

Research dossier

Research report

Title

Living with Body Dysmorphic Disorder or Obsessive Compulsive Disorder. An IPA study.

Critical review

Introduction

Body Dysmorphic Disorder (BDD) and Obsessive Compulsive Disorder (OCD) share many similarities such as the presence of obsessions and compulsions, a similar age of onset and also similar activation of underlying structures within the brain related to obsessions and compulsion formation. The recently published DSM-V (Diagnostic and Statistical Manual for Mental Disorders; American Psychiatric Association, 2013) has grouped the two conditions together in a chapter entitled Obsessive Compulsive -and related disorders, recognising the similarities in presentation. This appeared to echo the classification within the NICE guidelines for OCD and BDD (National Institute for Health and Care Excellence, 2006) where the two conditions were grouped together on the presence of obsessions and compulsions, neurological evidence pointing to the activation of brain areas responsible for obsessive thoughts and compulsive acts alongside strong familial links. Both OCD and BDD were understood (from both sets of guidelines) to respond well to the use of Selective Serotonin Re-uptake Inhibitors and the treatment use of Cognitive Behavioural Therapy.

This qualitative research study focuses on the gap in existing literature by studying the lived experience of individuals living with obsessions and compulsions. Much focus has historically remained on understanding the clinical symptomology and underlying constructs as related to living with obsessions and compulsions, through the use of questionnaires or brain imaging. With recent changes in the DSM-V (Statistical Manual for mental Disorders; American Psychiatric Association, 2013) recognising OCD and BDD as part of the same

family of conditions, it appeared timely to focus on the individuals living with OCD or BDD and their sense and meaning making as informed by their experiences of obsessions and compulsions.

Classification and understanding up to date

The NICE guidelines (National Institute for Health and Care Excellence, 2006) described an obsession as “an unwanted intrusive thought, image or urge, which were acknowledged as originating in the person’s mind, and not imposed by an outside agency. (p.15). Obsessions were reported to usually [be] regarded by the individual as unreasonable and excessive” whilst compulsions were described as “repetitive behaviours or mental acts that the person feels driven to perform (p.15). A compulsion [could] either be overt and observable by others, such as checking that a door [was] locked, or a covert mental act that [could not] be observed as in repeating a certain phrase in the mind” (p.15). It appeared easy to make use of covert compulsions as it would remain unknown to anyone other than the person performing them. Compulsions were not pleasurable or effecting instant gratification illuminating the distress associated with living with obsessions and compulsions. The NICE guidelines (National Institute for Health and Care Excellence, 2006) described OCD as “*the name given to a condition in which a person has obsessions and/ or compulsions, but usually both*” (p.7) and went on to describe BDD as “the name given to a condition where a person spends a lot of time concerned about their appearance. They may compare their looks with other people’s , worry that they are physically flawed and spend a long time in front of a mirror concealing what they believe is a defect.” (p.9). Diagnoses of both OCD and BDD were said to relate directly to the impact and level of distress as reported by the individual in both their personal and professional lives.

The general public was said to experience intrusive thoughts whereas the difference in people living with OCD was “[they] tend to believe that intrusive thoughts and urges are dangerous or immoral and that they are able to prevent harm occurring either to the self or a vulnerable person (Salkovskis, Richards and Forrester, 1995). People living with OCD were reported to ruminate in over-thinking specific thoughts and questions, continually searching for answers with regards their obsessions. Compulsions ranging from checking, organising, counting- and cleaning behaviours, needed to be continually repeated and were motivated by irrational fears or perceived threats. These behaviours could include arranging or ordering objects perfectly symmetrical, hoarding objects of no clear value, failing to throw objects away or having an excessive amount of objects related to a perceived threat. Mental compulsions included counting or structuring thoughts according to an individual’s own rules in order to reduce anxiety, a process similar to the use of neutralising thoughts by allowing the thought of a positive image to momentarily cancel out a negative image. People living with OCD were said to follow neutralising behaviours and safety seeking behaviours to avoid harm or to “feel right”, and could alternatively avoid activities or objects associated with obsessions and worry in order to avoid any flare ups of anxiety.

BDD was characterised (according to the NICE guidelines, 2006, p. 25) as “*a preoccupation with an imagined defect in one’s appearance or, in the case of a slight physical anomaly, the person’s concern is markedly excessive*”. The individual could report one or many affected areas in his or her body, including concern about asymmetrical body parts, skin flaws, complexion concerns or feeling ugly and unattractive. Compulsions could include mirror gazing, reassurance seeking, comparing physical features with those of other people, compulsive skin picking, intimacy avoidance and social avoidance and camouflage (through the use of make up or pieces of clothing). Social interaction was said to be anxiety provoking and was tolerated through the use of alcohol or drugs.

In the ICD-10 (International Statistical Classification of Diseases and Related Health Problems; World Health Organization, 2010), OCD was grouped together with all “neurotic, stress-related and somatoform disorders. These disorders were characterized by psychological symptoms (fear, anxiety) and somatic manifestations (e.g. panic attacks) of anxiety. In OCD, the focused repertoire of obsessions, their intrusiveness and ego-dystonic nature, combined with the associated stereotypical compulsive rituals helped differentiate obsessions from the ruminations of generalized anxiety disorder (GAD) and symptoms of other anxiety disorders. Obsessive Compulsive-spectrum disorders appeared to share with OCD both prominent obsessions and compulsions (e.g. trichotyllomania, tic disorders) whilst people living with BDD were reported to experience similar obsessions, such as related to a specific bodily area being asymmetrical, and compulsions such as mirror gazing, related to the obsession in question. Other similarities existed in BDD and OCD including: higher rates of perfectionism than those found in controls (Buhlmann, Etcoff and Wilhelm, 2008); low levels of extraversion and high levels of neuroticism (Phillips and McElroy, 2000, Fullana et al., 2004).

Prevalence rates

The reported prevalence rates for BDD and OCD seem to differ widely according to study. Rief, Buhlmann, Wilhelm, Borkenhagen and Bähler (2006) reported a prevalence rate of 1.7 per cent and Buhlmann et al., (2010) a 1.8 per cent prevalence of BDD in Germany. Otto, Wilhelm, Cohen and Marlow (2001) reported a rate of 0.7 per cent in the United States of America. Kessler, Chiu, Demler and Walters (2005) stated 2.2 million adults in the United States of America to have OCD, whilst Torres, Prince and Bebbington (2007) stated prevalence in the UK to be 1.1 per cent of the population.

Table 1

Prevalence rates of BDD and OCD

	BDD	OCD
Germany	1.7%	.39 % (12 month prevalence)
USA	1.8%	1 % (12 month prevalence)
UK	0.7%	1.2 %
		1 %

Recent developments with regards classification

Within the DSM-V (Diagnostic and statistical manual for Mental Disorders, APA, 2013) a new chapter was created which grouped together OCD and BDD on the basis of the presence of obsessions and compulsions, underlying neurobiology related to the activation of the caudate nucleus and putamen as relevant to causing obsessions and compulsions, familiarity, course of illness in showing chronicity of symptoms over the lifetime and treatment response to Cognitive Behavioural Therapy and Selective Serotonin Re-uptake Inhibitors. The NICE guidelines (National Institute for Health and Care Excellence, 2006) described OCD and BDD as two distinct conditions both of which showed similarities in the presence of obsessions and compulsions and response to treatment (either pharmacological use of Selective Serotonin Re-uptake Inhibitors or SSRIs or through the use of Cognitive Therapy, Behavioural Therapy or Cognitive Behavioural Therapy). Other diagnoses also included in this chapter include trichotillomania and hoarding disorder.

The DSM-V writers described how conditions in this chapter shared “obsessive preoccupations and repetitive behaviours “(Obsessive Compulsive and related disorders, American Psychiatric Association, 2013). It was hoped by grouping these conditions together clinicians would look for family history of this group of conditions and also consider the comorbidity of the two diagnoses in question. A scale was designed to evaluate and interpret

“insight” as present in individuals presenting with OCD or BDD (American Psychiatric Association, 2013) which reflected how individuals could vary across a dimension of having fair insight (into the believability of their obsessions and compulsions) to having absent or no insight. This scale was focused on attenuating clinicians to diagnoses of either OCD or BDD as appropriate rather than diagnoses of psychosis or schizophrenia and that insight could be a component of OCD or BDD. It was especially important to recognise the delusionality and insight as present in OCD and BDD as historically anti-psychotic medication would be the first choice of treatment whereas the DSM-V writers urged clinicians to use Selective Serotonin Re-uptake Inhibitors instead as delusionality was part and parcel of the disorders and not a sign of psychosis presentation.

The British Psychological Society (BPS) offered comment regarding the proposed changes to the DSM-V (British Psychological Society, 2011) and was especially concerned with the over-medicalisation and categorisation of what they termed “natural and normal responses to their experiences” (p.15). The BPS was concerned that the possible role of contextual influences (such as relationship- and social stresses) would be ignored when diagnosing individuals with “disorders”. The BPS appeared equally concerned regarding what it termed the “over use” of pharmacological treatments for conditions identified. It appeared to recognise the usefulness of presenting distress related to compulsions and obsessions within one section of the DSM-V publication but also called for understanding of context and individual experience in assessment and treatment of psychological distress. Within this study the aim was to acknowledge the usefulness of changes to the DSM-V in recognising the similarities between BDD and OCD (re the presence of obsessions and compulsions) and its understanding of the conditions as belonging to the same family of “disorders”, but most importantly to reflect on individual experience of obsessions and

compulsions through the use of qualitative semi-structured interviews through the use of Interpretative Phenomenological Analysis (Smith, 1996).

Quality of life, social impairment and brain morphology

Didie, Pinto, Mancebo, Rasmussen and Phillips (2007) acknowledged that people living with either BDD or OCD illustrated signs of poor quality of life and psycho-social functioning. Didie et al.(2007) hypothesized that due to its interpersonal nature, people living with BDD would show higher scores on impaired social functioning. Despite the presence of differing core beliefs, similar scores for impaired social functioning were observed for individuals living with OCD as compared to those living with BDD. Core beliefs for individuals living with BDD were hypothesised to relate to interpersonal themes, leading the individual to believe he or she would land up isolated or be rejected as a result of their perceived imperfections (Veale, 2004), whilst people living with OCD were hypothesized to have core beliefs related to “inflated responsibility, importance of control, and overestimation of harm” (Obsessive Compulsive Cognitions Working Group, 1997, as cited in Didie et al., 2007).

Many brain morphology similarities have been proposed for BDD and OCD. Feusner et al., (2010) carried out a functional Magnetic Resonance Imaging study and reported how individuals living with BDD showed an activation of the left orbito-frontal cortex and bilateral head of caudate when viewing a photo of the participant’s own face vs. a photo of a familiar face. These areas were reported to be activated in people living with OCD and were said to be closely related to obsessions and compulsive acts. Unfortunately the Feusner et al. study made use of very small numbers of participants (n = 17 for the BDD group and n =16 as control group) which related to very small power effects for the outcome of the study. Equally Feusner et al. agreed that subjective ratings of anxiety could have affected results as

no measure of subjective anxiety was put in place prior to the study. Equally faces shown to the participants were from one gender alone and not necessarily reflexive of the participants' gender. It could be by choosing to show only one gender, the researchers created a confounding variable which could have affected the results. Whiteside, Port and Abramowitz (2004) carried out a meta-analysis of papers focusing on the scanning techniques used with individuals living with OCD and confirmed the activation of the orbital gyri and the caudate nucleus. It appeared the strength of findings in this meta-analysis could be diluted as no clarity existed for the brain areas to be compared across studies. Whiteside et al. expressed concern as the exact brain regions studied, were not specified sufficiently across the studies involved in the meta-analysis and they called for standardization of methods used when carrying out imaging studies in the future. A further drawback from this study would be the small amount of studies included in the meta-analysis, these being a total of thirteen, which could place doubt on the generalisability of the findings. Kestenbaum (2013) described how abnormal serotonin-, glutamate- and dopamine levels could be connected to the presence of obsessions and compulsions (Jenike, Baer, Minichiello, 1998 in Kestenbaum, 2013) where glutamate was believed to act as neurotransmitter in the cortico-striatal-thalamic-cortical circuits and where dysfunction of these specific brain circuits had been identified in individuals living with OCD (Brennan, Rauch, Jensen and Pope, 2012). Kestenbaum described BDD as a variant of OCD and situated on the OC spectrum. This paper was published just prior to the recent DSM-V (Diagnostic and Statistical Manual for Mental Disorders; American Psychiatric Association, 2013). Wu, Hanna, Rosenberg and Arnold (2011) recognised the role of glutamate as neurotransmitter and reported on the use of medical treatments for clients living with obsessions and compulsions (using Riluzole or Memantine) to lower glutamate levels and obsessions and compulsions as a result. Their

results also point towards the recognition of diagnoses related to obsessions and compulsions being grouped together as a result of the neurotransmitters involved.

Behaviour change and the brain

Some scientific researchers have focused on the plasticity of the brain and how behaviour change could affect brain activation. Schwartz and Beyette (1996) described how the poor functioning of the caudate nucleus and putamen (collectively referred to as the Striatum) could cause messages to become stuck as if in a broken car transmission and the individual could then feel compelled to carry out repetitive behaviours or compulsions. The ineffective striatum was said to combine with the orbital cortex (an area of the brain involved in identifying possible dangers or acting as an early warning system to dangers) to interpret innocuous situations and messages as dangerous. Feelings of dread were said to be activated by the cingulate gyrus, compounding the sense of foreboding. When the striatum was working ineffectively, the cortex of the brain was said to become overtly involved in trying to resist urges and obsessions, calling on much energy from the individual to resist compulsive acts. By using their four stages of behaviour change entitled relabeling, re-attribution, refocusing and revaluing, Schwartz and Beyette reported individuals would be able to change their reactions to the faulty messages and could through resisting compulsions, change the activation of the striatum area in the brain. As a result of this behaviour change, the brain could respond and activate accordingly. Schwartz and Beyette's findings were also replicated and extended in more recent scientific research papers such as Linden (2006) who described through the use of Cognitive Behavioural Therapy or the use of Selective Serotonin Re-uptake Inhibitors, a decreased metabolism occurred in the caudate nucleus, leading to a lessening of obsessive and compulsive symptoms in individuals living with OCD. Through the use of fMRI (functional Magnetic Resonance Imaging), PET (Positron Emission Tomography) and- SPECT (Single Photon Emission Computed Tomography) scanning,

Linden was able to show the effectiveness of psychotherapy- and pharmacological treatment regimes without the need for invasive procedures. The effectiveness of psychotherapeutic treatments could be evaluated and the most useful treatment method employed. It was necessary to establish standardized protocols in relation to Linden's study as mention was made of the test results used from a variety of scanning procedures which were not all focused on using the same method of scanning or the same biological process occurring. As useful as Linden's findings were, it remains important to standardize procedures with regards the experience of obsessions and compulsions so as to be very clear in research how change and improvement could be brought about for individuals living with psychological distress. Further studies are needed to focus on individuals living with obsessions and compulsions to clarify whether all instances thereof would respond similarly to the individuals who partook in Linden's study.

Delusional thinking

People living with BDD or OCD were reported to have in common low levels of insight and high levels of *delusional* (Phillips et al., 2007). Phillips et al., reported how people living with BDD were reported to have no awareness of holding delusional beliefs, whereas individuals living with OCD were aware that the beliefs they held, were irrational. Phillips described how, despite having insight, people living with OCD still felt compelled to carry out repeated safety behaviours despite this insight. Eisen, Phillips, Coles, and Rasmussen (2004) reported 39 per cent of 85 participants with BDD, to have experienced delusional thinking, whilst only 2 per cent of 64 subjects with OCD described similar thinking. A drawback to the Eisen et al. study, was its pharmacotherapy nature. It could be participants were coaxed into participating due to the support of one specific pharmacotherapy company in doing the study. The absence of a control group and use of knowledgeable participants also detracted from its findings as participants could answer

questions posed so as to fulfil researcher expectations. With a small number of participants, (n = 64 in OCD group, n = 85 in BDD group) and by collectively using data from different trials, the findings could be drawn into further doubt.

Through the use of an implicit association test, Feusner, Neziroglu, Wilhelm, Mancusi and Bohon (2010) illustrated how people living with BDD were unaware of their associations made between physical attractiveness and capability and how this positively correlated with BDD symptom severity. Feusner et al. (2010) suggested “*that maladaptive behaviours in BDD might be fuelled by automatic processes outside of conscious control.*” (p. 351). A subgroup was reported to exist in people living with OCD (Catapano et al., 2010) which consisted of people with poorer insight, who didn’t respond to medicine and showed an overall poor prognosis. This three -year long study showed validity through its use of the Brown Assessment of Beliefs Scale (Eisen et al., 1998) to study levels of insight.

Most recently the DSM-V (Diagnostic and Statistical manual for Mental Disorders; American Psychiatric Association, 2013) added a scale to the new chapter entitled Obsessive Compulsive and related disorders, to reflect the variability and presence of delusionality and insight as components in both BDD and OCD. This scale was also related to the treatment guidelines in calling on clinicians to make use of Selective Serotonin Re-uptake Inhibitors (SSRIs) instead of anti-psychotic medicines as delusionality was recognised as part of OCD and BDD.

Demographics

Phillips et al., (2007) described a higher proportion of female participants to live with OCD or BDD (58. 6 % of OCD group and 66. 7 % of BDD group) whilst Frare, Perugi, Ruffolo and Toni (2004) reported 55. 9 % of their sample of participants living with BDD to be male and 51. 9 % of their OCD sample to consist of males. Both Frare et al. and Phillips

et al. reported higher figures of single people from the BDD groups of participants and married participants to reside in the OCD group. Phillips et al. carried out a longitudinal questionnaire –based study between OCD, BDD and a co-morbid group of participants. For the sake of convenience all participants were drawn from one large metropolitan area in Massachusetts and had to already be in receipt of mental health treatment. According to Phillips et al., (2007) and Frare Perugi, Ruffolo and Toni (2004), both OCD and BDD showed similar patterns in, a) times of onset during adolescence and b) similar demographics. It appears possible in the Phillips et al. study that individuals who resided in more rural or urban areas could offer different interpretations and thus the choice of a selected geographic area for participants could have affected results. It was also possible that the chosen participants, who were already familiar with mental health treatments, would offer different perspectives than those who were perhaps not in receipt of mental health treatments and results could not be applied directly to such groups. Frare et al. made use of semi-structured interviews with participants attending at the Institute of Psychiatry at the University of Pisa for psychological treatment. Participant numbers were limited (n=34 in the OCD group and n=79 in the BDD group) and as participants were already familiar with psychological treatments it seemed possible the results obtained could not be applied to those individuals who had not received any psychological treatments.

Genetic- and cultural links

Feusner, Neziroglu, Wilhelm, Mancusi and Bohon (2010) recognised a possible genetic link to having BDD and OCD, in stating that 8 per cent of people with BDD could have a first relation with BDD. People living with BDD would have 7 per cent of family members with OCD, whilst people with OCD stood a 6 per cent chance of having BDD in their immediate family. Bienvenu et al., (2000) contested that “[Their] results suggest that certain somatoform disorders (especially BDD) and pathologic grooming behaviors are

transmitted in families of patients with OCD and can be considered part of a familial OCD spectrum.” (p.291). It is important to recognize how both BDD and OCD varied across cultures, and how the focus of a particular cultural understanding of beauty, might affect the prevalence within that community. Taqui et al., (2008) reported a prevalence rate of 5.8 per cent for BDD amongst medical students in Pakistan. These findings might be related to the importance of beauty in Pakistani culture. The study was further affected by cultural taboos, in that behaviour and beliefs surrounding *acceptability*, would have been influenced by its Islamic culture. Participants in Phillips et al., (2007) study had all received prior treatment and no inter-rater reliability was established. Participants within the co-morbid group showed a higher percentage of primary BDD and this could have affected overall scores. Phillips et al. (2007) made use of the DSM -IV inclusion criteria for both OCD and BDD, the SCID I (First, Spitzer, Gibbon and Williams 1996 and 2002) and SCID II (First, Gibbon, Spitzer and Williams, 1997). The validity of the DSM-IV, has been criticized for having arbitrary categories and excluding the context and cultural understanding of a person (Kress, Eriksen, Rayle and Ford, 2005). Its use could contribute to psychological distress through the internalizing and personification of a given diagnosis (Honos-Webb and Leitner, 2001).

