Major Research Project

How Young People Make Sense of Developing and Getting Help for Obsessive Compulsive Disorder

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I dedicate my thesis to every person who have experienced or is currently experiencing OCD.

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ABSTRACT

There has been an abundance of studies that have adopted positivist approaches, employing quantitative methods, to research OCD ‘symptoms’ and their underlying neurobiology and neurochemistry. There appears to be a lack of research investigating how OCD is experienced by those living with the diagnosis, and in particular the experiences of young people diagnosed with OCD.

Ten young people, aged 14-17 years old, with a diagnosis of OCD were recruited from Child and Adolescent Mental Health Services (CAMHS). The young people were interviewed and a Thematic Analysis (TA) was used to analyse data.

Four themes were developed through the analysis. The first theme ‘Traumatic and stressful life events’ found that 9 out of the 10 participants experienced at least one of the following three life events just prior to the development of their OCD: ‘Hostility in the family’, ‘Illness and death’, ‘Bullying and friendlessness’. Four subthemes, ‘Lack of understanding of the behaviour’, ‘Being secretive’, ‘I thought I was going crazy’, and ‘Feeling different’, provided a richer understanding to the theme ‘Responses to signs of OCD’. The four subthemes ‘Feeling ‘right’’, ‘I was taking on all the responsibility’, ‘It’s ruined everything’, ‘Everyday life is now in my bedroom’ explored the third theme ‘The battle of living with OCD’. The last theme ‘Ambivalent relationship to help’ described the conflict that most participants had over exposure therapy and accommodation of their OCD. Lastly, most participants felt the long waiting time for help was frustrating. The theme is fully explored by the following three subthemes: ‘Conflicts of exposure therapy’, ‘Conflicts about accommodation of the OCD’, ‘and ‘Frustrations of long waiting lists’.

The themes that emerged may provide important information for clinicians and the implications of the research findings are discussed. The strengths and limitations of the study are noted and there are suggestions for future research.

CHAPTER ONE: INTRODUCTION

This chapter will begin by sharing an understanding of the position the researcher has taken towards the present study. A definition of OCD will be outlined as well as how common the condition is, including its phenomenology. The scope of the chapter will then widen to consider the main theories and research that have attempted to explain the development of OCD. A critique of the different treatments for OCD will be provided whilst evaluating the literature and research studies. The chapter will end with the rationale for the present study and its aims and research questions.

Literature Search Strategy

Scientific journal articles and books were identified using the EBSCO search engine and MEDLINE, Pubmed, PsycINFO, PsycBOOKS, and PsycARTICLES databases. Additional Google and Google Scholar searches were conducted to access reports and policy papers from government and non-government organisations. The second supervisor to the study, a very experienced clinician in the field of OCD, also suggested further relevant reading.

No time limits were imposed and the search terms included: ‘OCD’; ‘young people’; ‘stressful life events’; ‘traumatic life events’; ‘attachment theory’; ‘treatment for OCD’; ‘Cognitive Behaviour Therapy (CBT)’; ‘medication’; and ‘family therapy’. These terms were then used in different combinations. Studies were excluded if they were not reported in English.

Use of Language

Psychiatry avoids emphasising life experiences for the development of mental distress. Boyle (2011) notes how psychiatry converts distress to ‘symptoms’ and ‘disorders’ and focuses entirely on these and their associated diagnostic categories. The diagnostic term ‘OCD’ ascribes to the idea that it is a ‘disorder’. Blashfield and Fuller (1996) note how diagnoses have become a regular occurrence, with the number of categories of disorder increased from 128 in DSM-I (American Psychiatric Association; APA, 1952) to 357 in DSM-IV (APA, 1994). In the space of twenty-six years, the number of psychiatric diagnoses has doubled. This explosion of “vocabularies of deficit” (Gergen, 1990) has been accompanied by a rapid growth in the mental health professions. However, medicalised language, such as diagnoses, to describe mental distress is contentious and not universally shared:

> "Although it is often claimed that use of diagnosis aids communication between professionals, in my experience such terms always needed supplementing with further information, since two people with the same diagnosis could be experiencing quite different forms of distress" (Harper, 2014, p.4).

The Diagnostic and Statistical Manual of Mental Disorder's (DSM) conceptualizes each of the 'mental disorders' listed as: 'a clinically significant behavioural or psychological syndrome or pattern that occurs *in an individual'* (APA, 1994, emphasis added). Boyle (2011) notes how locating mental distress within a 'pathological' individual ignores the fact that people have complex lived experience:

> "Pure avoidance strategies thus work together to produce the overall effect of obscuring the fact that there is even a person behind these symptoms and deficits, far less one with an actual, contextualized life" (Boyle, 2011, p.29).

Formulation has been proposed as an alternative to diagnosis. Whereas a diagnosis is often little more than a label, a formulation is more like a story or narrative. Within the discipline of psychology, it has been defined as involving the development of hypotheses about experience based on psychological theory (Division of Clinical Psychology, 2011; Johnstone & Dallos, 2013). Harper (2014) notes the importance of developing rich, contextualised, non-pathologising formulations.

From the researcher's personal and professional position she is comfortable with the nature of mental distress being a distinct phenomenon that requires psychological treatment. Simultaneously, the researcher holds the belief that OCD is a condition shaped by the context of environmental and social factors in a problem-saturated system i.e. not an internal deficit located in the 'pathological' individual. Moreover, the researcher holds the position that it is a complex interactional process of all these factors combined that forms the condition. Therefore, she believes that psychological treatment should be placed in the context of people's personal experience, such as traumatic experiences and attachment issues.

Even though the focus of this research is on personal experiences of OCD, the researcher has included the dominant medicalised perspective throughout the introduction. This decision was made as the majority of research on OCD has been quantitative in nature and have drawn on this understanding. However, it is hoped that the results of this qualitative study will provide an alternative perspective that reflects individual meaning-making.

Statement of Position in Research

I was able to move between an insider perspective from the participant's viewpoint and a position of standing alongside and offering a different perspective during the present study by using a reflexive journal (See Appendix 1). The journal was kept throughout the duration of the study, from development and through to the writing up. The journal aided the reflective process and helped to 'bracket off' my own values, assumptions, perspectives and experiences to limit their impact on the analytic process (Ahern, 1999).

What is OCD?

OCD has been identified as one of the most chronic and costly forms of mental health difficulty (Dupont, 1993; Lopez & Murray, 1998). It has also been rated as a leading case of disability by the World Health Organisation (1996). DSM-5 (APA, 2013) categorises OCD in the obsessive-compulsive and related disorders (OCRD) section where previously it was classified as an anxiety-based problem.

According to the DSM-5 (APA, 2013), OCD involves (a) intrusive unwanted thoughts, ideas, or images that evoke anxiety (obsessions), and/or (b) behavioural or mental ritual performed to neutralize this distress (compulsions). The DSM-5 defines obsessions as recurrent and persistent thoughts, urges, or impulses that are experienced, at some time during the disturbance, as intrusive and unwanted, and that in most individuals cause marked anxiety or distress. Obsessions are seen as egodystonic and the individual attempts to ignore or suppress such thoughts, urges, or images, or to neutralize them with some other thought or action (i.e., by performing a compulsion). Compulsions are defined as repetitive behaviours (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly. The behaviours or mental acts are aimed at preventing or reducing anxiety or distress, or preventing some dreaded event or situation. However, these behaviours or mental acts are not connected in a realistic way with what they are designed to neutralize or prevent, or are clearly excessive.

In order to meet the criteria for the diagnosis, severity aspects are also considered. The obsessions or compulsions must be a significant source of distress to the person, or interfere with social, or role functioning (Thomsen, 1998; Piacentini, Peris, Bergman, Chang, & Jaffer, 2007) and quality of life (Lack et al., 2009). OCD often has a profoundly negative effect on family relationships (Cooper, 1996), peer interactions (Allsopp & Verduyn, 1990) and school performance (Toro, Cervera, Osejo, & Salamero, 1992).

Critique of Diagnosis of OCD

A critical perspective on the diagnosis of OCD would propose that the DSM-5 (APA, 2013) offers a general definition of OCD that includes obsessions and/or compulsions (either may be present in conjunction with or in the absence of the other), although the specific manifestation of these experiences varies widely from person to person. For example, obsessive thoughts about contamination, illness, harming, morality, exactness, and intrusive unwanted disturbing images are all common (Rachman & Hodgson, 1980). In response to these obsessive thoughts, people may perform a variety of compulsive actions or neutralizing responses, such as washing, checking, arranging, or mental rituals, as well as avoidance of situations that provoke the obsessive feelings and thoughts.

Another critique of the diagnosis of OCD is that the DSM-5's definition of OCD does not fully reflect that obsessive thoughts and compulsive actions are functionally related.

Another criticism of the DSM-5 diagnosis of OCD is that it provides only a vague overview of how OCD and the other OCRDs are related and why they have been grouped together. After a brief description highlighting the repetitiveness of obsessional thinking and compulsive behaviour, the manual states that “some other obsessive-compulsive and related disorders are also characterized by preoccupations and by repetitive behaviours or mental acts in response to the preoccupations. Other obsessive-compulsive and related disorders are characterized primarily by recurrent body-focused repetitive behaviours (e.g., hair pulling, skin picking) and repeated attempts to decrease or stop the behaviours” (APA, 2013, p. 235). Proponents also assert that the repetitive thinking or behaviour patterns fall along a spectrum of failure in behaviour inhibition—the inability to cease one’s actions—with compulsive (i.e. OCD) and impulsive behaviours (i.e. skin picking and hair pulling) at the opposite ends (Fineberg, Saxena, Zohar, & Craig, 2011). Thus, the unifying factor among the OCRDs is the presence of repetitive behaviours that the person seemingly cannot stop performing. By emphasizing the presence of repetitive behaviours as a criterion for the OCRD class, this approach overlooks other essential (and arguably more fundamental) features of people’s difficulties. This oversight is argued to be consistent with the DSM’s largely descriptive and atheoretical approach to taxonomy, wherein the ‘disorders’ are defined merely by lists of signs and symptoms rather than by theoretically grounded conceptual models with empirical support.

Those who adopt a critical perspective on the diagnosis of OCD would argue that the DSM-5 (APA, 2013) distorts research on OCD by directing research efforts to the ‘ill’ or ‘deficient’ individual in whose brain or psyche is the fundamental cause of their OCD ‘symptoms’. Yet there is strong evidence that emotional distress and behavioural problems are understandable responses to or ways of actively trying to manage adverse circumstances and relationships (Johnstone, 2002). The theoretical and practical implications of this evidence are often minimised by, for example, presenting adverse environments and relationships largely as consequences of ‘having a mental disorder’ rather than as antecedents of a range of meaningful and purposive – if problematic – responses to adversity.

The Division of Clinical Psychology (DCP) position statement on the classification of behaviour and experience in relation to functional psychiatric diagnoses states serious concerns have been raised about the increasing medicalisation of distress and behaviour in both adults and children (BPS, 2011; Conrad, 2007).

The position should not be read as a denial of the role of biology in mediating and enabling all forms of human experience, behaviour and distress (Cromby, Harper & Reavey, 2013), as is demonstrated, for example, in emerging epigenetic research (e.g. Read & Bentall, 2012; Szyf & Bick, 2013.) It recognises the complexity of the relationship between social, psychological and biological factors. In relation to the experiences that give rise to a functional psychiatric diagnosis, it calls for an approach that fully acknowledges the growing amount of evidence for psychosocial causal factors, but which does not assign an unevidenced role for biology as a primary cause, and that is transparent about the very limited support for the 'disease' model in such conditions. Such an approach would need to be multi-factorial, to contextualise distress and behaviour, and to acknowledge the complexity of the interactions involved, in keeping with the core principles of formulation in Clinical Psychology (DCP, 2011).

The position also highlights that the diagnostic interpretation is presented as objective fact: Psychiatric diagnosis is often presented as an objective statement of fact, but is, in essence, a clinical judgement based on observation and interpretation of behaviour and self-report, and thus subject to variation and bias (e.g. Kirk & Kutchins, 1994).

A final criticism on the diagnosis of OCD is its poor inter-rater reliability. Only one DSM-5 'diagnosis' was higher than 0.7 in the field trials. This was major neurocognitive disorder (essentially dementia). However OCD was 0.31 (Hickey, 2013). Thus, if one psychiatrist 'diagnosed' a person with OCD, another psychiatrist was quite likely to come up with another 'diagnosis'. The agreement figures for DSM-5 are noticeably poorer than the figures for DSM-IV (APA, 1994). The likely reason for this is APA's persistent desire to widen the net. This has been a consequence of making the criteria less precise, which inevitably means that different raters will apply them differently. Hickey (2013) argues that the DSM-5 has never been about science, but rather it is about marketing. Steinberger and Schuch (2002), found large differences between DSM-IV (APA, 1994) and International Statistical Classification of Diseases and Related Health Problems (ICD-10) in their diagnoses of children and adolescents having experiences of obsessions and compulsions. Using DSM-IV criteria, 95% of the young people were diagnosed with OCD, compared to only 46% using ICD-10 criteria. This suggests reliability of diagnosis is an issue.

Despite this critical perspective on diagnoses many psychologists continue to use them. The standard defence is that, whilst problematic, diagnosis provides a useful ‘shorthand’ form of communication important for multi-disciplinary work. Yet if diagnoses are unsatisfactory, one could question why psychologists should use them. The barrier could perhaps be finding other ways of talking about distress or perhaps turning around the super tanker of psychiatric classification, which brings about a huge financial turnover.

Despite the negative impact of OCD, fewer than 20% of young people receive treatment (Flament et al., 1988). OCD typically goes undetected for many years before an accurate diagnosis is made (Stengler et al., 2013). Whilst it is possible that such delay may arise as a result of children’s lack of awareness, it is also possible that denial may be due to secrecy as a way of coping with wishing not to appear ‘different’ (Leonard, Lenane & Swedo, 1993; Rapoport et al., 2000).

How common is OCD?

Childhood OCD was once considered a rare condition, although recent epidemiological data rank OCD as the fourth most common mental health difficulty, making it twice as common as diagnoses such as panic or schizophrenia (Barrett & Healy, 2003). OCD is diagnosed in approximately 0.25% of 5 to 15 year olds in the United Kingdom (Heyman et al., 2003). In a clinical population Hollingsworth, Tanguay, Grossmann, and Pabst (1980) found 0.2-1.2% of children and adolescents with OCD, a finding which was later supported by Thomsen and Mikkelsen (1991).

Reports of onset in childhood OCD are variable; however, the mean age of onset of OCD is around 10 years (range 6.9 – 12.5 years) (Stewart et al., 2004). The mean age of diagnosis in paediatric OCD is 13.2 years (Geller et al., 1998). OCD is found to be diagnosed between 0.1 and 4% of children and adolescents under 18 years in other countries (Douglass, Moffitt, Dar, McGee & Silva, 1995).

Most studies of paediatric OCD report that OCD has a slight increased presence in males (Geller, 2006; Jaisoorya, Reddy, & Srinath, 2003) with an average of 3:2 male-female ratio (Geller et al., 1998). However, the male to female ratio equalizes in adolescence and the percentage of females with OCD may surpass that of men by adulthood (Flament et al., 1988).

Whilst there are similarities in the nature of obsessive and compulsive characteristics between children and adults with OCD, a key difference in the diagnosis of OCD in young people, in comparison to the adult population, is that they are not required to recognise the obsessions or compulsions as unreasonable or excessive (Carr, 2004). Stewart et al. (2004) reported the following results of a meta-analysis on outcome in 16 samples of children with OCD: 41% persisted into adulthood (60% if sub threshold cases were included) and a majority kept some traits.

In the United Kingdom current estimates suggest that 1.2% of the population will have a diagnosis of OCD, which equates to 12 out of every 1000 people, and based on the current estimates for the UK population, these statistics mean that potentially, approximately 741,504 people are living with OCD at any one time (OCD-UK, 2013).

Community studies have estimated lifetime prevalence of OCD in childhood and adolescence as being between 1.9% (Flament et al., 1988) and 3% (Valleni-Basile et al., 1994). Follow-up studies indicate that OCD frequently persists into adulthood (Flament et al., 1990; Rasmussen & Eisen, 1990), and that treatment in childhood and adolescence improves long-term outcome (Bolton, Luckie, & Steinberg, 1995; Leonard et al., 1993). It has been estimated that 30-80% of adults with OCD recall onset before 18 (Rasmussen & Eisen, 1992; Pauls, Alsobrook, Goodman, Rasmussen, Leckman, 1995). Examination of the adult population estimates that up to 50% of adults referred with OCD recall an onset in childhood yet did not access treatment at this stage (Heyman, 2005).

OCD is associated with high degrees of comorbidity, including major depression and other anxiety-related diagnoses (APA, 1994). Ruscio, Stein, Chiu, and Kessler (2010) in their epidemiological study of OCD in the National Comorbidity Survey Replication found that 90% of respondents with lifetime DSM-IV OCD met criteria for another lifetime DSM-IV diagnosis. The most common comorbid conditions were anxiety related difficulties (75.8%), followed by mood difficulties (63.3%), impulse-control difficulties (55.9%), and substance use difficulties (38.6%).

The initial presentation of OCD may be misinterpreted. For example, significant attention problems, due to preoccupation with obsessions and compulsions, may be initially conceptualized as having attention-deficit hyperactivity disorder rather than OCD (Moore, Mariaskin, March, & Franklin, 2007). Similarly oppositional defiant disorder may be inaccurately diagnosed in a child experiencing OCD, particularly if one focuses on problem behaviours themselves rather than the reasons that precipitate them (Jacob & Storch, 2013). For example, a child may struggle to complete a school assignment due to excessive rereading/rewriting compulsions, and they may then be perceived as a problem student. Young people may also present with obsessions with aggressive content (e.g., thoughts of harming others) that could be misconstrued as oppositionality. A child may also appear oppositional if they complete a compulsive behaviour that they were told not to engage in. Thus, an adult may infer that a child is intentionally misbehaving when in fact the behaviour is due to OCD.

Phenomenology

The most common features seen in approximately half of children with a diagnosis of OCD are fear of contamination/washing compulsions (Thomsen, 1998). Checking is also a very frequent sign of OCD which is seen in approximately half of children (Thomsen, 1998).

In young people who have compulsions without obsessions it can be difficult to identify the basis for compulsive behaviour and the young person would often say that the compulsion is driven by a sense that ‘it doesn’t feel right’ until the ritual has been carried out. Shafran (2001) notes that it is unclear whether there is an absence of obsessions driving the compulsion or whether the young person lacks the cognitive ability to communicate their internal mental events.

Ideas on the Development of OCD

Introduction

According to Thomsen (1998), families must be informed that the exact cause of OCD in young people and adults is still unknown. OCD is believed to be influenced by biological, psychological, and social interactions with regard to the onset and course of difficulties (Cromer, Schmidt, & Murphy, 2007). In this section the researcher will consider the psychological factors first, then discuss the social environment, and lastly outline the biological factors.

Psychological model for the development of OCD

Through the lens of the cognitive model, it is thought that underlying cognitive misinterpretations are predisposing, enduring beliefs that become “activated” when an unwanted mental intrusion occurs (Obsessive Compulsive Cognitions Working Group; OCCWG, 2003). The OCCWG (1997) has described six categories of OC-related beliefs: inflated responsibility, over importance of thoughts, overestimations of threat, perfectionism, intolerance of uncertainty and importance of controlling one’s thoughts. Recent work has shown that these cognitive appraisals characterize OCD not only in adults but also in children and adolescents (Barrett & Healy, 2003; Farrell & Barrett, 2006; Libby, Reynolds, Derisley, & Clark, 2004).

Salkovskis (1985, 1999) argued that specific intrusions become more frequent, intense, and distressing as a result of a person’s inflated sense of responsibility. He defined an inflated sense of responsibility as a person’s tendency to believe that they may be pivotally responsible for causing or failing to prevent harm to themselves or others.

There is growing evidence to support an association between inflated responsibility and OCD behaviour in young people. Clinical samples of young people with OCD show significantly higher levels of inflated responsibility appraisals than a non-clinical sample of young people aged 7–11 years (Barrett & Healy, 2003) and young people aged 11-18 years with other anxiety difficulties (Libby et al., 2004).

Reeves, Reynolds, Coker, and Wilson (2010) also investigated whether Salkovskis' (1985) inflated responsibility model of OCD applied to children. In an experimental design, 81 children aged 9-12 years were randomly allocated to three conditions: an inflated responsibility group, a moderate responsibility group, and a reduced responsibility group. In all groups children were asked to sort sweets according to whether or not they contained nuts. There was a significant effect of responsibility level on the behavioural variables of time taken, hesitations, and checking; as perceived responsibility increased children took longer to complete the task and checked and hesitated more often. The results offer preliminary support for the link between inflated responsibility and increased checking behaviours in children.

Given the substantial documentation linking heightened responsibility beliefs to OCD, it is striking that there is little research examining the aetiology of these beliefs and general neglect of developmental issues, such as early attachment and parenting (Guidano & Liotti, 1983). This may perhaps be because of the prevailing view that it is most useful to concentrate on the maintaining factors of OCD, as this invariably is the target of treatment (Shafran, 2005). Elucidating the origins of inflated responsibility beliefs (and ultimately other OCD-related beliefs) may have significant implications for conceptualization, treatment, and prevention.

Given the importance of this task, Salkovskis, Shafran, Rachman, and Freeston, (1999) proposed five primary pathways to the development of inflated responsibility beliefs. The first pathway refers to children who have increased levels of responsibility when young. For example, they may be asked to perform tasks that are typically performed by adults, perhaps due to a SLE in the family. The second pathway refers to rigid and extreme codes of conduct as a child by parents, school, or religious settings. Failure to follow these strict behavioural codes would lead to blame, guilt, or punishment. Overprotective and critical parenting leading to a lack of experience with responsibility as a child forms the third pathway. The fourth pathway refers to a SLE that affects the health of oneself due to their actions or inactions. The final pathway refers to incidents in which it appears that one's actions/inactions influenced a serious misfortune. A limitation of this study is that it uses non-clinical samples of undergraduates as opposed to a clinical sample.

Lawrence and Williams (2002) extended Salkovskis et al.'s (1999) study by comparing the five primary pathways with sixteen adolescents with a history of OCD and sixteen adolescents with no history of OCD. The groups differed on one pathway; the clinical group reported a higher sense of responsibility for significant incidents with a negative outcome prior to onset of OCD. Thus, an inflated sense of responsibility, in combination with the occurrence of specific incidents, might act as a vulnerability factor for development of OCD.

Perfectionism is defined as the tendency to "believe there is a perfect solution to every problem, that doing something perfectly (i.e. mistake free) is not only possible, but also necessary, and that even minor mistakes will have serious consequences" (OCCWG, 1997, p. 678). Rasmussen & Eisen (1992) described OCD as being characterised by the core feature of incompleteness, which is the result of an inner sense of imperfection.

A number of studies have found a link between perfectionism and OCD. Using a non-clinical sample, Rhéaume, Freeston, Dugas, Letarte, and Ladouceur, (1995) .found that perfectionism was moderately correlated with signs of OCD after controlling for responsibility. Frost and Steketee (1997) found people with a diagnosis of OCD scored higher in perfectionism than controls.

Coles, Frost, Heimberg, and Rhéaume (2003) have reported on the phenomenon of "not just right experiences" (NJREs), or uncomfortable sensations of things not being just right hypothesised to lead to compulsions in order to achieve a sense of perfection. Using student samples they found that NJREs were more strongly correlated with features of OCD compared with other domains of mental health difficulties such as social phobia and depression.

To summarise, there has been growing literature suggesting that cognitive models of OCD may apply to children. Clinical samples of young people with OCD show significantly higher levels of inflated responsibility appraisals than a non-clinical sample of young people or young people experiencing other anxiety-related difficulties. There is also literature suggesting that a SLE that places the young person in a position of responsibility may be a pathway to the development of inflated responsibility beliefs (Salkovskis et al., 1999). A number of studies have found a link between perfectionism and OCD (Rhéaume et al., 1995; Frost & Steketee, 1997). Coles et al. (2003) have found that NJREs lead to compulsions in order to achieve a sense of perfection.

Stressful life events and trauma as a context for the development of OCD

As well as cognitive processes, which were previously described, the role of SLEs in the genesis of OCD has also been recognised (Rachman & Hodgson, 1980; de Silva & Rachman, 1998). However, research has not found the mechanisms or processes whereby responses to trauma can take the form of OCD.

There has been experimental data to suggest that SLEs may act as catalysts for the onset of OCD (Paykel & Dowlatshahi, 1988; Zvolensky, Eifert, & Lejuez, 2001). There is also evidence that in many cases stresses can lead to recurrence of OCD (Metzner, 1963; Marks, 1987).

Janet, an early theorist on OCD, considered that in some cases the OCD was caused by emotional shock (Janet, 1903; Pitman, 1984, 1987). Studies have found a significantly elevated rate of SLEs reported in the 6 months (Khanna, Rajendra, & Channabasavanna, 1988) or one year (Gothelf, Aharonovsky, Horesh, Carty, & Apter, 2004) prior to onset of OCD in children in an outpatient setting, and they perceived these life events as having more impact than for controls. The 28 children with OCD in this latter study were compared with 28 children with other anxiety diagnoses, and 24 controls using the Life Events Checklist (Sarason, Johnson, & Siegel, 1978) and the Junior Temperament and Character Inventory (Cloninger, Svrakic, Bayon, & Przybeck, 1999). The findings showed that the only specific life event that was significantly more common in children with OCD than other anxiety diagnoses was a major illness in a relative. However, this quantitative study holds limitations, such as the small sample size. A similar finding of the SLE of experiencing an illness of self or other (8%, 19 events) was found in another study that examined severity and features in 265 people with a diagnosis of OCD (Cromer et al., 2007). A limitation of the study is that it only used adult participants and there is a gap in the research of using a sample of young people. Another limitation of their sample is that 62.9% of participants were female, which reduced the representativeness of the sample.

Thus far, only one study has provided evidence to show an association between the SLE of peer victimization and the development of OCD in young people (Storch et al., 2005). The study has its limitations as it is based on one case-report and therefore not generalizable to the wider OCD population in adolescents. Additionally, the study noted that the adolescents' compulsions developed through coincidental or perceived associations between performing a ritual and teasing. However, it could be the case that overt characteristics associated with having OCD or an anxious temperament contributed to the development of negative peer experiences.

Correlational clinical investigations have shown an association between SLEs/traumatic life events (TLEs) and OCD. Studies of traumatised populations have found that in addition to the onset of post-traumatic stress disorder (PTSD), OCD can emerge following exposure to an upsetting event, and that traumatised (versus non-traumatised) populations are more likely to meet criteria for diagnosis for OCD (Jordan et al., 1991; Solomon, 1993). Adults with OCD have been found to have higher rates of childhood trauma than controls (Lochner et al., 2002).

Lafleur, et al. (2011) examined the prevalence of TLEs and PTSD in a large sample of children with OCD. OCD symptoms and severity were assessed using the Children Yale-Brown Obsessive Compulsive Scale (CYBOCS; Goodman et al., 1989) in those with and without concurrent PTSD. The findings showed the rate of PTSD and trauma exposure was higher in children with OCD than a control group. This study concludes that a history of traumatic events may be over-represented in children with OCD.

In summary, studies have found a significantly elevated rate of SLEs/TLEs reported prior to onset of OCD in young people. In several studies the SLE/TLE of illness of self or other has been found to occur prior to the onset of OCD (Gothelf et al., 2004; Cromer et al., 2007). It is also clear that little research has been conducted to explore the association between the SLE of peer victimization and the development of OCD in young people. However, one case study has provided evidence for this association (Storch et al., 2005).

The link between attachment and the development of OCD

The work of attachment theory fits the overriding theoretical framework of the present study. Bowlby (1973) speculated that all anxiety difficulties are correlated with attachment insecurities. It could be argued that SLEs/TLEs that involve other people (i.e., parental separation/divorce, deaths, physical illness, abuse, and bullying) could lead to attachment insecurities.

The relationship between separation from a parent and anxiety is a basic tenant of Bowlby's (1982) theory of attachment. Attachment refers to the emotional bind that arises between infant and primary caregiver. This bind is marked by the child seeking out this specific attachment figure in times of need (e.g. stress), and using this figure as a secure base in the exploration of the world.

According to Bowlby (1969, 1973), the emotional bond between an infant and their main caregiver affects their later social, psychological and biological capacities through the construction of internal working models (IWMs). IWMs are internalised representations of the "self" and "other" based on a child's interactions with their main caregivers. It is hypothesised that these representations contain information about whether the caregiver is perceived as a person who responds to calls for support or protection, and whether the self is worthy of receiving help from anyone, in particular the caregiver. Bowlby (1969) noted that a child experiencing their parents as emotionally available, responsive, and supportive will construct a self-model as being lovable and competent. Conversely, experiences of a disrupted attachment leading to experiences of rejection, emotional unavailability, and lack of support (e.g. SLEs) will lead to the construction of an unlovable, unworthy, and incompetent self-model. (Bowlby, 1982; Sroufe, Egeland, & Kreutzer, 1990).

Although OCD has received little attention in the more recent history of psychoanalysis, psychoanalytic theory has provided important insights into the nature of OCD which could be argued to fit with attachment theory (e.g., Chessick, 2001; Esman, 1989; Fenichel, 1945). It was Freud (1896/1966) who first distinguished a clinical entity that he termed "obsessional neurosis". Freud (1913) stated that obsessional neurosis "usually shows its first symptoms in the second period of childhood (between the ages of six and eight)" (p. 318). Freud (1926) hypothesised that anxiety was a reaction to experiencing SLEs involving danger and loss.

In his analysis of the Rat Man, Freud (1909/1955) referred to the conflict between feelings of love and hate directed towards the father and a strong repression of this hate. This aggression towards a caregiver is perhaps due to a SLE/TLE whereby the attachment figure harmed or rejected the individual. Typical personality characteristics of the person with OCD, such as perfectionism, are understood as attempts to control warded-off hostile wishes through the mechanism of reaction formation (Freud, 1926/1959). Nevertheless, aggressive impulses would frequently break through this defence, mostly in the form of immoral obsessions. Thoughts are even endowed with a magical meaning aimed at controlling intolerable impulses. This "magical thinking" is also implied in the mechanism of "undoing", whereby the person with OCD completes certain rituals to neutralize an unacceptable thought or action (Fenichel, 1945). Magical thinking may also lead to exaggerated feelings of responsibility.

Guidano and Liotti (1983) propose a model of OCD that draws on attachment and cognitive theories. They view early attachment relationships as the medium through which an infant's developing self-knowledge is constructed. Guidano (1987) argues that individuals with OCD have experienced an early home environment in which the parents have emphasised strong moral and ethical values as well as demanding a sense of responsibility in the child. Alongside this, individuals who develop OCD may have experienced ambivalent attachments. These are characterised as insecure parent-child transactions, where children are uncertain of the degree to which they are loved, wanted or worthy. Perfectionism and compulsive behaviours develop as means of securing approval and unifying one's self-perceptions as a worthy and lovable individual. Guidano and Liotti (1983) argued that a child's perception of the world as being threatening, due to SLEs/a disruptive attachment, but controllable translates into active attempts to control the environment through their OCD.

When exploring studies that examine attachment styles, insecure forms of attachment were found to be more common in participants with OCD. 60% of participants with OCD classified as having an insecure attachment were commonly associated with SLEs (Ivarsson, Granqvist, Gillberg, & Broberg, 2010). Myhr, Sookman, and Pinard (2004) compared 36 outpatients with OCD, 16 outpatients with a diagnosis of depression, and 26 controls and found that individuals with OCD showed more insecure attachment styles than others. Thus, they proposed that insecure attachment may predispose children to developing OCD.

To summarise, psychoanalytic theory proposed that SLEs comprising a disruptive attachment relationship can lead an individual to experience aggressive impulses. Compulsions are understood as attempts to control these aggressive impulses. Nevertheless, aggressive impulses would frequently break through this defence, mostly in the form of obsessions. Guidano (1987) argues that individuals with OCD have experienced an early home environment in which their parents demanded a sense of responsibility. Guidano and Liotti (1983) argue that ambivalent attachments lead children to feel uncertain of the degree to which they are loved resulting in compulsive behaviours. Lastly, the section shows that studies have found that insecure attachment may predispose children to developing OCD.

Family relationships and the development of OCD

It has been suggested that high expressed emotion may exacerbate OCD (Bressi & Guggeri, 1996). ‘Expressed emotion’ refers to a family environment characterised by hostility, criticism, or emotional over involvement. Whilst it is unclear whether such family dynamics are causal factors it is likely that they may be maintenance factors if not at least additional stressors.

Hibbs (1991) investigated 128 families who had a child diagnosed with either disruptive behaviour problems, OCD, or with no clinical diagnosis. The findings indicated that 73% of mothers and 46% of fathers in the OCD group were classified as high in expressed emotion, compared to 22% and 31% of fathers and mothers of children with no clinical diagnosis, respectively.

