Adolescent OCD

OCD symptoms impact on the patient's functioning. According to the DSM-IV-TR OCD is associated with impairments in occupational, social, and interpersonal domains (American Psychiatric Association, 2000). For example, a person with OCD may avoid certain social situations because those situations provoke his/her obsessions or compulsions. With regard to children, the manual indicates that there have been reports that schoolwork is negatively affected, but that lack of concentration at school is a bigger problem caused by OCD than are general problems with schoolwork. Also, the manual states that children are more likely to conduct their rituals at home than in other places. An example that demonstrates the link between the obsessive and/or compulsive symptom and the resulting functional impairment is of a child with dirt/germ concerns which leads to excessive hand-washing. This compulsive behaviour in turn may lead to extensive periods of time spent in the bathroom, bringing him/her in constant conflict with other family members who also wish to make use of these facilities. Additionally, the excessive time taken up by hand-washing prevents him/her from engaging in other social activities or school-work.

The assessment of functional impairment associated with obsessions and/or compulsions is one of the deciding factors that determines whether OCD or subclinical OCD is diagnosed (Angold et

al., 1999; Valderhaug & Ivarsson, 2005). Therefore, subjective distress and functional impairment largely determines “caseness” (Winters, Collett, & Myers, 2005).

Although functional impairment is frequently confused with a mere description of the severity of a disorder, it is more adequately defined as “specific deficits in multiple domains of functioning developing subsequent to a disorder” (Winters et al., 2005, p. 309). Severity of illness does not explicitly point to the areas of life in which the person is functionally impaired, nor does it imply how the person has adapted to his/her disorder or which areas of functioning are not affected by the disorder.

Winters and colleagues (2005) provide a number of reasons why it is vital to assess a patients’ functional impairment: First, researchers and clinicians have realised that even if symptoms of a psychiatric disorder are no longer experienced by a person, this does not always correlate with treatment response and functional improvement. Second, scales measuring functional impairment can determine the impact of the disorder on children, determine treatment targets, point to fundamental service needs, and monitor whether treatment has been successful or not. Third, functional outcomes such as the child being able to live at home with his/her family and go to school are favorable for the child and the family.

Kramer et al. (2004) point to the importance of correctly evaluating the extent and nature of an adolescents’ functional impairment. They indicate that there sometimes are disagreements between parents and their children’s ratings of their functional impairment in a particular domain. Knowing the source(s) of this disagreement may affect treatment planning and treatment

response. For instance, if a parent's report is different to that of the adolescent because the adolescent hides their "problematic" behaviour from his parents, this fact can inform treatment. Therefore, Kramer et al. (2004) emphasized the importance of correctly evaluating an adolescent's functioning and functional impairments (i.e. getting information from both parent and adolescent), so that he/she can be correctly diagnosed, enrolled in a suitable treatment programme, and have their treatment progress monitored in an appropriate manner.

Although numerous studies regarding functional impairment in OCD have been conducted in adult samples (e.g., Calvocoressi et al., 1995; Cooper, 1996; Koran, Thienemann, & Davenport, 1996), the range and degree of specific functional impairment due to OCD have not been extensively documented in children. Additionally, most of the studies of functional impairment in children and adolescents with OCD suffer from numerous methodological limitations. For instance, Allsopp and Verduyn (1990) and Toro, Cevera, Osejo, and Salamero (1992) analyzed clinical descriptions of adolescents with OCD. Although these studies suggest that children and adolescents with OCD show marked functional impairment (e.g., relationship and academic problems), the fact that the authors relied on clinical records and not objective measures to assess the nature and extent of that impairment, is problematic. Clinical records are highly subjective and are therefore not always a valid representation of functional impairment in the child/adolescent with OCD. Furthermore, Allsopp and Verduyn (1990) admit that there are limitations (e.g., incomplete data, clinician bias) to conducting a retrospective study of case-note data.

Given such methodological limitations, it is true to say that until about 6 years ago there was little reliable and valid knowledge about the functional impairments of children and adolescents with OCD. Some recent studies have, however, attempted to address this gap in the literature.

A recent and important development is the introduction of a measure that specifically assesses OCD-related functional impairment in children (i.e., the Child OCD Impact Scale (COIS)). The COIS consists of 2 sections (i.e. a parent- (COIS-R-P) and a child- (COIS-R-C) self-report questionnaire) that assess specific OCD-related functional impairment in children and adolescents with OCD (Piacentini & Jaffer, 1999, as cited in Piacentini et al., 2003). Piacentini et al. (2003) and Valderhaug and Ivarsson (2005) found that the COIS correlated well with clinician-rated measures of OCD severity and global impairment. In addition, Valderhaug and Ivarsson (2005) found that the COIS contributes unique information about impairment associated with OCD (i.e., these authors found that it supplements other impairment measures). Moreover, both studies reported good agreement between COIS parent and child reports. These studies also suggested that the COIS should be used in epidemiological and treatment outcome studies, and that clinicians should use it in clinical practice when making diagnostic decisions about OCD in children and adolescents.

Some studies have used the COIS along with other measures (i.e., OCD-specific measures) to examine specific functional problems associated with childhood OCD. For instance, Storch et al. (2008) examined sleep-related problems in childhood OCD using the CY-BOCS (Scahill et al. 1997), the Child Behavior Checklist (CBCL: Achenbach & Rescorla, 2001), the parent version of the COIS (Piacentini & Jaffer, 1999, as cited in Piacentini et al., 2003), the Multidimensional

Anxiety Scale for Children (March, Parker, Sullivan, Stallings, & Conners, 1997), the Children's Depression Inventory (Kovacs, 1992) and the Sleep Composite Measure (Alfano, Ginsberg, & Kingery, 2007). They found that 92% of their 41 participants (mean age = 12.4 years) had at least one sleep-related problem, while 27.3% indicated that they had five or more sleep-related problems. Moreover, OCD symptom severity, self-rated anxiety and parent-proxy ratings of internalizing issues were linked to the number of sleep-related problems that the child had (i.e., the more sleep-related problems, the more severe the child's OCD). Importantly, however, sleep-related problems were not significantly associated with OCD functional impairment. These researchers suggested that this lack of association may be attributable to the fact that the parent version of the COIS does not examine the kinds of impairments in which sleep problems typically result.

A recent study by the same research group examined family accommodation (i.e., participation in symptoms; Peris et al., 2008) in childhood OCD (Storch et al., 2007). Fifty-one children and adolescents (mean age = 12.99 years) with OCD were administered the COIS and other OCD-related measures (e.g., the Family Accommodation Scale; Calvocoressi et al., 1995, 1999) and the CY-BOCS), as well as measures of general impairment (e.g., the CBCL). Results showed that family accommodation was positively linked to OCD symptom gravity, parent-reported functional impairment (but not child-reported impairment) and externalizing and internalizing symptoms.

Other studies have used the COIS to assess the domain of functioning most frequently affected by the child's OCD: i.e., their most frequently endorsed specific functional problems; the

differences between adolescents and children with regards to their OCD-related functional impairment; and the differences between males and females with regards to childhood OCD-related functional impairment.

For instance, Piacentini et al. (2003) used the COIS to study the functional impairments of a sample of 151 clinic-referred children and adolescents with primary OCD. The sample ranged in age from 5 to 17 years old (mean = 11.8). Eighty-three percent of the participants were white, and 68% had a comorbid psychiatric disorder. Both the child/adolescent and his/her primary caretaker completed a COIS in order to assess the impact of OCD on the child's school, social and family functioning. Results suggested that OCD was associated with significant and invasive impairments in academic, home and social functioning. For example, in the academic domain, children and adolescents with OCD frequently struggled to concentrate on school work. At home, getting ready for bed at night was a problem for some, and in the social domain, being with a group of strangers was often a problem. Interestingly, more areas of impairment were reported with regard to home/family and school/academic functioning than were reported with regard to social functioning. Furthermore, the authors found that parents were more likely than their children to rate specific problems in the home/family and school/academic as being significantly disruptive. This discrepancy shows that to comprehensively understand functional impairments associated with OCD one must consider parent reports as well as child/adolescent reports.

In the study described above, age and gender did not affect the prevalence rates of any specific functional impairments. The authors note that this finding may lend support to the idea that OCD

is a heterogeneous disorder (echoing some of the findings described earlier), affecting functioning differently for different children. The most significant problem that emerged in the Piacentini et al. (2003) study, difficulty concentrating on schoolwork, was only endorsed by 47% of parents and 37% of the children/adolescents. Nearly all children/adolescents pointed out at least one significant problem area, however, and most items were endorsed by at least a modest number of participants. In addition, Piacentini et al. (2003) described a modest positive correlation between clinician-rated OCD severity (i.e., ratings on clinician-rated assessment scales) and number of impairments that were rated as significant problems by either parent or child/adolescent. They suggest that this finding provides “some support for the validity of interference ratings and is consistent with the clinical observation that severity of illness and psychosocial dysfunction go hand in hand” (p. S67), although as described above symptom severity is not invariably associated with the severity of the child’s functional impairment.

Valderhaug and Ivarsson (2005), using a Scandinavian sample, replicated the design of the study described above. Their sample consisted of 68 participants, ranging in age from 8 to 17 years old (mean = 12.9), with primary OCD. Sixty-eight percent of the sample had one or more comorbid disorders (e.g., Tourette’s Syndrome, other anxiety disorders, depression, or disruptive disorders). Using the COIS, these researchers found that, unlike in the Piacentini et al. (2003) sample, functional impairments mostly occurred at home, but also often occurred in school and social domains. Also, in contrast to Piacentini et al. (2003) finding that age and gender did not impact the prevalence rates of any specific impairments, Valderhaug and Ivarsson (2005) found that (a) girls reported more areas of functional impairment than did boys, (b) adolescents (ages 13-17 years) reported more areas of impairment than did children (ages 8-12 years), and (c)

parent reports suggested a positive association between age and number of impaired areas in girls, but a negative association between age and number of impaired areas in boys. Furthermore, these authors (2005) reported that individuals with comorbid disorders reported more areas of impairment, whereas Piacentini et al. (2003) did not report such a finding. In addition, Valderhaug and Ivarsson (2005) found that items associated with the most severe functional impairments were about situations related to bedtime, activities that required concentration, and building or maintaining social relations. In contrast, Piacentini et al. (2003) found that the most significant functional problem in their sample was difficulty concentrating on schoolwork. Finally, Valderhaug and Ivarsson (2005) replicated the earlier finding that parents tend to report higher rates of impairments than do their children. Valderhaug and Ivarsson (2005) also found that when children/adolescents reported a high score for impairments, parent ratings of impairment were higher than were child/adolescent self-ratings. (See Table 2 for a comparison of these two studies.)

Table 2
Comparison of Findings in Two Previous Studies in this Research Area

	Piacentini et al. (2003)	Valderhaug & Ivarsson (2005)
Most Significant:		
Domain(s) of impairment	Home/family; School/academic	Home
Individual problem	Difficulty concentrating on schoolwork	Situations related to bedtime; Activities requiring concentration; Building or maintaining social relations
Child-Parent Rating Differences	Parents rated problems as more significant	Parents rated problems as more significant
Impairment Prevalence Rates:		
Impact of age	None	Adolescents reported more impairments than children
Impact of gender	None	Girls reported more impairments than boys
Impact of comorbid disorders	Not reported	Comorbidity associated with higher reported rates of impairment

Limitations of recent studies. Piacentini et al.(2003) indicated that a major limitation of their study was that it required replication in independent samples containing people of different races/ethnicities/nationalities; their study was conducted with a wholly American sample that was predominantly white. The importance of conducting cross-cultural studies in this domain is illustrated by the differences in findings between Piacentini et al. (2003) and Valderhaug and Ivarsson (2005). Present day views of culture point much more to people's social world than past ideas about culture which centered on the individual. What is especially noteworthy is people's daily routines and how these are linked to families, neighborhoods, villages and the social milieu (Lopez & Guarnaccia, 2000). However, cultures on an individual basis can be expressed through aspects such as ethnicity, race, religion, gender, sexual orientation, regional affiliation, socio-economic status, and disability status (Allen, 2007). Thus, if one wants to examine whether or not culture plays a role in OCD-related functional impairment, one needs to study the impact that all these cultural features have on childhood OCD-related functional impairment.

Further, Piacentini et al. (2003) note that they did not compare their OCD sample to another group; thus they cannot be conclusive with regards to their findings. For instance, they might have employed one or more of the following control groups: (i) children and adolescents with no form of psychopathology (i.e., healthy, typically developing children/adolescents), (ii) children and adolescents with psychiatric disorders other than OCD, and (iii) children and adolescents with previously-undiagnosed OCD. However, it is evident that in some ways it is not practical to employ a control group, as the COIS is a clinical measure that specifically assesses the functioning of a child with OCD, and therefore cannot assess the functioning of a child without OCD.

Another clear limitation of the Piacentini et al. (2003) study was that they did not account for the effect of ADHD comorbidity on their results. The importance of this comorbidity factor is illustrated by the findings of a few studies that found that when ADHD is present as a comorbid condition with OCD, functional impairment is more significant (Geller, et al., 2004; Masi, et al., 2006; Sukhodolsky, et al., 2005). Moreover, a recent meta-analysis of the long-term outcome of childhood OCD found that comorbid diagnoses were evident in many of the studies as possible predictors of severity, persistence and greater functional impairment (Stewart et al. 2004).

A limitation of the Valderhaug and Ivarsson (2005) study is that they drew their sample from two nationally different groups, a strategy that caused problems when attempting to draw conclusions from the data. With regard to the differences between the two national groupings, the authors note that “the SS [Swedish sample] had a higher proportion of females, and had higher rates of comorbid tics and Tourette’s syndrome, usage of OCD-specific medication, and parents in the SS had higher ratings of child impairment than the NS [Norwegian Sample]” (p. 172). They make clear that these differences between the groups may be due to the fact that different sampling methods were used in composing the groups. For instance, participants with Tourette’s syndrome were excluded from the Norwegian sample; also, the Norwegian sample was drawn from primary health care services, whereas the Swedish sample came from a secondary care centre.

Both studies described above used the same research instrument to measure OCD-related functional impairment. Although useful, that measure did result in some of the limitations mentioned above.

Limitations of the COIS. With regard to problems associated with using the COIS, Valderhaug and Ivarsson (2005) found that the degree of functional impairment associated with OCD, as measured by the COIS, was influenced by comorbid disorders. In other words, the COIS, as used in their study, was unable to distinguish between functional impairments that arose as a result of OCD and those that arose as a result of another, comorbid disorder.

Furthermore, this study also suggests that different versions of the COIS (e.g., one for adolescents and one for children) could be useful. They noted that the use of different versions may allow the contents of each item on the questionnaire to be better tailored to the developmental stage and reading abilities of different age groups.

Partially in response to the above critiques, and partially in response to “a growing call for evidence-based assessments of child and adolescent anxiety disorders” (Silverman & Ollendick, 2005, as cited in Piacentini, Peris, Bergman, Chang, & Jaffer, 2007, p. 652), Piacentini et al. (2007) developed a revised version of the COIS (the COIS-R). This instrument has improved psychometric properties and features separate parent and child/adolescent report forms (the COIS-R-P and COIS-R-C, respectively; see Appendixes B and C).

With regard to psychometric properties, the COIS was divided into 3 factors (viz., school, social, home/family) that had never been empirically tested. To address this shortcoming, Piacentini et al. (2007) used exploratory factor analysis and found that 4 factors (viz., Daily Living Skills, Family, Social, and School) described the items on the COIS-R-P. Similarly, 3 factors (viz., School, Social and Activities) described the items on the COIS-R-C.

The finding that different combinations of factors fully describe the items on the COIS-R-C and COIS-R-P forms shows that both reports must be used to fully understand the functional impairment profile of a child/adolescent with OCD. Moreover, the developers of the revised instrument make clear that the specific constitution of each factor allows for useful future applications of this measure. For instance, one might compare the parent and child ratings on the COIS-R school factor, and thus come to a more comprehensive understanding of the child's OCD-related functional impairment (Piacentini et al., 2007).

Piacentini et al. (2007) found that both the COIS-R-C and COIS-R-P are developmentally robust. This means that parent and child forms had similar correlations with the child's age, which indicates that the measure is suitable to assess the functional impairment of children of different ages. This addresses Valderhaug and Ivarsson's (2005) recommendation that separate measures should be developed for children and adolescents. Furthermore, analysis of the revised measure showed that both parent and child/adolescent report forms add to an understanding of functional impairment that is specific to childhood/adolescent OCD. Otherwise stated, the COIS-R, unlike the COIS, is able to measure a child/adolescent's specific OCD-related impairment, over and above the impairment that is related to the severity of the child/adolescent's OCD and/or the impairment that results from their comorbid disorder/s. This finding regarding comorbidity addresses Valderhaug and Ivarsson's (2005) finding that COIS scores were influenced by comorbid disorders.

Piacentini et al. (2007) also found that both the COIS-R-P and COIS-R-C had good internal consistency, concurrent validity and 2-week test-retest reliability. Thus, they claim that the

COIS-R “fills an important methodological gap in the field” (p. 15). Nonetheless, the instrument still has some limitations, which will be discussed later in this paper.

RATIONALE FOR THE CURRENT RESEARCH

The literature presented thus far demonstrates that there is paucity of research into childhood and adolescent OCD-related functional impairment. Therefore, there are multiple reasons behind conducting a study on the functional impairment of South African children and adolescents with OCD.

Firstly, there are developmental differences between children with OCD, adults with later onset OCD and adult patients whose OCD began in childhood or adolescence (Jaisooriya, Janardhan Reddy, & Srinath, 2003). This should warn us against using adult findings to understand OCD in children and adolescents (Ivarsson & Valderhaug, 2006). With specific regard to functional impairment in children and adolescents with OCD, relatively little is known. Thus, more research is needed in order to comprehensively understand childhood/adolescent OCD.

Secondly, South Africa has the sixth highest prevalence for anxiety disorders, compared to the 14 other countries included in the World Mental Health Survey (Stein et al., 2007). Additionally, that survey found that anxiety disorders have the greatest lifetime prevalence in South Africa, and that anxiety disorders are frequently found among all races and in all the different provinces.

Thirdly, because prevalence and clinical characteristics of OCD in children and adolescents have been found to be different in different studies, more research is needed in community samples in diverse cultures (Brynska & Wolanczyk, 2005). For instance, with specific regard to OCD-related functional impairment in children and adolescents, the most methodologically sound studies have differed in their findings: North American children/adolescents' functional impairments are apparently somewhat different to that of Scandinavian children/adolescents (Piacentini et al. 2003; Valderhaug & Ivarsson, 2005). These findings demonstrate that culture may play a role with regard to an individual's OCD-related functional impairments. Indeed, Kleinman (1988) pointed out in his groundbreaking review of culture, psychopathology, and similar research that culture is vitally important with regards to the study and treatment of psychiatric disorders.

The value of conducting cross-cultural OCD research is clear. The DSM-IV-TR (American Psychiatric Association, 2000) states that religious and cultural beliefs may play a role in the types of themes and manifestations of obsessions and compulsions displayed by the individual with OCD. Several empirical studies have documented the impact of culture on OCD-related symptomatology. For instance, a study of people with OCD in Bali ($N=19$) showed that Balinese culture substantially contributed to the formation of those people's OCD-related symptoms (Lemelson, 2003). For example, many of these patients experienced somatic obsessions and much of their OCD-symptoms centred on religious themes involving witchcraft and spirits. Another study compared adult OCD patients from a university clinic in Rio de Janeiro, Brazil ($N=101$ adults) to 15 clinical samples from North and Latin America, Europe, Africa and Asia and also found that culture may have an impact on the content of OCD obsessions (Fontenelle,

Mendlowicz, Marques, & Versiani, 2004). The entire sample was mainly female and had an early-age of onset. Aggressive and religious obsessions were predominantly found in the Brazilian and Middle Eastern samples. A more recent study of university students in North America ($N = 895$, including African-American, White, Hispanic/Latino, Southeast Asian, South Asian/East Indian participants) revealed that even if one has a lot of OCD symptoms and behaviours this does not necessarily correspond to increased severity, in Southeast Asian students (Washington, Norton, & Temple, 2008). This pattern of data may arise because Southeast Asian individuals have certain obsessive-compulsive behaviours that do not meet diagnostic criteria for OCD, but are reflective of their traditions, cultural characteristics and/or beliefs.