The role of qualitative research in the study of obsessions and compulsions

There were many psychometrically based studies used in this area of research (as mentioned in this critical review), but very few qualitative studies. These could enlighten practitioners to the context and experience of living with obsessions and compulsions and ultimately inform treatment strategies. Because BDD and OCD appeared difficult to diagnose and often occurred alongside other conditions, increased discussion and research, were essential. Ongoing imaging and psychometrically based studies, combined with experiential studies, could offer a clearer understanding of BDD and OCD. It might be that qualitative studies will be able to focus on the detailed experience of living with either OCD or BDD.

Murphy and Perera-Delcourt (2012) highlighted the personal experiences of individuals living with OCD and their struggle in the face of stigma (both self- and social stigma), trying to make sense of the impact of OCD on their sense of self. In their study Murphy and Perera-Delcourt made use of Interpretative Phenomenological Analysis (IPA) focusing on the lived experience and interpretations of nine adults living with an OCD diagnosis. Deficit identities were described in individuals living with OCD and yet dissonance appeared to also exist as participants struggled to let go of their OCD identities. The value of a therapeutic relationship was one of the reported outcomes of this study where participants talked highly of being listened to and taken seriously, however Cognitive Behavioural Therapy was described as getting in the way of the narrative or retelling of events which the participants were said to hope for. Murphy and Perera-Delcourt also reported on the desire of participants to fit in successfully, and feeling they failed at life and life stages due to struggling with OCD.

Despite looking at only nine participants' interpretations and perceptions Murphy and Perera-Delcourt recognised the importance of moving away from a pathology of mental distress and a renewed focus on lived experience which could inform clinical practice. The strength of qualitative studies such as Murphy and Perera-Delcourt lay in the description and exploration of context and the meaning participants had made of living with psychological distress. This type of knowledge could perhaps be transferred to other areas or contexts where a detailed exploration of personal experience could highlight human suffering and offer a glimpse into the lived worlds of people living with distress. Brooks (2011) detailed from an ethnographic point of view, her own experiences of living with OCD and her battle to tolerate and overcome the daily onslaught of the disorder. Brooks described how she lived with two personas one being a very public acceptance of her difficulty and the accompanying therapy whilst the second was reported as a private persona where she could hate the OCD, her experience of desensitising in the therapy sessions and the compliance her public persona had

shown. Brooks detailed the coping strategies employed in living with OCD as her public persona acted as manager and seemed to be calm and in control whilst her internal persona appeared embarrassed to live with OCD and to struggle with the obsessions and compulsions and the therapy which tried to remove safety behaviours. The strength of Brooks' ethnography lies in its exploration of depth of experience and its honest reflection of a personal struggle. It laid bare the context within which the writer was battling her own distress and gave a true reflection of personal experience. This type of qualitative paper was not intent on creating nomothetic or repeatable data but rather focused on an exploration and report of subjective experience hoping to inform practice through personal narrative. Olson, Vera and Perez (2007) carried out in-depth qualitative interviews with ten adults living with OCD. They explored the individual meaning making participants employed and noted how living with OCD appeared associated with stigma and lead to hiding of symptoms. It appeared participants in this study were actively searching for help and support but found only pharmacological avenues of support available. Olson, Vera and Perez identified how individuals living with OCD were often very talented individuals but were unemployed due to their psychological struggles and their potential remained largely untapped. The importance of being connected to something (a person, a place, a spiritual concept) appeared to loom large for participants as it offered a necessary support structure to aid living with psychological difficulties. Olson, Vera and Perez identified the importance of adequate and appropriate treatment methods for OCD as it appeared to remain a largely misunderstood condition within the setting of Hawaii where the participants resided. As a result participants reported on inadequate treatments and failure to improve symptoms. Another important themes related to the ego-dystonic nature of the participants in rejecting the OCD as "not part of themselves" and its "crazy" characteristics (perhaps referring to compulsions). Its detailed exploration of human experience and perception highlighted the importance of education of

mental health practitioners in the appropriate treatment of psychological distress and the effects mental difficulties could have on independent sense of self. Silver and Reavey (2010) made use of a narrative analytic approach in exploring the self concept of individuals living with BDD. They made use of both visual and narrative data in asking participants to bring photographs of happy periods in their lives and also to draw during the interviews a picture of themselves in the present. The narrative component was fulfilled in a structured interview (following the narrative analytic approach) and they reported on themes related to the participants' great sense of loss as they changed from a seemingly idealised concept of young and attractive selves to older and malformed adults living with BDD. It was reported the participants in this study felt free of blemishes and responsibilities only as children and expressed a desire to return to a safe and free childhood without any responsibility. This study highlighted the changing sense of selfhood across time and called for other research studies to include a focus on concepts wider than the immediate sense of ugliness or defect as perhaps representative around BDD in general. Silver and Reavey identified the sense of loss individuals could feel through seeing a change in their selves through living with mental distress and yet their study did not explore at sufficient depth the embodiment and rich description of individual lived experience. The writers proposed a combination of visual methods and qualitative methodologies which strength laid in eliciting detailed and rich description in future studies. Through these very personal and subjective papers, the individual journeys of psychological distress were highlighted and described, bringing validity to the individuals concerned but also detailing and informing the reader as to the impact and personal experience of living with psychological distress, a necessary tool in assisting and understanding the individuals concerned. Qualitative studies showed strength in focusing on individual experience in bringing detailed meaning and perception to the fore. It would not aim at generalizability but rather highlight detailed exploration of subjective

experience (across a homogenous group) which could inform on subjective experiences in other contexts.

The aim in this study is to report on the perceptions and impressions of individuals and the meaning they make of living with either OCD or BDD. The NICE guidelines for OCD and BDD (National Institute for Health and Care Excellence, 2006) included qualitative entries written by individuals living with either OCD or BDD as well as their carers in an attempt to show the variety of individual experience but also to point out the needs and requirements individuals and their families had with regards support and the concerns and fears they each faced. In view of these qualitative entries this study aims to contribute further to the exploration of experiences and perceptions as related to living with obsessions and compulsions. The purpose of the present study is to explore at an in depth level the views of participants with regards their sense of self, their relationships, their sense of the world as stimulated by their experiences of living with obsessions and compulsions. It is hoped that the findings from this research could enrich the field of Counselling Psychology with particular focus on subjective understanding of psychological distress and how to create supportive and appropriate frameworks for individuals who struggled therewith.

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Abstract

Body Dysmorphic Disorder (BDD) and Obsessive Compulsive Disorder (OCD) are understood to be related conditions due to the presence of obsessions and compulsions. Within the recent DSM-V (Diagnostic and Statistical Manual of Mental Disorders; American Psychiatric Association, 2013) a new chapter was created for Obsessive Compulsive –and related disorders which recognised the similarities in the causality and presentation of the two diagnoses in question. Further similarities related to treatment responses, familiarity and prevalence rates. These aspects of presentation will be discussed in view of setting the scene for a qualitative study focusing on eliciting the experience of obsessions and compulsions through the use of Interpretative Phenomenological Analysis. The overarching methods of study in this field as yet have included mainly quantitative methodologies including psychometric testing, survey data, brain scanning and interview data. Due to limited number of qualitative studies in existence focusing on the experience of obsessions and compulsions, this study aimed to elicit in-depth subjective accounts which could offer the practitioner useful information in the understanding of the experience of obsessions and compulsions. Three overarching themes arose from participants, these being conflicted control, relationships and finding ways forward. Participant perceptions and interpretations highlighted conflicted positions in relation to their understanding of themselves, their relationships and their meaning making of obsessions and compulsions and its impact. Implications of the research are discussed.

Introduction and rationale

This research study focused on the lived experience of adults living with obsessions and compulsions. It will focus on the perceptions and impressions from adults living with obsessions and compulsions and how they make sense of the impact of obsessions and compulsions in their lives.

Setting the scene

Most recently the DSM-V (Diagnostic and Statistical manual for Mental Disorders, American Psychiatric Association, 2013) included a new chapter in its fifth edition where OCD was combined with other conditions which were also identified through the presence of obsessions and compulsions. As a result “BDD”, “trichotyllomania” and “hoarding disorder” were all recognised as belonging to the same family of complaints. It was hoped this new grouping could encourage clinicians to research family components regarding OCD and BDD (as family members were often reported to live with either the same diagnosis or with the second condition mentioned (Feusner, Neziroglu, Wilhelm, Mancusi and Bohon, 2010) and equally to highlight the similarities between the conditions now sharing the same group. Similarities extended to how both difficulties shared the presence of distressing obsessions and compulsions, how both were shown to have activity in the caudate nucleus and putamen areas of the brain which were involved in the regulation of obsessive thoughts and compulsive acts and both responded well to treatment with Selective Serotonin Re-uptake Inhibitors (SSRIs) and Cognitive Behavioural Therapy (NICE guidelines for OCD and BDD; National Institute for Health and Care Excellence, 2006) to name but a few. Sadly very few researchers have studied the lived experience of individuals living with obsessions and compulsions, leaving this specific field of study seemingly a medical one where questionnaires, scanning procedures and drug trials were manifold. Notwithstanding the

information obtained from quantitative measures were of vital importance in recognising the patho-physiology of BDD and OCD and also in discovering underlying constructs and brain devices perhaps related to the psychological distress experienced such as reported by Schwartz and Beyette (1996). However qualitative studies could elicit a wholly different type of research material which offers a glimpse or snapshot of detailed lived experience which would not attempt to generalise but could elucidate subjective and contextual perceptions and meaning making which could be transferred to other contexts.

Qualitative contributions to existing research

A qualitative study could contribute to existing literature in bringing in depth experiential material to the fore, recognising from a social constructivist perspective the validity in each individual's experience. By focusing on the double hermeneutic circle related to the interpretations of individual experience (and re-interpretation by the researcher), through the use of Interpretative Phenomenological analysis (IPA) themes were developed from a phenomenological stand point. This method was appropriate as it explored at great depth the experiences of individual participants, it treated each view point as equal and recognised the situatedness of each participant within a specific context regarding both time and place. By recognising the individuals' cultural and social embeddedness, richer strands of material could be developed regarding the impact and understandings of mental distress rather than focusing on symptomology alone.

It was especially important in relation to existing gaps in the qualitative literature to explore how individuals made sense of their experiences of living with obsessions and compulsions, what meaning it held for participants and to reflect on their subjective experiences within this context. Olson, Vera and Perez (2007) described (through their qualitative study) how individuals living with OCD often hid their distress for fear of being

stigmatised. It appeared in their study, participants had strongly dis-identified with having OCD as a means of distancing from the stigma they feared or the “mad” character of OCD which existed in the public view. The lack of appropriate treatment regimes appeared to contribute to a sense of despair as the participants in this study were often treated for family distress/ issues which related to psychodynamic concepts of family distress rather than being offered evidence based treatments. Murphy and Perera-Delcourt (2012) interviewed 9 adults living with OCD and reported on a distinct deficit identity when the participants appeared to feel a failure for not reaching age- and life stage appropriate goals (as a result of their psychological struggles). Brooks (2011) described her individual (ethnographic) experience of living with OCD and described two personas, one being her public persona which seemed to manage her OCD symptoms very well through attending therapy and following therapeutic interventions whilst in stark contrast she described a second internal and more private persona which was necessary to help her hide her embarrassment about living with OCD and could offer an outlet for anger and hatred for the treatment regime she had to endure in order to control OCD symptoms.

It was proposed the understanding and treatment of obsessions and compulsions would best be summed up as complex and ongoing. The fields of MRI scanning and questionnaire use each continue to have their rightful place in research relating to obsessions and compulsions. Knowledgeable researchers have been able to explain the core beliefs related to this type of psychological distress, and have shown the underlying brain differences perhaps contributing to processing differences (such as the piecemeal processing of facial stimuli leading an individual to be unable to update a visual image even if it had changed, in individuals living with BDD, (Feusner, Neziroglu, Wilhelm, Mancusi and Bohon, 2010). It was acknowledged by Larkin, Eatough and Osbourn (2011) how cognitive psychology could be informed by qualitative research. It was proposed to build, through the combination of

already existing quantitative materials and developing qualitative studies such as this study, a wider and more fully encompassing picture which could recognise different types of knowledge, each as important as the other in building understanding and each possibly contributing to more useful and helpful treatments for individuals living with mental distress.

Focusing on the present research study

It can be argued individuals made sense of themselves through symbolic interactionism (Blumer, 1969), by deriving individual meaning from social interactions and amending meanings as a result of interactions experienced. An individual was understood to react to his surroundings and objects within the surroundings, using these as bases for courses of action. By recognising the negative concepts in existence regarding mental illness, individuals could internalise parts of the negative concepts as a defunct self. Within the present research study the social nature of mental health difficulties appeared especially important as symbolic interactionism helped to define how individuals would interpret and adapt to their challenging experiences with regards to management of mental distress, and would suggest a vital and fruitful part of the exploration of lived experience. As a practitioner it might be useful to be more aware of the implications of maintaining obsessions and compulsions and also to highlight the individual lived experiences whether positive or negative.

The importance of lived experience

In this research study the focus will remain on the sense and meaning making participants brought to their lives through an exploration of their obsessions and compulsions. It might be other individuals in similar positions could find the courage to speak out about their mental distress as the result of the bravery of the participants in this study who described their lives warts and all. Much of the existing research within this field of study has focused

almost entirely on quantitative data through the use of questionnaires and studies of the brain to explore morphological differences and similarities between i) individuals living with obsessions and compulsions and ii) individuals with no psychological distress. As important as it was to recognise, for example, the links between poor volitional control and insight, very few studies have approached individuals living with mental distress to ask about their experiences. As basis for this study was the inspiration from Schwartz and Wiggins (1985) and Estroff (1989) in stating all research started with a person. These writers described the building of theory and interventions which initially were informed by the individuals' experiences of psychological distress. Strauss (1986) described how, in seeing how individuals made sense of distress and how it affected their sense of self, we could as social science researchers learn how individuals chose from available support structures and could as a result, learn how to support them more effectively. The present study hopes to follow in a similar vein in exploring the experiences of individuals so as to inform practice within Counselling Psychology.

Recognising the impact of living with obsessions and compulsions

Bandura (1978, 2000) highlighted the importance of agency in individual sense of control. Within mental health research an understanding of 'illness' as internal to an individual appeared to cause greater distress (Lakoff and Johnson, 1980), creating greater opportunity for engulfment (Estroff, 1989, Lally 1989). Living with psychological distress could in itself relate to formation of friendships with like minded individuals or the alienation of individuals in question. Within this research these concepts will be explored to clarify participants' understandings of their roles and place within society and within their immediate families. Particular focus will also be applied to explore the participants' understanding of agency and control with regards obsessions and compulsions.

Misconceptions and stigma

A particular reason for focusing on the lived experience of psychological distress rather than the naming of specific mental health difficulties related to Ben-Zeev, Young and Corrigan (2010) who warned against homogenising whole groups of people. By focusing on individual lived experience of obsessions and compulsions it was possible to elicit individual perceptions and observations without the need to label individuals who participated in the study. By recognising the social nature of mental health difficulties (Hatfield and Lefley, 1993) it became clear how easily misconceptions regarding individuals living with mental distress, such as being dangerous (Riskind and Wahl, 1992) could exist. Internalized stigma related to mental 'illness' has been reported to relate to poor prognosis (Seligman, 1975) whilst being given unsupportive labels or negative social identities (Goffmann, 1963), was also said to impact on the self worth and overall functioning of individuals. Within this study the possible impact of stigma and personal and social understandings of psychological distress will be explored.

There appeared to exist many misconceptions about psychological distress related to obsessions and compulsions such as linking and limiting it to repeated hand washing (NICE; National Institute for Health and Care Excellence, 2006) or vanity (Phillips, 2005) and it was hoped this research study could aid in creating clearer understandings regarding distress. This clarity would also recognise the variety of experience and ways of meaning making as employed by the participant group in question. There appeared also to exist much stigma about acknowledging the presence of mental health difficulties. There appeared to exist a sense of failure as individuals living with psychological distress could become demoralized and depressed when incapable of resolving the distress themselves (Seligman, 1975). The validity of 'mental illness' historically appeared to relate to availability of diagnosis (Hatfield and Lefley, 1993) but equally diagnosis could exclude context and culture (Pescosolido et al.,

2010) and highlight the permanence of the distress in question (Corrigan, Markowitz and Watson, 2004). As clinicians, our duties included recognition and respect for the distress incurred and a hope to support and establish ways of work which might alleviate distress but also educate and inform both service users and the general public regarding misconceptions and the stigmatizing that may ensue. The impact of living with psychological distress, where the viability and validity of their experiences were explored with responsibility for recovery will also be explored.

Basis for the research study

The primary outcome of this research study will be the re-interpretations made by the researcher, based on the descriptions and interpretations offered by participants of their individual experiences. These will be reflected through the use of verbatim extracts as analysed through the use of Interpretative Phenomenological Analysis (IPA) (Smith, Flowers and Larkin, 2009). IPA was concerned with the detailed examination of lived experience” (Smith Flowers and Larkin, 2009, p.32) and within this study particular focus will be placed on in-depth descriptions which could highlight the individual subjective experiences in context. Within this study the terms obsessions and compulsions will be applied to descriptions of OCD and BDD as the study was focused on the lived experience and meaning making employed by participants who lived with obsessions and compulsions. Eight adults, living with obsessions and compulsions, were invited to participate in semi-structured interviews.

Research questions and focus

As the present research study will follow a qualitative paradigm no clear hypothesis of findings could be extrapolated prior to completion of interviews and analysis thereof. However, clear research questions existed in asking: What are the perceptions and views of

adults living with obsessions and compulsions? What impact does this experience have on their sense of agency and sense of control? Does the experience of living with obsessions and compulsions impact on their relationships with themselves and others? Does the experience show any cognitive struggles / dissonance in making sense or creating meaning of the lived experience for the participants?

Design

Measures.

The measures, being the interview schedule (see appendix C), was constructed to engage adults living with a diagnosis of either OCD or BDD in an exploration of their lived experience. The areas covered in the research schedule include:

- The sense of place OCD/BDD occupied in the participant's life at present
- The most recent experience of OCD/BDD
- The understanding of initial onset of OCD/BDD
- The place of OCD/BDD in relationships both in a professional and personal context
- The participant's view on living with either OCD/BDD as expressed over time
- Exploration of a positive future development with relation to living with either OCD/BDD
- The participant's view of him/herself
- The participant's impression of others' view of him/herself
- The participant's impression of the impact/effect of OCD/BDD on his/her life
- The effect of OCD/BDD on the relationship with self
- What might the future look like living with OCD/BDD

Participants.

The participants were chosen on the basis of a formal diagnosis of either OCD/BDD, as confirmed through their diagnosing clinician.

Anyone living with a co-morbidity of BDD and OCD were excluded from the study as there could be little clarity as to the influence of the co-morbidity in their answers and could confuse the picture as to the true experience of living with only a single diagnosis.

A diagnosis confirmation was sought on the grounds of attracting a specialised population, recognising other conditions existed which might seem similar to BDD or OCD but which could actually be attributable to a totally different population group and hence affect the validity of this research.

The research participation was limited to adults living within the UK to facilitate telephone/Skype or face to face interviews.

The client group consisted of eight adults living with a diagnosis of either BDD or OCD, who responded to the call for participants as advertised within the social media, paper leaflets at the University of Wolverhampton or via the clinicians based within the NHS, after ethical permission was granted to recruit from within the Dudley and Walsall Mental Health NHS Partnership Trust. A semi-structured interview schedule was drawn up for the use in either face-to-face/ telephone or Skype interviews. Interviews were sound recorded and transcribed, assigning a pseudonym for all participants.