Overprotection and lack of warmth have also been considered influential by some authors (Ehiobuche, 1988; Hoover & Insel, 1984). Compared to controls, adolescents with OCD reported significantly less emotional support and closeness in their family (Valleni-Basile et al., 1995). In a study of 40 children with OCD and 40 controls, Alonso, et al., (2004) examined parental rearing style and its relation to symptom dimensions. Participants with an OCD diagnosis perceived higher levels of rejection from their fathers.

It is important to note that one-quarter of parents will have an OCD diagnosis and a higher percentage (30-40%) will have subclinical signs of obsessive behaviour (Steketee & Van Noppen, 2003). Higher than average prevalence rates for OCD in immediate relatives have led some authors to speculate that the modelling of avoidance, caution, and fearfulness may predispose a vulnerable child to developing OCD (Henin & Kendall, 1997). Factors such as high parental anxiety (Kohlmann, Schumacher, & Streit, 1988), perceived lack of control over external events (Capps, Sigman, Sena, Henker, & Whalen, 1996), and the reinforcement of threat interpretations and avoidant plans of coping (Barrett, Rapee, Dadds, & Ryan, 1996) are also hypothesised to be relevant to the exacerbation of childhood OCD. Liakopoulou et al. (2010) reported on 31 children with an OCD diagnosis aged 8-15 years old and their parents and found that parental mental health difficulties was more prevalent than average. Derisley, Libby, Clark, and Reynolds (2005) found that parents of children experiencing OCD suffer from poorer mental health and have fewer coping strategies than parents of children who do not experience a mental health difficulty.

In recent years, research has been investigating the potential for family involvement in the rituals of people suffering from OCD (Calvocoressi et al., 1995), which is generally termed ‘family accommodation’. The level of accommodation in a particular family has been repeatedly tied to increased severity of OCD (Merlo, Lehmkuhl, Geffken, & Storch, 2009), higher degree of impairment (Storch et al., 2010), and worse treatment outcomes (Ferro et al., 2006). Cases of childhood onset OCD may pose a special risk for family accommodation. This is due to the natural reliance of children on their parents for assistance and reassurance and due to parents’ willingness to sacrifice in order to avoid children’s anger or distress (Waters & Barrett, 2000). Some of the forms accommodation can take are supplying the child with materials necessary for the performance of rituals, actively participating themselves in rituals, providing verbal reassurance, avoiding doing things or going places that arouse anxiety, or modifying their own routines (Lebowitz, Vitulano, & Omer, 2011).

Peris et al. (2008) studied parental accommodation in 65 young people; it was found that 46% of parents often participate in rituals. They found that parental mental health difficulties (particularly OCD), low family cohesion and organisation, and greater severity of OCD in children were particularly associated with accommodation.

Given the impact that OCD can have upon a family it is not surprising that children may attempt to conceal their OCD from their family (Rapoport et al., 2000) and that family members may attempt to cope with stigmatisation by attempting to conceal the young person's symptoms (Stengler-Wenzke, Trosbasch, Dietrich & Angermeyer, 2004).

This section has shown that high expressed emotion in a family member may exacerbate OCD behaviours (Bressi & Guggeri, 1996; Hibbs, 1991). Overprotection and lack of warmth have also been considered influential in the development of OCD (Ehiobuche, 1988; Hoover & Insel, 1984; Valleni-Basile et al., 1995). The level of accommodation of the OCD has been repeatedly tied to increased severity of OCD (Merlo et al., 2009), higher degree of impairment (Storch et al., 2010), and worse treatment outcomes (Ferro et al., 2006).

Biological explanations for the development of OCD

A variety of neurobiological models are proposed to account for OCD (Fitzgerald, MacMaster, Paulson, & Rosenberg, 1999). One possibility is that OCD is due to a problem with biochemical messenger systems such as neurotransmitters and/or neuro-hormones. The serotonin system modulates OCD symptoms, although it has been found that there is a problem with the serotonergic system (Rosenberg, 2000) in people experiencing OCD.

Results of a meta-analysis based on neuroimaging with young people with OCD found the cingular gyrus to be of greater volume and more active, the striatum to be diminished, gray matter density in the orbitofrontal cortex to be more elevated and voluminous on the right side, and thalamic volume and corpus callosum to be larger (MacMaster, O'Neill, & Rosenberg, 2008).

Neuropsychological studies (Irak & Flament, 2007) in adults and children with OCD have shown difficulties in various domains, such as planning and organization, mental flexibility, cognitive speed and response inhibition (Greisberg & Mckay, 2003; Shin et al., 2008). Ornstein, Arnold, Manassis, Mendlowitz, and Schachar (2010) compared 14 children with OCD and 24 controls on a series of neuropsychological tests; the children with OCD appeared to have reduced cognitive flexibility and planning abilities.

The onset of OCD is linked to group-A β-hemolytic streptococci (GAS) infections. In 1998, 50 children were described as exhibiting acute and dramatic onset or exacerbations of OCD following GAS infection, exposure to GAS, or non-cultured pharyngitis (Swedo et al., 1998). This outbreak prompted renewed interest in the relationship between OCD and an autoimmune hypothesis (Murphy, Sajid, & Goodman, 2006). The term paediatric autoimmune neuropsychiatric disorder (PANDAS) was identified by the National Institutes of Mental Health more than a decade ago. It was proposed that when rheumatic fever and Sydenham's chorea are secondary to GAS infections, then GAS may be related to an increased incidence of OCD as well (Swedo et al., 1998).

It has been argued that it does not follow that OCD in itself is hereditary, but rather, that a tendency towards it is actually passed on. Results from family and twin studies suggest genetic factors are implicated in the transmission and expression of some forms of OCD (do Rosario-Campos et al., 2005). Geller (2006) notes that in studies on family members of affected children there is a 25% relative risk. Lenane, et al. (1990) found that, in parents of children with severe OCD, 25% of the fathers and 9% of the mothers experienced OCD themselves.

In summary, it has been found that there is a problem in the serotonergic system (Rosenberg, 2000) in people experiencing OCD. Neuroimaging studies on people with OCD indicate increased involvement of the frontal lobe and basal ganglia (Sachdev & Malhi, 2005). Neuropsychological studies (Irak & Flament, 2007) in adults and children with OCD have shown difficulties in various domains. The onset of OCD is linked with GAS infections (Swedo, et al., 1998). It has been argued that it does not follow that OCD in itself is hereditary, but rather, that a tendency towards it is actually passed on.

Whilst it has been shown that there is some evidence for a biological explanation for the development of OCD, there have also been the following critiques of the biological theories of OCD. Firstly, results from research on serotonin dysfunction in OCD are equivocal (Shafran, 2005). For instance, some people with a diagnosis of OCD respond more poorly to Selective serotonin reuptake inhibitors (SSRIs) medication than to Clomipramine (Jenike, 2004) and some respond better to other forms of medication (such as atypical antipsychotic medication and certain benzodiazepines), suggesting that other neurotransmitters (such as dopamine) may also play a role

(Jenike & Rauch, 1994). It has been argued that successful treatment using SSRIs cannot be taken to indicate that OCD is caused by serotonin deficiencies, nor does it tell us about the mechanisms involved in its aetiology and maintenance (Salkovskis, 2002). Rather than searching for finer discriminatory clues in neurotransmitter activity in the brain, it could be argued that an alternative paradigm be explored - one that takes into account the phenomenological experience of the persons who engage in these thoughts and behaviours. Furthermore, this model would take into account the meaning and value of the behaviours to individuals performing them. Consequently, this might prove more valuable than the more narrowly focused neurotransmitter model, for understanding the etiology and course of these behaviours.

Secondly, as has been discussed, specific brain structures and the communication pathways between them have also been investigated in relation to OCD. However, the nature of the relationship between these OCD ‘symptoms’ is unknown (Menzies et al., 2008).

Lastly, a substantial proportion of OCD experienced is “sporadic,” with no other first-degree relatives affected (Samuels, 2009), suggesting a complex relationship between environmental and genetic factors. Furthermore, the genetic basis of OCD is not yet fully understood and specific genes causing OCD have not been conclusively identified (Samuels, 2009).

Understandings of those who experience OCD

Murphy and Parera-Delcourt (2012) conducted qualitative research on adults exploring psychosocial aspects of OCD and its treatment. Interpretative Phenomenological Analysis (IPA) was used to analyse the accounts. Two superordinate themes were reported – ‘Having OCD’ (with subordinate themes ‘Wanting to be normal and fit in’, ‘Failing at life’ and ‘Loving and hating OCD’) and ‘The Impact of Therapy’ (with subordinate themes of ‘Wanting therapy’, ‘Finding the roots’, and ‘A better self’). When referring to the first subordinate theme, the desire to be socially accepted by others was a common experience found in the participants’ accounts. Accounts of psychological distress associated with fitting in with peer groups were significant. When exploring the second subordinate theme, the participants perceived OCD to have adversely affected their education, careers and family/personal relationships. The subordinate theme of ‘Finding the roots’ related to several participants’ feeling that being able to locate the psychological causes of OCD helped them make sense of it as an anxiety-related problem.

Limitations of the study included interviewing a participant who had not been diagnosed and another participant who had self-informed OCD. Thus, the study might not be actually exploring OCD. Additionally, the authors did not use a trans-cultural group of participants. All participants were of White British origin. Another limitation of their study is that they interviewed only one female participant and the remaining participants were male, which reduces the representativeness of the sample.

Similar to the previously described subordinate theme of ‘Wanting to be normal and fit in’, in an auto-ethnography, Brooks (2011) described how she secretly performed her compulsions within the safety of her own home as she believed that public knowledge of her compulsions might be socially hazardous. She noted that fear of stigmatization, a strong sense of personal shame, and feeling “different” functioned to keep OCD-related thoughts private. She discussed how OCD is left untreated because of the personal suppression of it as a result of societal stigma.

Fennell and Liberato (2007) conducted a qualitative study to explore the lived experience of 27 adults with OCD. The findings showed the participants recognised OCD as a problem due to self-stigmatization. Participants claimed public images of OCD may be less harsh than those of ‘mental illness’ in general and referred as a “joke condition” resulting in people not realising the severity of their condition.

Summary: Ideas on the development of OCD

Exploring factors influencing the onset of OCD is essential to early treatment and the reduction of suffering in young people (Douglass, et al., 1995). Early identification and treatment in young people may also reduce adult morbidity related to this condition (March, Franklin, Nelson, & Foa, 2001). The exact cause of OCD in children, adolescents and adults is still unknown. However, as has been described, there are many ideas on the development of OCD.

Treatment for OCD

Introduction

Help-seeking

There is an abundance of research supporting CBT for paediatric OCD, but access to qualified professionals remains a salient concern (Goodwin, Koenen, Hellman, Guardino & Struening, 2002). ‘Help’ implies both formal and informal help. ‘Formal help’ would include psychological therapies and pharmacological treatment. ‘Informal help’ would consist of talking to family and friends, reading self-help books, and looking at websites.

It has been reported that many people who experience obsessions and compulsions often do not seek help. Data from different community-based survey studies suggest that only 34 to 40% of the people that meet screening criteria for OCD have received treatment (Goodwin, et al., 2002). Rasmussen and Tsuang (1986) found an average delay of 7.6 years from onset of difficulties to search for professional help in adults with signs of OCD. It has been reported in some studies that “help seeking” individuals have a higher total number of OCD features and other mental health difficulties than the “non-help seekers” (Zimmerman & Mattia, 2000).

The factors that could be influencing the concealment of obsessions and therefore leading people to not seek help are the fear of negative reactions from others and the feelings of shame associated with the obsessions (Newth & Rachman, 2001). Several obsession-related beliefs (need to control the thoughts, thought-action fusion beliefs) are also proposed as being related to the concealing of obsessions.

Psychological interventions for OCD will now be discussed. A critique of the different treatments for OCD will be provided whilst evaluating the literature and research studies.

Cognitive Behavioural Therapy

The major therapeutic intervention and recommended treatment for OCD is CBT (National Institute for Health & Clinical Excellence; NICE, 2005). Following the behavioural model, CBT involving exposure and response prevention (ERP) as manualized by March and Mulle (1998), is the most well-studied psychological treatment for OCD (March & Leonard, 1996). It is considered the treatment of choice for children and adolescents (March, Frances, Carpenter & Kahn, 1997). ERP aims to weaken associations between obsessions and increased anxiety, and between compulsions and anxiety relief. Treatment involves repeated and prolonged confrontation with stimuli that evoked fear whilst simultaneously refraining from compulsive behaviours (March & Mulle, 1998). The fear dissipates without rituals, the person learns that compulsive rituals are not necessary to prevent disaster or reduce anxiety.

ERP appears to be successful in reducing OCD symptoms in approximately 50% of children (Leonard et al., 1993; Thomsen & Mikkelsen, 1991). Although studies support the effectiveness of ERP (Steketee & Frost, 1998), problems with this type of treatment remain. For example, dropout rates are typically high which is possibly due to the distressing nature of the exposure tasks (Abramowitz, Whiteside, & Deacon 2005). Approximately one-quarter to one-third of individuals treated with ERP have a poor treatment response, supporting the necessity for additional and augmented treatment modalities (Whittal, Thordarson, & McLean, 2005). Factors such as OCD severity, the young person having other psychological difficulties, age and the familial involvement in the obsessive-compulsive behaviours explain the varying responses to the same treatment.

Recent interest in the cognitive model of OCD emerged from an attempt to address the limitations of the behavioural approach (Clark, 2004). The cognitive appraisal model proposes that people who experience OCD develop symptoms because they interpret their unwanted, intrusive thoughts as highly significant or threatening. This is based on Beck’s (1976) model of emotional disorders which posits that mental health difficulties results from unhelpful beliefs concerning the self, the environmental context and the future. Appraising such thoughts in this way leads to attempts to control the thought or neutralise the distress associated with it (Wells, 1997). However, the addition of cognitive techniques is a controversial issue in the field, due to the current evidence that cognitive therapy is no more effective than behaviour therapy alone (NICE, 2005).

The POTS study (POTS Team, 2004) represents the first randomized controlled comparison of CBT, psychopharmacological treatment (Sertraline), their combination, and pill placebo for young people with OCD. The POTS study randomised 112 individuals with OCD aged 7-17 years recruited from three academic centres in the United States. The manualized CBT protocol was adapted from March and Mulle (1998) and consisted of 14 sessions conducted over 12 weeks, involving psycho-education, cognitive training, symptom mapping, ERP, and three parent sessions. The findings showed that all active treatments were significantly superior to the placebo condition in reducing OCD severity as measured by the CYBOCS. It was found that the combined treatment proved to be superior to CBT or Sertraline alone, which did not differ from one another. However, when clinical remission was used as the primary outcome measure, a significant advantage was found for the two CBT conditions, with the following response rates emerging: combination, 53.6%; CBT only, 39%; SSRI only, 21%; placebo, 3%. The study holds limitations; for example, it has a small sample size and limited power. Additionally, it does not include qualitative data to indicate why the treatment was helpful or not.

To counteract the limitation of using a non-clinical setting, Nakatani, Mataix-Cols, Micali, Turner, and Heyman (2009) conducted a case note review of 318 young people attending an OCD clinic. Outcomes of CBT for 75 young people who received treatment in the clinic were analysed. The findings showed that following treatment, total CYBOCS scores were significantly reduced and gains were maintained at long-term follow-up. A limitation of this study is that approximately half of the participants reported having previously taken or were taking medication and therefore it is not possible to ascertain if the addition of medication enhanced their response to CBT. Another limitation was that treatment assignment was made on the basis of clinical judgement and patient choice, rather than randomly.

Family involvement

The involvement of families in CBT is recommended (NICE, 2005). As highlighted, families can be involved in the causation, development and maintenance of OCD in children and everyone in the family system can be affected. Taking account of the systemic issues in OCD and how family's accommodation plays a powerful maintaining role, it could be argued that families should be involved in the treatment of OCD for the young person as opposed to treating solely the young person with CBT. Exposure is anxiety provoking, and parents can support their children with exposure practice and help maintain treatment gains beyond the end of therapy (Reynolds et al., 2013).

Reynolds et al. (2013) conducted a randomized controlled trial of parental-enhanced CBT compared with individual CBT for young people experiencing OCD. Fifty young people aged 12-17 years with OCD were randomly allocated to individual CBT or parent-enhanced CBT. In parent-enhanced CBT parents attended all treatment sessions; in individual CBT, parents attended sessions 1, 7, and the final session. Participants received up to 14 sessions of CBT. Self-report data suggested that for participants who engaged in CBT, high parental involvement led to significantly lower anxiety than did CBT with low parental involvement.

Knox, Albano and Barlow (1996) investigated the contribution of parents to the individual CBT of four children diagnosed with OCD. The results showed that the parent component was an important and potentially necessary part of the treatment of OCD in children. Specifically, ERP alone resulted in little or no change in the frequency of compulsions (with one child's increasing markedly), whilst ERP applied by the parents saw eventual improvements in all four children.

Grunes, Neziroglu, and Mckay (2001) reported that family cognitive behavioural therapy (FCBT) results in a greater reduction of OCD behaviour than does a treatment delivered without family participation. Additionally, Ginsburg and Schlossberg (2002) found that 60 to 90% of the children who received FCBT did not relapse after treatment.

Waters, Barrett and March (2001) provided pilot data on the efficacy of a 14-week FCBT for 7 children with OCD. Treatment included components on education, parental participation in childhood relaxation training, reduction of accommodation, parental anxiety management, family support of ERP and problem solving skills training. The treatment led to considerable benefits for 6 of the 7 children at post-test and for all at 3-month follow-up.

Barrett, Farrell, Pina, Peris, and Piacentini, (2008) found that 'the highest dose' of family involvement in CBT was the most effective. This suggests that to achieve the highest level of success families must be substantially involved.

Family therapy is recommended in cases where the child's behaviour has involved and disturbed family patterns or in cases where treatment has been complicated by conflicts between the parents and the young person. If the child has been made a scapegoat by other family members, family therapy could possibly change this pattern (Thomsen, 1998).

Pharmacological treatment

Pharmacological interventions may be implemented with children (aged 8-11 years) presenting with moderate-severe OCD who did not have an adequate response to CBT (NICE, 2005). For a young person (12-18 years) not responding to CBT, pharmacological interventions should be implemented (NICE, 2005). SSRIs are thought to be effective through their action on serotonin neurotransmission. Due to the potential for relapse upon discontinuation, SSRI therapy is usually long term (Leonard et al., 1989). Abramowitz et al. (2005) found that SSRI medication and ERP are effective in reducing paediatric OCD. Their findings showed that ERP was associated with larger effect sizes on OCD measures and fewer residual symptoms compared to SSRIs.

Summary: Treatment for OCD

When concluding on the treatment for OCD in young people, it is important to emphasise Boileau's (2011) argument that even if CBT is recognized, along with SRI as the basis of treatment, new modes of distribution appear such as intensive, family-based interventions. He stresses that the understanding of (and work on) family dynamics is fundamental for the development of therapeutic alliance, compliance, and success of treatment, even if one knows more about the genetic, neurological, and pharmacological aspects of OCD.

Rationale for the present study

As has been shown, many studies have adopted positivist approaches. These studies employ primarily quantitative methods, such as randomised controlled trials, to investigate simple causal or correlational relationships between different treatment groups and variables such as age, type, and duration of OCD ‘symptoms’. Few OCD studies exemplify social psychological enquiry into the everyday lives of people experiencing OCD.

Whilst the literature on OCD in young people consistently describes it as a debilitating condition, there appears to be a lack of research investigating how it is experienced by young people. To the researcher’s knowledge no qualitative research has been conducted with young peoples’ experiences of OCD, which is an important rationale for the present study. This is surprising as it is generally held that OCD first presents itself during childhood and adolescence (Bland, Newman & Orn, 1988).

Our knowledge of the underlying neurobiology and neurochemistry of OCD (i.e., what is wrong within the individual) has increased substantially in the last decade. However, research focusing on psychosocial factors (i.e., what has happened to the individual) and the meaning-making of environmental vulnerability factors, such as SLEs/TLEs, remain unknown. However, it is important to acknowledge that young people develop within the context of a family, school and community and understanding of and help for their OCD should reflect this fact. Therefore, another objective of the present study is to investigate participants’ accounts of possible psychosocial risk factors in the development of OCD.

It is hoped that the findings from the present study will help clinicians to offer interventions that target the psychosocial risk factors as opposed to only the maintenance factors using CBT. The intention is that these findings would contribute to our knowledge of what is most useful as a preventative approach and of what will enable long-term maintenance of gains in OCD treatment.

It is hoped that the present study will make a novel and interesting contribution to the field of clinical psychology. This is because in addition to contributing qualitative data on young people’s experience of their OCD, it is hoped to identify what young people experience as helpful and unhelpful in the treatment for OCD. Due to the severe and chronic nature of OCD during childhood long-term durability of treatment effects is critical to assure clinicians and young people that the deteriorating course of OCD can be halted with appropriate treatment strategies. Given the fact that childhood onset of OCD predicts adult morbidity, identifying effective interventions for this condition in paediatric populations is imperative.

A final objective of the present study is to start work on collecting narratives using audio/video recordings and transcripts that would be uploaded, with the young peoples'/parents' consent, on a website (www.healthtalk.org) in the future. The website is run by the charity DIPEx (personal experiences of health and illness) with a research group (Health Experiences Research Group) based at the University of Oxford. However, currently, there is no section on OCD on the adult or youth website. It is an aim that health care professionals, particularly those who diagnose OCD in young people, will be aware of the website and signpost young people to it. Consequently, this may help young people access psychological therapy sooner and reduce stigma and shame.

Aims of the research and research questions

The broad aims of the present study are to explore and understand psychosocial aspects of OCD and provide qualitative accounts of the experience of the condition and its treatment rather than concentrating on its psychopathology. The two essential research questions are the following:

1) What do young people experience as the contextual factors/triggers for OCD?

2) What is experienced by young people as helpful and unhelpful in getting help for OCD?

CHAPTER TWO: METHODOLOGY

Epistemology

The present study adopts a critical realist epistemological position, acknowledging that one can study ‘persons-in-context’ (Larkin, Watts, & Cliffton, 2006), integrating the individual’s lived experience and meaning-making specific to time, location and socio-political conditions. More specifically, a critical realist holds the position that reality is ‘out there’, but access to it is always mediated by socio-cultural meanings, and, in the case of qualitative analysis, the participant’s and the researcher’s interpretative resources. Thus, people’s words provide access to their particular version of reality; research produces interpretations of this reality.

The present study takes the position that the aetiology of OCD is undeniably multifaceted, involving a combination of risk factors, including childhood experiences, life events, mood difficulties, and genetics, which needs to be critically evaluated. This fits with a critical realist position that there is a real genetic pre-disposition. However, the present study holds the view that one must be critical of this being a pure cause of OCD. Therefore the present study holds the belief that environmental factors play a part in the development of OCD.

Design of the Study

The qualitative methodology of TA (Braun & Clarke, 2006; Joffe, 2012) was used to guide the data collection and analysis of semi-structured interview data exploring the experiences of young people who have received treatment for OCD.

Rationale for using a qualitative approach

The methodology of the research is qualitative, as it aims to examine themes between a group of young people experiencing OCD. Through staying as close to individual’s experience as possible, qualitative techniques aim to understand lived experience (Elliott et al., 1999). They can explore facilitators of change and potential barriers to any change (Starks & Brown-Trinidad, 2007) and are particularly suited to research of an exploratory nature, therefore well suited to research exploring themes of young peoples’ experiences of the development and help for OCD. The views of how young people make sense of their OCD have not been captured in research using a qualitative methodology. This methodology is considered apt at being able to explore more novel topics, as well as giving voice to a population under study (Barker, Pistrang, & Elliott, 2002).

Rationale for using Thematic Analysis

All qualitative research methods were considered. The researcher was initially considering using IPA in order to explore the young people's experiences of OCD in an in-depth manner. However, the researcher decided to use TA with the advice from the Health Experiences Research Group, University of Oxford. This is because TA is not wedded to any pre-existing theoretical framework (Braun & Clarke, 2006). This is important as it can be a 'contextualist' method, sitting between the two poles of realism and constructionism, and characterised by theories such as critical realism, which as previously described, is the epistemological position the researcher adopts (Willig, 1999). Therefore, TA can be a method that works both to reflect reality and to unpick or unravel the surface of reality (Braun & Clarke, 2006).

Additionally, TA enabled the researcher to use a larger sample size than other qualitative methodologies and to look at themes between all the participants that comprise the group of young people with OCD.

Braun and Clarke (2006) note that researchers cannot free themselves of their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum. Therefore, the researcher's personal experience of OCD and use of an attachment theoretical framework, meant that they were more deductive and theory driven in the analysis. However, an open-minded inductive data-driven approach was also used. Joffe (2012) recommends that the researcher uses deductive and inductive approaches, whereby one goes to the data with certain preconceived categories derived from theories, yet one also remains open to new concepts that emerge. The preference of using a deductive and inductive approach influenced the researcher to use TA.

The researcher used TA as she wished to write within an empathic hermeneutic approach giving voice to young people with OCD. Moreover, the theoretical flexibility of TA means that reflexivity is crucial to successful implementation.

Process of analysis

The analytic process involved a progression from description, where the data simply was organised to show patterns in semantic content, and summarized, to interpretation, where an attempt was made to theorize the significance of the patterns and their broader meanings and implications (Patton, 1990).

A theme refers to a specific pattern of meaning found in the data. It can contain *manifest* content, which is something directly observable such as mentions of stigma across a series of interview transcripts. Alternatively, it can contain more *latent* content, such as references in the transcripts, which refer to stigma implicitly (Joffe, 2012). The analysis in the present study at the latent level was conducted whereby underlying ideas, assumptions, conceptualizations and ideologies – that are theorized as shaping or informing the semantic content of the data was examined. Braun and Clarke (2006) state that TA which focuses on 'latent' themes tends to be more constructionist than realist, which fits the researcher's epistemological position.

The phases of TA outlined by Braun and Clarke (2006) were followed in a recursive process. The researcher familiarised them self with the data by reading the data at least twice. During the second read through sentence by sentence coding of initial ideas, interpretations and thoughts that emerged were written into the margin on the left hand side. Writing initial thoughts regarding the data was a way of ensuring self-reflexivity and keeping track of biases and assumptions that emerged during the analysis. The next stage of Braun and Clarke's (2006) method of TA involved coding features of interest for all ten transcripts. At this stage a list of potential codes was made and these codes were compared and contrasted. This list of codes was then examined and collated into potential themes and subthemes. Similarities and differences were noted under each over-arching theme. The themes were reviewed by checking if the themes worked in relation to the coded extracts. The themes were then defined and named by an on-going analysis to refine the specifics of each theme, and the overall story the analysis told, generating clear definitions and names for each theme. A table was formed to show reoccurrence of themes across the participants (See Appendix 2). The report was then produced by selecting vivid, compelling extract examples from the data relating back to the research question and literature.

Quality and Validity in Qualitative Research

Criteria for evaluating the quality and validity of qualitative research including TA has been developed by several authors (Elliott et al., 1999; Spencer, Ritchie, Lewis, & Dillon 2003; Stiles, 1993; Yardley, 2000), and have been applied to the development and conduct of the present study. Good quality, rigorous research requires a coherent and transparent description of the procedure, design and analysis (Spencer et al., 2003; Yardley, 2000) and should be systematic and transparent with regards to data collection, analysis and interpretation of data (Spencer et al., 2003). Credibility checks are also recommended to accomplish this (Elliott et al., 1999; Spencer et al., 2003; Willig, 2001).

The repetition of the steps of the TA guidelines were checked over by the research supervisors and peer-reviewed by a clinical psychologist. Additionally, the transcripts were sent to all the participants to check and change. This should have minimised any bias towards a particular theoretical or overly personal perspective in order to ensure reliability. This would have also minimised the researcher to under-code and only select hot spots that resonated with her personal experience of OCD. An example of the analytic process for one interview transcript has been included (See Appendix 3).

Ethics

The Health Experiences Research Group, University of Oxford acted as a consultant for the present study. The qualitative studies conducted by the Health Experiences Research Group have been approved by the Berkshire Research Ethics Committee for all health conditions involving participants aged from 10 years old. The wider study was rolled out to NHS Trusts in England initially and then Scotland, Wales and Northern Ireland in 2012. At present the majority of NHS Trusts in England, Scotland and Wales have agreed to act as participant identification centre (PIC) sites. As the present study was part of their wider study on narratives of health and illness, it was covered by NHS ethics approval (See Appendix 4).

The study was also registered with the University of Hertfordshire's Ethics Committee (See Appendix 5).

Due to the specific ethical approval conditions, the researcher was not permitted to interview on NHS sites and interviews were always conducted in people's homes. Therefore, the researcher wore her university identification badge in order to help the young people and their parent/s trust that she was the researcher when she visited their homes.

Informed Consent

Participant information sheets were given to participants by their clinician, whereby one was adapted for 13-15 year olds (See Appendix 6) and one was suitable for 16-18 year olds (See Appendix 7). For participants that were aged less than 16 years old, an additional information sheet was given to their parents by the young person's clinician (See Appendix 8).

Before the interview was carried out, the researcher checked that the participant and their family (if the young person was 15 years and below) read the participant information sheet. The opportunity to see a demonstration of the website and the chance to ask any questions was provided.

In line with The British Psychological Society's Code of Conduct (British Psychological Society, 2006), the parents of participants aged less than 16 years were asked for written informed consent and the participants were asked for written assent using the Consent Form (See Appendix 9) before the interview was conducted. Participants aged 16-18 years provided written informed consent using the Consent Form before the interview was carried out (See Appendix 10).

After providing consent, the participants were asked to complete a 'Respondent Details' form (See Appendix 11). All participants and parents of the 13-15 year olds were then made aware that the interview would be tape-recorded or video recorded and were given the choice.

The participant/parent was told that more research may be carried out at a later stage in order to collect more interviews with young people experiencing OCD. They were told that at a later stage their interview will be uploaded onto the Healthtalkonline website onto a new OCD section for young people. They were given the choice of the format of how their interview would appear on the website. These potential formats included snippets of transcript, audio-recording, video recording, and having an actor/actress recite their words (the researcher was provided with training to use the video equipment through the research delivery project manager). Participants were told that the Health Experiences Research Group would only select 5-6 clips from each interview and will choose sections where they saying something that will be of interest to others.

The researcher told participants that after the interview they would post them the transcript in order to give them the opportunity to check it, change, remove, identify sections to be withheld, or add information. They were also posted a Copyright Form (See Appendix 13) which allowed them to specify the format of the interview they wanted to use on the website if it was to be uploaded at a later stage. This form gives copyright to the University of Oxford to use the material in research, teaching, publications and broadcasting. The Copyright Form was based on that used for deposits at the National Sound Archive of the British Library. Participants aged 15 years old and below would sign the Copyright Form as well as their parent (Appendix 12). Additionally, the researcher posted a Biography Form (See Appendix 14), whereby the researcher wrote down demographic information (and the participant's preferred name) and a summary of the young person's story, which would be uploaded on the website with their interview. The young person had the opportunity to change any of the information and they signed the form. The Biography Form is to provide some context about the participant's whole story, because Health Experiences Research Group use only clips, not the whole interview. A parent of participants aged 15 years old and below also signed the Biography Form. The transcript, Copyright Form, and Biography Form were posted back to the researcher with a stamped self-addressed envelope that was provided.

Possibility of Distress and Prevention of Harm

There was an ethical concern that the young people would become distressed whilst recalling their difficulties during the interview. Therefore, participants were informed that they had a right to not answer any questions they did not want to, to have a break or end the interview if they needed to, or withdraw from the study at any time, without any implications for their care. Furthermore, the researcher used her clinical skills to conduct the interviews in a thoughtful and sensitive manner and put participants at ease as much as possible. Finally, the participants were debriefed using information provided in a debrief leaflet (See Appendix 15), which contained details of people or services they could contact if they became distressed after the interview. However, ethical issues were reduced as most of the young people received the majority of their course of psychological therapy and therefore were not at the peak of psychological distress. None of the participants became worryingly distressed.

Confidentiality

Before conducting the interview, participants were informed that names of health care professionals, CAMHS, and places should be avoided. Additionally, the researcher encouraged the participant not to use names of their friends and relatives (unless they were happy to be identified – written information was needed from the person whose name was used). Parents had the right to give permission for children's names to be used as long as the child was under 16 years old. Names of health care staff and clinics were always removed from the transcripts.

The exception to confidentiality was if any information was shared during the interview that raised concern about the safety and wellbeing of the young person or of someone else. Fortunately, no such circumstances arose.

All recordings and transcripts were stored securely on two external hard drives (one for the researcher's use and one for Health Experiences Research Groups use), saved as a unique code and number, and stored in a locked drawer separately from demographic information. The interviews were deleted from the researcher's computer, camera, and digital audio recorder. The digital audio file was sent recorded delivery to a transcriber working for Health Experiences Research Group who had signed a confidentiality agreement.