In terms of research into OCD-related cultural differences in pediatric OCD, an epidemiological study of non-referred Polish adolescents ($N = 3100$; (Brynska & Wolanczyk, 2005) showed that adolescents who met criteria for OCD ($N = 11$) displayed similar OCD features to the adolescents described in previous research studies in other countries (i.e., those in clinical and non referred samples). A more recent study of children, adolescents, and adults with OCD examined the differences in the presentation and expression of OCD symptoms between Latin Americans (from Costa Rica; $n = 26$) and North Americans (from the United States; $n = 52$; Chavira et al. 2008). The authors reported that the groups presented with a similar OCD symptom profile: contamination, symmetry and hoarding were found to be the most frequently reported symptom subtypes. Interestingly, the Costa Rican group was less impaired (i.e., as measured by the Yale-Brown Obsessive Compulsive Scale (Y-BOCS): Goodman et al. 1989). In addition, the groups reported different OCD severity levels on the Y-BOCS (this included their

associated distress, impairment and the time occupied with obsessions and compulsions). Moreover, a regression analysis further indicated that ethnicity contributes to OCD severity. In summary, the studies above show that culture/ethnicity may play a role in OCD. Although the relationship between the OCD symptomatology and OCD-related functional impairment has not yet been explicated, there is enough in the extant literature to suggest that culture/ethnicity may play a role in OCD-related functional impairment. Moreover, only two studies have examined childhood OCD-related functional impairment and these studies were conducted in developed countries. There have been no studies of this nature conducted in developing/resource-poor countries. Therefore, a study examining the functional impairments of South African children and adolescents with OCD would be very useful in improving our understanding of childhood OCD specifically.

Rationale of the Methods

Another valuable aspect of the current study is it is the first study to use the COIS-R to measure functional impairment in children and adolescents with OCD. Earlier studies of OCD-related functional impairment in this population used the COIS, which the authors acknowledge is a flawed instrument.

SPECIFIC AIMS

This is a descriptive study with four specific aims: (a) to describe the functional impairments of South African children and adolescents with OCD; (b) to examine agreement and disagreement between child and parent informants; (c) to examine relationships between parent-reported and child-reported impairments and clinician's assessments; and (d) to compare the functional

impairments found in South African children and adolescents with OCD to those found in American and Scandinavian children with OCD. A secondary aim that emerges from these four primary aims is to examine the appropriateness of the COIS-R for use in South African children and adolescents with OCD.

University of Cape Town

DESIGN AND METHODS

Design

This study uses quantitative methods and instruments that have been used by previous researchers in this field. More specifically, data were collected via semi-structured and structured interviews that were conducted with the child and parent, and via a self-report questionnaire that both the child and parent completed.

Participants

Many different sources were used in order to recruit participants for the study. The primary recruiting sources were the following: (1) The Medical Research Council (MRC) Unit on Anxiety and Stress Disorders Research Unit based in the Department of Psychiatry at the University of Stellenbosch (US); (2) private-practice clinicians (psychiatrists and psychologists) in Cape Town, Durban and Johannesburg, many of whom agreed to advertise the study to their patients by placing notices in their waiting rooms and by giving parents of their patients a letter describing the study; (3) various newspapers in KwaZulu-Natal and the Western Cape, several of whom agreed to include an article about OCD and the study; (4) posters advertising the study were placed in Groote Schuur Hospital, the Departments of Psychiatry at UCT and US, the Psychology Department at the University of KwaZulu-Natal, and the UCT Child Guidance Clinic; (5) A notice informing people about the study and providing contact details for the researchers was placed on the UCT website, on several different mental health blogs, on the Health24 website (<http://www.health24.com/>), on the gumtree advertising site (<http://www.gumtree.co.za>), on Facebook (<http://www.facebook.com>), and on the South African

Depression and Anxiety Disorder Group website (<http://www.sadag.co.za/>); (6) the primary researcher (author of this thesis) was interviewed about the study on two Radio Stations (Cape Talk, Cape Community FM); (7) the primary researcher spoke at a number of different professional conferences about the preliminary results of the study; these talks served as a means to advertise the study to clinicians to encourage referrals (e.g., 2008 International Anxiety Disorders Symposium, the 2008 Psycho Energetix Conference: ADHD/Anxiety in Children, Durban, and the 2008 14th South African Psychology Congress); and (8) some children were also recruited by means of others who had participated in the study (i.e., snowballing method of recruitment).

Exclusion and inclusion criteria. Some of the participants that took part in the study had been diagnosed with OCD previously and some not. In all cases, however, a current diagnosis of OCD was confirmed using the Schedule for Affective Disorders and Schizophrenia for School-Age Children-Present and Lifetime Version (K-SADS-PL; Kaufman et al., 1997) or the Mini International Neuropsychiatric Interview For Children and Adolescents Version 5 (MINIKID 5.0; Sheehan et al., 1998). If the child met the criteria for a past, but not current, diagnosis of OCD, he/she was excluded from the study. Thus, the child had to meet the DMS-IV diagnostic criteria of current OCD to take part in the study.

Children with other comorbid disorders (aside from psychotic disorders) were included in the study. Consistent with the samples described by Valderhaug and Ivarsson (2005) and Piacentini et al. (2003), and with the description of OCD characteristics in the DSM-IV-TR (American Psychiatric Association, 2000), most of the children in this study's sample presented with

comorbid psychiatric disorders. Furthermore, the inclusion of children with comorbid disorders arguably did not affect this study's findings regarding impairment since the COIS-R measures functional impairment that is specific to OCD (Piacentini et al., 2007).

Children were included if they were English or Afrikaans speaking. The age range of the sample was limited to 6-18 years. There were two primary reasons for this inclusion criterion: First, the instruments employed were designed for use with this age group; and second, the present study's aim was to assess functional impairment in childhood and adolescent OCD. Children that were not attending school even though they were of school-going age were excluded from the study. This inclusion criterion was put in place because the school domain is one of the functional areas examined by the COIS-R; in other words, children who do not attend school would find that many of the COIS-R items do not apply to them.

One child met past criteria for OCD, but not criteria for current OCD and was therefore excluded from the study. Another child withdrew from the study after informed consent was obtained, as he decided that he no longer wanted to participate. Moreover, one more child was excluded as she presented with psychotic features. Therefore, the final sample of participants consisted of 26 children with a primary diagnosis of OCD (14 males and 12 females). They ranged in age from 6 to 18 years ($M = 13.54$, $SD = 3.26$).

Materials

A demographic questionnaire (see Appendix D) was completed by the parents. This demographic questionnaire was designed by the primary researcher. She based it on the

demographic questionnaire used by the Medical Research Council of South Africa. It was designed to capture many different demographic factors (e.g., income level, age, gender, education, religion). These were captured so that participant characteristics could be compared to those of previous study participants.

The *K-SADS-PL* (Kaufman et al., 1997) is a semi-structured diagnostic interview done with both children and their parents to assess current and past episodes of psychopathology in accordance with DSM-III-R (American Psychiatric Association, 1987) and DSM-IV (American Psychiatric Association, 1994) diagnostic criteria.

Kaufman et al. (1997) found that, overall, the K-SADS-PL is reliable and valid for making child psychiatric diagnoses, particularly with regard to affective and anxiety disorders. More specifically, they reported that test-retest reliability was very good for present and/or lifetime diagnoses of major depression, any bipolar disorder, generalized anxiety disorder, posttraumatic stress disorder, attention-deficit hyperactivity disorder, conduct disorder and oppositional defiant disorder. They also found that the measure has good concurrent validity and inter-rater reliability between the two different components (child/parent) that are used to produce a diagnosis.

The Mini International Neuropsychiatric Interview For Children and Adolescents, Version 5 (MINIKID 5.0; Sheehan et al., 1998) is a short structured diagnostic interview used to assess for DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organization, 1992) diagnoses. This measure was used as an alternative to the K-SADS-PL. The MINIKID 5.0 screens for common disorders of childhood and adolescence. Both parent and child are

interviewed if the child is younger than 13.

The MINI (adult version of the MINIKID; Sheehan et al., 1998) was used to assess diagnostic status of adults and has proved overall to be a reliable and valid instrument. The MINI has demonstrated good inter-rater reliability (kappa range: 0.88-1.0) and test-retest reliability (kappa range: 0.76-0.93) (Lecrubier et al., 1997). In addition, it has good concurrent validity with the CIDI, and with the SCID-P (Lecrubier, et al., 1997; Sheehan, et al., 1997). Validation studies of the MINIKID 5.0 are yet to be published. However, one of the researchers working on a validation study of the MINIKID commented, that their group has “just finished a large validation study of the MINIKID comparing it to the K-SADS-PL. The MINIKID came out very favorably and could be done in a third of the time that the K-SADS-PL took” (J Janavs, personal communication, 16 April 2008).

The *Children's Global Assessment Scale* (CGAS; Shaffer et al., 1983) is designed to measure the overall severity of functional impairment in children aged 4-16 years. The instrument requires the clinician or researcher to rate the child's global functioning on a 0-100 scale, where 0 indicates acute functional impairment and 100 no serious functional impairment. Individuals who score above 70 are deemed healthy. The instrument's developers report that it has good test-retest and inter-rater reliability and good discriminant and concurrent validity (Shaffer et al., 1983). Independently, a review of studies conducted on the CGAS found that reliability of the measure ranged from adequate to good (Schorre & Vandik, 2004). Additionally, although Piacentini et al. (2007) indicate that findings with regard to concurrent validity of the CGAS

have been inconsistent, Steinhausen et al. (2001) found positive correlations between the CGAS and other measures of psychological impairment.

The *Children's Yale-Brown Obsessive Compulsive Scale* (CY-BOCS; Scahill et al., 1997) is a 10-item-, semi-structured, clinician-rated measure of how critical a child/adolescent's OCD symptoms were during the week prior to the test. The clinician interviews both the parent and the child either together or separately, depending on the age and emotional state of the child. The items on the interview are divided into a 5-item obsession checklist and a 5-item compulsion checklist. Each item is scored on a Likert-type scale from 0 to 4, where higher scores indicate a more significant problem with regard to the child/adolescent's obsessions/compulsions. Thus, the closer the overall score is to the maximum of 40, the more acute the child/adolescent's OCD symptoms were in the past week. The *Clinical Global Impression Scale* (CGI) is a part of CY-BOCS and contains one item, rated on a 0-6 scale where 0 indicates that the child/adolescent does not have an illness and 6 indicates that he/she has an acute or very serious illness. Scahill et al. (1997) found that there was good inter-rater reliability between total and subscale scores of the CY-BOCS. They also concluded that the test generates valid and reliable subscale and total scores, but that reliability and validity seem to be affected by age and by problems associated with bringing together information obtained from parents and children. With regard to the psychometric properties of the scale being affected by age, Scahill et al. (1997) demonstrated that the ability and willingness of a child to discuss their internal experiences is variable, and that this variability may be more evident in younger children.

As described above, the COIS-R (Piacentini et al., 2007) is used to assess the functional impairment associated with OCD. It consists of separate parent and child report forms, each containing 33 items. Children are asked to rate the extent to which their OCD has caused problems in different areas of their lives in the past month, on a scale where 0 indicates “not at all” and 3 “very much.” The parent and child forms contain similar items but some of the items are unique to each measure. Piacentini et al. (2007) reported that both parent and child forms had good test-retest reliability, internal consistency, and concurrent validity. In addition, there were positive significant associations between the COIS-R and the CGAS when comorbidity and the gravity of the OCD were controlled. The authors make clear that this finding indicates that the COIS-R assesses the functional impairments that are not simply due to other comorbid disorders and/or to the gravity of the child/adolescent’s OCD. Thus, they concluded that the instrument is useful for evaluating the impact of OCD symptoms on a child or adolescent’s functioning.

As mentioned above, Piacentini et al. (2007) used exploratory factor analysis and found that 4 factors (viz., Daily Living Skills, Family, Social, and School) described the domains on the COIS-R parent report form of the questionnaire. Similarly, 3 factors (viz., School, Social and Activities) described the items on the COIS-R child/adolescent report form. The entire parent form of the COIS-R is shown in Appendix B and the child form in Appendix C. Items on the parent form subsumed under the School factor are items 31, 7, 1, 20, 28 and 32; under the Family/Activities factor are items 12, 18, 21, 17, 8, 14, 23, 15 and 4; under the Social factor are items 6, 29, 5, 22, 16, 25, 2, 27, 11, 26, 9, 3 and 24; and under the Daily Living Skills factor are items 30, 33, 13, 19 and 10. Items on the child form subsumed under the School factor are 31,

32, 33, 20, 28, 1, 10, 7, 24 and 3; under the Activities factor are 9, 21, 18, 17, 8, 12, 14, 19, 23, 30, 13, 27, 6, 29, 16, 4 and 15; and under the Social factor are 22, 11, 5, 2, 26 and 25.

For the current study, the researchers were granted permission from Prof. Piacentini to make minor changes to the wording of some of the items on the COIS-R. This was done so that the items could be more easily understood by South African participants. On the child report, “Getting good grades” and “Going on a family vacation” were changed to “Getting good marks at school” and “Going on a family holiday”, respectively. On the parent report, “Doing fun things during recess or free time;” “Doing chores that he/she is asked to do, like washing the dishes, taking the garbage out or cleaning his/her room;” “Going to temple or church;” and “Going on a family vacation” were changed to “Doing fun things during break or free time” “Doing chores that he/she is asked to do, like washing the dishes, taking the rubbish out or cleaning his/her room;” “Going to temple, church or mosque;” and “Going on a family holiday.” Prof. Piacentini indicated that these changes do not seem to change the meaning of the COIS-R items in any way and thus are acceptable changes to the instrument (personal correspondence, 7 March 2008).

The K-SADS-PL, MINIKID, CY-BOCS and CGAS have been used internationally (e.g., Kar & Bastia, 2006; Piacentini, et al., 2003; Storch, et al., 2006; Valderhaug & Ivarsson, 2005) and the COIS-R has proved to be a reliable and valid measure of children’s OCD-related functional impairments with a North American sample (Piacentini et al. 2007). In addition, the K-SADS-PL and the MINI have been used repeatedly in South African research before (e.g., Myer, et al.,

2008; Suliman, Kaminer, Seedat, & Stein, 2005). Thus, it was assumed that these measures are appropriate for use in the South African context.

Procedure

As described above, children/adolescents and parents were interviewed separately; the interviews were conducted by two people. One important reason for interviewing the parent and the child/adolescent is that problems in functioning may only occur in particular situations (Winters et al., 2005). Therefore, multiple informants are needed to elucidate a comprehensive account of the child/adolescent's functional impairment.

A Psychology Master's degree student assisted the primary researcher with the first 8 interviews; a Psychology Honours' student assisted the primary researcher for the remaining 18 interviews. In order to comply with the regulations set out by the developers of the measures, the primary researcher and the two research assistants were trained by a clinical psychologist (the supervisor) to use the abovementioned measures.

In most cases, the primary researcher interviewed the child/adolescent while the research assistant interviewed the parent. However, a few of the children only spoke Afrikaans. In those cases, the research assistant interviewed the child/adolescent while the primary researcher interviewed the parent (both research assistants were fluent Afrikaans speakers). There were some instances when the one of the researcher's conducted the full assessment on their own, as either the primary researcher or the research assistant was unable to be present for the assessment. In cases such as these, the same procedure as above was followed, except that one

researcher interviewed the parent and the child/adolescent separately on the CY-BOCS (i.e., one after the other).

Some of the interviews were conducted at UCT and others were conducted in the homes of participants, depending on what was most convenient. Participants were reimbursed for travel costs associated with the study.

All study procedures were approved by the Research Ethics Committee of the UCT Department of Psychology, the Research Ethics Committee of UCT Faculty of Health Sciences and the Red Cross Children's Hospital.

The interviews. For the first eight interviews, the K-SADS-PL was used in order to obtain clinical diagnoses of the participants. This instrument takes longer to administer than the MINIKID 5.0 (Sheehan et al., 1998). Therefore, the procedure differed according to the type of diagnostic interview used. The researchers replaced the one with the other during the study, as the MINIKID 5.0 was found to take much less time to administer. The MINIKID 5.0 can be administered in one session, compared to when the KSADS-PL was used, which required two separate sessions on different days. Moreover, there is concurrent validity between these two instruments (J Janavs, personal communication, 16 April 2008). Therefore, it was decided to change instruments in order to save interview session time (i.e., more parents were keen to take part when they knew that taking part in the study only involved one interview as opposed to two separate sessions).

When the K-SADS-PL was used, the parent and the child/adolescent each participated in two interview sessions. Each interview lasted approximately 150 minutes. The two sessions were conducted on separate days.

In the first session, informed consent was obtained from the parents (see Appendix E) and the child completed an assent form (see Appendix F). The parents were provided with both these forms which contained the primary researcher's contact details should they have questions at a later stage. Any questions that the participants had at that point were answered by the researchers.

The parents then completed a demographic questionnaire (see Appendix D). The primary researcher then interviewed the child/adolescent and parent together in order to complete the background interview section of the K-SADS-PL (Kaufman et al., 1997). This section of the interview, which lasted approximately 25 minutes, covered the child/adolescent's general health history, psychiatric history and the presenting complaint(-s). The research assistant then interviewed the parent on the main section (screening) of the K-SADS-PL, while the primary researcher interviewed the child/adolescent on the same section. These interviews were conducted in separate rooms, so that the child/adolescent and parent could not hear each other's responses. The parent and child/adolescent then separately completed the COIS-R.

Subsequently the researchers discussed the scores obtained on the K-SADS-PL screening section and reached consensus on the final summary score recorded for each item. If there was uncertainty about the scoring of any item, the research supervisor was consulted. Based on the

summary scores, the appropriate supplement sections of the K-SADS-PL were chosen for the next session.

During the second session (which, as noted above, took place on a separate day), the parent and child/adolescent were again interviewed separately with the appropriate K-SADS-PL supplements. Once this interview was completed, they separately completed the CY-BOCS. After completion of both interviews, the researchers combined the K-SADS-PL data obtained from both informants in order to produce a diagnosis/diagnoses. The researchers also reached consensus with regard to the summary scores for the CY-BOCS. Lastly, they discussed the appropriate score for the child/adolescent on the CGAS. This score was based on the information obtained during the two interview sessions and the discussions about the child/adolescent that followed each session.

These interviewing and diagnostic procedures are similar to those employed in previous studies (e.g., Piacentini, et al., 2003; Valderhaug & Ivarsson, 2005).

When the MINIKID 5.0 was used as a diagnostic tool, the researchers were able to administer all the measures in one interview session of approximately 120 mins. During these interviews, informed consent was obtained from the parent/s, and assent was obtained from the child/adolescent. The parents then completed the demographic questionnaire.

Then either the primary researcher or the honours student interviewed the child on the MINIKID 5.0. For the current study, the parent was always present for the MINIKID 5.0 if the child was

younger than 13 years. However, when the child was older, most of the time the parent was also present and he/she was told that they could interject when they felt that they could provide extra information relevant to the questions that were directed at the adolescent. The researcher administering the MINIKID 5.0 formulated the diagnoses as they were interviewing the child/adolescent (this is in accordance with the structured interview format of the MINIKID 5.0: i.e., each diagnostic supplement/interview is followed by diagnostic criteria, so that a diagnosis can be derived).

After the MINIKID 5.0 was completed, the child was interviewed on the CY-BOCS and the COIS-R by the same researcher who administered the diagnostic instrument. The parent CY-BOCS and COIS-R interviews were conducted by the other researcher. These interviews were conducted in separate rooms, so that the child/adolescent and parent could not hear each other's responses.

After the interview session, the Honours student and the primary researcher came to a consensus with regards to the CY-BOCS scores and discussed the appropriate score for the child/adolescent on the CGAS. As described above, this score was based on the information obtained during the interviews and the discussions about the child/adolescent that followed each interview.