Method

Methodological rationale

Epistemology.

As stated in the critical review this study is focusing on the lived experience of individuals living with obsessions and compulsions through the use of Interpretative Phenomenological analysis (IPA). IPA calls on the researcher to interpret and reflect on the participant data to bring to the fore meaning beyond the surface. As a result it calls on a re-interpretation of the participant materials (following a double hermeneutic) and treats each participant's data as equally important in an iterative process where the essence of an experience is the focus.

IPA has been used extensively since its inception (Smith, 1996) and is an approach suitable for a variety of research areas including health psychology, social psychology and clinical psychology for example Reid, Flowers and Larkin (2005) commented on the usefulness of IPA to elicit service users' experiences of the NHS to inform on practice and policy making. IPA is focused on eliciting individual (idiographic) materials within a specified context and could be applied to any homogenous group such as in this research study where participants were chosen on the basis that they lived with obsessions and compulsions.

By choosing a qualitative methodology this research will focus on individual experience as opposed to quantitative studies which focus on cause and effect and repeatable results. This study follows a relativist stance in treating all experience as equally important and no one reality (as described by the participants) was more important than any other. There is no single truth in existence and the researcher focused on putting aside her own preconceptions prior to interviews so as to allow the participants' views and perceptions to come to the fore. As stated in the critical review very few qualitative sources existed focusing on the experience of obsessions and compulsions and this study aims to add to these sources and offer further experiences and perceptions as noted by the participants.

Carla Willig (2008) made use of three questions when describing the focus and basis for qualitative studies. Within this section I will also use these three questions to explicate the epistemological and ontological basis of the study.

Question 1: What kind of knowledge does the methodology aim to produce?

In this study I have made use of a qualitative paradigm and in particular Interpretative Phenomenological analysis (IPA) which has a basis in the phenomenological tradition. This study is based within the phenomenological tradition and Creswell, Hanson, Clark Plano and Morales (2007) described how phenomenology aimed to get at the essence of experience and to collect data first hand from people who had experienced a specific phenomenon. This study aims to interpret what the participants described in the research interviews, to bring their experiences to the fore and to capture what it meant for each of the participants to live with obsessions and compulsions.

IPA, the chosen research method, has absorbed many different qualities from phenomenology for example Husserl's invitation (1927, as cited in Smith, Flowers and Larkin, 2009) to put aside our own interpretations and to focus on understanding the essence of an experience after following a series of reductions. It was important to mention how IPA research differed from Husserl in stating individuals could never truly be objective as all people had a subjective viewpoint. IPA acknowledges the researcher's role in creating and participating in the research process by collecting idiographic materials and then re-interpreting these to arrive at the essence and depth of meaning. Heidegger (1962/1927 as cited in Smith, Flowers and Larkin, 2009) instructed phenomenological researchers to remember they were always bound to a context and a time, how they were thrown into the world and could never escape this context. Heidegger added how all people were in relation

to someone, how everyone was inter-subjective and meaning had to be made through understanding the relationships present within the individual's context.

Within this research study the researcher added short descriptions of each of the participants and their contexts to offer background information to the reader. A short table was also included showing the marital status, employment status and gender of the participants. A similar aim for contextuality was proposed by Schleiermacher (1998, as cited in Smith, Flowers and Larkin, 2009) who urged phenomenological researchers to focus on the context within materials were written to truly understand its meaning and impact for the individual.

Heidegger (1962/1927, as cited in Smith, Flowers and Larkin, 2009) described how phenomenology could see something for what it was on the surface but could also look beyond this and find the implicit meaning. Within this IPA study this was possible through reading and re-reading the participant texts and reinterpreting their experiences and the meaning of these experiences in the Analysis section. Creswell (1998) described how phenomenological research wanted to answer the "How?" or "What?" questions and not the "Why?" Polkinghorne (2005) and Creswell described how qualitative research went beyond the superficial meaning and explored at depth what the experience of a specific phenomenon was like. Within this research study the "what" question referred to what it felt like to be living with obsessions and compulsions and the "how" question referred to how the participants made sense of their experiences of obsessions and compulsions.

Heidegger (1962/1927, as cited in Smith, Flowers and Larkin, 2009) warned that each reader of a text would hold preconceptions which could colour the reading and the meaning of what was written. He encouraged stepping away, keeping subjective preconceptions from filtering into the text (now described as *epoche*) so that the true meaning could flow through

without getting mixed with the reader's interpretations. Within this study the use of a reflective diary enabled the researcher to reflect on her own preconceptions.

Morrow (2007) described how qualitative research aimed to produce emic or "insider" and idiographic knowledge. Categories could arise from the insiders' descriptions, each of these were specific or idiographic to their experiences. Smith, Flowers and Larkin (2009) picked up on this point in stating how IPA had a commitment to the particular in the sense of detail and depth of analysis. This would link to Yardley's measures (2000) to ensure quality of qualitative research in her call for researchers to bring sensitivity to the context and closely engage with the idiographic in all research in order to let the true participant meaning shine through.

Morrow described how through a cyclical process of bottom up and top down processing it was possible to create a piece of qualitative research. Within this research study an iterative cycle was formed consisting of collecting and listening to participant material, and then to create categories and themes from this data through a "top down" reasoning. The researcher continually returned to the data, re-listened to the recordings and re-read the transcripts to ensure the perceptions and meaning of the participants shined through.

Question 2: What kind of assumptions does the methodology make about the world?

IPA corresponds to a relativist ontology where different subjective experiences and realities each were equally important. Each of the participants in this study had their own story to tell and each of their renditions was of equal importance.

Within this research meaning was co-constructed through the participant and the researcher as a transaction. Morrow (2007) reiterated how objectivity was impossible and

how the researcher and participants were inter-subjectively linked in the research process. The researcher re-interpreted the participants' perceptions and interpretations and represented these through themes and sub-themes within the Analysis section. The researcher entered the participants' worlds through the use of semi-structured research interviews and by attending to their meaning-making and idiographic experiences the participants shared, was able to build a picture of each participant's lifeworld.

It was important to mention how the research study was also offering only one interpretation of the participant materials or stated differently only one more reality rather than stating this was the epitome of all realities in existence.

Question 3: How does the methodology conceptualise the role of the researcher in the research process?

IPA was based on a double hermeneutic process where the participants' interpretations were studied and reinterpreted by the researcher to elicit meaning and understanding beyond the superficial and allow latent meaning in the texts to shine through. A continuous cycle was followed in this study moving back and forth between the participants' words and descriptions, to the researcher reinterpreting their words to arrive at the deeper meaning it might hold. In this study the researcher used a research diary to notate any personal opinions and interpretations she had made of the research subject of obsessions and compulsions, her impressions in meeting the participants and also any of her own experiences of the research process and its impact on her beliefs and understandings. The research diary was important as it allowed the researcher to focus entirely on the participants' words and the meaning they made of their experiences without these becoming coloured with her own preconceptions. Please refer to Appendix AE for extracts from the researcher's personal reflexive research diary. Sciarra (1999) in Morrow (2007) described the researcher

as expert who uses their knowledge and experience to gain access to a participant and then to step back and learn from the participant and their world. Within this study this was possible through the use of semi-structured interviews which followed the participants' lead and offered them a chance to guide the content and direction within the research interviews.

Procedure

Ethical approval.

The research study formed part of study in the Practitioner Doctorate in Counselling Psychology and was given ethical approval by the Behavioural Sciences Ethical Committee as well as the School Ethics Committee (for Social Sciences) at the University of Wolverhampton. Due to its focus on a vulnerable population a Res20b application was sought and granted. The study was also granted ethical permission through the NHS IRAS application procedure and permission was granted to obtain participants via the NHS, using Dudley and Walsall NHS Mental Health Partnership Trust as base Trust.

The ethical approval is explicitly applied to the research aim as detailed within the Appendices P and Y.

Recruitment.

Participants were recruited through the use of online message boards and online advertisements were placed on a variety of web pages including Anxiety UK, B.O.D.Y. (for BDD), Beat Body Dysmorphic Disorder and OCD- UK. An advertisement was placed on the Rethink website after completion of their specific ethical approval, an advertisement was also placed on the b-eat page as well as on the web pages for the BDD foundation and Anxiety UK organisations. The researcher contacted via telephone and email, a number of support groups listed on the OCD-UK web page and leaflets for recruitment were placed in the

University of Wolverhampton library. Permission was granted to place the invitation to participate on the electronic notice board on the University of Wolverhampton city campus, whilst emails were sent to clinicians working in the Dudley and Walsall Mental Health NHS Trust (after IRAS ethical approval) who might come into contact with clients living with diagnosis of either OCD/BDD. Individual independent practitioners were also contacted via email. These included psychologists and psychiatrists working for independent mental health organisations such as the Priory group or members of the BABCP (British Association of Behavioural and Cognitive Psychotherapies) and had mentioned an interest or special focus in working with the two disorders in question. Invitations to participate were also placed on a variety of message boards and forums including the SAUK forum (for people living with social anxiety), No More Panic forum (for individuals living with anxiety concerns), OCD tribe and Anxiety tribe (forums for individuals living with OCD or anxiety) and the BDD yahoo group's message board on the yahoo website. University lecturers within the psychology department at the University of Wolverhampton emailed the invitation to participate to their colleagues working independently or within other NHS Trusts further afield.

All prospective participants were sent (electronically) an invitation to participate, an introduction to the research as well as consent and contact sheets for their perusal. When participants agreed to participate and any queries or questions were fully answered to their satisfaction, paper copies were posted to participants, including a SASE for their return to the University of Wolverhampton Psychology Department for the research student's attention. After receipt of signed consent and contact forms the research student contacted clinicians as designated in participant consent forms. This was in order to obtain a confirmation of diagnosis prior to research commencement and a copy of the signed contact and consent forms were sent to clinicians, with a SASE to return to the research student. Due to time

constraints copies of signed consent and contact forms were emailed to one clinician in question. He confirmed diagnosis for the two participants in question also via email, which facilitated a quicker turnaround to arrange individual research interviews.

Semi-structured interview schedule.

The semi-structured interview schedule was designed according to instructions in IPA (Smith, Flowers and Larkin, 2009).

The interview schedule contained prompts to elicit detailed information from participants, avoiding closed questions where possible. The interview schedule formed part of the ethical approval for this study. The research schedule was used as basis for interviews but the research student followed the participants' leads during interviews with regards to their direction and focus (as related to living with obsessions and compulsions) and used the schedule as a guide in these instances. Amendments and leeway was sought from the ethical board to use wider questions and prompts as applicable within the interviews.

Semi-structured interviews.

Participants were initially contacted via telephone or email offering an opportunity to study the consent sheet, contact sheet, invitation to participate and information sheet re the study. The initial email/telephone discussion focused on building rapport and answering any questions or queries the prospective participant might have. All participants were asked to consider obtaining diagnosis confirmation from their clinician as precursor to participation. Participants were asked for their postal address in order to obtain written consent to participate in the study. Once these forms were returned via post, clinicians were contacted either via post or email, with copies of signed consent and contact forms. Once clinician

diagnosis confirmation was obtained, participants were again contacted via email or telephone to arrange a suitable time/place for the interview.

At the start of interviews a sound check was carried out to ensure the sound recording device was working properly. The research student explained that she would be quiet during interviews in order to focus on and obtain detailed information from participants. Participants were asked to pick a pseudonym for the recording and subsequent transcripts so as to protect their identity throughout the research process. Some participants did not want to use a pseudonym but these were assigned to their transcripts and recordings none the less.

All identifiable data (such as place names and names of partners or clinicians) were obscured within transcripts by using asterisks *.

Telephone (3) and Skype interviews (1) took place from a designated room on the University of Wolverhampton premises as arranged via the psychology technicians. Face to face interviews took place at the participants' homes (4) at a suitable time arranged with participants.

All participants were asked to arrange a safe, secure and quiet place for interviews for a maximum of 90 minutes.

Questions were designed to elicit aspects of self, relational impact and past / present / future implications of living with OCD/BDD.

Hatfield and Lefley (1993) described in doing qualitative research, the researcher would remain close to the individual's subjective experience, and as such by remaining with the human being, the person, we could better understand his experience and be in a position to help and assist.

Estroff (1989) recognised the effect on sense of self, from living with a disorder and described, similarly to Lally (1989) how a person could become consumed thereby. It might be the individual could struggle to see boundaries between the self and the disorder. Strauss and Estroff (1989) recognised that as researchers we often did not share the exact experiences of our participants, how we had to rely on their knowledge and expertise in experiencing (in this instance the experience of living with obsessions and compulsions) to “connect the dots” between thoughts, feelings and sense of self as related to their experiences. They encouraged researchers to listen to participants (clinicians to listen to their clients) to glean essential materials, commenting again on how phenomenological psychiatry would fail in this regard (Strauss, 1989b). Different types of data and information were proposed to exist, one of which was individual experience. This could be combined with objective data, to design a fuller picture of a specific area of research, adding to information used to educate and support individuals living with mental distress (Lally, 1989). Psychology professionals were encouraged to learn from subjective experiences of their clients as these individuals could be trained as advocates within the wider society, where they could share their experiences as a means of demystifying and informing others about mental distress (Roe and Lachmann, 2005).

Harper and Thompson (2012) reported the usefulness of qualitative research has been recognised through the call for expertise such as the White paper entitled Equity and Excellence-Liberating the NHS (2010). They described the usefulness of qualitative research by exploring existing policies and making recommendations in line with experiential data, taking into account the underlying beliefs and cultures which might have lead to the creation of policies in the first instance.

Much of the research in existence with regards to obsessions and compulsions, appeared to be quantitative in nature. As a result it appeared to focus on identifying

underlying differences in brain structure which might contribute to obsessive and compulsive thoughts and behaviours (Rotge et al., 2008 and Stein, Goldin, Sareen, Zorilla and Brown, 2002). Very few papers exist (Brooks, 2011 and Murphy and Perera-Delcourt, 2012) focusing on the individual experience of people living with either BDD or OCD and the subjective experience of these individuals remained unexplored. Many of the participants in this study mentioned how obsessions and compulsions remained misunderstood as there were public misconceptions perhaps aided by the media portrayal of the disorders, for example the misunderstanding that they related to vanity or excessive hand washing. As long as the misconceptions remained, the personal and experienced side of the living with obsessions and compulsions would go unnoticed and unacknowledged. Qualitative research could offer a means of addressing this imbalance and offer an opportunity for individuals to speak openly and honestly of their experiences, facilitating acknowledgement of diversity.

Method of data analysis.

Within this piece of research it was decided to use interchangeably the terms “struggle”, “distress” and “illness” as related to the participants’ distress. The terms “obsessions and compulsions” were applied to describe lived experience across the participant group.

Transcription took place according to the audio files collected during interview. The recordings were replayed and checked numerous times to ensure it remained true to the recordings and the opinions of the participants themselves. Transcription was verbatim, including all moments of hesitance, pause and repetition in order to elicit the participants’ experiences.

Transcripts were initially annotated with analysis focusing on the overall content and meaning making participants brought to their understandings of living with obsessions and

compulsions. Notes were made of hesitance, pauses and repetitions and specific metaphors participants used. Discrepancies or moments of conflict were also noted alongside the use of humour as a coping mechanism with regards to obsession and compulsion experience.

A continuous process of revisiting the transcripts and amending or adding to the notes followed. This allowed for emergent themes to develop from the transcripts. At first I looked for larger concepts and themes within a single transcript, branching out to each of the transcripts in order to see if there were similar concepts or ideas, whether from one side of an argument or the other.

A table was drawn up to represent Super-ordinate and sub-themes, illustrated through the use of transcript extracts. Please refer to the analysis section for Table 3.2.

Interpretative Phenomenological Analysis (IPA) could be described as an iterative process, where the participants' elicitations formed the basis for any emergent themes. The researcher returned to the data to ensure her understanding of the data remained as close as possible to the participants' understandings of their experience. IPA is also understood to form part of a double hermeneutic, where the researcher formed on the basis of the participants' interviews, her own interpretation of the material gathered.

The research process contained a constant reflection of the impact of carrying out the research as a Trainee Counselling Psychologist. Within the research report the reflections were compiled in the critical appraisal of the research process section. It was important to let the participants' interviews not become entangled with the researcher's own ideas and biases. As best as possible epoche was employed both during interviews and the subsequent analysis to ensure it remained true to the participants' interpretations.

Sample descriptions

Eight adult participants took part in the interview process. They varied in marital status as well as employment history. Please refer to Appendix A for detailed background descriptions of the participants.

Table 3.1 Sample descriptions of participants

Pseudonym	Gender	Marital status	Employment
Barbara	Female	Married	Unemployed
Jane	Female	Married	Unemployed
Diane	Female	Divorced	Employed
Scarlet	Female	Partner	Unemployed
Isiah	Male	Single	Employed
Allan	Male	Married	Employed
Nigel	Male	Partner	Unemployed
Tom	Male	Partner	Unemployed

Themes emerging from clients’ interview data

Three super-ordinate themes were identified from the transcripts, these being i) Conflicted control, ii) Relationships, and iii) Finding ways forward. It appeared the themes were not discrete entities but would often interrelate. Throughout the analysis and discussion sections the intermingled and connected nature of the themes will be explored and identified. The themes were summarised in the table 3.2

Table 3.2 Summary of main themes and sub themes

Theme	Sub theme	Transcript key words	Indicator line
Conflicted control	Feeling consumed	<i>“It’s there and you can’t do anything about it but..I Don’t think you ever Really accept it and you’re always hoping that it</i>	S 30-33

will go but knowing, deep down

that it won't"

"So uhhm you know it's it's B 26-30

really things I I do it almost

automatically..Now it's the

things that have been so

ingrained from when I was

younger,..that I do them without

even thinking at times."