The Consent Form, Copyright Form and Respondent Details Sheet all contained the unique code and number for each participant and were kept in a locked drawer. A password protected external hard drive with the recordings and transcripts as well as all the forms were provided to the Health Experiences Research Group at University of Oxford in order to be kept indefinitely. The recordings for the researcher's use would be kept for a maximum of 5 years and then be destroyed. If the participant/parent did not sign the Copyright Form, the interview could not be uploaded on the Healthtalkonline website in the future.

Right to Withdraw

It was made clear to participants and their parent/s that participation was voluntary and that taking part or not would not impact on their care. They were informed that they had the right to withdraw at any point and that they had the right to decline answering any questions. If a participant was to withdraw from the study all copies of the video, audio and transcript files would be deleted.

Service-user Involvement

Service-user involvement in research is extremely important as it increases the potential that the research will be conducted in a way that is sensitive to the needs of the group it is trying to support. Faulkner (2012) notes that service user-involvement is important as they can analyse and interpret the voices of their peers and ensure that the findings get back to the communities from which they arise with the aim of bringing about positive change in people's lives.

Service-user involvement occurred early on in conducting the present study. The researcher had a consultation session with two service-users, who have self-informed OCD, on ideas that arose from the researcher's major research project presentation. The two service users provided information about the design of the interview schedule. For example, they advised to have space at the end of the interview for the young person to talk freely on any other comments they wished to make. The service users suggested that this may keep the young people focused on answering the specific questions.

The researcher also attended a support group for people with OCD run by the Charity OCD-UK, in order to gain feedback on potential areas to focus on in the interview schedule. The service-users discussed the importance of asking prompt questions around potential social triggers for OCD such as school, relationship to peers, and family circumstances. This impacted on the interview schedule as the researcher included prompt questions that focused on those areas.

A pilot interview was conducted with a service user, who wrote a book on his experiences of OCD when he was an adolescent (Wells, 2006) and he acted as further expert by experience consultant to the project. The rationale for conducting a pilot interview was to develop the researcher's interviewing skills and gain further feedback on the interview schedule. The expert by experience consultant provided helpful feedback such as the researcher slowing down her pace and moving a couple of questions to different places in the interview. He also described how he delayed seeking help due to shame and stigma. This prompted the researcher to explore the literature around this and ensure this was explored in further interviews. The expert by experience consultant highlighted the positives of a health care professional providing him with a CD consisting of interviews of other young people experiencing OCD. For example, he expressed how the CD made him feel less alone. This provided further justification of uploading the interviews onto the Healthtalkonline website in the future. The pilot interview was not used as data as the service user did not meet the age criteria.

Recruitment of Participants

Inclusion and exclusion criteria

All participants had a formal diagnosis of OCD from a psychiatrist or a psychologist as per the DSM-IV criteria (APA, 1994). Participants were only included if their primary diagnosis was OCD. However, in order to ensure the sample was representative, participants with a comorbid secondary presenting difficulty were included.

Participants were excluded if they had a learning disability of the severity that they were unable to communicate their views or understand the requirements of participating in the study.

Recruitment strategy

A purposive sample (Marshall, 1996) of 10 participants was recruited through three Tier 3 CAMHS. The researcher presented information regarding the present study in team meetings when requested to. The researcher interviewed those who volunteered and were readily available. The recruitment from different parts of the country was carried out due to increasing the different socio-economic and cultural backgrounds.

Participants were recruited from the NHS, as this ensured that participants had a confirmed diagnosis of OCD.

Clinicians invited their clients to participate and provided them with Participant Information Sheets. Clinicians also provided parents of the young people below the age of 16 years old with an information sheet. If they agreed to participate the clinician completed the reply sheet (See Appendix 16) and posted it in the stamped self-addressed envelope provided. The potential participant was contacted by telephone by the researcher in order to answer any questions and arrange a convenient date/time for the interview. Potential participants were given time to study the information sheet carefully, and time to discuss the project with their family, if they wished.

Participants

Participants were both males and females between the ages of 13-18 years of age. The range of ages was 14-17 years old. The mean age is 15 years and 7 months. There were 5 males and 5 females interviewed. Nine participants were White British and one was Brazilian. Nine of the participants were students, attending school, sixth form, or college. One participant left school and was unemployed at the time of the interview due to her mental health difficulties. It was important to interview people at different stages of experiencing OCD. Therefore, participants were at any stage of therapy or had been discharged from CAMHS.

While the cohort of participants were diverse in terms of gender, age, socio-economic background and length of time since diagnosis, and despite efforts in recruitment, it is interesting to note that 9 out of 10 of participants were White British. This fits with previous qualitative studies (i.e., Murphy and Parera-Delcourt, 2012; Fennell and Liberato, 2007). It will be important to hold this in mind when interpreting the findings of the study.

Participants were referred to by pseudonyms for the write-up. Below is a table of participants.

Table 1

Description of Participants.

Pseudonym	Gender	Date of Diagnosis	Delay in seeking professional help	Comorbidity	Educational issues	Employment	Home Circumstances
Alison	Female	2011	3 months.	None.	Scared to go to school if her friends/mother did not meet her at the gate after school. Crossed work out due to writing compulsions. Sometimes could not put pen to paper due to avoidance behaviour and she got told off by teachers.	School student	Parental verbal arguments and separations when she developed OCD. Court case for mother when she developed OCD. Parents currently have new partners. Lives with her mother only.
Gemma	Female	2013	No delay.	Secondary presenting problem of panic attacks and depression.	Grades lowered. Had to underline/recopy work. Schoolwork had to be in a set structure. Avoided people in class due to contamination fears. Avoided the Duke of Edinburgh due to contamination fears. Left class due to panic attacks. Avoided touching the	A-Level student	Parents had an unhappy long divorce – both parents have new partners. At the time of developing OCD she was living half the time

					keyboards at sixth form. Dropped an A-Level due to OCD.		with each parent. At the time of developing OCD her father was having verbal arguments with his partner. Father went through the courts for custody and Gemma was interviewed and asked who she (and her younger siblings) wanted to live with at 12 years old.
Tobias	Male	2014	9 months.	None.	School work took longer due to crossing words out three times and re-writing them – he became behind in work.	A-Level student	One month prior to noticing OCD his sister was ill with a blood disease.
Bradley	Male	2012	8 years.	Secondary presenting problem of depression.	He went over his writing a few times, which made his writing untidy, and he lost marks.	School student	At the same time as developing OCD his sister's boyfriend got into physical fights with his parents. Bradley witnessed the

							fights and a lot of swearing. His sister's boyfriend was unfaithful towards his sister and was imprisoned for raping a woman. He threatened to kill Bradley via telephone. 2 years after he first noticed the OCD, his teenage cousin died. After this, he witnessed his parents having marital verbal arguments.
Nicholas	Male	2009	Few months.	None.	No issues.	School student	Lives at home with parents and sister – no difficulties.
Bella	Female	2009	3 years.	None.	Had to complete school work in a certain way. She became stressed completing homework.	A-Level student	Parents separated when Bella was 4. She lives with her mother but stays at her father's house. Her mother has a new partner and has children with him. When she developed OCD, she witnessed her father's partner push her son down the stairs. Her father blamed Bella

							and said she was lying. Social Services interviewed Bella. Her father chose his partner over Bella. Her father and his partner later broke up and her father blamed Bella for the relationship break-up.
Amy	Female	2003	No delay for 1st episode. 3 year delay for 2nd episode of OCD.	Secondary presenting problem of panic attacks.	She left education and did not complete sixth-form. She found the academic component difficult. The panic attacks and OCD made sixth form more difficult for Amy.	Unemployed due to her OCD and panic attacks	Lives at home with her siblings and parents. 2-3 years prior to her 2nd episode of OCD, Amy was seriously ill with blood poisoning her great aunt and uncle died.
Charles	Male	2012	1.5 years.	None.	Charles found his compulsion to fold the corners of his schoolwork distracting.	A-Level student	Charles lives with his parents and siblings – no issues.
Jack	Male	2011	5 years.	Secondary presenting problem of Asperger’s Syndrome.	Jack underwent his hand washing compulsions during school lessons and therefore this impacted learning.	School student	Jack lives at home with his parents and his sister – no issues.
Jade	Female	2014	3 months.	Secondary presenting problem of Tourette’s Syndrome.	Jade avoided a lot of college work as she had to carry out a compulsion when she used the computer. Jade distracted herself from her compulsions in her class at college by talking to others and therefore she did not complete her work.	BTEC Media Studies college student	There were a few deaths in the family when Jade developed OCD. She lives with her parents.

Suggested Measures and Data Collection

Semi-structured interviews were conducted with all participants individually as this allowed freedom for the participants to respond in their own words and own ways. The researcher and the two research supervisors devised an interview schedule (See Appendix 17), informed by the research, clinical literature, clinical experience and service-user input.

The interview schedule was used flexibly to facilitate the participants to determine the direction of the interview. Specific questions in the form of prompts were asked in response to the material raised by the participants. The interviews lasted a maximum of one hour and participants were offered to take a break whenever they required.

The interviews were transcribed by a professional transcriber who used the Health Experiences Research Group's transcription format which was described on the 'Style Sheet for the Transcriber' (See Appendix 18).

CHAPTER THREE: RESULTS

This section presents the findings of a TA of how young people made sense of developing and getting help for OCD.

Four themes emerged from the data analysis: ‘Traumatic and stressful life events’, ‘Responses to signs of OCD’, ‘The battle of living with OCD’, and ‘Ambivalent relationship to help’. The themes and subthemes are presented in Table 2.

Table 2

A summary of themes and subthemes.

Themes	Subthemes
Traumatic and stressful life events	Hostility in the family Illness and death Bullying and friendlessness
Responses to signs of OCD	Lack of understanding of the behaviour Being secretive “I thought I was going crazy” Feeling different
The battle of living with OCD	Feeling ‘right’ “I was taking on all the responsibility” “It’s ruined everything” “Everyday life is now in my bedroom”
Ambivalent relationship to help	Conflicts of exposure therapy Conflicts about accommodation of the OCD Frustrations of long waiting lists

Traumatic and stressful life events

As researcher, and within the context of the focus in clinical psychology on formulation, there was an interest in contexts of trauma for the development of OCD. Thus it is important to emphasise that this frame was deliberately introduced into the research by the questions of the researcher. However, it is argued that TLEs and the connection with the development of OCD has earned its way into the analysis (Charmaz, 2006) from the significant amount of data reflecting serious trauma.

The theme ‘Traumatic and stressful life events’ describes how 9 out of the 10 participants experienced at least one of the following three TLEs/SLEs: ‘Hostility in the family’, ‘Illness and death’, ‘Bullying and friendlessness’. It was interesting that all the participants experienced the life event just prior or within a couple of months before the development of their OCD.

Hostility in the family

4 participants experienced the TLE/SLE of hostility in the family. ‘Hostility in the family’ refers to the participants witnessing verbal and/or physical arguments between family members. The subtheme also comprises of parental separation and divorce.

Alison[1] described witnessing her parents arguing. She discussed how she was worried about the future after her parents’ divorce and whether she would be accepted and alludes to the fear of being rejected by their new partners:

“I know there was arguments between parents. Obviously that, that does make you sad because you like, you want them both to be happy. And like sometimes it’s not and you see like their arguments. Also that was a worry ‘cos you think, “Oh god”. ‘Cos that where I am so close to my mum that we’re best friends like I couldn’t do that. And that leaves you worried but Yeah because they, they had just break up, they used to be together and then they weren’t together but that was it really. But I can remember I was obviously sad because you wonder what is going to happen next like. Why like what happens when they divorce, who are they going to meet, what are them new people going to be like. Are they going to be nice, you know” (pg.7, line no. 121).

Like Alison, Gemma discussed how she witnessed her father and his partner arguing. There is a sense of being rejected by her father as he prioritised his time with his girlfriend. Gemma described how she did not feel contained by her father as he was preoccupied with his relationship with his girlfriend:

“My dad and his partner weren’t getting on at the time. There was a lot of arguing [um] and it was a quite stressful situation so that’s why I have chosen to stay in one place. It wasn’t a happy divorce. It was like a car crash. It was horrible for years. Mostly mum because at the time I was not really living in the land with my dad because

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[1] Pseudonyms are used in order to protect confidentiality.

he was arguing a lot with his girlfriend and I would take myself away and just stay in my room all the time. And I didn't feel I could talk to dad because he'd obviously had a lot more going on in his life which was his girlfriend" (pg.7, line no. 71).

Similar to Gemma, Bella described how she was rejected and uncontained by her father as he chose his girlfriend over her after she witnessed his girlfriend being violent towards her son:

"Yeah that was, well my parents never really got on that well and also I'd like. I obviously prefer my mum [laugh] That sounds really bad but like whenever my dad used to put me to bed I'd always want my mum and my mum like always tells me that when I was younger that I'd sort of like ask for them. I think I was about 5 or something my dad was in a relationship with this woman and it was like going quite well in that she'd sometimes stay over and she had a son that was quite a bit older than me. And one night [um] my dad like had done something for her son, I don't know what it was. He got him something and he didn't say 'thank you'. So when my dad went in the toilet she went and had a go at her son like saying, 'Why didn't you say thank you? You're not a very polite boy.' And he walked out and she pushed him down the stairs and I witnessed it. [um] And then obviously when I, I got really stressed out I thought she was at the school play and then the school sort of got involved and they were like, 'You ok?' I was like, 'No I think she is here'. And my dad sort of had no, he just said, 'I was lying and then made it up' and said that I made it up when I hadn't. Well my, well obviously social services got involved because obviously I was getting really stressed out about it so they interviewed me and my mum. And they, oh what happened? I think, yeah I think they, my mum got her solicitors involved and asked, like told my dad that it's either her or us. And I think like at first he chose her. So he didn't want us" (pg.6, line no. 62).

Like the other participants, Bradley also witnessed verbal and physical arguments in the family:

"I think that's when my sister got her like weird boyfriend. Who [pause] [sigh] trouble. Basically he, [um] he was quite violent and he got in fights with my dad a few times and yeah, he's, yeah a bad person. I can't remember the dates but I think it started around 5. He, [um] he was like cheating on my sister and loads of stuff which

my parents didn't really approve of and they'd get in fights. I think the police got involved a few times. [um] He'd, I'm pretty sure he once phoned up and threatened to kill me. I remember seeing some fights and stuff at some point. There was a lot of swear. I was there for a lot of the words and swearing and stuff which wasn't particularly nice" (pg.9, line no. 139).

This subtheme shows the hostility that the young people witnessed. Some of the young people were close with one parent. However, some were distant and felt rejected and uncontained by the other parent.

Illness and death

3 participants experienced serious illness (in family members or themselves) and deaths of family members and a teacher just prior to the onset of their OCD.

Tobias described how his teacher died and his sister was seriously ill 1-2 months prior to the development of his OCD. It is interesting how he repeated the word "serious" to highlight the extent of the illness:

"One of my teachers [ah] died a few months, a couple months earlier and then about a month or two later my sister got ill with a. She has a blood disease, [ah] ITP xx and it's quite serious like and she, [ah] she's taking stuff and yeah like bad side effects. So it is quite serious. She, just before, like in June [um] got, started getting really bad in July but in June [um] she was getting like bumps that she didn't even remember from like nights out or anything like that. She just fell and she'd be getting like bruises. They were like that big covering almost her whole leg. And [um] she was feeling like sick sometimes. And [ah] they found that she didn't have enough platelets. She had like. You are meant to have something between like 180 to 300 so then she had one. And [ah] yeah and [ah] she'd been taking stuff but are like some steroids but it's. She had like bad side effects to it like [um] she, her hair started to fall out and stuff like that" (pg.4, line no. 54).

Like Tobias, Jade described how she experienced deaths in her family and immediately after this SLE she developed OCD:

"There were quite a few deaths in the family it was mainly on my mum's side. Her aunts and uncles all started dying of cancer unfortunately and because of that I developed a new compulsion where I was obsessed with death" (pg.5, line no. 37).

In addition to experiencing a SLE ('Bullying and friendlessness') just prior to developing her first and second episode of OCD, Amy also experienced a serious illness and the death of family members two-three years prior to developing her second episode. The illness that she experienced was serious, just like Tobias' sister's:

"Yeah. [um] I had like a form of blood poisoning so yeah. And it all started from like a scratch on my arm which then developed into a cold and then just got worse and worse. Well like the hospital didn't really know what it was so touch and go they said I could of died so" (pg.10, line no. 169).

Bradley experienced hostility in the family and immediately after this he developed OCD. However, he experienced another SLE (death of a family member) 2 years after the onset and this coincided with a worsening of the OCD:

"I think the next big thing that happened was my teenage cousin died but I can't. [Um] I think it got, it got a bit worse. It did. I got, I think 'cos even though her death didn't affect me as much as it affected the family, the rest of the family, seeing the rest of the family upset me that stressed me out and I think that just increased the OCD a bit 'cos I sort of started worrying for other people" (pg.12, line no. 237).

This subtheme shows how a serious illness experienced by themselves or family members and deaths of family members and a teacher occurred prior to the development of OCD. It is noticeable that the participants' obsessions shifted to worries about family members and fears of death after the SLE. It was also interesting how some participants were very aware of the family's distress and perhaps felt uncontained after a death of a family member.

Bullying and friendlessness

6 of the 10 participants experienced either being bullied or having difficulties making any friends just prior to the onset of their OCD. The majority of participants had difficulties with peers during the transition to a new school.

Alison developed OCD immediately after witnessing her parents arguing and separating. At the same time she moved to a new house with her mother and did not have any friends in the new neighbourhood:

"I used to be literally housebound because I didn't know anybody in X. So I wouldn't play out with any of my friends. I didn't have any friends around there so obviously it was quite a lot worse because like I couldn't go out and be, you know, play" (pg.6, line no. 115).

At the same time of the SLE of witnessing hostility in her family, Bella was bullied at primary school. Immediately following these two SLEs she developed OCD:

"Well throughout my whole period of [um] at primary school I was bullied by [um] one girl in particular" (pg.13, line no. 280).

Nicholas described how he found it difficult to make friends when he transitioned to middle school and immediately after this SLE he developed OCD. The following quote captures the difficulty tolerating the uncertainty due to the change in school:

"I just started middle school and, and I had, I was quite worried about that. So that might have been one of the causes of OCD. I it was just a big, bigger, much bigger school. [um] It, it had a lot, lots of different buildings, little bit buildings and stuff and like [um] compared to my old school which was only a small school. This was quite [um] a bit bigger" (pg.6, line no. 83).

Nicholas also discussed how he was bullied when he moved to secondary school. Immediately after this SLE he developed his second episode of OCD:

"It was just a few problems with friendships and stuff. I felt more lonely, I just felt a bit, yeah just a bit on my own a bit more [um] rather than with them" (pg.10, line no. 198).

Like Nicholas, both of Amy's episodes of OCD were connected to difficulties with peers and being bullied when transitioning to her first school and secondary school. Her difficulty tolerating uncertainty of being in a new situation of transitioning to a new school is conveyed in the following quote:

"I think probably it was just starting school like properly. I don't know, [um] probably because I'd been at home all the time with like my mum and then I was being left and it was a bit strange" (pg.6, line no. 33).

Similarly to Nicholas and Amy, Jack also found it hard to make friends when he transitioned to his first school:

"I knew even at that time I found it very hard to make friends. That I did know. I, [pause] had barely any, like 2 or 3 and although there is enough for a person I, you know, they had friends so most of the time I was not with friends" (pg.12, line no. 308).

Jack's OCD worsened when he was bullied during secondary school:

"Well I was being pretty harshly bullied at that school so basically most of my mental energy was concentrated on that but I had big issues with pretty much everyone in the school. It was pretty hard. Mostly verbal but [um] sometimes normally when it started it got physical" (pg.6, line no. 111).

Like the other participants, Jade found it difficult to make friends when she transitioned to a new college. She also found it difficult to tolerate the uncertainty of being in a new environment and studying a new subject. Her sense of being alone is also shown in the following quote:

"I was struggling with course work a bit because it was really new. I was really anxious to be in a new place when I'd been used to going to the same school for five years. [um] A couple of my friends I fell out of contact with. [um] To begin with it was incredibly scary because I was the only person in that class that I knew from my school apart from one person I didn't particularly talk to. And so I had to start all over again and I'm already a very shy introverted person. And then [um] I kind of found some of the course work a bit of a struggle as well because it was just so different from anything I had ever done before" (pg.5, line no. 38).

This subtheme shows how the development of OCD occurred immediately after the young people were being bullied or found it difficult to make friends. It was interesting that most participants talked about difficulties tolerating uncertainty after transitioning to either a new neighbourhood or a new school. There was also a real sense of being rejected and alone from the participants.

Responses to signs of OCD

The theme 'Responses to signs of OCD' describes the personal meanings that the participants had when they noticed OCD behaviours. Four subthemes, 'Lack of understanding of the behaviour', 'Being secretive', 'I thought I was going crazy', 'Feeling different', provide a richer understanding to the different responses to signs of OCD.

Lack of understanding of the behaviour

Participants in this subtheme felt they or others lacked understanding of their behaviour. Many participants were not familiar with the label 'OCD' or did not understand what it meant or connect it with their own experiences. Most participants thought that their behaviour was 'normal' as it was so habitual from such a young age. Most of the participants explained that their parents thought their behaviour were childhood quirks and would pass without seeking help.

Charles discussed how his OCD was so habitual and consequently he did not explore the understanding that it was OCD:

"I didn't know what OCD was then. I didn't realise what I was doing but to me it was part of life that it wasn't out of the question" (pg.14, line no. 347).

The following quote is from Gemma and provides an example of her mother's lack of understanding about her behaviour:

"I must have been maybe 14 just turning 15 so kind of yeah it was, yeah roughly mum was sort of bordering on, maybe there is something there, but she is not sure. If she was maybe more aware of what OCD was as an issue she might have probably seen the boxes and ticked them that I was doing that and that's probably what it was. Because we were a bit clueless in what OCD was it probably dragged on a bit longer than it should of" (pg.16, line no. 354).

Charles noted how his mother thought his behaviour would pass without seeking help:

"Mum was hoping I would grow out of it I think. It was yeah I remember one year after seeing the film going, 'Oh yeah this like the one year anniversary of seeing the film'. And I realised I hadn't really changed to how I was when I first saw the film. And [um] we eventually got help" (pg.22, line no. 579).

Bradley explained that his parents also felt that his behaviour would pass and was not aware of it being OCD and he waited 8 years before he sought help:

"But I think back then my parents just thought it was, you know, like a fad and dismissed it" (pg.17, line no. 415).

Once participants did seek help, most believed that their GP did not fully understand their behaviour, did not take their mental health condition seriously, and therefore did not diagnose them or refer them on for psychological help.

Bella highlighted the lack of understanding about OCD by her GP and she emphasised this by comparing the GP's vast understanding of physical health issues. She alluded to how persons do not perceive OCD as a "real" condition as it is not tangible. She explained that this lack of understanding led to the GP not being able to diagnose her:

"It kind of makes me feel like maybe like it makes you feel like it's not something real because you feel like GPs should know it like quite a lot. If there is a disease they pretty much know about it but to not like sort of see the signs and the symptoms of OCD it does make you feel, 'Oh well obviously it's not normal' because they can see the signs and it would be better if they knew it and they'd be like, 'Oh I think you have this' sort of thing. So you just know in your head, 'Oh it might be that" (pg.24, line no. 625).

In agreement with Bella, Jade also felt GPs lack the understanding of mental health issues:

"I had a bit of a bad experience with a doctor. [um] I went to my doctor's and explained to them about the tics. I explained to them about the obsessive checking and I said that I had done some research online and that I didn't know it was for definite but I really wanted to be checked for Tourette's and OCD so I could start a treatment if that's what it was or at least find out what it was. And my doctor actually didn't help at all. He laughed to be honest. [um] I think with normal GPs they don't tend to

understand the mental health side of things. They look at physical problems and he just laughed and I refused to leave the office. So he just handed me a piece of paper and said, 'Call that number' and threw me out. And on this piece of paper was the number of a counsellor who I began seeing and she was lovely and she told me that she couldn't actually diagnose me though because she wasn't a trained [um] medical professional" (pg.16, line no. 392).

Most participants believed that school did not understand their OCD difficulties, often mistaking it for misbehaving. Additionally, 2 participants were negatively judged by friends for their OCD behaviours. 2 participants lost friendships following disclosure of their behaviour, in their view due to a lack of understanding of OCD, with many participants feeling that others did not take their OCD seriously.

The following quote provides an example of the lack of understanding at Alison's school:

"And no one helped me in school. The school was really bad because I used to cross things out but no one would help me. They just thought I was a normal school girl and they would shout at me if I didn't put pen to paper because I can't write on all the lines and before they didn't help me. They would tell me off because I wouldn't write it or I wouldn't do homework because I couldn't put pen to paper, not that I was being lazy" (pg10, line no. 233).

Gemma highlighted how her peers at school did not understand OCD and she believes there is a lack of understanding of how serious the condition is. She alluded to the lack of understanding due to it being a psychological condition as opposed to a physical one:

"It was kind of like I'd been labelled as OCD and it was kind of like a bad thing but when I spoke to other people at school they kind of like pushed it off as it's not a big deal but people don't realise that it is. I know it is not as big as cancer and leukaemia and proper, like big diseases like that but it still affects you in everyday life as opposed to someone who doesn't have it" (pg.12, line no. 227).

Lastly, all participants felt that the general public did not understand the nature of OCD and perceived it in a stereotypical way, which did not acknowledge the seriousness of their distress and how it negatively affects peoples' lives in different ways.

Tobias discussed how the general public have a stereotypical understanding that OCD involves a one-off quirk. He noted how the term 'OCD' is common language in society and is used by everyone. He highlighted that the general public do not take the condition seriously:

> *"That OCD isn't just having your pens in a like co-ordinated order and saying, "Oh I've got OCD". You don't but [ah] yeah and that it's more serious than that as well that it isn't just putting stuff in order. It's a lot of stuff. It's a much wider broader thing than people think really and that it's much more serious" (pg.33, line no. 991).*

In this subtheme it was shown that a universal lack of understanding of OCD and lack of awareness about what it means delayed participants and their parents seeking help, instead arguing that it is something that will pass, or something less serious. Most participants despite experiencing high levels of distress and constraints on their quality of life delayed seeking help for their OCD for some time from when they first noticed the signs. The period of delay varied between participants from 3 months to 8 years. Once participants and their parents did seek help, GPs appeared to be dismissive at times or miss the signs of OCD, thus not referring participants on for psychological help. Participants also felt that the communities they were part of (e.g., school, friends) and also the wider society did not understand or accept the serious implications of OCD. As described below most participants appreciated the diagnosis of OCD but were frustrated by people's lack of understanding of the different personal meanings and how difficult it was to live with.

Being secretive

All participants displayed elements of being secretive about their OCD and hiding their signs of their OCD from family members and peers.

Bella kept her OCD a secret for two-three years since first noticing the signs:

"Yeah like I said it wasn't 'til I told my mum which was probably two or three years after I'd sort of developed them [um] that I realised that I wasn't exactly like classified as normal behaviour" (pg.14, line no. 312).

Jade recommended families and clinical psychologists to be mindful that one can be secretive about their obsessions due to them being personal:

"Don't put too much pressure on them. [um] It can be very personal. It can be thoughts in your head which you just don't want anyone to know about" (pg.30, line no. 849).

The following quote provides an example of how Alison's (and most participants') OCD was better and reduced in front of her friends due to her attempts at keeping the OCD a secret:

"When I'm with friends it's not as bad because I try and hide it from them because I don't want them thinking I'm a weirdo, you know" (pg.10, line no. 229).

Similarly to Alison, Bella also hides her OCD in front of her friends by performing her compulsions quickly. Her OCD increases when she is on her own as she is more comfortable undergoing her compulsions as nobody can see her behaviour:

"It's just that also like at school it stresses me out a bit because I'm worried that someone is going to notice that I'm doing these things. Like 'cos I hate, I don't like my left hand so that I can't touch anything with my left hand. So if I do I will quickly touch with my right sort of thing. So I'm really worried that people are going to see me and be like, 'Oh what's she doing? But I think that when I am on my own I feel a lot more comfortable 'cos I know that no one is going to see sort of thing" (pg.9, line no. 145).

Most participants told a couple-few friends about their diagnosis of OCD. However, both Nicholas and Charles have still not told any friends about their OCD. Bella had not actively told any of her friends too but her mother "accidentally let it slip" in front of all her friends.

Alison talked about feeling ashamed about having the diagnosis and consequently this leading to being secretive about her OCD:

> *"No I thought, I found I was ashamed of it. You feel quite ashamed so I kept it to myself" (pg.24, line no. 673).*

Gemma noted how she tried to keep the OCD hidden at school and therefore avoided using her Time Out card:

> *"You know, I got given a Time Out Card but it's embarrassing to be in class to then get out your Time Out Card and be like, 'Can I be excused for this reason?'" (pg.21, line no. 516)*

In this subtheme it was shown how most participants kept their OCD behaviours a secret. The interviews found two main reasons for being secretive. Firstly, secrecy around OCD behaviours is due to the personal and private nature of the obsessions and intrusive thoughts/images. The second reason for the secrecy is due to the stigma and shame around having a mental health 'disorder'. The secrecy also partly explains why most participants delayed seeking help for their OCD behaviours.

This subtheme evokes a real sense of the pressure placed on someone trying to navigate between the strength of their compulsions and social convention of how to act, trying to fit in and not appear "weird". When the young people were alone, even though their OCD would worsen, there seemed to be a sense of relief, a letting go, when they could carry out their compulsions without worrying about others noticing. This captures a real conflict in the participants' minds. It is almost as if young people are talking here in a way that does not indicate that OCD is the problem, but rather managing all the pressures associated with carrying out compulsions where there are others that might judge is the problem. This may explain why a later subtheme describes how the participants withdraw from others as they can spend their time alone as a way to resolve this tension for themselves.

"I thought I was going crazy"

Most participants thought they were experiencing a serious mental health condition and feared they were going "crazy". It seems that the meaning of the term "crazy" implies a serious mental health illness resulting in them losing control over their minds and lives. This would consequently lead them not to fit with those that form the status quo and perhaps this would lead to stigmatisation.

The following quote provides an example of the subtheme whereby Alison thought she was going crazy before seeking help:

"I thought I was going crazy. You think you are going mad" (pg.11, line no. 262).

Bradley delayed seeking help as he feared that he would have to change school to a specialist school due to his difficulties:

"I was being really stubborn and like putting off going to the doctor 'cos I guess I was scared about, you know, something was majorly up. I am not too keen on doctors anyway and [um] I think I was scared that he'd say [ah] 'You have to go, you know, change school or something like that'. But I suppose I was being young and stupid because I don't know that I had something, you know, quite bad mentally and emotionally and stuff like that" (pg.25, line no. 674).

Like Bradley, Jade also delayed seeking help due to the fear that she was going "crazy":

"But then in the September I was just so awful that it really affected me. I couldn't sleep and I came down and started crying and my parents forced me to go to the doctor's because I was just so scared that [um] there would be something really wrong with me. I wasn't comfortable asking people for help. [um] I never really liked asking for help. I like doing things myself. I kind of felt that if I told people they might not understand and think I was crazy and I was just very scared to talk to anyone about it. It was only when it really got hold of me and I started crying that my parents said, 'No you need help and you need to get help as soon as possible'" (pg.15, line no. 366).

Gemma described how she appreciated her diagnosis of OCD as she feared she was going "crazy":

"Probably that it was finally admitted and that was it, that was like, I wasn't bordering on, you know, I felt like, I felt crazy at the time. I was thinking, you know, things like that but [um] for him to say, 'Right it's OCD I'm looking at right.' He's actually saying something. I'm not going crazy it's all good. So it's things like that" (pg.26, line no.687).

Like Gemma, Tobias also appreciated having a diagnosis of OCD as he also feared he was going "crazy":

“I was happy because like it’s good to, it’s good like know you’re not crazy or something like that and that what you have has a name and like everyone knows OCD like most people” (pg.27, line no. 788).

Jack also appreciated his diagnosis of OCD as for him it meant that he was not going crazy:

“Not really. It was just, you know, I was just grateful that I’m not insane” (pg.32, line no. 958).

Jade recommended young people who are experiencing OCD to seek help quicker and she emphasised that they are not “crazy”:

“Don’t be afraid to ask for help. You’re not odd. You’re not mad. You’re not crazy” (pg.29, line no. 801).

In this subtheme, many of the young people had an intense fear that they were ‘going crazy’. Thus, there was for many an extended period of trying to hide their distress from others and not asking for help, while having very powerful experiences of losing control of themselves/their lives. Thus, clearly this could potentially powerfully add to the distress they are experiencing and the isolation they feel. This contributes to an explanation of why an OCD diagnosis came as such a welcome relief to many of the young people. OCD seems to be much less of a concern than what they had been imagining the problem might be; thus, there is a sense of OCD being ‘not so bad’, actually being a good thing, proof that they were not ‘mad’.