DATA ANALYSIS

Descriptive statistics were used for parent and child ratings on the COIS-R items with computations of means and standard deviations. Parametric assumptions were tested in order to identify the appropriate statistical tests to perform on the data. Ratings of agreement between

informants were analysed by means of the Kappa test and the McNemar test for disagreement. The Mann-Whitney *U*-Test was used to compare parent and child ratings on individual COIS-R items. The social and school factors (factors common to both COIS-R-P and COIS-R-C) were analyzed by means of a Mann-Whitney *U*-Test for the social factor and a *t*-Test for the school factor. The impact of ADHD comorbidity on COIS-R score was examined by means of Independent Samples *t*-test. Moreover, the association between the number of comorbid disorders and (a) COIS-R scores and (b) CGAS score was measured by means of a Pearson's correlation coefficient. Kendall's τ correlations between the COIS-R and other impairment and severity measures (CY-BOCS and CGAS) were also calculated. For all tests an alpha level of $p < 0.05$ was used, unless otherwise specified.

All children completed the full assessment, except for two children. One child had developmental delays and chronic Attention Deficit Hyperactivity Disorder and as a result was unable to complete the CY-BOCS. Another child also had chronic Attention Deficit Hyperactivity Disorder and therefore was also unable to complete the CY-BOCS. In these cases the researchers relied solely on parent report to obtain the CY-BOCS scores.

RESULTS

Demographic Characteristics of the Sample

The final sample consisted of 26 children (14 males and 12 females), ranging in age from 6 to 18 years. The sample was relatively homogenous in terms of most demographic variables, although there were a few differences with regards to their household income level (see Table 3).

Table 3
Demographic Characteristics of the Current Sample

Variable	
Age (years):	
Range	6-18
Mean (<i>SD</i>)	13.54 (3.26)
Gender:	
Males:Females	14:12
Education:	
Mean Years (<i>SD</i>)	6.81 (3.37)
Urban:Rural	24:2
Repeated a grade:Never repeated a grade	7:19
Race:	
White:Coloured:Other	23:2:1
Home Language:	
English	17
Afrikaans	8
English and Afrikaans	1
Religion:	
Christian	16
Jewish	1
Muslim	1
Other	3
None	5
Household Income Level ^a :	
Low	4
Low Average	9
High Average	12
High	1

^aIncome category was defined following the taxonomy introduced by Seedat et al. (2008):

Per capita income was calculated by dividing household income by the number of household members and defining four income categories as follows: low income was defined as less than half the median income per family member of the entire sample. Low-average income was defined as income one-half to the whole of the median per capita income of the sample, high-average income was defined as income between one and two times the median per capita income and high income was defined as greater than twice the median (p. 891).

Clinical Characteristics of the Sample

The children in this study had a mean CGAS score of 59.92 ($SD = 12.77$). Moreover, twenty-three of the 26 children in the sample (88.46%) presented with at least one comorbid disorder. A number of comorbid disorders were present in the sample (see Figure 1). The most prevalent of these disorders being specific phobia and separation anxiety disorder. Not surprisingly, then, anxiety disorders were the most prevalent category of comorbid disorders (see Figure 2). With regard to other clinical characteristics of the children, one child had been previously diagnosed with Asperger's Disorder, one child with Developmental Apraxia, and one child with Poland Syndrome (Dextre R). These diagnoses were neither confirmed nor refuted in by the current study's diagnostic interviews, given that they fall outside the range of the MINIKID 5.0 and K-SADS-PL diagnostic supplements.

Exclusions due to clinical characteristics. Two children were excluded; one presenting with psychosis and the other who only had OCD in the past (not current). Additionally, one participant had developmental delays and chronic ADHD and was unable to complete the CY-BOCS; another also had chronic ADHD and could not complete the CY-BOCS. These latter two children were still included in the final sample, but only the parents' rating on the CY-BOCS was used in these cases.

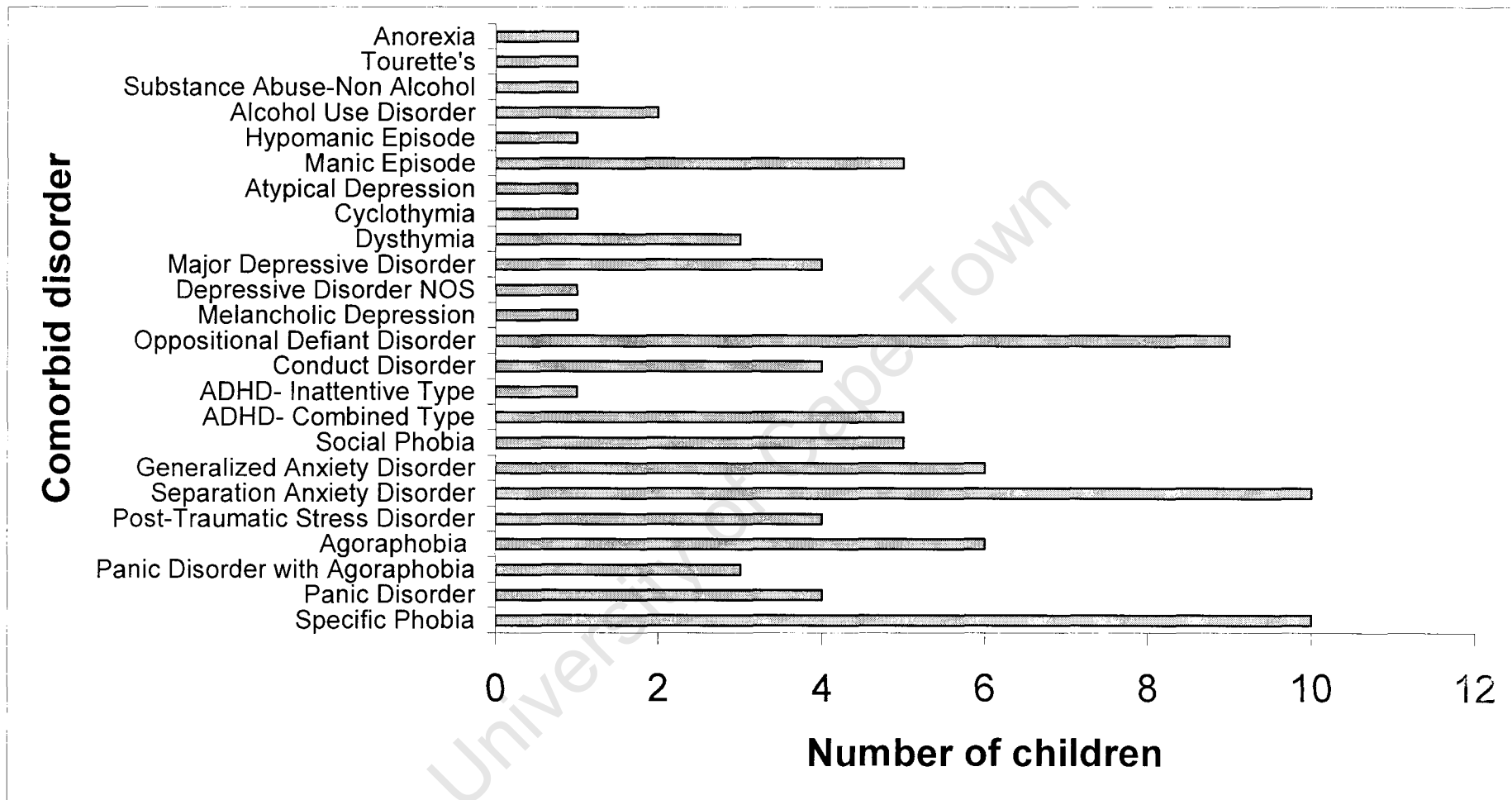


Figure 1. Comorbidity in the current sample of OCD children/adolescents

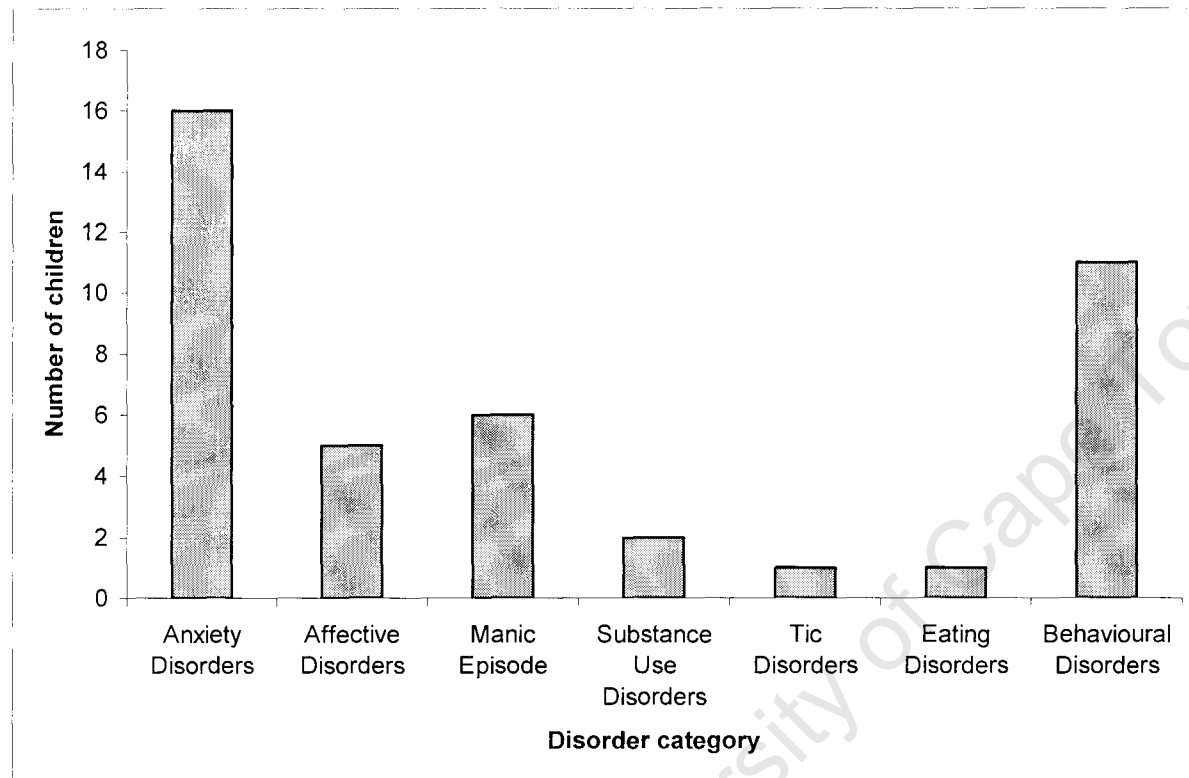


Figure 2. Number of children with at least one comorbid disorder in the behavioural, affective and anxiety disorder categories

Distribution of the Data

In order to determine which statistical analyses would be most appropriate to perform, the data distributions for outcome variables related to the CGAS, CY-BOCS, and COIS-R were thoroughly examined.

CGAS and CY-BOCS. First, the skewness and kurtosis of the sample data on the CGAS Current Score and CY-BOCS Obsessions Score, CY-BOCS Compulsions Score, and CY-BOCS Total Score were analyzed. Because the sample size was small, $p < 0.01$ was used as the threshold for statistical significance (i.e., 2.58 cut-off z -score) in these analyses (Field, et al., 2005). The results of these analyses showed that there was no significant skewness or kurtosis in the distribution of data for CGAS Current Score, CY-BOCS Obsessions Score, CY-BOCS Compulsions Score, or CY-BOCS Total Score (see Table 4).

Table 4
Analysis of the Distribution of CGAS and CY-BOCS Scores

Measure	Skewness			Kurtosis		
	Value	SE	z	Value	SE	z
CGAS Current Score	-0.43	0.46	-0.93	-0.91	0.89	-1.02
CY-BOCS						
Obsessions score	-0.14	0.46	-0.30	-0.79	0.89	-0.89
Compulsions score	-0.37	0.46	-0.80	0.17	0.89	0.19
Total score	-0.17	0.46	-0.37	-0.04	0.89	-0.04

Note: SE = standard error. The z -score was calculated are calculated by dividing the skewness/kurtosis value by the standard error.

** $p < 0.01$

Next, the Kolmogorov-Smirnov Test was used to determine whether the data for these outcome variables were normally distributed. Table 5 shows that the distributions were all normal (i.e., the Kolmogorov-Smirnov Test statistic is not significant in any of the cases).

Table 5
Assessment of the Normality of the Distribution of Data for Two Impairment Ratings

Measure	K-S statistic	<i>p</i>
CGAS Current Score	0.131	0.200
CY-BOCS		
Obsessions score	0.099	0.200
Compulsions score	0.127	0.200
Total score	0.108	0.200

Note. In each case, the degrees of freedom on which the statistic was evaluated was 26.

The COIS-R. First, the skewness and kurtosis of the sample data on the COIS-R-C and COIS-R-P total scores analyzed. Because the sample size was small, $p < 0.01$ was used as the threshold for statistical significance (i.e., 2.58 cut-off *z*-score) in these analyses (Field, et al., 2005). The results of these analyses showed that there was no significant skewness or kurtosis in the distribution of data for these outcome variables (see Table 6).

Table 6
Analysis of the Distribution of COIS-R-C and COIS-R-P Total Scores

Measure	Skewness			Kurtosis		
	Value	<i>SE</i>	<i>z</i>	Value	<i>SE</i>	<i>z</i>
COIS-R-C total score	0.38	0.46	0.82	-1.04	0.89	-1.17
COIS-R-P total score	0.70	0.46	1.54	-0.06	0.89	-0.06

Note: *SE* = standard error. The *z*-score was calculated are calculated by dividing the skewness/kurtosis value by the standard error.

** $p < 0.01$

Next, the Kolmogorov-Smirnov Test was used to determine whether the data for these two outcome variables were normally distributed. Table 7 shows that the COIS-R-P total score is normally distributed (i.e., the Kolmogorov-Smirnov test statistic is not significant in this case), but the COIS-R-C total score is not normally distributed (i.e., the Kolmogorov-Smirnov test statistic is significant in this case).

Table 7

Assessment of the Normality of the Distribution of Data from the COIS-R

Measure	K-S statistic	<i>p</i>
COIS-R-C total score	0.206	0.006*
COIS-R-P total score	0.163	0.075

Note. In each case, the degrees of freedom on which the statistic was evaluated was 26.

* $p < 0.05$

Finally, the Kolmogorov-Smirnov Test was used on the COIS-R-C and COIS-R-P data in order to test whether the data for the each item common to both scales were normally distributed.

Table 8 shows that data for all of the items were not normally distributed (i.e., the Kolmogorov-Smirnov test statistic is significant on all the items).

In summary, parametric tests can be used in inferential statistical analyses of CY-BOCS, CGAS, and COIS-R-P outcome variables. However, non-parametric tests need to be used in inferential statistical analyses of COIS-R individual item data and the COIS-R-C total score data.

Table 8
Assessment of the Normality of the Distribution of Data on Individual COIS-R Items

COIS-R Item	COIS-R Version	K-S Statistic Value	<i>p</i>
Taking tests or exams	Parent	0.250	< .001***
	Child	0.186	.022*
Being with a group of strangers	Parent	0.211	.004**
	Child	0.194	.013*
Going shopping or trying on clothes	Parent	0.269	< .001***
	Child	0.233	.001**
Making new friends	Parent	0.256	< .001***
	Child	0.227	.001**
Going to a friends house during the day	Parent	0.256	< .001***
	Child	0.257	< .001***
Writing in class	Parent	0.244	< .001***
	Child	0.188	.019**
Eating in a public place other than a restaurant ...	Parent	0.335	< .001***
	Child	0.292	< .001***
Getting to school on time in the morning	Parent	0.217	.003**
	Child	0.236	.001***
Going on a date	Parent	0.391	< .001***
	Child	0.361	< .001***
Visiting relatives	Parent	0.319	< .001***
	Child	0.359	< .001***
Being with a group of people that he/she knows	Parent	0.302	< .001***
	Child	0.258	< .001***
Going on a family holiday	Parent	0.394	< .001***
	Child	0.251	< .001***
Having relatives visit	Parent	0.317	< .001***
	Child	0.383	< .001***
Concentrating on his/her work	Parent	0.252	< .001***
	Child	0.243	< .001***
Going to a restaurant/fast food place	Parent	0.335	< .001***
	Child	0.231	.001**
Having a boyfriend/girlfriend	Parent	0.402	< .001***
	Child	0.335	< .001***
Keeping friends she/he already has	Parent	0.283	< .001***
	Child	0.261	< .001***
Eating lunch with other kids	Parent	0.361	< .001***
	Child	0.262	< .001***
Having someone spend the night at his/her house	Parent	0.316	< .001***
	Child	0.295	< .001***
Being prepared for class ...	Parent	0.215	.003**
	Child	0.228	.001**
Bathroom or grooming ...	Parent	0.189	.018*
	Child	0.226	.001**
Completing assignments in class	Parent	0.274	< .001***
	Child	0.221	.002**
Doing homework	Parent	0.195	.012*
	Child	0.227	.001**

Note. The items listed here are those that appear on both the parent and child versions of the COIS-R. In each case, the degrees of freedom on which the statistic was evaluated was 26.
 * $p < 0.05$, ** $p < 0.01$, *** $p < .001$

The Influence of Comorbid Disorders on Measures of Functional Impairment

Impact of ADHD on COIS-R total score. Some studies have shown that comorbid ADHD with OCD significantly contributes to a child's functional impairment (Geller et al., 2004). Therefore, before any further analyses can be performed one needs to determine whether those participants with a comorbid ADHD diagnosis ($n = 6$) have significantly different COIS-R total scores than those participants without a comorbid ADHD diagnosis ($n = 20$). With regard to the COIS-R-P data, participants in the OCD + ADHD group scored higher ($M = 44.50, SD = 19.95$) than did participants in the OCD + no ADHD group ($M = 34.45, SD = 21.82$). Assumptions underlying the appropriate between-groups statistical analysis (an independent samples t -test) were all upheld: Levene's test suggested that the assumption of homogeneity of variance between the two groups was upheld ($p = 0.444$), the assumption of normality of data was met (see Figure 3) and given the manner of data collection there was independence of observations. Therefore, an independent samples t -test was used to compare the two groups on COIS-R-P total score. The analysis uncovered no statistically significant between-group differences, $t(24) = 1.007, p = 0.324, r = 0.20$.

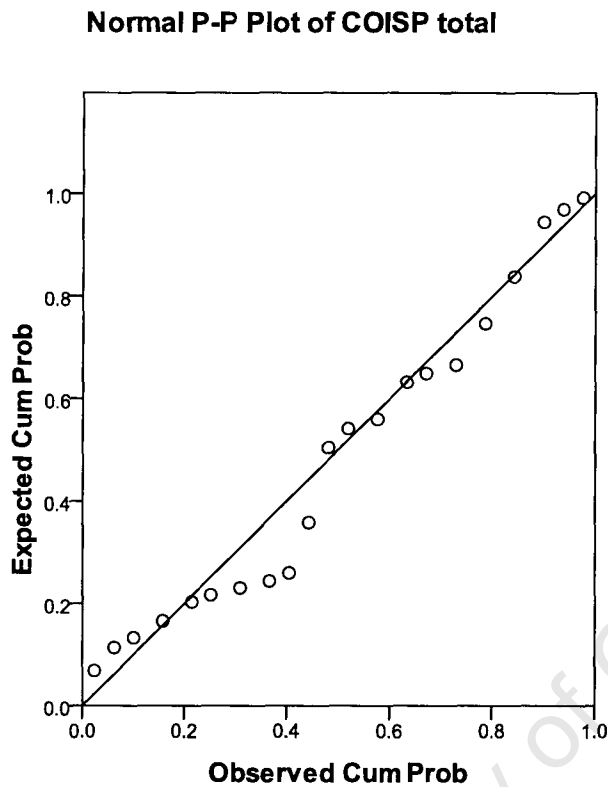


Figure 3. COIS-R-P total score normal probability plot

With regard to the COIS-R-C data, the COIS-R-C total score was not normally distributed (see above and Table 7). Therefore, the assumption of normality was not upheld and so an independent samples *t*-test could not be performed. Therefore, a non-parametric statistic, the Mann-Whitney *U*-test, was used to examine the data. The exact test was used to calculate the Mann-Whitney *U*-test statistic, as recommended by Field (2005) when using data from small samples.