"It's better at times than J 79-89

others..It's not always but it still

is there. It's also battling the

time to try and not engage in the

rituals and..and not engage not

asking for reassurance and

knowing when you're stronger

that's OK but when you're

feeling really weak..There's the

strength it required Not to ask

reassurance is really hard and

then you feel a failure for asking

because you know it's probably

not the best thing to do

"..to be honest I don't know N 1263-
1276

which way to turn for the

best..like I just feel trapped to

be honest..Like I mean in a web

*like..I mean like I say to C** me*

*partner..I forgot how to smile
properly now..through it. So it's
uhh..I just exactly can't be
myself"*

"Almost if it's been good all day S 783-784
*you don't wanna go to bed. You
just feel like I just wanna stop
up 'cause it could change."*

"I feel it's going in me N 732-
energy and that like. 'Cause 736
*when I was young I could
probably put up with it more.
'Cause I was I was young
were I like..Whereas I'm
getting older it's making me I
don't it's like your body's
getting older can't put up
with it."*

"yeah it never you don't T 621-629
*relax very often it's all it
spins like it's Your brain but
you can't you can't control
it..Which ain't very good. But
then like but when I say that I
Do believe I'm ugly ..And*

*perhaps I am or perhaps I'm
not..But I should be able to
deal with it anyway just carry
on with it but it don't let you
do that."*

"It's that Fighting going on. I 838-848

*Cognitive fighting which
anyways just engages you
with the OCD it keeps you
games..So I guess now..I ..I
I'm not so worried about
getting..I'm not so like I Have
to get that out I'm not that
frustrated that I'm not getting
better. I am getting better
but..There's that frustration
has has gone down a
Lot..Possibly because I have
made some big steps..I'm not
spending most of the day
worrying about molesting
people or whatever."*

"Because I sort of think well I D 816-822

*got this for a Reason..and if I
can't utilize it in the best*

*way..it's going to eat me..alive
so, I've got to us it into a
positive."*

"It used to just engulf me the S 689-692
*suicide attempts the work and
not getting out but now I Do
make more effort to go out
sometimes I do I do give in to
it and I'll stay in bed and I
won't go out and I won't
bother but the majority of the
time I do Try and do what
I've planned."*

" the checking or the J 683-696
*reassurance seeking becomes
a routine..whereas your
normal routines just would be
very Different hopefully very
normal..your routine then
becomes the checking..and if
I miss anything out of that
that that That creates panic
and fear..So I need to it's like
sometimes I'd focus and just
appreciate yourself and ..and*

*to not be so Self critical..to
actually look at the
positives.”*

Insight

*“I still carry him now just to
hide me face..to mask me face
like yeah..And uhhm he’s
getting he’s getting too big
now to do it and it’s like
when I’ve ..cause I know I
fear people at the school like
I went to school and they..like
when they’m talking to me
they must think “why don’t
he put his son down?”..They
talk and I’m here and son am
here and I’m trying to have a
conversation with them while
me son’s there like (laughs)”*

N 651-

662

*“Yeah I mean I only last
night my wife said why don’t
I start it again you know I
mean..she told me when
you’re doing it you’re a
different person she told*

A804-814

*me..she told me last night
again I never thought about
it..but she you're a different
person you're more calm
you're more connected uhhm
you're more uhhm
understanding..you know you
talk to me more”*

“hugging my sisters I127-136

*Really..cause a lot of
anxiety.. 'cause I feel their
breasts and that's hard
because I am their brother
(laughs) Uhhm..And so like
but my sister likes hugging
me closely and and actually
sh she finds it really hard
when I reject her, what comes
across as a rejection..and so
sometimes, yeah, the focus is
on well actually this is for her
for her hugging her.”*

“but the way I read it it made B793-797

me sound to me..that I was

*sitting there planning how to
harm children and I said "I
can't have that on my record
it it can you change it?"*

*"So I have to fill in a medical B 346-369
form and it says how long..
have you been off..and what
have you been off with. And
uhhm..I'm not happy saying
I've been off for six months
or so with OCD and
anxiety..Uhhm and my doctor
turned around to me and said
"Why not?"..and I said
because I don't think
employers would..See that in
the same light..as they see
other uhhm..illnesses. and the
doctor turned around to me
and said that as far as He
was concerned me recovering
from a bout of OCD..wasn't
any different and and going
back to what I wasn't any
different to somebody*

*breaking their arm or
leg..and That being be put
right.. before they go back to
work.”*

*“ I think I think if you get N 545-
labelled with something it 552
like it can be burden you in
life like...like if you was
getting a job or something.
Uhhm uhhm I think if you get
labelled you can be like if I
went to an interview and I
told them about this or like I I
put on the CV or whatever..I
think that would probably go
against me like.”*

*“because if I haven’t got it T 787-789
and if someone is explaining
it to me I’d think “ooh bloody
hel” you’d think the last the
last thing you want people to
think it is vanity you know.”*

*“..There is a concern and I 870-878
that you understood rightly,*

*particularly with these
thoughts of harming people,
because with standard
disclaimer with these people
the risk thing you know
anything is confidential
unless you..Risk
(laughs)..which is awkward
in the words of my friend Nic
I should give mental health
professionals a Bit more
credit for understanding the
OCD experience.”*

*“I had to go all the way to * T 1239-
to get your diagnosis, you get 1244
a diagnosis but you just don’t
even know if I take that
somewhere say like **
Mental Health they could try
and say that’s not right say
no mate that’s not right..they
prefer to say it’s uhh general
anxiety it’s an easier thing to
say than BDD.”*

*“..there’re rather negative I 682-691
images of what OCD is as the
Mad person checking
things..but like I present it as
fear..present something as
what I’m scared of..I
wouldn’t talk about the hours
and hours of checking or
whatever..So like when I’m
talking about my friends they
agree in what context we can
pray for one another”*

*“’Cause worrying about I 165-168
you’re a paedophile being a
paedophile doesn’t sound
(laughs) like you have a
mental health problem. It’s
so shameful and there’s not
really someone you can chat
with”*

Belonging versus
escape *“We would often joke about I 748-758
harming each other or
whatever..or are you got a
knife there you know..Silly*

things like that..Which only people with OCD would get..and there's a shared connection and an exclusive connection in that shared experience..Uhhm and I guess within the OCD group."

"you know uhh uhh at the support group the lovely thing is that we're all OCD and if we want to be OCD..in that particular environment, we Can." B 263-264

"I think I've known her about 7 years..And I didn't know at the time we met that she's got mental health problems..And my other friend that I'm close to she's actually moving down stairs and she's got mental health problems as well..It's almost like we all (laughs) not Knowingly but S 662-676

*you all grated to each other
you know. So we do our best
to support each other you
know..Because the worst is
when we both are going
through a bad stretch
together because we can't do
much for each other but you
know hopefully if one's good
and one's as bad you try and
help the other one and
stuff..like that.*

*“..and I've got one D 273-
particular..male 279
friend..who..he because he's
sort of on the spectrum as
well..and maybe it's because
he is on the spectrum but he
Really gets it..he really gets
me like I get him?”*

*“one a particular one that B1607-
came straight to mind uhhm 1612
was dementia..If you've got
dementia when you're*

*older,..You know wh there's
no room for the OCD
(laughs)”*

*“..I remember watching
uhhm on Youtube this these
guys on video with this
woman reversing a car and
then reversing reversing and
checking..I can understand it
was hilarious to watch and I
can also understand the
amount of distress that poor
woman was under..Uhhm
which they probably didn't
know and uhh I think if they
understood that they'd be a
lot more compassionate
sympathetic”*

Theme 2 Relationships	Living with uncertainty and being unconfirmed	<i>“..Because unlike things like depression which are the whole thing about OCD is you are not even sure it is OCD.”</i>	I 1133- 1134
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*“I'd wake up in the morning
and it would almost be like*

B 442-448

*frightened to go in and see if
the kids..were awake because
you the fear that you did
something To them in the
middle of the night..without
knowing.”*

*“It is Best to get out but it’s
just..getting out because you
almost feel everyone’s gonna
look at you and start and
“look at that” and when they
don’t you go “well why
not!”..It’s very confusing.”*

*“And I think self–acceptance
is easy and it’s not..believing
that you’re a Freak
and..that’s something that
people with mental illness
often consider themselves I
know I used to consider that
and I meet people all the time
who’ll say “I know it sounds
a bit weird and I know you
think I’m a freak” and..they*

S 735-738

D 1278-
1296

*say that before they say
everything about what they
do..and until you stop
thinking that and until you
get over that..and you realise
that you know you've actually
got an illness..can't that you
can't control..it..you're able
to look at it from an
outsider's perspective rather
than just seeing it..from Your
perspective.”*

*“in the article he put
everybody looks in the mirror
and everybody's got a small
form of BDD..And I wrote in
to say you know they haven't
BDD is when you when I got
it severely I lost me fiance,
job I lost my friends,
finances..family and
everything you know..you
can't equate that to people
going “Ooh God I look a bit
today”” ‘Cause I know*

S 395-411

*people I felt I feel today just
before I suffered like I do you
do have that "Oh God" you
know and your hair won't go
right..but it is a totally
different feeling..when it
overtakes your whole..life."*

*"I had to go all the way to **
to get your diagnosis, you get
a diagnosis but you just don't
even know if I take that
somewhere say like Mental
Health they could try and say
that's not right say no mate
that's not right..they prefer to
say it's uhh general anxiety
it's an easier thing to say
than BDD."*

T 1239-
1244

*"Because I sort of think well
I got this for a Reason..and if
I can't utilize it in the best
way..it's going to eat
me..alive so, I've got to use it
into a positive."*

D 816-
822

"But there's still that anxiety

S 283-290

all the time you know when I go to the toilet I look in the mirror and I was like “Oh God” you know..And you I’m waiting for people to treat me different and look at me different but they don’t and that sort of you know I know that they don’t see it you know..but it’s weird how can you not?’Cause it’s such a severe change from one face from this to that and you think..how can you (laugh) not notice it? And then you know well over the years I’ve thought well is it my is it my brain or is it my eyes?”

Validity of mental distress

“count yourself lucky you haven’t got cancer or any other terrible disease which is how you feel at times”

J 543-544

“that’s another thing like you see these programmes on the telly of them people being

N 1021-1028

*burnt and that..It makes me
want to think well I ain't that
bad as them if you look at it
that way like..I've tried
to..make me think that sort of
way but it ain't work like."*

"Even though you might you J 496-516
*know if you were physically
ill they could see it and
they'd immediately say "Are
you all right do you need any
help?" ..you're reticent to ask
for help it still doesn't feel a
valid enough reason..you
know it's Not physical it's not
it's not Stopping me from
walking to school..and back
to take or collect the kids or
functioning in some
capacity..even though I might
underneath actually just want
to sit and cry..it could be at
that point that you hold it all
back..to get through the bits
that you've got to do. So yeah*

*a lot of the time you don't tell
people how you're feeling or
what it is at times you
Can..But it isn't something
you want to do too often
because you don't want them
to not like you for it."*

*"..I'm sure you know, is even J 181-195
More frustrating because if I
got flu or a broken leg and I
felt like I needed some time
on my own or at home be
Nursed, or just looked
after..Fine with a particular
illness but you don't ever feel
you can ever ask for it..when
it's mental illness..Because
there isn't anything specific
anyone can see..It's all
happening here..People don't
wanna know I believe
really..really want to know."*

*" was having time off work S 434-441
the doctor was signing*

*me..off he just put uhhm what
is it called something
really...I can't even
remember what he he he
called it it was really strange
was nothing to do with what
it was it was just saying..that
work wouldn't question it..”*

Impact on
relationships

*“It's like talking to people
but it's all in the back of me
mind all people looking at
me..All this I don't want to
look at people am I grotesque
am I ugly and uhhm..and
basically your whole day
would be like that. On a bad
day..Come break time I I
stopped going like you know
when you sit down with
people..I didn't want to do
that..I'd sit in me own so.”*

T 483-494

*“..it was sort of something
he'd discovered over a like a
six month period..and it did it*

D 238-
246

Did cause problems in our relationship..but he learnt...he learnt to live with it..but I was still never fully able to talk to him about it but I think ..that's part of our relationship.”

“So uhhm my husband coming to collect me, is actually my safeguard against having to worry about whether or not I have locked up properly..because he's there to to watch me and to make sure that I Do it.”

B 694-697

“uhhm I mean I've hardly worked..and I get quite a bit of stick off my family for that they keep saying and I don't think they understand..the condition fully like but I've tried to explain but..they just keep saying “Why don't you get a job do this ?” and

N 749-758

*'cause they ain't gone
through it I don't think they
understand me like."*

*"..if the mind is not clear you
can not have heart to heart
you can not uhh express your
feelings..you just want to be
left alone."*

*"If I have CBT, and it cures
me of the OCD..am I still
going to be as protective
towards my family..as I am
now?..Because I wouldn't
want to give up uhhm their
safety..in return for my
uhhm..wellbeing."*

*" and..I think..if she'd taken
me to the doctors she would
have had to address her
Own..obsessions that that's
the conclusion that I've come
to. And I know my mom
passed away last year but
even ..when I finally seeked*

help and when I I'd gone through fourteen years of therapy,..She'd still find it difficult to talk to me about it..She would refer to it as my problem."

"..I think particularly when the children were young, I had to keep them safe because I didn't want my Mother, to think..I was being a bad parent..and we would end up arguing, she picks arguments quite easily. So I felt when they were little, there was an extra pressure on me..to keep them safe..so that mum couldn't turn around and say well I told you"

B 168-179

Sense of self

"I've even thought of breaking me nose meself..Uhh punching meself like and stuff..and suicidal

N 1357-1365

*thoughts at times..Not all the
time..When I'm it grates it
just grates you down like it
gets on your nerves."*

*"because because I put on
this bravado..and I put on
this brave brave face all the
time..and I am this strong
person that will not be
defeated by anything..But
really often inside a lot I feel
like that lost girl..that girl
that's scared of everything."*

D 295-
303

*"I don't think I could have
coped with any more trauma.
And I almost didn't want my
mom and dad who were
finding it hard to cope with if
you like disappointing Them
any further..So I thought if I
can make sure everything's
all right..They'll still love me
they'll still look after me
they're not going to*

J 745-754

be..slagging me off..like I was hearing.”

“We did try for a long time but I think she found my illness hard to cope with..Because I lost a lot of friends she was all I had at one stage and I’d phone up crying and swearing and doing this ..and it’s hard when you’re in that and I think she couldn’t really cope so she told me in the end she didn’t want anything more to do with me (intake of breath).”

“I’d had like four showers and I’d washed my daughter like four times and..I was Crying and..there was the smell of disinfectant everywhere and I just thought I can’t Do this any more..I’m so exhausted..But just just

S 627-632

D 891-902

*something I just looked at her
and thought I have to get
better...Because if I
Don't..my daughter's not
gonna have a mom..And I'm
being selfish."*

*"I mean it's really I don't
know it's really hard to put
on an act the the act
on..'Cause I don't wanna do
it like..I think that's what
Graham's trying to say to me
like..Were I like try to just let
go and like and you'll see it
ain't as bad as it is..I think
that's what he's trying to say
like..But I just can't do it."*

N 1212-
1222

*"it helped but parts were still
there like you know..uhhm so
(breath out) so I went home I
was like I didn't know what
to do ..everybody told me I I
was fine I was OK you
know..only my parents and*

A 158-
164

*my little sister know about
this and my wife now.”*

*“You don’t want to be the
sort of person who isn’t
functioning and you’re
moaning Again..because
you’re saying this that and
the other and it is going to be
all right and not awful and so
times you Don’t say..Even
though you might know if you
were physically ill they could
see it and they’d immediately
say “Are you all right do you
need any help?” you’re
reticent to Ask for help it still
doesn’t feel a valid enough
reason.”*

Theme 3 Finding
ways forward

Coping

*“I don’t know I just feel like
before the BDD got worse I
put on an act Years ago like
at home you know all this
stuff that was going on at
home and other people didn’t*

S 184-186

know (intake of breath). It's almost like that's what I've been like for years."

"But to a psychiatrist well to my psychiatrist..you just end up really you end up in an argument because (laughs) you feel like you'm arguing because they're not helping ya..It ain't in all honesty he's asked me what you want to do..what you want me to do I don't know because I'm not a psychiatrist..and he also asked me what tablets I wanted to prescribe so I prescribe my own tablets last time with him..It don't give me lost of confidence because I'm thinking you shouldn't really prescribe me telling you what to prescribe."

"I got into quite a few fist fights about it fist

T 410-423

N 977-983

*fights..Uhhm 'cause I was I
 was like a teenager and
 young like..Like I can't really
 I don't want to argue with
 people as I'm older now..as
 I'm adult like."*

"I do I do give in to it and I'll S 690-694
 *stay in bed and I won't go out
 and I won't bother but the
 majority of the time I do Try
 and do what I've
 planned..And I do try and
 override it and I think "well
 my life is just wasting away."*

"and..I just remembered D 888-
 looking at my daughter the 902
 *one day...and I'd had a
 Really bad day with cleaning
 and..I'd had like four
 showers and I'd washed my
 daughter like four times
 and ..I was Crying and ..there
 was the smell of disinfectant
 everywhere and I just thought*

*I can't Do this any more..I'm
so exhausted..But just just
something I just looked at her
and thought I have to get
better...Because if I
Don't ..my daughter's not
gonna have a mom..And I'm
being selfish."*

*"And only last night my wife
said why don't I start it again
you know I mean..she told me
when you're doing it you're a
different person she told
me..she told me last night
again I never thought about
it."*

A 804-
809

Distancing

*" I guess I'm a lot more
accepting of genetic
explanations I can understand
that this is a physiological th
there is a very physiological
process that goes on that
somehow is used to interact with
my cognition"*

I 1709-
1712

*"the chemicals play up you
know.."*

A 180

"Uhhm I don't know you

N 46-51

	<i>can..pick up on other people</i>	
	<i>how they..look and how they</i>	
	<i>make and that..and I can usually</i>	
	<i>sense like something's gonna be</i>	
	<i>said or anything like trouble like</i>	
	<i>that"</i>	
	<i>" Well at the moment I see my</i>	B 1552-
	<i>OCD as something...I use to</i>	1553
	<i>protect my family"</i>	
Dissonance	<i>"Specifically that's what I</i>	N 1492
	<i>remember that's what started it</i>	
	<i>all. My mom."</i>	
	<i>"Uhh excuse me language</i>	
	<i>excuse me language big nose</i>	N 1496-
	<i>bastard like..Uhhm that that</i>	1498
	<i>that digs that stuck in my</i>	
	<i>mind."</i>	
	<i>"but actually saying the act</i>	I 1150-
	<i>of saying this is OCD is an</i>	1154
	<i>interview for OCD or this is a</i>	
	<i>group for people with</i>	
	<i>OCD..Has huge imp has huge</i>	
	<i>therapeutic impact in itself by</i>	
	<i>labelling this condition as</i>	
	<i>OCD because the whole thing</i>	
	<i>with OCD is you just don't</i>	

know that it is.”

*“I..hope it’s obvious that I
suffer from extreme OCD,
but..why need a diagnostic
label, do I need that stigma for
the rest of my life, when, who
who’s to be honest, my my
psychiatrist who I I basically
suggested to Him I had OCD.”*

I 1926-
1929

*“Planning planning plays a
big big part in..in anybody
anybody’s life in any job any
college uhhm..any school any
relationship..I just couldn’t I
just couldn’t ..couldn’t
concentrate..I couldn’t plan
anything you know I mean
this was the whole it was like
was like some somebody
sitting on my back..like a
monkey sitting on my
back..and I just try to shake it
off it won’t go away so I
couldn’t plan anything”*

A 137-
150

*“uhhm and then my friend
said you know what I took
some yoga ex
ercises..doing yoga and
meditation and that helped..I
have to say that helped I
mean uhhm if I have to give it
a percentage I would say it
helped me about helped me
about 50 to 70 ..75%
depending on the day.”*

*“So uhhm and it’s nice it’s nice
again for just to be with other
people with OCD so they don’t
think I’m mad when I ..double
check things.”*

*“So at the moment the OCD is
uhhm I would say, uhhm
controlled..Even if it is
subconsciously controlled.”*

*“If I have CBT, and it cures me
of the OCD..am I still going to
be as protective towards my
family as I am now?”*

*“..because I think uhhm BDD
makes you vulnerable...and
you’m like you know how easily*

A 184-191

B 727-730

B 40-42

B 1555-1559

T 751-759

*hurt you can get you just try not
to do that to other
people...because you know how
it makes You feel...the last thing
you wanna do is make someone
feel bad.”*

*“Well actually my
mom..showed a lot of
obsessive traits..and I think
some of those I picked
up..But my mom was a very
quiet, shy person who
lacked..confidence and she
had a lot of physical
illness..and..I think..if she
had taken me to the doctors
she would have had to
address her Own..obsessions
that that’s the conclusion that
I’ve come to.”*

D 158-
171

*“I guess the positive spin off is
that maybe I’m more aware of
suffering in the world”*

I 1038-
1039

Analysis

Themes

Within all themes a particular focus was applied to the understanding of personal and subjective experience and perceptions of the self, with regards living with obsessions and

compulsions as linked to a sense of time and embodiment. These concepts were used as a guide for each subtheme.

Please refer to Appendix AE for personal reflections and extracts taken from the researcher's research diary.

Theme 1 Conflicted control.

The first over-arching theme was described as conflicted control. This referred to the participants' experiences of being controlled by their condition or exerting control over it. Different coping strategies existed for each participant aimed at diminishing and containing the impact of the conditions described. The participants commented also on the unrelenting aspect of their difficulty, how it was present in a variety of ways and how it impacted on their sense of being in or out of control.

Feeling consumed.

Many of the participants commented on the amount of control they felt the psychological distress exerted on their lives. It seemed the conditions were an inescapable central point to their existence and participants had to accept its permanence and debilitating impact. It seemed as if the difficulties were almost all encompassing and present in all areas of the lives of the participants. The participants' sense of being consumed appeared to related to the movement of time (which indicted their continuous struggles) and also reflected on their understandings of their selves as related to living with continuous obsessions and compulsions, hence the particular focus on sense of self, embodiment and time.