Feeling different

This subtheme describes how all the participants felt ‘different’ when experiencing the signs of OCD. This may be due to the personal nature of the thoughts people were having, which was described previously. Additionally, others seem to also be isolated by what they see as the horribleness of their thoughts and/or the ‘weirdness’ of having such thoughts. It was interesting to note that some participants had appraisals of themselves as a bad and horrible person. It is important to note that even when in relationship with those trying to help them (and who are professionally trained) they did not feel understood. There was such a sense in these quotes of being alone and longing to be understood by someone who really knows what it is like from the inside. This sense of only being understood by someone with the same experiences, led the young people to appreciate any intervention that connected them to others with similar experiences (e.g. reading a leaflet/book they could relate to, or wishing for support groups).

This first quote describes how Gemma's experience of her OCD led her to hold a sense of herself as being 'different':

"It kind of [ufff] just sort of made me feel different from everyone else" (pg.12, line no. 235).

Similarly to Gemma, Bradley saw himself as being 'different' when he noticed his signs of OCD:

"I think, you know, like, 'Am I a bit of a freak or what? Why am I so different?'" (pg.21, line no. 536)

Amy also identified herself as being 'different' once she noticed her OCD behaviour during both her episodes when she was 6 and 13 years old:

"Again that I was different 'cos no one else had to do it and no one else was as worried" (pg.16, line no. 363).

For both episodes of OCD Nicholas felt 'different' but he felt less different to others when his parents explained to him how common OCD was:

"Yeah I felt a little bit different to other people but [um] when I was told that [um] a lot of other people have it then [um] yeah I felt a bit more normal" (pg.18, line no. 477).

Alison found that the lack of understanding from her learning support teacher led to her feeling alone. She alluded to the view that having lived experience of OCD leads to better understanding and can lead to better help:

"But obviously she doesn't understand it right. She's not trained in it. No one is trained in OCD because no one actually knows what it is like" (pg.18, line no. 487).

Bradley, like Alison, also felt alone as the professional that was helping him did not experience OCD, and although could understand the theory of OCD they did not understand the feeling of it. A lot of participants, like Bradley, recommended that young people with OCD should connect with each other, through support groups or on the Internet, in order to feel less alone:

"It was slightly isolating I think because it was me. You know, although it helped I felt like well I'm on my own doing these things and that wasn't. I think it may have helped if, you know, I think talking to other people that actually have OCD because it's hard talking to a psychologist that doesn't actually have it because although they sort of understand. They don't. They understand but they don't know what it feels like. It's hard to take advice from someone that doesn't know what you're going through. [ha] Yeah. I think if you have OCD and you do need to talk to people there should be like forums or some way to connect or. Yeah or Facebook or something. Some form of community to sort of talk about your compulsions and things you do" (pg.31, line no. 848).

Bella agreed with Bradley that connecting with young people experiencing OCD through clubs or on the Internet would make her feel less alone:

"I think it would be really helpful if they like set up sort of a club or something outside of the therapy sessions where you could just go up and meet or even chat online just to talk, just for like show your own experiences like talk about experiences and know that you're not the only one that has it. And just get to know people and I think that would be a good, good way to, yeah, just sort of feel a bit more relaxed and you'll know that you are not being judged because we all have it like at the place so. So maybe like at a youth centre or somewhere like that or go and meet up and they just hold it may be like once a month or something like that just so like you just, you know, sort of yeah just get to know people and understand it a bit more" (pg.28, line no. 765).

Jade had also noted the lack of support groups for young people experiencing OCD and how she believed that they would make people feel less alone:

“There should definitely be a lot more support groups out there. Support groups I think are great because talking to people that don’t have OCD they might not understand it completely and when you talk to people who have OCD and you explain your thoughts and your compulsions they will understand. They will probably sit there and say they have the same thoughts as you and you probably won’t feel so alone and you won’t feel like you’re a horrible person having these thoughts. You will think I am just a person with OCD” (pg.31, line no. 870).

Like Bradley, Jade also felt that reading leaflets about OCD made her feel less alone. She described how she felt less alone and how this eradicated her appraisal of being a “horrible person”:

“I was just terrified that I was just an awful human being imagining these violent, aggressive images of people and then seeing that other people suffer from that, it’s quite common. I thought, ‘I’m not some horrible person. It’s just normal’” (pg.21, line no. 565).

The following quote is a recommendation from Amy for young people experiencing OCD. She noted how important seeking help is in order to feel less alone:

“I was always told, ‘You are not the only person suffering from this’” (pg.40, line no. 1144).

This subtheme conveys an overwhelming sense of aloneness; negative identity conclusions drawn due to the nature of thoughts; isolating self from others – thoughts as a barrier to connection; longing for connection and feeling understood; and a clear sense that only others with OCD can truly understand.

The battle of living with OCD

This theme ‘The battle of living with OCD’ describes the main cognitive features that affected the participants; namely feeling right and heightened sense of responsibility. The theme also highlights how all encompassing, compelling, and time-consuming it is to live with OCD. Lastly, the theme shows how most of the participants believed that their OCD led them to withdraw from life. The four subthemes ‘Feeling ‘right’’, ‘I was taking on all the responsibility’, ‘It’s ruined everything’, ‘Everyday life is now in my bedroom’ explore the participants’ battle of living with OCD.

Feeling ‘right’

This subtheme encapsulates the emotional search for feeling right that takes over for all the participants. However they can achieve that for a moment by completing their compulsions, but it does not last and soon they have to work for that feeling of rightness again.

Most participants had a special or ‘right’ number that they performed their compulsions to. For example, during his first episode of OCD at 9 years old Nicholas had to perform his compulsions the ‘right’ number of times:

“It was repetitive things. So it was to do with numbers so like looking at things a special amount of times [um] was one of the problems. And like touching things such an amount of times” (pg.5, line no. 56).

When exploring the concept of ‘feeling right’ most participants described compulsions that related to perfectionism. For example, ordering and arranging items in the ‘right’ place or even performing the compulsion correctly. The following quote from Jack describes the latter:

“I wasn’t really able to spend much time relaxing because I had to constantly concentrate on making sure I performed the ritual correctly” (pg.10, line no. 242).

Jade also described the importance of undergoing her compulsions correctly in the ‘right’ way:

“I felt like I had to do it once but sometimes I would tic and accidentally touch it twice and then I had the fear that it would cancel it out. So I always had to do an odd number of times to make sure it was right” (pg.7, line no. 115).

Alison explained that when she was younger she had to have her toys in the ‘right’ place. The repetition of the word ‘specific’ and the fact that she had to keep a drawing of the exact place her toys were positioned highlights her level of distress around this ‘rightness’:

“Well they’d all be in a specific place and they’d be in such a specific, like the place that I want to I’d draw their places” (pg.5, line no. 68).

The specificity of performing compulsions in a certain way is described in the following quote from Bella:

"I couldn't go out without shutting a door in a certain way" (pg.5, line no. 24).

Bradley also described how everything had to be in the 'right' place when he first noticed the signs of his OCD. The word 'everything' emphasises the all-encompassing nature of being 'right':

"Sort of, everything had to be in its right sort of place" (pg.5, line no. 15).

In his quote, Charles also shows the all-encompassing need for objects to be in the 'right' order by also repeating the word 'everything':

"At night time I'd to go through a set routine every night to check. I'd got so used to going through these rooms checking things were in order I would do that. So I might check everything was lined up right. I might check that everything was facing a certain way, things like that it sort of stuck. All the things I'd got in my room. Things like my desk, things say the window sill a few things there, bookshelf. I wanted them lined up. It's not just lined up sometimes it's got to be facing a certain way or everything has got to be at right angles to each other" (pg.4, line no. 18).

Charles used metaphors to explain the 'feeling right' and NJRE:

"Yes I was lining things up 'cos it just feels right just 'cos it. I can't even when I am saying now I don't know how to say it. It's just if I didn't it would seem weird and if you break something you have been doing your whole life, say it's a tradition you do at Christmas or something like that. A tradition you've done all your whole life and you sort of don't do it. You get sort of, [unk] ok sort of odd feeling. I guess it was like that but with loads of little things. Sort of as if you have been doing something your whole life, say you, you always, I don't know, slept with a cuddly toy or something you suddenly didn't have one you'd be a bit, don't know what to do with your arms. You didn't know how to lie. You'd be a bit, feel a bit exposed and sort of like that, that sort of feeling" (pg.16, line no. 395).

Gemma emphasised how the NJRE of being unclean is the most distressing aspect of her OCD:

"And I am although I am doing it, the feeling is still there. And that's what I kind of wanted to work on which was the feeling of feeling like everything is not clean. You know I can, I can easily pick up something someone else has touched quite happily but it's the feeling and the thoughts that are just like, that someone else has touched that" (pg.23, line no. 580).

Like Bradley, Alison described an item which did not feel 'right' and she emphasised how the NJRE angers her:

"I tapped anything and if I walked past and a piece of paper was the wrong way around [swish noise] I'd tap it and put it that way but it would take me ages because it didn't feel or look right. It wasn't right in my head it was like, 'That's not right, that's not right'. But and then it would make me angered because I can't do it right" (pg.6, line no. 99).

These young people shared the sense of not being 'right' and worked hard through their compulsions to achieve a sense of 'right'-ness. However, this was all consuming, taking incredible amounts of time and energy, and even when achieved, did not last. Thus, it could lead to frustration, anger or at times despair. It is interesting to reflect on what does this tell us about things feeling not right for them emotionally, perhaps due to their TLEs/SLEs, and thus these compulsions being attempts to address this sense of wrongness.

"I was taking on all the responsibility"

Half of the participants highlighted a sense of heightened responsibility.

Gemma discussed how she was put in a position of responsibility by deciding who her and her younger siblings would live with two years prior to developing OCD. She explained how this led her to hold a heightened sense of responsibility and to develop OCD:

"I sort of had to grow up before I should have really because at age 12 I was making serious decisions and things like that. And obviously my brother and sister were a lot younger so. Yeah. I had to just be mature because I was speaking to adults and I felt like right I have to be mature about this. So I kind of grew up my brother and

sister were [um] obviously quite young and didn't know what was going on. I was taking on all the responsibility myself and I was taking on the responsibility of everything, every single thing. So it was kind of like I'm responsible for how clean my room is" (pg.27, line no. 719).

Bella witnessed her father's partner pushing her son down the stairs. Her father's partner ended the relationship with her father and her father blamed this on Bella. In this first quote, Bella described how being blamed for the relationship break-up led her to take on a heightened sense of responsibility:

"I think the main point was when he liked blamed me for it afterwards. I feel that that was when it 'cos I just felt so bad and felt so guilty and obviously like, I was cry, I just remember like holding his head and just crying when he was like, 'Why do that? Why that?' And I think that was probably like the biggest thing that. 'Cos I just felt responsible for everything I think but yeah" (pg.12, line no. 239).

In this second quote Bella described how the heightened sense of responsibility drove her to undergo compulsions:

"I like the sense of sort of control that and the feeling that I won't be responsible for what's happened because I've carried out this routine or I've done this" (pg.11, line no. 202).

Jade felt that it was her responsibility to undergo her compulsions in order to keep her family safe and protect them:

"I felt like it was all my responsibility. I felt it was my responsibility to keep everyone safe. And if I didn't do these things bad things would happen" (pg.7, line no. 109).

Similarly to Bradley, Charles also has a heightened sense of responsibility around his own belongings in his own house, which worsens his OCD. His sense of responsibility reduces around other peoples' belongings and this decreases his OCD:

"At school when I am with friends I don't think about it. I use the back of my mind so my OCD is a lot less and I feel it's not my territory. I don't need to make it perfect. It's someone else's responsibility sort of thinking in the back of my mind. At home when it was just me and just close family living here and me, my room I felt in

the back of my mind it's sort of like my responsibility to make sure it's all in the right place. I thought, 'I'm doing it for them'. I thought the fact that if I check stuff then my brother or mum wouldn't have to check their rooms because I already have, things like that. And I thought the zombie would go for me because I'm the most scared of them and it wouldn't go for everyone else" (pg.8, line no. 149).

In this subtheme it was shown that SLEs that puts the young person in a position of a heightened sense of responsibility contributed to their OCD behaviours. The participants seem to connect physical and emotional or relational responsibility.

"It's ruined everything"

All participants described how their OCD impacted on their everyday activities due to its all-encompassing, compelling, and time-consuming nature. Most participants used a war metaphor to highlight how living with OCD was a 'battle' that they had to 'fight', 'conquer', and 'combat'.

Gemma highlighted how her OCD impacted her school work and holidays due to the time-consuming nature of her hand washing compulsions:

"I was washing my hands nearly sort of 20 times a day. So I was quite into my studies and school was a big thing for me and that kind of dropped back. And we noticed my grades were going slightly. Going on holiday is so stressful when it shouldn't be. It's meant to be a time of relaxing and having fun" (pg.6, line no. 31).

Like Gemma, Alison discussed how the OCD had impacted school and holidays. She used the word 'ruined' repeatedly to emphasise the extent of the impact. The following quote also highlights the compelling nature of OCD:

"It just ruined it. It still does. It's like. It's like someone's talking to me. Like all I remember I used to hear voices in my head like when I was little and now I think about it back to it now like I actually had, I did have voices in my head but like the voice isn't there like telling me to do stuff and I don't do it: "You're gonna have it, like you're gonna die, you're gonna" No it's like, like it takes over my life because I was scared to go to school and it ruined holidays" (pg.8, line no. 151).

The most frequently described area of the participants' lives that the OCD negatively impacted was school.

Tobias noted how his OCD had a negative impact on his school work:

"*Probably like in school work, things take, took me much longer because I would scribble words out like three times sometimes and write them. So kinda behind on work sort of" (pg.8, line no. 163).*

Similarly to Tobias, Bradley also explained how OCD negatively impacted his education:

"If I was writing something I would go over it a few times, sometimes so some of my writing is like really scruffy and I think I lost marks" (pg.19, line no. 479).

The following quote also shows how OCD negatively impacted Jade's school work:

"Looking at the computer gave me a headache because I was constantly trying to align the corners with the lines. So I couldn't do any of my work. It impacted quite a bit because as I said with the lines I couldn't really look at computers for long periods of time. It would distract me. So I decided to distract myself from that by talking and then if you are talking in class you are not working but when I was working I couldn't really work anyway" (pg.10, line no. 212).

In the following quote, Charles highlighted the compelling nature of OCD and how it distracts him from his school work:

"I'll say the routine of lining up or just plain habits you could say things like folding corners of paper. I still feel like a really strong urge to do it. You know, like you might fold a page to be like a book mark or something. I'd want to do that for almost every page I see and [um] even sometimes my school work I'd end up folding down the corner and it's getting quite an issue. It's sort of, but if I don't do it it's really bugging me. It's right in the front of my mind. It's sort of like that, 'Fold this corner'. So that corner is folded, that one isn't it's a bit unsymmetrical and I feel like I've got to, you know, sort of distracting, can be a bit distracting" (pg.9, line no. 182).

Gemma described how she had to stop pleasurable activities due to her OCD. She used the word 'ruined' to highlight the extent that OCD impacted her activities:

"It stopped me doing things which was a big indicator that it was a big thing. I stopped going swimming, not down to my local swimming pool because I know other

people had been swimming there. [um] I've recently just quit football because I can't, I can't do it because, you know, you play in the rain, you get muddy, you know, you have to wear your kit. You get hot. You get sweaty. So I've stopped that. Obviously I didn't want to go out. I don't have sleep-overs anymore. I wouldn't really want to do anything like going to a restaurant. I touched a sticky spoon and the whole evening was ruined for me because I just sat there" (pg.7, line no. 81).

Bella repeatedly used the word 'can't' to emphasise how her OCD has led her to stop certain activities:

"I can't just go in my wardrobe and wear whatever I want. I can't just turn on a channel. I can't listen to a certain song whenever I want to. I can't wear some socks. Like it does control a lot of my life that I can't go to some places that I know I'll never going back to and it does, it does yeah control a lot what I do sort of thing" (pg.9, line no. 130).

The following quote shows how compelling Jack's OCD was when he sacrificed his own safety due to the need to undergo his compulsions:

"And at one point I was even washing my hands through a fire alarm which was not the best thing. It was not the best. My hands used to bleed" (pg.4, line no. 59).

Alison described the time-consuming nature of OCD by emphasising the amount of times she had to undergo her compulsion:

"There used to be a crack in our floor. I used to stand there tap it over 30 like. I sometimes I'd do it 100 times" (pg.4, line no. 24).

Jack also highlighted how time-consuming his OCD was when he discussed how much time he had lost due to carrying out his compulsions:

"Well we did actually calculate that I lost 2 months of washing my hands a year. At one point there were times when I would spend literally sixty minutes washing my hands" (pg.9, line no. 198).

Alison used the war metaphor of OCD being a battle to live with when she described how she felt when she was diagnosed:

"Sad that's what made me cry because I thought to myself, 'Oh my god this is a battle now'" (pg.22, line no. 606).

Gemma also used the war metaphor when she provided a message to young people experiencing OCD:

"I would probably tell them that, 'Yes you've got it. It doesn't mean your life is over. It is a struggle and it will be a constant battle but if you are willing to go through it when you come out of it you'll feel so happy with yourself'" (pg.29, line no. 761).

Like Gemma, Charles used language of war, such as the use of the word 'combat', 'external enemy' and 'fighting', when providing a message to young people experiencing OCD:

"It's not the items that need to be moved. It's me that needs to move the items, you know. It's things like that. It's not them telling me what to do. It's, I am arguing with myself. I am not trying to combat a sort of external enemy. You know, [ha] it's me and that sort of made sense that, you know, people say that the brain is muscle and you can control it and stuff. I think I've realised I'm still fighting myself and that means I can win 'cos it's me" (pg.36, line no. 1058).

The participants' use of war language really captures the battle of living with OCD. This subtheme shows the all-encompassing, compelling, and time-consuming nature of OCD as well as the impact of the OCD on all areas of these young people's lives and the restrictions it places on them.

"Everyday life is now in my bedroom"

Most participants described how they withdrew from family members and peers and wanted to be by themselves in their bedrooms. The main reasons for withdrawing were due to contamination fears around others, the bedroom being a safe place, fears of acting on violent thoughts, fears of not being able to carry out one's compulsions, and wanting to close their eyes and block out their obsessions and compulsions.

In the following quote, Gemma noted how she isolated herself as her contamination fears were strongest around other people:

“I started to not want to hug mum or dad [um] even people just sitting right next to me like in class. If they were to turn around and talk to me I would not meanfully but I would sort of move away because I don’t like people at the proximity. It’s things like that. [um] Yeah so that definitely increased a lot and I kind of just isolated myself” (pg.8, line no. 92).

Similarly to Gemma, Amy described how she started to withdraw as her contamination fears were strongest being out and about amongst people:

“I suppose I sort of avoided going out with friends ‘cos I didn’t want to go out like where everyone would be touching doors and that” (pg.12, line no. 235).

Gemma described how she felt happier alone in her bedroom as she could control it:

“If I was alone in my bedroom I’m in a nice happy, clean place. Everything is mine. I know that no one else has come in here and touched everything” (pg.8, line no. 109).

Tobias noted how he felt safer alone in his bedroom and that he withdrew from other people due to his fears of acting on violent thoughts:

“Well I like for ages I just wanted to stay in my room because kind of felt safer sort of. Well because I didn’t want to like do anything because I was scared of doing like bad things like violent things or anything like because of the OCD. So I didn’t want to like put anyone at risk or. I just wanted to stay by myself” (pg.5, line no. 96).

The following quote from Jade shows how she isolated herself because of the fear she would not be able to complete her compulsions in the outside world:

“I couldn’t walk into a room without drawing curtains ‘cos I just wanted to be completely shut off from everyone. [um] I just felt like I couldn’t go outside because if I went outside and there was no wood around for me to touch. I just became completely isolated” (pg.8, line no. 137).

Like Jade, Bella also started to withdraw due to the fear that she could not complete her compulsions outside her home:

“It does stop me going places like it was. There was a certain period where I didn’t actually want to go out. Like I was just like so, so worried that I wasn’t going to

be able to complete a routine and stuff like that and it, like I did, just didn't want to leave the house" (pg.10, line no. 187).

The last quote shows how Jade had to physically move herself to her bedroom and close her eyes and try and sleep in order to manage her OCD:

"And [um] there was one time where my friends invited me into town after college I just couldn't stop making the lines in my mind of pavement until I felt ill and I just had to go home. And whenever I came home I would just shut myself in my room and just close my eyes and try to sleep. I didn't want to look at anything because I was scared that I would keep on seeing these images in my mind" (pg.11, line no. 235).

This subtheme powerfully captures the isolation these young people experience and the different drives for withdrawing.

Ambivalent relationship to help

The theme 'Ambivalent relationship to help' describes the internal conflict that most participants had over the importance of engaging in the help and fighting the OCD but it being easier to give in to the OCD and not engage in the help. Lastly, most participants felt the long waiting time for help was frustrating and led them to an ambivalent relationship to help before therapy even commenced. The theme is fully explored by the following three subthemes: 'Conflicts of exposure therapy', 'Conflicts about accommodation of the OCD', 'and 'Frustrations of long waiting lists'.

Conflicts of exposure therapy

Most participants had the conflict of wanting to resist undergoing the exposure therapy but knew this was unhelpful in the long-term. Most participants wanted their psychologists or members of their systems to guide them through the ERP in a gradual way outside of the therapy room. This conflicting experience led to ambivalence in relation to therapy at times.

The conflict of knowing ERP will be beneficial but ensuring it is delivered in a graded way due to it being anxiety-provoking was captured by Amy:

"But the way they were trying to do it I didn't find helpful like they were trying to get me to touch the bottom of my shoe and that. And then I had one session with the

counsellor but he licked the bottom of his shoe and like I didn't go back after that" (pg.29, line no. 775).

The internal conflict of not wanting to undergo the exposure tasks but knowing one should was described by Charles:

"Well it, I doesn't really combat what I was trying not to combat but I guess that is actually helpful. Short term it was unhelpful because it sort of increased fear. It made me sort of try and not go with the flow, sort of go against the flow which is always sort of risky. [um] Obviously long term this was a benefit not a disadvantage. In short term it was, it was tricky and it made me sort of more tired and things like that because I was often awake and there was something over there not lined up and I'd sort of be lying in bed looking at it. It's like, 'It's there and I can't go'. And you tell myself, 'Don't get out of bed.' And part of me is going, 'Do get out of bed' and there is almost sort of like, 'Yeah a good sleep it'll be fine'. But in reality unless you do that it's internal conflict" (pg.26, line no. 717).

Even though Charles experienced an internal conflict of not wanting to undergo the exposure tasks, he talked about how helpful it was when his mother guided the ERP:

"Yes sometimes she would take something that I always used to line up and leave it in her room overnight. Yes 'cos she did directly intervene which was helpful 'cos sometimes she almost forced me to stop by taking something out of the room" (pg.34, line no. 963).

Like Charles, Jack also felt that the exposure therapy was uncomfortable but he experienced a conflict as it helped when he was guided and rewarded by his parents:

"Well from experience I've learnt that exposure therapy works but it is not the most. It is rather uncomfortable. And though it may take a while it, it does work. I found a reward system for fighting the OCD very effective" (pg.39, line no. 1179).

In the following quote Gemma highlighted the extent to which she resisted the ERP due to finding it too stressful, which shows her ambivalent relationship to help:

"I then started to not want to go to CAMHS because the exposure tasks were too much and It's like going to somewhere that makes you miserable. You don't want

to go there. So it kind of resulted in me being like, 'I think I want to take a break'" (pg.18, line no. 425).

However, the conflict over exposure therapy is highlighted when Gemma wanted more support outside of the therapy room:

"I watched a TV programme. It was two episodes called 'OCD Camp' and I was very jealous by watching that because although these people had it a bit worse than I did [um] they actually were better after going to the OCD camp. So I thought, you know, I kind of got my hopes up that maybe there was something I could do like that like go to a camp and get sorted. Because after watching these two episodes they, they were 17 to 23 age range and [um] they went on expeditions and they got right to the point about their OCD and when they left they all left better than when they went. And I thought that maybe if they did something like that I would try and get on to a programme like that" (pg.23, line no. 589).

Alison highlighted the conflict of resisting the exposure therapy due to it being too difficult but also wanting to engage in it but needing more support and thus leading to an ambivalent relationship to help. Like Gemma, she recommended that more support should be given outside of the therapy room in her everyday life. For example, she discussed how it would be helpful if her mother and teacher could guide the exposure therapy:

"I don't like it when they give me experiments to do 'cos it is like. If I had someone with me 24/7 that like, like, say you went into like a camp for like a week and you have someone following you a whole week. I suppose that would be better because they would be following me. Because they give me experiments and expect me to go home and I'm going to be on my own again it's like, no. It's a bit like prison if you go into prison you are going to be good because you are being watched. But as soon as you go out of prison no one is watching you. And you're like, "Oh I'm free". Show me I can do it but because I can't get myself to do it it's not going to be helpful. I need someone to watch me when I am. Yeah I need mum to watch me. Or someone anyone and teachers. I need someone in class with me. Yeah. We don't. It's just you are taking us into a room all the time and get. It's like we are having a meeting. Of

course we are not going to listen, we are children. We want to do something maybe take us somewhere so that we, so you can see how we are or maybe come to our houses or take us to somewhere" (pg.19, line no. 515).

Bella also suggested how one needs more support from others outside of the therapy room even though there is the conflict that exposure therapy in her "normal surroundings" is more difficult:

"Or like it may be even at home sometimes like because I feel like in a therapy room it's a bit different but when you are actually at your home and you are with your like normal surroundings it's a lot more difficult because it's your things not sort of theirs" (pg.20, line no. 485).

In this subtheme, participants conveyed a conflict as although all of the participants felt that they wanted to resist the ERP, they felt that it would be helpful in the long term. Thus, this suggests an ambivalent relationship to help. They discussed the need for more support from psychologists, teachers and parents in guiding them through the exposure therapy in a graded manner in their everyday lives.

Conflicts about accommodation of the OCD

In this subtheme most participants wanted people in their systems to accommodate their OCD but knew in the long-term this was unhelpful. This conflicting experience led to ambivalence in relation to gaining help.

In the first quote, Bella described the conflict of wanting her mother to accommodate her OCD. However, the second quote shows that Bella also believed that her mother should gain guidance on managing the accommodation from the therapist:

"Like 'cos sometimes I've asked my mum to like, 'Hand me a black cardigan. I can't touch that would you be able to touch that?' And I think if she said, 'No'. Then I don't know, I think I'd just start crying 'cos I'd get so like upset and I would get worried" (pg.27, line no. 711).

"I think so definitely 'cos obviously my mum didn't really know much about it and obviously she was trying to give me advice and obviously she didn't really understand what I was doing and why I was doing it. And I think definitely if they were

a lot more sort of, if they had a better relationship as well I think it would be a lot better sort of thing" (pg.27, line no. 722).

Jade discussed how her friends and family try and accommodate her OCD but she highlighted the conflict by explaining how this is unhelpful in the long-term even if easier in the short-term:

"One of my friends offered [um] because I was really anxious and nearly started crying when I couldn't touch the wood. And she went, 'Do you want me to touch it for you?' And I was like, 'Well that's not going to help me get better. I'm just living out my compulsions through you that way'. But yeah a couple of my friends and family have gone, 'Do you want me to do it for you and just watch me do it?' I think it's nice of them to offer and they think they are helping but I think, 'No'. Because then I'll still be carrying out compulsions just through someone else. Whenever something stressful happens I'll just be going to other people going, 'Oh will you do it for me?'" (pg.23, line no. 624)

Amy highlighted the conflict of appreciating her family accommodating the OCD but knowing that this is unhelpful in the long-term:

"Well normally I'm with my parents and my family so they will do it or I will use like my clothing. No they just like, they know that I won't touch them so they'll sort of just touch it for me 'cos they will be there at the same time. My mum always carries a [um] like an anti-bac hand gel so if I don't have one my mum's always got one. Not in the long term probably but in the short term it's nice to know that there is something there that she can help me." (pg.37, line no. 1047).

From the first quote Jack described how he felt angered when his father did not accommodate his OCD:

"That was basically when he would stop me going in the kitchen to wash my hands. And I would just, you know, tried to shove him out the way and yell at him and scream at him and stuff" (pg.17, line no. 479).

However, later in the interview, Jack discusses how he found it helpful that his parents did not accommodate his OCD. Thus, highlighting his inner conflict and how he has shifted his belief about accommodation of his OCD with the benefit of hindsight:

“My parents were also absolutely huge support during the course of my going better. If I wanted to wash my hands and it was not a good reason to they would stop me and. [breath intake] Well there were just so many ways and [sigh] I don’t really don’t know if I can thank them enough” (pg.25, line no. 736).

This subtheme shows the conflict for the participants over wanting members of their system to accommodate their OCD but knowing that this is unhelpful in the long-term. From this subtheme, one can recognise the challenge for and ambivalence in the parents, family and friends. This challenge and ambivalence for members of the young person’s system may be driven by the desire to alleviate the distress for the young person.

Frustrations of long waiting lists

Most participants discussed how they experienced long waiting lists for CAMHS input and how this delayed getting help. This led to an ambivalent relationship to help seeking due to the young people wanting therapy but feeling frustrated and annoyed at the long waiting lists.

Bradley had to wait 1.5 years for his first therapy session at CAMHS. Bradley also highlighted how it would be helpful if the CAMHS professional could give an approximation of the waiting time:

“Well he said, ‘Oh we’ll get back to you at some point’. Which wasn’t for a year and a half, which was frustrating” (pg. 27, line no. 737).

Bella’s OCD behaviours worsened whilst on the long waiting list. Bella discussed how it took her one year to get an assessment at CAMHS. She also explained how she got lost on the system and consequently waited for therapy at CAMHS for 2 years 2 months:

“So obviously my mum got in contact and said that she, I did want help and then it was. Yeah about two, about two years after that that my mum called up and said, ‘Oh we are still waiting for help like we, you know we haven’t received any calls or emails or anything. And then they said that they had lost me on the system and then it took a couple of months obviously to get me back on the system. And then I got it but the wait was annoying” (pg.16, line no. 361).

This subtheme shows how most of the participants were frustrated over the long waiting lists for CAMHS input. Consequently, this led the young people to have an ambivalent relationship to help at the point when their motivation for change should be at the highest.

CHAPTER FOUR: DISCUSSION

An overview of the findings will be discussed, in the context of the research questions, with reference to theories and prior research. It is usual within TA for new and unexpected themes to emerge during the research process and as a result some of the literature presented below has been introduced to reflect this (Braun & Clarke, 2006). Implications for clinical practice will be discussed, strengths and limitations of the present study will be outlined, suggestions for future research will be considered, and the process of research is reflected upon.

Overview of findings

The overall aims of the present study were to discuss how young people made sense of contextual factors/triggers for their OCD as well as the help they sought.

Four themes emerged from the data: ‘Traumatic and stressful life events’, ‘Responses to signs of OCD’, ‘The battle of living with OCD’, and ‘Ambivalent relationship to help’.

Traumatic and stressful life events

The theme ‘Traumatic and stressful life events’ comprised of three subthemes: ‘Hostility in the family’, ‘Illness and death’, ‘Bullying and friendlessness’. 9 of the 10 participants experienced at least one of these SLEs/TLEs immediately preceding the development of OCD. The researcher is not suggesting a direct ‘causal link’ between TLEs/SLEs and the development of OCD but is highlighting that OCD is a possible outcome of the young person experiencing SLEs/TLEs.

There was a sense of rejection often from fathers and friends. 6 of the 10 participants experienced either bullying or difficulties making friends just prior to the onset of their OCD commonly during the transition to a new school. 3 participants experienced serious illness (in family members or themselves) and deaths (family & teacher) just before the onset started.

Responses to signs of OCD

The theme ‘Responses to signs of OCD’ comprised of four subthemes: ‘Lack of understanding of the behaviour’, ‘Being secretive’, ‘I thought I was going crazy’, ‘Feeling different’. These subthemes describe the combination of reasons for the delay in seeking help for OCD. The period of delay varied from 3 months to 8 years.

Participants felt they or others lacked understanding of their behaviour. Most participants’ parents thought their OCD behaviours were childhood quirks and would pass without treatment. Once participants did seek help, most participants believed that their GP did not fully understand their behaviour, did not take it seriously, and therefore did not diagnose it or refer for psychological help. Most participants believed that school did not understand their OCD behaviour, often mistaking it for misbehaving. Lastly, all participants felt that the general public did not understand the nature of OCD and perceived it in a stereotypical way, which did not acknowledge the seriousness of their distress.

All participants displayed elements of being secretive about their OCD amongst family members and peers. The interviews found two main reasons for being secretive about their OCD behaviours. Firstly, the young people coped with the ‘badness’ or ‘horribleness’ of their thoughts and/or the ‘weirdness’ of having such thoughts by keeping them a secret. The second reason for the secrecy is due to the anticipated stigma and shame around having a mental health ‘disorder’.

Most participants feared they were going “crazy”. They appreciated the diagnosis of OCD as it confirmed that they were not ‘crazy’, but were frustrated by people’s lack of understanding of the personal meanings of OCD.

