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**The Young Persons' Voice within Mental Health Research**


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A thesis submitted in partial fulfilment of the requirements for the degree of

Doctor of Clinical Psychology


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**List of Abbreviations**

ADHD        Attention Deficit Hyperactivity Disorders

ARMS        At Risk Mental State

ASSIA       Applied Social Sciences Index and Abstract

CAMHS       Child and Adolescent Mental Health Services

CBT         Cognitive Behavioural Therapy

CINAHL      Cumulative Index to Nursing and Allied Health Literature

DOH         Department of Health

EIS         Early Intervention Service

ERP         Exposure and Response Prevention Therapy

GAD         Generalised Anxiety Disorder

IPA         Interpretative Phenomenological Analysis

IRAS        Integrated Research Application System

NHS         National Health Service

NICE        National Institute of Clinical Excellence

OCD         Obsessive Compulsive Disorder

ODD         Oppositional Defiance Disorder

PRISMA      Preferred Reporting Items for Systematic Reviews and Meta

            Analyses

PTSD        Post Traumatic Stress Disorder

UK          United Kingdom

USA         United States of America

## List of Appendices

## Acknowledgments

## Declaration

This thesis has been written for submission as a partial fulfilment for the requirements for the Universities of Coventry and Warwick Clinical Psychology Doctorate programme.  This thesis has not been submitted for a degree at any other University.

This thesis was carried out under the academic and clinical supervision of Jacky Knibbs (Clinical Psychologist and Clinical Tutor, Coventry University) and Dr Sarah Simmonds (Clinical Psychologist and Clinical Tutor, Coventry University). The named supervisors provided suggestions and feedback throughout the research process including the reading of chapter drafts.  Apart from these collaborations this thesis is the candidates own work.

Chapters One and Two are written for submission to the journal of, *Clinical Child Psychology and Psychiatry.*  Authorship of published papers will be shared with the candidate's supervisors.

**Summary of Chapters**

This thesis provides insight into young people's experience of living with mental health difficulties. Chapter one contains a systematic review of the qualitative literature exploring lived experiences of young people with mental health difficulties.  A total of 15 articles were included in this review and subjected to a meta-synthesis.  Eight themes were identified highlighting a number of common themes which were experienced universally irrespective of the mental health condition experienced.  Methodological limitations of the review are identified and implications of the findings are discussed alongside recommendations for future research.

Chapter two explores the experiences of children and young people living with a diagnosis of Obsessive-Compulsive Disorder (OCD).  This Interpretive Phenomenological Analysis provides a rich understanding of the young person's experience of living with OCD, with particular attention to their experiences of relationships, identity formation and the difficulties they encountered whilst striving for recovery.  Clinical implications are identified and recommendations for further research are considered.

Finally, chapter three provides a reflective account of the researcher's relationship and experience of the research process, capturing the parallel process in relation to the findings within the previous chapters.  Areas of personal and professional development are also highlighted.

**Total Word Count: 18,755**

**Chapter One: Literature Review**

Experiences of Children and Young People with Mental Health Difficulties:

A Systematic Review and Meta-Synthesis of the Qualitative Literature

Chapter Word Count: 8043 (excluding tables, illustrative quotes, footnotes and

references)

In preparation for submission to *Clinical Child Psychology and Psychiatry*

(See Appendix A for author guidelines)

**Abstract**

This current paper aims to critically evaluate and further understand the way in which children and young people with a mental health condition make sense of their difficulties and the impact it has on their lives. Following a systematic review and meta-synthesis based on the principles of meta-ethnography (Noblit & Hare, 1988), the following eight themes were identified: Concealed Distress and Difficulties; Moving into Awareness; Connection; Feeling of Difference; Understanding of Difficulties: Moving Between a Medical and a Psychological discourse; Experience of Symptoms and Secondary Consequences; Experience of Support: Listen and Understand Me; Finding a Way Forward. Findings highlight the difficulties participants had in identifying and understanding their mental health difficulties and the differing frameworks they use to make sense of their experiences. They also outline the range of secondary difficulties experienced by participants alongside their mental health condition. The importance of therapeutic relationships and the factors associated with an individual's understanding of, and experience of recovery were also detailed. Clinical implications and limitations of the findings are also explored.

**Keywords:** Child, Adolescence, Mental Health Difficulties, Review, Meta-Synthesis.

**Introduction**

**Mental Health Difficulties in Children and Young People**

In 2004, a survey of the prevalence of mental health difficulties[1] amongst children and young people in Great Britain, found 10% of children aged between 5-16 had a clinically diagnosed mental health condition (Green, McGinnity, Meltzer, Ford & Goodman, 2005).  The most common are emotional disorders such as anxiety and depression, conduct disorders, Attention Deficit Hyperactivity Disorders (ADHD) and Autistic Spectrum Disorders (Green *et al.,* 2005).  Such difficulties are often associated with a number of social, psychological and biological factors (World Health Organisation, 2016).

**Impact of Mental Health Difficulties on the Young Person**

Significant mental health difficulties in childhood cause considerable distress and impact widely on many areas of a young persons' life (e.g. education, physical health, and relationships), often affecting a young person's life chances as they move into adulthood (Murphy & Fonagy, 2013).  Research suggests that up to 75% of mental health difficulties experienced by adults began before the age of 24 (Kessler *et al*., 2005), and having a mental health disorder in childhood or adolescence is a substantial risk factor for developing a range of psychiatric problems later in life (Copeland *et al.,* 2013).

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[1] Throughout this review, the term mental health difficulties and mental health conditions will be used interchangeably when referring to the range of mental health disorders experienced by children and young people.  Original author's terminology has however been used when detailing the studies findings.

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Children with mental health difficulties are more likely to be absent from school. One study reported (Green *et al.,* 2005) that 17% of children with emotional disorders, 14% of those with a conduct disorder, and 11% of those with hyperkinetic disorder were absent from school for more than 15 days in one school term, in comparison to just 4% of their peers. It is perceived that children with mental health conditions also experience more general physical health difficulties and some of their school absence is related to this (Green *et al.,* 2005).

As well as the impact on education and physical health, children and young people with mental health difficulties also have to deal with the stigmatisation associated with such difficulties (Hinshaw, 2005). In comparison to the adult literature, there is a paucity of research looking at young peoples' experiences of stigma in relation to living with a mental health condition (Moses, 2010). A review of the evidence, however, concluded that such stigma is pervasive, and while it affects all individuals differently, it is likely to impact on a young person's self-esteem and sense of worth, further compounding their existing mental health difficulties (Young Minds, 2010).

**Experiences of Living with a Mental Health Condition**

Adult mental health literature has considered the perspective of individuals with mental health difficulties and often recognises them as experts on their own condition and health care needs. The individual's viewpoint is considered to be of extreme importance, making valuable contributions to service planning and redesign, education, training and staff selection (Tait &

Lester, 2005).  Within the field of paediatric mental health, the perspectives of the children and young people who engage with these services appear to be less prominent.  Historically, research within the area of child and adolescent mental health has predominantly been concerned with epidemiological factors (Bennett, Coggan & Adams, 2003) or has focused on the experiences of those living and working with children with these conditions (e.g. Barnett & Hunter 2012; Storch, *et al.,* 2009; Stormont & Stebbins, 2005).

In the early 1980s however, the need for qualitative research that explored this area from the child's viewpoint, was acknowledged (Woodgate, 2001).  Subsequently, there has been a gradual increase in research examining the first hand experiences of children and young people with mental health difficulties.  This looks at areas such as the young people's experiences of mental health services (Buston, 2002; Donnellan, Murray & Harrison, 2012; Newton, Larkin, Melhuish & Wykes, 2007; Salamone-violi, Chur-Hansen, & Winefield, 2015), views of professionals who help them (Freake, Barley & Kent, 2007) as well experiences of living with neurodevelopmental disorders such as Attention-Deficit/Hyperactivity Disorder (Kendall, Hatton, Beckett, & Leo, 2003; Walker-Noack, Corkum, Elik, Fearon, 2013) and Autistic Spectrum Disorder (Huws & Jones 2008).  There have been a growing number of studies exploring young people's experiences of living with a mental health condition.  However, it continues to remain underexplored in relation to the adult literature (Buston, 2002).

In light of the growing literature around the first hand experiences of young people with a mental health difficulty, and the prevalence and impact of such difficulties on a young person, it is important to continue to explore their experiences and consider these within the context of policy and practice.

## Aims of the Review

This paper will systematically review the literature on the lived experiences of children and young people living with mental health difficulties.

The proposed review aims to;

1) Understand the way in which children and young people with a mental health condition make sense of their difficulties and the impact it has on their lives.

2) Critically evaluate what we know so far about the experiences of children and young people living with a mental health difficulty.

3) Identify implications for clinical interventions, service development and areas for future research.

## Methodology

## Literature Search

### Search Process.

A systematic review of the qualitative literature exploring lived experiences of young people with mental health difficulties was carried out between November 2015 and January 2016.  Databases covering literature

within health and social sciences, including disciplines of psychology, nursing, medicine and social services were searched.  These included Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science: Core collection, PsychINFO, Scopus, PubMED, Applied Social Sciences Index and Abstract (ASSIA).

**Search Terms.**

Table 1.1 presents an overview of the search terms used which were formulated from the research question and subject area.  A Boolean search strategy was used with each concept being combined with OR then AND.  The search terms were also truncated where appropriate with a wildcard (*) to pick up all possible word endings.

**Table 1.1:** *Search Terms*

|  | Search Terms |
|---|---|
| Concept One | "mental illness*", "mental health problem*", camhs, "psychological difficulties" *Combined with OR then AND* |
| Concept Two | perception*, experience*, "service user perspective*", "child's voice*", "first person account*", "lived experience*" *Combined with OR then AND* |
| Concept Three | Qualitative, phenomenology*, Narrative* *Combined with OR then AND* |
| Concept Four | child*, adolesce*, "young person", paediatric, pediatric, "young people" *Combined with OR then AND* |

**Inclusion and Exclusion Criteria**

Titles and abstracts were screened and retained if they were written in English, peer reviewed and looked at experiences of children and young people with significant mental health difficulties[2]. Articles looking at the experiences of young people up to the age of 25 were included in order to cover the literature that has looked at experiences of young people within early intervention services.

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[2] For the purpose of this review mental health difficulties were defined as a recognised mental health condition or psychological distress of an extent that required support from services.

The specific inclusion and exclusion criteria used in this systematic review are described in Table 1.2.

**Table 1.2:** *Study Selection Inclusion and Exclusion Criteria*

| Inclusion Criteria | 1. Study explored participants' direct personal perceptions and experiences of living with a mental health difficulty.<br>2. Participants were under the age of 25.<br>3. Had a defined qualitative methodology.<br>4. Article was available for review. |
|---|---|
| Exclusion Criteria | 1. Study looked at a specific sub group of young people e.g. Young Offenders, Looked After Children.<br>2. Study was of mixed methodology.<br>3. Study looked at neurodevelopmental disorders.<br>4. Studies where it was not possible to separate data from the young person from data gathered from other e.g. family member.<br>5. Studies were specific to only one aspect of a young person's experience. |

**Systematic Study Selection Process**

In order to ensure the quality of reporting within this review, the systematic process of selection was recorded using the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman, 2009).

In the identification phase, 1707 articles were identified from the search process. These were then screened for duplicates, leaving 903 to be considered with regard to the inclusion /exclusion criteria. The remaining articles were then manually screened and a further 891 excluded as not relevant.

The remaining 12 articles were then reviewed for eligibility and a further three were excluded. The remaining nine articles were included for review and manual searches were undertaken of citations and reference sections which generated a further six articles for inclusion. A total of 15 articles were therefore included in this review. This process is illustrated in Figure 1.1

**Identification**

Records identified through database searching
(n = **1707**)

Records excluded as duplicates.
(n = **804**)

**Screening**

Records after duplicates removed.
Screened titles / abstracts.
(n = **903**)

Records excluded.
(n = **891**)

**Eligibility**

Full-text articles assessed for eligibility.
(n = **12**)

Full-text articles excluded, with reasons.
(n = **3**)

- *Focus on group process (n=1)*

- *Age outside of specified age range (n=1)*

- *Main focus on help seeking behaviours (n=1)*

**Included**

Studies included in qualitative synthesis.
(n = **9**)

Manual searches identified an additional **6** studies

Total eligible studies included in synthesis.
(n = **15**)

***Figure 1.1:* Study Selection Procedure**

**Quality Assessment**

All articles were reviewed using a quality appraisal checklist in order to establish the quality of their contribution to the review. A complex debate surrounds the use of Appraisal Tools within qualitative research, e.g. whether criteria from the quantitative field should be applied or whether different criteria should be used. Mays and Pope (2006) reported that the main concerns centre around the concepts of validity and reliability. However, despite this debate it was felt the use of an Appraisal Tool was important, in order to provide transparency, ensuring the reader can see the quality of the evidence presented.

This review uses Walsh and Downe's (2006) Quality Appraisal Checklist (Appendix B). This checklist brings together characteristics of eight existing qualitative appraisal tools in order to provide a comprehensive summary that allows the credibility, transferability, dependability and confirmability of the research to be assessed. This appraisal tool allows a rating from A-D to be given, which facilitates a hierarchical overview of the articles reviewed. For example, articles described as having an 'A' rating are described as having 'No/Few flaws' and their credibility, transferability, dependability and confirmability is described as high. An article that is described as having a 'D' rating is described as having significant flaws which are very likely to affect the credibility, transferability, dependability, and/or confirmability of the study.

All papers were subjected to appraisal across the following eight areas; scope and purpose, methodological design, sampling strategy, analysis, interpretation, reflexivity, ethical dimensions, and relevance and transferability (Walsh & Downe, 2006).  The areas were scored with regard to the presence of essential criteria (Yes, Partial or No), and given an overall rating of A to D.

**Findings of Quality Appraisal Checklist**

Of the fifteen studies appraised, four were given a quality rating of 'A', seven of 'B' and four of 'C' (See Table 1.3).  All studies reviewed clearly stated their rationale and research aims and used data to support their interpretations through the use of interview quotes when discussing the study's findings.  They also gave a clear description of how interpretations led to conclusions.  All studies were embedded within existing literature, although none of the studies showed evidence that a systematic approach to their literature review had been undertaken.

All studies demonstrated a clear audit trail and evidence of the relevance and transferability of their findings.  Whilst all studies stated the methodological approach and design they used and discussed the rationale for the chosen method, three papers did not discuss the epistemological grounding for their study and the rationale for the specific qualitative method chosen (Cadario *et al.*, 2011; Gilbert, Farrand & Lankshear, 2012; Welsh & Tiffin, 2012).  In addition to this, Gilbert and colleagues (2012) did not explicitly state the analytic approach used, only referring to use of conventions for coding and development of themes from qualitative data supported by the use of ATLAS.ti software.

The quality appraisal highlighted limitations within the area of reflexivity, with only two studies fully demonstrating reflexivity of the researcher (MacDonald, Sauer, Howie and Albiston, 2005; Farmer, 2002). These studies documented the process of bracketing and field notes during the initial research stages and analysis in order to minimise the influence of any preconceptions and biases, allowing them to remain open to unexpected findings. MacDonald and colleagues (2005) also acknowledged the pre-existing relationship between researcher and participants and preconceptions about young people's social relationships following a first episode of psychosis.

Two further studies partially met the criteria for reflexivity as they documented the use of a reflective diary (Hill & Dallos, 2011) or referred to the use of bracketing and self-reflection during their research process (Leavey, 2005). The position and beliefs of the researcher are an important consideration when conducting hermeneutic research as these will influence the findings. It is possible, however, that information regarding reflexivity has not been documented in studies due to journal word limits.

Journal word counts may also account for the limited detail regarding ethical considerations. All studies documented ethical approval and briefly described how issues of anonymity, confidentiality and consent were addressed. However only two studies (Meadus, 2007; Shaw, Dallos & Shoebridge, 2009) documented a more detailed description of how informed consent was obtained. Despite the above limitations, no significant ethical concerns were noted in any of the studies reviewed.

**Characteristics of Study**

      A summary of the key characteristics of the 15 studies reviewed can be found in Table 1.3.  All reviewed studies were qualitative in design, seven took place in the UK, two in Australia, three in Canada, two in the USA, and one in New Zealand.

**Table 1.3:** *Characteristics of Studies*

| Author, Date and Country of Origin, and Quality Review rating | Experiences Explored | Sample Size, Recruitment strategy and location. | Data Collection Methods & Data Analysis | Participant Details (age, diagnosis & ethnicity) | Summary of Key Findings |
|---|---|---|---|---|---|
| **Brooks & Dallos (2009).**<br><br>**Country of Origin**<br><br>**UK**<br><br>**Quality Review Rating**<br><br>**B** | Young women's understanding of development of difficulties. | Sample Size<br>5.<br><br>Recruited From<br>CAMHS, Southwest of England.<br><br>Strategy<br>Young people experiencing distress/ difficulties who were accessing CAMHS invited to participate. | Data Collection<br>Biographical Narrative interview.<br><br>Data Analysis<br>Narrative Analysis (Labor & Watesky Framework, 1967). | Sex<br>Female.<br><br>Age<br>15-17.<br><br>Diagnosis<br>N/A.<br><br>Ethnicity<br>Not Known. | Narratives were all situated within relational and social contexts. Young people drew upon a socially shared discourse in order to position themselves.<br><br>Focus on a socially shared discourse in making sense of life events. Individuals positioned themselves within a medical or psychological discourse.<br><br>A vulnerability to medical narratives highlighted potential for adolescents to become constrained by their narrative; highlighted opportunities to work with young person to develop less self-blaming narrative.<br><br>Sub-narrative of Hidden Distress<br>Partly a response to parents/ others being unavailable partly due to ambivalence regarding balance of being dependant on parent for support vs becoming independent, self-reliant and connected to peers. |

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| **Cadario *et al.*, (2011).**<br><br>**Country of Origin**<br><br>**New Zealand**<br><br>**Quality Review rating**<br><br>**C** | Experience of first episode psychosis and treatment. | <u>Sample Size</u><br>12.<br><br><u>Recruited From</u><br>CAMHS (1 inpatient unit, 3 community-based units).<br><br><u>Strategy</u><br>Clinician approached young person.<br><br>The individuals care giver was also interviewed however this data is excluded from this review. | <u>Data Collection</u><br>Mix of unstructured and structured interviews.<br><br><u>Data Analysis</u><br>General Inductive Approach. | <u>Sex</u><br>7 males, 5 females.<br><br><u>Age</u><br>12-18.<br><br><u>Diagnosis</u><br>First episode of psychosis.<br><br><u>Ethnicity</u><br>Not Known. | **Six Themes**<br><br><u>Difficulties Noticed</u><br>Changes in behaviour, conduct and interests, mood disturbances, hallucinations, delusions, difficulties in thinking.<br><br><u>Lack of Awareness of Mental Illness</u><br>Difficulties not attributed to Mental Health Condition, made sense of in terms of illegal drugs, physical illness, and spiritual experiences.<br><br><u>How was Help Sought and what Service was Approached</u><br>Parents, extended family, friends, and school counsellor.  Others did not approach others but changed behaviour.<br><br><u>Thoughts about Illness Precipitants</u><br>Psychoactive substances, stressful experiences, family life events.<br><br><u>Experience of Service & Suggestions</u><br>Positive experiences related to perceptions that staff and services were accessible, supportive and sensitive, adequate provision of information, continuity of care and peer support, inpatient facilities.<br><br>Negative experiences – being hospitalised, exposed to peers who were unwell, staff who they perceived as insensitive. |

Pharmacological aspects of treatment both positive and negative; seen as only one part of a more comprehensive treatment package.

Beliefs and Knowledge of Mental Illness
Limited knowledge of Mental Health Condition prior to own experience, sense of acceptance, and some valued experience as enriching.

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| **Farmer (2002).**<br><br>**Country of Origin**<br><br>**USA**<br><br>**Quality Review Rating**<br><br>**B** | Experiences of major depression. | Sample Size<br>5.<br><br>Recruited From<br>South Western Outpatient Mental Health Facility.<br><br>Strategy<br>Clinicians working within service identified and approached potential participants. | Data Collection<br>In depth Interviews.<br><br>Data Analysis<br>Phenomenological approach. Adaptation of Colaizzi's method. | Sex<br>3 females, 2 males.<br><br>Age<br>13-17.<br><br>Diagnosis<br>Depression.<br><br>Ethnicity<br>Caucasian, Hispanic & African American. | **Eight Themes**<br><br>Dispirited Weariness<br>Constant fatigue, Anxious misery, physical symptoms, academic downslide & loss of academic self-esteem.<br><br>Emotional Homelessness: Apartness from Others<br>Apartness from others, loss of connection with self, loss of connection with higher power, unexpected losses & mourning the loss of closeness.<br><br>Emotional Homelessness: Constant Threat of Abuse, No Safety Where Expected<br>Constant threat of abuse, uncertainty of parental support, compared unfavourably with siblings & issues of trust.<br><br>Unrelenting Anger<br>Nature of anger, manifestation of anger, seeking the root of anger, directed expression of anger & cost of anger. |

Parental Break-Up: Caught in the Middle
Helplessly watching disintegration, grieving, aligning with one parent against other, watching parents fail again, awareness of abuse, tension takes personal toll & seeing the good amidst the changes.

Spectrum of Escape From Pain
Means of temporary escape, losing stake in self, deserving punishment & suicide as definitive means of escape.

Perspectives on Friendship
Friends not always reliable, handling rejection, friends as constants & friends as caretakers.

Gaining a Sense of Getting Well
Therapy: finding a safe base, self care, the up and down course, reconnecting through faith, acquiring new skills, measuring symptomatic improvement, assessing progress at home, looking back: depression is hard to explain, looking forward unresolved issues & feeling better but not well yet.