The sense of hopelessness seemed to emanate from many of the participant extracts such as Scarlet who described "*It's there and you can't do anything about it but..I Don't think you ever Really accept it and you're always hoping that it will go but knowing, deep down that it*

won't"(S 30-33) alluding to a sense of desperation to be rid of distress which seemed to be permanent and unrelenting. In meeting Scarlet she appeared bubbly and friendly and yet a sadness seemed to exist also as she was clearly feeling stuck and burdened with psychological distress. Scarlet's words allude to her sense of time and space as she includes references to the past and the present where her distress remains active and powerful in her life. It seems for an extended period of time Scarlet has hoped for release from the power of the obsessions and compulsions as a way of protecting herself from accepting its permanence. In this extract Scarlet appeared exhausted and as if she had relented to the power of her distress and she had finally acknowledged its permanence.

Jane described a different feeling of powerlessness where she seemed stuck between two masters, one being the OCD thoughts and behaviours and the other the strategies she had learnt to cope with the obsessions and compulsions *"It's better at times than others..It's not always but it still is there. It's also battling the time to try and not engage in the rituals and..and not engage not asking for reassurance and knowing when you're stronger that's OK but when you're feeling really weak..There's the strength it required Not to ask reassurance is really hard and then you feel a failure for asking because you know it's probably not the best thing to do"* (Jane 79-89). Jane appeared riddled with guilt for at times failing to resist the temptation of OCD behaviours and thoughts and she appeared to feel a failure for not being able to break this cycle. Jane's sense of time appeared to depend on her symptoms and whether she was successful in resisting the compulsions or whether she "failed" and gave in to them. Jane's sense of selfhood appeared to relate to how successful she was as a person in resisting the OCD obsessions and compulsions and her language reflected extremes of success (feeling strong and able to resist "giving in") and failure ("giving in") as the only two options. It appeared Jane's sense of space was also taken over completely by her battle to resist obsessions and compulsions. It appeared she lived in an

internal world where she battled continuously against strong urges to ask for reassurance. Jane seemed desperate throughout the interview to convey the ongoing nature of distress against which she felt powerless, stuck and equally vulnerable as if at the behest of an uncontrollable tempest.

Nigel described a similar sense of being taken over and his sense of self erased as he could not remember who he was prior to living with BDD “*..to be honest I don't know which way to turn for the best..like I just feel trapped to be honest..Like I mean in a web like..I mean like I say to C** me partner..I forgot how to smile properly now..through it. So it's uhh..I just exactly can't be myself*”(Nigel 1263-1276). Meeting Nigel in his home I was struck by a family man who was eager to be an active dad with his children and a supportive partner and yet throughout the interview Nigel remained ill at ease sitting at an angle which hurt his back muscles but he tolerated this for fear of showing his seemingly defective nose. Nigel talked of feeling erased and wiped out by the BDD and how he did not know whom he was any longer and could not discern where his “old self” had gotten lost. Nigel showed a huge amount of insight and reflection about his BDD and it appeared this deepened his sadness as he realised it was encroaching and enveloping him, how the obsessions and compulsions were controlling his every move and he felt powerless to act against these controls. Nigel's use of metaphor appeared to convey the BDD as a spider with him trapped in the spider's web. This metaphor conveys his sense of fear and dread as the spider appeared to move continually closer over time, continually erasing more of Nigel's essence and the person he wished he could be.

Debbie lived with OCD and had recently started facilitating her own OCD support group. She had survived the end of a marriage and had created a new self through a new diet, new hobbies and also a new attitude to tackling OCD. “*Because I sort of think well I got this for a Reason..and if I can't utilize it in the best way..it's going to eat me..alive so, I've got to*

us it into a positive.”(Debbie 816-822). Debbie had set up a support group for OCD and found this served a purpose in offering her a focus and outlet for her caring nature but equally there appeared to exist an ongoing desperate feeling to control the OCD or face annihilation. Debbie seemed to be on a knife edge where either she fought the OCD tooth and nail or face collapse. It seemed Debbie had made a choice to fight the OCD and yet in talking with her it seemed her choices were both stark and harsh and she had very little leeway between being condemned or remaining a permanent soldier. There appeared to exist a sense of a higher power giving Debbie the OCD for a specific purpose (“I got this for a reason”). This “gift” of OCD appeared to test Debbie’s resolve and it showed her powerlessness in having to accept something which she never chose to have in the first instance.

Scarlet described a sense of desperation for positive changes to remain. She talked of her face constantly changing and having to check in the mirror what her face looked like prior to tailoring her mood. It seemed when a “good face” showed itself, Scarlet felt almost it was too good to be true *“Almost if it’s been good all day you don’t wanna go to bed. You just feel like I just wanna stop up ‘cause it could change.”*(Scarlet 783-784). Scarlet seemed to cling to every last moment of positivity in the hope it would remain permanently. It seemed desperate as Scarlet knew on a deeper level she could not know or foresee how her face might change and she was powerless against the ebb and flow of changes. It seemed Scarlet would always be let down by her face as it changed without warning, leaving her vulnerable and frustrated. Scarlet’s sense of time appeared to relate to her experience of BDD. The positive times seemed fleeting whilst the challenging times appeared inevitable and were always around the corner. The sense of permanence links to the previous extract from Scarlet (lines 30-33) where BDD was a presence which was seemingly permanent and outside of Scarlet’s control. Scarlet’s sense of self appeared to link to her BDD too as she continually had to check if her face had changed prior to knowing how she felt about herself. There

appeared no permanent sense of self but rather a series of continual changes which would destabilise and embody Scarlet without her having a choice in the matter.

Barbara talked of her OCD as if it was a natural element of herself and how she had become so used to it that it almost faded into the background. *“So uhhm you know it’s it’s really things I I do it almost automatically..Now it’s the things that have been so ingrained from when I was younger,..that I do them without even thinking at times.”* Barbara 26-30). Sitting with Barbara I became aware of her struggles through deep depression and suicidal ideation to the day of the interview where she felt the OCD had subsided and become almost imperceptible. It seemed though Barbara had experienced a process of “ingraining” which implied pain and force where the OCD stamped itself onto her person through repetition. Barbara described how the OCD seemed almost unconsciously controlled *“So at the moment the OCD is uhhm I would say, uhhm controlled..Even if it is subconsciously controlled.”* (Barbara 40-42) which implied she was on some level unaware of controlling the OCD and yet she admitted it remained present such as an undercurrent might do. It seemed the OCD had become very quiet and subdued and hence Barbara felt in control of the OCD.

Insight.

The participants elicited varying levels of insight with regards the impact the psychological distress had made on them and others. They appeared to find great sadness and struggle in constantly trying to adapt and change to the difficulties they were experiencing such as Nigel who seemed very reflective about his daily school trip where he dropped his son off but instead of letting him walk through the school gates, continued to carry him, even when in conversation with other parents

“I still carry him now just to hide me face..to mask me face like yeah..And uhhm he’s getting he’s getting too big now to do it and it’s like when I’ve ..cause I know I fear

people at the school like I went to school and they..like when they'm talking to me they must think "why don't he put his son down?"..They talk and I'm here and son am here and I'm trying to have a conversation with them while me son's there like (laughs)"(Nigel 651-662).

Nigel seemed reflexive about his behaviour and its possible impact it might have on other parents at his sons' school. He seemed embarrassed and frustrated with the daily repetition of his carrying his son and yet there were no other coping strategies he could use without becoming anxious and distressed. Nigel seemed to have insight and understand he stood out due to his behaviour and despite being an attentive and caring father he only noticed his own shortcomings and odd behaviours, dismissing his caring attitude towards his children. It appeared Nigel also showed lack of insight as he was unaware of his courage in getting out of the house on a daily basis despite feeling anxious and worried about how he might be received. It seemed he was trapped by this cycle of behaviour and was powerless to change it. The sense of feeling trapped linked to Nigel's previous extract (lines 1263-1276) where he described being stuck on a spider's web with no chance of escaping. It appeared as if time was repeating itself for Nigel as he was stuck in a daily repetition of behaviours.

Isiah showed a similarly reflexive attitude in considering the feelings of his sisters when hugging them. It seemed for Isiah insight related to understanding his struggles could impact on his close relationships and in order to prevent this from happening he had to focus on the needs of others. Isiah described great struggles with obsessive thoughts when making bodily contact and yet by focusing on his sister's needs for closeness and warmth, he could tolerate a battle between his obsessions and his sister's closeness and contentment. *"hugging my sisters Really..cause a lot of anxiety..'cause I feel their breasts and that's hard because I am their brother (laughs) Uhhm..And so like but my sister likes hugging me closely and and actually sh she finds it really hard when I reject her, what comes across as a rejection..and*

so sometimes, yeah, the focus is on well actually this is for her for her hugging her.”(Isiah 127-136). It seemed Isiah desperately wanted to be the best brother possible and had learnt brothers and sisters hugged to show affection. Isiah seemed very lonely as a bodily action such as a hug which otherwise would not seem very important or noticeable, held enormous implications for experiencing closeness laden with psychological distress. It seemed Isiah was confronted with these decisions on a daily, repetitive basis, making his struggle continuous and unrelenting. It seemed Isiah could create closeness and belonging through his choice to fight his own obsessions and compulsions.

Tom described a journey to obtain a clear diagnosis of his psychological distress, leaving him more anxious and distressed as *“I had to go all the way to * to get your diagnosis, you get a diagnosis but you just don’t even know if I take that somewhere say like ** Mental Health they could try and say that’s not right say no mate that’s not right..they prefer to say it’s uhh general anxiety it’s an easier thing to say than BDD.”(Tom 1239-1244).* It seemed Tom had found the medical- and mental health professions powerful parties in deciding if he deserved help and support. Tom related how he had paid an exorbitant fee in order to meet with a clinician who could, after 25 years, offer him a name for his psychological distress and validate his years of struggle. Tom embarked on this journey despite having no money and being unemployed. It appears having obtained this diagnosis Tom was reminded of the power invested in his local mental health services who could disbelieve his diagnosis and fail to offer him the appropriate care and support he desperately needed. In Tom’s past powerful substances offered a means of escape from his mental struggles whereas in his present life Tom recognised the power invested in systems controlling access to support for individuals living with mental distress. Nowhere has Tom experienced a sense of empowerment and yet he remained searching for a means of accessing support which could enable him to bring about change in his life.

Barbara approached her GP cautiously as she feared a similar rejection with regards mental distress but found

“So I have to fill in a medical form and it says how long.. have you been off..and what have you been off with. And uhhm..I’m not happy saying I’ve been off for six months or so with OCD and anxiety..Uhhm and my doctor turned around to me and said “Why not?”..and I said because I don’t think employers would..See that in the same light..as they see other uhhm..illnesses. and the doctor turned around to me and said that as far as He was concerned me recovering from a bout of OCD..wasn’t any different and and going back to what I wasn’t any different to somebody breaking their arm or leg..and That being be put right.. before they go back to work.”(Barbara 346-369)

her fears were baseless. It seemed Barbara disbelieved OCD as a valid reason for sick leave perhaps through learning mental distress was not equal to physical distress. Barbara seemed to feel powerless against the perceived stigma about living with obsessions and compulsions. She seemed to expect to be discriminated against even when attending another very powerful figure, her GP. Barbara also seemed helpless in fighting a battle against misconceptions about mental distress and appeared to feel a failure for needing to have time off work but also because the reason for this time off work is related to her mental struggles. Barbara appeared to expect no care or support from anyone and her insight was based on her previous experiences of discrimination and stigma. It might have been functional for her to expect nothing from anyone as she had been let down on many occasions and it might have protected Barbara from feeling even more hurt. What seemed surprising and unexpected was her GP’s support and his confirmation of her distress as valid. It appears this incident had remained with Barbara as it offered hope and care, something she had not experienced for a very long time.

Isiah appeared to recognise there were acceptable images and information surrounding the idea of mental distress. *“..there’re rather negative images of what OCD is as the Mad person checking things..but like I present it as fear..present something as what I’m scared of..I wouldn’t talk about the hours and hours of checking or whatever..So like when I’m talking about my friends they agree in what context we can pray for one another”*(Isiah 682-691). It appeared Isiah had gained insight from understanding the misconceptions in the outside world and how negative depictions existed of people living with OCD (the mad hand washers). It appeared necessary for Isiah to protect himself from being seen as one of the extreme people he described and also he needed to protect his position in his social group. By using the word “presentation” it sounded almost as if Isiah was an actor in a play where he wore a mask which hid extreme obsessions and compulsions. Similarly by using the word “anxiety” he appeared to appease himself and his friends about his psychological distress. The words seemed necessary to help him diminish distress which he at other instances in the interview described as his lens

“It’s sometimes it can be so encompassing and so big it’s it’s like part of my life...it’s only One part of my life but sometimes the thinking processes uhhm and the safety behavioe urs and all of that that comes with it..so much so big, it’s just..it’s...I I don’t wanna say who I am but it’s it’s a huge part of my outlook on life” (Isiah 20-25)

By playing this “acting” role Isiah was able to gain support and care (through his friends’ prayers). It seemed Isiah was able to take some control back from the power of the obsessions and compulsions in the words he used. It seemed he benefited from using words which his friends related to as it lessened the chance of rejection but it also acted as a flood defence which kept him from being taken over.

Nigel described his fear if he was ever associated with mental illness. “ *I think I think if you get labelled with something it like it can be burden you in life like...like if you was getting a job or something. Uhhm uhhm I think if you get labelled you can be like if I went to an interview and I told them about this or like I I put on the CV or whatever..I think that would probably go against me like.*”(Nigel 545-552). It seemed Nigel had learnt that BDD was a blemish he could never be rid of and yet remained desperate to make something of himself in his career. Nigel described a history of poor support and disdain from family members who believed him to be a layabout and yet he retained a strong sense of purpose and determination to become employed and to build a good life with his partner and children. It seemed Nigel had to keep his distress a secret for fear of exposure and the possible end to a career which had not yet bloomed. It appeared Nigel sensed a powerlessness against the label of mental illness. He appeared to have created in his mind, a negative future, with limited opportunities awaiting him. The secret Nigel was keeping (about living with mental distress) appeared to serve a purpose in keeping him from being exposed or feeling vulnerable but equally it appeared to distance him from validating a recognised illness.

Belonging versus escape.

The sense of forming part of a group where there was a shared understanding and acceptance of one another appeared essential to the participants. It might be that these moments of belonging were especially important as many participants were living constricted lives where they hid their experience of OCD and BDD from all people outside their immediate family. It almost seemed that having psychological difficulties were to be frowned upon and the participants could not risk being stigmatised or discriminated against.

Isiah described an exclusive sense of belonging to an OCD group where he felt free to reflect upon, poke fun at and feel accepted within a community who all shared OCD. “*We*

would often joke about harming each other or whatever..or are you got a knife there you know..Silly things like that..Which only people with OCD would get..and there's a shared connection and an exclusive connection in that shared experience..Uhhm and I guess within the OCD group.”(Isiah 748-758).It became apparent how important it was to distinguish between who belonged in this group and who did not as the insiders had rights bestowed upon them which allowed a dark sense of humour to surface and they could poke fun at the very serious subject of self harm and living with mental distress. It seemed Isiah was very protective of this group as it symbolised safety and security and community and the integrity of the group was protected by other individuals who shared his sense of freedom and protection within the confines of the group. Isiah seemed outside of the OCD group an outsider who also had a foot in a different group of young people who watched video clips of funny behaviour. Within this second group it seemed Isiah did not have freedom to talk about what mental distress meant and yet he appeared desperate to create empathy for the person in the video clip who lived with OCD and was obsessively trying to park a car

“..I remember watching uhhm on Youtube this these guys on video with this woman reversing a car and then reversing reversing and checking..I can understand it was hilarious to watch and I can also understand the amount of distress that poor woman was under..Uhhm which they probably didn't know and uhh I think if they understood that they'd be a lot more compassionate sympathetic”(Isiah 706-714)

It seemed as a person living with OCD Isiah had a foot in both camps in that he was able to call upon the support from others who lived with OCD and equally formed part of a community of young people who do not live with mental distress. It seemed Isiah felt sad and conflicted in having knowledge about distress and a personal experience of OCD which he could not share or discuss with the group of young people he watched video clips with. It seemed two different worlds within which Isiah was living and he had freedom within the

confines of the OCD group and obeyed rules outside of this OCD group which stopped him from talking about OCD perhaps as a result of fear of discrimination or being seen as different. It appeared Isiah's extract was an indirect comment about the duplicitous role people living with obsessions and compulsions were fulfilling. In one sense the woman he described in the youtube video was funny but on another level she appeared also sad and misunderstood. Within the group of friends Isiah was with it appeared he seemed reticent to openly identify with the character in the video clip, possibly related to his fears of upsetting friends or acknowledging openly he struggled with psychological concerns himself and being unsure how this would be received. On a deeper level still there seemed an intimacy between Isiah and the video character as they both appeared to share obsessive behaviours and yet these remained unknown and unexplained to his friends. It could be Isiah was hopeful for some empathy as he was identifying with the video character and as a result of the secrecy surrounding psychological distress (in his experience) nobody was aware of his internal struggles.

Barbara described a similar experience in feeling free within the OCD support group she attended. *"you know uhh uhh at the support group the lovely thing is that we're all OCD and if we want to be OCD..in that particular environment, we Can."*(Barbara 263-264). It seemed especially important to Barbara to be in a community where she was not judged but accepted. Within the OCD group Barbara had found safety and security and had met others who were struggling with exactly the same concerns as her and they could together feel stronger as a group. It appeared an OCD group removed any sense of power, whether it was Barbara fighting the OCD or the OCD fighting Barbara in every other setting in her life, within the confines of the group she could freely embody OCD completely without feeling overburdened. Barbara showed how strongly she identified with the group as she spoke of "us" and "we" which increases her sense of belonging and connectedness to the other group

members. In contrast to the sense of belonging Barbara described, there appeared a strong urge to be rid of the OCD and its horrifying memories such as the accompanying depression and self harm Barbara had experienced “*one a particular one that came straight to mind uhhm was dementia..If you’ve got dementia when you’re older,..You know wh there’s no room for the OCD (laughs)*”(Barbara 1607-1612).It seemed a wish Barbara held to somehow escape the OCD through developing dementia, which could remove all memories of the difficult and challenging times she had experienced. It seemed almost Barbara was desperate to belong in a group of like minded people who supported and comforted her but equally outside that group she remained desperate to forget the distress she had experienced even if it meant living with no memory at all. The sense of belongingness Barbara received in the OCD group could be considered a way of escaping the outside world where OCD was often misunderstood and judged. Within the OCD group Barbara experienced comfort and nurturing alongside a sense of power to let the OCD be seen and to let it run free without any embarrassment or fear of being found out.

Scarlet described how having friends who lived with psychological distress offered her a sense of community

“I think I’ve known her about 7 years..And I didn’t know at the time we met that she’s got mental health problems..And my other friend that I’m close to she’s actually moving down stairs and she’s got mental health problems as well..It’s almost like we all (laughs) not Knowingly but you all grated to each other you know. So we do our best to support each other you know..Because the worst is when we both are going through a bad stretch together because we can’t do much for each other but you know hopefully if one’s good and one’s as bad you try and help the other one and stuff..like that.”(Scarlet 662-676).

Scarlet seemed almost fated to meet others who lived with mental distress and yet she recognised and feared the double edged sword of being friends with people who themselves were vulnerable in that they could support one another with a deep sense of shared understanding but equally could cause one another more psychological distress if they were both vulnerable and unable to offer support. It appeared important to be understood and to be accepted and Scarlet's friends offered her a sense of belongingness. The commitment and investment taken in each other appeared to be the protective factor in Scarlet's friendships. Interestingly Scarlet commented on not knowing of her friend's psychological concerns when they met, almost as if these were invisible at the time. This could also be said of her constantly changing faces which she had described as invisible to the naked eye but disabling and controlling none the less. A sense of empathy and understanding resonates from Scarlet's description of her friends' struggles with mental distress. It appeared Scarlet could identify with her friends' vulnerability and need for support as these were also what she experienced.

Theme 2 Relationships.

Living with uncertainty and being unconfirmed.