All the participants felt ‘different’ and alone when experiencing OCD. It is important to note that even when in relationship with those trying to help them they did not feel understood. There was a sense of longing to be understood by someone who knows what it is like from the inside. This led the participants to appreciate any intervention that connected them to others with similar experiences (e.g., reading a leaflet/book they could relate to, or wishing for support groups for young people).

The battle of living with OCD

The four subthemes ‘Feeling ‘right’’, ‘I was taking on all the responsibility’, ‘It’s ruined everything’, ‘Everyday life is now in my bedroom’ comprised the theme ‘The battle of living with OCD’.

Most participants seem to be undergoing compulsions connected to perfectionism or constantly searching for that emotional feeling of things ‘feeling right’.

Some participants were placed in a position of responsibility when they were younger due to SLE/TLEs. They described how this led them to hold a heightened sense of responsibility and in their experience this contributed to developing OCD.

All participants described how their OCD impacted on their everyday activities, particularly their school work, due to its all-encompassing, compelling, and time-consuming nature.

Most participants described how they withdrew from family members and peers and wanted to be by themselves in their bedrooms. The main reasons for withdrawing were due to contamination fears, the bedroom being a safe place that could be controlled, fears of acting on violent thoughts, fears of not being able to carry out one’s compulsions, and lastly because they wanted to close their eyes and block out their obsessions/compulsions.

Ambivalent relationship to help

The last theme ‘Ambivalent relationship to help’ comprises three subthemes: ‘Conflicts of exposure therapy’, ‘Conflicts about accommodation of the OCD’, and ‘Frustrations of long waiting lists’.

Most participants had the conflict of wanting to resist undergoing ERP, but knew this was unhelpful in the long-term. Most participants wanted their psychologists or members of their systems to guide them through the exposure therapy in a gradual way outside of the therapy room.

Most participants wanted people in their systems to accommodate their OCD but knew in the long-term this was unhelpful. This conflicting experience led to ambivalence in relation to gaining help. In the experience of the young people, there was a challenge for and ambivalence in the parents, family and friends, which appears to be driven by the desire to alleviate the distress for the young person.

Lastly, most participants discussed how they experienced long waiting lists for CAMHS input and how this delayed getting help.

The current findings in relation to theoretical issues and research

Findings in relation to attachment theory and trauma

The present study found that the onset of OCD occurred immediately after the participants experienced a SLE/TLE. This is consistent with the clinical and research literature that shows that the development of OCD often occurs in the period following or during a SLE, such as ‘hostility in the family’ and ‘illness and death’ (Rachman & Hodgson, 1980; Marks, 1987). Studies have found a significantly elevated rate of “negative life events” reported in the 6 months (Khanna et al., 1988) or one year (Gothelf et al., 2004) prior to onset of children in an outpatient setting.

A SLE/TLE that was experienced by a number of the participants in the present study was illness in self or others. This was also found in two studies examining SLEs experienced by children with OCD (Gothelf et al., 2004; Cromer et al., 2007)

A SLE/TLE that was experienced by many participants in the present study was being bullied or finding it difficult to make friends just prior to the development of OCD. This finding adds to limited research of the impact on negative relationships with peers and the onset of OCD. This result of the present study fits with the findings of a study by Storch et al. (2006). 52 controls, 52 young people with Type 1 diabetes and 52 young people diagnosed with OCD were compared. Greater rates of peer victimization was found in the young people with OCD. Both the present study and the study by Storch et al. (2006) recognise the magnitude of the problem and contribution problematic peer relations may play in young people with OCD.

Storch et al. (2006) note how there are a number of reasons to hypothesise that peer victimization may be a frequent experience in the lives of young people with OCD. First, many rituals and avoidance behaviours are observable to peers. For example, like some of the participants in the present study, children might leave the classroom frequently during the school day to wash their hands or might rewrite assignments during class. The nature of some children’s OCD symptoms, like some of the participants in the present study, might cause them to avoid classmates because of fear of contamination. As other children are unlikely to understand the nature of these behaviours, like some of the participants in the present study, children with OCD may be rejected by peers. As is the case with some of the participants in the present study, children with OCD may have a smaller network of friends because they miss out on pleasurable activities due to OCD such as playing football due to the fear of getting muddy and being ‘contaminated’. Finally, like some participants in the present study, many children with OCD have co-morbid diagnoses (e.g., poor social skills in Asperger’s Syndrome and tics in Tourette’s Syndrome) and this may be another factor leading them to be bullied.

The present study found that most participants felt ‘different’ and did not fit in with peer groups. This fits with the subordinate theme of ‘Wanting to be normal and fit in’ that was constructed in the qualitative study conducted by Murphy and Perera-Delcourt (2012).

The results of the present study found that some participants showed intolerance of uncertainty, particularly when transitioning to a new school/college. To the researcher’s knowledge, the findings centring on the difficulties around transitioning to new schools is new in the field of OCD. Intolerance of uncertainty can be defined as being unable to tolerate uncertain, unpredictable or ambiguous situations (OCCWG, 1997; Tolin, Abramowitz, Brigidi, & Foa, 2003).

The present study shows the importance of environmental factors and their contribution to the development of OCD. This fits with the current developments in the position of clinical psychology and critical psychology. For example, Boyle (2011) notes the importance of de-medicalizing misery, by highlighting the impact of people’s context, such as SLEs/TLEs, as major causes, not just consequences, of emotional distress. She recommends both clinical psychology and psychiatry to give prominence to people’s context in their theory, research and practice.

All the participants in the present study wished there to be an emphasis on their individual meanings of OCD as opposed to the general public’s stereotypical view of having a diagnosis of OCD. This fits with the DCP’s Core Purpose and Philosophy of the Profession document (Division of Clinical Psychology, 2001), emphasising the importance of a rich formulation, positioning the client in context and focusing on their life events and individual meanings, and from there to develop a treatment plan. However, most formulations are generally individualistic even though psychological difficulties arise in a social context (Johnstone, 2002). Harper and Moss (2003) view formulations as ‘thick’ and rich descriptions rather than the superficial ‘thin’ descriptions which diagnosis offers.

It is interesting to look at the current findings through the lens of attachment theory (Bowlby, 1969, 1973). It seems that there was a sense of rejection during SLEs/TLEs such as hostility in the family, bullying or difficulties making friends. The data in the present study found an emergent theme that the young people felt uncontained by their attachment figures during the SLEs/TLEs. Doron and Kyrios (2005) proposed that compulsions might be carried out because the child has learned to rely on their own behaviour to cope, rather than to seek the support of their attachment figures, which would mirror the avoidant stance described by Ainsworth, Blehar, Waters, and Wall (1978). These experiences may have led the young people to develop IWMs of feeling unwanted due to being unprotected as some of their attachment figures were emotionally unavailable. Guidano and Liotti (1983) argued that a perception of the world as being threatening but controllable translates into active attempts to control the environment in order to make it feel more ‘right’ in individuals experiencing OCD.

Some participants in the present study described a sense of rejection or distant attachment manifested and exemplified by their fathers and a close attachment to their mothers. This result fits with the findings of a study conducted by Alonso et al. (2004), whereby children with OCD perceived higher rejection from their fathers. This also fits with Freud’s (1909, 1955) famous analysis of the Rat Man. Freud (1909, 1955) referred to the role of a conflict between feelings of love and hate directed towards the father, followed by a strong repression of this hate out of love for the father.

Research in relation to the lack of understanding of the behaviour, the secrecy of OCD, feeling different, and the fear of going crazy

Due to the lack of qualitative research exploring the lived experience of OCD in young people, the findings under the theme of ‘Responses to signs of OCD’ add a novel contribution to the literature. However, as can be seen below, the researcher has found that the subthemes have emerged from qualitative research exploring the lived experience of adults with OCD.

The subtheme of the present study, ‘Lack of understanding of the behaviour’ and specifically the stereotypical view of OCD that all the participants discussed were found in a qualitative study conducted by Fennell and Liberato (2007). In their study, the 27 adult participants with OCD discussed the lack of understanding of OCD by the general public and how it is referred to as a “joke condition” and thus not realising the severity of the condition. Fennell and Liberato (2007) emphasise the need for more public information on the lived experience of OCD.

Like all of the participants in the present study, in an auto-ethnography, Brooks (2011) described how she secretly performed her compulsions within the safety of her own home. Like all the participants in the present study, Brooks (2011) discussed how she maintained a public persona while suffering a kind of private torment due to her fears that public knowledge of her compulsions would lead to stigmatization. Brooks (2011) noted how people experiencing OCD put on a healthy front but are slaves to their compulsions. This is because people who deviate from expected social performances face the spoiling of their identity (Goffman, 1963). People choose “to display or not display” (Goffman, 1963, p.42) certain personal characteristics based on their fear of being stigmatized in their communities. People experiencing OCD do indeed hide both obsessions and compulsions for such societal purposes as maintaining relationships (Grayson, 2003).

Along with the concern about stigmatization, most of the participants in the present study discussed how a strong sense of personal shame and feeling ‘different’ functioned to keep their OCD behaviour secret. This was also discussed by Brooks (2011) as she described how she kept her OCD a secret due to the stigma tied to being “different”.

The sense of feeling different and wanting to connect with other people experiencing OCD was discussed by most of the participants in the present study. This finding was also found by Fennell and Liberato (2007), who noted that connecting with others who have OCD gave participants a sense of shared identity. They discussed how it provides those with OCD with information and resources, which can help them resist stigma. Goffman (1963) talked about ‘‘in-group alignments’’, which refers to people connecting with each other due to sharing similar experiences. For example, people experiencing OCD may then seek to be ‘normal’ in comparison to others, to be like and identify with others who have OCD. As discussed previously, in their qualitative study, Murphy and Perera-Delcourt (2012) discovered a subordinate theme of

‘Wanting to be normal and fit in’. They also found that participants felt relief through identifying with others who had OCD. This allowed them to appease themselves and begin to ‘normalise’ the experience of OCD.

Most of the participants in the present study felt a relief when they were diagnosed with OCD as it meant for them that they were not “crazy”. This was also described by participants in the study by Fennell and Liberato (2007). However, as previously described, the participants in the present study experienced the diagnosis is misunderstood by society and viewed in a stereotypical way, which does not take into account the individual meanings of the experience.

The present study found that most participants often went to significant lengths to hide their behaviour from others, and suffered a long time before seeking help. In their study, Belloch, del Valle, Morillo, Carrió, and Cabedo (2009) explored the issues involved in the help-seeking process among people with OCD. The results showed a mean length of delay in seeking treatment was 39.38 months for 26 people with OCD. The main barriers to the help-seeking were the fears of stigma and the meaning of the thought contents. These two barriers were described by most participants in the present study.

Research in relation to responsibility, feeling ‘right’, impact of OCD and withdrawing from others

Two of the six categories of the OCCWG (1997) emerged as subthemes in the present study; namely inflated sense of responsibility and perfectionism.

There have been few attempts to explore these categories in clinical groups of young people. Libby et al. (2004) conducted a study where they compared young people aged between 11-18 years with OCD, young people with other types of anxiety diagnoses and a non-clinical group on three questionnaire measures of cognitive appraisals. These were inflated responsibility, thought-action fusion, and perfectionism. It was found that the young people with OCD had significantly higher scores on the three types of cognitive appraisals. The results showed that inflated responsibility was the only significant predictor of OCD.

Some of the participants in the present study described how they were placed in a position of responsibility when they were younger and how they felt this contributed to the development of OCD. This result fits with the research conducted by Salkovskis et al. (1999) and their proposal of a pathway of having heightened responsibility as a child and then developing OCD.

The results of the present study showed how some participants described the need to feel ‘right’. This is consistent with the study conducted by Ravid, Franklin, Khanna, Storch and Coles (2014) which assessed NJREs in an unselected sample of adolescents (ages 14-17). Findings from questionnaires completed on the Internet were consistent with previous findings in adults, 81% of adolescents endorsed recently having a NJRE.

Most of the participants in the present study described how their OCD negatively affected their education. This was also found in a study by Toro et al. (1992) which examined the clinical records of 72 young people aged 5-18 years with a diagnosis of OCD. Only 15% of children experiencing OCD did averagely at school. Approximately 60% showed a decrease in school performance during the OCD episode.

Withdrawal from family and friends was common amongst the participants in the present study. This finding is consistent with the study conducted by Toro et al. (1992) as they also found that there was a tendency for withdrawal, which was more frequent among children experiencing OCD.

Research in relation to help for OCD

A theme of ‘Ambivalent relationship to help’ was found in the present study. This theme was also discovered in the study by Murphy and Perera-Delcourt (2012) as they found that while participants valued a diagnosis of OCD, there was ambivalence about ‘letting go’ of OCD behaviours. They found that CBT simultaneously produced a push-pull tension – participants were relieved that there is a treatment in the form of CBT but conversely, their security, familiarity and attachment to OCD becomes problematic if threatened. They noted that we should be aware of such ambivalence towards treatment; otherwise we would continue to classify OCD using a flat medical categorization that will be further reified through the therapeutic intervention itself.

Most participants in the present study described how they wanted more support from others, such as parents, in guiding the ERP outside of the therapy room. Studies have found that parents guiding ERP is helpful. For example, Knox, et al. (1996) investigated the contribution of parents to the individual CBT of four children diagnosed with OCD. The results showed that the parent component was an important and potentially necessary part of the treatment. Specifically, ERP alone resulted in little or no change in the frequency of compulsions (with one child's increasing markedly), whilst ERP applied by the parents saw eventual improvements in all four children. Waters et al. (2001) also found the effectiveness of family members being involved in guiding the ERP in a treatment comprising components on education, parental participation in childhood relaxation training, reduction of accommodation, parental anxiety management, family support of ERP and problem solving skills training. The treatment led to considerable benefits for 6 of the 7 children at post-test (CYBOCS reduced from a mean of 22.1 to 9.0) and for all at 3-month follow-up (average CYBOCS was 6.9).

The results of the present study found that family accommodation occurs in the rituals of the participants, which is consistent with current research (Calvocoressi et al., 1995). The family members' ambivalent relationship to family accommodation of the young person's OCD was also found in the present study. Waters and Barrett (2000) noted how family members hold an ambivalent relationship to family accommodation due to parents' willingness to sacrifice in order to avoid children's anger or distress.

The findings of the present study showed how most of the participants were frustrated with the long waiting times for CAMHS. Feedback from clients and their families is increasingly being seen as essential to the assessment of service provision quality, in addition to being a central feature of NHS policy and service development, as highlighted by the Care Quality Commission (CQC) (Department of Health, 2004, 2009; CQC, 2009). The CQC has collated information obtained from the past five mental health National Patient Surveys, using results to identify areas for improvement (CQC, 2008). However, these surveys have focused on working age adults and therefore the feedback of the experience of young people using CAMHS has not been systematically collected. Thus, the participants' frustrations of the long waiting times have not been recognised.

The long waiting times that were described by the participants in the present study can be argued to be caused by the lack of CAMHS budget. Young Minds (http://www.youngminds.org.uk/about/our_campaigns/cuts_to_camhs_services) asked all ‘top tier’ local authorities in England via the Freedom of Information what their CAMHS budget was for 2010/2011, 2011/2012 and 2012/2013. Data was received from 51 of these authorities. 34 out of 51 (two-thirds) local authorities in England have reduced their CAMHS budget since 2010. One council reported to Young Minds a drop of 41% in their CAMHS budget from 2010.

Harper (2015) shared his concern about the impact that government ‘austerity’ policies are having on the lives of those who use mental health services. He stated how there are a series of reports that have demonstrated clear links between economic policies and mental health (Marmot, 2010; Wilkinson & Pickett, 2009). Despite this evidence, he noted how he feels that the policies of the major political parties are largely aimed at reducing public expenditure rather than addressing the widely acknowledged causes of the 2008 financial crisis – poor regulation of the financial sector and an unbalanced economy – or finding alternative ways of raising revenue. This political landscape has had a negative impact on the personal and local level for young people experiencing OCD and may have contributed to the long waiting times for CAMHS input.

Implications for clinical practice

Introduction

The implications for clinical practice will be considered under three headings:

1. individual therapy,
2. involvement of the family, school and peers,
3. wider organizational /service-structure and society.

Ideas for individual therapy

Given the significant finding of the prevalence of SLEs in the lives of the young people who participated in the present study a focus on a rich formulation at the beginning of treatment seems imperative. The formulation should explore the lived experience of the individual in the context of their life events. Individual meanings of the young person’s experience of OCD should also be explored. This will allow for a more personalised and potentially more meaningful intervention for young people.

The lack of understanding that their behaviour was signs of OCD, sense of secrecy, fear of going ‘crazy’, and feeling different seems to have delayed accessing help for the participants in the present study. Therefore, it would be helpful to make resources on OCD more available and advertise them more widely. For example, it would be important to complete the OCD section on the Healthtalkonline website, in order to help young people understand their behaviour and show how common their symptoms are. This may help young people to access appropriate treatment sooner and reduce shame.

The sense of difference and shame was evident across the accounts of participants and impacted on trusting others and engaging in treatment. Given the tendency for young people with OCD to conceal their thoughts and behaviours, the impact of their engagement and ‘sharing their secret’ must be more fully considered and the potential for young people to explore this in therapy may be useful. Therapists’ sensitivity to this could allow for a stage of ‘talking about talking’, allowing the fears about sharing secrets to be addressed gradually for the young person, building to where they feel more able to talk about their thoughts.

Once in treatment, it could be helpful for clinicians to tell young people that obsessive thoughts are occasionally experienced by almost everybody in order to reduce their fear of going “crazy” and feeling different.

Distinguishing between behaviours motivated to prevent a feared consequence and those motivated by reducing a NJRE may have important implications for treatment. Moreover, specifically designing exposure exercises with the goal of eliciting a NJRE may improve outcomes.

Given the findings in the present study that indicate how OCD leads to a shrinking in the worlds of young people and a withdrawal from social activities, it might be necessary to help children re-engage in the social world that they both overtly and more subtly avoid due to OCD. This might include helping children to discover interests that they want to pursue (e.g. joining a sports team) and developing the skills to establish and maintain friendships with children.

Given the link found in the present study between transitioning to a new school/college and the development of OCD, CAMHS clinicians should consider implementing group therapy for young people experiencing anxiety before/during the transition. This group could focus on decreasing anxiety, improving self-confidence/the ability to cope on their own, and improve the ability to tolerate uncertainty in the school context. It is hoped that that an improvement in these areas would have a positive impact on preventing or reducing OCD.

A key finding of the present study was young people's wish to be connected to others who also experience OCD. Thus, interventions that help connect young people with OCD should be given priority. For example, support groups for young people experiencing OCD could be formed. There is a real lack of OCD support groups being delivered in CAMHS and the two leading OCD Charities in the UK are not delivering support groups specifically for young people.

There does appear to be discussion forums on the Internet on the OCD-UK website (http://www.ocdforums.org/;http://www.ocdforums.org/index.php?s=9016dea142098c1f396a951cb94e99cb&showforum=6) and OCD Action website (http://www.ocdaction.org.uk/forum; http://ocdyouth.org/groups/support/). However, the discussion forums specifically for young people are being underused. Additionally, the immediacy of electronic communication may also pose a problem, particularly if a quick response to a person's experience is posted without time for reflection (McLellan, 1998). Furthermore, this critique of Internet forums leads us to understand the value of the Healthtalkonline website. An increased administration of books (i.e. Wells, 2006) and leaflets (i.e. http://www.ocduk.org/young-peoples-ocd-guide) that show other young peoples' experiences of OCD could also be implemented, as the participants in the current study indicated that they found these very useful. These interventions could prevent young people with OCD feeling different, alone in their experiences and worried that they may be going "crazy".

In summary, when working with individuals in clinical practice, clinicians should focus on a rich formulation and the therapeutic relationship. Clinicians should distinguish the drives for undergoing compulsions for the individual they are working with (e.g., either obsessions about catastrophes or NJREs). More groups for young people who are transitioning to a new school could be implemented. Lastly, the implementation of more interventions (e.g., support groups, books, leaflets) that connect young people who experience OCD would be helpful.

Ideas for involvement of the family, school and peers

A systemic approach to treatment is highlighted as potentially useful by participants in the present study, and it could be argued that this should be routinely offered to young people and their families. For example, clinicians and families could help guide the ERP in a graded manner in the young person's every day settings outside of the therapy room. Families should also be included in the therapy for the young person in order to receive psycho-education on the negative impact of accommodation of the OCD.

Participants in the present study indicated that their teachers did not understand OCD. Thus, training/teaching sessions tailored to a particular child with OCD, as part of a treatment plan, could be implemented by clinicians in schools in order to help teachers understand OCD and how to respond to it. Clinicians could provide consultation to teachers in order to guide them through the ERP and explain the negative impact of accommodation of OCD. There appears to be a need for increased identification and intervention for bullying in settings such as schools to decrease its impact and therefore training and consultation could be provided to all members of staff in schools.

It seems important that emotional wellbeing lessons, including a session on OCD, should be implemented across all schools for children in order to reduce shame and stigma.

To summarise, a systemic approach to working with OCD in young people should be implemented. For example, clinicians and families could work together in the young person's every day setting in order to guide ERP. Psycho-education on the negative impact of accommodation of OCD could also be provided to the young person's family. Further work could be carried out in the young person's school. For example, clinicians could provide consultation to teachers regarding OCD, ERP, accommodation, and bullying. Finally, psycho-education on OCD could be provided to peers in their class in order to reduce shame and prevent bullying.

Ideas for wider organizational /service-structure and society

There seems to be a lack of awareness/understanding about OCD in the general population. It seems that others assume one reality of what OCD is, based on the diagnosis, which results in a stereotypical view of the condition. Common language of OCD does not convey the seriousness of the condition. However, the present study showed that there are multiple truths based on different personal meanings of OCD. Thus, there is a need to implement active policies based on these different personal meanings and disseminate knowledge about the different signs of the condition. For example, posters could be disseminated in schools and GP surgeries as a public health awareness raising project.

An increase in public health campaigns on OCD could also be implemented in order to decrease stigma. Disseminated on television at appropriate times for when young people would be watching, radio stations and social media could be considered. 'Time to Change' has a section on OCD for young people on their website (http://www.time-to-change.org.uk/category/blog/ocd). However, this could be extended and disseminated across different mediums.

Once the OCD section on the Healthtalkonline website is completed, it should be used to educate peers, families, health care professionals, commissioners to mental health services, and the general public by providing multiple meanings and experiences of OCD as opposed to the one stereotypical view.

OCD-Action has run an OCD Youth project since 2014, which is managed by a group of volunteers, under the age of 25 years, who experience OCD. The panel of volunteers work together with The Maudsley Hospital in order to form information leaflets on OCD for young people and their parents. User-generated blogs and personal stories are shared on the website. The panel of volunteers also organise two events per year to offer a space for young people experiencing OCD to connect with each other through different pleasurable activities. However, due to the lack of funding for each area to have a volunteer facilitator, there are no support groups for young people. A patient participation group, set up like OCD Youth, comprised of young people experiencing OCD could be implemented in CAMHS, whereby they could collaboratively work with the CAMHS clinicians to disseminate information and ensure support groups are delivered.

It can be argued that the current political landscape has had a negative impact on the funding for CAMHS and affected waiting times and potentially the quality of care received by young people experiencing OCD. It is encouraged that clinicians have a responsibility both as professionals and as citizens to speak out against cuts to public services and to advocate for fairer economic and social policies to improve public mental health for young people.

In summary, the dissemination of information on the signs of OCD through different mediums and public health campaigns could be implemented in order to increase understanding of OCD and reduce stigma. Patient participation groups run by young people experiencing OCD could be set up in CAMHS in order for young people and clinicians to work collaboratively to shape interventions and produce information leaflets. Lastly, clinicians have a responsibility to speak out about cuts to the funding of CAMHS and advocate for fairer policies to improve mental health for young people.

The strength/limitations of the present study as well as suggestions for future research will be discussed next.

Strengths of the study

An important strength of the present study is that it adds qualitative understanding to the field of OCD. To the researcher's knowledge, the present study is the first qualitative study exploring the lived experience of OCD in young people.

Another strength of the study was that the researcher followed criteria for evaluating TA, which added to the quality of the research (Yardley, 2000, 2008). Specifically, Yardley (2000) proposed that the researcher is firstly sensitive to context. Therefore, the researcher in the present study conducted a relevant literature review and gained participants' perspectives. Secondly, Yardley (2000) notes the importance of rigour in the analysis of data. Therefore, in the present study the coding was checked by the two research supervisors and peer-reviewed by a clinical psychologist. Additionally, the transcripts were checked by the participants. Yardley (2008) notes that this ensures that the analysis is not confined to one perspective, and makes sense to other people. Thirdly, Yardley (2000) highlights the importance of transparency in the presentation of the analysis and data presentation. The present study achieved transparency by detailing the process of data analysis and presenting relevant quotes. Additionally, the researcher showed reflexivity in the write-up and used a reflective diary and included extracts of it. Lastly, Yardley (2000) stated that the research should be evaluated on its impact and importance. The present study has made clear the practical clinical implications for the community, policy makers, and health workers.

A strength of the present study is that there is an equal distribution of males and females that were interviewed. The participants were of different class backgrounds and were interviewed at different times since their diagnosis which adds to the richness and meaningfulness of the findings.

A key strength of the present study is that participants presented with a primary presenting problem of OCD and a co-morbid secondary presenting problem. This is a strength as it is a representative sample due to the high co-morbidity rates connected with OCD.

The balance between deductive and inductive coding is another strength of the present study.

Lastly, the use of service-user involvement is a key strength of the present study.

Limitations of the study

Qualitative studies of the type reported here can be criticised for their focus on narratives provided by a small sample of participants. The themes that were identified from the present study may not be transferable to the broader OCD population (Harper & Thompson, 2012).

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

It could be argued that a limitation of the study was that the participants were/had been involved in psychological therapy. This is because this could have had a potential impact on the data. For example, the participants may have avoided sharing information with the researcher due to fears that the researcher knew their clinicians. Additionally, the participants may have been socialised to specific jargon and language from psychological therapy, which may have affected the way they described their experiences, which may have been different to the way they would have described them prior to commencing psychological therapy.

Participants in the study were predominantly White British (with the exception of a Brazilian participant) in ethnic origin which limits the representativeness of the findings to other ethnic groups.

Suggestions for future research

An important feature of Healthtalkonline is that each of the projects comprise of approximately 30-50 narrative interviews. Therefore, future research will be carried out in order to gain at least an additional 20 participants and a large enough sample for the interviews to be uploaded on the website. Work would then need to be carried out in order to promote the website to health care professionals (particularly those that diagnose OCD and could signpost the young people to the website), young people, and families. The present study has shown that there is often a delay in the young person seeking help for OCD due to feeling “different” or thinking that they are “going crazy”. Thus, having access to interviews of young people with OCD may allow them to feel that they are not alone and access treatment more quickly. Therefore, the present study could result in a direct intervention for young people experiencing OCD.

Future research could be conducted on comparing the length of time before accessing formal psychological therapy after either viewing the OCD section on Healthtalkonline or not. This would evaluate the efficacy of the Healthtalkonline OCD section for potentially reducing the delay in help seeking for young people with a diagnosis of OCD.

Qualitative research could also be conducted with young people with a diagnosis of OCD and who have accessed the Healthtalkonline website for OCD to assess the impact on the themes developed in the present study.

At moments the data hinted at the participants witnessing attachment figures upset after the SLE and worrying about them, not turning to attachment figures for support perhaps playing a function to protect them. The data hinted that the attachment figure was (emotionally) absent, perhaps due to coping and being pre-occupied with the SLE. It seems that the participants were emotionally coping by themselves and not being contained by their attachment figure. Future qualitative research should explicitly focus on the mechanism and processes, such as support and containment of attachment figures and the responsibility being with the young people to work through their distress from the SLE, and developing OCD. This could be conducted by interviewing both the young person and their parent.

Future qualitative research could also focus on the implications of one's own identity after being bullied and developing OCD. For example, it may be that the young people may feel a sense of rejection or 'being wrong' and consequently develop OCD in order to 'feel right'.

Future research exploring compassion-focused treatment for OCD experienced by young people could be conducted due to the shame and self-stigmatisation that was found in most of the participants in the present study.

The researcher aims to disseminate the findings across as many settings as possible, such as CAMHS, conferences, and also OCD-UK and OCD Action Charities. Research could be conducted to evaluate impact/effectiveness of the recommendations outlined in the present study.

Reflection

Throughout this research I have been committed to spending time reflecting on the process, using a journal and using discussion with supervisors. Reviewing the journal confirmed my experience of feeling inspired and excited throughout the research process.

Conducting a thorough review of the literature and using the reflective diary to record my assumptions enabled me the distance to be more objective.

The participants' experiences increased my belief that a systemic view is important, and that one should consider the child in context, and how their psychological difficulties were influenced and/or maintained by their system, as opposed to being an internal deficit located within the child.

I was struck by the frequency with which the young people referred to their peer group and the associated difficulties of managing such relationships whilst coping with OCD. Specifically, this arose from managing feelings of difference and shame. When the subtheme of ‘Lack of understanding of the behaviour’ emerged, I felt even more connected to the young people as I could relate to their frustrations, having insider knowledge, about how OCD is talked about in everyday common language.

By listening to the views of participants and how they kept the secret of having OCD, I was able to consider how I may improve my practice as a clinician. In future I shall be more mindful of the anxiety that young people face when coming to see a clinician for the first time and the requirement for them to build up trust with you. As a clinician, I think it is easy to become desensitised to how anxiety provoking it must be to discuss your innermost personal concerns with a stranger. The interviews and reflecting upon my childhood experiences have led me to consider more fully young peoples’ fears of disclosing their secret of OCD, sharing their personal thoughts, and building trust in me as their SLEs/TLEs may have involved being threatened, rejected, or losing a member in their system.

My epistemological position of critical realism has only been secured further from conducting the research. From listening to the interviews, my belief has been strengthened that OCD is not an internal deficit fixed within a ‘pathological’ individual that defines them, but is influenced by environmental factors and life experiences. Consequently, I feel even more strongly that formulation is key in clinical practice in order to reflect on the rich lived experience of the individual.

CHAPTER FIVE: CONCLUSION

This present study has shown that SLEs/TLEs involving danger and loss, such as hostility in families/peers and deaths/illness in self and others may be important environmental factors in the development of OCD for young people. The young people and members of their system responded to their OCD behaviours in different ways, which may have contributed to the delay in seeking help. It seemed that their behaviour was misunderstood by themselves, parents, GPs, peers and schools. The sense of shame was striking amongst all of the young people, whereby they kept their OCD a secret due to them feeling "crazy" and different. The battle of fighting the OCD was shown through the young peoples' search for an emotional feeling of things 'feeling right' or to alleviate a sense of responsibility. The all-encompassing, compelling, and time-consuming nature of OCD led the young people to withdraw into their bedroom as a way of blocking out the obsessions and compulsions. Most of the young people experienced an inner conflict of fighting the OCD through exposure therapy and not letting their loved ones accommodate it or just giving in to the OCD. Therefore this inner conflict, as well as the long waiting times for CAMHS, led the young people to experience an ambivalent relationship to help.

These findings are significant for clinical work. For example, skills in building a therapeutic relationship is important particularly in helping the young people unveil the secrecy of their OCD. A focus on a rich formulation is imperative and should explore the lived experience of the individual in the context of their life events. It was clear that the participants were frustrated by the dominant (and misunderstood) discourse describing a diagnosis of OCD. Lastly, a systemic approach to the help for young people experiencing OCD has been emphasised. For example, guidance of ERP and psycho-education on the negative effect of accommodation should be provided to families and teachers.

Final Reflections

I will end with a quote from Joe Wells, who was an expert by experience consultant to the present study, from his book that he wrote about his experiences of OCD when he was an adolescent. I feel that the quote captures a powerful message that by letting go of the secret condition of OCD, young people can share their experiences with each other, feel connected and accepted:

“OCD’s effectiveness relies on its secrecy, so think of it as a secret organisation – as soon as everyone knows where members meet and what they do, it’s no longer the secret organisation it used to be” (Wells, 2006, p.103).

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APPENDICES

Appendix 1: Extracts from reflexive journal

It was interesting to reflect on how the two subthemes of 'feeling right' and 'I was taking on all the responsibility' connected with one another. For example, it seemed that the participants found it difficult when things did not feel right for them emotionally, perhaps due to their TLEs and SLEs and thus these compulsions being attempts to address this sense of wrongness. It also seemed that they felt a heightened sense of responsibility to undergo the compulsions, perhaps as some participants were placed in a role of responsibility during the TLEs/SLEs.

Initially the process of conducting an interview as a researcher felt in conflict to my role as a trainee clinical psychologist and I found myself wanting to reflect on issues raised and to provide support for the young person. I learned to be more comfortable in my role as a researcher and to enable myself to have a different relationship with the young people, one in which they were providing potentially useful insights to guide clinical practice. I felt the need to jump in and rescue less after conducting more interviews. This is an important skill for my role as a clinical psychologist in working with clients in the therapy room. I found that by providing the participants with an opportunity to share their opinions and trusting in their ability to do so, I was rewarded with unique insights and it enabled me to grow in my own confidence in interviewing skills.