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| **Gilbert *et al.,* (2012).**<br><br>**Country of Origin**<br><br>**UK** | Experiences of young people who were at risk of personality disorder. | Sample Size<br> 27.<br><br>Recruited From<br>Third sector street level early intervention service (EIS) | Data Collection<br>Semi structured Interviews.<br><br>Data Analysis<br>Not explicitly stated- possibly a thematic approach. | Sex<br>17 females, 10 males.<br><br>Age<br>16-25.<br><br>Diagnosis | **Three themes**<br><br>A Life In Turmoil: Responding To Chaos<br>Individuals described chaotic lifestyles fraught with difficulties (e.g. Homelessness, substance misuse, abusive relationships).<br><br>Difficult Relationships: Instability Trauma and Isolation |

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| **Quality Review Rating**<br><br>**C** | | Strategy<br>Letters sent to young people within the EIS inviting them to take part in study. | | At risk of personality disorder.<br><br>Ethnicity<br>All except one were White British. | Paucity of support for individuals. Relationships were at best unsupportive leaving some individuals feeling abandoned. For others relationships were traumatic.<br><br>The Case Coordinators<br>With regard to support, participants reflected the importance of being able to discuss issues with someone, get practical help, and the importance of being taken seriously and not judged. Individuals feared moving on from the service. |
| **Hill & Dallos, (2011).**<br><br>**Country of Origin**<br><br>**UK**<br><br>**Quality Review Rating**<br><br>**A** | Experiences of adolescents who have engaged in self-harm. | Sample Size<br>6.<br><br>Recruited From<br>Charity for young people who experience or may be at risk of mental health difficulties.<br><br>Strategy<br>All adolescents using the service who self-harmed were invited to take part. | Data Collection<br>Data was collected in three phases: a life story interview, a reflective interview, and a member validation process.<br><br>Data Analysis<br>Narrative Analysis. | Sex<br>5 Females, 1 male.<br><br>Age<br>13-18.<br><br>Diagnosis<br>Engaged in self-harming behaviours; Defined as direct actions that injure the body, e.g. cutting, burning, scratching, gouging and other similar actions. | **Three Themes**<br><br>People Just Don't Understand Self-Harm is my Way of Coping; It Doesn't Mean That I am Weird or Crazy<br>Feelings of being misunderstood that alienated the young person from those around them. Individuals subsequently hid their self-harm.<br><br>Talking is Difficult So I Keep it All Inside<br>The young people's stories and the way they told their stories powerfully illustrated how difficult they find it to talk.<br><br>Putting the Anger Inwards<br>Young people described blaming themselves or believed they deserved to be punished, and deserved the self-harm. |

|  |  |  |  | Ethnicity<br>Not reported. |  |
|---|---|---|---|---|---|

| **Leavey (2005).**<br><br>**<u>Country of Origin</u>**<br><br>**Canada**<br><br>**<u>Quality Review Rating</u>**<br><br>**A** | Experiences of becoming, living with, and recovering from Mental Health Condition amongst transitional – aged youth. | <u>Sample Size</u><br>13.<br><br><u>Recruited From</u><br>Psychosocial Rehabilitation Centre within a large urban Canadian community.<br><br><u>Strategy</u><br>Recruitment poster and distribution of study details to potential participants by centre staff. | <u>Data Collection</u><br>Semi structured interviews.<br><br><u>Data Analysis</u><br>Grounded Theory. | <u>Sex</u><br>6 Females, 7 males.<br><br><u>Age</u><br>17-23.<br><br><u>Diagnosis</u><br>Mixed sample some participants presented with more than one diagnosis: schizophrenia, psychosis, delusional disorder, OCD, depression, suicidal ideation, eating disorder, anxiety disorder, bipolar disorder, mood disorder, PTSD, personality disorder and learning disability. | **Four Themes**<br><br><u>Emergence</u><br>Problem getting the right diagnosis; labelling; Stigma.<br><br><u>Loss</u><br>Loss of Identity; Loss of independence; Loss of Academic Functioning; Loss of family status; Loss of friends; Interrupted intimate relationship development; Interrupted career development.<br><br><u>Adaptation</u><br>Coping strategies and Acceptance.<br><br><u>Recovery</u><br>Conditions for recovery; Reintegration; Volunteering; Hope for the future. |

| | | | | Ethnicity<br>Not known. | |
|---|---|---|---|---|---|

| **MacDonald _et al.,_ (2005).**<br><br>**Country of Origin**<br><br>**Australia**<br><br>**Quality Review Rating**<br><br>**A** | Experience of social relationships during recovery phase of first episode psychosis. | Sample Size<br>6.<br><br>Recruited From<br>Recovery Group Program at Early Psychosis Prevention & Intervention Centre (EPPIC).<br><br>Strategy<br>Potential participants identified by group facilitators as able to give detailed description of their social experiences. | Data Collection<br>In depth Phenomenological interviews, open-ended and unstructured, completed twice.<br><br>Data Analysis<br>Phenomenological Analysis (Colaizzi 1978; & Moustakas 1994). | Sex<br>5 males, 1 female.<br><br>Age<br>19-25.<br><br>Diagnosis<br>First episode psychosis.<br><br>Ethnicity<br>Caucasian. | **Five Themes**<br><br>Hanging Out with People Who I Like and Understand Me<br>Participants wanted to take part in social activities typically enjoyed by those of their age group. Sought out others who shared their experiences of Psychosis.<br><br>Valuing Families and Other Supports<br>Participants relied on parents to discuss problems and support them with managing on a daily basis, and valued the support they got from family members and professionals.<br><br>Spending Less Time with Old Friends<br>Felt others would not understand or felt misunderstood by previous friends therefore preferred to spend time with those who did understand them. Other factors not specific to their experience of psychosis also resulted in changes in relationships with peers e.g. finishing school.<br><br>Something Happened to Me: Being Different Now<br>Participants believed other people now perceived them differently. |

|  |  |  |  |  | Building New Relationship |
| --- | --- | --- | --- | --- | --- |
|  |  |  |  |  | Following experiences, individuals reflected on their personal values and beliefs which led to changes in their decisions around social interactions. |
| **McCann *et al.*, (2012).**<br><br>**Country of Origin**<br><br>**Australia**<br><br>**Quality Review Rating**<br><br>**B** | Experience of young people diagnosed with depression. | Sample Size<br>26.<br><br>Recruited From<br>Government funded Youth Mental Health, enhanced primary care service in large Australian city.<br><br>Strategy<br>Service clinicians identified and approached potential participants. | Data Collection<br>Semi structured Interviews.<br><br>Data Analysis<br>IPA. | Sex<br>16 females, 10 males.<br><br>Age<br>16-25.<br><br>Diagnosis<br>7 depression, 13 depression & anxiety, 1 depression & substance misuse, 3 depression, anxiety & substance misuse, 2 missing data.<br><br>Ethnicity<br>21 Australian, 4 Asia – Pacific Countries, 1 African countries. | **Four Themes**<br><br>Overlapping themes reflecting the young people's difficulties in coming to terms with and responding to their depression in self-protective, harmful and at times life-threatening ways.<br><br>Struggling to Make Sense of Their Situation<br>Individuals tried to make sense of the confusing situation they found themselves in, sometimes questioning themselves about why they were different.<br><br>Spiralling Down<br>As depression became more prominent, individuals felt that their quality of life was spiralling down. As their mental state deteriorated, it negatively affected self-esteem and confidence. They experienced mental and physical fatigue, and difficulties with depression dominated their life.<br><br>Withdrawing<br>One consequence of spiralling down was that individuals withdrew form those around them. |

| | | | | | Contemplating Self-Harm or Suicide<br>Another consequence of spiralling down was that some individuals contemplated self harm or suicide. |
|---|---|---|---|---|---|
| **Meadus (2007).**<br><br>**Country of Origin**<br><br>**Canada**<br><br>**Quality Review Rating**<br><br>**B** | Coping as experienced by adolescents with a mood disorder. | Sample Size<br>9.<br><br>Recruited From<br>Inpatient & outpatient services where participants were under the care of psychiatrist of family physician.<br><br>Strategy<br>Not known. | Data Collection<br>Unstructured Interviews and review of Participants health records.<br><br>Data Analysis<br>Grounded Theory. | Sex<br>8, female, 1 male.<br><br>Age<br>15-20.<br><br>Diagnosis<br>Mood Disorder.<br><br>Ethnicity<br>Not Known. | **An Unplanned Journey – Coping Through Connections**<br><br>Theory consists of four phases made up of the following categories; Feeling Different, Cutting Off Connections, Facing the Challenge/ Reconnecting, Learning from the Experience.<br><br>Phases are not linear and the adolescent may move back and forth through these whilst coping with their mood disorder. |
| **Midgley *et al.,* (2015).**<br><br>**Country of Origin**<br><br>**UK**<br><br>**Quality Review Rating**<br><br>**C** | Experiences of depression in clinically referred adolescents. | Sample Size<br>77.<br><br>Recruited From<br>Five CAMHS across London.<br><br>Strategy<br>Participants were part of a larger study (Improving Mood with | Data Collection<br>Semi structured interviews using schedule that had been developed for IMPACT study.<br><br>Data Analysis<br>Thematic Approach using Framework Analysis. | Sex<br>55 Female, 22 Male.<br><br>Age<br>11-17.<br><br>Diagnosis<br>Unipolar depression of a moderate to | **Five themes**<br><br>Misery, Despair and Tears<br>Individuals described feeling sad, upset, depressed etc. repeatedly throughout the interview when asked how they were feeling.<br><br>Anger and Violence Towards Self and Others<br>Individuals reported feelings of anger and aggression directed at themselves or others |

| | | | | severe impairment. | either explicitly during interview or through their tone of voice during the interview. |
|---|---|---|---|---|---|
| | | Psychoanalytical & Cognitive Therapies – IMPACT).<br><br>This present study used the baseline phase data collected as part of original study.<br><br>Participants were invited to take part in study once IMPACT baseline data had been collected. | | Co- morbidities noted: GAD, Avoidant disorder, ODD, Phobias, and PTSD.<br><br>Ethnicity<br>50% White British, 14% Mixed 7% Black/ Black British, 5% Asian/Asian British, 8% Other Ethnic Group. | A Bleak View of Everything<br>Most individuals described being preoccupied with negative thoughts.<br><br>Isolation and Cutting off from the World<br>A sense of isolation was described by participants either as a result of active withdrawal from relationships or through rejection.<br><br>The Impact on Education<br>An individuals progress and experience of school was affected by the lack of energy, loss of interest and wish to withdraw form the world. |
| **Shaw *et al.,* (2009).**<br><br>**Country of Origin**<br><br>**UK**<br><br>**Quality Review Rating**<br><br>**A** | Young women's experiences of depression. | Sample Size<br>6.<br><br>Recruited From<br>CAMHS.<br><br>Strategy<br>Clinicians within the service identified and approached potential participants. | Data Collection<br>Semi structured Interviews.<br><br>Data Analysis<br>IPA. | Sex<br>All Female.<br><br>Age<br>14-17.<br><br>Diagnosis/ Difficulties<br>High levels subjective of distress, Low Mood & | **Three Themes**<br><br>Communication<br>Not talking, wanted to talk but unable to communicate.<br><br>Hurt Self<br>Worthless self, self-hatred, feeling unwanted, lost identity.<br><br>Difference<br> A sense of feeling different and being not normal. |

| | | thoughts of self-harm.<br><br>Ethnicity<br>Caucasian. | |
|---|---|---|---|

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|---|---|---|---|---|---|
| **Simonds et al., (2014).**<br><br>**Country of Origin**<br><br>**UK**<br><br>**Quality Review Rating**<br><br>**B** | Understanding the process of experiencing anxiety and depression in young people. | Sample Size<br>9.<br><br>Recruited From<br>CAMHS in the south of England.<br><br>Strategy<br>Identified by Consultant Clinical Psychologist within service. 150 letters sent to eligible families inviting them to take part. | Data Collection<br>Semi structured Interviews.<br><br>Data Analysis<br>Thematic Analysis.<br><br>12 mothers/guardians were also interviewed- this data is not considered within this review. | Sex<br>7, Female, 2 Male.<br><br>Age<br>14-16.<br><br>Diagnosis<br>3 Depression, 7 met criteria for Anxiety Disorders (2 OCD, 1 Panic, 3 GAD).<br><br>Ethnicity<br>White British. | **Three Themes**<br><br>Loss of Self<br>Challenges to how the individual relates to themselves and others leads to a relational transformation resulting in a lost self.<br><br>Renegotiating of the Self<br>Renegotiation of the lost self, a process marked by ambivalence and uncertainty.<br><br>Anticipation of Future Self<br>Individuals identified goals and future aspirations, and a hope of a future which is symptom free.<br><br>Findings indicated that young people do experience a process of recovery.<br><br>Process described has some congruence with the earlier stages of adult recovery model (Biographical disruption and the development of new meanings and changes in sense of identity).<br><br>However divergence from later stages of adult model with regard to developing sense of hope and responsibility. |

| Welsh & Tiffin (2012). | Exploring experiences and understanding of adolescents with an At-Risk Mental State (ARMS) label. | Sample Size 6. | Data Collection Semi structured Interviews. | Sex 3 females, 3 males. | Three Themes |
|---|---|---|---|---|---|
| **Country of Origin** | | Recruited From Not reported. | Data Analysis IPA. | Age 13-18. | "It's Better to Say It" Consensus from participants that they wanted to be informed about their condition and for mental health services to be upfront and honest with them. |
| **UK** | | Strategy Participants drawn from previous study aimed at categorising how adolescents with ARMS initially present to services. | | Diagnosis At Risk Mental State (ARMS). | |
| **Quality Review Rating** | | | | | "How Others Would Take Me" Concerns around whether or not to tell others about their diagnosis. |
| **C** | | | | Ethnicity Not Reported. | "Just to Have Somebody to Talk to" What was particularly valuable in their encounter with mental health services' e.g. sharing experiences in a safe environment. |

| Wisdom & Green (2004). | Teenagers experience of depression. | Sample Size 15. | Data Collection was a two-part process: | Sex 8 Females, 7 Males. | Theoretical Scheme Developed |
|---|---|---|---|---|---|
| **Country of Origin** | | Recruited From Non Profit Group Model Health Maintenance Organisation. | Preliminary Investigations This involved a focus group to gather basic data on teenager's ideas about healthcare from seven young people aged 15 who were recruited from local high school. | Age 14-19. | Moves in a chronological order from; |
| **USA; Portland, Oregon** | | | | Diagnosis Unipolar depression. | A Growth of Distress Individuals described a slow growth of distress, often precipitated by a significant life event. |
| **Quality Review Rating** | | Strategy Potential participants were contacted by letter or phone to invite | | Ethnicity | Being in a Funk Experiences of depression as distressing and disturbing, individuals felt weighed down. |
| **B** | | | | | |

| | | | | 13 white (non-Hispanic)<br>2 Hispanic. | Consideration of Whether They Were Depressed<br>Reflected on difference between times before they were depressed and what it was like to be in a funk. |
| --- | --- | --- | --- | --- | --- |
| | | them to take part in study. | Main Investigation<br>Involved In-depth Interviews.<br><br>Data Analysis<br>Grounded Theory. | | |
| | | | | | Receiving the Diagnosis<br>Different reactions to receiving diagnosis characterised as being; Labellers, Medicalisers, Identity Infusers. |
| | | | | | Making Sense of Their Depression<br>Upon receiving diagnosis individuals decide whether to agree with label, integrate information regarding diagnosis into self-image, participate in recommended treatment and interventions or decline treatment. |
| | | | | | Understanding of the way in which adolescents respond to diagnosis (Labellers, Medicalisers, Identity Infusers) useful for clinicians in understanding how to engage and support the young person and the likelihood of adherence to treatment options. |
| **Woodgate (2006).**<br><br><u>**Country of Origin**</u><br><br>**Canada** | Experience of what it is like to be an adolescent living with depression. | Sample Size<br>14.<br><br>Recruited From<br>Adolescent Outpatient Treatment units.<br><br>Strategy | Data Collection<br>Individual Open ended interviews.<br><br>Data Analysis<br>Van Manen's Hermeneutic Phenomenology Approach to Analysis. | Sex<br>11 Females, 3 Males.<br><br>Age<br>13½ - 18.<br><br>Diagnosis<br>Depression, | **Themes**<br><br>Essence: Living in The Shadow of Fear<br><br>Containing the Shadow of Fear<br>Accepting your depression; Taking responsibility in getting better; Staying in the positive. |

| | | | | |
|---|---|---|---|---|
| **Quality Review Rating**<br><br>**B** | Nurse intermediaries within the service identified and approached potential participants. | A descriptive & interpretive phenomenological approach. With the aim of grasping the essence (meta-theme). | 12 participants had other mental health difficulties or a learning disability.<br><br>Ethnicity<br>12 Caucasian, other ethnicities not reported. | Keeping the Self-Alive<br>Getting in touch with your feelings; Believing in yourself; Being good to yourself.<br><br>Maintaining a Sense of Belonging in the World<br>Knowing others are trying to understand; Knowing others are making 'check-ins'; Knowing others are making a difference.<br><br>Feeling Valued as a Human Being<br>Knowing that healthcare professionals are focused on the adolescent.  Knowing that healthcare professionals are flexible in their approach.  Knowing that healthcare professionals will never give up on the adolescent. |

**Abbreviations used within table:** Obsessive Compulsive Disorder (OCD), Post-traumatic Stress Disorder (PTSD), General Anxiety Disorder (GAD), Oppositional Defiance disorder (ODD).

**Aims of Reviewed Studies.**

Seven of the studies reviewed looked at experiences of young people living with depression.  Two studies explored young people's experiences of first episode psychosis.  Of the remaining studies, one paper explored experiences of adolescents with a mood disorder focusing on coping (Meadus, 2007).  Another study examined adolescents' attempts to make sense of their self-harming behaviour and their life events (Hill & Dallos, 2011).  Welsh and Tiffin (2012) considered how adolescents with an At Risk Mental State (ARMS) label understood and explored their condition, whilst another study looked at the experiences of young people at risk of a diagnosis of personality disorder (Gilbert *et al.,* 2012).  Leavey (2005) explored the experiences of living with a mental health diagnosis amongst transitional aged youth[3].

The final study was the only paper reviewed that took a non-diagnostic approach and considered young women's narratives about the important experiences in their lives and the difficulties that led them to Child and Adolescent Mental Health Services (CAMHS) (Brooks & Dallos, 2009).

**Recruitment and Participant Characteristics.**

All studies used purposive sampling, with clinicians within services and organisations identifying potential participants.  One study also used posters displayed within their service to recruit participants (Leavey, 2005).  Participants

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[3] Young people who are of an age where a move between child and adult services is required.

were aged between 11 and 25 years of age and were all drawn from clinical populations.

Four studies recruited from CAMHS, within the UK (Brooks & Dallos 2009; Midgley *et al.,* 2015; Shaw *et al.*, 2009; Simmonds *et al.*, 2014).  One study approached young people who were attending an Early Intervention Service (EIS) (Gilbert *et al*., 2012).  Two studies recruited participants who were already participating in larger studies (Welsh & Tiffin 2012; Midgley *et al.*, 2015).  Four studies recruited young people from community or outpatient CAMHS outside the UK (Cadario *et al.*, 2011; Farmer, 2002; Meadus, 2007; Woodgate, 2006).  One study recruited participants attending a recovery group programme for first episode psychosis (MacDonald *et al.,* 2005).  The final four studies recruited participants from third sector organisations.  These included a charity for young people at risk of mental health difficulties in the UK (Hill & Dallos, 2011), an Enhanced Primary Care service in Australia (McCann, Lubman & Clarke, 2012), a non-profit health maintenance organisation in the USA (Wisdom & Green, 2004) and a psychosocial rehabilitation centre for young people in a large urban community in Canada (Leavey, 2005).

**Synthesis of Studies Reviewed**

There is some debate about synthesising qualitative research as it is suggested that it is specific to the research context, time and sample population and therefore not generalisable (Thomas & Harden, 2008).  However Morse (1999) argues this is only the case when generalisability is considered through the lens of quantitative generalisability (e.g. sampling and statistical

significance), and that the use of purposive sampling means the knowledge gained can be applied to similar contexts and is not limited to a particular group. Others have argued the process of synthesising qualitative findings is epistemologically and ethically inappropriate, as it results in loss of the uniqueness, depth and insight of the individual projects (Sandelowski, Docherty & Emden, 1997).

Whilst acknowledging the above debate, it is felt due to the value of qualitative literature in informing practice, a systematic review and synthesis of qualitative papers is important in order to bring together pockets of knowledge that individual research studies provide.  This current review draws upon the principles of meta-ethnography as originally described by Noblit and Hare (1988).  This involves identifying key concepts from studies and translating them into one another, producing substantive interpretations about the experiences being considered, accounting for similarities and differences within papers (Aveyard, 2010).

## Results

The current review aims to gain understanding of the way in which young people with a mental health condition make sense of their difficulties and the impact it has on their lives.  Following a synthesis of the reviewed studies, the following eight themes were identified.  Table 1.4 (Appendix C) gives an overview of the original article themes, and the themes identified following synthesis.  Participant quotes from the original articles are also shown to ensure the findings are grounded in the young person's experiences.

**Concealed Distress and Difficulties**

'*Concealed Distress and Difficulties*' encapsulates the way in which young people internalised their distress and kept it hidden from others. At times, this resulted in their difficulties not being identified until they were either disclosed or unable to be kept hidden any longer, sometimes resulting in a delay in them gaining support;

> *I think I eventually told my mum what happened. I didn't want to tell anyone else, yeah I think I eventually told them what I was feeling and stuff.*

> (Cadario *et al.*, 2011, p 86)

'Hidden Distress' was also recognised as a sub narrative that was prominent across the stories told by the participants in the study by Brooks and Dallos (2009).

There appeared to be many reasons for the young person's distress being concealed. At times it may have been internalised because it was too difficult to communicate it with others (Hill & Dallos, 2011). However, at other times the participants hid their distress and difficulties as they were concerned about how others would respond (Shaw *et al.*, 2009). Other participants described withdrawing from those around them in order to stop them becoming aware of their situation as they were fearful of the perceived stigma and potential loss of relationships that might come if others knew the full story (McCann *et al.,* 2012; Welsh & Tiffin, 2012). In addition, another study found a

sense of shame was a reason for the participants to conceal their difficulties (Simonds *et al.*, 2014).

In three of the nine studies highlighting the theme of '*Concealed Distress and Difficulties*', the concealment of distress led to a delay in seeking help. This appeared to be because the young person's situation had deteriorated to a point where they were no longer able to conceal their difficulties, and had reached crisis point (Brooks & Dallos, 2009; Cadario *et al.,* 2011; Farmer, 2002).

## Moving into Awareness

'*Moving into Awareness'* refers to aspects of a process of becoming aware of distress and difficulties and of how this led to accessing help.

### "I never thought it was unusual" (Cadario *et al*., 2011, p. 95).

Participants rarely conceptualised their difficulties as being experiences of a mental health condition. A number of studies described how participants frequently failed to identify their difficulties as something of concern (Brooks & Dallos, 2009);

> *I never thought it was unusual at the time, it came and I didn't even realise I had it.*

> (Cadario *et al.*, 2011, p. 95)

Others interpreted their difficulties as being a normal part of adolescence, or described how they thought it would pass and kept giving it more time, thinking it would go away (Meadus, 2007). This attribution of

difficulties to a normal development phase was also reported by Wisdom and Green (2004). Others described how they noticed something was not right but attributed it to the effects of substances, physical illness or spiritual experiences (Cadario *et al.*, 2011).

### A Growth of Awareness.

'*Moving into Awareness'* was documented by Meadus (2007) as a phase of "Feeling Different". Meadus (2007) described how the experience of feeling different was indicated by the onset of difficulties that led to disruption in school, family and social relationships. One participant described how they became aware that things were different when they no longer found pleasure from anything. Others described becoming aware of emotional changes that signified the beginning of their difficulties.

Wisdom and Green (2004) also illustrated the process of '*Moving into Awareness'* within their theoretical scheme of 'Growth of Distress'. Within this study, participants described how the distress they experienced which they felt was triggered by significant events in their lives, was initially unnoticeable, but over several months or even years became incapacitating. Participants described a process of no longer being able to normalise symptoms as being part of adolescence, as they no longer fitted within what they considered to be typical of the experiences of their peers. Suicidal thoughts or the duration of the distress precluded it continually being dismissed (Wisdom & Green, 2004).

**Others Awareness.**

Once participants became aware of their difficulties, this was often the beginning of help and support being sought (Wisdom & Green 2004; Meadus, 2007) and the start of noticing their own need to feel better (Farmer, 2002). The young person's difficulties eventually moved into 'Others Awareness';

*I think my friends then started to suspect that something was wrong because I was normally a very happy bouncy person…*

(Brook & Dallos, 2009 p. 110)

At times, this awareness was quite sudden and is linked with the aspect of reaching crisis point (see '*Concealed Distress and Difficulties'*). For example, others became aware of one young person's distress following a hospital admission, after they jumped from a window at a party (Midgley *et al.*, 2015).

A family member often noticed a young person's difficulties. Cadario and colleagues (2011) noted teachers and complete strangers had also been in a position to notice difficulties, supporting participants to access relevant services. One study however reported young people's difficulties were sometimes dismissed as being unimportant by caregivers (Farmer, 2002).

**Connection**

One of the most prominent themes was of '*Connection*', which was present in all but three studies (Cadario *et al.*, 2011; Welsh & Tiffin, 2012; Wisdom & Green, 2004). This theme captures the difficulty participants experienced in maintaining relationships whilst living with a mental health

condition.  These relational difficulties often impacted on availability and access to networks that previously provided a sense of support.  The theme also reflects the importance of making connections with others.

Participants spoke about experiencing a loss of relationships (Brooks & Dallos, 2009; Hill & Dallos, 2011; Leavey, 2005; MacDonald *et al.,* 2005; Simmonds *et al.,* 2014*)* or a change in key relationships (Shaw *et al.,* 2009; Leavey, 2005) as well as a feeling of "distinct separateness" from others which led to their withdrawal (Farmer, 2002, p. 574).  One participant spoke about changes in her relationships following an episode of psychosis, which echoed the findings of the studies listed above;

> *Ever since my episode occurred I have been spending less and less time with my normal outside friends …so a lot of my friendships I suppose have been severed really, more or less.*
>
> (MacDonald *et al., 2005,* p. 136)

For some young people, loss of connection was a result of mental health difficulties and appeared to be about navigating risk or avoidance of burdening others.  Being in relationships exposed the participants to possible stigmatisation and risk of rejection (Farmer, 2002; MacDonald *et al.,* 2005; McCann *et al.*, 2012) and participants expressed fears of connecting with others due to concerns about upsetting peers with their difficulties (MacDonald *et al.,* 2005).