The relationships the participants held towards themselves and others appeared very conflicted. They seemed constantly to search for affirmation and acknowledgement and yet many of them were left frustrated as their distress was invisible to the naked eye. There appeared to exist a constant fight to have their distress acknowledged and recognised for its power and brutality as it seemed to shape the participants' lives without their permission and choice.

Isiah described how he could never be sure what his distress was “*..Because unlike things like depression which are the whole thing about OCD is you are not even sure it is OCD.*” (Isiah 1133-1134) which showed his constant battle to understand himself and the

process he was going through. It seemed Isiah was always searching for answers and clarity to explain his invisible distress and was powerless to pin down this elusive and phantom-like psychological distress he was experiencing. It appeared to be an impossible task for Isiah to explain what he was feeling and how to validate it as an acknowledged and understood psychological 'disorder' when he could not ever be sure what he was trying to describe. In this instance OCD appeared all-powerful in its control and management of Isiah's person. It appeared the OCD had almost embodied Isiah and yet this embodiment did not offer any clarity or explanation.

Scarlet similarly described a desperate urge to be understood and her distress to be validated

"But there's still that anxiety all the time you know when I go to the toilet I look in the mirror and I was like "Oh God" you know..And you I'm waiting for people to treat me different and look at me different but they don't and that sort of you know I know that they don't see it you know..but it's weird how can you not?'Cause it's such a severe change from one face from this to that and you think..how can you (laugh) not notice it? And then you know well over the years I've thought well is it my is it my brain or is it my eyes?"(Scarlet 283-290).

It seemed Scarlet could see sides of herself in the mirror which both frightened and confused her and as much as she was disgusted with her own reflection she remained desperate for her experience to be confirmed by an outsider. It seems Scarlet saw herself as faulty as she was questioning her eyes and brain, looking for possible answers to this disorientating experience of seeing changing faces in the mirror. It would appear Scarlet was in a conflicted position of wanting to be discovered and yet desperately wanting to hide these ugly faces she was experiencing. Within this extract Scarlet highlighted the sense of the flow

of time living with BDD. She described how things could have improved but “still” there remained anxieties and uncertainty every day. The use of the word “still” implies a sense of anger and frustration at the continuing process of distress she was experiencing. Scarlet alluded to time elapsing and passing into years where she remained trapped without any power to control her ever changing faces and had eventually arrived at a place where she appeared resigned with an internal failure of some sort. In this extract Scarlet’s sense of self is poignantly described as horrifying, fear invoking and ever changing, never allowing any sense of pause or a moment of calm. Further uncertainty appeared to reside in how Scarlet never knew how she would appear to herself and how her perception of herself was constantly changing and adjusting in line with the face she was wearing at the time.

Barbara described her anxieties as she could possibly be unaware of her own behaviour *“I’d wake up in the morning and it would almost be like frightened to go in and see if the kids..were awake because you the fear that you did something To them in the middle of the night..without knowing.”*(Barbara 442-448) and Barbara spoke of the important role of being a caring and loving mother to her children and yet she had to face the possibility of hurting and harming those she loved without any knowledge of doing so. It seemed Barbara was left feeling ashamed and saddened that her one goal in life (to be a good mother) was soiled by her psychological difficulties and that she could be an unsafe parent whilst she still felt responsible for ensuring the safety of her children despite her inner turmoil. This extract highlighted the unknown part of the self. It seemed living with OCD implied a sense of disconnectedness and not knowing about the actions which could take place outside of conscious awareness. Barbara’s sense of self appeared disjointed into facets outside of her consciousness and outside of her control. It seemed Barbara experienced both terror and horror at the possible actions her unknown self could perform and she seemed like a person who showed up after the fact, once a deed was done and someone else had to come and clean

up and repair the damage. This extract appeared especially poignant in view of Barbara's sense of disconnectedness she described from her own mother. She also described a strong urge to be proven to be a good mother to her children and as a result hid her OCD from her mother for fear of criticism.

Diane appeared to relate to Barbara's despair in recognising the self stigma and self critical stance present for those living with mental distress

“And I think self-acceptance is easy and it's not..believing that you're a Freak and..that's something that people with mental illness often consider themselves I know I used to consider that and I meet people all the time who'll say “I know it sounds a bit weird and I know you think I'm a freak” and..they say that before they say everything about what they do..and until you stop thinking that and until you get over that..and you realise that you know you've actually got an illness..can't that you can't control..it..you're able to look at it from an outsider's perspective rather than just seeing it..from Your perspective.”(Diane 1278-1296)

Diane seemed to feel a strong sense of injustice where people living with psychological difficulties were concerned and had stepped into a defensive position for all the self-stigma she recognises to exist for these individuals. It seems through having reflected on her own self loathing and name calling Diane was in a position to empathise and challenge the self-stigma in others and she seemed desperate to convince other people living with mental distress of the validity of OCD as an illness rather than a failure inside themselves. It seemed especially important as Diane had started hating herself when she relented to the ongoing cleaning of her home, herself and her daughter and felt trapped by compulsions. Diane described in the research interview how her mom also lived with OCD but never could voice this concern, which appeared to leave Diane alone in seeking help and support and perhaps

where she seemed the outsider in her family as a result. It might be this lone journey seeking answers and support made Diane more empathetic to others who were suffering as she did. Diane appeared to describe a journey which started with being taken over and then was followed with a process of escaping and stepping outside herself. It appeared when inside her own experience she could almost lose clarity and focus as a result of being taken over and by being manoeuvred by obsessions and compulsions. Through a process of distancing from herself, she seemed able to again gain clarity and understanding and was able to reflect on the hurt and harm caused by self-criticism. It appeared in this extract Diane's sense of self changed from self-loathing to self-respect and yet it appeared this change was only possible through an active stance in fighting misconceptions.

Scarlet talks of injustice when she read about BDD being trivialised

“in the article he put everybody looks in the mirror and everybody's got a small form of BDD..And I wrote in to say you know they haven't BDD is when you when I got it severely I lost me fiance, job I lost my friends, finances..family and everything you know..you can't equate that to people going “Ooh God I look a bit today”” ‘Cause I know people I felt I feel today just before I suffered like I do you do have that “Oh God” you know and your hair won't go right..but it is a totally different feeling..when it overtakes your whole..life.”(Scarlet 395-411).

In this extract Scarlet appeared to feel a sense of powerlessness not only as inflicted by BDD but also at the hands of the media (and their misconceptions about BDD). It seemed as if BDD had wiped all connections and feelings of connectedness to others. BDD appeared a powerful destabilising force which removed social connections. The power invested in the media gave it freedom to misreport and trivialise as there were no direct consequences for the writers of the magazine article, in stark contrast to Scarlet who appeared mortified and

enraged. It seemed the very powerful losses Scarlet had experienced as a result of living with psychological challenges were almost diminished and trivialized in a local magazine article and she fought to have her experience recognised in its depth and severity. Scarlet described during the research interview how she felt she was seen in her family to be too great a burden and as a result had seen her engagement nullified and relationships with her family wane and disappear. It seemed Scarlet recognised how in the news media BDD and its devastation was not recognised and as a consequence her experiences were not acknowledged either, leaving her furious and yet still powerless to prove this invisible distress she was living with permanently.

Validity of mental distress.

The participants appeared to have learnt that mental distress was less acceptable than physical ailments. As a result, many of them considered themselves and their individual distress as a failure or a blemish which could not be proven or validated. Physical distress appeared to be visible and uncontaminated by stigma such as a broken arm or leg was understood to heal in a specific period of time whereas mental distress was phantom like and unknowable.

Nigel seemed desperate to change from feeling overburdened and taken over by his distress and seemed willing to compare his distress to that of people in television programmes afflicted with skin burns in an attempt to almost shock himself out of feeling sorry for himself. *“that’s another thing like you see these programmes on the telly of them people being burnt and that..It makes me want to think well I ain’t that bad as them if you look at it that way like..I’ve tried to..make me think that sort of way but it ain’t work like.”*(Nigel 1021-1028). Nigel appeared to focus on others’ hardship in an attempt to diminish his own but it failed. It seemed Nigel felt guilty for having psychological distress when others were

suffering in physical pain and yet he appeared to also need containment and support for his distress, which at present was not available. It appears Nigel's measure of his intact physical body as a sign of health stands in contrast to his psychological distress. It appears a burns victim would show distress in flesh wounds whereas Nigel suffered with internal wounds which were outside of his control to change or sooth.

Jane seemed confused in feeling very distressed but not knowing how to have permission to ask for help and support.

“Even though you might you know if you were physically ill they could see it and they'd immediately say “Are you all right do you need any help?”..you're reticent to ask for help it still doesn't feel a valid enough reason..you know it's Not physical it's not it's not Stopping me from walking to school..and back to take or collect the kids or functioning in some capacity..even though I might underneath actually just want to sit and cry..it could be at that point that you hold it all back..to get through the bits that you've got to do. So yeah a lot of the time you don't tell people how you're feeling or what it is at times you Can..But it isn't something you want to do too often because you don't want them to not like you for it.”(Jane 496-516)

It appeared mental distress could be at once all consuming and phantom like. It seemed its power was internally hurting and consuming all energy and yet it did not show any signs externally. It seemed as Jane was able to maintain her day to day activities she felt she did not have the right to complain and yet she appeared angered and saddened knowing that had she a physical ailment she would immediately receive empathy and care. It seemed Jane had made her own rules about levels of disability and questioned her own standards where she felt she did not have the right to complain and yet she seemed frantic and frenzied in feeling so overcome internally. Jane seemed to be concerned about being seen as someone who

moaned and complained and yet she never did. It appeared her struggle remained hidden and secret and as she felt unable to ask for help or to show her distress without fear of rejection, she remained lonely and alone. It appeared mental distress was felt internally but not necessarily expressed externally.

Impact on relationships.

The participants described challenging environments both at home and in their employment where they appeared to feel a failure and stood out like sore thumbs. Tom described his struggle at work

“It’s like talking to people but it’s all in the back of me mind all people looking at me..All this I don’t want to look at people am I grotesque am I ugly and uhhm..and basically your whole day would be like that. On a bad day..Come break time I I stopped going like you know when you sit down with people..I didn’t want to do that..I’d sit in me own so.”(Tom 483-494)

where Tom felt completely rattled and frenzied in believing he was being watched and judged by fellow employees. It seemed Tom wanted to fit in and make friends and yet the only moments he felt relaxed was when he was on his own. It seemed very sad and distressing to imagine how for many years Tom struggled to leave his home and how on occasions he did manage this, he felt scrutinized and decided to keep his own company. Obsessions and compulsions appeared to encroach on all roles and would take up space and energy in its continuous attack. It appears a sense of rejection and of being found out to be defective were themes of selfhood present.

Nigel described the importance of employment in the face of his family where, because he felt unable to work, was deemed a layabout

“uhhm I mean I’ve hardly worked..and I get quite a bit of stick off my family for that they keep saying and I don’t think they understand..the condition fully like but I’ve tried to explain but..they just keep saying “Why don’t you get a job do this ?” and ‘cause they ain’t gone through it I don’t think they understand me like.”(Nigel 749-758)

it seemed how making something of himself and his life was a strong urge for Nigel and yet he felt unable to explain to his nearest and dearest why this was impossible and to offer believable evidence for his struggle. It seemed Nigel was trapped into a cycle of proving his worth not only to himself but also to his family and yet internally he felt a failure for not living up to his own ideals and those of his family. Nigel described in the research interview his manifold attempts at attending college courses or gym workouts but always seemed to feel overwhelmed and exposed outside his home leaving him to retreat to the safety of home life. The obsessions and compulsions appear to cause changes in Nigel’s intrapersonal relationship as it reinforces ideas of failure and stuckness. There appeared a sense of urgency to change this internal relationship as it reflected the interpersonal failures Nigel experienced and the valuing his family appeared to attach to his failures (to fail in becoming employed and making a decent living).

Barbara described the huge support and encouragement from her husband at facilitating her attendance at the local OCD support group *“So uhhh my husband coming to collect me, is actually my safeguard against having to worry about whether or not I have locked up properly..because he’s there to to watch me and to make sure that I Do it.”(Barbara 694-697)*. It appeared Barbara felt completely at ease as the result of her husband’s actions when locking the building. It seemed it served a purpose for Barbara to accept her husband’s help as she could facilitate the OCD group successfully with his support and through his support could keep her own compulsive behaviours at bay. By having a responsible figure (her

husband) to aid with obsessions and compulsions, Barbara appeared able to change the relationship within herself to obsessions and compulsions. As her husband availed himself to take care of locking up duties, Barbara seemed able to relinquish responsibility for addressing obsessions and compulsions.

Allan described how at times he felt unable to be close to his wife “*..if the mind is not clear you can not have heart to heart you can not uhh express your feelings..you just want to be left alone.*”(Allan 282-285). It appeared almost as if there existed a blockage between the couple which inhibited closeness in their relationship. It seemed as if Allan was saddened and demoralised as he could not be intimately close with his wife despite a strong urge to build intimacy with her. Allan described at other points in the research interview how he had only been married for a brief period of time and how he trusted his parents, sister and wife implicitly. It seemed heartbreaking to find he could not be completely be close to his wife and how he chose to keep his own company as a result of feeling embarrassed and sad. Allan seemed to comment on both a blockage within his mind and his heart due to obsessions and compulsions, his whole personhood appeared affected and inhibited by the impact of obsessions and compulsions and it seemed this inhibition also affected his interpersonal relationship with his wife in blocking any communication of his true feelings.

Diane described her love-hate relationship with her mom who lived with psychological distress herself and yet never sought help.

“ and..I think..if she’d taken me to the doctors she would have had to address her Own..obsessions that that’s the conclusion that I’ve come to. And I know my mom passed away last year but even ..when I finally seeked help and when I I’d gone through fourteen years of therapy,..She’d still find it difficult to talk to me about it..She would refer to it as my problem.”(Diane 168-178).

It seemed Diane was living with mixed emotions of sadness, resentment and anger towards her mom for never acknowledging she herself lived with mental health difficulties. It appeared Diane sought belonging and comfort when she was struggling with psychological distress over a period of many years and felt adrift without her mom's acknowledgement or support. It seemed Diane could only since her mother had passed away, let these conflicting emotions surface without the possibility of damaging or hurting her mother. Diane highlighted the presence of obsessions and compulsions in her personal life and in that of her mother. It seemed their relationship was fraught due to their individual treatments of obsessions and compulsions (Diane chose to accept help whilst her mother chose to keep it a secret). It appears Diane's understanding of obsessions and compulsions as valid reasons to seek help were called into conflict as she observed years where her mother living with similar struggles suffered in secret.

Sense of self.

The participants described conflicting views of themselves at times placing the blame for their distress with themselves and their failures to heal themselves. It seemed they were desperate to find solutions to the many psychological challenges they faced and struggled to understand who they were as individuals.

Nigel described his wretchedness at being saddled with a facial feature which was horrible and disfiguring *"I've even thought of breaking me nose meself..Uhh punching meself like and stuff..and suicidal thoughts at times..Not all the time..When I'm it grates it just grates you down like it gets on your nerves."*(Nigel 1357-1365) and he described being willing to hurt himself if it meant he could be rid of his physical disfigurement and the mental torture it accompanied. By describing his experience as grating Nigel alluded to the force and aggression being applied to his self concept and how it almost hollowed him out as a person.

Diane described her role in facilitating a duplicitous self as the only way she could cope with her mental anguish *“because because I put on this bravado..and I put on this brave brave face all the time..and I am this strong person that will not be defeated by anything..But really often inside a lot I feel like that lost girl..that girl that’s scared of everything.”*(Diane 295-303) which came across as a desperation to hide her internal anguish and to strengthen her exterior self to the outside world. Diane seemed to long for safety and security as she described herself as a little girl and yet she seemed ensnared by parts of herself which were pushing to retain a strong exterior. It became apparent through the interview how Diane battled to have mental distress recognised as it was experienced by herself and others and how this battle was fuelled by fears of being defeated and consumed by mental distress. At times it appears Diane felt incapable of fighting this battle as she was ill equipped (the figure of a lost girl) and the only strength she had was her words telling her otherwise (that she was strong and capable of the fight).

Allan appeared conflicted himself as he suffered with debilitating anxieties and attended therapy *“it helped but parts were still there like you know..uhhm so (breath out) so I went home I was like I didn’t know what to do ..everybody told me I I was fine I was OK you know..only my parents and my little sister know about this and my wife now.”*(Allan 158-164). It seemed as if Allan needed reassurance from his family that “nothing was wrong” and yet he seemed not to believe their statements as he remained distressed. It appeared Allan shared his distress with only the closest family members perhaps for fear of feeling ashamed or embarrassed and yet none of his family members could remove or soothe his distress. The words of trusted family members and friends appeared insufficient to allay an internal sense of something being amiss (“but parts were still there you know”). It seemed this sense of not knowing how to move forward or how to change the distress had to be hidden and Allan conformed to public opinion that all was well whilst internally feeling all was not well.

Theme 3 Finding ways forward.

Coping.

The participants each found individual ways of coping with their psychological distress. There seemed cross over with regards the sense of failure and self blame attached to having psychological distress. Tom described his disbelief and frustration as he attended at a psychiatrist for help with his struggles.

“But to a psychiatrist well to my psychiatrist..you just end up really you end up in an argument because (laughs) you feel like you’m arguing because they’re not helping ya..It ain’t in all honesty he’s asked me what you want to do..what you want me to do I don’t know because I’m not a psychiatrist..and he also asked me what tablets I wanted to prescribe so I prescribe my own tablets last time with him..It don’t give me lost of confidence because I’m thinking you shouldn’t really prescribe me telling you what to prescribe.”(Tom 410-423)

It seemed Tom had to play along with a game inside the psychiatric session in order to be given tablets which could relieve his distress. Not only did Tom have to tolerate the ridicule and mockery of his concerns but equally appeared to have to educate the psychiatrist with regards his medications. It seemed staggering how Tom had to stand strong against a discriminating experience such as this and how he desperately needed the help so could not refuse this opportunity despite it denying any sense of containment and support. This extract highlighted how Tom had to cope by himself, how he turned to a mental health service but came away with a sense of disbelief. It appeared the mental health system exerted power over Tom in that this was the only place he could approach for medicinal support for his obsessions and compulsions and yet he had to relinquish to their power (despite it being farcical) in order to control his obsessions and compulsions.

Diane described her sense of failure urging her on to bring about change

“and..I just remembered looking at my daughter the one day...and I’d had a Really bad day with cleaning and..I’d had like four showers and I’d washed my daughter like four times and ..I was Crying and ..there was the smell of disinfectant everywhere and I just thought I can’t Do this any more..I’m so exhausted..But just just something I just looked at her and thought I have to get better...Because if I Don’t ..my daughter’s not gonna have a mom..And I’m being selfish.”(Diane 888-902).

Diane seemed to cope by fighting the obsessions and compulsions tooth and nail as she was determined to stop it from impacting on her relationship with her daughter. It appeared Diane saw herself a failure every time she relented and “gave in” to the compulsions and yet earlier in the interview she fought for the recognition of psychological distress as a viable disease for which nobody was to blame. It seemed only by blaming herself and seeing herself as a failure Diane was empowered to change her life completely and to expel and castigate the obsessions and compulsions’ hold from her life. Sadly it appears Diane had to see herself as a deficit prior to feeling empowered to bring about change and to cope with the impact of obsessions and compulsions successfully.

Nigel showed an understanding of appropriate behaviours and rules in society as he stated *“I got into quite a few fist fights about it fist fights..Uhhm ‘cause I was I was like a teenager and young like..Like I can’t really I don’t want to argue with people as I’m older now..as I’m adult like.”(Nigel 977-983).* The conflict inside Nigel to remain a responsible adult whilst he felt like hitting and screaming, appeared enormous. It seemed Nigel had reflected on his coping strategies and found fist fighting to be useless as it did not improve his situation at all. Nigel seemed to have no choice but to remain calm and composed for the sake of his children perhaps to set a good example and yet internally he seemed conflicted

with anger and frustration. Nigel's extract alludes to the passing of time and how he had attempted different coping strategies (first fighting to a t present being calm on the outside whilst feeling angry and frustrated internally). Nigel's sense of self criticism of his historic coping strategies allude to a sense of understanding the rules in society, how he managed to fit in better by acting as an adult. It appeared Nigel continued an internal battle with regards the obsessions and compulsions and hid this battle so as to look as if he fitted in.