I found myself enthused by listening to the experiences of the young people and the potential for change to a person’s life by working with them at an early age in order for them to lead fulfilling lives in their adolescence and adulthood. This experience concreted my decision about the passion I have for working with young people and also their families and I have now accepted a qualified post working with children and families.

Appendix 2: A Table showing reoccurrence of themes across the participants

Themes	Subthemes	Alison	Gemma	Tobias	Bradley	Nicholas	Bella	Amy	Charles	Jack	Jade
Traumatic and stressful life events	Hostility in the family	✓	✓		✓		✓				
	Illness and death			✓	✓			✓			✓
	Bullying and friendlessness	✓				✓	✓	✓		✓	✓
Responses to signs of OCD	Lack of understanding of the behaviour	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Being secretive	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	“I thought I was going crazy”	✓	✓	✓	✓					✓	✓
	Feeling different	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
The battle of living with OCD	Feeling ‘right’	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	“I was taking on all the responsibility”		✓		✓		✓		✓		✓
	“It’s ruined everything”	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	“Everyday life is now in my bedroom”	✓	✓	✓		✓	✓	✓		✓	✓
Ambivalent relationship to help	Conflicts of exposure therapy	✓	✓	✓	✓		✓	✓	✓	✓	✓
	Conflicts about accommodation of the OCD	✓	✓		✓		✓	✓		✓	✓
	Frustrations of long waiting lists	✓		✓	✓	✓	✓	✓			✓

Appendix 3: An interview transcript

Pseudonym: Bella Date of Interview: 16/12/2014 Date of Transcription: 07/01/2015

Line number	Initial impressions and reflections	Data	First coding	Themes
	7 years old – first noticed signs of OCD. At the time of developing OCD, she was living with her mother for some time and her father for the other as they were separated. Just before she developed OCD she witnessed a traumatic event of his father's partner pushing her son down the stairs. Her father thought that she was making it up. The social services were interviewing her, which increased her stress levels. Her mother asked her father that he			

	could either see his partner or her daughter, to which he chose his partner. However, his partner left him eventually. There seemed to be a sense of her feeling rejected and the loss of an attachment figure. She felt blamed by her father for his breakup of his relationship. There seemed to be a sense of her taking on too much responsibility. At primary school, she was bullied by a particular girl. This stressful life event increased her OCD symptoms a few weeks later. She thought that she could stop being subjected by bullying through carrying out the compulsions.			

	It took a year to get an assessment at CAMHS after the GP saw her – long waiting list – unhelpful. Waiting list of two year for treatment at CAMHS due to being lost on the system – unhelpful. Meaning of OCD symptoms for her– she was not “normal”, “strange” – sense of being different to others. She recommends that psychologists should deliver the ERP outside the therapy room such as at home and using the young people’s belonging. Meaning of the diagnosis of being “weird” and not being “normal” – sense of being different. Her GP did not diagnose OCD – she was made to			

	feel that her difficulties were not real when the GP did not diagnose it – GP limited training in mental health – unhelpful. The psychologist did not provide any explanations for developing OCD – unhelpful. They provided no information or leaflets and she had to conduct her own research – unhelpful. She recommends psychologists to deliver clubs for young people experiencing OCD.			

"Strange" – did she see herself as being different. "I just thought was normal" – her appraisal of herself is not "normal". how did her mother not notice? Was her mother engaged too much with her own marital problems? Did she think it would fade? Worse at her father's house due	**I: So I'd like to hear about how you made sense of OCD. You could start from the point when you first noticed the OCD symptoms if that helps. And I would like you to tell me in as much detail as possible what the symptoms of OCD were like, how you got help, what happened next, what treatment and information you were given and how you feel about it now looking back. And I am particularly interested to know what was going on in your life around the time you developed symptoms of OCD and what helped. I will then ask you more questions to follow up on specific issues.** **So when did you first notice the signs of OCD?** R: Well like for quite a couple of years when I was younger like I just noticed strange things like I kept having to sniff up my hands like to make sure they didn't smell and like before I went to bed I had to do like a routine that I, I just thought was normal. And it wasn't until I was about 6 that I was just telling my mum about it and that I realised that it actually wasn't really normal and that most people in their day-to-day life didn't do the things I did which is obviously then when we went to my GP and sort of asked for help. [laugh] **I: So just talking about the OCD symptoms you noticed. So it's sniffing the hands in case they don't smell** R: Yeah like it was just like quite a lot of things that I couldn't touch things three times. I really didn't like the number 3 so I was constantly touching things like 4 times and [ah] like shutting doors. I couldn't go out without shutting a door in a certain way and it was just sort of. Like it was worse at my dad's than it was at my mum's but like going down the steps, coming out of my room. I'd, like breathing it affected like sort of everything and it wasn't really until **I: Breathing a certain number of times and?**	Sniffing hand compulsions. Routine before bed. It became habitual/normal when younger. Repeated "wasn't really normal" – appraisal of herself as being different from others. She told her mother about it at 6 years old. Touching Shut doors in a certain way. Breathing compulsions Three times – magical thinking. Lucky number of 4. "certain way" – being in an exact order. OCD symptoms being all encompassing.	Feeling different. Right structure. Ruined.

to insecure attachment? Due to the traumatic event? Laughter shows embarrassment – “weird” – appraisal of herself being “weird”. Was she unhappy and had to ensure her happiness herself by undergoing these compulsions? Was the living arrangements too chaotic with “living” with her mother “and then living” with her father every other weekend and on a Wednesday. “I obviously prefer my mum” –	R: [um] Yes sort of I couldn’t breathe out until I was sort of happy. So I’d just like hold my breath and then when I was sort of happy with where I was and like what I was looking at then I could breathe out sort of thing. It was kind a weird [laugh] but yeah no that, that’s what I could sort of. [clicking sound] **I: And how old were you when you first noticed the signs of OCD? [clicking sounds in background]** R: [um] Probably about [pause] six I would say, yeah. **I: Six years old.** R: [uh huh] **I: And what school year were you in then?** R: Oh probably about Year, oh that must have been Year 1 or Year 2, one of the two. [laugh] **I: Ok. And where were you living at the time?** R: [um] Well my mum and dad are separated so I was living [um] on the X with my mum in X and then I was living ‘round the corner with my dad sort of thing. Yeah. **I: Ok. So you were living half the time with your mum and?** R: [um] More of the time with my mum. I lived, I stayed with her [ah] sort of all the time then my dad every other weekend and on a Wednesday. So yeah. **I: Ok. Was anything else happening around the time that you developed these symptoms? You mentioned your parents separated.**	“it affected like sort of everything”. First noticed the signs of OCD at 6. Year 1 or 2 first noticed the signs of OCD. At the time of developing her OCD her parents were separated – living with mother and then father. Knowledge of knowing that her parents never really got on from such a young age. Very conscious about being a bad person – nervous laughter – “That sounds really bad”. Perhaps	Feeling right.

insecure attachment to father. She seemed to feel at threat and perhaps was worried about her safety if the father's partner was at her school play. Sense of feeling unloved by father and rejected – he said she had made up the story.	R: Yeah that was, well my parents never really got on that well and also I'd like. I obviously prefer my mum [laugh] That sounds really bad but like whenever my dad used to put me to bed I'd always want my mum and my mum like always tells me that when I was younger that I'd sort of like ask for them. Like if my mum could move out sort of thing but obviously I didn't realise at the time that they'd actually already split up so in a way like it was quite good. It didn't really affect me that much. But when I was about, oh I think I was about 5 or something my dad was in a relationship with this woman and it was like going quite well in that she'd sometimes stay over and she had a son that was quite a bit older than me. And one night [um] my dad like had done something for the, her son, I don't know what it was. He got him something and he didn't say 'thank you'. So when my dad went in the toilet she went and had a go at her son like saying, 'Why didn't you say thank you? You're not a very polite boy.' And he walked out and she pushed him down the stairs and I witnessed it. [um] And then obviously when I, I got really stressed out I thought she was at the school play and then the school sort of got involved and they were like, 'You ok X?' I was like, 'No I think she is here'. And my dad sort of had no, he just said, 'I was lying and then made it up' and said that I made it up when I hadn't.	separation anxiety and extremely close to mother. Wanting not to be separated from mum when put to bed. She witnessed a traumatic event when she was 5 years olf of her father's ex-partner pushing her son down the stairs, which led to her experiencing stress. Her father said she had made up the story.	SLE/TLE HOSTILITY IN FAMILY SAME TIME AS DEVELOPED OCD – witnessed abuse and blamed and told responsible for father's break-up.
	I: So this woman pushed her son down the stairs?		
	R: Yeah.		
	I: Gosh and you were 5 years old.		
	R: [uh huh] I think yeah, I think yeah I was about that age yeah.		
	I: Ok. And then what happened? Did they stay together or?		
	R: [um] Well my, well obviously social services got involved because obviously I was getting really stressed out about it so they interviewed me and my mum. And they, oh what happened? I think, yeah I think they, my mum got her solicitors involved and asked, like told my dad that it's either her or us. And I think like at first he chose her. So he didn't want us. And then he, and then because she left him he	Stress of being interviewed by social services and solicitors	

Stress of being interviewed by social services and solicitors being involved – position of responsibility perhaps increased the OCD. Something more vulnerable blaming her at night time – her being separated from her close attachment figure (her mother). Almost feeling of being harassed –	then, we then started seeing him again sort of thing. So yeah. But now I should think, I don't. One minute, I can't remember but I think I might have been about 7 actually. Sorry, yeah I don't think I was. 'Cos I remember being in my classroom actually. I think I was about 7, sorry, yeah. [laugh] **I: That's ok. So about 7 years old?** R: Yeah. **I: And you were in school year?** R: I think it was about 3 **I: Three** R: Yeah **I: Ok. And was the pushing of that lady's son down the stairs which you witnessed was that [um] around the time you developed the symptoms of OCD?** R: I think so. It was around that. Yeah obviously I'd had that slight once before but like it, then it. I think it got progressively worse because also due to the fact that when I used to go to my dad's after she left [um] he'd constantly at night be like, 'Why did you do that? Why did you split?' Like he blamed the relationship on me and he would like the fact that they'd split up. And he was like, 'Why did you do that to me?' And like he'd follow me everywhere and just ask me these questions and I just remember like crying and I **I: So your dad did that to you?** R: Yeah.	being involved when she was 7 years old. Father actually rejected her when her mother asked him to choose her daughter or his partner – loss of an attachment figure – "So he didn't want us". Only because her father's partner left him, he started seeing her again. School year 3 – when she witnessed the traumatic event. Developed OCD at the same time of witnessing traumatic event – 7 years old. OCD worsened after her father's ex-partner left him and she started seeing her father again. This is because he blamed her for the relationship break-up. "I got assessed and then obviously it was 2 years until I got actually seen by someone". OCD got	

"And like he'd follow me everywhere and just ask me these questions" – feeling of being blamed and taking on the responsibility for his father's relationship break-up at such a young age.	**I: Ok. And how did your experience of OCD [um] kind of manifest in your life? So yeah how did it impact on your life?** R: [um] Well it kind of got to a stage 'cos obviously we were seeing. I got assessed and then obviously it was 2 years until I got actually seen by someone. So and between that period it got really bad like to the point. And it's still kind of now that bad now like but I can't just go in my wardrobe and wear whatever I want. I can't just turn on a channel. I can't listen to a certain song whenever I want to. I can't wear some socks. Like it is, it does control a lot of my life that I can't go to some places that I know I'll never going back to and it does, it does yeah control a lot what I do sort of thing. But yeah. **I: And were the OCD symptoms or are the OCD symptoms worse? So do they increase in certain places: on your own or with certain people?** R: [ah] With my dad they like when I go around my dad's house they do get like a lot worse. I can definitely feel that yeah it does stress me out [ha] a lot more at my dad's than it does at my mum's but yeah. **I: [um] And so, and how about on your own is it?** R: [um] Yeah I am, yeah I'd say I'm ok on my own. It's just that also like at school it stresses me out a bit because I'm worried that someone is going to notice that I'm doing these things. Like 'cos I hate, I don't like my left hand so that I can't touch anything with my left hand. So if I do I will quickly touch with my right sort of thing. So I'm really worried that people are going to see me and be like, 'Oh what's she doing?' Because it probably looks, someone who doesn't have it, it will look really strange 'cos obviously they don't really understand it. But I think that when I am on my own I feel a lot more comfortable 'cos I know that no one is going to see sort of thing. **I: So do you think the OCD symptoms decrease when you are on your own?**	really bad when on the waiting list. 2 years before got treatment – long waiting list was unhelpful. The lack of help for her OCD led to the worsening of it. Repetition of the word "can't" highlights how OCD restricts her and how much power/control it has over her life – "Like it is, it does control a lot of my life that I can't go to some places that I know I'll never going back to and it does, it does yeah control a lot what I do sort of thing. But yeah" – compelling/all en-compassing. Felling vulnerable/unsafe/bad person/stressed makes her OCD worse – for example at her father's house. "I'm worried that someone is going to notice that I'm doing these things" – keeping OCD hidden/a secret with peers at school. Lack of understanding of OCD from peers.	Long waiting list. Ruined. Secretive. Not understanding. Secretive.

Why does she hide them in front of her mother? Is she protecting her mother? Why did her mother not notice the OCD – was she busy working – due to being a single mother? She had to stay at her nan's house after school as her mother was working.	R: Yeah. **I: And with your mum or not?** R: [um] They sort, they're sort of the same because I try to hide them a bit more so like but then I still sort of have to do them so they don't really get much worse sort of thing but yeah. **I: Ok. And who else noticed the OCD symptoms when you were 7?** R: No one. I don't think no one had noticed them. It wasn't until like me and my mum were having a chat sort of thing and I was just explaining to her, 'Oh it takes me such a long time to get to sleep because I have to do all this like routine'. And she was like, 'Oh I never knew this.' No one really but I must admit though my nan with my hands when I had to sniff my hands she noticed a lot more 'cos I used to go to her house after school every day 'cos my mum had to work. So like she noticed like 'cos obviously I was just constantly like that [sniff] sniffing my hands all the time and she was like, 'Oh why are you doing that?' **I: And that was when you were 7?** R: Yeah. **I: Ok. So your nan and you noticed it really.** C: Yeah. **I: Ok. And so you talked a little bit about the impact on your life how does it or did it negatively impact on your life?** R: [um] Well it like obviously stresses me out all the time like I can't really. I never really feel like I can relax. I am always worrying about or whether I've done that, whether I've done this. [um] It does stop me going places like it was. There was	"Because it probably looks, someone who doesn't have it, it will look really strange 'cos obviously they don't really understand it". More comfortable on her own as she does not have to hide the OCD. "But I think that when I am on my own I feel a lot more comfortable 'cos I know that no one is going to see sort of thing". "No one. I don't think no one had noticed them" – kept OCD well hidden/secretive even in front of family – "It wasn't until like me and my mum were having a chat sort of thing and I was just explaining to her, 'Oh it takes me such a long time to get to sleep because I have to do all this like routine'. And she was like, 'Oh I never knew this.'" Feeling of constant stress and extreme worry. Not being able to relax – "Well it like obviously stresses me	Secretive. Secretive/hidden . Ruined. Withdrawing.

Need for her room to be ordered – is that her place of safety? Her constant place – particularly when she lives part the time with her mother and the other time with her father? Appraisal of being a bad person. Nervous laughter. Did she feel out of control with her parents' separation, moving to lie with each parent, and when she	a certain period where I didn't actually want to go out. Like I was just like so, so worried that I wasn't going to be able to complete a routine and stuff like that and it, like I did, just didn't want to leave the house. [um] I guess it's sort of affects like my friendships and like relationships 'cos I don't really like bringing them back to my house. I'm scared they are going to mess up like my room or anything. Like with siblings as well 'cos obviously I have quite a few and I'm always like worried that they are going to come in. And I think I really do, don't feel ____ I feel like such a horrible person when they come in and take some of my stuff and I'm like, 'Oh can you leave that there'. 'Cos they just want to play with it but it just stresses me out a lot. So I guess, you know, I feel kind of bad [laugh] but. **I: Ok. And how about positively? How does it positively impact on your life?** R: Well like when I follow through with the routines and stuff it does make me feel a little more relaxed afterwards 'cos I know I've done it. I like the sense of sort of control that and the feeling that I won't be responsible for what's happened because I've carried out this routine or I've done this. That's sort of, it does make me feel a little bit better once I've done it sort of thing. **I: Ok. And what did you think the OCD symptoms meant? So maybe initially when you were kind of a young child, you know, from 7 in your childhood** R: Yeah **I: What did you think they symptoms meant?** R: [um] What, what, I don't. Sorry what do you mean like? **I: Yeah**	out all the time like I can't really. I never really feel like I can relax". Feeling of self-doubt difficulty tolerating uncertainty – "I am always worrying about or whether I've done that, whether I've done this". Stopped going to places- impacted on daily activities. "I've done that, whether I've done this. [um] It does stop me going places like it was. There was a certain period where I didn't actually want to go out. Like I was just like so, so worried that I wasn't going to be able to complete a routine and stuff like that and it, like I did, just didn't want to leave the house" – withdrawing from others. Feeling of quite right relaxing her after undergoing the compulsion. "I like the sense of sort of control that and the feeling that I won't be	Ruined. Feeling responsible.

witnessed the traumatic event? Interesting she mentioned aspects of herself being negative as opposed to her environment. ‘Cos I just felt responsible for everything’ – black and white thinking/all or nothing thinking.	R: [laugh] **I: That’s ok. What did it say about you as a person that you had these OCD symptoms?** R: That I was strange, that I wasn’t really normal, that I wasn’t like everyone else. Yeah but I just wasn’t, yeah. **I: Ok.** R: [ha] **I: We talked about the stressful events going on in your life around the time you developed the OCD symptoms. So it sounds like definitely the [um] your father’s ex partner pushing her son down the stairs and you witnessing that caused quite a lot of stress perhaps around the time** R: Yeah **I: you developed OCD** R: Yeah it was, it was that. I think the main point was when he liked blamed me for it afterwards. I feel that that was when it ‘cos I just felt so bad and felt so guilty and obviously like, I was cry, I just remember like holding his head and just crying when he was like, ‘Why do that? Why that?’ And I think that was probably like the biggest thing that. ‘Cos I just felt responsible for everything I think but yeah. **I: [mm] And was there anything else going on maybe around well before that or after that that was, you know, quite stressful?** R: [um] I think rem____ remember I don’t think. I know that my mum had a few miscarriages [um] that obviously I didn’t really like seeing her upset [um] which	responsible for what’s happened because I’ve carried out this routine or I’ve done this” - Feeling of in control Undergoing the compulsions diminishes the feeling of being responsible. Meaning of OCD symptoms at 7 – her being strange, not “normal” and being different to others. She identified it was not even the event that was so stressful but it was her father blaming her and making her feel responsible for his relationship breakup – feeling guilty and feeling like a bad person stressed herthe most. This led to her	Feeling different. Feeling responsible.

Taking on responsibility that her mother was ok after her mother's miscarriages perhaps?	obviously was stressing out and every time of that. I'd say that was quite, they were quite stressful times but yeah. **I: How did that affect your OCD symptoms seeing mum upset?** R: It made them worse. Yeah a bit. **I: And was it around the same time that they were made, they got worse or was it a period after your mum's miscarriages?** R: [um] I'd probably say it wasn't at the time. It was a little bit after when I sort of not registered it but like it sort of [noise] come into play and I was like, 'Oh actually it was a lot worse. 'Cos obviously at the time I was just concentrating on my mum, making sure she was ok. It wasn't until afterwards that I was, it got a lot worse. **I: And you also mentioned your mum was quite upset around, you know, her and her, you know, your father not getting on. Did you witness that or?** R: [um] Not as such no, not really. **I: Ok.** R: No you know, and I, I'd say I was kind of too young to remember anything like. I just, yeah I don't really remember anything like that. **I: So when did they separate? How old were you?** R: I was 4 I think. Yeah I was 4. It was just before I started school. **I: Yeah. Ok. Was there anything else going on in your life around the time of developing OCD at the age of 7?**	taking on inflated responsibility for everything – "'Cos I just felt responsible for everything I think but yeah". Seeing her mother upset (her close attachment figure) due to her miscarriages increased her OCD symptoms a little after. Stressful event of parents separating at 4 just before another stressful event of going to school.	SLE/TLE BULLIED SAME TIME DEVELOPING OCD.

	R: [um] Well throughout my whole period of [um] at primary school I was bullied by [um] one girl in particular. [um] But yeah like it obviously at the time it really stressed me out and obviously it stopped me from doing things that I enjoyed doing and yeah it was, it wasn't very nice but yes that's probably another thing that probably didn't help it but.	Stressful event of being bullied at 7 at the same time of witnessing the traumatic event– disrupted attachment – increased her OCD symptoms.	
	I: And did you notice that [um] increasing the symptoms of OCD?		
	R: Definitely, definitely.		
	I: And was that around the same time or a period after or before?		
	R: [um] Cor I'm not sure. Probably after because I felt like I could stop her bullying me by carrying out these rituals. Like if I did it I'd know there was probably a less likely chance like not that it really made any difference but in my head that's how I felt sort of thing.	Magical thinking – She thought by undergoing compulsions she could stop the bullying. Ego dystonic – knew that it was irrational but had to undergo the compulsion.	
	I: Ok. So how much after did the rituals?		
	R: [um]		
	I: Get worse?		
	R: [pause] It's like so [whisper] probably. Oh I'm not really sure. [um] [laugh]		
	I: Was it weeks or months?		Secretive.
	R: Yeah weeks.		
	I: Ok. So how quickly did you decide you needed to get help [um] after you were, you know after the age of 7 when you developed the symptoms?	Weeks after the bullying she underwent the compulsions.	

	R: Well it wasn’t until quite a while until I sort of realised that everyone else doesn’t do it. I just sort of saw myself, ‘Oh everyone does it. Like it’s ok, don’t worry’. [um] Yeah like I said it wasn’t ‘til I told my mum which was probably two or three years after I’d sort of developed them [um] that I realised that I wasn’t exactly like classified as normal behaviour which is then when I [whistle] went to [laugh] . **I: And so how old were you when you decided, a couple of years did you say?** R: Yes I must have been about 9, 9 or 10 yeah. **I: Right. And what made you decide to get help?** R: Well like that was. When I told my mum it was getting to a point where it was starting to definitely control my life a lot more than I’d, like expected it to. Like at the start it wasn’t really too bad. It was just the odd thing there and the odd thing there, here. Sort of that but yeah that’s when I realised it, it was obviously affecting me, my school life, my work and everything like that. It just, yeah. **I: How did it affect your work?** R: Like school work and stuff with like homework. You know, I wanted to complete it in a certain way or I wouldn’t like. I would just get always stressed out about homework because I wasn’t sure when to do it and like just, just yeah ____ [laugh] there. **I: Ok. And was anyone else involved in the decision to get help?** R: My mum, yeah. **I: So what kind of help did you have?**	OCD became habitual – thought it was what everyone did. Only when she saw herself as different (at around 10) she told her mother about it. “Yeah like I said it wasn’t ‘til I told my mum which was probably two or three years after I’d sort of developed them [um] that I realised that I wasn’t exactly like classified as normal behaviour which is then when I [whistle] went to [laugh]”. Time consuming/compelling/ all encompassing. “Sort of that but yeah that’s when I realised it, it was obviously affecting me, my school life, my work and everything like that. It just, yeah”. At the start the OCD wasn’t too bad but gradually it started to control. OCD making her complete her homework in a “certain” way, which stressed her– alludes to	Right structure. Not understanding.

Relationship between liking the school nurse and the school nurse being good? “wrote off” alluding to the GP not doing their duty to help? Was she not fully trained in mental health to diagnose OCD?	R: [um] So obviously I went to my GP and then I think it took like a couple of months, actually no I think it took longer than that. Oh no actually well at school obviously [um] my mum after she’d asked me I went to the school as well as my GP and the school. I used to have like weekly meetings with the school nurse. And like we’d just talk about it was kind of like therapy sessions in a way. Talk about what was upsetting me that week and sort of how to deal with it. And she was really good and I really liked her and it did, definitely help at the time. And obviously I spoke to my GP about it and she [um] wrote off to get me assessed. And I think it took, think it’s like a year or something before I got assessed. **I: Where was that? Was that in CAMHS or?** R: I don’t, Oh I think it was, I think it was in CAMHS yeah, [um] yeah. **I: And then what kind of help did you have after that?** R: Well I, after I got assessed [um] I think it was a couple of, I think it was just before Christmas. Then at Christmas I got a write up of what they said, I said which wasn’t accurate. [um] And then they said because I hadn’t got in contact with them that they were just going to like leave, [um] like leave me alone and like not do anything about it. So obviously my mum got in contact and said that she, I did want help and then it was. Yeah about two, about two years after that that my mum called up and said, ‘Oh we are still waiting for help like we, you know we haven’t received any calls or emails or anything. And then they said that they had lost me on the system and then it took a couple of months obviously to get me back on the system. And then I got it. **I: And what sort of help did you eventually get?** R: [um] So I saw X [um] on a weekly basis. [um] Sometimes, obviously sometimes we couldn’t do every week so it would be like two weeks or three weeks. [um] And obviously we’d just talk about everything and obviously she’d tried. She	completing tasks in a ‘right’ order. Helpful to have support whilst waiting for the assessment at CAMHS. Helpful support whilst she was being subjected to bullying. Did not get assessed by GP. Long waiting list to get an assessment at CAMHS – one year – unhelpful. “And I think it took, think it’s like a year or something before I got assessed”. The assessment report from CAMHS was not accurate – unhelpful. Miscommunication was unhelpful. 2 years of waiting as CAMHS lost her on the system and they had to wait another two months to get her back on the system.	Long waiting list. Long waiting list.

She never mentioned the support from her father? Did she feel loved by her mother and unloved by her father due to the lack of support?	like would give me the booklets and just try to help me to like overcome all the things that I had to do sort of thing. **I: So she’s a psychologist?** R: I think so yeah. **I: And that’s at CAMHS was it?** R: Yeah **I: Yeah and what form of therapy was that? Can you remember? Was it cognitive, CBT Cognitive Behaviour Therapy or** R: I think so, yeah, I think, yeah I think it was that yeah. **I: And was there any other help that you had like support groups or from friends, parents, websites?** R: [um] I sort of had support from my mum. Obviously she tried to do the best she could. Obviously she didn’t really understand it so she obviously thought like tried to do her best and also my friend like recently. It wasn’t until I told her about three years ago that [um] she has been really supportive. Actually she has always helped me ‘cos she sort of had a few sort of issues that would. She doesn’t like leaving lights on and stuff so sometimes we’d just talk about it and how frustrating it was and it did actually help me to know that it wasn’t just me on my own. Obviously other people have it too but yeah but other than that no. **I: How many sessions of the school nurse? Are you still seeing the school nurse?**	Booklets given during CBT by the psychologist. “Obviously she didn’t really understand it so she obviously thought like tried to do her best”. Lack of awareness of what OCD was and how to manage the OCD by mother. She found support from her friend very helpful since she told her about the OCD a few years ago. She felt “it was helpful “to know that it wasn’t just me on my own” – feeling alone.	Not understanding. Feeling alone. Not understanding.

Did she tell her friend about her OCD as she had OCD too and therefore she didn't feel different. This may be perhaps that her friend had OCD and could understand her. Sense of embarrassment to explain to people (her mother) that do not understand OCD – perhaps would have been helpful if the GP/CAMHS explained to her mother more.	R: Oh no that was in primary school that it like. It was about for a year [um] in my last year of school but yeah no that was really good. [ha] **I: And [um] I suppose what was helpful about the either talking to friends or the CBT or the school therapy sessions with the school nurse, support sessions with the school nurse. What was helpful?** R: [um] Just like being able to talk about it like because obviously it's hard with my mum because obviously, like obviously she sometimes she doesn't understand. She's like, 'Oh X why are you doing that?' And it's hard to explain to her but with people that actually know and sort of understand what it's all about and why we sort of do these things it's a lot easier to sort of explain and not feel so stupid around like. Do you know what I mean? [um] Yeah and it was just like nice and obviously with X obviously she challenged me. And sometimes I did need that like just for that like seriously let's think about this in a like, radical way and like rat, rationalise everything sort of thing. It did actually help me and determine me to like sort of stop. [laugh] But yeah. **I: Was there anything else about the CBT that was helpful?** R: [um] [pause] Other like, I just felt it really helped me like. It gave me more determination to stop like although in a good way it made me feel like I shouldn't be doing it and like it was like, like obviously it helped me a lot and it was in a good way not in a bad way or anything. [um] So obviously like when I'd come home it would be like for the first couple of days I'd be like, stopping like quite a lot of things but then it'd start again sort of the third, fourth, fifth day. So I think like weekly sessions are good but I feel like maybe they should be a bit like closer together because I just don't feel like it's, it's just too long in a way **I: Yeah** R: Although it's only a week it's, it's	She found it unhelpful – "hard" that her mother did not understand why she was undergoing the compulsions – "Just like being able to talk about it like because obviously it's hard with my mum because obviously, like obviously she sometimes she doesn't understand". "not feel so stupid" – sense of embarrassment to explain to people (her mother) that do not understand OCD. "So obviously like when I'd come home it would be like for the first couple of days I'd be like, stopping like quite a lot of things but then it'd start again sort of the third, fourth, fifth day" – compelling OCD. Alluded to how difficult it is to maintain the resisting of compulsions – as the OCD can take control back. Recommendation for psychologists to keep the momentum of	Conflict to exposure therapy.

	I: So what was unhelpful about the treatment? R: [um] I found that the booklets were quite helpful but I don't really think they helped that much. Like although it, you know they come to give you a way you sort of, I don't know like I tried, you know, quickly sort of do it and try and fill it out but I just didn't really find that they really made much of a difference and that. **I: [mm]** R: And it, yeah just, you know, I didn't really find. **I: What else was unhelpful, sorry about the process of getting the treatment or?** R: It took a long time [laugh] definitely like I didn't obviously I didn't expect to take no where near that long. I thought, 'Oh maybe like a month or two but not like 2 years. I, yeah definitely the time that, how long it took to see someone that was, that was **I: Anything else about what's going on with the treatment at the moment or?** R: [um] Well obviously X left and so she said that I, she was going to get someone else to take because she said I needed another 6-week [um] sort of like sessions. [um] But I haven't heard anything back and that was like a couple of months ago so I don't really know when I am going to hear anything from them. **I: Anything else unhelpful about therapy or any of the help that you got?** R: [um] [pause] I guess sometimes it's good like letting it out but I feel that sometimes it needs to be a little bit more because obviously it's ok in like me telling me, telling you, 'Oh yeah I can't do this and I can't do that but like to actually try and. Like there was one time where I did have to like do something that I didn't want	the ERP going by making the sessions close together. The long waiting time was unhelpful. "It took a long time [laugh] definitely like I didn't obviously I didn't expect to take no where near that long. I thought, 'Oh maybe like a month or two but not like 2 years. I, yeah definitely the time that, how long it took to see someone that was, that was". Change of psychologist unhelpful – lack of communication from CAMHS. Sense of uncertainty – unhelpful.	Long waiting list. Long waiting list. Conflict of exposure therapy.

	to do but like that was only sort of once and although that really helped me that one time I think it would be a bit better to do more of that sort of thing than like obviously it is good probably for the first couple of sessions to talk and like to get a bit of understanding but I think like maybe focus more on the sort of, yeah other things. [laugh]	Need for more doing and less talking. Found the in-session behavioural experiment helpful but wanted more of this later in therapy.	
	I: And how would that be done? How should that be done do you think?		
	R: [um] Well just probably that same stuff like me it's touching things with my left hand. So what X did was make me like touch tissue and chuck it away with my left hand so I knew I could never touch it again sort of thing. And just things like that so whatever their problem is so whether they say they need to wash their hands five times whatever. Make them do it three times and then like leave it 5 minutes or whatever, just something like each week maybe like progress.	Recommendation of in-session behavioural experiments each work and gradual progress each week to more difficult experiments.	Conflict with exposure therapy.
	I: And that's in the therapy room?		
	R: Yeah in the, yeah I'd probably say yeah. Or like it may be even at home sometimes like because I feel like in a therapy room it's a bit different but when you are actually at your home and you are with your like normal surroundings it's a lot more difficult because it's your things not sort of theirs. So like if it's my tissue I think it would be a bit different to just using theirs sort of thing but yeah.	"because I feel like in a therapy room it's a bit different but when you are actually at your home and you are with your like normal surroundings it's a lot more difficult because it's your things not sort of theirs".	
Is the therapy room different from her being at her house due to the level of responsibility increasing – as "it's your things not sort of theirs", which makes the behavioural experiment more difficult.	**I: Would the psychologist come into the home or?** R: [um] Yeah I think yeah I think that would probably be a good idea like 'cos I think also you need. I feel like you need to feel closer to them a bit. Well obviously you do feel close to them but I think like a better relationship would definitely help it so even if they do come to your home sometimes. Obviously I know it's harder like if you have sibling if you brought all those in but just at a time maybe. Just like something to just carry out a ritual like that would like try and stop it. I think like once or something would be a good idea.	Recommendation of the psychologist going into the young person's surroundings more – such as their home. "Or like it may be even at home sometimes like	Feeling responsible.