At other times, connecting with others was just too overwhelming, and withdrawal was the only way to manage these feelings (Farmer, 2002; Macdonald *et al.,* 2005; McCann *et al.*, 2012; Meadus, 2007).  Participants who experienced anxiety and depression experienced what Simonds and colleagues (2014, p. 293) described as a *"diminishing interpersonal world".*  Participants withdrew from relationships (McCann *et al.*, 2012) and demonstrated a preference for being alone (Meadus, 2007; Shaw *et al.*, 2009).  The cost of this disconnection was the participant often feeling lonely or unloved (Farmer, 2002; Midgley *et al.*, 2015; Shaw *et al.*, 2009), whilst others described feeling as though they were "*unknown to other*s" (Shaw *et al.,* 2009.p 176).

For others, the loss of connection precipitated their difficulties and was due to living in isolating environments, which lacked safety and affection and did not facilitate the participant maintaining connection with others (Farmer, 2002; Gilbert *et al*., 2012).  One study also acknowledged the loss of connection as a natural part of changing friendships in adolescence (MacDonald *et al.*, 2005).

Some participants described how important it was to connect with those who understand (Farmer, 2002; MacDonald *et al.*, 2005).  They mentioned peers who were going through similar things (Leavey, 2005), for example when engaging in group therapy;

*You don't feel as bad because there's other people that go through the same things as you. I mean for whatever reason they're basically there for depression.*

(Farmer, 2002, p.579)

This was also reported outside of therapeutic programmes. One participant described socialising with friends who she had met as part of a group programme for psychosis (MacDonald *et al.,* 2005). One study noted being around peers who were also unwell could at times be a frightening experience (Cadario *et al.*, 2011).

Woodgate (2006) acknowledged the importance of connecting with others within the theme '*Maintaining a Sense of Belonging in the World'*. This theme described a number of factors that participants felt contributed to the sense of connection with others, which included: knowing that those close to them were trying to understand, that they would be checked on even if they had withdrawn themselves from others, and that others were trying to make a difference in the young person's life (p. 266).

**Feeling of Difference**

'*Feeling of Difference'* represents the sense of difference that participants experienced due to living with mental health difficulties. It includes the experience of difference in relation to self, and the impact on the young person's identity, as well as feelings of difference in relation to others, and

acknowledges the experience of stigma as a result of difference.  It was noted in all but four of the studies reviewed (see Table 1.4, Appendix C).

Difference was a subtheme for Shaw and colleagues (2009).  They illustrated how participants often felt a sense of difference from others, which affected their view of self;

> *I'm a bit different, I'm not like everyone else my age really.  Umm …but like I can't change who I am so I've got to live with it, if you see what I mean…I have a different perspective on life I think.  I think about things in strange ways.*
>
> (Shaw *et al*., 2009, p.175)

Changes in an individual's sense of self following the onset of their difficulties was also apparent in other studies (Meadus, 2007; Leavey, 2005).  This often contributed to a sense of loss of the self they once knew (Woodgate, 2006) or a disruption in the way the participant related to themselves (Simmonds *et al.*, 2014; Wisdom & Green 2004);

> *The safety of waking up and 'knowing who you are' which most people take for granted had suddenly vanished.*
>
> (Leavey, 2005, p.115)

Participants felt that others viewing them as different brought with it a stigma (McCann *et al*., 2012; Leavey, 2005).  This was illustrated within MacDonald and colleagues' (2005) subtheme of '*Something Happened to Me: Being Different Now*';

*It's just that they [former friends] view me differently now you know,*

*because I've become psychotic they think that you are now a waste of*

*life or something…. they just think you're a looney or something like that*

*which is not good.*

<div align="right">(MacDonald <em>et al.</em>, 2005, p. 137)</div>

Woodgate (2006) described how it was not uncommon for participants within their study to feel stigmatised and like "*outcasts*" (p.266).  In another study a participant described how friends called them "*emo*" and made '*mocking gestures*' and '*noises*' towards them which was felt to be because they did not understand their self-harm (Hill & Dallos, 2011, p. 466).  Others' understanding of a young person's difficulties appears to be linked to the young person's sense of difference.  When the participant felt their difficulties were misunderstood, they experienced an increased sense of stigmatisation.

The fear of being seen as different and being stigmatised often impacted on an individual's sense of wanting to engage with others, as they risked exposing this difference (Farmer, 2002).  This led to a participant withdrawing from others and isolating themselves as a way of protection, a process which overlaps with the previous theme of connection.

A '*Feeling of Difference*' was also apparent for one person in the way they were compared to their siblings, leading to a sense that they were not loved as much (Farmer, 2002).  Similarly, one participant described being treated differently to siblings and how this left her feeling like an outsider (Gilbert *et al.,* 2012).  Shaw and colleagues (2009) noted similar themes with

individuals describing a sense of not being wanted or not fitting in with their families or friends.  Simonds and colleagues (2014) however, noted that participants who were able to find a way to accept their difficulties, as part of the human condition, were able to reduce their sense of difference potentially helping them to re-engage with others.

**Understanding of Difficulties: Moving Between a Medical and Psychological Discourse**

Within the studies reviewed, participants appeared to make sense of their difficulties within either a medical or psychological discourse, although other studies reflected ways in which the participants moved between these (Brooks & Dallos, 2009).

A medical framework for understanding was present in a number of studies (Brooks & Dallos, 2009; Hills & Dallos, 2011; Leavey, 2005; Welsh & Tiffin, 2012).  Participants identified with a medical discourse, and difficulties were attributed to a physiological cause and understood within the parameters of diagnostic labels;

> *Umm I suffer from obsessive-compulsive disorder.  Umm I'm not really sure how I'd get it but they tell me it's sort of hereditary thing there's part of my brain that doesn't work properly, um but it's triggered by stress mainly.*
>
> (Brooks & Dallos, 2009 p. 108)

This participant appears to have made sense of their difficulties in terms of having a biological basis that is then triggered by environmental factors. Other studies also referred to a physiological basis for the young person's difficulties with individuals describing precipitants such as use of substances (Cadario, *et al.*, 2011).

For some, a diagnosis provided relief as it meant that their difficulties were understood by professionals, that other people had similar difficulties, and that mental health services would be able to help (Welsh & Tiffin, 2012; Wisdom & Green, 2004). Some participants described how they had experienced problems in getting an accurate and timely diagnosis. This may have left them feeling confused and unable to make sense of what was happening. For others, receiving a label for their difficulties came as a shock and was a distressing experience (Leavey, 2005). In some cases, it was seen as something that was harmful and may impede recovery, as participants might have integrated the condition into their identity and therefore may struggle to recover as they view the condition as a part of themselves (Wisdom & Green, 2004).

In contrast to a medical discourse, a number of participants made sense of their difficulties using a psychosocial framework. Participants reported a number of events that precipitated the onset of their difficulties, such as divorce or abuse (Brooks & Dallos, 2009; Farmer, 2002; Gilbert *et al.,* 2012; Wisdom & Green, 2004) or illness within the family (Cadario *et al.,* 2011*).* Many participants had made connections between difficult life events and their current

difficulties, although to varying degrees.  One young person described how their difficulties came about after their boyfriend took his own life (Hill & Dallos, 2011).  Another described how theirs began after two family members were diagnosed with Cancer;

> *Mum was also… she was diagnosed like the same day as my nanna, so they both had cancer, so it was a bit of a trigger.*
>
> (Cadario *et al.*, 2011 p. 97)

Other participants had not made such explicit links between difficult life events and their current difficulties (Hill & Dallos, 2011).

Some participants however struggled to make sense of what was happening to them and to find ways of understanding;

> *It's kind of confusing, you know that something's wrong and you try and progress on things, but it's kind of hard when you know there is something going on in your mind or whatever else, and you try and figure it out or fix it, and its just kind of hard sometimes and confusing.*
>
> (McCann *et al.,* 2012, p. 337)

This sense of confusion was also articulated within other papers (Shaw *et al.,* 2009; Simmonds *et al*., 2014).

**Experience of Symptoms and Secondary Consequences**

In 12 of the studies reviewed (See Table 1.4, Appendix C) participants described a constellation of difficulties, some of which could be understood

within a diagnostic framework and others which appeared to be in addition to the diagnostically labelled distress.  These were described by one participant as being on top of the difficulties typically experienced by adolescents (Wisdom & Green, 2004).

Significant emotional distress which one participant described as affecting more than just mood (McCann *et al.,* 2012) was present across over half the studies reviewed (Farmer, 2002; Hill & Dallos, 2011; McCann *et al.,* 2012; Midgley *et al.,* 2015; Shaw *et al.,* 2009; Wisdom & Green, 2004; Woodgate, 2006).  One study in particular referred to painful feelings about self (e.g. "*I'm dumb*", "*undeserving", "worthless''*) as a powerful superordinate theme within their study of female adolescent experiences of depression (Shaw *et al*., 2009, p. 173).  This was represented within other studies as low self-esteem and confidence (Farmer, 2002; McCann *et al.,* 2012; Midgley *et al.,* 2015; Simmonds *et al.,* 2014).

Participants also experienced sleep difficulties (Brooks & Dallos, 2009; Cadario *et al.*, 2011; Farmer, 2002) and a sense of fatigue (Farmer, 2002; McCann *et al*., 2012; Midgley *et al.,* 2015).  Some participants spoke of how their distress manifested itself in their body, for example feeling physically sick or experiencing a suffocating feeling in their chest (Midgley *et al.,* 2015).

Additional difficulties came from trying to escape emotional distress. Farmer (2002) talks about this within their theme of '*Continuum of Escape from Pain'* which encapsulates how participants seek escape from their difficulties in a variety of ways ranging from harmless temporary escapes (e.g. isolation,

distraction through intensive involvement in activities) to potentially permanent ones (e.g. suicide attempts).  This was reflected in other studies where participants reported engaging in sexually promiscuous behaviour and substance abuse as a way of coping, and also contemplated suicide (McCann *et al.,* 2012; Midgley *et al.,* 2015).  For some young people, hurting themselves was identified as a way of coping and as a way of managing the distress they experienced (Hill & Dallos, 2011; Gilbert *et al*., 2012).  This is further reflected in Hill and Dallos' (2011) theme '*Putting the Anger Inwards'.*

Anger towards others was a theme that was present in a few of the studies reviewed (Farmer, 2002; Midgley *et al.,* 2015).  The anger experienced by participants within these studies was described as explosive and subsequently impacted on relationships.  It also led to the participant engaging in impulsive acts, which at times resulted in the participants hurting themselves or others;

> *I would tip over chairs and stuff like just throw something I just brought at her [mother].*

(Farmer, 2002, p. 576)

Other participants engaged in aggressive acts towards objects as a way of expressing or resolving emotional turmoil (Gilbert *et al*., 2012, Midgley *et al.,* 2015).

Another difficulty was the impact of the young person's difficulties on their education (Cadario *et al.*, 2011; Farmer, 2002; Leavey, 2005; Midgley *et*

*al*., 2015; Woodgate, 2006).  Participants in Midgley and colleagues study (2015) spoke in detail about the impact on education within the theme '*Impact on Education: I Can't Learn Anything'*.  Participants expressed difficulties they encountered in both attending school and concentrating on work once they were there.  For some, the difficulties in concentrating were attributed to a loss of interest.  Others described feeling overwhelmed and anxious which impeded their ability to focus.  This potentially impacted on their academic success and career development;

> *Yeah I wanted to be a doctor but it didn't work out because of my illness.*
>
> (Leavey, 2005, p. 117)

An additional difficulty described in one of the studies was a 'Loss of Independence' (Leavey, 2005).  Participants described how they continued to be dependent upon their family for help with housing and finances, as well as emotional support.  This was one of the few studies that looked at the older age range (17-23 years old), which is more in keeping with the age of which young people may be going to university or finding employment.

**Experience of Support: Listen and Understand Me**

Eleven studies reviewed contained content related to the theme '*Experience of Support: Listen and Understand Me'* (See Table 1.4, Appendix C).  This theme captures how participants described their experiences of gaining support and help from family and friends.  In particular, the importance of being heard by others and having the understanding of others.

For some participants this experience was not a positive one; many spoke about not being understood by family and friends (MacDonald *et al.*, 2002; Shaw *et al.*, 2009; Hills & Dallos, 2011; Simmonds *et al.*, 2014; Midgley *et al.*, 2015). One participant described her isolation;

> *You feel quite alone when your growing up with like things like that because there's not really anyone who understands it.*

(Simmonds *et al.*, 2014. p. 294)

Whilst many participants felt as though their difficulties were not understood by those around them, a number of participants spoke about how much they valued support of family and friends (Leavey, 2005; MacDonald *et al.*, 2005; Meadus, 2007; Woodgate, 2006). In one study, participants described the importance of having people who tried to understand living with depression;

> *I think what would help is for people to realise that it is not just feeling down, it is actually an illness. That is the hardest part getting people to realise – it is not just... Say oh 'oh you woke on the wrong side of the bed' I think the most helpful part is knowing that someone out there understands.*

(Woodgate, 2006, p. 266)

When describing their experiences of accessing mental health services, participants reported how having the opportunity to be able to open up and to share their experiences in a safe environment, with someone who was outside

of their social networks, was the thing they valued most (Welsh & Tiffin, 2012; Gilbert *et al.*, 2012).  Others describe how they appreciated support that was sensitive and where there was continuity of care, although this was not everyone's experience (Cadario *et al.*, 2011).

In addition to being listened to and understood, participants appreciated it when the professionals they were working with were honest and upfront about their condition (Welsh & Tiffin, 2012).  Woodgate (2006) described how participants valued professionals who not only made an effort to understand them but were also sincere.  Professionals who saw them not just as a condition or collection of symptoms, but as a human being and were able to be flexible in order to suit their needs.

**Finding A Way Forward**

'*Finding a Way Forward'* was the theme noted in 11 of the studies reviewed (see Table 1.4, Appendix C).  This seeks to describe the processes and ideas participants spoke of in relation to recovery.  Recovery was viewed by some as a process that waxed and waned (Farmer, 2002; Meadus, 2007; Simmonds *et al.*, 2014; Woodgate, 2006).  Within the theme of '*Gaining a Sense of Well-Being',* Farmer (2002) reported how participants used a variety of different factors to monitor the ups and downs of their recovery process.  This included the prevalence of symptoms, levels of anger and weariness, changes in school grades, changes in and amounts of medications, and reconnecting with others and their faith.  For others, recovery was about re-establishing a

sense of social identity and negotiating a new self-identity in relation to their difficulties and their friends (Leavey, 2005).

Participants spoke about factors that were important in helping them find a way to manage their symptoms, such as supportive peer relationships (MacDonald *et al.,* 2005) the right medication, and support from professionals within mental health services (Leavey, 2005). Acceptance and finding a way to live with the difficulties was voiced by participants in a number of studies as an important part of moving forward (Cadario e*t al.*, 2011; Meadus, 2007; Simmonds *et al.*, 2014; Woodgate, 2006).

Others recognised changes would have to be made to their lifestyle or relationships (MacDonald *et al.,* 2005; Meadus, 2007). One participant voiced how their view of the world now differed following a psychotic episode;

> *Since I've become psychotic and that, all my views have changed. I view*
> *the world differently now. I look at things differently than I used to…I*
> *don't want to get back into that lifestyle that I lived before […].*
>
> (MacDonald *et al.,* 2005, p. 137)

The sense of recovery being within one's control was also apparent in Woodgate's study (2006). Participants suggested the idea that whilst the help of others was important, they needed to take charge of their health in order to recover, and therefore it was essential to make changes that enabled them to move forward;

> *Try to stay away from things that hurt you or things or friends that make*
> *you feel bad about yourself.*

> (Woodgate, 2006, p. 265)

For many young people, an important part of moving forward was about making sense of their experiences and integrating events into their personal narrative (Farmer, 2002; Hill & Dallos, 2011).  This was a process that for some was undertaken in therapy (Simmonds *et al.,* 2014), or through contact with mental health services (Welsh & Tiffin, 2012) and often helped them develop a different understanding of self.  For others, recovery was something that happened once time had passed and was only considered complete once they were symptom free (Simmonds *et al.*, 2014).

Within the studies reviewed, two papers described how the experience of living with a mental health condition had enriched the participants' lives as they had been able to learn about themselves (Cadario *et al.,* 2011; Meadus, 2007). Others found out they had strength and sense of resilience (Simmonds *et al.*, 2014; Woodgate, 2006), which resulted in improved self-esteem and confidence;

> *I don't get embarrassed like if I did something wrong.  I just get up and*
> *try again. Whereas before I wouldn't.*

> (Simmonds *et al.,* 2014, p. 295)

For participants transitioning between services, as they were approaching the upper age limit, there were fears regarding the future.  They

described wondering how they would manage once access to services was no longer available;

> *I'm not a young person any more.  It's like sh\*t what do I do now I can't come down to here anymore.  But what if I need support after that? Who do you ring where do you go?*
>
> (Gilbert *et al.,* 2012, p. 751)

A final key part of the process of recovery noted in a number of the studies reviewed was the importance of hope.  This was often something that at times was instilled by others (Cadario *et al.,* 2011).  However, a number of studies documented how a number of participants described how they themselves developed a sense of hope that things would improve (Farmer, 2002; Leavey, 2005; Meadus, 2007; Welsh & Tiffin. 2012; Woodgate, 2006).

## Discussion

### Statement of Findings

This review aimed to critically evaluate what we know so far about young people's experiences of living with a mental health difficulty and identify implications for service development and areas for future research.  The above synthesis illustrates how participants with mental health conditions can experience difficulties in identifying and making sense of their experience, and how, at times, they may perceive it to be a typical part of adolescence, delaying attempts to seek help from others.  The findings suggest that in addition to the impact of the symptoms and distress associated with the different mental health

conditions, a number of secondary consequences were also observed.  These included loss of relationships, perceived stigma, problems with education, low self-esteem and confidence and changes to sense of self.  Findings also emphasised factors associated with a young person's understanding of and experience of recovery.

Young people's experiences of mental health services and other support agencies highlighted the importance of the therapeutic relationship, with regard to empathic understanding, positive regard and congruence (Lambert & Barley, 2001).  An individual's understanding of their difficulties was something that appeared to develop over time, although was often a confusing process. Participants began to understand their difficulties within differing frameworks (e.g. medical, psychological).  However, it is unclear what influenced these differing perspectives and how much of this was shaped by those around them and the professionals they came into contact with.

**Significance of Main Findings**

The findings of this review highlight the difficulties participants and those around them have in negotiating what are typical adolescent experiences and what may be signs of difficulties with an individual's mental health. Adolescence is a critical time in an individual's development with changes in biological, physical, psychological and behavioural domains (Kerig & Schulz, 2012).  However, literature surrounding this period often refers to it as a period fraught with problematic behaviour, despite the evidence suggesting most individuals pass through this period without significant social, emotional, or

behavioural difficulties (Steinberg & Morris, 2001). The societal view that the

adolescent period is one of emotional turmoil (Buchanan & Hughes, 2009)

means significant difficulties may be seen as a developmental phase and

dismissed, rather than being acknowledged and addressed. Despite attempts

within the field to ameliorate this myth (Offer & Schonert-Reichl, 1992;

Steinberg & Morris, 2001), it continues and is reflected in the experiences of the

young people within the reviewed papers.

The presence of stigma was a common experience for the young people

within the studies reviewed. This is not an unexpected finding as it is reported

widely across the mental health literature (Young Minds, 2010). However, it is

particularly important during a developmental stage where there is a focus on

social image, peer- acceptance and identity consolidation (Moses, 2010), and

due impact on self-esteem and confidence (Kranke, 2010). This review

however adds richness to our understanding of how this stigmatisation takes

place and the impact on the individual. The significance of feeling different from

others was a key theme from the papers reviewed, suggesting that having

mental health difficulties can impact on young people's experiences of being

accepted by peers. The use of secrecy and concealment has been found to be

an important strategy amongst individuals in response to stigma (Hinshaw,

2005; Moses 2009), and was again reflected within the findings of the review.

Difficulties in identifying symptoms of a mental health condition, and

experiences of stigma are a recognised barrier to help seeking amongst young

people (Gulliver, Griffiths & Christensen, 2010). The findings of this current

review illustrate how young people often kept their difficulties hidden, due to concerns of how they would be perceived by others or due to difficulties themselves in identifying what was happening.

The findings of this study indicate that despite the differences within the symptomology of mental health conditions, there are areas of commonality experienced by young people with mental health conditions, such as the experience of stigmatisation and relationship difficulties.  It is however unclear where and how these are intertwined with this developmental period or indeed if they are at all.

**Implications for Policy and Practice**

This review highlights the importance of education regarding mental health difficulties amongst children and young people and those who live and work with them.  Early recognition of mental health difficulties can make a positive difference in the short and long term outcomes (Royal College of Nursing, 2004) and is raised in the Future in Mind report by the Government's Children and Young People's Mental Health Taskforce (DoH, 2015).  The findings of this review however suggest that before young people are able to approach services for help, they first need to be able to recognise they are experiencing difficulties that require help and also feel comfortable in accessing help without fear of being stigmatised.

In order to reduce stigma, clinical psychologists and other mental health professionals need to continue to actively involve themselves in improving mental health literacy amongst children, young people and the systems around

them.  The media has been implicated in the prevalence of stigma associated with mental health, often portraying mental health difficulties as being solely within a medical model, positioning the difficulties within the individual and not as a reaction to difficulties within the wider social systems or as a response to trauma (Bentall, 2016).  Clinical psychologists are in a position to influence these views, and moving forward it is important they utilise the use of a variety of media outlets to share an alternative perspective of mental health and wellbeing and influence the negative discourse associated with mental health difficulties from a position outside of the clinical room.

Young people described the importance of being around those who understood them and reported the importance of meeting with others experiencing similar difficulties.  It is therefore important to consider the use of therapeutic groups or peer support groups with this population as it may be beneficial in reducing the likelihood of social isolation and help young people to make sense of their experiences and gain support from others who are experiencing similar difficulties.

**Research Limitations**

There are several limitations to this study which need to be considered. Firstly, searching for qualitative literature is known to be challenging due to differences in the way they are recorded or indexed within the main electronic databases (Pope *et al*., 2007; Evans, 2002).  These difficulties can lead to articles unintentionally being missed out (Atkins *et al*., 2008).  So whilst this

review aimed to identify all suitable qualitative papers within the literature this may not have been achieved.

A second limitation is that for practical reasons (e.g. accessibility) this review excluded unpublished papers. This may have resulted in a bias of the type of papers reviewed and also may have limited the number of suitable papers found. It is also noted it is good practice for verification of the synthesis to be sought from the original authors, a process similar to respondent validation in primary qualitative research (Pope *et al.*, 2007). However due to time limitations this was not possible.

**Future Directions**

It would be useful for future research to compare the experiences and factors related to typical adolescence, and the issues prominent within this review, in order to help better understand the way in which this developmental period is impacted on by mental health difficulties. Further qualitative research exploring the experience of stigma amongst young people with mental health difficulties would also be useful to inform health interventions within this area.

One of the papers reviewed suggested that if a young person was able to see their difficulties as part of the human condition, it might help reduce a young person's experience of feeling different from others (Simmonds *et al.,* 2014, p. 295*)*. It could therefore be worthwhile to further explore this due to the useful implications for clinical work.

**Conclusions**

The aim of this review was to understand the way in which children and young people with a mental health condition make sense of their difficulties and the impact it has on their lives.  A systematic review of the literature identified 15 papers, four of which were considered to be of high quality.  None of the papers reviewed received a quality rating that raised concerns.  Findings of the review suggest there are a number of common themes within the literature that are experienced universally, irrespective of which mental health condition is experienced.  These include the impact of mental health difficulties on a young person's relationships, their identity and sense of self, experience of stigmatisation and barriers to and facilitators to seeking help.  This review highlights the difficulty individuals and some mental health professionals, have in separating the difference between typical adolescent development and the beginning of mental health difficulties that warrant support from specialist services.  This review invites consideration of future research within the areas identified, in order to further develop our understanding of young people's experiences of living with a mental health condition.