Scarlet described a similar experience to that of Diane in feeling guilty when allowing her obsessions and compulsions to take over, but described *"I do I do give in to it and I'll stay in bed and I won't go out and I won't bother but the majority of the time I do Try and do what I've planned..And I do try and override it and I think "well my life is just wasting away."*(Scarlet 690-694). It appeared Scarlet's sense of coping related to how she could acknowledge how far she had come in her changing view of herself and her mental distress from a position of feeling a failure to moving to acknowledging even the smallest improvement. It seemed essential in the daily battle against psychological challenges to acknowledge any small victory such as Scarlet being able to get out of bed and leave her home. It seemed Scarlet had taken ownership of bringing about change in her life and fought to re-establish a quality of life she longed for.

Contrary to Scarlet, Allan seemed to notice deficits only when pointed out to him *"And only last night my wife said why don't I start it again you know I mean..she told me when you're doing it you're a different person she told me..she told me last night again I never thought about it."*(Allan 804-809). Allan seemed bemused by his wife's encouragement to start using yoga and meditation again as he did not seem to notice the gap in their relationship widening. It appeared Allan's wife played a crucial part in his coping as she noticed changes prior to him and could offer him encouragement and support. Earlier in the research interview Allan reported how therapy had improved his experience of obsessions and compulsions by

75% and how he felt much improved. It seemed the conflict in Allan existed with the improvements he noticed and the lapses which appeared to occur without his knowledge.

Distancing.

The participants seemed to feel strongly about finding reasons for causation of their psychological distress. It appeared very important to not only understand the literature about obsessions and compulsions but also to relate it to themselves and their experiences thereof. It was as if having an external cause for the distress or causation outside of the control of the participants, could allow them a forgiving attitude in view of the distress they continued to suffer and their sense of failure for not being able to heal themselves.

Isiah appeared to have read much about obsessions and compulsions and its causation and the knowledge about possible genetic links seemed to allay his fears about living with psychological distress. “ *I guess I’m a lot more accepting of genetic explanations I can understand that this is a physiological th there is a very physiological process that goes on that somehow is used to interact with my cognition*”(Isiah 1709-1712). It almost appeared as if Isiah clung to this information as a means of steadying himself because conversely at many points in the research interview he referred to the all-encompassing effect of living with psychological distress. By knowing some genetic components were responsible for causing mental distress, blame could move from Isiah to forces beyond his control. The sense of powerlessness against the obsessions and compulsions appeared allayed by knowledge about causation and finding increasingly more up to date knowledge served a purpose in ameliorating Isiah’s sense of responsibility and guilt for living with mental distress.

In a similar fashion Allan described how “*the chemicals play up you know..*”(Allan 180). Allan appeared to find this information a confirmation of causation outside his immediate control and it seemed almost as though he could believe a scientific link to explain

psychological distress. As a result Allan could distance himself from the responsibility for living with obsessions and compulsions. Early on in the interview Allan reported having been offered anti-depressants which after one day of use he decided to stop taking as he felt very strange and feared it was impacting on his concentration. It appeared Allan understood part of his brain chemistry was perhaps outside of his control and yet he chose not to use chemicals to change it further even if it could offer some relief. It seemed Allan could tolerate the knowledge of chemical changes in his brain and yet felt introducing chemicals which could alter the state of his mind would introduce a sense of increased powerlessness. It appeared Allan could reconcile his own chemicals in his mind “acting up” with distancing from responsibility for the causality of psychological distress but equally distanced himself from chemicals being introduced to change his brain chemistry.

Nigel alluded to how he could spot trouble miles away and could almost sense negative comments about his appearance “*Uhhm I don’t know you can..pick up on other people how they..look and how they make and that..and I can usually sense like something’s gonna be said or anything like trouble like that*”(Nigel 46-51). It appeared Nigel understood himself to be at the behest of outsiders whose comments could create his inner turmoil. Nigel mentioned in the research interview how as a young man he often got involved in fist fights when nasty comments were made, however he seemed at present to cope by avoiding confrontation altogether and following an almost solitary routine. It seemed to Nigel the outside world was an unsafe and uncontrollable place he had to tolerate at best and avoid if at all possible. In effect Nigel distanced himself from the outside world as he came to the conclusion many interactions were malicious. Nigel gave the impression of being a victim of circumstance where in the hands of unscrupulous people he developed psychological distress which could only be controlled by isolating himself at home.

Barbara described conversely how she experienced benefit from living with psychological distress as she stated “*Well at the moment I see my OCD as something...I use to protect my family*”(Barbara 1552-1553). It seemed almost as if Barbara had found obsessions and compulsions served her well as it made her more acutely aware of her motherly duties and the needs of her family. Barbara’s comment seems especially pertinent as she mentioned at an earlier point in the interview how she hoped (jokingly) to develop Alzheimer’s disease which could remove all memory of her historical struggles with psychological distress. It seemed Barbara had built a life where she understood psychological worries and its costs and benefits and had made a decision as to allow it to remain unchanged through further therapy or intervention. It appeared Barbara did not feel a need to distance at all from the obsessions and compulsions as they served a purpose in her life in making her a more protective parent. It appeared Barbara did not only tolerate but invited the obsessions and compulsions into her life as they were useful guides and guards in her role as a parent.

Dissonance.

The participants appeared to live with many conflicting and uncomfortable understandings of themselves, the people in their lives and their progress in relation to successfully living with psychological worries. It seemed each participant had made decisions which served a purpose of allaying fears and making life however narrow, possible. Dissonance related to how the participants held these conflicting beliefs about themselves, others and the world together and how they attempted to rationalise and understand the conflicting beliefs they held.

Nigel described how his psychological concerns started with comments voiced by his mom “*Specifically that’s what I remember that’s what started it all. My mom.*”(Nigel 1492) and “*Uhh excuse me language excuse me language big nose bastard like..Uhhm that that*

that digs that stuck in my mind.”(Nigel 1496-1498). It seemed Nigel had suffered great sadness at needing and hankering after a containing and supportive relationship with his mom and only found rejection and discrimination, starting when he was a young boy. It also linked closely to Nigel’s desperation to amend his visual appearance in order to fit in with his family and how he used his father’s tie bound around his face to lessen the size of his nose. What appears most striking is Nigel’s memory of these hurtful comments and how if they were made by someone he loved they carried a lot of weight. It almost seemed Nigel was mistrusting of any comments and could not believe he had any redeeming qualities despite his success at finding a successful relationship and being a doting father to his two boys. The dissonance appeared related to the power of hurtful comments and despite having been spoken many years ago they still exerted power over Nigel’s sense of self belief. By revisiting the hurtful comments it appeared to keep Nigel from moving forward with his distress. It seemed almost as if the comments were spoken in the present when in actuality they were controlling in the present but spoken in the past.

Isiah described feeling relieved and appreciative regarding the focus of the research interview as it was strictly about the experience of living with obsessions and compulsions *“but actually saying the act of saying this is OCD is an interview for OCD or this is a group for people with OCD..Has huge imp has huge therapeutic impact in itself by labelling this condition as OCD because the whole thing with OCD is you just don’t know that it is.”(Isiah 1150-1154).* Isiah’s comments alluded to his search for recognition for his own distress and feeling as yet unconfirmed. This search appeared to include an understanding and deconstruction of what it meant to live with obsessions and compulsions and yet Isiah found the research participation and naming of the distress necessary in his battle to be validated. Conversely it appeared Isiah found obsessions and compulsions a heavy burden to live with *“I..hope it’s obvious that I suffer from extreme OCD, but..why need a diagnostic label, do I*

need that stigma for the rest of my life, when, who who's to be honest, my my psychiatrist who I I basically suggested to Him I had OCD.”(Isiah 1926-1929). It seemed Isiah's relief could only be momentary as he could still not trust there would ever be any freedom or relief from the obvious distress he was experiencing. Isiah's dissonance appeared to relate to feeling labelled (by using the term OCD) as he recognised and rejected its negative attributes of being dangerous, risky, flaky or at worst a mad person. Within the research interview Isiah referred to OCD sufferers as misunderstood as mad hand washers and spoke of his shame of having paedophilic thoughts. It appeared by giving his distress a name he still could not remove the shame attached to his lived experience. It seemed Isiah was stuck searching for answers but found the answers he had found were unacceptable and undesirable. The social stigma of obsessions and compulsions appeared to become personal in this extract and its power to design and delineate a person appeared almost all-encompassing. The sense of power also appeared to relate to needing a diagnosis to obtain validity and equally rejecting it for its negative connotations to self. It appeared living with obsessions and compulsions was not visible and not “obvious” to anyone (including the psychiatrist in this extract) hinting at its elusive and personal nature.

Allan appeared to be in a conflicted position as he described his experience of psychological conflict as greatly impacting on his daily life leaving him a victim to a force outside of his control

“Planning planning plays a big big part in..in anybody anybody's life in any job any college uhhm..any school any relationship..I just couldn't I just couldn't ..couldn't concentrate..I couldn't plan anything you know I mean this was the whole it was like was like some somebody sitting on my back..like a monkey sitting on my back..and I just try to shake it off it won't go away so I couldn't plan anything”(Allan 137-150)

and conversely Allan described feeling much relief after following advice from a friend “uhhm and then my friend said you know what I took some yoga ex exercises..doing yoga and meditation and that helped..I have to say that helped I mean uhhm if I have to give it a percentage I would say it helped me about helped me about 50 to 70 ..75% depending on the day.”(Allan 184-191). Allan’s comments appeared to relate to his hopes of making a breakthrough with his psychological worries. It seemed he was living a very dynamic and changeable life where he felt simultaneously ill at ease and relieved. It seemed to serve a purpose for Allan to describe his psychological state as improved as then perhaps he could feel less overwhelmed when reflecting on the negative impact of psychological concerns on his intimate relationship with his wife and the struggle to move ahead in his work as a result of planning difficulties. Allan described at length his commitment to his employment and how he had big dreams for his future. It seemed Allan was very vulnerable as his future prospects could be curtailed if the psychological challenges overpowered his sense of improvement. Allan’s sense of desperation appeared to remain as he attended for surgery in Europe and also group therapy with a renowned clinician hundreds of miles from his home. It appeared a continuous search for answers and treatments were at the forefront of Allan’s mind and finding a cure could be the only way of ameliorating dissonance.

Barbara seemed to experience her psychological worries as reassuring as it offered her a chance to belong and be free with others who shared similar complaints “So uhhm and it’s nice it’s nice again for just to be with other people with OCD so they don’t think I’m mad when I ..double check things.”(Barbara 727-730) and yet she reflected on the unusual behaviour of checking which would stand out in any other context than the OCD group where she felt safe. Barbara seemed to have struggled very much in her life with a variety of psychological worries and had finally found relief with a group of people who acknowledged and accepted her for what she was. The dissonance appeared to relate to Barbara talking of

OCD being controlled “*So at the moment the OCD is uhhm I would say, uhhm controlled..Even if it is subconsciously controlled.*” (Barbara 40-42), which stood in stark contrast to how, in the OCD group, obsessions and compulsions were allowed to run free. It seemed Barbara’s experience of the impact of the obsessions and compulsions had lessened to a degree where the accompanying distress had become very limited. Barbara described living with obsessions and compulsions as a quality which enabled better mothering skills and yet it offered her very limited freedom only within a small group of individuals with similar concerns.

Hoping for reciprocated care.

The participants described lives involving great turmoil and stress where they were often struggling to make sense of themselves. It appeared they found through their struggles they could empathise more directly with other people’s struggles and could only hope to find care and support for themselves.

Tom described a life of drug- and alcohol abuse and anxieties which kept him from leaving his home. Drugs and alcohol functioned as ways of escaping distress in Tom’s past. He appeared to feel through his own sense of vulnerability he could recognise pain and suffering and was desperate for nobody to be hurt by his actions. It seemed that personal vulnerability created a sense of role in protecting others who were equally vulnerable.

“..because I think uhhm BDD makes you vulnerable...and you’ m like you know how easily hurt you can get you just try not to do that to other people...because you know how it makes You feel...the last thing you wanna do is make someone feel bad.” (Tom 751-759).

Tom seemed protective of others who were suffering and yet he himself remained isolated and without adequate support. Tom showed great reflection and humility in the face of an ongoing storm in his psychological life and seemed hopeful of positive support being returned to him at some point in time. Similar to other participants Tom appeared to live with uncertainty in not knowing when or how his struggles would be validated and recognised and perhaps by involving himself in creating a fairer world for individuals living with distress, Tom was able to see a sense of purpose.

Diane equally appeared to have reflected on her own experience of psychological worries and that of her mother

“Well actually my mom..showed a lot of obsessive traits..and I think some of those I picked up..But my mom was a very quiet, shy person who lacked..confidence and she had a lot of physical illness..and..I think..if she had taken me to the doctors she would have had to address her Own..obsessions that that’s the conclusion that I’ve come to.”(Diane 158-171).

Diane appeared in the research interview to acknowledge her mom’s role in anger and upset as her mom chose to leave her own struggles unaddressed whilst pushing Diane to get help and support. It conversely seemed Diane had found forgiveness and understanding for her mother’s reticence to admit she lived with psychological concerns. It appeared Diane herself knew the anxiety and stigma attached to saying you lived with a ‘mental disorder’ and the overwhelming feeling this could have created for her mom. It seemed Diane acted as container for her mom’s distress and their roles had swopped from Diane having been the child who needed containment herself.

Isiah remarked how he had himself suffered and could understand and hold empathy for those who suffered similarly *“I guess the positive spin off is that maybe I’m more aware of*

suffering in the world” (Isiah 1038-1039). It appeared to serve a purpose for Isiah to remark on positive gains as his life had been greatly affected by psychological distress. It seemed important to hang on to hope and positive uses of distress which could at times appear all-consuming. Isiah had trained in the mental health profession and was best placed to offer support and encouragement to those who similarly had experienced psychological worries.

Discussion

The preceding analysis section laid out the findings with regards living with obsessions and compulsions. The findings were representative of both individual participants’ views and

experiences but also showed collective ideas and perceptions across the group of participants. Within this discussion section the relationship between emergent themes and existing literature will be explored alongside possible implications for treatment. Methodological considerations and limitations and future suggestions will also form part of the discussion. The three themes explored were 1) Conflicted control 2) Relationships and 3) Finding ways forward.

Summary of analysis

The theme entitled conflicted control appeared to relate to the participants feeling taken over or consumed by their distress, they described feeling unable to escape the struggles and could not begin to describe where the distress began and ended. It almost seemed the psychological concerns had become fused to their identities as people and they could not distinguish where they as people were separate from the distress any more. The participants appeared to feel a great sense of failure for living with obsessions and compulsions and being unable to prove their distress. They seemed to have internal battles with this invisible distress they never could prove to anyone despite it feeling so powerful in taking over their lives. It appeared the participants were unsure if they would ever get better, or if it meant a lifetime of coping or just managing without any improvement which caused sadness and despair. Overall the participants (with exception of Allan) showed great insight into their distress and tried to make it easier for other people either by using softer names in the description focusing in their needs (such as Isiah in hugging or Diane fighting for her daughter's sake). It seemed the participants had learnt that having a mental "disease/disorder"/living with obsessions and compulsions was something to hide/ be ashamed of and keep secret. In society it seems they learnt it came with all sorts of health warnings that the label meant you were someone who couldn't be trusted. The participants appeared to feel they were not listened to or never heard (their families didn't understand, their doctors didn't get it and doctors showed a great sense

of lack of insight in not knowing how to adequately meet the care needs of the participants. The only way forward was to diminish it when explaining it to friends, and to search for validity, to rationalise the causation as external to their control-using different names to distance from the severity and also saying it is chemicals or hormones outside of my control. A saving grace appeared the in-groups created with other sufferers who allowed them to be free, accepted and to feel normal. It was very clear who was allowed in or out and a way of creating a special community.

The second theme was entitled Relationships and referred both to the participants' relationships with themselves as well as interpersonal relationships. It highlighted the confusing and unconfirmed experiences the participants reported related to living with obsessions and compulsions. The participants described obsessions and compulsions as invisible and invalid. They appeared unable to ever prove their distress and on the outside seemed fine but internally were struggling. It seemed the participants were desperate to be acknowledged and to be recognised as valid people but often described feeling a failure for not reaching goals in their personal lives or their employment. It appeared they had internalised many social (mis)understandings of mental distress related to being dangerous, risky or mad and as a result reported on feeling embarrassed and unsafe as individuals. The participants understood having a diagnosis as offering some validity to their distress but equally it could be easily removed or misunderstood due to the lack of education and training amongst mental health professionals. Living with obsessions and compulsions appeared to have a negative impact on both personal and professional relationships. It seemed the participants felt discriminated and misunderstood in a variety of settings and lived on the whole isolated lives.

Finding ways forward is the title of the third theme and it related to coping strategies in living with obsessions and compulsions. It appeared some participants were able to self

motivate whilst others were unaware of the obsessions and compulsions impacting on them unless it was pointed out. Many of the participants reflected on cognitive dissonance for example one participant related his joy at being invited to a research interview focusing on OCD and equally felt angered that he needed to have this “label” of OCD to take part in the research study. Other aspects of cognitive dissonance included conflicted personal relationships and the impact of OCD and BDD being described as both catastrophic and inconsequential. Participants appeared to understand human suffering as a result of their individual struggles with obsessions and compulsions and seemed desperate to receive reciprocated care. Equally they described their strong sense of empathy for anyone else who was suffering as an outflow of their own vulnerabilities.

Stigma and its relationship to the present study

Within this study the concept of stigma appeared to loom large. Many of the participants appeared aware of stigma related to mental illness and had also feared discrimination in their work place (Isiah and Barbara, Jane, Allan, Nigel) and its impact in their personal lives (Diane, Tom. It appeared the participants had learnt about mental illness or having a mental illness label could have consequences in being i) helpful to finally offer an answer to their distress or ii) making them realise they stood out and were living with permanent distress which they could not escape. The research of Warner, Taylor, Powers and Hyman (1989) appears relevant to the present research study as it explicated the impact of the knowledge of stigma on individuals living with mental distress. Warner et al., made use of self report measures presented to 42 mental health patients at a mental health centre in Colorado. Their questions focused on word associations with mental illness and included a self-esteem scale and locus of control scale. Within their study they found individuals who accepted the label of “mental disorder” showed low self esteem (provided they were aware of the stigma which exists regarding mental illness). These individuals were said to have external loci of control

and were said to focus on finding biological causes for their “disorder”. An individual who was struggling with mental health difficulties was said to feel a lack of self control and could choose to adopt the label of “mental disorder” in order to give away any responsibility for his or her actions. It was also reported individuals who accepted their mental illness diagnosis were said to show better treatment outcomes and an internal locus of control. These individuals still showed low self esteem and a poor sense of mastery but this was not indicative of any increases in symptoms or poorer functioning. Similar to Warner et al., the participants in the present study showed a poor sense of control with regards obsessions and compulsions. The obsessions and compulsions seemed to exert control over the participants’ lives in an unrelenting fashion and it seemed important for participants to distance themselves from the blame for the causation of obsessions and compulsions by adopting evidence for the presence of chemical- or brain disturbances (which would fall outside of volitional control). Warner et al., failed to make use of clinicians who were blind to the participants’ functioning and pathology and could as a result have marked these participants in an overtly positive way, affecting the results of the study. Participants were assumed to be compliant with their medicinal treatments but no clear indicator or check was performed and as a result the scores could have been influenced by participants who were not compliant but said that they were.