Although the means show that participants in the OCD + ADHD group scored higher ($M = 40.00$, $SD = 22.04$) than did participants in the OCD + no ADHD group ($M = 32.60$, $SD =$

20.77), the Mann-Whitney U -test statistic was not statistically significant, $U = 46.50$, $p = 0.430$, $r = -0.16$. Therefore, this analysis uncovered no statistically significant between-group differences.

In summary, the COIS-R total scores of children/adolescents with OCD and a comorbid diagnosis of ADHD were not significantly different from those of children/adolescents with OCD and no comorbid ADHD. Therefore, the COIS-R total scores were not influenced by a comorbid diagnosis of ADHD, suggesting that the COIS-R is a measure that specifically assesses OCD-related functional impairment.

Association between the presence of multiple comorbid disorders and CGAS score. In order to determine whether meeting DSM-IV-TR (American Psychiatric Association, 2000) diagnostic criteria for multiple comorbid disorders had an impact on overall functional impairment, the number of comorbid disorders that each child presented with was correlated with their current CGAS score. Because the data for both number of comorbid disorders and for CGAS Current Score were normally distributed (see Figures 4 and 5, respectively), there were no problems with performing a simple Pearson's correlation. The value of the correlation coefficient was $r = -0.49$ ($p = 0.010$). The size of this coefficient is defined by Guilford (1956) as being "[m]oderate" and indicative of a "substantial relationship" (p. 145). Furthermore, the association is in the expected direction: the more comorbid disorders a child/adolescent with OCD has, the more functional impairment that child will tend to exhibit.

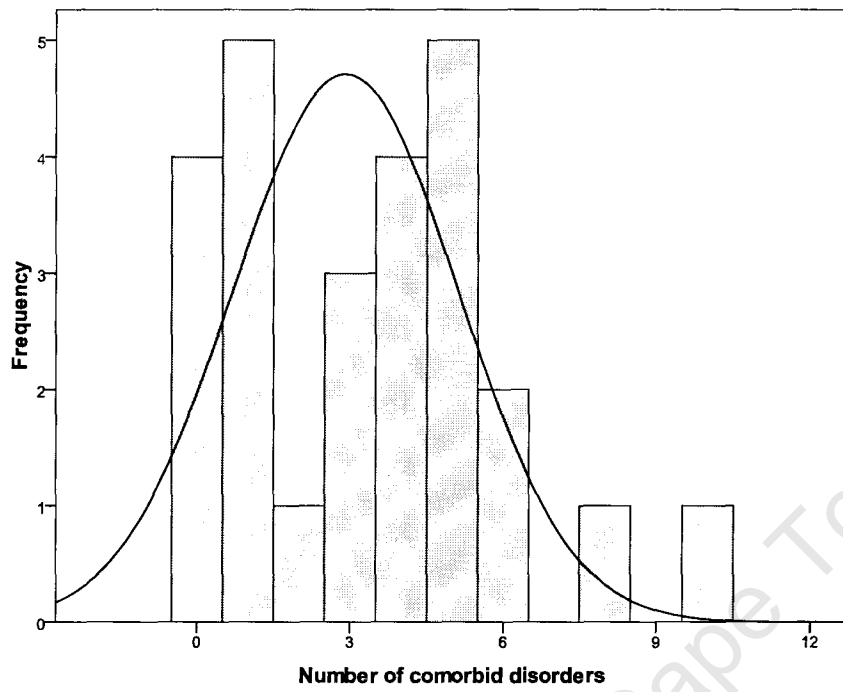


Figure 4. Histogram of number of comorbid disorders

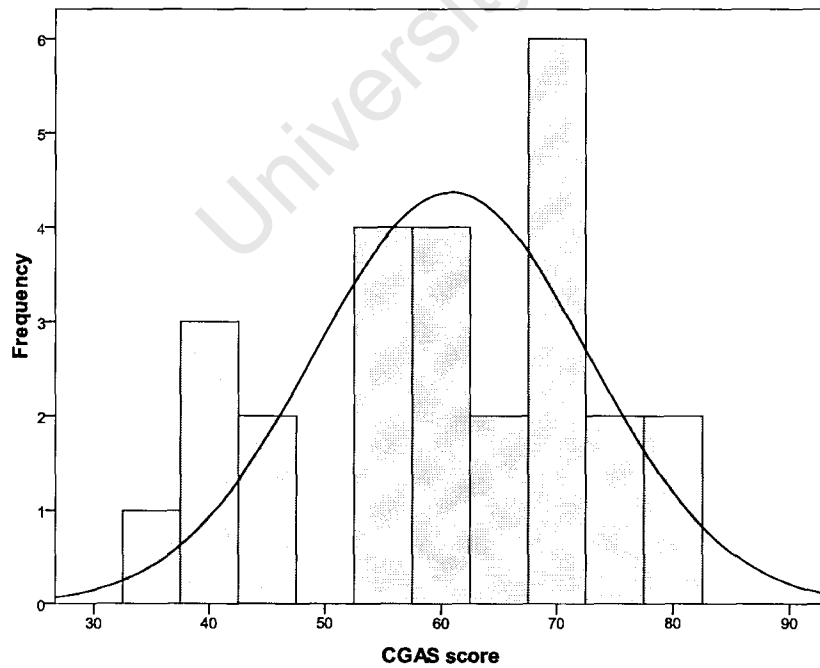


Figure 5. Histogram of CGAS current score

Association between the presence of multiple comorbid disorders and COIS-R-C and COIS-R-P total scores. In order to examine the association between the presence of multiple comorbid disorders and OCD-related functional impairment, correlational analyses between the COIS-R total scores and the number of comorbid disorders were performed. These analyses served to answer the question of whether the COIS-R response ratings were influenced by the number of multiple comorbid disorders. Because the data for number of comorbid disorders, and for COIS-R-P total scores, were normally distributed (see Figure 3), there was no problem performing a simple Pearson's correlation. The value of the correlation coefficient for the association between number of comorbid disorders and COIS-R-P total score was $r = 0.31$ ($p = 0.121$). On the other hand, the COIS-R-C total scores were not normally distributed (see Table 7). Therefore, a Spearman's rho (ρ) correlation was performed. The value of the correlation coefficient for the association between number of comorbid disorders and COIS-R-C Total score was $\rho = 0.39$ ($p = 0.046$). Although the latter correlation was slightly larger than the former, the range into which they both fall is defined by Guilford (1956) as indicating "[l]ow correlation" and a "definite but small relationship" (p. 145).²

In summary, these data suggest that both the COIS-R-P and the COIS-R-C are useful in assessing specific OCD-related functional impairment in South African children and adolescents, but are slightly influenced by the presence of multiple comorbid disorders in the current sample. Although this slight influence is unexpected (previous psychometric studies show that COIS-R

²An alternative to these simple correlational analyses would have been to conduct multiple regression analyses with CY-BOCS total score (as a measure of OCD symptomatology) and number of comorbid disorders as predictors of COIS-R total score. In this way, one could have addressed the question of whether number of comorbid disorders added to the power of OCD symptomatology in predicting COIS-R total scores (as a measure of OCD-related functional impairment). Such analyses could not be conducted, however, as aspects of the dataset did not meet the assumptions of multiple regression analysis.

scores are not at all affected by the presence of multiple comorbid disorders; Piacentini et al., 2007), further analyses can still be performed to outline this sample's OCD-related domains of impairment and functional problems as measured by the COIS-R (especially because, as noted above, COIS-R total scores were not influenced by the presence of ADHD, a very commonly comorbid disorder).

Domains of OCD-Related Functional Impairment

Because the data distributions have been examined and the usefulness of the COIS-R in assessing OCD-related functional impairment in this sample has been established, the major aims of the study can now be addressed. The first major aim is to address this question of interest: what are the major functional impairments of South African children and adolescents with OCD, and in which domain(s) of functioning is/are these individuals the most impaired. As noted earlier, Piacentini et al. (2007) showed, using statistical analyses, that the COIS-R-P could be resolved into four factors, each referring to a separate domain of impairment: School, Family/Activities, Social, and Daily Living Skills. Similarly, they showed that the COIS-R-C could be resolved into these three factors: School, Activities, and Social. The average parent

rating for the current sample in each COIS-R-P domain of impairment is shown in Figure 6. The average child rating for the current sample in each COIS-R-C domain of impairment is shown in Figure 7.

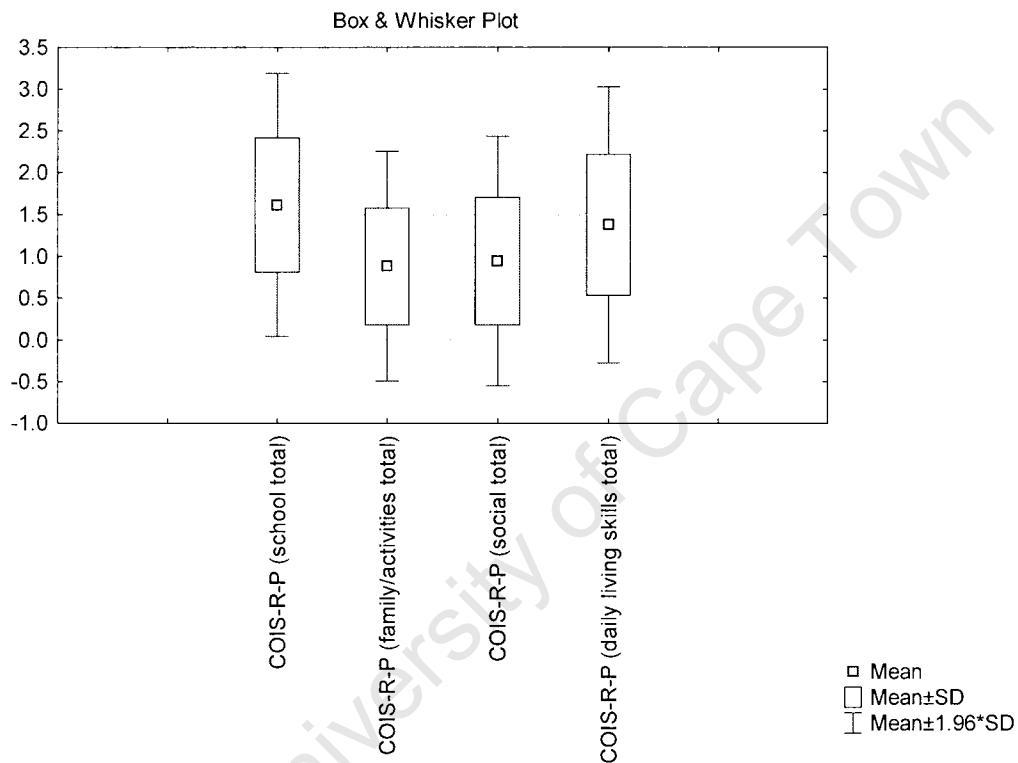


Figure 6. COIS-R domains of impairment: parent ratings

Figure 6 shows that parents rated the school domain as being the most impaired domain of functioning. It must be noted, however, that parents did not regard impairment in any one domain as being much more serious than in any other domain. Similarly, Figure 7 shows that, although children/adolescents rated the school domain as being slightly more impaired by their OCD than the other domains, they did not regard impairment in any one domain of functioning as being much more serious than in any other domain.

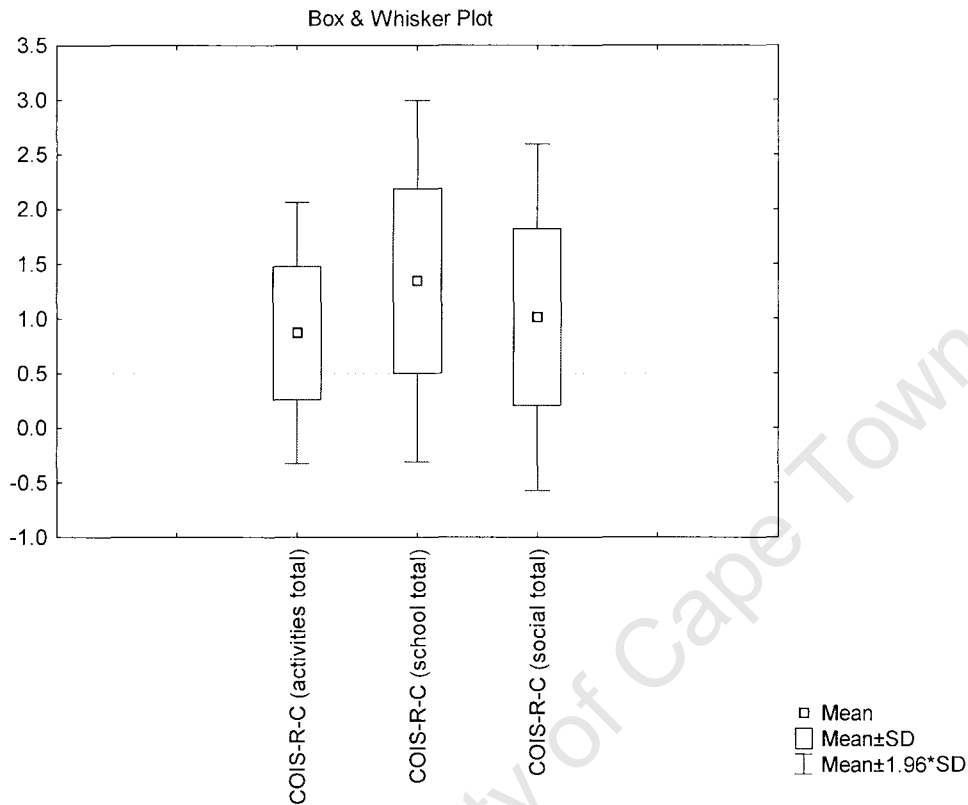


Figure 7. COIS-R domains of impairment: child/adolescent ratings

Parents and children differed in terms of the number of items per domain endorsed as being OCD-related problems (Table 9). Parents endorsed more items in the school domain as being problematic (i.e., relative to the number of items in that domain) than in other domains.

Additionally, parents rated more items as being OCD-related functional problems on the report than did children (11.85 vs. 10.38).

Table 9

Number of Items Endorsed as Significant Problems on the Different Factors of the COIS-R

Instrument and Domain of Impairment	Number of Items in Domain	Mean (SD)
COIS-R-P		
School	6	3.31 (2.09)
Family/Activities	9	2.50 (2.76)
Social	13	3.85 (3.84)
Daily Living Skills	5	2.19 (1.83)
Total	33	11.85 (8.70)
COIS-R-C		
School	10	4.38 (3.23)
Activities	17	4.15 (4.00)
Social	6	1.85 (1.93)
Total	33	10.38 (8.09)

Parent-child differences in reporting domains of OCD-related functional impairment. As

previously mentioned, the School and Social factors are common to the COIS-R-P and the COIS-R-C. Therefore, one can examine the differences between parent and child reports on these two factors. Such an analysis addresses one of the major aims of this study (i.e., are there differences between parent and child/adolescent reports of OCD-related functional impairment). The mean scores for each participant (calculated from the raw scores on the individual items comprising each factor) on these factors were used for this analysis.

Firstly, in terms of the assumptions of an independent samples *t*-test, both the COIS-R-P School factor and the COIS-R-C School factor were normally distributed (see Figures 8 and 9).

Levene's test was not statistically significant ($p = 0.785$), indicating that the assumption of homogeneity of variance was upheld. Also, given the way the data were collected, there was independence of observations. Thus, the assumptions of the *t*-test were met and an independent samples *t*-test was performed.

A box-and-whisker plot suggests that the mean of the COIS-R-P School factor is much higher than the mean of the COIS-R-C School factor (1.62 ($SD = 0.84$) vs. 1.35 ($SD = 0.80$)); see Figure 10). However, the t -test was not statistically significant, $t(50) = -1.18$, $p = 0.244$, $r = 0.17$.

Therefore, parents and children produced similar ratings of the child's functional impairment in the school domain.