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**Chapter Two: Empirical Paper**

Living with Obsessive-Compulsive Disorder:

The Young Persons' Perspective

Chapter Work Count: 7877 (excluding, tables, illustrative quotes, footnotes and

references)

In preparation for submission to Clinical Child Psychology and Psychiatry

(See Appendix A for author guidelines)

## Abstract

Obsessive-Compulsive Disorder (OCD) in childhood is a debilitating and intrusive condition which can leave an individual feeling socially isolated, impact on their self-esteem and significantly affect their overall quality of life. Previous research within the field of OCD has focused on epidemiology, treatment and experiences of parents, with little attention given to those children and young people growing up with the condition. This current study expands on previous research by exploring the experiences of children living with a diagnosis of OCD within a psychological framework. It specifically looks at their experiences in relation to: their sense of self, relationships with others and experience of accessing and engaging with help. Six young people (aged 12-18) with a diagnosis of OCD were interviewed using semi-structured interviews which were then analysed using Interpretative Phenomenological Analysis. Three superordinate themes emerged from the findings; 'Understanding the Difference', 'Changing Shape of a Monster' and 'The Battle'. Participants' experiences are considered within the context of existing literature and clinical implications and recommendations for further research are considered.

**Keywords**: Obsessive-Compulsive Disorder, OCD, Child, Adolescent, Phenomenology, Experience.

**Introduction**

**Obsessive-Compulsive Disorder and Childhood**

Obsessive-Compulsive Disorder (OCD) is a condition, which is characterised by distressing obsessional or worrying thoughts and compulsions or rituals, which reduce the anxiety that accompanies the obsessional thoughts (Carr, 2006).  Obsessional thoughts are part of the human experience, and ritualistic behaviours are often considered to be a typical part of development (Carr, 2006; Zohar & Felz, 2001) in children under the age of 8 (Leonard, Goldberger, Rapoport, Cheslow, & Swedo, 1990).  For children whose obsessions and compulsions fall outside of this typical range, and are severe enough to meet the diagnostic criteria for OCD, they are a cause of considerable distress which can ultimately become debilitating, causing disruption to a child's social, educational, and emotional development (Leonard *et al.*, 1993).

**Impact of Obsessive-Compulsive Disorder in Childhood**

The significant and pervasive impairment, across the social, familial and academic domains, associated with childhood OCD (Piacentini, Bergman, Keller, & McCracken, 2003) is linked to a decrease in a child's quality of life in comparison to their peer group (Lack *et al.,* 2009).  Within the school environment, children often find it difficult to concentrate on their work due to the intrusive nature of their obsessions and the fact that they are often left exhausted from the need to complete rituals (Adams, 2004).

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As well as affecting academic performance, OCD also impacts on a child's relationships.  Positive peer relationships are associated with greater wellbeing (Berndt, 2002).  However, for children with OCD, making and maintaining friendships is often difficult.  They may struggle to engage in activities with their peers either directly, due to the debilitating nature of their symptoms, or from their attempts to keep symptoms secret (Piacentini, *et al*, 2003; Thomsen, 1994).  Peer victimisation is also reported to be common amongst children with OCD.  Reports suggest that more than a quarter of children with OCD are regularly victimised by peers; significantly more than healthy counterparts (Storch *et al.,* 2006).

Research suggests that adolescents with anxiety disorders have lower self-esteem on average than healthy peers.  Self-esteem in adolescents with OCD seems to decline as they move into adulthood (Maldonado *et al.,* 2013).  Early diagnosis and intervention in childhood OCD is therefore imperative to minimise distress and the likelihood of children experiencing a secondary handicap (Nakatani, Mataix-Cols, Micali, Turner & Heyman, 2009).  This is particularly important as 80% of adults with OCD report the onset of symptoms in childhood or adolescence (Pauls, Alsobrook, Goodman, Rasmussen, & Leckman, 1995).

**Developmental Aspects of Obsessive-Compulsive Disorder in Childhood.**

The body of research into the epidemiology, aetiology, co-morbidity and pharmacological and psychological treatment of paediatric OCD continues to grow (Thomsen, 1994; Geller, 2003).

Examination of the developmental differences in the presentation of paediatric OCD (Bernstein, Victor, Nelson & Lee, 2013), found that the most common symptoms of OCD in children and young people were aggressive obsessions (e.g. thoughts of harm to self or others), contamination obsessions, and checking, washing and cleaning compulsions.  In comparison to adults with OCD, children and adolescents are more likely to present with multiple obsessions and compulsions, and sexual obsessions are more likely to be reported by adolescents (Gellar *et al.,* 2001; Bernstein *et al.*, 2013).

OCD in childhood can be difficult to assess and diagnose, especially when typical compulsions (e.g. excessive checking) are not present (Barrow, Heyman, Scott & Krebs, 2014).  This can be further complicated by feelings of shame or embarrassment, which leave the individual reluctant to disclose their difficulties to others, resulting in a delay in help being sought (Chung & Heyman, 2008).

Low levels of insight into the unrealistic nature of obsessional thoughts (e.g. unrealistic association between cause and events) experienced by individuals with OCD is reported to be more prevalent in children and young people than their adult counterparts (Geller *et al*, 2001).  It has been suggested that this may be due to developmental factors such as the use of 'magical' thinking in childhood (Adelman & Lebowits, 2012).

Guidance on treatment of OCD in childhood from NICE (2005) recommends the use of Cognitive Behavioural Therapy (CBT) including Exposure and Response Prevention Therapy (ERP) in the first instance, before

the introduction of pharmacological therapy.  Despite its proven efficacy, it is

reported that only 39% of young people with OCD showed a large enough

reduction in symptomology[4] to be considered to be in remission following CBT

and only 59% following combined CBT and medication (Pediatric OCD

Treatment Study Team, 2004).  Insight may be one factor that might be

contributing to these figures, as low levels of insight have been implicated in

poor treatment outcomes in cognitive therapy (Lewin *et al*., 2010).

**Lived Experiences of Children and Young people with OCD.**

Despite increasing research into OCD in childhood, exploration of either

retrospective accounts or current lived experiences of children with OCD is

lacking.  Empirical research has explored the experiences of the young person's

family and the impact of OCD on family members.  However, experiences of the

young person with OCD have largely been expressed through autobiographical

books (e.g. Wells, 2006), through personal blogs and first-hand accounts on

social media, and websites dedicated to child and adolescent mental health

(e.g. Young Minds[5] and OCD Youth[6]).

There is one unpublished piece of research that explores the lived

experiences of children with a diagnosis of OCD (Simmonds, 2009).  This

qualitative study explored the experiences of seven children (mean age 13.4)

with a diagnosis of OCD who had completed either group or individual Cognitive

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[4] As indicated by a Children's Yale –Brown Obsessive –compulsive scale (CY-BOCS) total score of less
than or equal to ten.
[5] http://www.youngminds.org.uk
[6] http://ocdyouth.org

Behavioural Therapy for OCD.  Findings of the study identified three major themes: "Control", "Emotional Consequences of OCD" and "OCD and relationships".  The study described how participants struggled to control the conflicting reality of the thoughts, feelings and behaviours associated with their OCD and the expectations of societal norms.  The study highlighted the emotional consequences of living with OCD, with participants describing a range of emotions (depression, anger, stress, embarrassment and shame) and the way in which this influenced their sense of self, and contributed to a feeling of difference.  The effect of OCD on peer and family relationships was also described.  Participants spoke about how they disguised their condition due to fear of judgement, and acknowledged the effect their condition had on their independence and ability to trust others.  It also highlighted the effect that engagement in treatment had on relationships.  Simmonds (2009) recommends that further research should explore children's experience of living with OCD within different age groups, as well as those accessing services in differing geographical areas, in order to add to the literature and contribute to clinical practice.

**Aims of Current Research**

Previous research within the field of OCD has focused on epidemiology, treatment and experiences of parents, with little attention given to those children and young people growing up with the condition.  Research looking at the impact of OCD on social functioning in particular, especially during pre-adolescence is scarce (Borda *et al*., 2013).  To the authors' knowledge, there is

only one known unpublished study looking at the first hand experiences of children and young people living with OCD.

The present study aims to explore young peoples' experiences of living with OCD within a psychological framework, specifically looking at their lived experiences in relation to their sense of self, their relationships with others and the way in which they understand and manage OCD.  Where applicable, this may also include experiences of accessing and engaging with help.

In order to expand the knowledge base, the present study will recruit from a wider geographical area than Simmonds (2009) and seeks to include children between the ages of 8 and 18 as this is in line with the reported age of onset of OCD (Carter & Pollock, 2000). This study also aims to include individuals who have engaged with psychological interventions other than group Cognitive Behavioural Therapy (CBT) for OCD.  Six of the seven children within the Simmonds study (2009) were undertaking this and so it could have contributed to shaping their experiences and understanding of their difficulties.

## Methodology

### Research Design

A qualitative research design was employed using a phenomenological and ideographic approach in order to provide a rich and detailed examination of the experiences of children and young people living with OCD.  In keeping with the above research position, Interpretative Phenomenological Analysis (IPA) was the chosen method of analysis, as it allows examination of the way a

person perceives their experiences, specifically focusing on how they make

sense of their personal and social world (Smith & Osborn, 2003).

**Participants**

In line with the IPA approach, a small sample size was employed and six

young people were recruited to the study.  This number allowed for the

researcher to explore the detailed account of the individual's experience,

comparing the similarities and differences between individuals without

becoming overwhelmed by the data (Smith, Flowers & Larkin, 2009).  The

sample consisted of five females and one male aged between 12 - 18 years of

age (Mean age 14.1), all of White British ethnicity.  Two participants within the

sample disclosed that they had experienced an eating disorder, one prior to the

onset of OCD and one following the onset of OCD.  One participant reported

having a diagnosis of Autistic Spectrum Disorder, and another reported a

diagnosis of Asperger's Syndrome.  Neither of these were of a severity that met

the criteria for exclusion from this study.

Participants who met the inclusion and exclusion criteria as outlined in

Table 2.1 were recruited through Child and Adolescent Mental Health Services

(CAMHS) within the West Midlands.

**Table 2.1 *Participant Inclusion and Exclusion Criteria***

| | |
|---|---|
| **Inclusion Criteria** | 1. Aged between 8 and 18 years of age. |
| | 2. Diagnosis of OCD. |
| **Exclusion Criteria** | 1. Learning Disability or Autistic Spectrum Disorder of a severity that would prevent them from communicating their views and experiences to the level required for this study. |
| | 2. Known current risk to self. |
| | 3. Non-English speaking. |

## Procedure

### Ethical Considerations.

This study was designed and conducted in line with The British Psychological Society Code of Human Research Ethics (2010). Ethical approval for the study was also sought from Coventry University Ethics Committee (Appendix D), National Research Ethics Committee (Appendix E) via the Integrated Research Application System (IRAS) and the local Research and Development Departments of the NHS Trusts involved (Appendix F).

### Materials.

A demographic Information sheet was used to collect information regarding age, gender and ethnicity from all participants (Appendix G). This allowed consideration of the context in which the data was collected and will

allow others to judge the range of individuals and situations to which the findings may be relevant (Elliott, Fischer, & Rennie, 1999).

The researcher used a semi-structured interview schedule (Appendix H) in line with the principles detailed by Smith, Flowers and Larkin (2009).  This schedule was based upon the research aims and was developed in collaboration with clinicians.

**Recruitment.**

Clinicians within the CAMHS teams were approached and asked to identify and contact potential participants in line with the inclusion criteria, inviting them to take part.  An invitation to participate letter was utilised to support this process (Appendix I) along with copies of the Participant Information Sheets (Appendix J).  Parent Information Sheets were supplied if participants were under the age of 16 (Appendix K).  Participants or parents then either gave verbal consent to the clinician for their details to be passed on to the researcher, details of which were recorded in their clinical notes, or returned a reply slip giving written consent.

The researcher contacted participants who had expressed an interest in taking part in the research to answer any questions they may have and to arrange an interview date.

**Interview Protocol.**

Interviews took place at either the CAMHS where the participant usually attended, in a private room, or the individual's home at the young person or

parent's request.  Before the interview commenced, participants and their parents were asked to revisit the Participant / Parent Information Sheets and had the opportunity to ask any further questions and explore any concerns. Written consent was then obtained from parents (Appendix L) and written assent from the young person (Appendix M).  Basic demographic information was then collected.

The young person was free to choose if they wanted their parent with them throughout the interview, and two young people took this option.  It was explained to the parent that the aim of the interview was to explore the young person's experiences.  They were therefore respectfully asked to refrain from contributing to the interview process until the end, when time would be made available for them to share their views.

All interviews were digitally recorded and interviews lasted between 22 minutes and 97 minutes (mean length 43 minutes).  Following completion of the interview, a verbal debrief was given and both participants and parents were given written debrief sheets containing an outline of what happens next and information regarding appropriate support services (Appendix N & O).

**Method of Data Analysis**

Following each interview, the audio recording was transcribed verbatim. All identifiable data was removed and participants were assigned a pseudonym. Transcripts were then analysed in concordance with Smith, Flowers and Larkin's (2009) process for IPA analysis (Appendix P).

Once each individual transcript had been analysed, the emergent themes from each participant were examined by creating a visual map using different coloured post-it notes.  This allowed similarities and differences across participant data to be explored and the creation of superordinate themes.  An excerpt from a transcript (Appendix Q) and photographs of the analysis are provided to illustrate this process (Appendix R).

During analysis, the researcher invited two independent analysts who were familiar with the IPA process to audit excerpts from two interviews in order to check the credibility of the emergent themes (Elliott, Fischer, & Rennie,1999).  Discussions were also held within an IPA peer support forum throughout the analysis process in order to aid reflection and bracketing of ideas.

**Position of the Researcher**

The researcher is a female Trainee Clinical Psychologist with an interest in working with children and young people, drawing upon systemic and narrative models and ways of working.  She is also a mother.  The researcher was not working therapeutically with any of the young people involved in the study.  The researcher had previously completed a six-month placement at one of the services that the young people were recruited from but had left the service before the recruitment phase commenced.

In order to explore the researcher's position in relation to the study, a reflective research journal was used from the outset.  This has been described as an essential component that aids a researcher's ability to bracket off or put aside their own beliefs and assumptions about the phenomenon being

examined (Aherns,1999; Chan, Fung & Chien, 2013).  Reflections on the

interview process both directly following interview and during the transcription

process were recorded by the researcher.  These were reflected upon and used

to aid reflexivity during the process of analysis, as suggested by Mays and

Pope (2006).

Prior to the recruitment phase, a bracketing interview (Rolls & Relf, 2006)

was completed with a research colleague familiar with the chosen

epistemological approach.  This was again revisited during the analysis phase

and write up of the results.

## Results

Following analysis, three superordinate themes emerged from the data;

'*Understanding the Difference*, '*Changing Shape of a Monster*' and '*The Battle'*.

Within each superordinate theme, a number of subordinate themes were

identified.  An overview of these is illustrated in Table 2.2. Each theme will now

be discussed and verbatim quotes[7] from the young people used to illustrate

findings.

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[7] Some changes have been made to improve the readability of quotes; minor hesitations, word repetitions
and utterances have been removed and replaced with dotted lines.  Missing text is indicated by dotted
lines with square brackets e.g. […]

**Table 2.2:** *Identified Superordinate and Subordinate Themes*

| Superordinate Themes | Subordinate Themes |
|---|---|
| **Understanding the Difference** | The Monster Within |
| | Pulling Together or Pulling Apart |
| | Judged for the Monster |
| **Changing Shape of a Monster** | Creeping In |
| | Tipping Point |
| | The Impact |
| **The Battle** | The Challenge of Finding Freedom |
| | Regaining Control |
| | Finding Comrades |

## Understanding the Difference

*'Understanding the Difference'* had a strong presence across all participants' accounts. This theme captured the way in which living with OCD changed the young person's relationships, both with self and others, and illustrates the way societal views and understanding of OCD contributes to a feeling of difference. This was reflected in the cluster of subordinate themes; '*The Monster Within', 'Pulling Together and Pulling Apart' and 'Judged for the Monster'.*

### The Monster Within.

The subtheme of *'The Monster Within'* emerged for four of the participants. Participants' relationship with OCD was multifaceted, and spoke to the way in which '*The Monster Within'* impacted on and shaped their identity.

OCD changed the sense of who they were, leaving them feeling different to others.  During interviews, this was often expressed through comparison with others, as illustrated by the following quote;

*You think they're more or less normal and they don't have anything wrong with them cause they're really relaxed and don't really care about anything.  But if you looked at me and saw my records and attendance is pretty much 100% and to have had no… detentions and stuff like that, never been late.  So I think if you went looking at records you could tell.*

(Abby, 178-183)

At one level this sense of difference was positive, and something the young person valued;

*I definitely feel unique and a bit different, it's nice to feel different I like being different.*

(Emily, 332-333)

However, at another level there may have been fewer positive connotations attached to it consequently leading the young person to feel a sense of embarrassment or shame.  Alice described feeling a sense of difference with regard to the severity of the OCD she experienced, which culminated in her requiring specialist treatment;

*I was like ooh I'm special but obviously it's not something to be proud of.*

(Alice, 1276- 1277)

For some, OCD was seen as a core part of who they were, and contributed to how they made sense of the world and the experiences of those around them;

> *If you didn't have it, or you wouldn't be who you are… if you didn't have it…you wouldn't know…you'd be wondering what it would be like to live with it.*

> (Oscar, 15-18)

The process of separating OCD from self was highlighted by others as something they had learnt to do within therapy.  It appeared that externalising OCD allowed the young person's view of self to be protected from the views and feelings they have towards OCD;

> *I try and separate it from me, it's like a different, I'm me and that's the OCD and that's like…I don't like to think of it as part of me.*

> (Abby, 247-249)

Abby had earlier described the impact of viewing OCD as part of herself, illustrating the protective nature of externalising OCD;

> *It was like attached to me and so I pictured it as with me… but… I used to hit myself and stuff like that.*

> (Abby, 254-256)

The experience of hospitalisation appeared to have contributed to a change in Emily's identity;

> *…I became a different person…I used to wear really quite bright*
>
> *clothes…But I kinda went a little bit dark, into dark stuff.*

<div align="right">(Emily, 172-175)</div>

This change may have been a reflection of her internal state at the time, or potentially have been influenced by a new peer group, and be about fitting in with the group.

### Pulling Together or Pulling Apart.

All participants contributed to this subtheme which captured a sense of the impact OCD had on participants' relationships with family and friends. Often as a result of the demands of the rituals and obsessions.

It demonstrated the way OCD became a barrier to meaningful relationships for the majority of participants. For most this was due to the time consuming nature of rituals which made engagement with others difficult, and at times impossible. This ultimately impacted on their availability to others, and led to a sense of isolation from their family and peers, as is evident here;

> *Hmm I would go to a normal school and I would have friends and I'd*
>
> *have more time to… talk to friends and stuff but instead, instead I'm just*
>
> *at home cleaning.*

<div align="right">(Emily, 222-224)</div>

Oscar described how OCD affected the interpersonal communication within his relationships, which appeared to lead to a breakdown in his peer relationships;

*I used to have quite a lot of friends, I'm just getting too angry and bossy*

*around other people now.*

(Oscar, 193-194)

The second part of the quote suggests that Oscar's difficulties led to him becoming isolated from others. This appeared to be a shared experience for Oscar, Alice and Emily;

*I couldn't, I didn't see friends for a long-time.*

(Alice, 863-864)

Others were able to maintain peer relationships and keep OCD hidden from view;

*My friends don't really know about it…when I go to sleep over with*

*friends and I wake up at seven I just stay awake and just wait until they*

*get up.*

(Abby, 157-159)

The differences between participants' experiences may be due to the differing severity and presentation of rituals and obsessions and may help us to understand the changing impact of OCD on relationships, and the time at which young people are most at risk of isolation.

Tilly and Alice's experiences of OCD within their family, suggested that OCD had the potential to make relationships stronger;

*It kind of tears you apart but…underneath the surface, if I look deeper, I think it actually makes you stronger as a family coming out the other end of it.*

(Alice, 843-846)

This illustrates how sharing this challenging experience appeared to bring the family together, although the description of being torn apart suggests that at times it may not have felt like the family relationships were going to survive. For Tilly developing a mutual understanding of OCD during family therapy had strengthened relationships and enabled them to work together to fight OCD;

*Good to hear how everybody else felt, so we could all work together […] we supported each other backed each other up.*

(Tilly, 645-652)

OCD impacted on and changed the relationship participants had with their parents. Emily, Alice and Tilly spoke of the shift of their parents into the role of carer due to the debilitating nature of their difficulties; for example having to have their parents with them whilst they carried out daily activities such as showering or brushing their teeth. This change in role may bring about a sense of loss for both parent and child or contribute to a feeling of burdening others due to their difficulties;

*I feel sorry for them because they have to deal with me, and it's quite hard…but my mum's really good because she became my full time carer.*

(Emily, 147-148)

Some of the participants spoke of the emotional impact living with OCD had on those around them.  Alice describes how the whole family became isolated due to the severity of her rituals and obsessions;

*Huge impact on your family massive impact … consequences of that they couldn't have friends round dad couldn't have people round mum and dad would get depressed siblings will get depressed … and even our dog she knew and she would pace around.*

(Alice, 234-239)

The process of accessing and engaging in treatment, was something that also impacted on relationships to a greater or lesser extent across all accounts. Inpatient treatment caused disruption to relationships either through creating physical distance or through missing out on shared events;

*They were still all… talking about school and stuff and I didn't really bother and they were…I was really…different… I liked completely different things to them so I couldn't really talk to them about things because I didn't know what to talk about.*

*(Emily, 185-189)*

It also became apparent that undertaking therapy may also put stress on, and potentially cause conflict in an individual's relationships;

*I know when mum says to me…'I'm just doing this to fight OCD I'm not doing this to fight you' I mean you are fighting me cause I have it inside of me that it it's really hard so when she says [participants name] 'I'm*

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*trying to hurt OCD here I'm not trying to hurt you- I'm not trying to give*

*you anxiety but…we need to get rid of OCD' and I'm so, yes but it is*

*giving me anxiety and obviously OCD is inside of me.*

<div align="right">(Alice, 778-790)</div>

**Judged for the Monster.**

This third subtheme reflected participants' experiences of society's understanding of OCD.  Participants experiences included others lack of understanding, and how the term OCD was often used by others in jest;

*When you say that to someone that you've got OCD they think that*

*you're kind of… you don't like it when something's not straight stuff like*

*that*.

<div align="right">(Abby, 61-63)</div>

Others naivety about difficulties appeared to contribute to the sense of difference ('*The Monster Within'),* and led to concerns that others would judge them;

*If you went to someone in our school someone's got a mental illness*

*they'd think argh they're crazy*.

<div align="right">(Abby, 596-597)</div>

Being judged or feelings of embarrassment may have led to Tilly being selective with details following her hospital admission, choosing to tell only those she was close to, the real reason for her absence from school;

*Some people depending on how close I was to them I told, some people I just said I was ill.*

Discomfort about telling others or allowing others to see OCD, is expressed by Alex and Emily and may possibly be related to concerns about being stigmatised;

*It's bad because you don't want anyone to notice what you're doing.*

Emily suggests being around others who also experienced difficulties reduced this sense of stigma;

*Well you've got your own problems so you don't really judge people for what they've got.*

The need for others to be better informed and educated about OCD and mental health difficulties was reflected across a number of accounts;

*If they'd had this kinda taught group like the whole school when I was the year seven, when I was just starting, I think everyone would have had a better understanding and wouldn't think I was having a heart attack when I was having a panic attack.*

The dilemma of whether one needed to have experienced OCD in order to understand it emerged from Oscar's and Alice's accounts;

*Well its better cause they can like talk to you because they know what it's like so they know a lot of things about it.*

(Oscar, 82-83)

There appeared however to be a mismatch between their views. At times they suggested it was imperative for others to have OCD in order to understand. Later however they described feeling understood by the professionals they worked with. It is wondered whether their views were changed by their experiences of the professionals involved with their care, although may have been a barrier to help seeking initially if they felt that outsiders to OCD would not be able to understand their experiences.

**Changing Shape of a Monster**

"Changing Shape of a Monster" captures participants' portrayal of the onset and experience of OCD. There were several aspects encapsulated within the subordinate themes, '*Creeping in', 'Tipping Point'* and '*The Impact'.*

**Creeping In.**

'*Creeping in'* reflected four of the participants' experiences of the onset of OCD. It illustrates the way OCD entered participants' lives, and their attempts to make sense of or normalise OCD.