	I: Ok. What information have you used or been given that you found particularly helpful. That could be any information like a self-help book or a leaflet or Internet. R: [um] Like I def, like I definitely find some of the parts of the booklet that she gave me was definitely helpful. Just the fact that it was explaining what OCD was about and like before I researched it on the Internet and just the fact that like I need to stop feeling like responsible for everything which was mainly, was in the booklet sometimes which did sort of help me sort of think about things differently and there was like a pie chart with like responsibilities actually helped me like draw out. So if something goes wrong like how much of the, percentage like is it my fault and how much is it other people's and that definitely did help me sort of see it in a clearer sort of view but yeah. **I: Ok. And where are you now in terms of every day life and OCD?** R: [um] I'd say I have obviously it has got a little bit better but because obviously [um] I've stopped seeing X and now waiting again it's sort of progressively getting worse again. [um] Yeah I still find it difficult just to turn the TV on, to pick out some clothes like. **I: Is that with your left hand or just generally?** R: Generally and with left hand. And like when I go in class if I pick up a pen I have to do it with my right even if I've got stuff in my right. I'll move it to my left. And I think it does still take up a lot of time and effort and it does stress me out a lot. I just feel my head is just crammed full of all this information that I need to remember to do. Like when I do anything really but yeah. **I: Ok. So in terms to get the diagnosis how long did it take again to?**	because I feel like in a therapy room it's a bit different but when you are actually at your home and you are with your like normal surroundings it's a lot more difficult because it's your things not sort of theirs". "I feel like you need to feel closer to them a bit" – alluding to the importance of trust in the relationship, would help with the ERP. Recognising her symptoms of feeling responsible for everything was in the booklet – made her feel that other people felt like this. She linked the lack of therapy and her OCD getting worse "progressively" – sense of it being like a disease slowly getting worse. Sense of feeling not quite right or. "And like when I go in class if I pick up a pen I have to do it with my right	Long waiting list. Ruined. Long waiting list.

	R: [um] Well it took about I'd say like about 6 months before I saw someone and then it took about a couple of months for them to do the write up and then, then it took 2 years to see someone so yeah. **I: But initially it took 6 months to get the diagnosis? And who told you that you had OCD? Was it the GP or?** R: [um] No I think it was, I think it was a child psychologist that told me that I had it 'cos I met two of them. One was doing obviously the, was trying to get me to do the cognitive behavioural therapy and the other one was talking about drugs and how that would help me. And obviously I chose the cognitive behavioural therapy but yeah they sort of said that they think that I had it and [um] that I yeah should go down one of the routes, yeah. **I: Ok, ok. So how old were you then remind me? Sorry** R: That's alright. [um] I must have been about 11 then, 10 or 11 yeah. **I: Ok. And how did you feel about the diagnosis at 11, 10 or 11?** R: Well I'd never, it never really crossed my mind that I had OCD. I'd never heard about it before like all you hear about at school is that, 'Oh you need to clean your hands, you've got OCD'. So to when I got told that I had it there. I just thought, Oh they must, that must be like, they must have made a mistake like I don't have it. That's, I didn't know what it was. [um] So obviously when I found out that I had it and you don't really realise how many, how much people say, 'Oh I have OCD' because you need to go wash your hands. And then like when people say that, you sort of think, 'Well you don't actually know how hard it is'. And it does sort of upset you and it does get you a little bit angry and just like upset and just you think, 'Oh my gosh I must look really stupid if anyone ever actually found out all the rituals I have to go through'. It's not just washing your hands or anything like that but yeah.	even if I've got stuff in my right". OCD is time consuming, effortful, and stressful. Feeling of having no space from the OCD – "And I think it does still take up a lot of time and effort and it does stress me out a lot. I just feel my head is just crammed full of all this information that I need to remember to do. Like when I do anything really but yeah". The GP did not diagnose the OCD and referred her to CAMHS for an assessment, which took a long time to get (6 months) – unhelpful. Diagnosed with OCD by psychologist at 10 or 11. Lack of awareness for children about what OCD is. Alluded to thinking about stereotypes of	Not understanding. Secretive. Feeling different.

Her main appraisal is of herself being “stupid”. Did her father influence this appraisal of herself when he blamed her for the break-up of his relationship?	**I: [mm] So how, how did it say, I suppose what did it say about you as a person that you had this diagnosis?** R: That I was just really weird and I wasn’t normal when that. I was a bit stupid for believing something like that that’s probably not true but in my head it was sort of telling me that it was, that yeah. [laugh] **I: Ok. Were you happy with the way you were told about, that you had OCD?** R: [um] Yeah no I’d say yeah there wasn’t really anything that like upset me or anything ‘cos obviously I guess at the time I just wanted to know what it was and just to like help it get better. ‘Cos obviously it was, really stressed me out at the time. So I wouldn’t really say that how I was told was [mutter] **I: Ok. What was helpful, can you remember what was helpful about the way you were told?** R: [um] [pause] I can’t. I just remember like being in the room and they were just like, ‘Oh we think’. You just like they told me why they thought I had it and like obviously what to go next on to doing. So it wasn’t just that, ‘Oh you have OCD good bye’, sort of thing. It was like, ok to help you we can do this or this and that was quite helpful to know that I, it could be sort of treated. **I: And was anything unhelpful about the way you were told?** R: [um] I don’t think so. No I’d. Well because, actually I remember now. [um] Because before obviously I got told I had OCD obviously I had to do the questionnaire. [um] They called my mum up. They were like, ‘Oh I think your child has OCD. We need to’. Obviously the doctor never told me that they thought that was even in the question sort of thing. And it wasn’t until my mum was, ‘Oh you have OCD’. I think like they should have maybe told me like face-to-face or something but	contamination fears (hand washing) for OCD at school, which upsets and angers her. She feels misunderstood about how serious and hard to live with OCD it is. However, on the other hand she wants to keep the seriousness of OCD hidden from people and not explain her compulsions due to the fear of looking “stupid” Her meaning of having a diagnosis of OCD was that she was weird and not “normal” implying that she was different to others. Wanted to know what the problem was and how to get better. Feeling of being contained and guided by the professionals diagnosing her was important/helpful. Being told out of the blue (as the GP did not	Contradicting views on explanations.

	‘cos my, they called my mum and told my mum that sort of over the phone I think maybe **I: The GP did that?** R: [um] No I think it was, I don’t know who it was but I just remember my mum being like, ‘Oh there’s a lady on the phone she needs you to fill out a questionnaire’ like while we were on the phone. So I didn’t even have, get to fill it out myself. I was just telling my mum things and the woman was writing it down. So yeah. **I: And that was before you met the psychologists.** R: Yeah, yeah that then told me that I had it. **I: So that was unhelpful?** R: Yeah. **I: And the GP what was the GP? Did you have an appointment with the GP?** R: Yeah **I: And they referred you to the child psychologist that diagnosed you.** R: Yeah. **I: So the GP didn’t actually tell you that it was OCD?** R: No, no. **I: And how do you feel about that?**	say anything about OCD) that she might have OCD and being told to do a questionnaire over the telephone was unhelpful. Sense that she did not feel validated by the GP for the GP not	Not understanding.

Alludes to the GP's knowledge about physical health issues but not mental health issues. Did this influence her to feel as though the GP did not believe her? – "it makes you feel like it's not something real". Alternatively, did she feel like she was going mad as he did not mention OCD but she could see the signs of something "not normal".	R: [um] It kind of makes me feel like maybe like it makes you feel like it's not something real because you feel like GPs should know it like quite a lot. If there is a disease they pretty much know about it but to not like sort of see the signs and the symptoms of OCD it makes you do. It does make you feel, 'Oh well obviously it's not normal' because they can see the signs and it would be better if they knew it and they'd be like, 'Oh I think you have this' sort of thing. So you just know in your head, 'Oh it might be that' than just be told sort of over the phone that they think you might have it so. **I: Ok. And the child psychologists, what explanations did they? Oh first of all, sorry what were the reactions of your family that you had this diagnosis?** R: [um] I think they were all pretty surprised like most of them didn't really know that I had anything wrong with me. [um] My mum yeah I think she, yes she was quite surprised. My nan wasn't too much because obviously she knows about the hand sniffing and stuff and my granddad was quite surprised. They all thought that it was obviously a little bit strange for me to have like a mental sort of illness as such but yeah, no they were all really supportive about it though so yeah. **I: Ok. Did any of your friends get to know that you had the diagnosis of OCD?** R: Not at the time. It wasn't until I started seeing X that [um] my mum accidentally let it slip in front of all my friends. And then I sort of explained it to her and then yes, I didn't really tell anyone of my friends at the start. **I: And what explanations did the child psychologists give for you having, developing OCD?** R: I didn't give me any explanations, no. **I: Ok. And how do you feel about that?**	picking up that she had OCD. Alludes to the GP's knowledge about physical health issues but not mental health issues. Alludes to the secrecy of her OCD – "I think they were all pretty surprised like most of them didn't really know that I had anything wrong with me." She kept OCD hidden – did not tell her friends. "I think they were all pretty surprised like most of them didn't really know that I had anything wrong with me". "Not at the time. It wasn't until I started seeing X that [um] my mum accidentally let it slip in front of all my friends. And then I sort of explained it to her and then yes, I didn't really tell anyone of my friends at the start".	Secretive. Contradicting views on explanations. Contradicting views on explanations.

What couldn't she cope with? Her father blaming her for his relationship break up? Her parents being separated? Living with each	R: [ah] I think it would have been nice because obviously it wasn't until I saw X that she sort of helped me understand. Because I never really understood why I had it like why all these thoughts were going around in my head and it wasn't until I saw X and she sort of, she worked it out and she told me that I realised. I think it would have been a lot easier if I found out earlier on because now I have a better understanding a bit it helps me a lot more when I try to conquer it because obviously before I was like I don't know why I am having these thoughts. I don't know how to stop it. Whereas now I know it's a lot easier to think, 'Right X', you know, 'It's not this. It's not'. Do you know, yeah so. **I: Ok. So we are coming towards the end of the interview so a few questions about messages for other people. And I was wondering what your messages would be for other people based on your experiences so maybe young people who have OCD at the moment.** R: [uh huh] **I: What would your messages be for them?** R: Just to like you don't have to feel like you are the only one. There's lots of people with it and you don't have to feel stupid. You don't, you're not abnormal you're just someone that just like can't really just cope with some things that others can. And I think that if, you know, if you're feeling like on a good day you feel like, 'Oh maybe I could try something'. Just try it for 5 minutes maybe_. Although it doesn't seem a long time the actual trying not do a ritual or not do something that you'd usually do just that just sort of makes you feel a bit better and it does help you to sort of conquer it in the end I think. Yeah. **I: And how about messages for parents or families of young people living with OCD?** R: Like try not to judge them too quickly and don't think that they are weird and stop like if, don't call them something like a freak or anything just because they have	The professionals diagnosing the OCD did not give explanations for the development of it. Knowing about the development at diagnosis stage would have been beneficial as it would helped her "conquer" it. Use of language alludes to a type of battle with OCD of how compelling it was. "Just to like you don't have to feel like you are the only one. There's lots of people with it and you don't have to feel stupid". The first message that she felt was important is that young people are not on their own and therefore they should not feel "stupid" – highlights her own sense of feeling alone and feeling like a stupid person and "abnormal".	Feeling alone. Conflict of exposure therapy. Conflict of exposure therapy.

parent? Witnessing the abuse? The bullying? Seeing her mother upset with her miscarriages? – how about the psychologist training the parents in terms of when and how to react to their	to carry it out in front of you. And I think telling them to stop it is actually really aggravating because you can't. Like if because I know that a couple of times my parents I've done a ritual and they are like, 'Why, just stop it X you don't have to do that'. And it just sort of makes me feel like even more stupid but and I just think, yeah if you could just sort of let them get on with it sort of thing. Just like be there to comfort them if they, if they ask for your help or they, you know, ask your support but I think give it to them but just try not to get too involved 'cos it's kind of embarrassing [laugh] but yeah. **I: What could they do to help then?** R: [um] I think just definitely just be there for them and make sure that they know that if they can talk to anyone they can talk to you and just like, yeah just try and give them as much help but like not in that sort of way. It's possible just,' But are you ok? Having a good day?' Like, 'Is there anything you want me to do or do you want me to help you with anything?' Just stuff like that, just yeah not get too involved. [laugh] **I: Not involved in actually helping the young people do the ritual or telling them to stop it or both?** R: To tell them to stop it. Like 'cos sometimes I've asked my mum to like, 'Hand me a black cardigan. I can't touch that would you be able to touch that?' And I think if she said, 'No'. Then I don't know, I think I'd just start crying 'cos I'd get so like upset and I would get worried. So I think like if they do ask you to help them with a ritual then I think you should do it but like if you're. I think sort of leave it to the psychologists to try and help them to stop it like because I don't really. 'Cos obviously they I don't know like as much about it as they probably should if they are like giving you sort of advice like that sort of thing. **I: So do you think they need more. The families need to work with the psychologist to get more advice?**	Repetition of the word "conquer" – alluding to ERP is similar to a battle. OCD is so compelling. It seems that she is very conscious of being a "weird" person for having OCD. It seems that she thinks that parents/families should be educated to know how to react to their child's compulsions. Additionally, she alludes to them not getting too involved as she found it embarrassing. It seems that she would cry/get upset/and be worried if her mother did not accommodate the compulsions. She advises to leave it up to the psychologists to deliver the ERP as parents "don't know like as much about it as they probably should" . She recommends that families need to work	Conflict about accommodation. Not understanding. Not understanding.

child's compulsions?	R: [uh huh] I think so definitely 'cos obviously my mum didn't really know much about it and obviously she was trying to give me advice and obviously she didn't really understand what I was doing and why I was doing it. And I think definitely if they were a lot more sort of, if they had a better relationship as well I think it would be a lot better sort of thing. Yeah. **I: Ok. And messages for the general public. What would your messages be for the general public about OCD?** R: Like don't judge too quickly. I think you should find out things. And it's not just because you need to wash your hands like that you have OCD it's a lot more serious than that and yeah just yeah. [laugh] **I: [mm] And how about messages for people that diagnose OCD. So this could be GPs, this could be clinical psychologists, this could be psychiatrists.** R: [um] I feel like definitely when you are explaining it probably give them a reason if you can like just try and find out any reason why it could be caught like why, what's caused the OCD and try and give them as much detail and information as they can. Also like give them a lot of information about the OCD because when I found out I had OCD at the time I had to do all my own research. I didn't know anything about OCD. I didn't really know what it was. [um] So I think if you can just explain that to them. Just give them like a brief explanation even if like at that just what it is, sort of why we, like why you think people have it and then yeah just going through with the treatments and explain like how it can be helped because just being told you have something is actually really scary and if you explain to them, 'Oh you have this but we can help you by doing this or doing that'. I think it is a lot re, like a lot of reassurance to the person. Yeah. **I: And how about messages for clinical psychologists or therapists that deliver the therapy?**	with the psychologist to get more advice. She talked about the lack of awareness from mother – "I think so definitely 'cos obviously my mum didn't really know much about it and obviously she was trying to give me advice and obviously she didn't really understand what I was doing and why I was doing it". She indicates that the general public think of OCD in a stereotypical way (lack of awareness/understanding), which makes it seems less serious than it is. She recommends that professionals that diagnose should provide explanations about the development of OCD. She recommends they provide information about OCD and how it can be helped as she had to do all her own research. "I didn't know anything about OCD. I	Conflicting views about explanations. Conflict about exposure therapy.

	R: [um] I'd definitely say that it does help sometimes to talk about it but like I say, I think that they should sort of carry out a few more things where [ah] we have to obviously do something we don't actually want to do to help us to conquer the fears. Obviously if the person is not really willing to do it then that's fine but I think, you know, I think yeah they should do a bit more of that in the sessions. **I: [mmm] And what other help do you think would be helpful apart from more kind of tasks that allow you to stop the rituals either at home or in the sessions. What other help do you think would be beneficial?** R: I think it would be really helpful if they like set up sort of a club or something outside [laugh] of the therapy sessions where you could just go up and meet or even chat online just to talk, just for like show your own experiences like talk about experiences and know that you're not the only one that has it. And just get to know people and I think that would be a good, good way to, yeah, just sort of feel a bit more relaxed and you'll know that you are not being judged because we all have it like at the place so. So yeah something like that. **I: So would that be a club or a group? How, what would that look like?** R: [um] So maybe like at a youth centre or somewhere like that or go and meet up and they just hold it maybe like once a month or something like that just so like you just, you know, sort of yeah just get to know people and understand it a bit more. **I: And anything else that they could offer?** R: [um] **I: For you or for anyone?** R: Maybe just like a, like just so like be able to talk to them at any stage like just say you're having a really bad day and you just need to talk to someone about it that understands it. I think would be good if there was just someone you could talk to	didn't really know what it was" – she lacked awareness of OCD. Repetition of the word "conquer" – to highlight the battle of fighting back OCD. Compelling OCD. Recommendation for psychologists to conduct more in-session behavioural experiments. She wants to connect with other young people who experience OCD to feel less alone – "like talk about experiences and know that you're not the only one that has it" and recognise that she would not be judged by talking about OCD in front of young people. Meeting with other young people experiencing OCD in a youth club not in mental health setting once per month would be helpful. People understanding more – alludes to lack	Feeling alone – wanting support groups. Feeling alone – wanting support groups.

	about it that would, could like help you if you're really stressed out because you couldn't commit a ritual. Just having someone there that you know understands why you're feeling like that, just to have that sort of reassurance of, don't like, don't worry it's going to be ok. You'll be fine and like it will be, yeah. Something like that would be good. **I: Ok. And is there anything else you'd like to tell me about how you made sense of OCD?** R: [um] Yeah I definitely think it helped once I knew sort of why I had it. Like obviously due to responsibility. I found that that was one of my main reasons I felt like I was responsible for everything so I had to carry out all these like rituals. [um] So like once I found out that it was a lot easier to sort of try and think a bit more rationally and to understand it a lot better and yeah I think yeah that has definitely helped. **I: [uum] Is there anything else that you'd like to tell me about your experiences of OCD, about the help you got or how you developed it?** R: [um] I don't think so. [laugh] I don't think so. **I: And are there any reflections about your experience of taking part in this interview? Any thoughts or feeling about taking part?** R: [um] I just, I just hope that obviously it helps people in that they, the messages get across of what OCD is 'cos I don't feel like anyone, like quite a lot of people really know what it is and I think that does affect 'cos then you do feel a lot more stupid and I think if this does help to spread the message across and help other people with OCD to get treated quick or whatever I think that would definitely be good, yeah. So yeah I hope that it does. [laugh] **I: And is there anything else you would like to add about your experiences?**	of understanding about OCD generally. She realised personal responsibility impacted her OCD. Highlights the importance of knowing why she developed OCD. Sense of loneliness – of not feeling understood makes her feel "stupid".	Feeling responsible. Not understanding.

		R: No I don’t think so. [laugh] **I: Thank you very, very much for taking part. I am very grateful.** **Words [8,509 5 hrs.**	Indicates the importance of seeking help quickly.	

Appendix 4: NHS Ethics Approval

NHS
Health Research Authority

NRES Committee South Central - Berkshire
Bristol REC Centre
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 3421389
Facsimile: 0117 3420445

07 September 2012

Ms Sue Ziebland
Reader in Qualitative Health Research
University of Oxford
23-38 Hythe Bridge Street
Oxford, OX1 2ET

Dear Ms Ziebland,

Study title: **Narratives of health and illness for www.healthtalkonline.org (formerly DIPEx)and www.youthhealthtalk.org**
REC reference: **12/SC/0495**

The Proportionate Review Sub-committee of the NRES Committee South Central - Berkshire reviewed the above application on 05 September 2012.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

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

Conditions of the favourable opinion

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

1. Please complete the highlighted 'xxxx' and '[]' with the correct information on all patient information sheets.

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

A Research Ethics Committee established by the Health Research Authority

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Advertisement	Generic Recruitment for Metro Evening Standard: Version 1	21 August 2012
Advertisement	PPI Health Research Flyer: Version 1	21 August 2012
Advertisement	YHT Generic Flyer: Version 1	21 August 2012
Covering Letter		20 August 2012
Investigator CV	Sue Ziebland	
Letter from Sponsor		21 August 2012
Other: Copyright Form HTO	1	21 August 2012
Other: Copyright Form YHT 10-15	1	21 August 2012
Other: Copyright Form YHT 16-25	1	21 August 2012
Participant Consent Form: HTO	1	21 August 2012
Participant Consent Form: YHT 10-15	1	21 August 2012
Participant Consent Form: YHT 16-25	1	16 August 2012
Participant Information Sheet: Generic	1	21 August 2012
Participant Information Sheet: Service User Researcher	1	21 August 2012
Participant Information Sheet: Mental Health	1	21 August 2012
Participant Information Sheet: PPI	1	01 July 2012
Participant Information Sheet: Staff	1	21 August 2012
Participant Information Sheet: YHT 16-25	1	21 August 2012
Participant Information Sheet: YHT 10-15	1	21 August 2012
Participant Information Sheet: YHT Information for Parents	1	21 August 2012
Protocol	1	21 August 2012
REC application		21 August 2012

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

Feedback

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

Further information is available at National Research Ethics Service website > After Review

12/SC/0495	**Please quote this number on all correspondence**

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

Yours sincerely

pp Mr David Carpenter
Chair

Email: scsha.berksrec@nhs.net

Enclosures:	*List of names and professions of members who took part in the review*
	After ethical review – guidance for researchers
Copy to:	*Ms Heather House, University of Oxford*

NRES Committee South Central - Berkshire

Attendance at PRS Sub-Committee of the REC meeting on 05 September 2012

Committee Members:

Name	*Profession*	*Present*	*Notes*
Mr David Carpenter	Social Scientist	Yes	
Mr Richard Merewood	Director	Yes	
Ms Susan Tonks	Senior Research Support Associate	Yes	

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healthtalkonline.org
youthhealthtalk.org

Nuffield Department of Primary Care Health Sciences
Health Experiences Research Group

2nd floor, 23-38 Hythe Bridge Street, Oxford OX1 2ET, UK
Tel: +44 (0)1865 289328, Fax: +44 (0)1865 289287
E-mail: hergadmin@phc.ox.ac.uk

Carly Keyes
Doctorate in Clinical Psychology
University of Hertfordshire
Hatfield
Hertfordshire
AL10 9AB

7th May 2014

Dear Carly

I am writing to confirm that the research that you are conducting for your project 'how do young people make sense of developing Obsessive Compulsive Disorder (OCD) as well as getting help?' is compatible with the healthtalkonline project and is covered by ethics ref 12/SC/0495 (project : Narratives of health and illness for Healthtalkonline 2012). The University of Oxford is the research study sponsor.

Yours sincerely

Vanessa Eade

Vanessa Eade
Project Administrator

cc Sara Ryan

The Nuffield Department of Primary Care Health Sciences
is a member of the
NIHR National School for
Primary Care Research

Appendix 5: University of Hertfordshire's Ethics Committee Approval

UNIVERSITY OF
HERTFORDSHIRE
HEALTH & HUMAN
SCIENCES

ETHICS VALIDATION

TO	**Carly Keyes**
CC	**Lizette Nolte, Liz Nolan**
FROM	**Rachel Stirton, Ethics Administration**
DATE	**13 June 2014**

Protocol number: LMS/PG/NHS/00211

The UH protocol number above has now been validated for the study detailed below. Please quote this number should you need to contact us.

Study title: **How do young people make sense of developing Obsessive Compulsive Disorder as well as getting help?**

REC reference: 12/SC/0495 **CSP Ref: 112111**
NRES Committee South Central – Berkshire

Amendment number:
(if applicable)
Amendment date: (if
applicable) IRAS
project ID:

Appendix 6: Participation Information Sheet for 13-15 year olds

DIPEx is a registered charity number 1087019 and a company limited by guarantee, company number 04178865, whose registered office is at 41 Cornmarket Street, Oxford OX1 3HA.

Many thanks for reading this information sheet!

Notes:
- The study has been approved by Berkshire Ethics Committee REC No 12/SC/0495

What if there is a problem

Given the nature of this study, it is highly unlikely that you will suffer harm by taking part, However, the University has arrangements in place to provide for harm arising from participation in the study for which the University is the

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youthhealthtalk.org
healthtalkonline.org

Department of Primary Care Health Sciences
Health Experiences Research Group
23-38 Hythe Bridge Street, Oxford OX1 2ET UK
Tel: +44 (0)1865 289328
E-mail: hergadmin@phc.ox.ac.uk

INFORMATION SHEET

PROJECT TITLE: YOUTHHEALTHTALK

HOW YOUNG PEOPLE MAKE SENSE OF DEVELOPING AND GETTING HELP FOR OBSESSIVE COMPULSIVE DISORDER

Research Sponsor. If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Sue Ziebland of the Health Experiences Research team on 01865 289302 or the head of CTRG, email ctrg@admin.ox.ac.uk

- Ask me if you have any questions – my contact details are at the top of this page
- **Please take as much time as you like to decide**

WHAT IS YOUTH HEALTH TALK?

www.youthhealthtalk.org is a website containing:

- young people's stories of health, illness and lifestyles
- information about tests and treatments
- links to support groups & websites

Hello, my name is Carly Keyes and I am a researcher. I am asking you to take part in research. Before you decide if you want to take part or not, please:

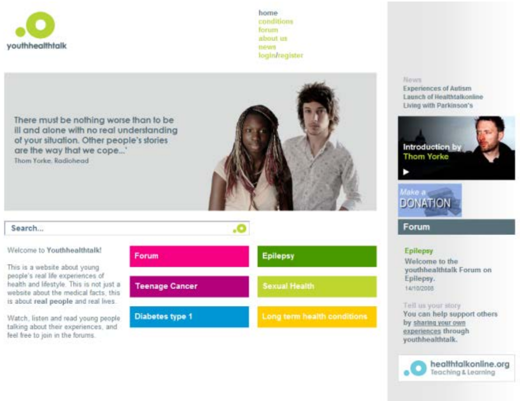
- Read this leaflet carefully
- Show this leaflet to your parents (or legal guardian) and discuss your decision with them

IF I DECIDE TO TAKE PART, WHAT SHOULD I DO NEXT?

1. If you and your parents/guardian are interested in the study fill in the participant 'reply slip' and post it to me in the reply paid envelope (in your information pack).
2. I will contact you to arrange an interview.

WHAT IF I CHANGE MY MIND?

You are free to leave the project at **any time**. If you leave after your interview, we will destroy all recordings, transcripts and typing of your interview. If you leave after the Website has been finished, we will remove all your information from the site, but we will not be able to destroy



There must be nothing worse than to be ill and alone with no real understanding of your situation. Other people's stories are the way that we cope...'
Thom Yorke, Radiohead

Welcome to **Youthhealthtalk!**

This is a website about young people's real life experiences of health and lifestyle. This is not just a website about the medical facts, this is about **real people** and real lives.

Watch, listen and read young people talking about their experiences, and feel free to join in the forums.

News
Experiences of Autism
Launch of Healthtalkonline
Living with Parkinson's

Epilepsy
Welcome to the youthhealthtalk Forum on Epilepsy.
14/10/2008

Tell us your story
You can help support others by sharing your own experiences through youthhealthtalk.

WHY ARE YOU DOING THIS PROJECT?

Youthhealthtalk aims to:

- help young people understand & cope with health problems and lifestyle choices
- help parents, doctors, and nurses understand what really matters to young people
- answer common questions and provide information that can help young people make health and lifestyle choices

WHAT DO YOU DO WITH MY INTERVIEW?

1. I label the recording with a code number and a typist types out everything you said. (The typist signs an agreement to keep everything you say in the interview secret.) Everything is kept in a secure place at the University of Oxford.

anything that other people had already copied from the Website.

I STILL HAVE SOME QUESTIONS…

For more information or to make a complaint, please contact:

1. Carly Keyes, researcher –
   email: c.v.keyes@herts.ac.uk telephone: 01865 289328
2. Sue Ziebland, Research Director –
   email: sue.ziebland@phc.ox.ac.uk
   telephone: 01865 289328

WHO IS DOING AND FUNDING THE RESEARCH?

The youthhealthtalk projects are based at the Department of Primary Care Health Sciences, University of Oxford. The project for 'How young people make sense of Obsessive

2. I write a summary of your interview and send this to you to check.

3. I send you a copy of your interview on paper or CD. You can decide if there is anything in your interview that you would like to change, remove, or keep secret.

4. You can choose a false name for yourself and others.

5. I give you a form (‘Further use of my interview’). On this form you can tell us how we can and can’t use your interview (see below). Your interview will not be used for advertising or purely commercial purposes.

6. If you sign this form, you give copyright - the right to copy and use your interview - to the University of Oxford. Please take time to think about this form before you sign it. I will also ask your parent or guardian to sign this form.

All data use is strictly within the terms of the Data Protection Act 1998. Anyone who has access to the Internet can use youthhealthtalk.

CAN I CHOOSE HOW MY INTERVIEW WILL APPEAR ON THE WEBSITE?

Compulsive Disorder as well as getting help?’ is funded by Cambridgeshire and Peterborough NHS Foundation Trust.

DO I HAVE TO TAKE PART?

No, it is your choice. If you decide to take part, you can stop at any time and we will not ask you why.

IF I TAKE PART WHAT WILL I HAVE TO DO?

I would like to interview you and to record our conversation. When we meet to do the interview, I will:

- Show you the website on a portable computer
- Answer your questions
- Check that you have read this information sheet
- Ask permission to record your interview
- Give you an ‘assent form’ - you only sign this form if you agree to take part in the interview
- We also ask your parent or guardian to sign a ‘consent form’ as well

WHAT’S THE ACTUAL INTERVIEW LIKE?

Yes. People who use the website will be able to see the summary of your interview and extracts from your interview in one of the following ways – the choice is yours:

1. We could use video or audio extracts from your interview – people will see you or hear your voice on the website.
2. We could use written extracts from your interview – people will only be able to read what you told me.
3. An actor could speak your words.
4. An animated image could speak your words, using your voice or the voice of an actor.

Before the website is available to the public, you can check the clips that we have used from your interview. If you don't like them, you can ask us to remove them or to record them again with an actor or animated image.

Please discuss your choices with members of your family, because they might be linked to your interview on the website. You may like to discuss your interview with someone you trust (a friend, family member or professional) before deciding whether and how you would like the material to appear in any resources.
If you have any doubts or concerns, talk to me, or I can find someone independent for you to talk to.

The interview is like a conversation, but I help you talk about yourself in your own words.

I will ask questions about:
- your experiences, thoughts and feelings
- how you got information
- the good and bad parts of your experience

You don't have to answer all my questions and you can stop at any time, without giving a reason.

You can also:
- Bring a friend or family member if you want
- Choose how long the interview lasts
- Choose where (home, school, somewhere else), when and what time we do the interview - I will pay for any special journeys you make

After the interview I give everyone a list of useful contacts, websites and information.

Appendix 7: Participation Information Sheet for 16-18 year olds

What if there is a problem

Given the nature of this study, it is highly unlikely that you will suffer harm by taking part. However, the University has arrangements in place to provide for harm arising from participation in the study for which the University is the Research Sponsor. If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Sue Ziebland of the Health Experiences Research team on 01865 289302 or the head of CTRG, email ctrg@admin.ox.ac.uk

Many thanks for reading this information sheet.
Carly Keyes

The Youthhealthtalk.org website is run by DIPEx which is a registered charity, number 1087019 and a company limited by

Tel. 01865 289328
www.youthhealthtalk.org

Health Experiences Research Group
Dept. of Primary Care Health Sciences, University of Oxford,
23 – 38 Hythe Bridge Street,
Oxford OX1 2ET
Email: hergadmin@phc.ox.ac.uk

PARTICIPANT INFORMATION SHEET

TAKING PART IN AN INTERVIEW - A YOUTHHEALTHTALK MODULE ON OBSESSIVE COMPULSIVE DISORDER – 'HOW YOUNG PEOPLE MAKE SENSE OF DEVELOPING AND GETTING HELP FOR OBSESSIVE COMPULSIVE DISORDER'

Hello

My name is Carly Keyes and I am a researcher. I am asking you to take part in research. Before you decide if you want to take part or not, I want to tell you why the research is being done, and what you can expect if you do take part. Please read what I have to say carefully. Talk about it with friends, relatives and your doctor or therapist if you wish. Ask me if you have any other questions. Please take as much time as you like to decide.

guarantee, company number 04178865, whose registered office is at 41 Cornmarket Street, Oxford OX1 3HA.