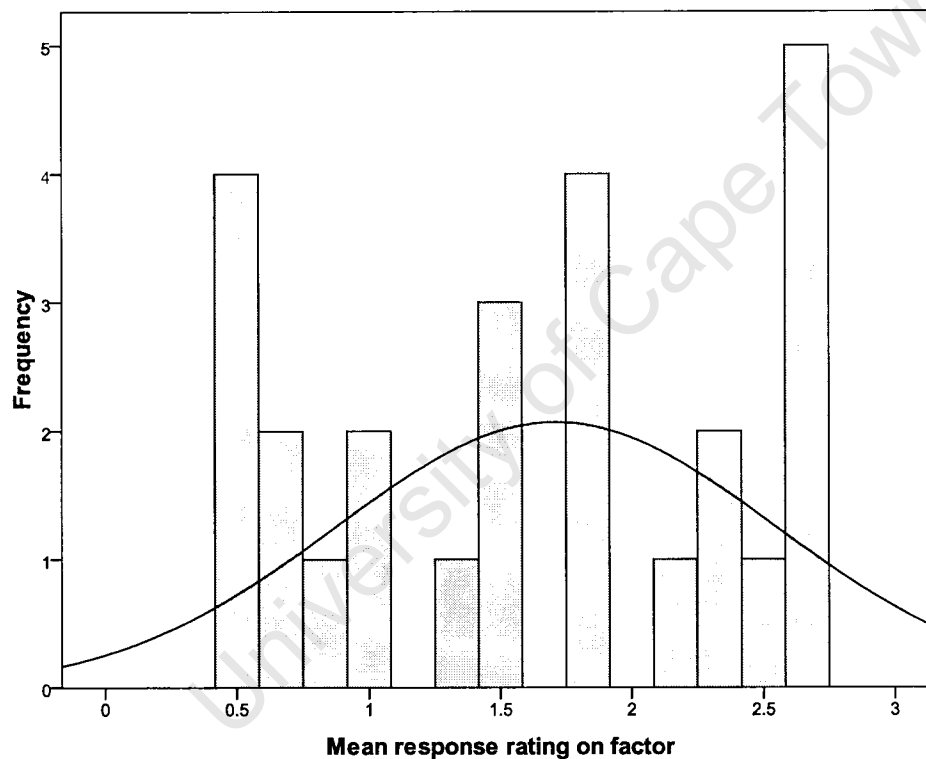


Figure 8. Histogram of COIS-R-P School factor

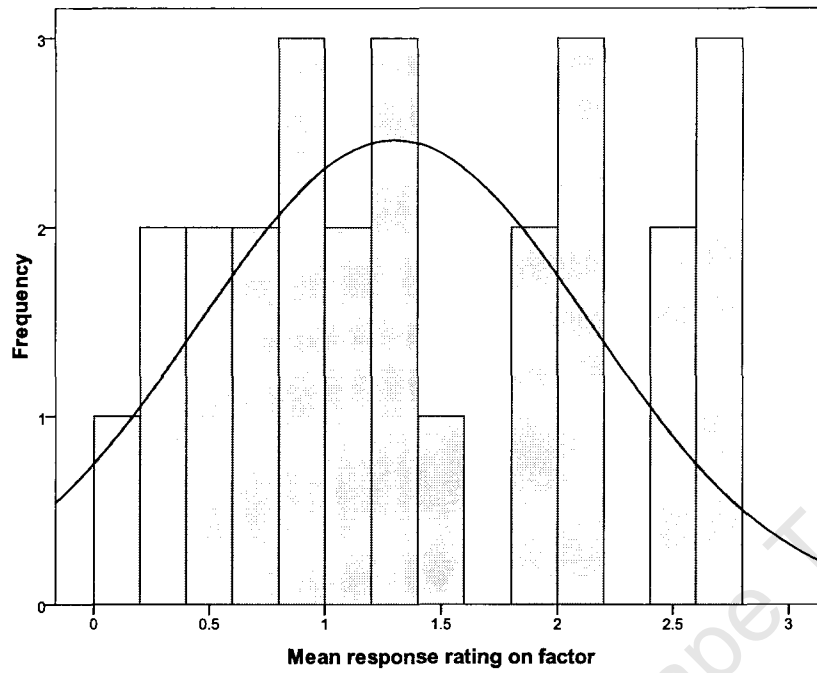


Figure 9. Histogram of COIS-R-C School factor

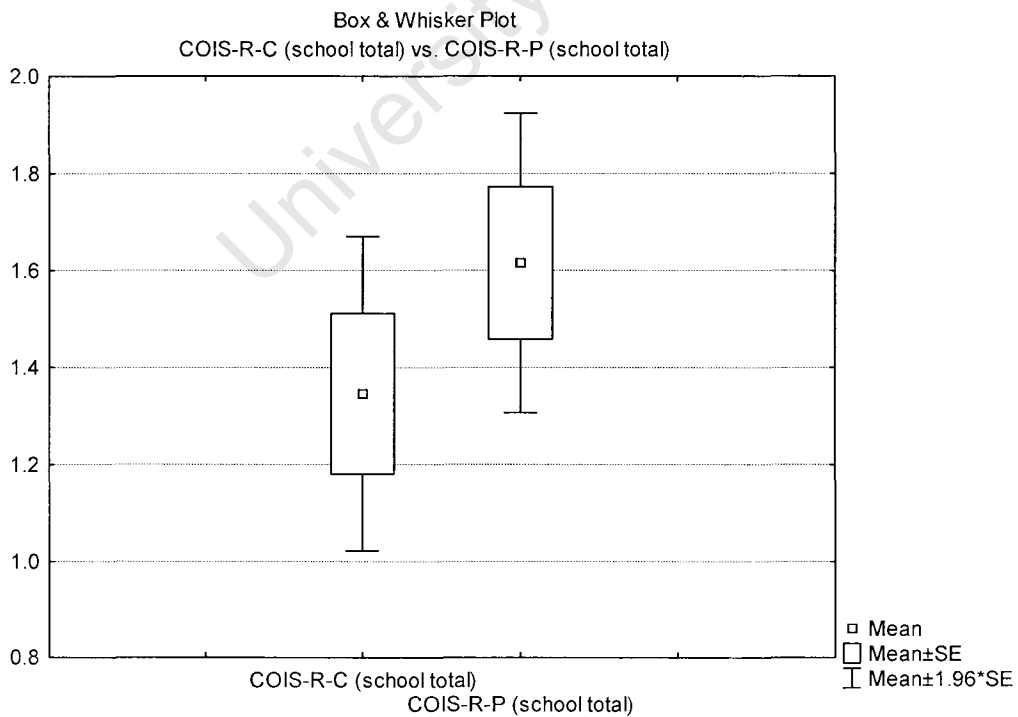


Figure 10. Box and whisker plot of COIS School factor

Differences between COIS-R-P and COIS-R-C scores on the Social factor were examined in much the same way as for the School factor above. Figure 11 shows that data on the COIS-R-P Social factor were normally distributed, whereas Figure 12 shows that the data on the COIS-R-C Social factor were not normally distributed. Therefore, the assumption of normality was not upheld and so an independent samples *t*-test could not be performed. Therefore, a non-parametric statistic, the Mann-Whitney *U*-test, was used to examine the data. The exact test was used to calculate the Mann-Whitney *U*-test statistic, as recommended by Field (2005) when using data from small samples.

Although the mean rank of the Social factor on the COIS-R-C was slightly higher than that of the COIS-R-P (27.02 vs. 25.98), the Mann-Whitney *U*-test statistic was not statistically significant ($U = 324.50, p = 0.810, r = -0.03$). Therefore, these data suggest that parents and children produced similar ratings of the child's functional impairment in the social domain.

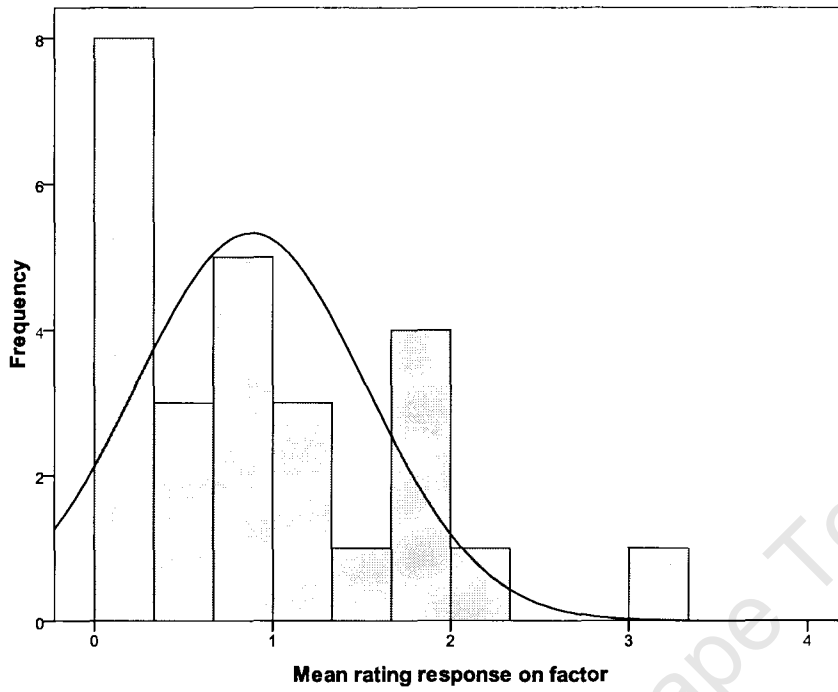


Figure 11. Histogram of COIS-R-P Social factor

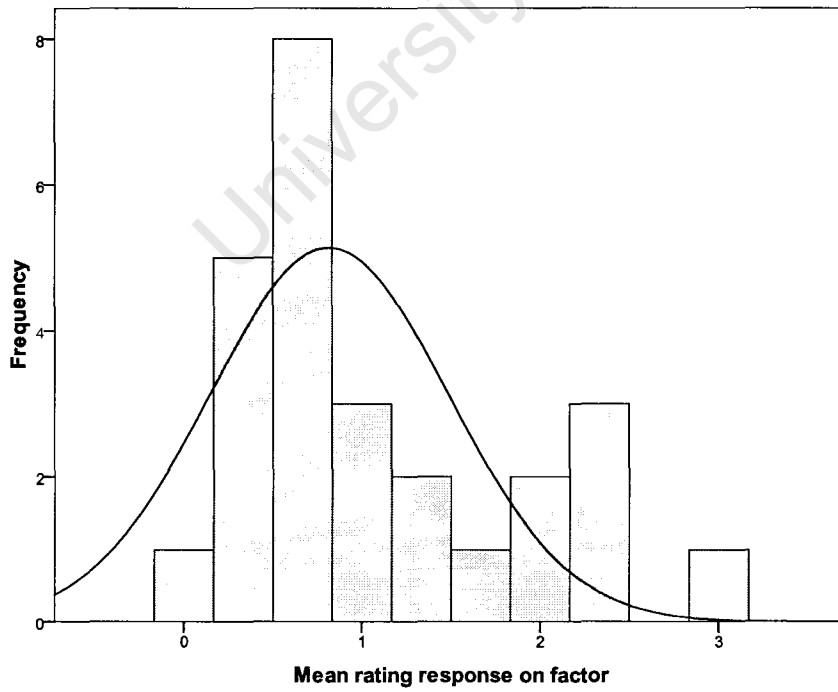


Figure 12. Histogram of COIS-R-C Social factor

Individual OCD-Related Functional Problems

Analyses in the previous section focused on domains of impairment (as noted in that section, each COIS-R item is subsumed under a particular domain of functioning, and so collections of items define those discrete domains). Analyses in this section, in contrast, will focus on individual functional activities (i.e., as represented by individual COIS-R items).

Individual OCD-related functional problems as reported on the Parent Version of the COIS-R.

The frequencies of items rated as “significant problems” and “no problem at all” on the COIS-R-P are shown in Tables 10 and 11. The item most frequently endorsed by parents as describing “a significant problem” was “concentrating on his/her work” (76.92%). The items most frequently endorsed by parents as being “no problem” were: “going to a restaurant/fastfood place” and “eating in a public place other than a restaurant...” Specifically, 22 parents (84.62%) thought that their child/adolescent’s symptoms did not affect the areas of functioning described by these latter two items.

Individual OCD-related functional problems as reported on the Child Version of the COIS-R.

The frequencies of items rated as “significant problems” and “no problem at all” on the COIS-R-C are shown in Tables 10 and 12. The item most frequently endorsed by children as describing “a significant problem” was “getting good grades” (61.54%). The item most frequently endorsed by children as being “no problem” was “watching television or listening to music.” Almost all of the children (92.31%) thought that their OCD symptoms did not affect this area of functioning.

Table 10

Parent and Child Impairment Ratings on Items Common to the Parent and Child Versions of the COIS-R, in Addition to Levels of Parent-Child Agreement and Disagreement on Those Items

COIS-R Item	No Problem		Significant Problem		Parent-Child Agreement (Kappa)	Parent-Child Disagreement (McNemar Test, parent > child)	Parent-Child Difference (Mann-Whitney U-Test, <i>U</i> value)	Parent-Child Difference (Mann-Whitney U-Test, <i>p</i> value)
	Parent (%)	Child (%)	Parent (%)	Child (%)				
Taking tests or exams	34.62	42.31	65.38	57.69	0.03	0.7728	329.000	0.884
Being with a group of strangers	61.54	53.85	38.46	46.15	0.06	0.7728	303.000	0.525
Going shopping or trying on clothes	76.92	69.23	23.08	30.77	0.22	0.7237	318.000	0.713
Making new friends	61.54	61.54	38.46	38.46	0.025	0.7728	316.000	0.675
Going to a friends house during the day	61.54	61.54	38.46	38.46	0.35	0.7237	328.000	0.853
Writing in class	53.85	57.69	46.15	42.31	-0.01	1.000	330.000	0.881
Eating in a public place other than a restaurant ...	84.62	80.77	15.38	19.23	0.6	1.000	265.500	0.161
Getting to school on time in the morning	53.85	57.69	46.15	42.31	0.3	1.000	331.000	0.915
Going on a date	76.92	80.77	23.08	19.23	0.19	1.000	333.500	0.955
Visiting relatives	76.92	84.62	23.08	15.38	0.26	0.6831	308.000	0.565
Being with a group of people that he/she knows	76.92	73.08	23.08	26.92	-0.13	1.000	312.000	0.663
Going on a family holiday	76.92	73.08	23.08	26.92	0.28	1.000	274.500	0.210
Having relatives visit	69.23	84.62	30.77	15.38	0.37	0.2207	284.000	0.280
Concentrating on his/her work	23.08	46.15	76.92	53.85	0.36	0.0771	294.000	0.398
Going to a restaurant/fast food place	84.62	69.23	15.38	30.77	0.37	0.2207	265.000	0.159
Having a boyfriend/girlfriend	73.08	80.77	26.92	19.23	0.14	0.7237	320.000	0.722

COIS-R Item	No Problem		Significant Problem		Parent-Child Agreement (Kappa)	Parent-Child Disagreement (McNemar Test, parent > child)	Parent-Child Difference (Mann-Whitney U-Test, <i>U</i> value)	Parent-Child Difference (Mann-Whitney U-Test, <i>p</i> value)
	Parent (%)	Child (%)	Parent (%)	Child (%)				
Keeping friends she/he already has	61.54	61.54	38.46	38.46	0.35	0.7237	336.000	0.996
Eating lunch with other kids	80.77	76.92	19.23	23.08	0.65	1.000	290.000	0.355
Having someone spend the night at his/her house	76.92	76.92	23.08	23.08	-0.08	0.7518	331.000	0.920
Being prepared for class ...	65.38	65.38	34.62	34.62	0.49	0.6831	325.500	0.833
Bathroom or grooming ...	53.85	57.69	46.15	42.31	0.3	1.000	335.500	0.956
Completing assignments in class	50.00	50.00	50.00	50.00	0.08	0.7728	286.000	0.318
Doing homework	42.31	53.85	57.69	46.15	0.01	0.5791	301.000	0.542

Note. The items listed here are those that appear in both the parent and child versions of the COIS-R.

Table 11
Parent Impairment Ratings on Items Unique to the Parent Version of the COIS-R

COIS-R Item	No Problem (%)	Significant Problem (%)
Leaving the house	76.92	23.08
Doing fun things during recess or free time	73.08	26.92
Getting ready for bed at night	61.54	38.46
Getting along with his/her parents	61.54	38.46
Getting along with his/her brothers/sisters	42.31	57.69
Doing chores that he/she is asked to do ...	46.15	53.85
Going to temple or church	76.92	23.08
Going to school outings or field trips	69.23	30.77
Spending the night at a friends' house	65.38	34.62
Getting dressed in the morning	65.38	34.62

Table 12
Child/Adolescent's Impairment Ratings on Items Unique to the Child Version of the COIS-R

COIS-R Item	No Problem (%)	Significant Problem (%)
Being absent from school	84.62	15.38
Eating meals at home	88.46	11.54
Going to the bathroom	61.54	38.46
Watching television or listening to music	92.31	7.69
Reading books or magazines for fun	73.08	26.92
Having a friend come to your house during the day	73.08	26.92
Going to the movies	69.23	30.77
Getting to classes on time during the day	65.38	34.62
Talking on the phone	96.15	3.85
Getting good grades	38.46	61.54

Evaluating the importance of individual functional problems by examining the distribution of scores on each individual COIS-R-P and COIS-R-C item. The next step in describing the OCD-related functional impairments of individuals in this study was to assess the skewness and kurtosis of the data derived from each individual COIS-R-P and COIS-R-C item.³ This analysis was done to point out which individual activities were especially problematic, and which were much less problematic, for the assessed children and adolescents. For instance, if all the parents rated a specific item as 1 (i.e., "just a little"), this means that the activity described by that item is

³Here, the raw scores on each item (i.e., response values 0-3) were used to assess the skewness and kurtosis of the data.

not really a functional problem experienced by children and adolescents in this sample. In contrast, if all the parents rated a specific item as 3 (i.e., “very much”), this means that the activity described by that item is a major functional problem experienced by these children and adolescents. For this analysis, $p < 0.01$ was used to indicate significance (i.e., 2.58 cut-off z-score), as the sample size was small (Field, et al., 2005).

Only a few of the items showed significantly skewed response distributions. On the COIS-R-P, these items were: “going on a date;” “going on a family holiday;” “going to a restaurant or fastfood place;” “going to temple, church or mosque;” and “eating lunch with other kids”. On the COIS-R-C, these items were: “being absent from school;” “eating meals at home;” “going on a date;” “visiting relatives;” “having relatives visit;” and “having a boyfriend or girlfriend.” Response distributions on all of these items were positively skewed, indicating that parents and children gave very low ratings on the items (i.e., suggested that the situations described were not functional problems for the children; see Figures 13-22 and Table 13).

Only one item, COIS-R-C “eating meals at home,” had significant kurtosis, indicating that most children gave this item a low rating (see Figure 18 and Table 13). This piece of data further supports what is described above (i.e., according to the child/adolescent respondents, they did not experience “eating meals at home” as a functional problem).

Table 13
Skewness and Kurtosis of the Data for Each Item on the COIS-R-P and COIS-R-C

	Skewness			Kurtosis		
	Value	SE	z	Value	SE	z
COIS-R-P Items						
Taking tests or exams	-0.40	0.46	-0.87	-0.58	0.89	-0.65
Being with a group of strangers	0.35	0.46	0.76	-1.09	0.89	-1.22
Leaving the house	0.86	0.46	1.87	-0.14	0.89	-0.16
Going shopping or trying on clothes	0.90	0.46	1.96	-0.54	0.89	-0.61
Making new friends	0.41	0.46	0.89	-1.57	0.89	-1.76
Going to a friends house during the day	0.41	0.46	0.89	-1.57	0.89	-1.76
Writing in class	0.21	0.46	0.46	-1.46	0.89	-1.64
Eating in public other than a restaurant ...	1.42	0.46	3.09	1.25	0.89	1.40
Doing fun things during recess or free time	0.78	0.46	1.70	-0.51	0.89	-0.57
Getting to school on time in the morning	0.18	0.46	0.39	-1.45	0.89	-1.63
Going on a date	1.26	0.46	2.74*	-0.03	0.89	-0.03
Visiting relatives	1.04	0.46	2.26	-0.06	0.89	-0.07
Getting ready for bed at night	0.33	0.46	0.72	-1.02	0.89	-1.15
Getting along with his/her parents	0.35	0.46	0.76	-1.08	0.89	-1.21
Getting along with his/her brothers or sisters	-0.29	0.46	-0.63	-0.98	0.89	-1.10
Being with a group of people that he/she knows	0.84	0.46	1.83	-0.34	0.89	-0.38
Going on a family holiday	1.27	0.46	2.76*	0.25	0.89	0.28

	Skewness			Kurtosis		
	Value	SE	z	Value	SE	z
Having relatives visit	0.41	0.46	0.89	-1.68	0.89	-1.89
Doing chores that he/she is asked to do ...	-0.10	0.46	-0.22	-1.64	0.89	-1.84
Concentrating on his/her work	-0.76	0.46	-1.65	-0.00	0.89	0
Going to a restaurant or fast food place	1.42	0.46	3.09*	1.25	0.89	1.40
Having a boyfriend or girlfriend	1.06	0.46	2.30	-0.44	0.89	-0.49
Going to temple, church or mosque	1.28	0.46	2.78*	0.17	0.89	0.19
Going to school outings or field trips	0.72	0.46	1.57	-0.91	0.89	-1.02
Keeping friends she/he already has	0.49	0.46	1.07	-1.39	0.89	-1.56
Eating lunch with other kids	1.36	0.46	2.96*	0.57	0.89	0.64
Having someone spend the night at his/her house	1.07	0.46	2.33	-0.11	0.89	-0.12
Being prepared for class ...	0.43	0.46	0.93	-0.83	0.89	-0.93
Spending the night at a friend's house	0.61	0.46	1.33	-1.13	0.89	-1.27
Bathroom or grooming ... in the morning	0.12	0.46	0.26	-1.55	0.89	-1.74
Completing assignments in class	-0.16	0.46	-0.35	-1.65	0.89	-1.85
Doing homework	-0.21	0.46	-0.46	-1.13	0.89	-1.27
Getting dressed in the morning	0.45	0.46	0.98	-1.21	0.89	-1.36
COIS-R-C Items						
Taking tests or exams	-0.25	0.46	-0.54	-1.29	0.89	-1.45

	Skewness			Kurtosis		
	Value	SE	z	Value	SE	z
Being with a group of strangers	0.11	0.46	0.24	-1.17	0.89	-1.31
Being absent from school	1.35	0.46	2.93**	0.64	0.89	0.72
Going shopping or trying on clothes	0.63	0.46	1.37	-1.00	0.89	-1.12
Making new friends	0.34	0.46	0.74	-1.11	0.89	-1.25
Going to a friends house during the day	0.45	0.46	0.98	-1.36	0.89	-1.53
Writing in class	0.24	0.46	0.52	-1.20	0.89	-1.35
Eating in public other than a restaurant ...	0.97	0.46	2.11	0.33	0.89	0.37
Eating meals at home	1.81	0.46	3.93**	2.65	0.89	2.98**
Getting to school on time in the morning	0.30	0.46	0.65	-1.52	0.89	-1.71
Going on a date	1.36	0.46	2.96**	0.57	0.89	0.64
Visiting relatives	1.51	0.46	3.28**	1.43	0.89	1.61
Going to the bathroom	0.49	0.46	1.07	-1.26	0.89	-1.42
Watching television or listening to music	0.96	0.46	2.09	-0.04	0.89	-0.04
Reading books or magazines for fun	0.66	0.46	1.43	-0.73	0.89	-0.82
Being with a group of people you know	0.59	0.46	1.28	-0.71	0.89	-0.80
Going on a family vacation	0.72	0.46	1.57	-0.49	0.89	-0.55
Having relatives visit	1.61	0.46	3.5**	1.65	0.89	1.85
Having a friend come to your house during the day	0.84	0.46	1.83	-0.51	0.89	-0.57
Concentrating on your work	-0.21	0.46	-0.46	-1.52	0.89	-1.71

	Skewness			Kurtosis		
	Value	SE	z	Value	SE	z
Going to a restaurant or fast food place	0.55	0.46	1.20	-0.75	0.89	-0.84
Having a boyfriend or girlfriend	1.28	0.46	2.78**	0.45	0.89	0.51
Going to the movies	0.67	0.46	1.46	-0.90	0.89	-1.01
Getting to classes on time during the day	0.56	0.46	1.22	-1.21	0.89	-1.36
Keeping friends you already have	0.44	0.46	0.96	-1.22	0.89	-1.37
Eating lunch with other kids	0.96	0.46	2.09	-0.33	0.89	-0.37
Having someone spend the night at your house	0.97	0.46	2.11	-0.11	0.89	-0.12
Being prepared for class ...	0.52	0.46	1.13	-1.06	0.89	-1.19
Talking on the phone	0.66	0.46	1.43	-0.48	0.89	-0.54
Bathroom or grooming ... in the morning	0.21	0.46	0.46	-1.24	0.89	-1.39
Completing assignments in class	0.05	0.46	0.11	-1.65	0.89	-1.85
Doing homework	0.04	0.46	0.09	-1.66	0.89	-1.87
Getting good grades	-0.23	0.46	-0.5	-1.62	0.89	-1.82

Note: SE = standard error. The z-score was calculated are calculated by dividing the skewness/kurtosis value by the standard error.