Participants spoke of a number of different insignificant events that with hindsight felt as though they had triggered the onset of OCD, such as a talk at

school from the fire service. It appeared from participants' experiences that OCD then continued to escalate;

> *I just remember…walking around school and starting to feel a little bit shaky at certain times of the day, … just kind of a little uncertain of things … and then the next things I can remember before I knew it I was looking through my bag more than once maybe just a few times at first … and … checking… my bag strap was positioned correctly… or my books.*

<div align="right">(Alice, 7-13)</div>

Others were however less conscious of the onset of OCD, and appeared to have normalised their behaviour quickly, adapting to having OCD in their life;

> *…..The rituals were really bad but I kind of just got on with them like they never really….until sort of the stage where I was going in to hospital.… I never really saw them as a dread they were sort of, cause it was so normal it became sort of part of my life.*

<div align="right">*(*Tilly, 299-304)</div>

It would appear the process of normalising rituals and obsessions may be related to the societal understanding of OCD and the common misuse of the phrase when describing personality characteristics such as perfectionism;

> *I think everyone has a bit of OCD and it might just be a little bit or it might be a lot, but I think everyone has a bit it can't just go away.*

<div align="right">(Abby, 230-233)</div>

Abby, Oscar and Tilly also reported having a family member who experienced OCD which may further normalise behaviour.

**Tipping Point.**

Whether OCD was normalised to begin with, hidden from others or just not recognised by the individual or those around them, for many participants there came a '*Tipping Point'.*  This was when OCD became so disruptive and debilitating that it consumed their life.

For some the '*Tipping Point'* led them to seek professional help, presumably as they felt they could no longer manage;

> *I couldn't … it all happened quite quickly I couldn't rest … I couldn't do*
> *anything that other people would do in the morning… so when I was*
> *putting my shoes on I couldn't do the Velcro or do anything. … I didn't*
> *like the noise I couldn't do it quick enough I was doing it so many times*
> *all I remember is one day just kind of sitting in my room and the bus had I*
> *think the bus had already left and … sitting on the floor crying and my*
> *mum was saying I think we need help…so at that point I think we went to*
> *the GP.*

<div align="right">(Alice, 78-87)</div>

Similarly, Tilly's experience spoke of her '*tipping point'* being a change in her relationship with OCD which appeared to be prompted by the escalation of rituals;

*I never really saw them as a dread they were sort of cause it was so normal it became sort of part of my life … but then when I realised that I couldn't actually cope with them anymore like there was just too many of them I couldn't actually cope with them that was when I realised I need help.*

For Oscar and Abby, the '*tipping point'* was less clear and appeared to be related to difficulties in relationships and impact of difficulties at school;

*I had panic attacks before and I would get really anxious over loud noises and claustrophobias and stuff […] So then at school it would be really difficult.*

(Abby, 17-21)

### The Impact.

'*The Impact*' was one of the strongest themes present within all participants' accounts and depicts the widespread and powerful impact that OCD had on participants' lives.

OCD appeared to be experienced by all but one of the participants (Oscar), to be powerful and all consuming.  Participants lacked control and were left with no option but to adhere to the demands of OCD;

*Like, you don't really feel like you have any other options you have to do*

*what it's saying, telling you.*

In other accounts participants reported that they "*have to*" (Alex, 145), *"I was*

*having to do things for longer"* (Tilly, 331-332).

The perceived impact of this was that OCD prevented participants from

doing the things they valued and began to affect their identity (see '*The Monster*

*Within').* It also impacted on their mood and feelings about themselves. The

distress that was experienced appeared to increase as OCD became more

powerful. For some this led to thoughts or acts of self-harm;

*… I was I started to hit myself more … and I was getting more teary and*

*more sort of frustrated and yeah my rituals were just getting generally*

*worse so I was having to do things for longer.*

The impact on self-esteem and confidence is evident in the following;

*Useless, dirty, … you feel quite embarrassed about yourself.*

These feelings may have been related to the content of the thoughts

experienced, as participants described how these could at times be extremely

distressing;

> *You get thoughts that you never really want to think and about like your*
>
> *family and stuff getting hurt.*

<div align="right">(Emily, 23-25)</div>

Alice described how her thoughts were of "*sexual violence*", "*murder*" and *"rape"* (315-319) and that these made her question whether she was "*psychotic*" (309). She spoke of the support she received during therapy to help her understand the prevalence of such aggressive obsessions within OCD.

OCD also impacted on participants' physical health; *"From retaining urine and not going I have constant bladder infections"* (Alice, 695-696), "*it makes my hands really sore*" (Emily, 6).  For others, OCD affected their ability to attend to their personal care, resulting in reduced hygiene (Alice, 359- 362).  When participants' obsessions and rituals impacted on tasks such as washing, parents often stepped in to supervise, compromising participants' privacy.

Education was another area of life affected.  For some, their obsessions were directly related to the content of lessons;

> *I … didn't use to say the number thirteen or twelve I didn't like those*
>
> *numbers…I wouldn't be around those numbers.*

<div align="right">*(*Alice 707-709)</div>

For others, the challenges were outside of lessons and in their personal relationships within the school environment (see *'Understanding the Difference'*).  Others managed to keep OCD under control at school, hiding it

from their teachers and peers, however this only delayed the impact until they were home;

> *I used to try and hide them as much as I could from friends at school and stuff and at home it was kind of I'd walk through the door and it was kind of a release. So all my rituals came out then so I'd be doing them from four till at the worst four till whenever I went to bed. Yeah so it was like a release at home.*

<div align="right">(Tilly 316-321)</div>

**The Battle**

This theme captures the ongoing battle participants had with OCD and the difficulties they encountered whilst striving for recovery.  This essence was captured within the subthemes of, '*The Challenge of Finding Freedom',* '*Regaining Control'* and *'Finding Comrades'.*

**The Challenge of Finding Freedom.**

This reflects the difficult and often distressing path that some participants followed in pursuit of a life without OCD.

Participants' decision to work towards recovery from OCD initially involved a sense of ambivalence attributed to the perceived cost of living without OCD.  Oscar suggested that having OCD allowed him to better understand others with OCD.  Therefore, there may be a sense of ambivalence about recovery as Oscar could feel less connected to his mother, who also had OCD;

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*I think it's good because if you know what they're feeling like all that time then they might be able to help you, and you might be able to help them*.

<div align="right">(Oscar, 74-76)</div>

It appeared that for others, OCD was seen as a protector and friend;

*It makes me feel like I won't get sick because I'm clean.*

<div align="right">(Emily, 33-34)</div>

Abby spoke about OCD helping to provide structure. It prevented things from becoming "*jumbled*" (Abby, 362), and stopped bad things from happening. There was a sense from participants that life without OCD may be more chaotic and frightening.

The idea that there could be a life without OCD was not shared by all. Alice's experiences suggested that this view could be held by mental health professionals;

*Many doctors many … psychiatrists, psychologists, consultants even… just say we will learn how to manage it whereas actually at the [name of hospital] …it will go … and … I want to get rid of it … and I think the main thing I have learnt is I don't have to manage it forever because you can get… completely rid of it.*

<div align="right">*(Alice 599*-605)</div>

For others there was a sense of hope that OCD could be extinguished. However, this appeared to come with a sense of uncertainty;

*It might, I'm not sure, cause it's really hard to say cause, I call it Bob, and*

*we fight Bob back into his box.*

(Emily, 195-196)

Alex described feeling like she was "*stuck*" with OCD (191-194), a view that was shared by, Oscar and Abby;

*I think it will just always be there…It might get better but I don't think it*

*will go away completely.*

(Abby, 355-357)

The emotional cost of '*the battle'* with OCD was often high, and brought additional distress.  Alice described treatment as "*harsh"* and described how you had to "*cross no-mans land*".  This portrayed a sense of being forced to take a serious risk by engaging in interventions such as ERP Therapy.  This risk may also bring with it a sense of vulnerability;

*When they try to make you do things because you know you need to do*

*these things but it's like really, like, annoying because it makes you feel*

*really, like, stressed [….] You get a lot sadder, like, you don't feel as*

*happy and you kinda just want to be alone and just deal, like, it's just*

*really like hard to explain.*

(Emily, 279-286)

For Tilly, *'the challenge of finding freedom'* involved being admitted to hospital.  The process of being taken away from her family was both frightening

and upsetting, and there is a sense that it also brought a realisation about the extent of her difficulties, making her feel like at some level she had failed;

> *…and I thought oh my god it's actually…cause I always heard like inpatient and stuff…cause I always thought oh that's not me I'm gonna get over this and then when I realised it was like reality, I was like oh my god.*

(Tilly, 443-447)

Others reflected on the difficulty of attending therapy sessions, due to the impact of OCD. This highlights the possibility that the severity of the OCD could be a barrier to accessing services;

> *I was walking around the hospital just seeing dead bodies and … being in PJ's…cause I couldn't get changed and … I think a few times it was … winter and the snow and I couldn't, I didn't want to touch the snow cause it was water … and … my dad had to lift me from the car in to the hospital.*

(Alice 340-345)

**Regaining control.**

'*Regaining Control'* illustrates the ways in which participants had tried to challenge OCD and the different aspects of help they had engaged with.

One aspect of this process present within all accounts, was the relationships with the professionals involved in their care. These relationships appeared to foster a sense of hope; *"They really believe you can do it"* (Emily,

295) and helped the young person feel as though they were not alone in their battle with OCD;

> *You don't feel like you're weird cause they understand everything so you've got someone to talk to.*

(Emily, 247-248)

For Tilly a sense of hope also came from her peers;

> *We are all battling through it together so like we're gonna get through it.*

(Tilly, 106-107)

It appeared for Emily that the relationship with the professionals involved in her care influenced how she perceived herself, leading her to question her sense of worth;

> *Why they care about me so much….I guess, it's their job really but they care about you like you're their own. How… like it's … they don't really have to care as much as they do, but they care a lot.*

(Emily, 302-305)

The importance of others' understanding was also present in Oscar and Alice's accounts.  These relationships provided a safe place to be able to make sense of their difficulties and talk about all aspects of OCD without feeling judged.  The importance of being seen as a young person first and foremost came across in a number of the accounts as illustrated in this quote;

> *To be in touch and connect with…. kind of me… focus on me and almost not the OCD so kind of talked to me as [participants' name].*

<div align="right">(Alice, 1152-1153)</div>

Tilly also highlighted this as something she valued within the hospital environment;

> *It was more of like a youth club rather than like a hospital.*

<div align="right">(Tilly, 477-478)</div>

Whilst all participants spoke about being taught a number of different techniques to help manage or rid them of OCD, there was a strong sense across all the accounts that the most helpful part of seeking help was the safe place to open up and the relationship with the professionals involved in their care;

> *[…] I saw her once a week or twice a week and she …also gave me lots of techniques and sort of … kind of a place where I could just tell her everything that I was feeling and stuff … and she would just like listen and ask questions at the end and stuff.*

<div align="right">(Tilly, 494-498)</div>

Participants who felt they had regained some level of control over OCD spoke of a sense of increased knowledge with regards to self, and a level of personal growth following their experiences.  This was reflected in the way Tilly spoke of feeling she could help others because of her experiences;

<div align="right">104</div>

*I've like I've currently got a friend whose gone into hospital too so I called*

*her and just tried to give her advice and things to help her cause I know*

*myself what it's like to be going into hospital, to have mental illness. So*

*it's good that I can help other people, try to help them.*

(Tilly, 619-613)

For some the process of regaining control appeared to bring with it increased confidence, whilst others gained understanding and acceptance;

*I feel more confident in myself and I don't feel like, I don't have to hide*

*anymore.*

(Abby, 557-558)

Alice reflected on the aftermath of her battle with OCD and suggested that the process could be *"rewarding"* and potentially make you a *"stronger better person"* (Alice, 1380, 1384). The sense that one's experience of OCD could facilitate personal growth was however not present within Alex and Oscar's experiences, and may have been reflective of the stage of '*the battle'* they were at with OCD.

**Finding Comrades.**

'*Finding comrades'* reflects how connecting with others who had experienced OCD or other mental health difficulties, appeared to be something a number of the young people valued.

For some, comrades were found through attending a school for young people with special educational needs or during an inpatient admission.  Abby's comrades were the other young people within her therapeutic group;

*Then they put me through to like a group with other children that had things, like difficulties with anxiety like me, and it help us like … connect to each other and see what our problems were.*

(Abby, 21-25)

Oscar described how having a parent with OCD was helpful for him;

*I think it's good because if you know what they're feeling like all that time then they might be able to help you, and you might be able to help them.*

(Oscar 74-76)

Whilst Tilly found others through internet blogs;

*Read like about people's…blogs about where they've had it … and how they sort of like…before and after and stuff that was quite positive… cause I wasn't sure exactly what it was at that point still …and them sort of explaining a bit more and sort of things you might experience and … sort of how they were feeling helped me to sort of relate to someone.*

(Tilly, 410-419)

Wherever the comrades came from, they appeared to help participants feel as though they were not alone and helped them make sense of their

difficulties. They also appeared to provide a sense of belonging which may consequently reduce the sense of difference participants felt.

## Discussion

### Summary of Findings

The current study aimed to explore young people's experiences of living with OCD within a psychological framework. Three themes emerged from analysis of participants accounts.

'*Understanding the Difference'* detailed the impact of OCD on participants' sense of self and on their developing identity. This theme captured the impact of OCD on the relational systems around participants and their experiences of the views and understanding held within society.

The second theme, '*Changing Shape of a Monster'* details participants' experiences of the onset and escalation of OCD. This captures '*The Impact'* of OCD on the individual, illustrating the destructive effect rituals and obsessions had on participant's lives.

'*The Battle'* illustrates the challenges participants experienced when accessing services and engaging in therapeutic interventions, as well as the aspects that helped them "*Regain Control'*. It also detailed the importance of finding and connecting with others who had experiences of living with OCD.

The findings of each theme will now be discussed, in relation to existing literature and clinical implications identified. Limitations of the current study as well as recommendations for future research will be considered*.*

**Discussion of Findings**

Participants' reflections on '*Understanding the Difference*' suggest that experiences associated with living with OCD were something that impacted on participants' view of self and developing identity.

The experience of obsessions about family members being harmed or obsessions of an aggressive or sexual nature, were particularly distressing for participants. The wider literature proposes that obsessions which are 'ego-dystonic' in nature could result in negative views of self if the content of obsessions are inconsistent with and contradict a part of the individual's value system or self-image (Purden & Clark, 1999). The ego-dystonic nature of obsessions within OCD may present a greater threat to an individual's identity development during adolescence, due to the importance of this period to individuals' attempts to develop a more defined sense of self (Kerig & Schulz, 2012).

Findings of the current study also highlighted the influence of inpatient treatment on participants' developing sense of self and relationships. Research suggests that an adolescent's developing identity could be threatened by a hospital admission, leading to a state of identity confusion or even an identification with the negative attributions associated with a psychiatric admission (Haynes, Eivors, & Crossley, 2011). This is consistent with the adult literature which suggests a hospital admission for mental health treatment can result in a loss of dignity, identity and social roles, ultimately impacting on the individual's sense of self (Roe & Ronen, 2003).

Participants within the current study articulated feeling a sense of difference in relation to others.  This is consistent with the experiences of young people from the previous study within this area (Simmonds, 2009) and also the wider qualitative literature exploring the experiences of young people with mental health difficulties (e.g. Shaw, Dallos & Shoebridge 2009).  Within the current study, this sense of difference brought with it negative connotations and concerns about being misunderstood, judged or rejected by others.  This is consistent within the literature around stigma and mental health difficulties. However, some participants described how having OCD in their lives and the experiences that came with this meant they viewed themselves as unique or special.  The function of a condition as something that makes the individual special or unique is something that is prominent within the eating disorder literature and can impact on an individual's motivation to engage in therapy due to the cost to self (Serpell, Treasure, Teasdale, & Sullivan, 1999).

In light of the negative affects the ego-dystonic nature of OCD has on the participant's view of self, as well as the impact of stigmatisation, it was interesting to note the experiences of those participants who had externalised OCD as part of therapy.  Within the Narrative approach (White & Epston, 1990), externalisation involves situating the problem outside of the individual. Subsequently, it is the problem that is viewed as the issue rather than the individual.  Findings within this study were consistent with the wider literature (McLukie, 2006), with participants speaking of the way in which externalisation of OCD protected them from both negative self-attributions as well as the negative attributions others hold regarding OCD.

A core concern noted within the current study was the impact of OCD on participants' relationships with others. '*Pulling Together or Pulling Apart*' illustrated the detrimental effect the demands of OCD have on participants' familial relationships, and their ability to make friends and sustain supportive relationships. Participants' experiences reflects the literature which reports increased difficulties within familial (Freeman *et al.,* 2003) and peer relationships (Borda, *et al*., 2013) in young people with OCD. Simmonds (2009) described the impact of treatment for OCD on participants' relationships, detailing how OCD influenced participants' ability to trust and depend upon others. The current study adds to this knowledge base by providing additional details of which aspects of OCD may have created barriers within young people's relationships.

For the majority of participants, the all-consuming and powerful nature of obsessions and rituals meant they had little time to engage in social activities, and spoke of loss of friendships. One participant described interpersonal communication difficulties impacting on friendships. There were however some differences noted between participants. It appeared that the impact of OCD on participants' relationships was related to the severity of rituals and obsessions. Whilst a causal relationship cannot be implied, these observations are in keeping with the quantitative literature (Piacentini *et al.,* 2007; Valderhaug & Ivarsson, 2005; Borda *et al*., 2013). These difficulties are especially salient for the participants within this study. The developmental tasks of early adolescence i.e. gaining autonomy through increased separation from family, developing supportive and meaningful peer relationships, and gaining

acceptance from peer group (Kerig & Schulz, 2012), may be thwarted by the rituals and obsessions associated with OCD.

Participants spoke of the emotional impact that their rituals and obsessions had on their family.  Some spoke of a sense of being a burden to their caregivers, and described how their difficulties interrupted daily family life, and how family members found it distressing to observe the effects of OCD on their child.  This is consistent with the wider literature which describes how parents of children with a diagnosis of OCD experience increased levels of negative emotions (Peris *et a*l., 2008), impacting on marital relationships, and siblings, restricting and changing family life completely (Futh, Simonds & Micali, 2012).  This current study highlights how the young person with OCD is aware of this impact.  The consequence of this on young people and relationships with their caregivers is not clear.

Despite being at an increased risk of peer relationship difficulties (Storch *et al*., 2006), participants within this study did not express direct accounts of victimisation amongst their peer group, something which differed from previous studies (Simmonds, 2009).  Participants, however, did express concerns about how they felt they were viewed by others, which affected their decisions to disclose.  This may suggest a perceived sense of societal stigma, contributed to by participants' experiences of others understanding of OCD and views regarding mental health.

Participants experienced OCD as time-consuming, distressing and often debilitating, impacting on their overall quality of life (Lack *et al., * 2009) and

psychosocial functioning (Piacentini *et al.,* 2003).  This current account is consistent with the literature within this area, but adds a richer, thicker dimension to the quantitative knowledge base, detailing the emotional consequences of living with OCD.  The emotional consequences of OCD described within this study are consistent with the Simmonds (2009) study where participants described the stress, depression and anger associated with coping with OCD.

The current study also adds to the literature by illustrating the challenges of accessing and engaging with therapeutic interventions for OCD and highlights the aspects of treatment that participants found particularly helpful.  A key aspect of "*The Battle"* was the "*Challenge of Finding Freedom".*

Whilst the efficacy of psychological interventions for OCD such as ERP Therapy [8] have been documented (McKay *et al*., 2015), very little is known about the experiences of young people engaging in such therapeutic interventions.  The current study adds to the knowledge base by highlighting the emotional consequences of such interventions.  Testing out hypotheses can feel like a huge risk for individuals, with significant perceived consequences. Participants' experiences within this study described how this can leave the young person questioning whether the risk is worth taking, which may ultimately impact on their willingness to engage in treatment.

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[8] Exposure Response Prevention Therapy

Participants' accounts reflected the aspects of help which were important in their pursuit of "*Regaining Control*".  All participants spoke of the importance of the relationship with professionals involved in their care.  Participants described how whilst contact with services provided a number of techniques that had been helpful, what appeared to be most beneficial and valued was having a safe therapeutic space, and someone who listened without judgment and was able to understand.  The therapeutic relationship also provided hope of recovery from OCD, and belief that participants could tolerate the anxiety and distress that was provoked when carrying out exposure work.  This is reflected in the evidence base which depicts the importance of the therapeutic process on treatment outcomes for young people (Karver *et al*., 2006; Shirk & Karver, 2003).  The therapist's interpersonal skills (e.g. empathy, warmth, congruence) in engaging young people in treatment and obtaining positive treatment outcomes (Karver *et al*, 2006), is also key.

Participants spoke of the importance of '*Finding Comrades'* through engagement with services.  The usefulness of such shared experiences is captured in the wider literature.  Connection with others during an inpatient stay has been found to be an important factor in individuals reaching their personal goals (Grossoehme & Gerbetz, 2004).  Whilst in the community, connecting with others through peer group support or therapeutic groups aids recovery (Leavey, 2005), and provides valuable means of support (MacDonald *et al.,* 2005).

**Clinical Implications**

In line with the wider literature, the findings of the current study illustrate the impact OCD can have on an individual's identity. With this in mind, professionals working with young people should ensure they support the young person to make sense of their identity within the context of OCD. Professionals should be mindful of the young persons' developing identity and the fragility of it during this developmental stage, ensuring therapeutic interventions focus on the young person before the symptoms of OCD. They should also ensure that professional language does not contribute to negative self-attributions. This can be supported by referring to OCD as being separate to the individual (White & Epston, 1990).

Experiences of aggressive/sexual obsessions are thought to contribute to feelings of shame and low self-esteem. Due to the increased prevalence within this population, in comparison to adults (Gellar, 2001; Bernstein *et al.*, 2013), this needs to be identified and discussed early on in order to reduce the potential for negative self-attributions. It is also important to think about professionals' responses to such disclosures, so that risk is explored carefully and without concrete action being taken unduly, as this could further damage young people's view of self.

The importance of professional relationships in providing a safe base for challenging therapeutic interventions suggests that time needs to be allowed for these relationships to develop before such therapeutic work is undertaken. With the current challenges within services to reduce waiting times and for

professionals to hold large caseloads, and work in a time limited manner, the importance of allowing time for such relationships to develop may feel like a luxury.  However, it is imperative that exposure work is not engaged with before this is in place.  As highlighted by Haynes, Eivors and Crossley (2011), it is also important that, within an inpatient setting, staffing levels allow time for nursing staff to provide the emotional support needed by the young people within their care.

The quality of the professional relationships with the young person as well as the suitability of environments to the young person's chronological age is thought to be important in order to provide optimal conditions to promote recovery. Environments should therapeutically hold the young person, allowing them to feel contained, safe and understood as these conditions allow the young person to focus on the emotional aspects of their recovery.  The creation of an environment which creates a safe space for the young person to be able to make emotional progress may be as relevant and important as the provision of one to one psychological therapy.

Due to the level of psychosocial impairment that can be experienced and the secondary consequences of such difficulties (e.g. isolation, depression, reduced self-esteem), services should also be mindful of the social and academic needs of the individual when developing care plans to support young people.  Encouraging access to others with similar experiences is key. Therapeutic group work, peer support forums, or online forums within charities

such as OCD Action[9] may help reduce the feeling of difference often felt by individuals, reducing feelings of isolation.

OCD impacts significantly on the systems around young people. Young people are often concerned that difficulties may be perceived by family members as distressing or a burden. As a result, all therapeutic work should include the system around the young person, such as Systemic Family Therapy (Carr, 2009), or a family based CBT approach (Freeman *et al*., 2003). This is also key in light of the effects of familial distress upon accommodation of symptoms (Amir, Freshman & Foe, 2000).

Within the current study, participants spoke of the difficulties in accessing treatment due to the severity of their rituals. Services may therefore need to consider interventions taking place within the environment in which the rituals hold most power (e.g. individuals' homes). Clearly this should always be considered case by case and within the limitations of the service.