What is the purpose of the study?

www.youthhealthtalk.org is a website that has:

- people's stories of health , illness and other health related issues
- other information that may be useful to people going through similar experiences

The idea is that Youthhealthtalk will help young people to:

- understand & cope with health problems and issues
- know what really matters to people when they are ill or are dealing with health issues; and
- answer common questions and provide information.

The idea is that seeing and listening to other people's experiences on Youthhealthtalk will provide people with additional help, emotional support and practical information. Health professionals who want to understand what it is like for people to have an illness or face health choices can also visit the website. To develop each Youthhealthtalk topic (such as this one) takes about one and a half years.

The research is being carried out as part of an educational qualification.

Thanks for reading this.

If you are recognised on a website, this would be a little like appearing on the TV. And as with TV, other people can record what they find there, and show it to others. If you have any doubts about how you want the interview to be included, talk to me, or I could find an independent adviser for you to talk to if you prefer.

Who is organising and funding the research?

The Youthhealthtalk project is based at the Department of Primary Health Care Sciences, University of Oxford. The University of Oxford is the sponsor of the research. The project for Obsessive Compulsive Disorder is being funded by Cambridgeshire and Peterborough NHS Foundation Trust.

Contact for further information

I hope that this information sheet has told you what you need to know before deciding whether or not to take part. If you have any queries at all about the project or wish to make a complaint please

Anyone who has access to the Internet is able to access Youthhealthtalk. Your interview will not be used for advertising or purely commercial purposes.

Why have I been chosen?

Your have been contacted because I want to interview young people who have had experience of Obsessive Compulsive Disorder. I will be interviewing 10 people who have had such experiences. Your name has not been given to us at the Health Experiences Research Group, so I will only be able to contact you if you fill in the patient 'reply slip' (in your information pack) and post it to me in the reply paid envelope.

If you do decide to allow your interview to be used for the Youthhealthtalk website, it would be used along with interviews from other young people who have had experience of Obsessive Compulsive Disorder. A summary of these interviews would be prepared. People who use the database would be able to see the summaries of the interviews as well as read extracts from the interviews and view the video clips of people who agree to this kind of use of their interviews. All data use is strictly within the terms of the Data Protection Act (DPA 1998).

Can I choose how my interview will appear on the Website?

telephone me on 01865 289328 or Sue Ziebland of the Health Experiences Research Group on 01865 289302.

Notes:

- I am a professional researcher and am paid for my work.
- The study has been approved by Berkshire Ethics Committee REC No 12/SC/0495

Do I have to take part?

No. It is entirely up to you to decide whether or not you want to take part. If you decide to take part, you will be given this information sheet to keep. You will also be asked to sign a 'consent form'. If you decide to take part, you are still free to stop at any time without giving a reason. No questions will be asked if you stop. Deciding whether or not to take part in the study will not affect the standard of medical care you receive.

What will happen if I take part?

If you complete and send back the enclosed 'reply slip', I will contact you to arrange an interview at a time and place that suits you. If this place is not your home, you will be paid for the cost of your

You will have a choice about whether a video, audio or just a written version of your interview is included. We may be able to offer that an actor would speak your words on video or use an animation to accompany your words. If you want to be anonymous, you will be invited to use an alias for yourself and others, and you can keep out of the interview anything, which might identify you. **You may wish to discuss this with members of your family, since they might possibly be connected to your appearance on the screen.**

You may like to discuss your interview with someone you trust (a friend, family member or professional) before deciding whether and how you would like the material to appear in any resources.

If you decide that you want your interview to be included, but do not want your own face or voice to be seen and heard, we could arrange for an actor to read your interview and be filmed and recorded for the website in your place.

travel. I will try to answer any questions you may have about the interview or the Youthhealthtalk project.

Before the interview I can show you the Youthhealthtalk website on a portable computer. You can see how other people's interviews look in video, audio and written formats.

What would the interview be like?

I will ask you if you are willing to have the interview video or audio recorded. You will be given the 'consent form'. You only sign this form if you agree to take part in the interview. You will be given a copy of the consent form to keep.

The interview will be a little like a conversation, but I will help you talk about yourself in your own words. I will ask you to talk about your experiences of Obsessive Compulsive Disorder. I will ask questions about what happened to you, what your thoughts and feelings have been at different stages, how you have got information, what you have done, and what have been the good and bad parts of the experience. <u>If you prefer we can interview you with a friend or a member of your family.</u>

While people sometimes find it helpful to talk about their story to researchers this research is not the same thing as counselling. However, I will give everyone a list of useful contacts which can be used to get more help if you want.

How long would the interview take?

What would happen after the interview?

I will label the interview recording with a code number and give it to a typist who will type out everything you said in the interview. The typist signs an agreement to keep everything you say in the interview secret. The digital recording and the typed up record (transcript), identified only by the code number, would be kept in a secure place at the Department of Primary Care Health Sciences at the University of Oxford.

I will send you a copy of the interview transcript to help you decide whether you want your whole interview to be made available to

The time it takes for an interview varies, depending on how much you have to say, but most interviews last at least an hour. If you would prefer, I can interview you on two different occasions. Remember, if you want to stop the interview at any time, you can do so without giving any reason at all.

What if I decide to withdraw after the interview has taken place?

You are free to leave the study at any time. If you decide to leave after an interview has taken place, all video recordings, transcripts and typing of your interview would be destroyed. However, if you decide to leave after the Website/DVD has been finished, we would remove your contribution from all later versions, but we would not be able to destroy existing material, which other people could copy from the Website.

Youthhealthtalk (a recording of the interview can also be provided if requested). You would be asked to read or listen to the interview and consider if there was anything you would like to change or remove, to keep anything secret or hide your identity, or to delete or change some of your interview. You can take as long as you need to do this. You can also choose how your interview will appear on the Website (see below).

How would the researcher use the interview tape and transcript?

You will be asked to sign a form '**Further use of my Youthhealthtalk interview**'. If you sign this form, you give copyright of the interview to the University of Oxford. It is very important that you take time to think about and if you wish discuss the copyright form with someone you trust, such as a family member, friend or doctor, before you sign it. This form is also used to spell out any limits that you wish to place on its use. You will be given a copy of this form to keep. The study data may be looked at by individuals from the University of Oxford, for the purpose of audit and monitoring.

Appendix 8: Information Sheet for Parents

Contact for further information

I hope that this information sheet about has told you what you need to know before you and your child decide whether or not to take part. Your child has been provided with their own information sheet about the project. If you have any queries at all about the project or wish to make a complaint please telephone Carly Keyes on 01865 289328 or Sue Ziebland of the Health Experiences Research team on 01865 289302.

Notes:

- I am a professional researcher and am paid for my work.
- The study has been approved by Berkshire Ethics Committee REC No 12/SC/0495

What if there is a problem

Given the nature of this study, it is highly unlikely that your child will suffer harm by taking part, However, the University has arrangements in place to provide for harm arising from participation in the study for which the University is the Research Sponsor. If you wish to complain about any aspect of the way in which you or your child have been approached or treated during the course of this study, you should contact Sue Ziebland of the Health Experiences Research team on 01865 289302 or the head of CTRG, email ctrg[@admin.ox.ac.uk](mailto:ctrg@admin.ox.ac.uk).

Tel : 01865 289328
www.healthtalkonline.org
Email :
hergadmin@phc.ox.ac.uk

Health Experiences Research Group
Nuffield Department of Primary Care Health Sciences,
University of Oxford, Gibson Building, Radcliffe Observatory Quarter, Woodstock Road, Oxford
OX2 6GG

INFORMATION SHEET FOR PARENTS/GUARDIANS TAKING PART IN AN INTERVIEW - A STUDY OF EXPERIENCES OF Obsessive Compulsive Disorder: How young people make sense of developing and getting help for Obsessive Compulsive Disorder

Hello

My name is Carly Keyes. I am a researcher working with the Health Experiences Research Group at the University of Oxford. I am asking your child to take part in research. Before you decide if you would like them to take part or not, I want to tell you why the research is being done, and what you can expect if they do take part. Please read what I have to say carefully. Talk about it with friends, relatives and your GP if you wish. Ask me if you have any other questions. Please take as much time as you like to decide. This research is being carried out as part of an educational qualification.

Many thanks for reading this information sheet.
Carly Keyes

The Healthtalkonline site is run by DIPEx, which is a registered charity number 1087019 and a company limited by guarantee, company number 04178865, whose registered office is at P O Box 428 Witney Oxfordshire OX28 9EU.

- to find out what is important to people faced with different health issues
- to contribute to the www.healthtalkonline.org and www.youthhealthtalk.org website which is run by the DIPEx charity
- to develop other support and information and training resources for people
- to train health and social care professionals
- to support quality improvement in healthcare
- to write research papers

www.healthtalkonline.org and www.youthhealthtalk.org are websites that have:

- people's stories of health, illness and other health-related issues
- information about tests and treatments
- other information that may be useful to people going through similar experiences
- a teaching and learning area for health and social care staff and anyone involved in healthcare

Thanks for reading this.

What is the purpose of the study?

The aim of our research programme is to improve understanding of people's experiences of health, illness and healthcare, and provide resources to support people living with a wide variety of health conditions, their families, friends and the health professionals involved in their care. We collect video, audio and written interviews, which may be used in several ways:

Can we choose how the interview will appear?

You and your child will have a choice about whether a video, audio or written version of your interview is included. We may be able to offer that an actor would speak your words on video or use an animation to accompany your words. If you would like your child to be anonymous, they will be invited to use an alias for themselves and others, and they can keep out of the interview anything which might identify them. **You may wish to discuss this with members of your family, since they might possibly be connected to your child's appearance on the screen.**

If they are recognised on a website or a DVD, this would be a little like appearing on the TV. The material on the website is protected by copyright and people are not allowed to copy or record what they find there but it is possible that they could. If you have any doubts about how you want the interview to be included, talk to me, or I could find an independent adviser for you to talk to if you prefer.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct by the Berkshire Ethics Committee.

The idea is that seeing and listening to other people's experiences on Healthtalkonline and Youthhealthtalk will provide people with additional help, emotional support and practical information.

Health and social care professionals, researchers and policy makers, who want to understand people's experiences can also visit the website.

Anyone who has access to the Internet is able to use Healthtalkonline and Youthhealthtalk.

Who is organising and funding the research?

The Health Experiences Research Group is based at the Department of Primary Care Health Sciences, University of Oxford. The project 'How do young people make sense of developing Obsessive Compulsive Disorder as well as getting help?' is being funded by Cambridgeshire and Peterborough NHS Foundation Trust.

I will send you a copy of the interview transcript to help you and your child decide whether you want their interview to be made available to use for our research, including on Youthhealthtalk and other audio-visual resources. A copy of the interview recording can also be provided if requested. Your child would be asked to read or listen to the interview and consider if there was anything they would like to change or remove, to keep anything secret or hide their identity, or to delete or change some of their interview. We can remove any sections that they do not want us to use. They can take as long as you need to do this. They can also choose how their interview will appear in any resources we produce (see below). Parents or legal guardians are required to sign the copyright form which indicates this.

How would the researcher use the interview tape and transcript?
You and your child will be asked to sign a form '**Further use of my interview**'. If you both sign this form, you give copyright of the interview to the University of Oxford. It is very important that you and your child take time to think about and discuss the copyright form before you sign it. You will be given a copy of this form to keep.

If you do decide to allow your interview to be used for the study, it would be used along with interviews from 9 other children who have experiences of Obsessive Compulsive Disorder. A summary of these interviews would be prepared for the youthhealthtalk website. People who use the site would be able to see the summaries of the interviews as well as read extracts from the interviews and view the video clips of people who agree to this kind of use of their interviews. All data use is strictly within the terms of the Data Protection Act

The interviews we collect contribute to the information presented on the sites, and extracts from many of them will be used to show what it is like for people facing illness or health issues. The interview will not be used for advertising or purely commercial purposes.

As well as the website, we may use interviews to help create other information and support resources, such as DVDs or short films. These may for example be shown to people by health professionals as part of their care or they may appear on other websites approved by the University of Oxford

Interviews may also be used to develop other resources for members of the public, patients and families, for health and social care professionals and for clinical research staff, so they can learn from people's experiences and improve the care they provide. Training materials may be presented on the teaching and learning area of the www.healthtalkonline.org website, on other approved websites, and on DVDs.
All the interviews we collect also contribute to research articles and papers.

Why have we been chosen?
You have been contacted because I want to interview children aged 13-18 who have had experience of health issues and decisions such as theirs. I will be interviewing a range of children who have had such experiences. Your name /your child's name has not been given to us at the Health Experiences Research Group, so I will only be able to contact you if you fill in the 'reply slip' (in your information pack) and post it to us in the reply paid envelope.
While children sometimes find it helpful to talk about their story to researchers this research is not the same thing as counselling.

(DPA 1998). The study data may be looked at by individuals from the University of Oxford, for the purpose of audit and monitoring.

Do they have to take part?

No. It is entirely up to you and your child to decide whether or not to take part. If they decide to take part and you consent to this, you will be given this information sheet to keep. You will also be asked to sign a 'consent form' and your child will be asked to give their assent also which is recorded on the consent form. They are still free to stop at any time without giving a reason. No questions will be asked if they stop. Deciding whether or not to take part in the study will not affect the standard of any medical care they receive.

What will happen if my child takes part?

If you complete and send back the enclosed 'reply slip', I will contact you to arrange an interview at a time and place that suits you and your child. If this place is not your home, you will be paid for the cost of your travel. I will try to answer any questions you may have about the interview or the Healthtalkonline project.

Before the interview I can show you and your child the Youthhealthtalk website on a laptop computer. You can see how clips from other people's interviews look in video, audio, animated, and written formats.

What would the interview be like?

I will ask you and your child if you are willing to have the interview video or audio tape recorded. You will be given the 'consent form'. You and your child only sign this form if you both agree to your child taking part in the interview. You will be given a copy of the consent form to keep. The interview will be a little like a conversation, in

However, I can give everyone a list of useful contacts which can be used to get more help if you or your child want.

How long would the interview take?

The time it takes for an interview varies, and children are able to choose how long they would like the interview to last. If you would prefer, I can interview your child on two different occasions. Remember, if your child wants to stop the interview at any time, they can do so without giving any reason at all. Your child can bring a friend or family member to the interview and you can choose where the interview takes place.

What if you and your child decide to withdraw after the interview has taken place?

You give your consent for your child to take part, and your child gives their assent also. Your child is free to leave the study at any time. If you /they decide to leave after an interview has taken place, all video recordings, transcripts and typing of your interview would be destroyed. If you/they decide to leave after the website or other audio-visual resources have been finished, we would remove their contribution from all later versions, but we would not be able to destroy existing material, which other people could already have seen or copied.

What would happen after the interview?

I will label the interview recording with a code number and give it to a typist who will type out everything your child said in the interview. The typist has signed an agreement to keep everything they say in the which I will ask your child to talk about their experiences of Obsessive Compulsive Disorder in their own words. I will ask questions about what happened to them, what their thoughts and feelings have been at different stages, how they have got information, what they have done, and what have been the good and bad parts of the experience.

interview secret. The digital recording and the typed up record (transcript), identified only by the code number, would be kept in a secure place at the University of Oxford or Department of Primary Care Health Sciences at the University of Oxford.

Appendix 9: Consent form for Participants aged 13-15 years old

youthhealthtalk.org
healthtalkonline.org

UNIVERSITY OF
OXFORD

Health Experiences Research Group
Nuffield Department of Primary Care
Health Sciences
Gibson Building, Radcliffe Observatory Quarter
Woodstock Road
Oxford, OX2 6GG
Tel: +44 (0)1865 289328, E-mail: hergadmin@phc.ox.ac.uk

Database reference number: OCD 0___________
Series title: How young people make sense of developing and getting help for Obsessive Compulsive Disorder_______________

CONSENT FORM

Title of Project: How young people make sense of developing and getting help for Obsessive Compulsive Disorder Youthhealthtalk : OCD
Name of Researcher: Carly Keyes

		Please put your initials in the box	
		Child	**Parent**
1	I confirm that I have read and understand the information sheet dated _11.10.12____________ (version _____2_________) for the above study and have had the opportunity to ask questions.	☐	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons, without my medical care or legal rights being affected.	☐	☐
3	I agree to take part in the above study.	☐	☐

____________________________ ____________________ ____________________________
Name of participant (**Block capitals**) Date Signature

Age of participant: ___________________

Name of parent or guardian (Block capitals)	Date	Signature
Name of person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Appendix 10: Consent form for Participants aged 16-18 years old

Health Experiences Research Group
Nuffield Department of Primary Care Health Sciences
University of Oxford
Gibson Building, Radcliffe Observatory Quarter,
Woodstock Road,
Oxford OX2 6GG

Tel: +44(0)1865 289 328
hergadmin@phc.ox.ac.uk
www.youthhealthtalk.org

Database reference number: OCD 0________________________

Series title: How young people make sense of developing and getting help for Obsessive Compulsive Disorder

CONSENT FORM

Title of Project: Youthhealthtalk – personal experiences of health & illness
How young people make sense of developing and getting help for Obsessive Compulsive Disorder
Name of Researcher: Carly Keyes

Please initial box

1 I confirm that I have read and understand the information sheet dated 11.10.12_____________ _____________ (version _2_____________) for the above study and have had the opportunity to ask questions. ☐

2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons, without my medical care or legal rights being affected. ☐

3 I understand that relevant data collected during the study may be looked at by individuals from the University of Oxford, for the purpose of audit and monitoring, and where it is relevant to my taking part in this research. I give permission for these individuals to have access to the records of my participation in this research. ☐

4 I agree to take part in the above study. ☐

Name of Participant (**block capitals**)	Date	Signature
Researcher	Date	Signature

YHT 16-25 consent form V1 August 2012 12/SC/0495

Appendix 11: Respondent Details Form

Respondent details **Database reference number OCD 0………………**

Name: ………………………………………………Age…… Gender…………….

Address: ……………………………………………………………………..…...……

……………………………………………………………………………….

……………………………………… Post Code: …..………………….

Telephone No.: ……………………………..……(Day) ……..……………………..(Evening)

Mobile No. ……………………………………. Contact Times: …………………………

Email address: ……………………………………………………………………………….

Name and telephone number of a friend or relative for alternative contact ……………………

…………………………………………………………………………………………...…

Preferred name for website …………………………………………………………….…….

Marital Status: ……………………………………… No. of Children: ………………...

Ages of Children: …………………………………… No. of persons in household: …...

Country of Birth: ……………………………… Ethnic Background: …………………….

Date of Diagnosis: ………………………………………Age at Diagnosis…………….….

What is/was your main job/occupation?
(if retired, note last employment) Full/Part time ……………....…………….…………………………………………………….………….(circle one)

Tick all appropriate boxes:
☐ employee
☐ self-employed ☐ working on own or with partner(s);
☐ with employees;
☐ supervisor

Number of people employed at workplace ☐ 1-9, ☐ 10-24, ☐ 25-499, ☐ >500

What does/did the firm/organisation you work(ed) for mainly make or do?

|
…………………………………………………………………………………………………….

What do/did you mainly do in your job?
………………………………..................................
……………………………………………………………………………………………..………..

ASK FOR VERBAL PERMISSION FOR RELEVANT INFORMATION TO BE SHOWN ON THE WEBSITE:Marital Status/Children/Occupation/Ethnic background
☐

Location of Interview: Home……………………………………………………….
(i.e. home/office/clinic etc)

Interview contact: ……………………………………………………………….
(i.e. GP/Support Group/Consultant etc)

Title of Series: How young people make sense of developing and getting help for Obsessive Compulsive Disorder ……………………………………………………………….

Interviewer: Carly Keyes…………………………… Date of Interview: …………..

Method of Recording:……………………Number of tapes:…………………………

Number of interviews with this respondent: …………………………………..

Notes:

Appendix 12: Copyright Form for participants aged 13-15 years old

youthhealthtalk.org
healthtalkonline.org

UNIVERSITY OF
OXFORD

Health Experiences Research Group
Nuffield Department of Primary Care Health Sciences
Gibson Building, Radcliffe Observatory Quarter, Woodstock Road
Oxford, OX2 6GG
Tel: +44 (0)1865 289328, E-mail: hergadmin@phc.ox.ac.uk

Future use of my interview

I intend that my interview will be available to researchers at Oxford University, and other universities under licence from Oxford, for use in teaching, broadcasting, research, the making of audio visual resources and other publications. I agree to all such uses including any translation of the material into other languages.

I also intend that my interview will be available to contribute to the collection of 'health and illness experiences' on the websites www.healthtalkonline.org and/or www.youthhealthtalk.org, which are run by the DIPEx charity. The websites will be freely available to the public and extracts from my interview may appear on other sites approved by the DIPEx charity.

I understand that for these purposes the material may be shared with and used by academics, broadcasters, developers of training courses, website developers, information providers and others. It will not be used for advertising or purely commercial purposes.

I understand that by agreeing that my interview and materials relating to it will be available on the internet, it will be accessible to internet users throughout the world including in countries that may have less extensive data protection laws than in the UK. I also understand that the research group may sometimes wish to collaborate with reputable partners in such countries and I consent to my interview and materials relating to it to be shared with and used by such partners.

I consent to the inclusion of my interview in the database in the following format(s).
Please tick ✓ all that apply:

☐ Video tape of interview
☐ Audio tape of interview
☐ Written transcript of interview

OR

☐ I do not want my voice to be used on the site, but I give permission for an actor/animated image to perform my words on video.

To enable the full use of my interview, I assign my copyright in my contribution to the University of Oxford. In return for my assignment my interview will only be used in the manner set out above. If I decide that I no longer want my interview to be used on the website (or for any other purpose) it will be removed, although I accept that it may not be possible to remove all existing copies from circulation.

Participant name: (block capitals) ________________________

Signature: ________________________**Date:** __________

Age:______________ **Date of Birth:** ________________

Address:

____

Parent or guardian name: (block capitals) _____________

Signature:________________________**Date:**__________

Interviewer:
Recording available as: ☐ Video ☐ Audio
Number of interviews with this respondent:
Database ID
Series title:

Appendix 13: Copyright Form for participants aged 16-18 years old

Health Experiences Research Group
Nuffield Department of Primary Care Health Sciences
Gibson Building, Radcliffe Observatory Quarter, Woodstock Road
Oxford, OX2 6GG
Tel: +44 (0)1865 289328, E-mail: hergadmin@phc.ox.ac.uk

Future use of my interview

I intend that my interview will be available to researchers at Oxford University, and other universities under licence from Oxford, for use in teaching, broadcasting, research, the making of audio visual resources and other publications. I agree to all such uses including any translation of the material into other languages.

I also intend that my interview will be available to contribute to the collection of 'health and illness experiences' on the websites www.healthtalkonline.org and/or www.youthhealthtalk.org, which are run by the DIPEx charity. The websites will be freely available to the public and extracts from my interview may appear on other sites approved by the DIPEx charity.

I understand that for these purposes the material may be shared with and used by academics, broadcasters, developers of training courses, website developers, information providers and others. It will not be used for advertising or purely commercial purposes.

I understand that by agreeing that my interview and materials relating to it will be available on the internet, it will be accessible to internet users throughout the world including in countries that may have less extensive data protection laws than in the UK. I also understand that the research group may sometimes wish to collaborate with reputable partners in such countries and I consent to my interview and materials relating to it to be shared with and used by such partners.

I consent to my interview being available in the following format(s):

Tick all that apply:

- ☐ Video recording of interview
- ☐ Audio recording of interview
- ☐ Written transcript of interview
- ☐ IF APPLICABLE: I do not want my image and voice to appear on the site, but I give permission for an actor to perform my words on video or for an animation to accompany my words.

To enable the full use of my interview, I assign my copyright in my contribution to the University of Oxford. In return for my assignment my interview will only be used in the manner set out above. If I decide that I no longer want my interview to be used on the website (or for any other purpose) it will be removed, although I accept that it may not be possible to remove all existing copies from circulation.

Name: (block capitals) ____

Signature: ____________________________________ **Date:** ______________

Age: ____________ **D.O.B:** ___________________

Address: ____

Interviewer:

Recording available as: ☐ Video ☐ Audio

Number of interviews with this respondent: Database ID
Series title:

Appendix 14: Biography Form

PARTICIPANT BIOGRAPHY DETAILS:
INFORMATION TO BE ADDED TO THE WEB SITE

Interview No.: OCD 0

Preferred name:

Age at Interview:

Sex:

Age at diagnosis:

Background: (in sentence format to include: occupation, marital status, number of children and their ages if they have any do not add 'No children', ethnic background) **(**Max. 255 characters with spaces)

Brief Outline: (Max. 255 characters with spaces).

Please tick YES or NO to indicate whether or not all this information is correct

YES, this is correct. ☐

NO, this is not correct. ☐ Please make the following changes
....
....

NO, I do not want the following details added to the site: ☐
....
....

PLEASE TURN OVER.

More about me

Please tick YES or NO to indicate whether or not all this information is correct

YES, this is correct. ☐

NO, this is not correct. ☐ Please make the following changes

....

....

....

Signed...

PRINT NAME...

Appendix 15: Debrief Leaflet

University of Hertfordshire

Doctorate in Clinical Psychology
University of Hertfordshire
College Lane, Hatfield AL10 9AB
Programme Director: Prof David Winter
Programme Administrator: Liz Day
Telephone: (01707) 286322
email: e.day2@herts.ac.uk

Thank you for taking part in the research project!

I am very grateful that you spoke to me about your experience of living with OCD. I hope you found it okay and interesting to do.

I shall listen to the recording of the things we talked about and have a think about all the things you told me.

I shall then put all the things together and write a research paper on it. This means that I shall look very carefully at the different things the young people said about developing OCD as well as getting help. I hope I can find out some new ideas about what influences the development of OCD and maybe some new ideas about what can help.

Remember:

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

- Speak to your Mum or Dad
- Speak to your therapist or psychologist
- Make an appointment to talk to your GP
- You can speak to someone at Child Line if you want to speak to someone who doesn't know you (0800 1111)
- You can access resources online from the two main OCD Charities: OCD – UK (www.ocduk.org/) and OCD Action (www.ocdaction.org.uk/)

If after the interview you do not want me to use the information we talked about in the research project then that is absolutely fine. You do not have to give any reason for this. I only want to use the information you said if you think that is okay. Please speak to your therapist or psychologist and they will help you to let me know.

Carly Keyes
Trainee Clinical Psychologist Doctorate in Clinical Psychology Programme
Health & Human Sciences Research Institute Room 1F414, Health Research Building
College Lane Campus
University of Hertfordshire
Hatfield AL10 9AB
Tel: (01707) 286322

Appendix 16: Reply Sheet

healthtalkonline.org
youthhealthtalk.org

www.healthtalkonline.org

Reply slip for Module: How young people make sense of developing and getting help for Obsessive Compulsive Disorder

Yes, I am happy for a researcher to contact me about this project.

Name: ……………………………………………………………………
(**Block Capitals**)
Address:…………………………………………………………………

……………………………………………………………………………

……………………………………… Post Code: ……………………

Telephone number: Day: …………………… Evening: ……………………

e-mail: ……………………………………………………………………………

Best time to contact me: ………………………………………………

Age: …………………

Gender: Male/Female

Date or year of diagnosis: ………………………………

Occupation: ……………………………………………….
(if retired please state and give last occupation)

Ethnic Background……………………………………….
(It is important for us to include perspectives from a range of ethnic groups in our research).

ADD/DELETE AS APPLICABLE
I would prefer to be interviewed by: Female researcher ☐

Male researcher ☐

Either ☐

Please return to:
Carly Keyes
Health & Human Sciences Research Institute Room 1F414, Health Research Building
College Lane Campus, University of Hertfordshire
Hatfield AL10 9AB

Appendix 17: Interview Schedule

How young people make sense of developing and getting help for Obsessive Compulsive Disorder (OCD)

Interview Schedule

I'd like to hear about how you made sense of OCD. You could start from the point when you first noticed the OCD symptoms, if that helps. I'd like you to tell me in as much detail as possible what the symptoms of OCD were like, how you got help, what happened next, what treatment and information you were given, and how you feel about it now looking back. *I'm particularly interested to know what was going on in your life around the time you developed symptoms of OCD and what helped.* I will then ask you more questions to follow up on some specific issues.

Prompts:

First symptoms

1. When did you first notice signs of OCD?
- What OCD symptoms did you notice? How old were you? Prompts: which school year were you in? Where were you living at the time? Anything else you can remember happening around then (might be a holiday)?
- What did you think they were?

2. How did you experience your OCD? What did you notice about how it manifested in your life?
- Were the OCD symptoms worse (or increased) in certain places, on your own, or with certain people? Did the OCD seem worse anywhere in particular?
- Were the OCD symptoms better (or decreased) in certain places, on your own, or with certain people? Did the OCD seem to be better or go away in certain places?

3. Who else noticed the OCD symptoms?
- Did others notice them before you/after you noticed? Who first noticed you were having difficulties?

4. How did OCD impact on your life? [Negatively and positively schoolwork, fun times with/without friends, home, holiday]

5. What did you think the OCD symptoms meant? What did it say about you as a person that you had these OCD symptoms?

6. Were there any stressful event/s going on in your life around the time you developed the OCD symptoms? Can you remember if there was anything else going on that might have been stressful or difficult to manage? Can you tell me about these stressful life event/s?
- How long was it between the stressful life event/s and developing the OCD symptoms?

Seeking help

1. How quickly did you decide you needed to get help?
[If delay, what made you wait before getting help?] When did you decide to get help? What made you decide to get help? Was anyone else involved in the decision to get help?

2. What kind of help did you have?
[If delay, friends, support group, parents, websites, a specific type of therapy?]

3. What happened when you sought help?
What was helpful?
What was unhelpful?

4. What information have you used, been given or found particularly helpful (including the internet)?

5. Where are you at now in terms of your everyday life and OCD?

Diagnosis

1. How long did it take to get a diagnosis?

2. When did someone first tell you what was wrong?

3. How did you feel about the diagnosis? What did it say about you as a person that you had a diagnosis of OCD?

4. Were you happy with the way you were told? [What was helpful about the way you were told? What was unhelpful about the way you were told?]

- Reaction of family etc. (Did any of your friends get to know about your OCD?)

5. What explanations were you given for developing OCD, if any?
- Did these make sense to you?
- Fit/not fit with your own explanations?

Messages for others

1. What would your messages be for other people, based on your experiences?
- Maybe young people who have OCD?

Messages for parents/families of young people living with OCD?
Messages for the general public?
Messages for health professionals? Messages for clinical psychologists?

2. Anything else that you'd like to tell me about how you made sense of OCD?
3. Any reflections about your experience of taking part in this interview?

Appendix 18: Style Sheet for the Transcriber

Style sheet for the Transcribers

- The Patient number should appear in the top left hand corner of the page in capitals and bold e.g. **PC01 - ORIGINAL**
- Pages should be numbered and contain the word ORIGINAL in the bottom right hand corner of the footer
- 1 1/2 line spacing
- Text should be left hand justified
- Do not use Widow and Orphans control
- **Put in all necessary punctuation** but do not use exclamation marks
  e.g. Use capital letters at the start of sentences
  Use a full stop at the end of a sentence
- Do not use italics or bold in the text
- The interview subjects should be identified with the following:
  - R: for respondent
  - RM = male respondent RF = female respondent (when interviewed in couples)
  - **I: for interviewer** (please put interviewer questions in bold)
  - Then put a carriage return between each paragraph of text
- Make sure the ers and ums are recorded **in brackets** as [um] or [er] (these are used for textual analysis)
- For reported speech the style is comma, inverted commas, capital letter, full stop, inverted commas e.g. he said, “I don't care.”
- The style for quotations is: "Text".
- Interruptions to tape and recording should be indicated and marked on the transcript
- Laughter, coughs and **long pauses of 2 secs or more should also be indicated** in square brackets: [laughs], [pause 3secs]
- Put in obvious background noises like [clock chime]
- If half or more than half a word is said, then transcribe it. For example, “I was very concern, concerned.”
- The transcription must be **VERBATIM** but do not transcribe words where the person only says less than half a word. For example, “ I suppose you could s- say my life blood was just ebbing away, I, I just felt.”

Other words which should be typed in full are :-
* 'wanna' 'want to'
'gonna' 'going to'
'cos' 'because'
'spose' 'suppose'

- If you cannot make out a word that either the respondent or the interviewer is saying **PLEASE DO NOT MAKE THE WORD UP,** just leave a blank space, or indicate with a row of xxxx's!
- When an interviewee is struggling to remember a word/phrase/incident and mumbles or trips over their words, suddenly correcting themselves – please leave all of this in when transcribing as it is useful for our qualitative research.
- Please highlight in yellow any names. The names could be people, places, hospitals, doctors etc. If you are unsure whether something should be highlighted, please highlight in any case so that it comes to the Researcher's attention.

- A copy of all transcripts must be sent via Oxfile to the relevant researcher and a copy sent to **Hergadmin@phc.ox.ac.uk**

*On young people's transcripts this might not be the case, so please discuss with the researcher who sends you the tape.