** $p < 0.01$

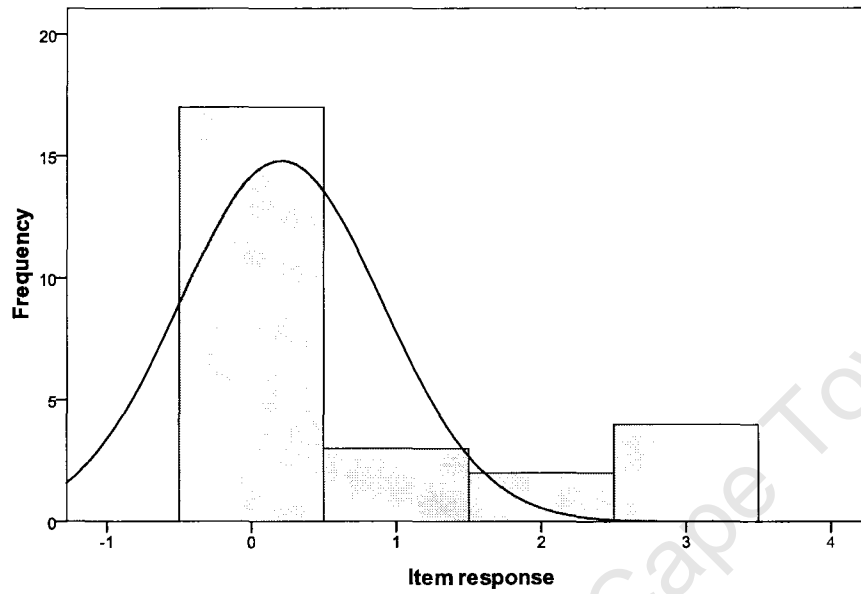


Figure 13. Histogram of COIS-R-P item 11 (going on a date) responses

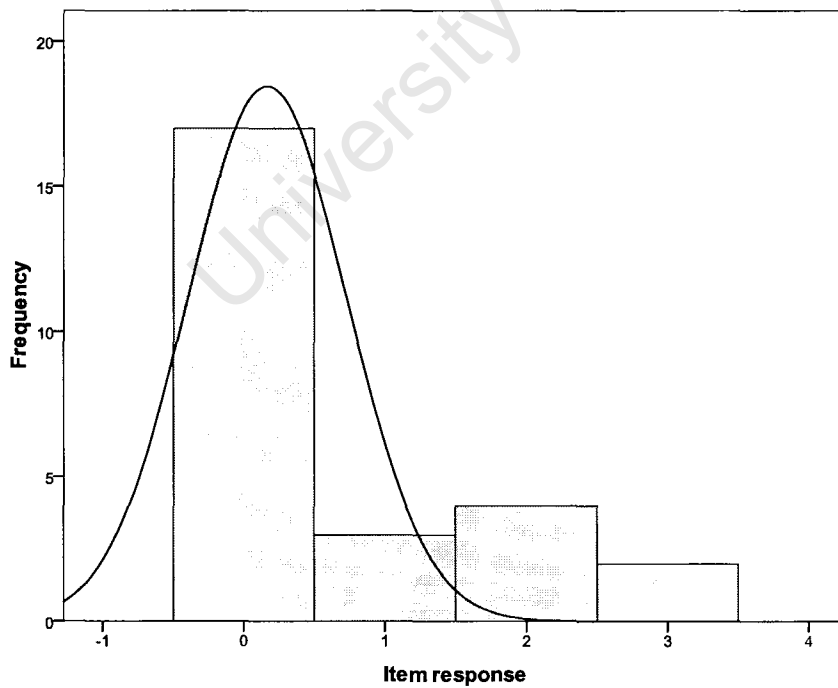


Figure 14. Histogram of COIS-R-P item 17 (going on a family holiday) responses

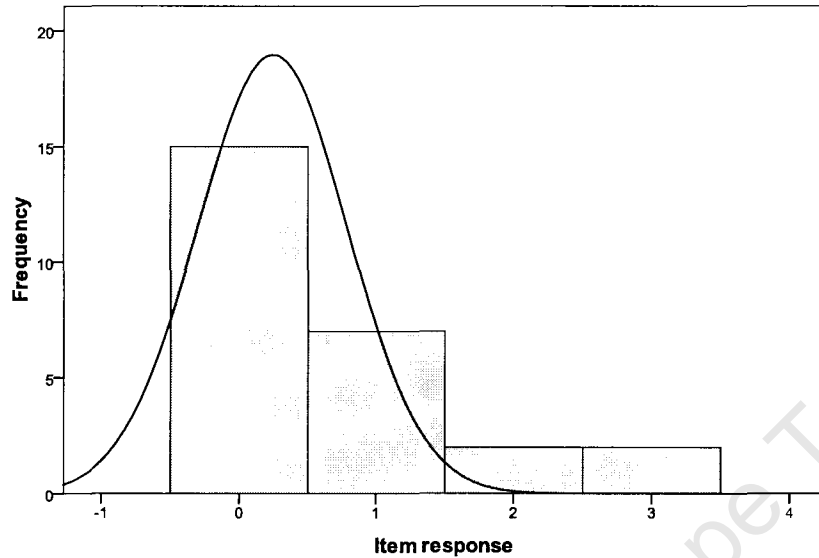


Figure 15. Histogram of COIS-R-P item 21 (going to a restaurant or fast food place) responses

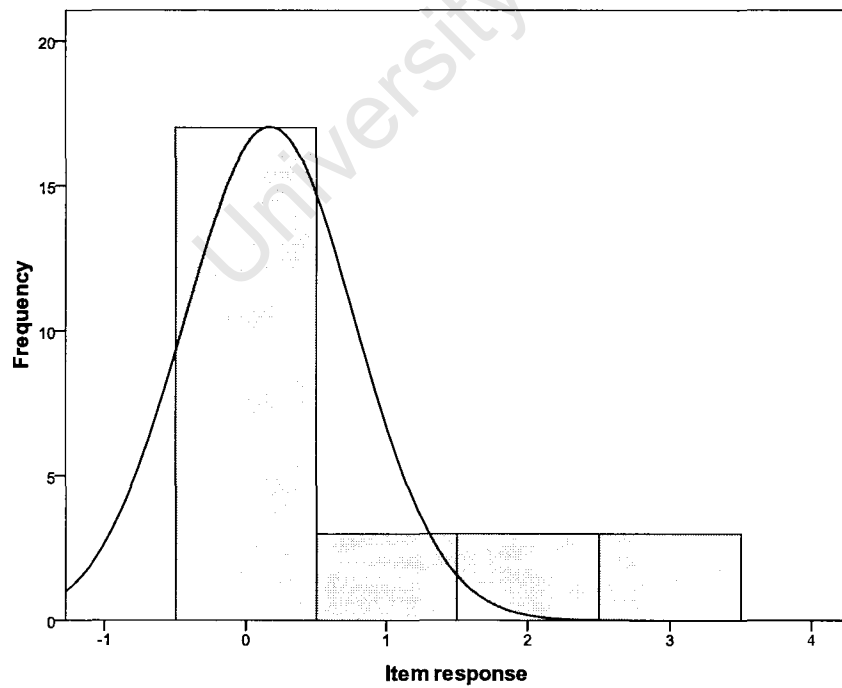


Figure 16. Histogram of COIS-R-P item 23 (going to temple, church or mosque) responses

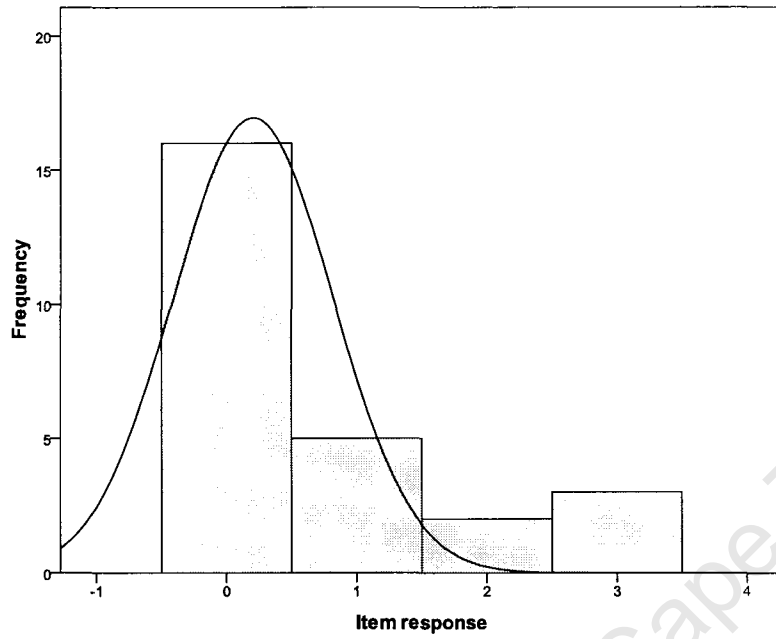


Figure 17. Histogram of COIS-R-P item 26 (eating lunch with other kids) responses

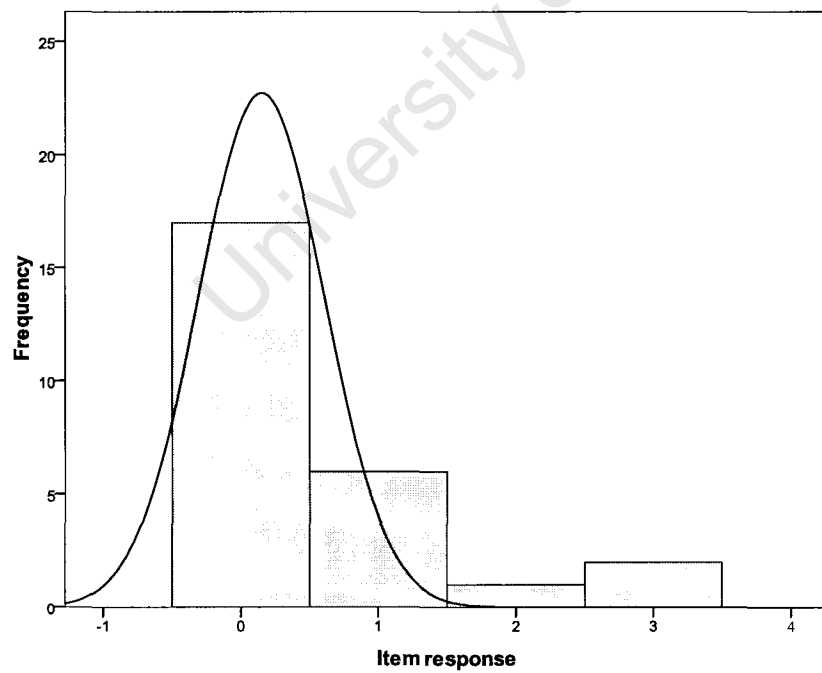


Figure 18. Histogram of COIS-R-C item 9 (eating meals at home) responses

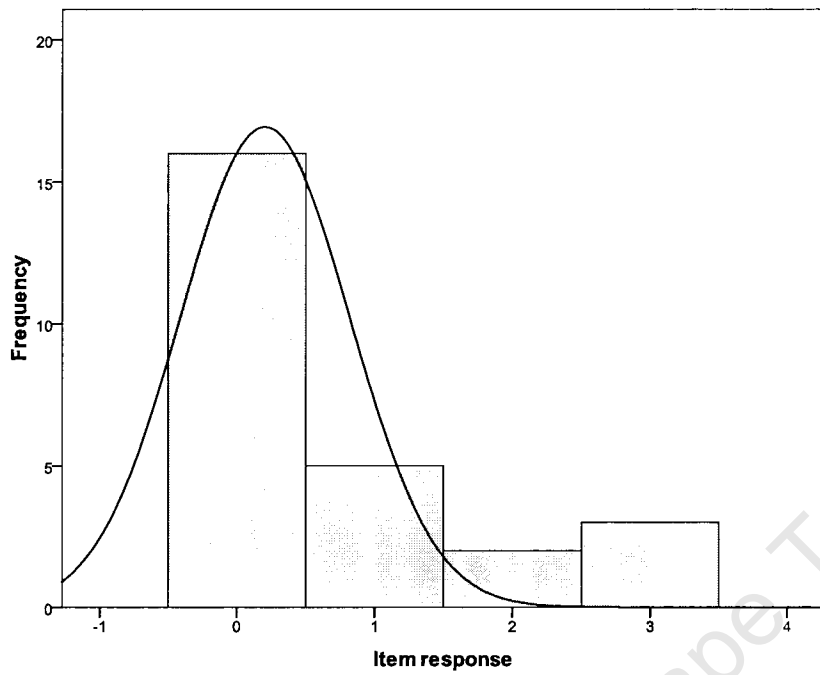


Figure 19. Histogram of COIS-R-C item 11 (going on a date) responses

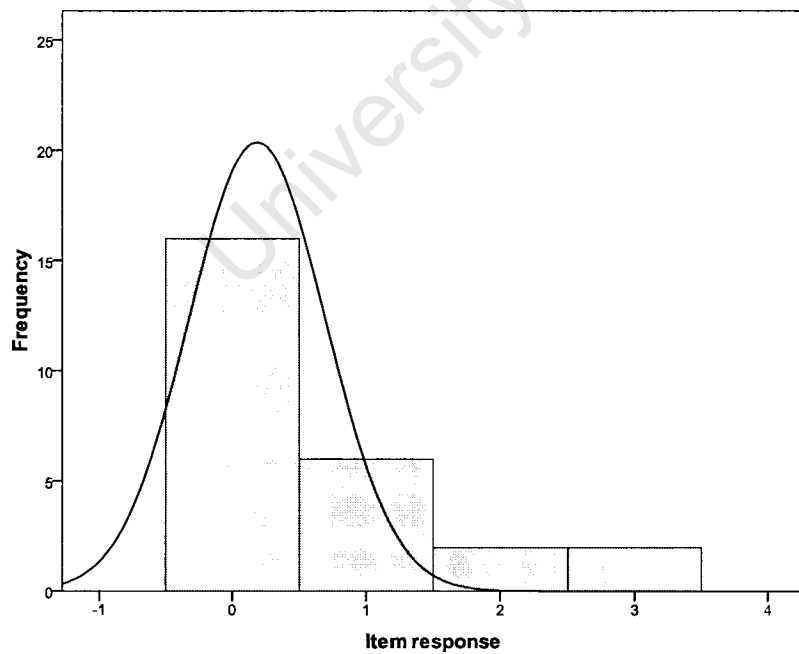


Figure 20. Histogram of COIS-R-C item 12 (visiting relatives) responses

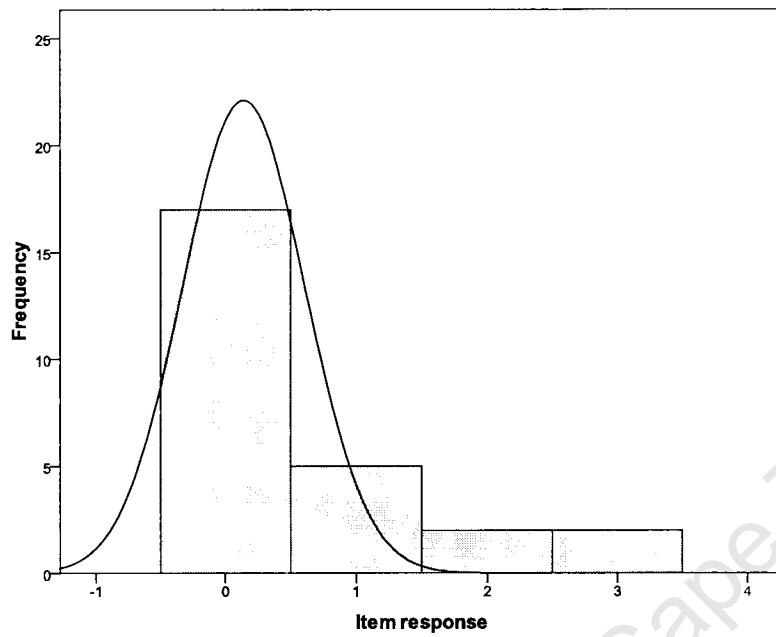


Figure 21. Histogram of COIS-R-C item 18 (having relatives visit) responses

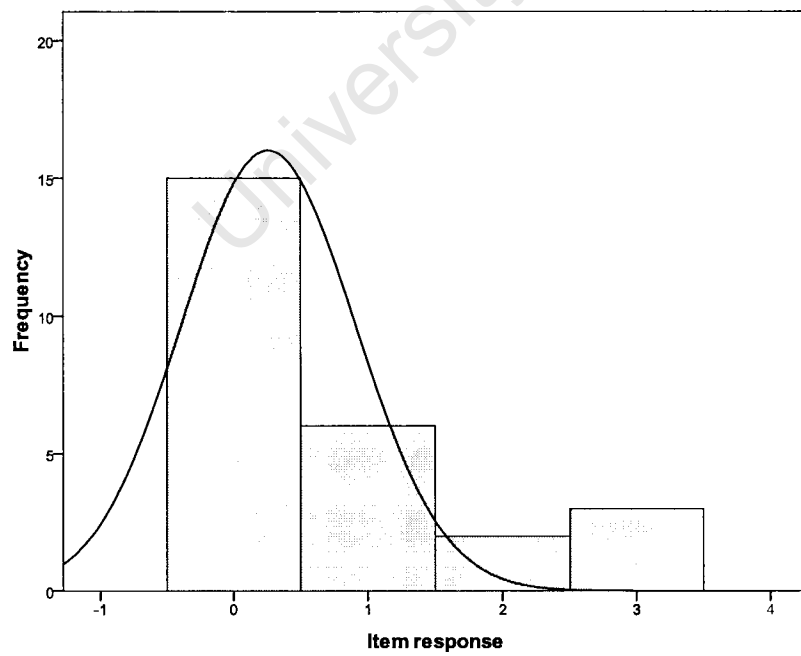


Figure 22. Histogram of COIS-R-C item 22 (having a boyfriend or girlfriend) responses

Parent-child differences in reporting individual OCD-related functional impairments. As previously mentioned, 23 items are common to the COIS-R-P and the COIS-R-C. Therefore, one can examine the differences between parent and child reports on these 23 common items. Such an analysis further addresses one of the major aims of this study (i.e., are there differences between parent and child/adolescent reports of OCD-related functional impairment).

Table 6 shows that data for all of the items in question are not normally distributed (i.e., the Kolmogorov-Smirnov Test statistic is significant on all 23 items). Therefore, *t*-tests could not be used to assess whether there was a statistically significant difference between parent and child reports on those 23 items. Therefore, non-parametric tests were employed to make this assessment.