The need for increased education around the presentation of OCD amongst teachers, school nurses, youth workers, and GPs in order to aid early intervention, was highlighted within the current research. Early recognition would enable young people to access help before their difficulties escalated, increasing the risk of secondary difficulties (Nakatani *et al.,* 2009). The focus needs to be on others awareness of difficulties as the findings of this study suggest that young people may struggle to differentiate OCD from typical

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[9] http://www.ocdaction.org.uk/

behaviours initially, or may be embarrassed and their difficulties kept hidden. The findings of this study, however, also suggest that there is still a long way to go in educating society in general about the true nature of OCD and mental health difficulties in general.

**Methodological Implications**

Findings of the current study should be considered within the context of its limitations.  Despite the recommendations for validity of emergent themes to be checked with participants, the young people within the current study were not contacted.  This was due to the additional disruption that arranging a second meeting would have caused participants and family members, especially as some participants were completing exams.

Participants' ages ranged from 12 to 18 years of age, with all but one participant being under the age of 16.  During interviews, it felt like there was a noticeable difference in the way that the younger participants spoke of their experiences in comparison to the older participant.  It may be that this was a result of the age differences, or could have also been contributed to by the qualities related to the older participants' diagnosis of Asperger's.  Future research may benefit from using a tighter age range in order to circumvent these differences.

Participants were asked about their experiences of help, and for the most part, experiences reported were positive in nature.  Participants were however aware that they were talking to a researcher who works within the NHS, and may have felt unable to express less positive experiences.  The researcher

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however felt during the interviews that participants spoke freely about their experiences and were able to discuss aspects of their care openly and without censorship.

Two participants had parents sit in with them throughout their interview. Whilst this was at the young person's request, it may have impacted on the interview process or impeded their ability to discuss things as openly as some of the questioning was focused on family relationships.

**Future Research**

The current research captures the rich details of what it is like to be a young person living with OCD and the impact of OCD on an individual's sense of self, and relationships, whilst detailing the experiences of accessing and engaging with mental health services. In light of the discussed findings and clinical implications, future research would benefit from looking at identity formation in adolescence within the context of mental health difficulties as well as further exploring the experiences of therapeutic interventions for OCD from the perspective of the family and young person.

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**Chapter Three: Reflective Paper**


Reflections on My Experience of the Monster


Chapter Word Count: 2835 (excluding references)

This paper was not prepared for submission to a specific journal.

**Abstract**

The following paper contains personal and professional reflections on the process of completing a systematic literature review on young people's experiences of living with a mental health condition and a study exploring young people's experiences of obsessive-compulsive disorder.  The paper will begin by considering reflexivity within the context of qualitative research and the processes which facilitated this within the current context.  The researcher will then move on to sharing personal reflections on the research process including areas which converged with participants' experiences.

**Introduction**

Reflective practice is a core component of clinical psychology training (British Psychological Society, 2014) and has a significant role to play in a clinicians' ongoing personal and professional development (Rønnestad & Skovholt, 2003).  Researcher reflexivity is also an essential component of conducting research in keeping with a phenomenological approach as the researcher is seen as an "*inclusive part of the world they are describing*" (Larkin, Watts & Clifton, 2006).  The IPA approach requires the researcher to interpret the individual's interpretations of their experiences; a double hermeneutic process (Smith, Flowers, & Larkin*,* 2009).  A critical self-awareness of the preconceptions and pre-existing knowledge that the researcher brings to this interaction is therefore essential (Finlay, 2012), and this reflexive stance should be maintained throughout the research journey, enabling the researcher to remain open to all findings within the data (Shaw, 2010).

**Process of Reflection**

In order to aid the process of reflexivity from the initial stages of formulating a research idea through to the write up as part of this doctoral thesis the following were utilised: completion of a bracketing interview (Rolls & Relf, 2006) prior to the interview stages and use of a reflective journal throughout the whole process. These were referred to throughout the analysis stages and write up and have been used to inform this reflective paper.

## Reflections on Area of Research

Child and adolescent mental health is an area I feel passionate about. This passion predates my clinical training and stems from a curiosity about the impact of childhood experiences on the development of psychological difficulties. My experiences within both adult and child and adolescent mental health services have further fuelled this passion and lent me to wonder how these experiences are made sense of by the young person, as well as the systems around them.

The decision to explore this topic area from a qualitative perspective was reached after initial engagement with the research area highlighted the dearth of research from the young person's perspective. This approach also fitted with my wider therapeutic stance which gives precedence to the individual voice whilst acknowledging the idea of multiple realities as described within the systemic therapy literature (Cecchin, 1987). This was an idea I first encountered whilst undertaking brief Systemic Family Therapy training. I have

continued to value these principles and during training have constantly drawn upon these and other systemic principles within my work.

The focus of my empirical paper arose from the above interest, and scarcity of research in the area. Prior to embarking on this research journey, I had little knowledge of obsessive–compulsive disorder (OCD) as experienced by either adults or young people, and no personal experience within this area. In retrospect I believe my perceptions of the condition were an interesting amalgamation of knowledge gained through teaching whilst on training and some of the naïve views held by society.

I recall reading some articles within the OCD literature which documented the debilitating nature of living with the rituals and obsessions associated with OCD, and trying to make sense of what this actually meant at an individual level. Returning to these articles after completing the analysis process I was struck by how empty the words felt when depicting the impact on the individual. The experience of having heard participants' experiences first hand had made me view things differently. For example, the word '*debilitating'* now invoked parts of the narratives that the young people had shared. As a clinician, I feel as though this process has allowed me to gain a richer understanding of some of the experiences individuals with OCD may face.

**Reflections on the Research Process**

What follows are my personal reflections on the research process. Themes from the empirical paper have respectfully been used to structure this account. However, it is in no way proposed that the experiences reflected upon

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within the following discussion are in anyway comparable to those experienced by the participants from whom the original themes emerged.

**The Monster Within**

The research process and the resulting thesis has at times been affectionately, and not so affectionately referred to as "*the beast*" within my reflective journal.  My relationship with '*the beast'* has, like the participants' relationships with OCD, been multifaceted.  The process of undertaking a research study and associated literature review woke '*the monster within'*.  The process appeared to tap into and magnify the power of the insecurities and doubts that I have experienced prior to and throughout clinical training.  The beginning of the process brought with it an anxiety about the magnitude of the journey about to be embarked on as this was the rite of passage from trainee to qualified Clinical Psychologist.  The pressure that accompanied the sense of importance I afforded this research, from a professional perspective, contributed to feelings of anxiety about being '*good enough'* to be able to carry out and write up such a piece of work.

**Finding Comrades**

The above difficulties were further complicated by the lack of understanding of those outside of the process.  In a parallel to the participants within my study, this also led me to find comfort and support from being with "*comrades"* who were able to share the challenges and excitement of the research process.  This experience made me reflect on how privileged I was to be in a position to know that there were others on this journey with me.  Even

though each of our experiences were shaped by the many factors and context within which our research took place, with differing challenges for us all, at one level there was someone I could relate to.  I wondered how had this not been the case, just how isolated I would have felt.  For me this process reiterated the power of the message that had been reflected within both my literature review and empirical paper; the importance of others who understand.

**Judged for the Monster**

I am aware however that at times I found that being around others, even those that understood, was a challenge due to the need to make comparisons. This often only highlighted difference and led me to perceive myself as being behind in the process, or left me with increased self-doubts about my abilities to complete an academic piece of work to the level required.

The difference I felt between myself and other trainees was also exacerbated by the fact that I am also a mother.  Balancing the demands of the research process with the demands of motherhood, again stirred '*the monster within'*.  I was riddled with guilt and often found myself caught in a 'no win' situation; I felt a need to constantly invest more time into my research in order to complete this to the best of my abilities.  However, I also needed to be with my little boy in order to be the mummy I wanted to be to him.  Whichever way I turned, I would not be 'good enough'.  Others understanding of the process also impacted on this and at times I felt judged for investing time into "*the beast*" when as far as they could fathom it was 'just' another piece of academic work.

**Changing Shape of a Monster**

The changing shape of the research process was something that I noted when reflecting on the process as I neared the end. I feel that as the research process changed shape, I also took up different positions in relation to this. Throughout the process I felt I moved between the position of researcher and clinician, from a position of 'powerful to powerless'.

External factors that hindered the process such as the complexity and length of the ethical approval process and the frustrations and difficulties within the recruitment phase left me feeling powerless and questioning my abilities to complete what was required of me. In order to reduce the sense of rising anxiety that I found myself experiencing, I found myself desperately trying to make headway with my literature review and trying to gain control of any aspects of the project I could. During this period '*the beast'* was all-consuming, both in an emotional sense as well as from a sense of the time it took in my life. This led me to question for the first time since embarking on training, whether I wanted to continue to pursue this due to the personal cost and impact on myself and my family. This was my *'tipping point'.*

I struggled with this on my own for a while before deciding that I needed to talk this through with a member of the course team. This for me was a personal challenge as it meant sharing my vulnerabilities and disclosing to someone who, in some respects, was in a position of power; would the course suddenly realise that I was indeed as incapable as I felt. On reflection, this process is a stark reminder of the risk clients take with clinicians every day.

The participants within my study described their experiences of talking to clinicians for the first time and their fears of being perceived as "*weird*" or judged.  I think at times I have forgotten just how difficult it can be for someone to begin to speak to professionals about their difficulties.  The therapy process is so familiar, that it is easy to forget it can initially feel quite frightening, or strange to both adults and children not used to this context.  These experiences for me once again highlight the importance of building strong therapeutic relationships but also serve to remind me to spend time exploring clients' expectations and experiences of accessing services.

As the research process developed, I found myself moving from a powerless position to one which felt uncomfortably powerful.  The position of researcher felt it brought with it a sense of power.  This presented in different ways throughout the process, with differing consequences.  As I embarked on the interview process, I was mindful of the differing power positions between myself and the participants; I was an adult, who was conducting research within the context of the NHS, a professional body that all participants were receiving care from.  Whilst I drew on my therapeutic skills in order to manage this power imbalance within the interview context, it will however, have remained to some extent, due to the social constructs held within society.  For me this power was experienced as a sense of responsibility; I felt that I had been trusted with participants' stories and I had a responsibility to fully represent their experiences through my research narrative.

Following the initial interviews, I reflected in my journal about how difficult I had found the interview process. This took me by surprise and made me wonder whether I had fully considered the notion of interviewing from a research perspective. In the first interview I was aware that I found myself trying to navigate between the role of clinician and researcher mostly without success. I found myself sticking rigidly to the interview schedule, which was in conflict to my therapeutic style of being led by the client. I felt a pressure to try and avoid being drawn in to my clinical role and afterwards felt that my fear of not being a 'researcher' may have cost me richness of data, which may have been gained by being led by and remaining curious about the participant's experience. I felt it had also blocked my ability to build rapport, by at times questioning whether I should be responding to the young person's experiences or be curious about their experiences and asking them to elaborate.

In pursuit of playing the 'researcher', I had blocked the skills that I had developed as a clinician that would in fact facilitate the qualitative research process (Dempster, 2011; Biggerstaff & Thompson, 2008). I think this was in part due to this being my first experience of conducting qualitative research. My experiences of research interviewing previously have been from a quantitative position. As my confidence developed and I let go of the idea of what being a 'researcher' entailed, I was able to utilise my clinical skills. I allowed myself to take a more person-centred approach to interviewing, using my interview schedule as a very loose guide to refer to along the way. I feel this enabled richer data, and allowed space for experiences outside of the interview schedule to come to the fore.

The analysis process was one which brought with it a mix of positive and negative emotions. The process of analysis involved in IPA initially involves working with each case to develop emerging themes. I found the process of becoming immersed in the participants' stories was fascinating and something I felt privileged to be able to do. This would however often turn to anxiety, due to doubts about the 'quality' of my emergent themes, and the fact that as a novice researcher, I had completely underestimated the time this process of analysis would take.

As the analysis moved through the next stages, I became aware that this required losing some of the themes and aspects of participant's stories that were not pertinent to the whole group. This loss of parts of the individual's narrative was something that continued during the interpretative process and final write up. I found myself struggling to decide which quotes to use and felt myself becoming frustrated with word limits that impeded me from representing all the young people's voices within my work. I felt a sense of letting them down. This was something I also struggled with whilst completing the meta-synthesis process of my literature review. However, this was to a lesser extent possibly due to the additional distance between myself and the young people within those studies. For me this process was further impacted upon by the sense that I was a novice and therefore not a 'good enough' researcher to complete the analysis to the standard that the participants deserved. I was afraid that I would lose the essence of their experiences through my interpretations and constraints imposed within the writing process.

**Challenge of Finding Freedom**

As described, the process of completing the different elements of this research have brought with it a number of positive and negative emotions which have been surprisingly strong at times. At times it has felt like the only way to manage this has been to 'just keep swimming' and have faith in the process itself.

The compressed nature of this process has really highlighted to me the 'dance' that is undertaken when completing academic work. This 'dance' is a familiar one, as often unknowingly I have seen it time and time again over my academic career. As I sat to begin writing this final chapter, I once again found myself engaging with the 'dance'. I found myself paralysed by the sense that I was "not clever enough" and felt a sense that it was "impossible". The familiarity of this dance should have brought with it comfort and a faith that every time I had taken on this battle in my academic pursuits, indeed many times in the preceding months to hand in, I had found a way through it. However, once again I trod this well-worn path of uncertainty and doubted that I would find a way through. I have come to the conclusion that this is my process and that the battle is not with the process itself but more about my acceptance of this, an acceptance of the 'dance'. What I have learnt is that the process becomes more distressing when I fight it, when I try to compare myself with others or work in a way that is not in keeping with my style. I have learnt that I need to give myself the same credence that I hope I have offered my clients and participants.

**Regaining Control**

This process has contributed to both a sense of personal and professional growth. I will be taking forward a number of things I have learnt about myself as well as many things that I hope will enhance my professional practice.

Research will continue to be a part of my professional life and I now have a richer understanding of this process. As with many aspects that I have encountered during clinical training, ongoing development within this area is key. Just as I hope the stories of the young people conveyed within the preceding chapters will contribute to the wider knowledge base and influence clinical practice; I know that my experiences within this process will continue to influence my personal and professional narrative as I move forward into my qualified life.

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# Appendices

**Appendix A: Author Guidelines**

# Clinical Child Psychology and Psychiatry

Clinical Child Psychology and Psychiatry is a peer reviewed journal that brings together clinically oriented work of the highest distinction from an international and multidisciplinary perspective, offering comprehensive coverage of clinical and treatment issues across the range of treatment modalities.

## Writing and submitting your manuscript

### 1. Article types

Clinical Child Psychology and Psychiatry is interested in advancing theory, practice and clinical research in the realm of child and adolescent psychology and psychiatry and related disciplines. Articles should not usually exceed 7,500 words and be clearly organized, with a clear hierarchy of headings and subheadings (3 weights maximum). Authors wishing to submit an article longer than 7,500 words should discuss this in advance with the journal editor.

### 2. Editorial Policies

#### 2.1 Peer review policy

The Editor will screen manuscripts for their overall fit with the aims and scope of the journal, especially in terms of having clear relevance for clinicians. Those that fit will be further reviewed by two or more independent reviewers in terms of merit, readability and interest.

As part of the submission process you will be asked to provide the names of X peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

• The reviewer should have no prior knowledge of your submission

• The reviewer should not have recently collaborated with any of the authors

• Reviewer nominees from the same institution as any of the authors are not permitted

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

#### 2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

### 3. Publishing Policies

### 3.1 Publication Ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway

### 3.1.1 Plagiarism

Clinical Child Psychology and Psychiatry and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

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All papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Authors will be asked to re-submit manuscripts that do not conform to these guidelines.

Clinical Child Psychology and Psychiatry is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit http://mc.manuscriptcentral.com/ccpp to login and submit your article online.

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### 5.1 File types.

Only electronic files conforming to the journal's guidelines will be accepted. Word DOC is the preferred format for the text and tables of your manuscript. Please also refer to additional guideline on submitting artwork [and supplemental files] below.

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### 5.3 Reference Style

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### 5.4 Manuscript Preparation

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point.

### 5.4.1 Preparation for blind peer review

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# Appendix B: Quality Appraisal Checklist

## Summary criteria for appraising qualitative research studies (Walsh & Downe, 2006).

| Stages | Essential criteria<br>Specific prompts | Scoring<br>(Yes, No, Partial ) |
|---|---|---|
| Scope and purpose | **Clear statement of, and rationale for, research question/aims/purposes**<br>• Clarity of focus demonstrated<br>• Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing<br>• Link between research and existing knowledge demonstrated<br><br>**Study thoroughly contextualised by existing literature**<br>• Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both | |
| Design | **Method/design apparent, and consistent with research intent**<br>• Rationale given for use of qualitative design<br>• Discussion of epistemological/ontological grounding Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology)<br>• Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims<br>• Setting appropriate<br><br>**Data collection strategy apparent and appropriate**<br>• Were data collection methods appropriate for type of data required and for specific qualitative method?<br>• Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?<br>• Was triangulation of data sources used if appropriate? | |
| Sampling strategy | **Sample and sampling method appropriate**<br>• Selection criteria detailed, and description of how sampling was undertaken<br>• Justification for sampling strategy given<br>• Thickness of description likely to be achieved from sampling<br>• Any disparity between planned and actual sample explained | |
| Analysis | **Analytic approach appropriate**<br>• Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory)<br>• Was it appropriate for the qualitative method chosen?<br>• Was data managed by software package or by hand and why?<br>• Discussion of how coding systems/conceptual frameworks evolved<br>• How was context of data retained during analysis<br>• Evidence that the subjective meanings of participants were portrayed<br>• Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance<br>• Did research participants have any involvement in analysis (e.g. member checking)<br>• Evidence provided that data reached saturation or discussion/rationale if it did not<br>• Evidence that deviant data was sought, or discussion/rationale if it was not | |

| | **interpretation** |
|---|---|
| | • Description of social/physical and interpersonal contexts of data collection |
| | • Evidence that researcher spent time 'dwelling with the |
| | • data', interrogating it for competing/alternative |
| | • explanations of phenomena |
| | **Clear audit trail given** |
| | • Sufficient discussion of research processes such that others can follow 'decision trail' |
| | **Data used to support interpretation** |
| | • Extensive use of field notes entries/verbatim interview |
| | • quotes in discussion of findings |
| | • Clear exposition of how interpretation led to conclusions |
| **Reflexivity** | **Researcher reflexivity demonstrated** |
| | • Discussion of relationship between researcher and |
| | • participants during fieldwork |
| | • Demonstration of researcher's influence on stages of |
| | • research process |
| | • Evidence of self-awareness/insight |
| | • Documentation of effects of the research on researcher |
| | • Evidence of how problems/complications met were dealt with |
| **Ethical dimensions** | **Demonstration of sensitivity to ethical concerns** |
| | • Ethical committee approval granted |
| | • Clear commitment to integrity, honesty, transparency, |
| | • equality and mutual respect in relationships with |
| | • participants |
| | • Evidence of fair dealing with all research participants |
| | • Recording of dilemmas met and how resolved in relation to ethical issues |
| | • Documentation of how autonomy, consent, confidentiality, anonymity were managed |
| **Relevance and transferability** | **Relevance and transferability evident** |
| | • Sufficient evidence for typicality specificity to be assessed |
| | • Analysis interwoven with existing theories and other |
| | • relevant explanatory literature drawn from similar settings and studies |
| | • Discussion of how explanatory propositions/emergent |
| | • theory may fit other contexts |
| | • Limitations/weaknesses of study clearly outlined |
| | • Clearly resonates with other knowledge and experience |
| | • Results/conclusions obviously supported by evidence |
| | • Interpretation plausible and 'makes sense' |
| | • Provides new insights and increases understanding |
| | • Significance for current policy and practice outlined |
| | • Assessment of value/empowerment for participants |
| | • Outlines further directions for investigation |
| | • Comment on whether aims/purposes of research were |
| | • achieved |
| | **Outcome:** |

A = no or few flaws. The study credibility, transferability, dependability, and confirmability is high; B = some flaws, unlikely to affect the credibility, transferability, dependability, and/or confirmability of the study; C = some flaws which may affect the credibility, transferability, dependability, and/or confirmability of the study; D = significant flaws which are very likely to affect the credibility, transferability, dependability, and/or confirmability of the study.

## Appendix C: Meta-Synthesis Overview

| Identified Themes | Original Articles and Themes | Example Quotes From Original Papers |
|---|---|---|
| **Concealed Distress and Difficulties** | Brooks & Dallos (2009). Hidden Distress; Discussion. | "I think I eventually told my mum what happened. I didn't want to tell anyone else, yeah I think I eventually told them what I was feeling and stuff" (Cadario et al, 2011, p. 86) |
| | Cadario et al (2011). How help was sought and which service was approached; Discussion. | "I don't want to talk about it that's why I cut because I don't want to talk about it" (Hill & Dallos, 2011, p. 467) |
| | Farmer (2002). Unrelenting Anger. | "I find to quite hard to talk to my Mum I think because I worry about what her reaction will be and I worry it will affect her so it's just better to pretend I'm OK." (Shaw, Dallos & Shoebridge, 2009 p.171) |
| | Hill & Dallos (2011). People just don't understand self-harm is my way of coping: It doesn't mean that I'm weird or crazy; Talking is difficult so I keep it all inside; Discussion: lack of understanding from others. | "I think the bad things would be the stigma associated with it because, it's not something that you'd want to go and tell any of your friends that you have it because you'd be perceived differently" (McCann et al 2012, p. 337) |
| | McCann et al (2012). Withdrawing. | "I don't go mentioning it to anyone" (Welsh & Tiffin, 2011, p. 216) |
| | Shaw, Dallos & Shoebridge (2009). Communication: Not talking | "and I was like so really frightened of seeing someone that I knew and then seeing me like that because I was so embarrassed about it" (Simmonds et al, 2014, p. 293) |
| | Simmonds et al (2014). Loss of self. | |
| | Welsh & Tiffin (2012). "How others will take me" | |
| **Moving into Awareness** | Brooks & Dallos (2009). Hidden Distress | "I never thought it was unusual" (Cadario et al, 2011, p. 95) |
| • **"I never thought It was unusual"** | Cadario et al (2011). How help was sought and which service was approached. | "It came and I didn't even realise I had it" (Cadario et al, 2011, p. 95) |
| • **A growth of awareness** | Farmer (2002). Friendships: Roles and Reactions. | "I didn't want to let myself think that I had something wrong; I thought it was just a stage I was going through" (Meadus, 2007, p. 213) |
| • **Others Awareness** | Meadus (2007). Feeling different. Facing the challenge / reconnecting. | "I was sad all the time, I don't know I couldn't get myself out |
| | Midgley et al (2015). Misery despair and tears: I have never been happy with my life, never... | |

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|---|---|
| Wisdom & Green (2004). Growth of distress. Considering whether they are depressed. | of it no matter what" (Meadus, 2007, p. 213)<br><br>"I think my friends then started to suspect that something was wrong because I was normally a very happy bouncy person ..." (Brook & Dallos, 2009 p. 110)<br><br>"Everything was just coming down around me, and then I ended up just bursting into tears with my head of year and telling her everything" (Midgley et al, 2015, p. 273). |
| **Connection** | |
| Brooks & Dallos (2009). Opening Narratives | |
| Farmer (2002). Emotional homelessness: sense of aloneness; Emotional homelessness: No safety where expected; Continuum of escape from Pain; Friendships: Roles and reactions; Gaining a sense of wellbeing. | "I just couldn't bear myself to be around people. I would stay in the house all day full stop but if I had to be around my sister and my mum, god forbid, so eventually I just stopped sleeping at like night and started sleeping in the day just to avoid them" (Simmonds et al, 2014, p. 293) |
| Gilbert, Farrand & Lankshear (2012). Difficult relationships: Instability trauma and isolation. | |
| Hill & Dallos (2011). Individual stories; Discussion: lack of understanding from others. | "yeah like everything's just harder to get through, and you don't actually want to be part of all the normal things" (McCann et al, 2012 p. 337) |
| Leavey (2005). Emergence: Stigma; Loss: Loss of friends; Interrupted intimate relationship development; Recovery: Conditions for recovery; community based youth support. | "I didn't go out as much I stayed home. I slept a lot and went to bed early, and didn't really want to get up" (Meadus, 2007, p. 213) |
| MacDonald et al (2005). Hanging out with people I like who understand me; Spending less time with old friends; Something happened to me – being different now; Building new relationships. | "I know they worried about me which is kind of comforting but kind of I wanted to them to go away and just leave me alone" (Shaw, Dallos & Shoebridge, 2009, p.172) |
| McCann et al (2012). Withdrawing. | "We all began not to see each other when we finished high school" (MacDonald et al, 2005, p.136) |
| Meadus (2007). Cutting off connections. | |
| Midgley et al (2015). A bleak view of everything: I feel like my heart is broken....but somehow I was the one who broke it; Isolation and cutting off from the world- even when I'm with people, I still feel alone. | "Ever since my episode occurred I have been spending less and less time with my normal outside friends ...so a lot of my friendships I suppose have been severed really, more or less." (MacDonald et al, 2005, p. 136) |

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|---|---|
| Shaw, Dallos & Shoebridge (2009). *Communication: Not talking; Wanting to talk but unable to communicate; Feeling unwanted; Discussion.* | "They [previous friends] wouldn't understand. They're just the sort of people that would laugh if somebody had an illness, and stir them up" (MacDonald et al, 2005, p. 136). |
| Simmonds et al (2014). *Loss of self; Renegotiating the self.* | "unknown to others" (Shaw, Dallos & Shoebridge, 2009, p. 176) |
| Woodgate (2006). *Maintaining a sense of belonging in the world; Feeling valued as a human being.* | "you don't feel as bad because there's other people that go through the same things as you. I mean for whatever reason they're basically there for depression" (Farmer, 2002, p. 579) |
| | "We can go out and have a good time, and I ....feel relaxed around them" (MacDonald et al 2005, p. 134) |
| **Feeling of Difference** | |
| Farmer (2002). *Emotional homelessness; sense of aloneness; Emotional homelessness: No safety where expected.* | "I'm a bit different, I'm not like everyone else my age really. Umm ...but like I can't change who I am so I've got to live with it, if you see what I mean...I have a different perspective on life I think. I think about things in strange ways" (Shaw, Dallos and Shoebridge, 2009, p.175) |
| Gilbert, Farrand & Lankshear (2012). *Difficult relationships; Instability trauma and isolation.* | "the safety of waking up and "knowing who you are" which most people take for granted had suddenly vanished" (Leavey, 2005, p. 115) |
| Hill & Dallos (2011). *People just don't understand self-harm is my way of coping; It doesn't mean that I'm weird or crazy.* | "I didn't know I wasn't myself, like I'm really outgoing and like I have a lot of friends and everything but I just feel different" (Meadus, 2007, p. 213) |
| Leavey (2005). *Emergence; Stigma; Loss; Loss of identity.* | "I miss the girl I was at times........ I remember running in the streets barefoot in the summer time with all the neighbourhood kids playing games every day..... they are probably my happiest times, out having fun and being a kid. I grew up too quickly and missed that whole childhood thing and I want to go back" (Wisdom & Green, 2001, p. 5) |
| MacDonald et al (2005). *Something happened to me; Being different now.* | |
| McCann et al (2012). *Struggling to make sense of the situation; Withdrawing.* | |
| Meadus (2007). *Feeling different.* | |
| Shaw, Dallos & Shoebridge (2009). *Feeling unwanted; Lost identity; Difference; Discussion.* | |
| Simmonds et al (2014). *Loss of self.* | |

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|---|---|
| Wisdom & Green (2004). Growth of distress.<br><br>Woodgate (2005). Maintaining a sense of belonging in the world. | "There is a stigma to it, it's like first when Aids came out, 'don't touch those people' yes something like that" (MacDonald et al, 2005, p.137)<br><br>"It's just that they [former friends] view me differently now you know, because I've become psychotic they think that you are now a waste of life or something..... they just think you're a looney or something like that which is not good" (MacDonald et al 2005, p. 137)<br><br>"How if I could talk to them [friends] I would, but I just didn't feel like I could talk to them, they would keep on going 'you're weird' or something" (Farmer 2002, p. 574) |
| **Understanding of Difficulties: Moving Between a Medical and Psychological Discourse.**<br><br>Brooks & Dallos (2009). Opening narratives; Discussion.<br><br>Cadario et al (2011). Difficulties noticed; lack of awareness of mental illness; thoughts about illness precipitants; Beliefs and knowledge of mental illness; Discussion.<br><br>Farmer (2002). Emotional homelessness: sense of aloneness; Emotional homelessness: No safety where expected; Parental break-ups: caught in the middle; Gaining a sense of wellbeing.<br><br>Gilbert, Farrand & Lankshear (2012). Difficult relationships instability trauma isolation.<br><br>Hill & Dallos (2011). Individual stories; How the adolescence told their stories: Structure – coherence, integration, resolution and defensive process.<br><br>Leavey (2005). Emergence; Problems getting the right diagnosis; Labelling.<br><br>McCann et al (2012). Struggling to make sense of the situation; Discussion.<br><br>Shaw, Dallos & Shoebridge (2009). Communication: Wanting to talk but unable to communicate.<br><br>Simmonds et al (2014). Loss of self; Renegotiating the self.<br><br>Welsh & Tiffin (2012). "It is better just to say it" | "Umm I suffer from obsessive compulsive disorder. Umm I'm not really sure how I'd get it but they tell me it's sort of hereditary thing there's part of my brain that doesn't work properly, um but it's triggered by stress mainly." (Brooks & Dallos, 2009, p.108)<br><br>"I started to get sick because I was smoking too many drugs" (Cadario, et al, 2011)<br><br>"Mum was also... she was diagnosed like the same day as my nana, so they both had cancer, so it was a bit of a trigger" (Cadario et al, 2011 p.97)<br><br>"At first the doctors thought I was schizophrenic, but then they said no and then they said I had a dissociative disorder....and then after that they said "no that's not it either" And then I went to [name of hospital]. And my doctor now says that I have bipolar, so that's how I got my...my diagnosis, as being bipolar" (Leavey, 2005, p. 114)<br><br>"I guess which is kind of like where it started probab....yeah about when it started" (Hill & Dallos, 2011, p.464) |

| | | |
|---|---|---|
| | Wisdom & Green (2004). Growth of distress; Considering whether they are depressed; Receiving the diagnosis; Making sense of depression. | "It's kind of confusing, you know that something's wrong and you try and progress on things, but it's kind of hard when you know there is something going on in your mind or whatever else, and you try and figure it out or fix it, and its just kind of hard sometimes and confusing"<br>(McCann et al, 2012, p.337)<br><br>"I didn't understand why I was feeling so low and I didn't know"<br>(Simmonds et al, 2014, p.292) |
| Experience of Symptoms and Secondary Consequences. | Brooks & Dallos (2009). Opening Narrative.<br><br>Farmer (2002). Disputed weariness; unrelenting anger; continuum of escape from Pain; Essential structure.<br><br>Gilbert, Farrand & Lankshear (2012). A life in turmoil "responding to chaos".<br><br>Hill & Dallos (2011). People just don't understand self-harm is my way of coping; It doesn't mean that I'm weird or crazy; Putting the anger inwards. Discussion: lack of understanding from others.<br><br>Leavey (2005). Loss: Loss of independence; Loss of academic functioning; Interrupted career development.<br><br>McCann et al (2012). Spiralling down; Contemplating self-harm or suicide; Discussion.<br><br>Midgley et al (2015). Misery despair and tears; I have never been happy with my life, never; Anger and Violence towards self and others; I feel bad because I take it out on people or myself; A bleak view of everything; I feel like my heart is broken....but somehow I was the one who broke it; The impact on education – I can't learn anything.<br><br>Shaw, Dallos & Shoebridge (2009). Hurt self- worthless self; self-hatred; Feeling unwanted; Discussion.<br><br>Simmonds et al (2014). Loss of self.<br><br>Wisdom & Green (2004). Being in a funk.<br><br>Woodgate (2006). Living in the shadow of fear; Containing the shadow of fear; Feeling valued as a human being. | I'm dumb", "undeserving" "thick" and "worthless" (Shaw, Dallos & Shoebridge, 2009, p.173)<br><br>"Well it lowers your confidence, it doesn't give you the confidence to do the things you want. Like it makes you more fatigued. You don't have the energy; you feel more restless; stuff like that. I don't know how to explain it"<br>(McCann et al, 2012, p. 337)<br><br>"I would tip over chairs and stuff like just throw something I just brought at her [mother]"<br>(Farmer, 2002, p. 576)<br><br>"It's like I shout at them or punch things or just say stuff I don't even like really mean....I even punched a car before"<br>(Midgley et al, 2015, p. 274)<br><br>"It's the way that I've taught myself to deal with things....It's the only way I can mentally cope with anything"<br>(Hill & Dallos, 2011, p. 467)<br><br>"It culminated in me totally smashing up my house and throwing the telly out the window....."<br>(Gilbert, Farrand, & Lankshear, 2012, p. 749)<br><br>"Yeah I wanted to be a doctor but it didn't work out because of my illness"<br>(Leavey, 2005, p. 117) |

| Experience of Support: Listen and understand me. | Cadario et al (2011). How help was sought and which service was approached; Experience of services and suggestions. | "You feel quite alone when you're growing up with like things like that because there's not really anyone who understands it" |
| | | (Simmonds et al, 2014, p. 294) |
| | Gilbert, Farrand & Lankshear (2012). The case coordinators. | |
| | Hill & Dallos (2011). Discussion: lack of understanding from others. | "Yeah well, my mother, you know, is like a saint" "Yeah my mother would be, if I had to say anybody it would be my mother who got me through it" |
| | Leavey (2005). Recovery: Conditions for recovery; Family support, The right therapist, A good doctor. | (Meadus, 2007, p. 213) |
| | MacDonald et al (2005). Valuing families and other supports; Spending less time with old friends. | "I think what would help is for people to realise that it is not just feeling down, it is actually an illness. That is the hardest part getting people to realise – it is not just... Say oh 'oh you woke on the wrong side of the bed' I think the most helpful part is knowing that someone out there understands." |
| | Meadus (2007). Facing the challenge / reconnecting. | (Woodgate, 2006, p. 266) |
| | Midgley et al (2015). A bleak view of everything; I feel like my heart is broken...but somehow I was the one who broke it; Isolation and cutting off form the world- Even when I'm with People, I still feel alone. | |
| | Shaw, Dallos & Shoebridge (2009). Communication: Wanting to talk but unable to communicate. | "I just get everything out in to the open and I don't have to worry about anything ....cos I don't exactly want to go and tell my mam about like if I have had an experience or anything, I just don't to make her feel upset" |
| | Simmonds et al (2014). Loss of self; Renegotiating the self. | (Welsh & Tiffin, 2012, p. 217) |
| | Welsh & Tiffin (2012). "It is better just to say it"; "How others will take me"; "Just to have somebody to talk to". | |
| | Woodgate (2006). Keeping the self-alive; Maintaining a sense of belonging in the world; Feeling valued as a human being. | |
| A Way Forward | Cadario et al (2011). Experience of services and suggestions; Beliefs and knowledge of mental illness. | "Since I've become psychotic and that, all my views have changed. I view the world differently now. I look at things differently than I used to ...I don't want to get back into that lifestyle that I lived before, it's not even living you know you're just a zombie, stoned every day" |
| | Farmer (2002). Gaining a sense of wellbeing. | (MacDonald et al 2005, p. 137) |
| | Hill & Dallos (2011). How the adolescence told their stories: Structure, coherence, integration, resolution and defensive process. | "Try to stay away from things that hurt you or things or friends that make you feel bad about yourself" |
| | Leavey (2005). Adaptation: coping strategies, acceptance, adjustment; Recovery: Reintegration, Hope for future. | (Woodgate, 2006, p. 265) |

MacDonald et al (2005). Hanging out with people I like who understand me; Building new relationships.

Meadus (2007). Learning from the experience.

Midgley et al (2015). A bleak view of everything; I feel like my heart is broken...but somehow I was the one who broke it.

Simmonds et al (2014). Renegotiating the self; Anticipation of future self.

Welsh & Tiffin (2012). "It is better just to say it".

Woodgate (2006). Living in the shadow of fear; Containing the shadow of fear; Keeping the self-alive; Feeling valued as a human being.

"In some ways it's good because if I hadn't had this experience then I wouldn't have learnt how to deal with stress"
(Cadario et al, 2011, p. 91)

"I don't get embarrassed like if I did something wrong, I just get up and try again. Whereas before I wouldn't"
(Simmonds et al 2014, p. 295)

"I think that once you accept it and your limitations it helps you see that you are not completely like a 'vegetable'. There are things you can do"
(Woodgate, 2006, p. 265)

"I'm not a young person any more. It's like shit what do I do now I can't come down to here anymore. But what if I need support after that? Who do you ring where do you go?"
(Gilbert, Farrand & Lankshear, 2012, p. 751)

# Appendix D: Coventry University Ethics Review Approval

**TO WHOM IT MAY CONCERN**                          QRS/Ethics/Sponsorlet

Monday, 20 April 2015

Dear Sir/Madam

**Researcher's name:**  **Helen Veater**
**Project Reference:**   **P18969**
**Project Title:**       **Living with Obsessive Compulsive Disorder: A Child's Perspective.**
                         **Exploring the impact of Obsessive Compulsive disorder on a child's**
                         **sense of self, their relationships and experience of help.**

The above named student has successfully completed the Coventry University Ethical Approval
process for her project to proceed.

I should like to confirm that Coventry University is happy to act as the sole sponsor for this student and
attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully

**Professor Ian Marshall**
**Deputy Vice-Chancellor, Academic**

Enc

# Appendix E: National Research Ethics Review Approval

**NHS**
Health Research Authority

**NRES Committee East Midlands - Nottingham 1**

Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839697

31 July 2015

Miss Helen Veater
110 Glenmore Drive
Longford
Coventry
CV6 6LZ

Dear Miss Veater,

| Study title: | **Living with Obsessive Compulsive Disorder : A Child's Perspective. Exploring the impact of Obsessive Compulsive Disorder on a child's sense of self, their relationships and their experience of help.** |
|---|---|
| REC reference: | **15/EM/0233** |
| IRAS project ID: | **145368** |

Thank you for your letter of 13<sup>th</sup> July 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter.  The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Ms Rachel Nelson, NRESCommittee.EastMidlands-Nottingham1@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

**Confirmation of ethical opinion**

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

**Conditions of the favourable opinion**

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

study.

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

*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.

*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*

<u>Registration of Clinical Trials</u>

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

**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).**

**Ethical review of research sites**

NHS 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).

Non-NHS sites

**Approved documents**

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

| Document | Version | Date |
|---|---|---|
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) | | |
| Interview schedules or topic guides for participants | | |
| Interview schedules or topic guides for participants [Interview Schedule ] | 2 | 09 July 2015 |
| IRAS Checklist XML [Checklist_07052015] | | 07 May 2015 |
| IRAS Checklist XML [Checklist_13072015] | | 13 July 2015 |
| Letter from sponsor | | |
| Letters of invitation to participant | 1 | 30 March 2015 |
| Letters of invitation to participant [Invitation Letter] | 2 | 09 July 2015 |
| Other [Participant Debrief] | 1 | 30 March 2015 |
| Other [Parent Debrief] | 1 | 30 March 2015 |
| Other [Liability Insurance] | 1 | 01 August 2014 |
| Other [Participant Debrief Form] | 2 | 09 July 2015 |
| Other [Parent/Guardian/Carer Debrief Sheet] | 2 | 09 July 2015 |
| Participant consent form [Assent] | 1 | 30 March 2015 |
| Participant consent form [Parent] | 1 | 30 March 2015 |
| Participant consent form [Participant Assent Form] | 2 | 09 July 2015 |
| Participant consent form [Parent/Guardian/Carer Consent Form] | 2 | 09 July 2015 |
| Participant information sheet (PIS) | 1 | 30 March 2015 |
| Participant information sheet (PIS) [Parent] | 1 | 30 March 2015 |
| Participant information sheet (PIS) [Participant Information Sheet] | 2 | 09 July 2015 |
| Participant information sheet (PIS) [Parent/Guardian/Carer Information Sheet] | 2 | 09 July 2015 |
| REC Application Form [REC_Form_07052015] | | 01 May 2015 |
| Research protocol or project proposal | 1 | 30 March 2015 |
| Summary CV for Chief Investigator (CI) [Helen Veater] | | 23 April 2015 |
| Summary CV for supervisor (student research) [Jacky Knibbs] | | 01 May 2015 |

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

**User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

**HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at
http://www.hra.nhs.uk/hra-training/

| 15/EM/0233 | Please quote this number on all correspondence |
|---|---|

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

Yours sincerely,

PP

**Dr Carl Edwards**
**Chair**

Email:              NRESCommittee.EastMidlands-Nottingham1@nhs.net

*Enclosures:*      "After ethical review – guidance for researchers"

*Copy to:*

Ms Jacqueline Knibbs

Ms Louise Alston

# Appendix F: Research and Development Review Approval

Coventry and Warwickshire Partnership **NHS**

NHS Trust

National Institute for Health Research
Clinical Research Network: West Midlands
Binley Business Park
Harry Weston Road
Coventry
CV3 2TX

13 October 2015

Miss Helen Veater
Trainee Clinical Psychologist
Coventry and Warwickshire Partnership NHS trust
St Michaels Hospital
St Michaels Road
Warwick
CV34 5QW

Dear Miss Veater

**Project Title: Living with Obsessive Compulsive Disorder: A Child's Perspective. Exploring the impact of Obsessive Compulsive Disorder on a child's sense of self, their relationships and their experience of help.**
**R&D Ref: CWPT230915B**
**REC Ref: 15/EM/0233**

I am pleased to inform you that the R&D review of the above project is complete, and NHS permission has been granted for the study at Coventry and Warwickshire Partnership NHS Trust. The details of your study have now been entered onto the Trust's database.

The permission has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

| Document | Version | Date |
|---|---|---|
| REC Favourable Opinion Letter | - | 31 July 2015 |
| Protocol | 1 | 30 March 2015 |
| Parent/Guardian/Carer Debrief Sheet | 2 | 09 July 2015 |
| Parent/Guardian/Carer Participant information sheet | 2 | 09 July 2015 |
| Parent/Guardian/Carer Participant consent form | 2 | 09 July 2015 |
| Parent Participant information sheet | 1 | 30 March 2015 |
| Parent Participant consent form | 1 | 30 March 2015 |
| Parent Debrief | 1 | 30 March 2015 |
| Participant information sheet | 2 | 09 July 2015 |
| Participant Debrief Form | 2 | 09 July 2015 |
| Participant consent Assent Form | 2 | 09 July 2015 |
| Interview schedules or topic guides for participants | 2 | 09 July 2015 |
| Letters of invitation to participant | 1 | 30 March 2015 |
| Letters of invitation to participant [Invitation Letter] | 2 | 09 July 2015 | - |
| Interview schedules or topic guides for participants | - | |
| Participant consent form Assent | 1 | 30 March 2015 |
| Participant information sheet | 1 | 30 March 2015 |
| Participant Debrief | 1 | 30 March 2015 |

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| R&F Form | 145368/782397/14/804 |
| SSI Form | 145368/782402/6/133/239219/323490 |

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF), to ICH-GCP standards (if applicable) and to NHS Trust policies and procedures. Permission is only granted for the activities agreed by the relevant authorities.

All amendments (including changes to the local research team and status of the project) need to be submitted to the REC and the R&D office in accordance with the guidance in IRAS. Any urgent safety measures required to protect research participants against immediate harm can be implemented immediately. You should notify the R&D Office within the same time frame as any other regulatory bodies.

It is your responsibility to keep the R&D Office and Sponsor informed of all Serious Adverse Events. All SAEs must be reported within the timeframes detailed within ICH-GCP statutory instruments and EU directives.

In order to ensure that research is carried out to the highest governance standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time, and you must co-operate with the auditors. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely

Shelley Grant
**Study Support Facilitator**

Copy:

Ian Marshall, Coventry University, Sponsor
Jacky Knibbs, Academic Supervisor
Michelle Rudd, Specialist Mental Health Service Manager

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Worcestershire Health and Care **NHS**

NHS Trust

Research & Development
Worcestershire Health and Care NHS Trust
Isaac Maddox House
Shrub Hill Road
Worcester
WR4 9RW

Tel: 01905 681514
samanthawhitby@nhs.net

Our Ref: 15_148_NP

**Helen Veater**
110 Glenmore Drive
Longford
Coventry
CV6 6LZ

10 August 2015

Dear Helen,

Thank you for your research application entitled *Living with Obsessive Compulsive Disorder; A Child's Perspective.*

I take great pleasure in informing you that your application has been granted Local Trust approval by the Research Review Group, on behalf of Worcestershire Health and Care NHS Trust.

Please accept this letter as official confirmation of Trust Approval.

I should like to take this opportunity to wish you well with your research, and look forward to seeing your final report and recommendations.

If I can be of further assistance please do not hesitate to contact me.

Yours sincerely,

**Sam Whitby**
Audit, Research & Clinical Effectiveness Manager

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## Appendix G: Demographic Information Sheet

**Demographic Questionnaire**

1. Your name:...................................................................................

2. Your gender: (please circle) Male  Female

3. Your age (in years):...................

4. Which ethnic group do you belong to:

| | | |
|---|---|---|
| White | British | |
| | Irish | |
| | Other White | |
| Mixed | White and Black Caribbean | |
| | White and Black African | |
| | White and Asian | |
| | Other Mixed | |
| Asian or Asian British | Pakistani | |
| | Indian | |
| | Bangladeshi | |
| | Other Asian | |
| Black or Black British | African | |
| | Caribbean | |
| | Other Black | |
| Chinese or other ethnic group | Chinese | |
| | Other ethnic group please specify | |

# Appendix H: Semi-Structured Interview Schedule

**Interview Schedule**
Study Title: Living with Obsessive Compulsive Disorder: A Child's Perspective
Researcher: Helen Veater

Note: Time will be spent at the beginning of the interview building a rapport and ascertaining what language the child uses to describe their difficulties with OCD. In light of this information, wording in the questions detailed below may be changed to ensure that the questions are in keeping with the individual child's discourse.

1. Tell me about why you come here to CAMHS/ to see [*name of professional*]

2. Tell me about what it is like to have OCD
   - What are the worst things about OCD?
   - Is there anything good about OCD?

3. When did you first notice OCD?
   - Do you know when it started?
   - Do you think anything caused it?

4. Who did you first tell about your OCD?
   - Did anyone else notice?

5. Have you told anyone about your OCD?
   - Who did you tell?
   - Why did you tell them?
   - What do they think about your OCD?
   - Are there people who you have not told?
   - What do you think they might think about it?

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

7. What things have you learnt about OCD?
   - Is there anything that helps OCD go away
   - Is there anything that makes OCD worse/ better

8. How does OCD make you feel about yourself?
   - About your family?
   - About your friends?
   - About school?

9. How does OCD make you feel about your future?
   - Do you think it may get better or go away?
   - Do you think it may get worse?

10. What would life be like if OCD went away?

Living with Obsessive Compulsive Disorder: A child's perspective/ Interview Schedule/ Version 2/ 09/07/2015

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

11. Has anyone tried to help you with your OCD? *Including access to internet websites and self help material.*
- Did the help make you feel better? How?
- Did the help make OCD easier to cope with / go away?

*If child has seen someone to support them with their OCD i.e. psychologist, Nurse, ask the following questions.*

12. What was it like seeing someone about your OCD?
- What was the best /most helpful part?
- What was the worst /most unhelpful part?
- What things will you remember the most about their help?
- What was the hardest part?
- What was the easiest part?

13. Have you learned new ways of coping with OCD?

14. Do you feel any different about OCD since you saw someone to help you?
- Do you feel any different about yourself?

15. What is life like with OCD since you got help?
- Is anything different to before?

16. Is there anything else that is important for me to know about what it is like to have OCD?

**Appendix I: Invitation to Participate Letter**

Coventry and Warwickshire NHS
Partnership Trust

**Child & Adolescent Mental Health Services**

███████████████████████
███████████████████████
███████████████████████
███████████████████████

Telephone: ████████████
Fax: ████████████

Dear Parent/Guardian/Carer,

Re: Research Study: Living with Obsessive Compulsive Disorder; A Child's Perspective.
Researcher: Helen Veater

I am writing to invite your child to take part in an interview as part of a study, looking at children's experiences of living with Obsessive Compulsive Disorder. This study forms part of a Doctorate in Clinical Psychology research project and is funded by Coventry and Warwick Universities.