The COIS-R has four response options for each item. Item raw scores (ranging from 0 to 3) were used to examine whether there were statistically significant differences between parent and child ratings on the 23 items common to the parent and child versions of the COIS-R. For the purposes of further data analysis (i.e., levels of parent-child agreement and disagreement), and consistent with Piacentini et al. (2003) and Valderhaug and Ivarsson (2005), these four options were converted into a dichotomous rating system by collapsing the 1, 2, and 3 responses into a single rating point (indicating “a significant problem”; as opposed to a response of 0, which signifies “no problem”). The results of these analyses are presented in Table 10.

As is shown in Table 10, parents rated more problems (10 out of 23) as being “significant” than did their children (7 out of 23). Nonetheless, there were no statistically significant disagreements

on any of the items. Note that the table presents statistics for both the McNemar and the Mann-Whitney *U*-Test. The latter statistic is presented because the sample violated the assumptions of the former (more specifically, for the McNemar test, comparisons on 15 out of the 23 items violated the assumption a minimum number of responses (10) being present across two separate cells in the 2 x 2 contingency table). The exact test was used for calculating the Mann-Whitney statistic, as the sample size in this study is small (Field, et al., 2005). Thus, the results of the Mann-Whitney *U*-test are more accurate with regards to parent and child differences, despite the fact that the trend detected by both tests (towards a lack of significant parent-child disagreement) is identical.

As also shown in Table 10, Kappa values for parent-child agreement indicated that the parents and children failed to agree on three of the items ($\kappa < 0$); had poor agreement on seven items ($\kappa = 0.0-0.19$); had fair agreement on 10 items ($\kappa = 0.20-0.39$); had a moderate level of agreement on one item ($\kappa = 0.40-0.59$); had a substantial level of agreement on two items ($\kappa = 0.60-0.79$); and had almost perfect agreement on none of the items ($\kappa = 0.80-1.00$).⁴

In summary, parents and children did not show significant agreement in their rating of many of the COIS-R items. At the same time, however, there was a lack of statistically significant parent-child disagreement on the items common to the COIS-R-P and COIS-R-C. There will be more interpretation of these data in the discussion.

⁴Landis and Koch's (1977) outline for the interpretation of Kappa values was used here.

Relationships between Measures

A third major aim of this study was to examine the relationship between the different measures of functional impairment used in this study. That is, the question of interest is whether these measures (CY-BOCS, CGAS, and COIS-R) are congruent with one another in reporting the presence/absence (and degree thereof) of functional impairment in children/adolescents with OCD.

In order to examine these relationships, Kendall's τ correlations⁵ were calculated between, on the one hand, the number of COIS-R items rated as describing significant problems, broken down by domain, and, on the other hand, scores on the CY-BOCS and CGAS. The results of these correlational analyses are presented in Tables 14 and 15.

Table 14 shows that eight correlations between the COIS-R-P and the CY-BOCS were statistically significant. In contrast, Table 15 shows that none of the correlations between the COIS-R-C and the CY-BOCS were significant. This pattern of data shows that, across measures, parents are more consistent in their ratings of OCD-related functional impairment and distress than are children/adolescents.

Of particular note in Table 14 is the positive, statistically significant correlation between the COIS-R-P total score and the CY-BOCS total score ($r = 0.29, p = 0.043$). This finding is in contrast to the relatively low positive (and statistically non-significant) correlation shown in Table 15 between the COIS-R-C total score and the CY-BOCS total score ($r = 0.18, p = 0.222$).

⁵ This correlation coefficient was calculated as the data were not normally distributed and there were many ties in the ranks.

Moreover, there are particularly high, statistically significant correlation between the COIS-R-P School factor and the CY-BOCS Compulsions score ($r = 0.41, p = 0.008$); and between the COIS-R-P school factor and the CY-BOCS Total score ($r = 0.41, p = 0.007$). These stand in contrast to the low (and statistically non-significant) correlation between the COIS-R-C School factor and the CY-BOCS Compulsions score ($r = -0.07, p = 0.638$); and between the COIS-R-C School factor and the CY-BOCS Total score ($r = 0.19, p = 0.203$). These data perhaps further illustrate that (a) South African children and adolescents with OCD are functionally impaired mainly in the school domain, and (b) parents are more able to accurately report this impairment (i.e., most of the OCD symptoms described by the CY-BOCS are in the school domain and therefore most of their functional impairment is exhibited in the school domain).

Tables 14 and 15 also show that all of the correlations between the CGAS and the COIS-R were in the expected direction (i.e., negative; the more impairment reported on the COIS-R, the lower the CGAS scores were). Of note, however, is that there was a substantially higher (and statistically significant) correlation between the COIS-R-P total score and the CGAS ($r = -0.59, p < 0.01$) than there was between the COIS-R-C total score and the CGAS ($r = -0.24, p = 0.097$). These data might suggest that parents rate their child/adolescent's global impairment more accurately than the child/adolescent rates his/her own global impairment; there is further discussion of this possibility in the next section.

Table 14

Kendall's tau Correlation Coefficient (τ) between Parent Reports on the COIS-R and Clinician Assessment on the CY-BOCS and CGAS

Instrument	COIS-R-P Domain				
	School	Family/Activities	Social	Daily Living Skills	Total
CY-BOCS					
Obsessions score	0.31*	0.11	0.15	0.28	0.21
Compulsions score	0.41*	0.36*	0.23	0.31*	0.36*
Total score	0.41*	0.23	0.16	0.33*	0.29*
CGAS Current score	-0.42*	-0.61*	-0.44*	-0.45*	-0.59*

* $p < 0.05$

Table 15

Kendall's tau Correlation Coefficient (τ) between Child Reports on the COIS-R and Clinician Assessment on the CY-BOCS and CGAS

Instrument	COIS-R-C Domain			
	Activities	School	Social	Total
CY-BOCS				
Obsessions score	0.21	0.25	0.07	0.20
Compulsions score	0.21	-0.07	-0.03	0.06
Total score	0.26	0.19	-0.01	0.18
CGAS Current score	-0.20	-0.15	-0.22	-0.24

DISCUSSION

This is the first study to examine the functional impairments of South African children and adolescents with OCD. Overall, it sought to provide a clearer picture of the phenomenological characteristics of childhood and adolescent OCD-related functional impairment. More specifically, the study had four aims: (a) to describe the functional impairments of South African children and adolescents with OCD, (b) to examine agreement and disagreement between child and parent reports about OCD-related functional impairment, (c) to examine relationships between parent-reported and child-reported impairments and clinician's assessments, and (d) to compare the functional impairments found in South African children and adolescents with OCD to those found in American and Scandinavian children with OCD. The first three aims were addressed in the Results section; the fourth aim will be addressed in this section.

Clinical Characteristics and OCD-related Functional Impairment in the Current Sample

The children in this study had a mean CGAS score that falls in the range described by (Kaufman et al., 1997, p. 57) as:

Variable functioning with sporadic difficulties or symptoms in several but not all social areas; disturbance would be apparent to those who encounter the child in a dysfunctional setting or time but not to those who see the child in other settings.
(p. 57)

The vast majority of participants (88.46%) presented with one or more disorders comorbid to their OCD. The most prevalent of these comorbid disorders were specific phobia and separation

anxiety disorder. Unsurprisingly, then, anxiety disorders was the most prevalent category of comorbid disorders. These data are consistent with those reported by Piacentini et al. (2003) (68.2% of their OCD sample presented with another DSM Axis I disorder, and anxiety disorders was the most prevalent category of comorbid disorders) and by Valderhaug and Ivarsson (2005) (67.7% of their OCD sample had at least one comorbid disorder, and anxiety disorders was the most prevalent category of comorbid disorders).

Piacentini et al. (2007) found that the COIS-R provides an explanation for OCD-related functional impairment (i.e., impairment that results from OCD symptomatology) over and above the functional impairment that results from the comorbid symptoms associated with their comorbid disorders. In the current study, the presence of multiple comorbid disorders had little impact on COIS-R-P total scores, and a small but significant influence on COIS-R-C total scores. This means that this COIS-R is a valuable measure of OCD-specific functional impairment, as comorbid disorders have little or no influence on the COIS-R response rates.

The impact on OCD-related functional impairment of one particular comorbid disorder (ADHD) was of particular interest. In childhood and adolescence, OCD and ADHD frequently co-exist in the same individual (e.g., Geller, Biedermann, Griffin, Jones, & Lefkowitz, 1996). When ADHD and OCD co-exist, functional impairment is frequently more severe, with both disorders making a unique contribution to the level and kind of impairment (Fischer, 2008; Geller, et al., 2004; Ivarsson, Melin, & Wallin, 2008; Masi, et al., 2006). Moreover, Geller et al. (2004) found that lack of concentration in children with OCD is not purely a consequence of obsessional anxiety. In addition, these authors found that in ADHD + OCD children these disorders may play a

contributory role in terms of having a negative impact on a child/adolescent's ability to concentrate. Moreover, children with OCD and their parents are often unaware that some of their functional impairment may be due to comorbid ADHD (Masi et al., 2006).

In this context, then, a measure such as the COIS-R that focuses exclusively on the functional impairment associated with OCD might be of great help distinguishing those areas of functional impairment specific to the child/adolescent's OCD versus those areas associated with other disorders.

Therefore, in the current study it was important to assess whether ADHD comorbidity had a significant impact on COIS-R scores. Given that, as mentioned above, the COIS-R focuses only on OCD-related functional impairment, the prediction was that there would be no statistically significant difference in COIS-R scores between a group of children with comorbid OCD and ADHD, and those with no comorbid ADHD (i.e., in line with the finding that multiple comorbid disorders do not have an impact on COIS-R response rates). This prediction was confirmed, suggesting that the COIS-R is indeed a valuable instrument for measuring specific OCD-related functional impairment in South African children and adolescents. However, it is imperative to note that there were only 6 children with OCD and comorbid ADHD and 20 children with OCD and no comorbid ADHD. Future studies that focus on this question should, naturally, try to obtain equal numbers of children/adolescents in those groups in order to obtain clearer results and draw firmer conclusions.

Functional problems and domains of functional impairment. In terms of treatment planning, it is important to note that South African children with OCD, and their parents, reported that they experienced the most impairment at school. More specifically, parents reported that the most significant functional problem was “concentrating on his/her work”, and children reported that the most significant functional problem was “getting good grades.”

Although previous studies in this field (Piacentini, et al., 2003; Valderhaug & Ivarsson, 2005) also reported that concentration was a functional problem related to OCD, those studies concluded that school is *not* the most important domain of OCD-related functional impairment in children and adolescents. For instance, Piacentini et al. (2003) found that home/family and school/academic were equally important and primary domains of impairment (with “concentrating on schoolwork and “getting ready for bed at night” the most significant problem areas experienced by children in their sample), while Valderhaug and Ivarsson (2005) found that home was the primary domain of impairment (with “situations related to bedtime” and “building or maintaining social relations” the most significant problem areas experienced by children in their sample).

Although some COIS-R items (e.g., “eating meals at home” on the COIS-R-C) were rated as not describing functional problems, this does not mean that these items should be removed from the instrument. Although these items may not describe major functional problems experienced by children/adolescents with OCD, they may still describe problems that are experienced to a certain extent.

Agreement and Disagreement between Ratings of Children/Adolescents and Parents

In the current study, parents consistently reported more functional problems than children/adolescents (i.e., they endorsed higher rates of significant functional problems on the COIS-R). This finding is consistent with those reported by the previous studies in this field (Piacentini, et al., 2003; Valderhaug & Ivarsson, 2005)

With regard to the rating of individual items on the COIS, Piacentini et al. (2003) reported that parents and children/adolescents significantly differed in their ratings on items related to school/academic and home/family problems. Similarly, Valderhaug and Ivarsson (2005) reported that parents and children generally did not agree in their ratings on the items of the COIS (i.e., kappa values ranged from 0.2 to 0.5). Moreover, in the latter study, parents and children showed statistically significant disagreement in their ratings of a few items, mainly those in the home/family domain (e.g., “doing household chores,” “getting ready for bed”).

Similarly, in the current study, kappa values for parent-child agreement were in the poor to fair range, varying from 0.0 to 0.39. Contrary to previous findings, however, in this study there was a lack of statistically significant parent-child disagreement on COIS-R items common to both parent and child versions of the measure. Therefore, parents and children did not disagree or agree in their rating of the items on the COIS-R, but they tended to rate the items in the same direction. The relatively small *N* in the current study could account for these differences in findings between the current study and previous studies in the field.

Relationships between Reported Impairments and Clinician's Assessments

Correlational analyses conducted on the current data revealed that parents are more accurate than their children in rating their child's global impairment (i.e., the correlations between the CGAS and the COIS-R-P were higher than the correlations between the CGAS and the COIS-R-C). Moreover, the measure of global impairment (CGAS) was negatively correlated with the measures of OCD-related functional impairment (COIS-R-P and COIS-R-C), implying that the COIS-R is a useful measure of OCD impairment. This finding is consistent with data presented by Piacentini et al. (2003) and by Valderhaug and Ivarsson (2005).

Additionally, correlations between an instrument rating the severity of childhood OCD (the CY-BOCS) and the COIS-R-P were higher than the correlations between that same instrument and the COIS-R-C. This piece of data suggests that parents are more accurate than children/adolescents in rating OCD-related functional impairment.

The correlations described above illustrate an important point with regard to the assessment of OCD-related functional impairment in children/adolescents: Obtaining a report from a parent/guardian is critical because those individuals tend to provide more accurate ratings, and better quality information, about the child/adolescent's functional impairment. The time spent obtaining reports from parents/guardians is thus extremely worthwhile for the clinician.

It is not clear why the current data suggest that children/adolescents provide less accurate information about their OCD-related functional impairment. However, one may speculate that children/adolescents find it difficult to distinguish between their global functional impairment

(i.e., functional impairment due to all of their comorbid conditions as well due to their primary OCD) and their OCD-related functional impairment. Additionally, the fact that the current dataset did not distinguish between adolescents and children may have influenced the findings, given that the researchers observed during interview sessions that the younger the child was the more difficult he/she found it to understand the COIS-R-C items.

Reasons for the Differences in Findings between the Current Study and Previous Studies

The differences between the findings of the current study and previous studies in this field may be attributed to three factors. These are: the current study used the COIS-R, as opposed to the COIS which was used in previous studies; the current study used different methods of recruitment to those used in previous studies; and culture may explain why there are differences between the current study's findings and those of previous studies. Each of these reasons will be addressed in turn.

First, Piacentini et al. (2003) and Valderhaug and Ivarsson (2005) used the original COIS, whereas in this study the revised version of the instrument was used. The COIS-R, as noted above, is different in form and content from the original version (for instance, some items were excluded from the revised version as factor analysis showed that these functional activities were already accounted for by other items on the measure) and represents a psychometric improvement over the original. Nonetheless, the COIS-R contains many of the items that were on the original scale, and statistical analyses confirmed the *a priori*, non-empirically derived factor structure of the original measure (Piacentini et al., 2007). Therefore, it is unlikely that this

factor alone can account for the differences in findings between this study and the two previous studies in the field.

Second, the present study used different recruitment methods to previous studies. Whereas both Piacentini et al. (2003) and Valderhaug and Ivarsson (2005) used large clinics as their only method of recruitment, in the current study many different community recruitment sources were used, but not large clinics. By definition, then, those previous studies used a treatment-seeking sample of patients, and the fact that they included only children recruited from child psychiatric outpatient clinics may limit the generalizability of their findings (Farrell & Barrett, 2006). In the current study, children who were not already receiving treatment were referred to appropriate clinicians subsequent to taking part in the study. However, treatment was not a benefit of taking part in this study, and some children had never been diagnosed with OCD before participating. Therefore, this study is much more generalisable to the population as we accessed communities from three main cities in South Africa (Durban, Johannesburg and Cape Town) and were not restricted to treatment centres. Therefore, the current sample may be fundamentally different from those of previous researchers. However, a principal investigator on one of the previous studies confirmed that the clinical characteristics of his sample were similar to those of the sample used in this study (e.g., none of the participants were inpatients; J. Piacentini, personal communication, 12 October 2007). Therefore, the most severe OCD cases were probably not included in any of these studies.

The third factor that may explain the differences in findings between this study and those from the previous two studies in this field is culture. Whereas Piacentini et al. (2003) drew their

sample from a cohort of children attending a clinic in Los Angeles, and Valderhaug and Ivarsson (2005) used cohorts from three different cities in Norway (Trondheim, Molde, and Aalesund) and from Göteborg in Sweden, the current study included a sample of South African children from communities in the Western Cape, Gauteng and KwaZulu-Natal.

These areas obviously represent very different cultural settings, and a reasonably large body of research (e.g., Lemelson, 2003) confirms that the manifestations of OCD symptoms differ across cultures. With specific regard to functional impairment associated with poor mental health, Canino, Costello, and Angold (1999, p. 96) write that “one observes different degrees of functional impairment in different cultures even when rates of psychiatric disorder are similar.”

One manifestation of culture that is particularly important to this study is education⁶.

Specifically, the four countries in which pediatric OCD-related functional impairment has now been studied (the United States, Norway, Sweden, and South Africa) have markedly different school systems. In the First World, resource-wealthy countries, class sizes tend to be smaller and teacher-student ratios tend to be lower than those in developing world, resource-poor countries such as South Africa. In ordinary public schools in South Africa teacher-student ratio is approximately 31:1 (South African Department of Education., 2008). An OCD-affected child/adolescent might get more support, assistance, and attention from a teacher who is taking charge of a reasonably small group of students, as typically happens in Norway and Sweden but rarely happens in South Africa. This added support may help to reduce OCD-related functional impairment in the school domain (e.g., by giving the child individual attention the

⁶ Allen (2007) makes clear that there are many different aspects of a person’s life, such race, socio-economic status, religion, and education, through which culture might be expressed.

child/adolescent's concentration on school work may improve), and may also lead to more rapid and efficient referrals for treatment. In other words, culture (as manifested in the school environment) may influence whether, and to what degree, a child/adolescent exhibits his/her OCD-related impairment in school compared to manifestation in other domains (home, social, etc.).

Following this line of reasoning, one can see why, in the current study, the school domain is reportedly the most negatively affected in terms of functional impairment for South African children/adolescents with OCD: These children might not be receiving the attention, support, and assistance they need from their teachers, particularly in situations where the teacher-student ratio is high. On the other hand, many of the participants in this study were from high socio-economic status families and attended private schools where the teacher-child ratio was more likely to approach that found in developed world, resource-wealthy countries. Therefore, a high teacher-student ratio and consequent less attention, support, and assistance from teachers to OCD-affected students cannot entirely explain why South African children and adolescents experience their primary OCD-related functional impairment in the school domain.

From the above argument, it is clear that symptomatology, symptom manifestations, and, consequently, functional impairment, can and do vary across cultures. So, with regard to OCD-related functional impairment, one child may differ from another as a consequence of culture.

Although each reason alone cannot account for the differences between the current study's findings and those of previous studies, together they may account for the differences in findings

of this study and previous studies. Future research will need to expand on this body of research in order to comprehensively understand childhood/adolescent OCD-related functional impairment across different countries and cultures.

Directions for Future Research

Future research on OCD in South Africa should examine the impact that cultural aspects (e.g., socio-economic status, race, religion) have on the impact of/impairment due to OCD. The current study was unable to examine closely the impact that culture had on childhood OCD, due to small sample size (i.e., not having enough people of each race, language group etc). Moreover, research based in the Western Cape should feature the inclusion of Xhosa-speaking children with OCD. The current study was unable to include patients from this population due to time constraints and the financial and practical constraints associated with translating the diagnostic interviews and questionnaires used in the study.

If one wants to conduct research with a Xhosa-speaking population one needs to adopt methods used by Flaherty et al. (1988) to achieve cross-cultural equivalence (e.g., establishing whether an instrument has been employed in other cultures). These methods were used for the first time in a South African study by Smit, Van den Berg, Bekker, Seedat, and Stein (2006). The researchers selected and modified a mental health battery so that they could use it in a cross-cultural environment. They used back-translation, consensus by committee and decentering methods to make sure that the content and semantics were similar to the English version (Maneesriwongul & Dixon, 2004; Smit, et al., 2006). Some studies (e.g., Smit, et al., 2006) have found that Xhosa-speaking people find it difficult to understand Likert-type questionnaires, as it is complex for

these individuals to differentiate between ‘most of the time’ and ‘some of the time’ response options. Therefore, the COIS-R, which is presented as a Likert-type scale, would need to be adapted if used in a Xhosa population.