I have enclosed some information about the project for you to read. If you would like to take part or find out more about the project then please complete the reply slip below and return in the stamped addressed envelope provided. Please return the reply slip by the 31st January 2016, and Helen will then contact you. Alternatively, you can email her at veaterh@coventry.ac.uk.

Yours sincerely,

**On behalf of** ████████████████ **CAMHS**

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

*Project Title: Living with Obsessive Compulsive Disorder; A Childs Perspective.*
*Researcher: Helen Veater*

I *would / would not like Helen Veater to contact me to find out more about taking part in the above project.

*Delete as Appropriate

Print…………………………………………………………………………………………..……

Signed ………………………………………………………………………………………………..

Contact Phone Number………………………………Email……………….….…………………

Living with Obsessive Compulsive Disorder: A child's perspective/ Invitation Letter/Version 2/ 09/07/2015

# Appendix J: Participant Information Sheet

Coventry and Warwickshire **NHS**
*Partnership Trust*

**Participant Information Sheet**
Study Title: Living with Obsessive Compulsive Disorder; A Childs Perspective
Researcher: Helen Veater

### Who I am?
My name is Helen Veater, and I am a trainee Clinical Psychologist. I work with adults and children who have Obsessive Compulsive Disorder (OCD) and other difficulties like depression and anxiety.

### What would I like?
I am doing a project to try to learn more about what it is like to have OCD and how this affects children and the different parts of their life. Like their friendships or school work.  Many researchers have done projects to help us understand more about OCD. They have looked at what might cause OCD, what people with OCD find difficult and what helps to make people feel better. In the past researchers often do not ask children or young people who have OCD what it is like for them, and what helps them to manage.

It is really important that researchers do this as children like you are the ones who are living with OCD every day. This means you might have ideas and thoughts that may help the researchers to understand more about OCD, and the more we know the more we will be able to do to help.

*Please Turn Over*

Living with Obsessive Compulsive Disorder: A child's perspective/ Participant Information Sheet/ Version 2/ 09/07/2015/ 2 copies: 1 for participant, 1 for the project notes

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**Why are you being asked to take part?**

You are being asked to take part in this project because you have OCD and I am interested in hearing about your experiences. I believe you are the best person to tell me about what it is like to live with OCD.

**What will you be asked to do?**

If you agree to be in this project then I will meet with you for an hour to talk about what you think it is like to have OCD. We will be able to take some breaks if we need it. It would be nice if I could talk to you on your own but if you would like your mum or dad or someone else to come with you that would be fine.

I want to make sure that you feel okay about talking to me, so you can speak to me without feeling worried. So when we talk if there are some things you are not sure about or that are difficult to talk about then this is okay. I will just find other things to talk about that will be easier for you.

After we have met, if you would like me to, I will contact you to tell you what I learnt from our talk, and when I have finished the project I can send you some information on what I found out.

**Do you have to take part?**

No, if you don't want to help with this project, you don't have to take part. Remember, helping with this project is up to you and no one will be upset if you don't want to take part or even if you change your mind later and want to stop. I will also ask your Parents/ Guardian/Carer to give their permission for you to take part in this study. But even if they say "yes" you can still decide not to do this.

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Living with Obsessive Compulsive Disorder: A child's perspective/ Participant Information Sheet/ Version 2/ 09/07/2015/ 2 copies: 1 for participant, 1 for the project notes

**How to get involved?**
If you would like to take part then please talk this over with your parents/guardian/carer and then return the reply slip to me. I will then contact you to arrange a time for us to meet.

You can ask me any questions that you have about taking part. If you have any questions you can email me [veaterh@coventry.ac.uk] or ask me when you see me. Thank you - I look forward to hearing from you.

## Appendix K: Parent Information Sheet

Coventry and Warwickshire **NHS**
Partnership Trust

**Parent/Guardian/Carer Information Sheet**
Study Title: Living with Obsessive Compulsive Disorder; A Child's Perspective
Researcher: Helen Veater

### What is the purpose of the research project?

The aim of the above research project is to speak with children and young people who have difficulties with what is often referred to as Obsessive Compulsive Disorder or OCD. It is hoped that by doing this we will be able to better understand their experiences and increase the knowledge base that informs practice for children and young people who suffer from the difficulties associated with the diagnosis of OCD.

### Why has my child been identified?

Your child has been identified by a clinician working at the [*insert name of service*] because they are aged between 8-18 years of age and they have a diagnosis of OCD. This research project aims to interview between 6 to 8 children about their experiences of OCD.

### Does my child have to take part?

No, it is up to you and your child to decide whether or not to take part. Both you and your child will be asked to give consent to participate before the research can take place. You can stop at any time; before, during or after the interview and you withdraw consent and ask for everything that your child said to be removed

*Please Turn Over*

from the study up to two weeks after the interview, without giving any reasons. Your decisions about this will not affect the standard of care your child will receive.

**What does the research project involve?**

The research project involves your child being interviewed by the researcher about what it is like for them to have OCD. The interview will be conducted by the researcher who is a Trainee Clinical Psychologist, their name is Helen Veater.

Helen will have a number of questions which will help your child to talk about their experiences. There are no right or wrong answers as the interview aims to capture your child's ideas and perspective about living with OCD.

If you would like to find out more about the project then you can meet with Helen before you decide, by contacting her using the details below.

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

If you and your child agree to take part in this project then the researcher will make sure you are both happy with the explanations you have been given about the purpose and nature of the research project and will ask you to complete a consent form. In addition to this your child will also be asked to sign an 'Assent Form', if they want to, to say they are happy to take part. You will have a copy of these signed forms for your records, along with a copy of this information about the research project.

If your child agrees to take part then they will be asked to take part in one interview which is anticipated to be about one hour long. During the interview if your child wants to take a break this will be fine. The interview will be digitally recorded to ensure your child's perspective is accurately recorded.

**Where will the interviews take place?**

The researcher is happy to conduct the interview at a time to best suit both you and your child and will take place in a private room at [*insert name of service*]. Any travel expenses will be covered by the researcher.

**What will happen after the interview?**

Following the interview you and your child will be thanked for taking part and will be given the chance to ask any questions. You will be given a debrief leaflet with details of who you can contact if you require further support following your participation in the research project and what will happen to your information. If you have given permission the researcher will contact you at an agreed time to feedback what was discussed and upon completion of

Living with Obsessive Compulsive Disorder: A child's perspective/  Parent/Guardian/Carer Information Sheet/
Version 3 / 18/12/2015

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the project will send you a summary of the findings. You will not be required to do anything further.

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

Every effort will be made to make your child feel comfortable and at ease during the interview. The possible disadvantages associated with taking part are that for some people talking about their experiences of OCD may lead them to feel upset during the interview or afterwards. If at any point your child becomes upset during the interview then the researcher will stop the interview and manage the immediate issues.

The interview will then only proceed if the child feels able to. If your child becomes distressed as a result of the interview once it has finished then you can speak to your case manager at CAMHS or to [*insert name of agreed professional*]. The phone number is [*insert phone number*].

**What are the possible benefits of taking part?**

The possible benefits of taking part are that your child will be provided with the opportunity to give their views on what it is like to live with OCD. It is really important that researchers listen to the views and perspectives of children living with OCD as they are the 'experts' in their own condition, and it is possible that this may help researchers and clinicians to understand OCD better. This may then further help to understand how to help children cope with OCD or even overcome their difficulties.

**If my child takes part in the research project will it be kept confidential?**

Yes, the audio recording and written transcript will be kept confidential and stored in a locked filing cabinet that only the researcher has access to, on NHS property. The final write up as part of the Doctorate study and where relevant the journal publication of the research project will not identify you or your child. Once the data has been used in the study it will be stored safely and confidentially at Coventry University for five years, following which it will be destroyed in a safe and confidential manner.

**What happens if I or my child changes their mind after taking part in the study?**

If following the interview either you or your child decide you do not wish their data to be used then your child's data can be withdrawn up to two weeks following the interview.

*Please Turn Over*

**What happens if my child discloses something of concern?**

If during your child's interview they disclose something which the researcher feels puts your child or someone else at risk then this will be reported to [*insert name of professional*] at CAMHS and the research supervisor. This may involve consideration of how to take this further, calling upon the local NHS Trust Child Protection guidelines.

**What if there is a problem?**

Any complaint about the way you or your child has been dealt with during this study or any possible harm you may suffer will be addressed. If you have a complaint relating to the research project then you are requested that in the first instance to inform the researcher, Helen Veater, who will try to resolve the matter. Failing this you may wish to contact the Coventry University Ethics Committee, [*insert contact name and position*] in writing at [*insert contact address*] or by telephone on [*insert telephone number*].  In the event of a complaint relating to the NHS Trust you should follow the NHS Trust complaints procedure. The Patient Liaison Advice Service (PALS) may also be contacted on [*insert phone number*].

**What will happen to the results of the research study?**

The results of the study will be anonymised so that any information that may identify your child is removed. The study will be written up and submitted as part of a final year thesis project for the researchers Doctorate in Clinical Psychology. It is hoped that the research paper will also be submitted to a scientific peer reviewed journal for publication. If accepted for publication, then the researcher will assist you in obtaining copies of the paper should you like to see it?

**Who is organising and funding the research?**

The research is funded by the Universities of Coventry and Warwick, and is organised by the following research team:

- Helen Veater (Trainee Clinical Psychologist/ Principal Researcher).
- Dr Jacqueline Knibbs, (Doctorate Course in Clinical Psychology, Admissions Tutor/ Clinical Psychologist/ Academic Research Supervisor for Helen Veater).
- Dr David Sanders (Clinical Psychologist/ Clinical Research Supervisor for Helen Veater).

Living with Obsessive Compulsive Disorder: A child's perspective/   Parent/Guardian/Carer Information Sheet/ Version 3 / 18/12/2015

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**Who has reviewed the study?**

The research has gained ethical approval from the following sources:

- Coventry University Ethics Committee,
- National Research Ethics Committee via the Integrated Research Application System (IRAS)
- Local Research and Development Departments of the NHS Trusts involved.

Thank you for taking time to read this. If you have any questions or concerns about taking part in this research or would like to discuss this further please contact either myself or my project supervisor.

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## Appendix L: Parent Consent Form

Coventry and Warwickshire **NHS**
Partnership Trust

**Parent/Guardian/ Carer Consent Form**
Study Title: Living with Obsessive Compulsive Disorder; A Child's Perspective
Researcher: Helen Veater

**Child's name:**

**Please initial box**

1.  I confirm that I have read and understand the Parent/Guardian/Carer Information Sheet for the above study. I have had the opportunity to consider the information and ask questions and have had these answered satisfactorily.

2.  I understand that my child's participation is voluntary and that I am free to withdraw their data anytime up to two weeks following the interview, without giving any reason, and without their care or legal rights being affected.

3.  I agree that my child's interview can be recorded using a digital audio recorder.

4.  I understand that my child's interview will be recorded and that direct quotes from the interview will be anonymised and then may be used in the research project and in subsequent publications.

*Please Turn Over*

Living with Obsessive Compulsive Disorder: A child's perspective/Parent/Guardian/Carer Consent Form/ Version 2/ 09/07/2015/
2 copies: 1 for participant, 1 for the project notes

5. I agree that my child can be contacted after the initial Interview in order to receive feedback on the information gathered.  ☐

6. I would / would not like to receive summary of results from this research project.  ☐

7. I understand that if the researcher feels my child or someone else is at risk they will follow NHS Safeguarding Policies.  ☐

8. I agree to my child taking part in the above study.  ☐


_____  _____  _____

Name of Parent/Guardian/Carer    Date    Signature


_____  _____  _____

Name of Researcher    Date    Signature


Contact Details of Project Supervisor: Dr Jacky Knibbs Clinical Tutor / Clinical Psychologist j.knibbs@coventry.ac.uk  Tel: 02476 888 328

Living with Obsessive Compulsive Disorder: A child's perspective/Parent/Guardian/Carer Consent Form/ Version 2/ 09/07/2015/ 2 copies: 1 for participant, 1 for the project notes

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## Appendix M: Participant Assent Form

Coventry and Warwickshire **NHS**
Partnership Trust

**Participant Assent Form**
Study Title: Living with Obsessive Compulsive Disorder; A Child's Perspective
Researcher: Helen Veater

**Please tick box**

1. I have read the yellow sheet which tells me all about the project. 👍 ☐

2. I have had time to talk to my Parent/Guardian/Carer about taking part in the project. 👍 ☐

3. I have had time to ask Helen any questions that I may have, and she has answered them for me. 👍 ☐

4. I would like to talk to Helen about what it is like to have OCD 👍 ☐

5. I understand that Helen will tell someone at CAMHS about what I have said if she is worried that I am not safe or someone else is not safe 👍 ☐

6. I am happy for the interview to be digitally recorded 👍 ☐

*Please Turn Over*

7.   I am happy for Helen to contact me after the interview so she can 👍 ☐
     feedback what we talked about.

8.   I understand that I have two weeks after my interview with Helen to tell 👍 ☐
     her if I have changed my mind about taking part.

9.   At the end of the project I would like Helen to send me information on 👍 ☐
     what she found out.

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

*(Write your name here)*_____

(Parent/Guardian/Carer signature here) _____

My supervisor's contact details are: Jacky Knibbs Clinical Tutor / Clinical
Psychologist  j.knibbs@coventry.ac.uk  Tel: 02476 888 328

## Appendix N: Participant Debrief Sheet

Coventry and Warwickshire **NHS**
Partnership Trust

**Participant Debrief Sheet**
Study Title: Living with Obsessive Compulsive Disorder: A Child's Perspective
Researcher: Helen Veater

**Thank you for taking part in this project** ☺

I am really grateful that you came to speak to me about what it is like to have Obsessive Compulsive Disorder (OCD). I hope you found it okay to come and see me and answer my questions.

I shall now listen to the recording of the things we spoke about and have a think about all the things that you have said. If it is all right with you I will then contact you to tell you what I have learnt.

I shall also do this with the other people I have spoken to as well. I shall then put all the things together and write a project on it. When I do this I will look very carefully at all the different things people said about OCD and what it is like to have it.

I hope that this project will help find out some new things about what living with OCD is like and maybe help come up with some ideas about what can make it easier for children who have OCD.

Hopefully the things I find out will help other children with OCD and also help the people who help them, like the people you see at CAMHS.

When I have finished writing my project I can send you some information on what I found out - if you would like me to?

*Please Turn Over*

**A few things to remember:**

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

- Try to speak to your Parent/ Guardian/Carer

- You can also speak to someone at CAMHS.

- If you prefer to speak to someone who doesn't know you then you can call Child Line (0800 11 11)

If after the interview you change your mind and decide you do not want me to use the things we talked about in my project then that is absolutely fine. Speak to your parents/guardian/carer and they will help you to contact me within two weeks to let me know. You will not upset me or get in trouble with anyone and you don't have to give a reason. I will only use the things you have said if you think this is okay.

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Contact Details of Project Supervisor: Dr Jacky Knibbs Clinical Tutor / Clinical Psychologist j.knibbs@coventry.ac.uk Tel: 02476 888 328

**Appendix O: Parent Debrief Sheet**

Coventry and Warwickshire **NHS**
Partnership Trust

Thank you for supporting your child to take part in this research project. If you or your child have any questions following the interview then please do not hesitate to get in touch.

Whilst it is unlikely, if following the interview your child experiences any distress then please do not hesitate to get in touch with [insert name of agreed CAMHS Clinician] at CAMHS who will be happy to support you both.

If after the interview either you or your child changes their mind about taking part and do not want the content of the interview to be used as part of this research project then you have two weeks in which to contact me to have your data withdrawn.

Should you wish to withdraw your child's data you will not have to give a reason and their care or legal rights will not be affected.

**What happens now?**

I shall now listen to the recording of the interview and If you have given permission I will contact you and your child to feedback what I have learnt from their interview.

This information will then be put together with the other interviews I have completed before interpreting the results.

*Please Turn Over*

Living with Obsessive Compulsive Disorder: A child's perspective/ Parent/Guardian/Carer Debrief Sheet/ Version  2/ 09/07/2015

When I have finished writing up the research project I will send you a summary of the results if you have requested them.

I hope that this project will help find out some new things about what living with OCD is like and maybe help come up with some ideas about what can make it easier for children who have OCD, and help improve the services they engage with.

If you would like some further information on the area I am researching then I have attached some references for your information.

Many thanks for your participation,

Helen Veater, Trainee Clinical Psychologist, Doctorate in Clinical Psychology Program, Universities of Coventry & Warwick, Coventry University, Priory Street Coventry, CV1 5FB. Email: veaterh@coventry.ac.uk  Tel: 02476 887 806

Contact Details of Project Supervisor: Dr Jacky Knibbs Clinical Tutor / Clinical Psychologist j.knibbs@coventry.ac.uk  Tel: 02476 888 328

**Research Information**

There is growing research into the causes, prevalence, co-morbidity and both pharmacological and psychological treatment of paediatric OCD (Thomsen, 1994). Presently however there is limited research on how children come to understand their diagnosis, or what it is like to live with a mental health condition in childhood. A recently published study (Bringewatt, 2013) looked at how emerging adults (aged 18-22) described and made sense of the mental health diagnosis they had received in childhood. The findings of the above study demonstrated how children actively seek and obtain information about their diagnosis over time, often moving between medical and non-medical accounts as they consider and negotiate differing narratives about their condition. What also emerged was the importance of gaining assurance from their parents about their diagnosis, as this helped to alleviate their fears and concerns and aid their overall understanding of their difficulties.

This study by Bringewatt (2013) allows us to begin to understand the process by which children make sense of their mental health condition and highlights the importance of discourse in their understanding and experience of negotiating the often confusing world of mental health. Whilst the above study has importantly begun to examine a previously neglected area of research, giving a voice to a previously under represented population there are a number of limitations. It is therefore important that future research in this area seeks to explore the experiences of children who are currently living with a mental health condition (Bringewatt, 2013).

At present the author is aware of only one unpublished piece of research that explores the lived experiences of children with a diagnosis of OCD (Simmonds, 2009). This study explored the experiences of seven children (mean age 13.4) with a diagnosis of OCD who had completed either a group or individual Cognitive Behavioural Therapy for OCD. The study described how participants struggled to control the conflicting reality of the thoughts, feelings and behaviours associated with their OCD and the expectations of societal norms. The study also highlighted the emotional consequences of living with OCD, with participants describing a range of emotions (depression, anger, stress, embarrassment and shame) and the way in which this impacted on their sense of self, and contributed to a feeling of difference. The impact of

**Appendix P: Overview of IPA Analysis Process**

| Stage | Key Task | Process |
|---|---|---|
| **Stage One** | Reading and Re-Reading | In order for the analyst to immerse themselves in the original data transcripts were read, and then read again a number of times.<br><br>The original recordings were also listened to again during this process. |
| **Stage Two** | Initial Noting | The analyst makes a detailed set of notes and comments in the right hand margin of the transcript.<br><br>These notes encompass significant comments made by the participant as well as the researcher's initial reflections.<br><br>This process happens concurrently with stage one as the analyst engages with the transcript. |
| **Stage Three** | Developing Emergent Themes | The focus of this stage is the initial notes.<br><br>These are re read and the analyst interprets these to identify an emergent theme that captures and reflects an understanding of the original transcript. |
| **Stage Four** | Searching for Connections Across Emergent Themes | This stage involves the analyst developing a map of how they think the emergent themes fit together. This involves looking for patterns and connections between the emergent themes and the creation of superordinate themes. |
| **Stage Five** | Moving to the next Case | Here the analyst moves their attention to the next transcript and repeats stages one to four. |
| **Stage Six** | Looking for Patterns Across Cases | This stage involves the analyst looking for patterns across all the transcripts that represent higher order concepts. |

*Adapted from Smith, Larkin & Flowers (2009)

# Appendix Q: Excerpt from Transcript



**Participant 6**

*Handwritten annotations (left margin, pink):*
Fear? of negative evaluations

Stigma

impact of OCD.

OCD & self image

others not understanding

societal views

*Handwritten annotations (top/right, blue):*
"ill"? OK to share ?shame — others asking Questions.

No choice

kept hidden from some.

wanted to explain
? fear of others evaluation of behaviour.

? Abnormal? — impact on shared activitie

Forced to explain.

Unclear what sense others had made of it.

Don't want OCD to affect the way others see me.

lack of knowledge → Avoidance.

Separating identity & OCD

others not knowing about OCD

Trust needed?
Just like other Personal diff. Info

*Transcript text:*

172 over time I just sort of like people like when I went back into
173 school they were like oh why were you off. Um and some
174 people depending on how close I was to them I told some
175 people I just said I was ill. Yeah

176 Q: So some people you gave different information to. Um you
177 talked about telling your close friends about this before you
178 knew you went into hospital and maybe a little bit before you
179 even knew you were going into hospital um why did you tell
180 them?

181 A: Um just in case like I was doing odd well rituals or something
182 like that when I was out and they um they thought oh why she
183 doing that, so I just thought I would let them know.

184 Q: Yeah.

185 A: Or actually sometimes I was I used to I was cycling to school
186 with my friends and uh I would often be late for her in the
187 morning s because of all the rituals so that's kind of the main
188 reason I told her.

189 Q: OK. And I mean you won't know this for sure but what do
190 you think they think about the OCD?

191 A: Um ...ur I dint know really I don't really know how much they
192 know about it like I don't think it's it like bothers them that much
193 I'm mean that's a good thing I don't want them to kind of think
194 about it too much I just want them to think of me as me.

195 Q: [in audible]

196 A: Yeah

197 Q: OK. Are there people that you haven't told so you mentioned
198 people?

199 A: Ah yeah there are some people just people that I'm not so
200 close to really.

7

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**Participant 6**

*Handwritten annotations (left margin, pink):*
• OCD & identity

• making sense of diagnosis

• identified by others

• Shame
• fear of negative evaluation

• outside of "Norms"

• confiding in others

*Handwritten annotations (right, blue):*
others making sense of

Adapted as explanation.

Did she notice?

others noticed — something unusual

evaluated by others (shame?)
others (Healthcare prof.) noticed something

– Severity of ritual

need to trust others?

only confided in close friends.

Private/Personal.

Able to tell about hospital admission as they knew already.

couldn't hide??

*Transcript text:*

144 A: Well um a lot of well doctors that I have seen some of them
145 like who I saw here and things they have always put me down
146 described me as like a perfectionist kind of maybe that's a bit
147 why.

148 Q: OK. So that might have contributed to it. OK. And who did
149 you first tell about the OCD if you told anyone?

150 A: Urm I don't think I don't know if I actually told anyone I think it
151 was more it was more noticed I'd yeah.

152 Q: And who was it that first noticed?

153 A: Hmm mum and dad I think.

154 Q: yeah OK. And do you remember when mum first noticed do
155 you remember her or dad

156 A: Umm... I think the first ever thing that was a really real ritual
157 was brushing my teeth ur um and I even went to the dentist and
158 they asked how long I was doing it for and I said and I realised
159 that I was embarrassed to say how long I was doing it for and
160 that was the first time I though it's not right um and yeah.

161 Q: OK. And obviously that mum and dad first noticed and then
162 obviously things progressed and have you told people since
163 about OCD?

164 A: Yeah

165 Q: So tell me about who you have told.

166 A: urr well I have told my closest friends um about it um
167 probably about a year or two about a year and a half ago.

168 Q: mm hum

169 A: Um and because they knew and I told them when I was
170 going into hospital and they knew what it was for so I was I told
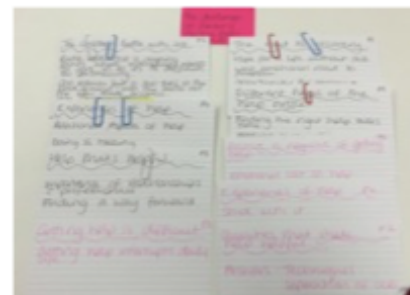171 them probably a few months before that um and then gradually

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**Appendix R: Analysis Illustration**

Analysis of Emergent Themes within Individual Case



Analysis of Themes Across Cases



Analysis of Superordinate Themes