The structures set in place by this study do, however, allow for full exploration of the role of culture in OCD-related functional impairment. Firstly, given the multi-cultural nature of South African society, this is an ideal location to conduct a study specifically examining the role of culture in psychiatric disorders and consequent psychosocial dysfunction. Secondly, a demographic questionnaire (Appendix D) has been created by the primary researcher to capture data related to the various aspects of a person’s life, such race, socio-economic status, religion, and education, through which culture might be expressed (Allen, 2007). The individual and collective influence of these cultural aspects on a child’s OCD-related functional impairment need to be examined in order to draw firm conclusions regarding the role culture plays in shaping those impairments.

Moreover, future research with larger samples should further examine the psychometric properties (e.g., cross-cultural and predictive validity, test-retest reliability with regard to effects of treatment) of the COIS-R. The instrument’s developers have expressed interest in guiding this process. With a large enough sample one may also be able to examine whether the recommended cut-off point for global functional impairment on the CGAS is as valid in South Africa as in the country for which it was developed (the United States; Canino et al., 1999). Mental health professionals are already aware that standards for functional impairment vary across cultures and

that "...[w]hat may be perceived as a mild functional limitation in one culture may be more troubling in another and vice-versa" (Winters et al., 2005, p. 311).

Future studies should also examine treatment-naïve OCD children. One can then examine OCD-related functional impairment without the effect of treatment on the COIS-R scores. Although previous studies (including this one; in South Africa it is difficult to recruit patients at baseline because there are no treatment OCD-specific treatment centres where subjects can be enrolled in a research study before receiving treatment) have been unable to recruit treatment-naïve children with OCD, it seems vital that this kind of research is also conducted.

With regard to data analysis, future research with larger samples may be able to examine more closely and accurately parent-child disagreement using statistical techniques such as the McNemar Test. With regard to parent-child disagreement, in the current study the achieved power for this comparison was 0.1 (Cohen's $d = 0.17$). Obviously, future studies with larger samples would be able to increase the power of this analysis. Moreover, with a larger sample size one would also be able to (a) examine the impact that age and gender have on the prevalence rates of any specific impairment, and to (b) use regression-based analyses to examine, for instance, the contributory role of various cultural features to OCD-related functional impairment.

Conclusion

This study demonstrated that South African children and adolescents experience OCD-related functional impairment largely in the School domain and that they experience a number of different individual functional problems (e.g., "concentrating on his/her work" and "getting good

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University of Cape Town

APPENDIX A

DSM-IV-TR Criteria for OCD

A. Either obsessions or compulsions:

Obsessions as defined by (1), (2), (3), and (4):

- (1) recurrent and persistent thoughts, impulses or images that are experienced, at some time during the disturbance, as intrusive and inappropriate and that cause marked anxiety or distress
- (2) the thought, impulses, or images are not simply excessive worries about real-life problems
- (3) the person attempts to ignore or suppress such thoughts, impulses or images, or to neutralize them with some other thought or action
- (4) the person recognizes that the obsessional thoughts, impulses, or images are a product of his or her own mind (not imposed from without as in thought insertion)

Compulsions as defined by (1) and (2):

- (1) repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly;
- (2) the behaviors or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however, these behaviors or mental acts either are not connected in a realistic way with what they are designed to neutralize or prevent or are clearly excessive

- B. At some point during the course of the disorder, the person has recognized that the obsessions or compulsions are excessive or unreasonable. **Note:** This does not apply to children.
- C. The obsessions or compulsions cause marked distress, are time consuming (take more than one hour a day), or significantly interfere with the person's normal routine, occupational (or academic) functioning, or usual social activities or relationships.

- D. If another Axis 1 disorder is present, the content of obsessions or compulsions is not restricted to it (e.g., preoccupation with food in the presence of Trichotillomania; concern with appearance in the presence of Body Dysmorphic Disorder; preoccupation with drugs in the presence of a Substance Use Disorder; preoccupation with having a serious illness in the presence of Hypochondriasis; preoccupation with sexual urges or fantasies in the presence of a Paraphilia; or guilty ruminations in the presence of a Major Depressive Disorder).
- E. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

Specify if:

With Poor Insight: if, for most of the time during the current episode, the person does not recognize that the obsessions and compulsions are excessive or unreasonable.

APPENDIX B

COIS-R Parent Report Form

Child OC Impact Scale - Revised (COIS - RP) Parent Report about Child

Name: _____ Age: _____ Date: _____

Please rate how much your child's obsessive compulsive symptoms (unwanted thoughts and/or rituals) have caused problems for him or her in the following areas over the past month. If a specific question does not apply, mark "Not at all".

In the past month, how much trouble has your child had doing the following things because of his or her OCD?	Not at all	Just a Little	Pretty Much	Very Much
1. Taking tests or exams	0	1	2	3
2. Being with a group of strangers	0	1	2	3
3. Leaving the house	0	1	2	3
4. Going shopping or trying on clothes	0	1	2	3
5. Making new friends	0	1	2	3
6. Going to a friend's house during the day	0	1	2	3
7. Writing in class	0	1	2	3
8. Eating in public other than a restaurant, like on a picnic, in the park, or at a friend's house	0	1	2	3
9. Doing fun things during break or free time	0	1	2	3
10. Getting to school on time in the morning	0	1	2	3
11. Going on a date	0	1	2	3
12. Visiting relatives	0	1	2	3
13. Getting ready for bed at night	0	1	2	3
14. Getting along with his/her parents	0	1	2	3
15. Getting along with his/her brothers or sisters	0	1	2	3
16. Being with a group of people that he/she knows	0	1	2	3
17. Going on a family holiday	0	1	2	3
18. Having relatives visit	0	1	2	3
19. Doing chores that he/she is asked to do, like washing the dishes, taking the rubbish out or cleaning his/her room	0	1	2	3

Name: _____

COIS-RP (parent-report about child)
Page 2

In the past month, how much trouble has your child had doing the following things because of his or her OCD?	Not at all	Just a Little	Pretty Much	Very Much
20. Concentrating on his/her work	0	1	2	3
21. Going to a restaurant or fast food place	0	1	2	3
22. Having a boyfriend/girlfriend	0	1	2	3
23. Going to temple, church or mosque	0	1	2	3
24. Going to school outings or field trips	0	1	2	3
25. Keeping friends he/she already has	0	1	2	3
26. Eating lunch with other kids	0	1	2	3
27. Having someone spend the night at his/her house	0	1	2	3
28. Being prepared for class, e.g., having his/her books, paper or pencils ready when needed	0	1	2	3
29. Spending the night at a friend's house	0	1	2	3
30. Bathroom or grooming (brushing his/her teeth or combing his/her hair) in the morning	0	1	2	3
31. Completing assignments in class	0	1	2	3
32. Doing homework	0	1	2	3
33. Getting dressed in the morning	0	1	2	3

APPENDIX C

COIS-R Child Self-Report Form

Child OC Impact Scale - Revised (COIS - RC)
Child Self-Report

Name: _____ Age: _____ Date: _____

Please rate how much your obsessive compulsive symptoms (unwanted thoughts and/or rituals) have caused problems for you in the following areas over the past month. If a specific question does not apply, mark "Not at all".

In the past month, how much trouble have you had doing the following things because of your OCD?	Not at all	Just a Little	Pretty Much	Very Much
1. Taking tests or exams	0	1	2	3
2. Being with a group of strangers	0	1	2	3
3. Being absent from school	0	1	2	3
4. Going shopping or trying on clothes	0	1	2	3
5. Making new friends	0	1	2	3
6. Going to a friend's house during the day	0	1	2	3
7. Writing in class	0	1	2	3
8. Eating in public other than a restaurant, like on a picnic, in the park, or at a friend's house	0	1	2	3
9. Eating meals at home	0	1	2	3
10. Getting to school on time in the morning	0	1	2	3
11. Going on a date	0	1	2	3
12. Visiting relatives	0	1	2	3
13. Going to the bathroom	0	1	2	3
14. Watching television or listening to music	0	1	2	3
15. Reading books or magazines for fun	0	1	2	3
16. Being with a group of people you know	0	1	2	3
17. Going on a family holiday	0	1	2	3
18. Having relatives visit	0	1	2	3
19. Having a friend come to your house during the day	0	1	2	3

Name: _____

COIS-RC (child self-report)
Page 2

In the past month, how much trouble have you had doing the following things because of your OCD?	Not at all	Just a Little	Pretty Much	Very Much
20. Concentrating on your work	0	1	2	3
21. Going to a restaurant or fast food place	0	1	2	3
22. Having a boyfriend/girlfriend	0	1	2	3
23. Going to the movies	0	1	2	3
24. Getting to classes on time during the day	0	1	2	3
25. Keeping friends you already have	0	1	2	3
26. Eating lunch with other kids	0	1	2	3
27. Having someone spend the night at your house	0	1	2	3
28. Being prepared for class, e.g., having your books, paper or pencils ready when needed	0	1	2	3
29. Talking on the phone	0	1	2	3
30. Bathroom or grooming (brushing your teeth or combing his/her hair) in the morning	0	1	2	3
31. Completing assignments in class	0	1	2	3
32. Doing homework	0	1	2	3
33. Getting good marks at school	0	1	2	3

APPENDIX D

Demographic Questionnaire

Child's Name: _____

Parent's Name: _____

1. Age: _____

2. Sex (circle one): Male Female

3. What is your race or ethnic background?

WHITE

AFRICAN

COLOURED

ASIAN

OTHER: (specify) _____

4. Religion: _____

5. How many times a month do you attend church/mosque/temple etc?

6. Home Language:

7. Size of house (indicate the number of rooms in the
house): _____

8. Number of people who live in the

house: _____

9. Who lives in your house (e.g., brother, step-father, mother, aunt)?

10. Are your parents married/divorce/living together?

11. Do you live with your extended family (e.g., aunts, cousins, grandparents)?

12. Do you spend time with your extended family?

13. How often do you see your extended family?

14.

14.1. What term best describes the kind of neighbourhood in which you live?

SUBURBAN

URBAN

TOWNSHIP

INTERMEDIATE

14.2. What is the name of the neighbourhood in which you live?

15. Household Income per annum (tick appropriate income category):

0-35000: _____

36000-75000: _____

76000-125000: _____

126000-175000: _____

176000-225000: _____

226000-275000: _____

276000-325000: _____

326000-375000: _____

376000-425000: _____

426000-475000: _____

476000-525000: _____

526000<: _____

- | | | |
|---|----|-----|
| 1. Tap with running water (circle one) | No | Yes |
| 2. Bedroom, living room, kitchen and bathroom | No | Yes |
| 3. Stove | No | Yes |
| 4. Fridge | No | Yes |
| 5. Flush toilet in house | No | Yes |
| 6. 2 people or less in bedroom | No | Yes |
| 7. Child sleeps in his/her bed | No | Yes |
| 8. TV | No | Yes |
| 9. Radio | No | Yes |
| 10. 20 or more hard cover books | No | Yes |
| 11. Child receive present on birthday from parents | No | Yes |
| 12. Child owns bought toys more than R50 | No | Yes |
| 13. Enough food for at least 2 meals a day | No | Yes |
| 14. Electricity / Gas | No | Yes |
| 15. One parent read one new newspaper/magazine per week | No | Yes |
| 16. Child adequately clothed | No | Yes |

APPENDIX E

UNIVERSITY OF CAPE TOWN



Department of Psychology

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01 June 2009

Informed Consent to Participate in Research and Authorization for Collection, Use, and Disclosure of Mental Health and Other Personal Data

You are being asked to take part in a research study. This form provides you with information about the study and seeks your authorization for the collection, use and disclosure of your mental health and other personal information necessary for the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Your participation is entirely voluntary. Before you decide whether or not you want your child and yourself to take part, read the information below and ask questions about anything you do not understand. By participating in this study you will not be penalized or lose any benefits to which you would otherwise be entitled.

1. Name of Participant ("Study Subject")**2. Title of Research Study**

Functional Impairments of Children and Adolescents with Obsessive-Compulsive Disorder in South Africa

3. Investigators and Telephone Number(s)

Kevin G. F. Thomas, Ph.D.
Senior Lecturer
Department of Psychology
University of Cape Town
Telephone: 021-650-4608

Lara Hoppe
 Honours Student
 Department of Psychology
 University of Cape Town
 Telephone: 0845010385

4. Source of Funding or Other Material Support

None

5. What is the purpose of this research study?

The purpose of this research study is to describe the nature of functional impairments in South African children and adolescents with Obsessive-Compulsive Disorder (OCD)

6. What will be done if your child/adolescent takes part in this research study?

In this study, you and your child will undergo two interviews that will ask you questions relating to your child's mental health. Both you and your child will undergo the same interview at separate times. In addition, both you and your child will separately complete a questionnaire relating to the impact that your child's OCD symptoms has had on their lives.

Possible locations for the interviews and filling out the questionnaires and completing the interviews are: the University of Cape Town's Department of Psychology; the Medical Research Council's Anxiety and Stress Disorders Research Unit; your child's OCD support group meeting place; child's clinicians' practice; or at your home. Each testing session will be individually conducted by a postgraduate psychology student who has been trained in the use of the measures that will be administered and who is under the supervision of a clinical psychologist.

After the testing session, you will have the opportunity to ask questions and thus learn more about psychological research. However, your child's particular results will not be disclosed.

If you have any questions now or at any time during the study, you may contact the Principal Investigator listed in #3 of this form.

7. If you choose to allow your child to participate in this study, how long will he/she be expected to participate in the research?

The study consists of 2 sessions, which will each last for a maximum of 2 hours and 30 minutes. If at any time, during the interviews or when filling out the questionnaire, you or your child finds any of the procedures uncomfortable, you are free to discontinue participation without penalty.

8. How many children are expected to participate in the research?

9. What are the possible discomforts and risks?

There are no known risks associated with participation in this study. The only possible discomfort your child may experience is slight fatigue. If he/she becomes tired during either of the interviews or when he/she is completing the questionnaire, we will take a break. Your child will be allowed to take breaks whenever requested. Your child may feel slight discomfort with the fact that he/she is taking part in an OCD study and that people at the venue of the study may know of his/her OCD diagnosis. However, privacy will be maintained, as best as is possible, in the place where the study is conducted.

If you wish to discuss the information above or any discomforts you or your child may experience, you may ask questions now or call the Principal Investigator listed on the front page of this form.

10a. What are the possible benefits to you and your child/adolescent?

You and your child may or may not personally benefit from the research

10b. What are the possible benefits to others?

This study will help validate or disconfirm previous research conducted on the functional impairments of children and adolescents with OCD. In particular, it will help to establish whether children and adolescents with OCD in South Africa exhibit different functional impairments to children and adolescents with OCD in other countries. All this will help inform the future treatment and diagnosis of OCD in children and adolescents.

11. If you choose to take part in this research study, will it cost you anything?

Participating in this study will not cost you anything.

12. Will you receive compensation for taking part in this research study?

You will receive R150 for taking part in the study to cover transport costs.

13a. Can you withdraw your child from this study?

You are free to withdraw your consent and to stop participating in this research study at any time. If you do withdraw your consent, there will be no penalty.

If you have any questions regarding your child's rights as a research participant, and your rights as the individual granting consent for research participation, you may phone the Psychology Department offices at 021-650-9111.

13b. If you withdraw your child from this study, can information about you still be used and/or collected?

Information already collected may be used.

14. Once personal and performance information is collected, how will it be kept secret (confidential) in order to protect your privacy?

Information collected will be stored in locked filing cabinets or in computers with security passwords. Only certain people have the right to review these research records. These people include the researchers for this study and certain University of Cape Town officials. Your research records will not be released without your permission unless required by law or a court order.

15. What information about your child may be collected, used and shared with others?

The information gathered from your child will be on their mental health status and functional impairments related to Obsessive Compulsive Disorder. If you agree that your child can be in this research study, it is possible that some of the information collected might be copied into a "limited data set" to be used for other research purposes. If so, the limited data set may only include information that does not directly identify you or your child. For example, the limited data set cannot include you or your child/adolescents' name, address, telephone number, ID number, or any other photographs, numbers, codes, or so forth that link you or your child/adolescent to the information in the limited data set.

The results of the research will be presented as part of an Honours research project for the University of Cape Town. Also, the results may be submitted for publication in a peer-reviewed journal. In both instances neither you nor your child will be identified in any way.

16. What should you tell your child?

You may wish to discuss the study with your child to find out or determine whether he/she feels comfortable taking part. Your child should know that he/she can choose not to participate in the study. Your child should also know that if he/she does choose to participate, he/she can withdraw at any time during the study with no negative consequences.

17. How will the researcher(s) benefit from your being in the study?

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator and others attached to this research project may benefit if the results of this study are presented at scientific meetings or in scientific journals.

18. Signatures

As a representative of this study, I have explained to the parent/guardian of the participant the purpose, the procedures, the possible benefits, and the risks of this research study; and how the participant's performance and other data will be collected, used, and shared with others:

Signature of Person Obtaining Consent and Authorization

Date

You have been informed about this study's purpose, procedures, possible benefits, and risks; and how your child's mental health status and OCD-related functional impairments and other data will be collected, used and shared with others. You have received a copy of this form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily consent to allow your child to participate in this study. You hereby authorize the collection, use and sharing of your child's mental health status and OCD-related functional impairments and other data. By signing this form, you are not waiving any of your legal rights.

Signature of Person Consenting and Authorizing

Date

Please indicate below if you would like to be notified of future research projects conducted by our research group:

_____ (initial) Yes, I would like to be added to your research participation pool and be notified of research projects in which I or my child might participate in the future.

Method of contact:

Phone number: _____

E-mail address: _____

Mailing address: _____

APPENDIX F

Child Assent form (school going age- under18 years old)

Project Title: Functional Impairments of South African Children with Obsessive-Compulsive Disorder

Principal Investigator: Lara J. Hoppe

Why are you here?

“Your doctors want to tell you about a research study involving children with Obsessive-Compulsive Disorder (OCD).

Research is a special way to learn about something. They want to see if you would like to be in this study. Lara Hoppe and some other researchers are doing this study.”

Why is this study being done?

“Your doctors are doing this study because they want to learn more about how OCD is affecting children’s lives, so that this can provide psychologists and psychiatrists with information that will help them to treat children with OCD.”

What will happen to you if you agree join this study?

“If you take part you will be asked some questions about your feelings and your life. Your mom/dad will also be asked the same questions about you. You and your parents will be asked these questions on two different days. But you will only be asked these questions if you join the study.”

“This study won’t make you feel better or get well. But the researchers might find out something that will help other children like you later.”

What if you have any questions?

“If you have questions about the study you can ask them at any time. You can ask now. You can also ask later. You can talk to the researchers or you can talk to someone else. Do you have any questions now?”

Who will know you are in the study?

“When the study is finished we will tell other researchers, psychiatrists and psychologists what we found out, but we won’t tell them your name.”

Do you have to be in the study?

“You don’t have to be the study. No one will be mad at you if you don’t want to

do this. If you don't want to be in this study, you just have to tell us. If you want to be in the study, you just have to tell us. You can say yes now and change your mind later. It is up to you."

"If you want to be in this study print your name here"

I want to be in this study

Signature or Mark of Subject or Legally Authorized
Representative

Date

Signature of Person Obtaining Consent

Date

University of Cape Town

GLOSSARY OF TERMS

Adolescence - describes the period from 12 years old to about 20 years old.

Apraxia - a neurological disorder characterized by loss of the ability to execute or carry out learned purposeful movements, even though the person has the desire and the physical ability to perform the movements.

Asperger's Syndrome - an autism spectrum disorder. It is a neurobiological syndrome which impacts on social and communication skills.

Childhood - describes the period from birth until approximately 12 years old.

COIS - Child OCD Impact Scale.

COIS-R - Child OCD Impact Scale-Revised.

Functional impairment - specific difficulties in many domains of functioning developing subsequent to a disorder.

OCD - Obsessive-Compulsive Disorder.

Poland Syndrome - a rare birth defect characterized by underdevelopment or lack of chest muscles on one side of the body and webbing of the fingers of the hand on the same side of the body.