Similar to Warner, Taylor, Powers and Hyman (1989), a distinction between internal and external locus of control was evidenced by Fournier and Jeanrie (2003) who noted the cultural meaning of mental illness. They highlighted the sense of blame and responsibility (for causality) so often present in individuals living with mental distress. Fournier and Jeanrie cited Rotter (1966) who explained how individuals could credit a sense of luck or fate (and hence showing an external locus of control), if a desired outcome was to follow without the direct control or planning of an individual. Conversely if an individual was said to believe outcomes were controlled as a whole by the individual’s behaviour, internal locus of control

was present. In the present study a sense of powerlessness and external control was evidenced through the participants' desperation to exert control over their lives (both present and future prospects) and yet they had no choice or control over the initial causation or development of obsessions and compulsions. Some participants appeared to experience what Warner et al., described, through making use of an external locus of control where they focused on the possible causes for their distress which fell outside of their volitional control (such as reported chemical changes in their brains or genetic links). It seemed by focusing on their distress as caused by something outside of volitional control the participants were able to feel less of a failure, less guilt. It appeared all the participants were aware of existing negative connotations with labels of "mental disorders". The participants described experiences of obsessions and compulsions which they hid for fear of appearing needy and helpless. They made use of many metaphors describing battles with their distress where they felt guilty if they gave in to the obsessions and compulsions but equally felt constantly tired from trying not to "give in".

The concept of control and its implications for participants

The importance of having control appeared to relate to self efficacy as described by Bandura (2000). Bandura described the sense of self-efficacy to relate to a judgement made as to how well an individual could carry out a course of action despite stress and pressures. People were said to avoid a situation if they thought the task exceeded their capabilities. In an overwhelming situation an individual was said to notice his or her deficiencies more as a result of feeling unable to complete the task at hand successfully. Individuals were said to learn vicariously through watching others with similar capabilities in similar situations. By observing their progress, an individual could make a judgement about his or her own chances of success. Within the current study it appeared the participants were making judgements about how they perceived others to receive them. Often it appeared the participants'

understandings of the label of mental distress and its apparent negative connotations would discourage them from sharing their concerns. The participants described great battles and struggles where they tried a variety of ways to resolve their inner conflict (without divulging to family members or friends for fear of rejection) related to living with obsessions and compulsions and having to fight these on a daily basis. It also appeared the participants had learnt about the negative image of mental distress existing in the public view and had identified with this label, internalising themselves as members of a failing group and describing failure as inevitable.

A different and yet applicable understanding of control and psychological distress was explicated by Foster (2003) who described control as a dynamic feature which could change rapidly and continually throughout the experience of psychological distress. Foster used two dimensions in describing possible concepts of control as either i) controllable or controlling, and ii) external or internal to the individual. Through eight weeks of ethnographic study, the study of newsletters used with mental health service users and narrative interviews of individuals living with longstanding psychological distress, Foster found surprising results. It appeared within the controlling-external dimension participants were said to report mental distress as living outside of the individual but exerting control over their every decision. It appeared important to participants to objectify mental illness so as to separate from the mental illness itself. Often metaphors of battles were reported and this would ring true to this research study where participants described feeling as if there was a “monkey on his back” (Allan) or an alien which would “eat her alive” (Diane). It appeared within this dimension the continuous battle with psychological distress enlarged the need for safety and within the present research study safety was represented through facilitating a support group for obsessions and compulsions (Diane). The changeable dynamic of control (as reported by Foster) also rang true in the present study as participants described throughout how they felt

powerless one moment and powerful the next. Within the controlling-internal dimension Foster reported how participants talked of the mental distress getting inside and suppressing their person completely. This could ring true to participants in the present study (Allan and Nigel) who described not being able to be themselves. Foster described a comparison with individuals living with diabetes who would not necessarily be assumed to exert control over the diabetes twenty four hours of a day and related this concept to mental distress where perhaps extremes of control were not possible either. Along the controllable-internal dimension Foster described how participants could settle the mental distress firmly inside themselves had they seen it as controllable. It appears having knowledge about mental distress and feeling “in possession of it” rather than being in its possession was the main characteristic of this dimension and could reflect how Barbara (in the current study) seemed to describe her obsessions and compulsions as “automatic” and “ingrained” and related to it as an aspect of herself she had become used to and were unwilling to change.

Within the present study the concept of control appeared a constant dynamic as Foster (2003) described. Within the transcripts there were present many ambivalent moments where participants appeared to feel very much in control of their lives and their psychological distress was reportedly minimal but these reports were contradicted by moments where psychological distress was described as all-encompassing and unrelenting. It appeared within the present study participants moved very quickly between the dimensions described by Foster and no one dimension was representative of a stable or unchanging relationship between the participants’ sense of control and its placement internally or externally.

An understanding of the self concept and psychological distress

In the present study it appeared participants had undergone a journey similar to that as described by Lally (1989) who cited three stages through which individuals would pass on

their journey to build a new self concept after having a diagnosis of mental distress. He described how “engulfment” could be the appropriate word to describe the process by which individuals’ sense of self increasingly became organised around the concept of mental illness. Lally focused on the experiences of individuals living with schizophrenia and their sense of self as affected by ongoing to and fro movements between hospitalisation and returning to the community. It appeared individuals were believed to initially resist the label of mental illness and would distance themselves from others living with the same label. This distancing appeared a coping strategy for fear of being grouped with individuals who were perceived as threatening the individual’s sense of self and that sense of self becoming organised around the concept of mental illness. Within the present study participants described their surprise and horror to find they were living with permanent obsessions and compulsions and alluded to the disturbing images of “mad hand washers (Isiah) or freaks (Diane). Lally described how individuals could, after initially distancing from, find closeness through aligning with others with the same label as they were perceived to understand the experience of being labelled. This was also true in the present study where many participants were friends with individuals who themselves lived with psychological distress (Scarlet, Isiah, Diane, Barbara). In the final stage Lally argued individuals could focus on being an insider (to a group of similar individuals who all were given the same label) and equally an outsider to those who do not live with the same label. It appeared within the present study participants had aligned with others living with psychological concerns. Many participants had joined or facilitated support groups for people living with obsessions and compulsions whilst others spoke of friendships with individuals who also lived with mental health concerns.

Mental distress as perceived in the public view

Within the present study the misgivings about mental distress as equivalent to danger appeared to loom large. Participants talked about feeling like a freak (Diane), a mad hand

washer or a paedophile (Isiah) and someone who was said to want to harm children (Barbara). These misgivings also occurred in the personal and professional relationships as participants doubted the reception they would receive, such as Barbara who appeared saddened as her obsessions and compulsions were impacting on her employment due to the perceived risk she posed to young children or Isiah who felt isolated at times as he struggled (and then avoided) to explain the presence and meaning of paedophilic thoughts to his friends. Within this study it became apparent how many participants seemed misunderstood and were desperate to bring about change, such as Tom who found a lack of support and encouragement from local psychiatric services and described his despair at having to guide his clinician in his choice of prescription medication. Diane appeared also very angry at the names having been associated with mental illness (such as “freak”) and her indignation appeared to have driven her to start a local support group where she could defend and support other individuals living with obsessions and compulsions and equally correct the misrepresentations in the public eye through newspaper interviews about her own struggle.

The participants’ experiences appeared to correlate very highly with Corrigan and Watson (2002) who described how stereotypes could exist in the public arena and these stereotypes could lead to discrimination and prejudice towards individuals living with mental health concerns. By studying the themes present in American print and media and in surveys of the American public (Brockington, Hall, Levings and Murphy, 1993 and Hyler, Gobbard and Schneider, 1991) individuals living with mental illness were often misrepresented as either murderous villains, helpless childlike figures or persons of weak character who were to blame for their lot. It appeared these misconceptions could hold damaging consequences for individuals living with psychological concerns as members of the public could choose to avoid them altogether, could withhold help and support, offer coercive treatment or place them in segregated institutions. Wahl (2003) described finding the incidence of

misrepresentation of individuals living with mental distress also in children's programmes where these characters were often unattractive, violent, criminals or figures for ridicule and putdowns. Mc Quail (1979 as cited in Wahl, 2003) described how individuals could learn about themselves through watching these programmes and could recognise how others saw them and their difficulties. It could also act as deterrent for any children who lived with psychological distress to come forward or seek help for fear of being ridiculed themselves. Corrigan and Watson stated a case for righteous anger to exist for individuals living with psychological worries and described how this could act as instigator for change and an active participation in treatments and rehabilitation.

Psychological distress and the social self

A further element of the social understanding of psychological distress would be symbolic interactionism. Individuals were said to become aware of the social and cultural understandings of psychological struggles by noticing how distress was received and interpreted by people in their community. As a result of seeing others' reactions, individuals could build a self concept based on these reactions. Blumer described how meaning was a social construct and how individuals would react towards an object based on the meaning this object held. Individuals were said to be in constant dialogue with the social world and would become changed through this interaction. Meanings were modified through experience and re-interpretation. In return the social world would also become changed through the individual's interactions. Cooley (1902) described symbolic interactionism as a mirror

A self-idea of this sort seems to have three principal elements: the imagination of our appearance to the other person; the imagination of his judgement of that appearance; and some sort of self-feeling; such as pride or mortification. The comparison with a looking glass hardly suggests the second element, the imagined judgement, which is

quite essential. The thing that moves us to pride and shame is not the mere mechanical reflection of ourselves, but an imputed sentiment, the imagined effect of this imagination upon another's mind...We always imagine, and in imagining share, the judgements of the other mind. (Cooley, 1902 pp.184-185)

Blumer (1969) urged any research to notice and focus on the context in which an individual was based so as to clearly understand the forces impacting and affecting changes on the individual. Markowitz, Angell and Greenberg (2011) referred to modified labelling theory (as coined by Link, Cullen, Struening, Shrout and Dohrenwend, 1989) and reported how an individual could pick up on the stereotypes of mental illness when diagnosed. At that point in time the meaning of mental illness was said to become personal to the individual alongside the stigmatising stereotypes in relation to this label and the individual could predict discrimination to follow. The individual could choose to cope by socially pulling away, become secretive and as a result of feeling demoralised and depressed could see an increase in symptoms of mental distress. It appears as a result of believing in the stereotypes of mental distress the individual's negative predictions could lead the individual to live a narrower life (withdrawing from social worlds, being unemployed) where social interaction was almost nonexistent, leading to further feelings of isolation. The views of Blumer, Markowitz et al., and Cooley appeared to relate directly to the participants' meaning making in the present study. Many participants reported living very narrow lives where they participated only marginally in their households. In particular Tom and Nigel both described the increase in worry when leaving the safety of their homes (neither were currently employed) and their struggles to complete menial daily tasks or to return to old social circles, college courses or the gym as all of these interactions created stress and fear. Both participants related their sense of being watched and judged and reported incidents of horror when nasty comments

were made or they were laughed at in public, in their minds due to their perceptions of their physical features.

Further evidence for the impact of isolation on mental distress was reported by Pearlin, Lieberman, Menaghan and Mullan (1981) who described how an isolated individual could experience an increase of stress due to being isolated and perhaps could see an increase of mental ill health. Their study entailed interviews over a four year period (2300 adults interviewed in 1972-1973 and 1106 adults interviewed in 1976-1977) focusing on identifying conflicts and frustrations present in the household, coping behaviours which helped to relieve stress, and any incidence of mental ill health. During the second set of interviews extra questions focused on significant life events and available social support. Drawbacks to this study would include its focus on only a small number of long term stressors and coping strategies (it would be impossible to include all life stressors and coping mechanisms) and also the four year time period between the two interviews could have resulted in selective reporting (a smaller time scale could have yielded different results).

An opposing view of the impact of socially held beliefs about mental distress was explicated by Gove (1970) who argued individuals were judged on their behaviour and that there were no links between the social label of mental illness and causes of distress. Gove stated individuals living with mental illness already were suffering with symptoms of that specific distress and the symptoms could make an individual withdraw socially or cause unusual emotional responses which could cause others to judge them as less competent and possibly harmful. Within the present study it appeared participants at times made use of camouflage (such as Nigel who carried his son to the school gates or Tom wearing a hat at all times) which could perhaps have attracted more attention. It has to be said many of the participants had in a general sense withdrawn from the outside world or followed strict regimes which were pre-planned often as a result of preconceived ideas about the world and

the reception they would receive had they ventured out. Some participants appeared to fear being judged or being seen as deficient and strange and as a result would avoid social interaction at all costs. It has to be said that one of the participants seemed to continue on her daily journey as if nothing was amiss (Jane who commented how despite feeling very distressed, still managed to pick up the children from school). It appeared Jane followed the rules of society in fitting in with the schedules and tasks in her daily schedule and yet throughout the interview her personal (and unacknowledged) distress appeared obvious and pronounced. Jane's experience appeared to resonate with that of Brooks' (2011) who described a combination of public and private personas which each fulfilled a role. Her public persona appeared necessary to communicate her acquiescence with therapy and its challenges whilst her private persona could focus on feelings of embarrassment and failure due to psychological distress. In a similar sense Jane described feeling distressed almost constantly but never could believe her distress would be sufficient to allow her support and care beyond what she was already receiving.

Validity of distress

Within the present study issues surrounding validity appeared plentiful. Participants described their journeys to find answers for their distress (looking for causation of obsessions and compulsions) and ways to prove their distress to their families who often misunderstood (such as Nigel who was accused of being a layabout or Scarlett who did not any longer have any contact with family members due to her psychological struggles). It appeared participants often felt invisible and without validity. This sense of invisibility appeared to relate to a variety of factors including having no proof of their distress (as it remained invisible to the naked eye) and a lack of public awareness and understanding of obsessions and compulsions (and equally a lack of knowledge within existing mental health services). Within existing qualitative studies such as Olson, Vera and Perez (2007) and Murphy and Perera-Delcourt

(2012) similar themes were presented. Olson et al., described how participants hid their distress due to fears of stigma and when they sought help they only received pharmacological support. Psychological therapies on offer were reportedly limited and without an evidence base which often addressed perceived (but flawed) causes not related to the obsessions and compulsions. It appeared Olson et al., stumbled upon huge gaps in appropriate treatments and lack of knowledge which directly impacted on the sort of support their participants received. In the present research study Tom described the lapses in appropriate support (from a variety of mental health professionals) whilst Allan retold a journey of hundreds of miles to attend a support group which he quickly abandoned. It appeared for both these participants their local services were judged to be lacking or no service provision existed, necessitating travelling at their own personal cost to seek out professional help. Murphy and Perera-Delcourt reported participant experiences related to a sense of failure for living with psychological distress (obsessions and compulsions). It seemed participants recognised when compared to people of a similar age, they were failing at age-appropriate life goals. Evidence-based psychological therapy (Cognitive Behavioural Therapy) was on offer but was reported to hinder participants from telling their stories, an aspect they greatly valued in their therapy.

Participant narratives offer a very important role in understanding personal experience of obsessions and compulsions and within the NICE guidelines for OCD and BDD (National Institute for Clinical Health and Care Excellence, 2006) excerpts from people living with obsessions and compulsions and their family members were included to show the great variety of concerns but also to bring validity to their struggles. NICE called for appropriate and timely education of all clinicians involved with individuals living with obsessions and compulsions and clarified appropriate treatments. In a similar vein the Department of Health (2011) published a document entitled No health without mental health in which it highlighted the need for improvements to existing mental health service provision. In this document

mental health was portrayed as everyone's responsibility and its links to good physical health and general outcomes such as improved education and employment prospects were postulated. The Department of Health in combination with voluntary organisations created another document entitled No decision about us without us (2012) inviting people living with psychological concerns (and their carers) to contribute to policies affecting local mental health support service design and provision. A variety of volunteer opportunities were presented including following social media links, creating petitions or writing to local members of parliament to affect change.

The openness and inclusiveness of endeavours such as No decision about us without us and No health without mental health envision a greater support and access for individuals living with psychological distress and yet from the present study, mental health provision at present remained patchy and poor education appeared to prevail in services supporting people living with obsessions and compulsions. For example Tom who travelled to see a specialist clinician who could offer him validity through a diagnosis for his psychological distress, feared his local services would not understand his needs and remove this diagnosis. Conversely pockets of support and care also existed such as for Barbara who expected discrimination from her GP and was surprised to find a respectful and supportive environment where her experiences were valued and believed. It was hoped government initiatives (such as those described) could go a long way in removing misunderstandings and introducing relevant and appropriate services for individuals (living with psychological worries) and their families and perhaps this could be possible through continuous effort from both clinicians and service users alike.

The role of Counselling Psychologists in alleviating psychological distress

Within Counselling Psychology literature the core conditions of empathy, congruence and unconditional positive regard formed the basis of all interaction with clients (Mearns and Thorne, 1999). Within a therapeutic setting all clients are believed to hold potential for growth and change and to do their best with available resources. By honouring the core conditions described, an environment of containment and support could be created where the client could experience trust and acceptance. It could be Counselling Psychology could offer validity of experience through the nature of its construction in being focused on the individual as a whole and retaining an interest in empowering the individual rather than being in powerful position over the client. Deegan (1995) described in her own experience of living with schizophrenia how

Those of us who have been labeled with mental illness are first and foremost human beings. We are more than the sum of the electro-chemical activity of our brain. Our hearts are not merely pumps. Our hearts are as real and as vulnerable and valuable as yours are. We are people. We are people who have experienced great distress and who face the challenge of recovery.(Deegan 1995, p. 3)

Within the present study the concept of validity appeared to relate to the stigma of mental distress and the participants' experiences of fear and sadness at living with distress which at times appeared all-consuming and never-ending. It could be the Counselling Psychologist working from a Humanistic philosophy which engendered valuing the client as a unique and complete being (Cooper, 2009) could offer acceptance and a road towards self-acceptance to these participants in treating and revering them as people (such as Deegan, 1995 described) rather than biological entities or chemicals. By offering an understanding and appreciation of the individuals' specific context and experience, Counselling Psychology could engender a sense of acceptance and stimulate personal growth. Cooper describes the stance of a Counselling psychologist to be

of welcoming the Other is an articulation of the essential ethic and politic that, for many of us, underlies counselling psychology. It is through this desire to respect and validate the Other in the totality of their being that we start with their unique subjective experiencing; relate to them as beings who have the capacity to grow; and understand them in terms of the social, economic and cultural limitations that they might face (Cooper, 2009, p. 8).

Belongingness in relation to Counselling Psychology and the present study

Within the present study participants expressed a strong urge and sense for belonging. Many talked of their distress at being left without family support such as Scarlet who described being “too much” for her mom to contend with or Jane who appeared fearful friends and colleagues could discard her were they to discover her struggles with obsessions and compulsions. It appeared imperative to find a place where the participants each could feel accepted and supported. Possibilities for belongingness included a support group (such as was the case for Isiah, Barbara and Diane) or experience of a supportive relationship (such as Nigel, Allan and Tom).

Baumeister and Leary (1995) described the belongingness hypothesis as a “*pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships.*” And the need for “*frequent, affectively pleasant interactions with a few other people, and secondly, these interactions must take place in the context of a temporally stable and enduring framework of affective concern for each other’s welfare*” (p. 497). They went on to describe how belongingness could provide an individual with a sense of being valued and his or her achievements validated and recognised by others. They reported how belongingness went beyond the obvious gain of economic prosperity in offering an individual a sense of connectedness which could be applied across cultural boundaries and

work within a multitude of settings. They reiterated how proximity was sufficient (rather than shared interests) to form close bonds between individuals and Schachter (1959, in Baumeister and Leary, 1995) reported how cognitive boundaries could become blurred between individuals who were mutually supportive. Baumeister and Leary highlighted the importance of the relationship component of therapeutic (psychological) contact and described and adapted unconditional positive regard (one of the tenets of person-centred counselling and the basis of Counselling Psychology practice) as unconditional social acceptance. Howe (1993) described the importance of the therapeutic relationship and core conditions (empathy, unconditional positive regard and congruence as stated in Merry, 2002) in person-centred therapy as

“critical in so far as they allow and promote talk, dialogue and the need to make sense. In themselves alliances and relationships can be pleasant, comforting and reassuring, but their role is to act as a catalyst which promotes the processes that bring about change and new understanding” (Howe, 1993, p. 4).

From their descriptions, Baumeister and Leary (1995) appeared to believe that belongingness was not only a necessary component within the social world but also the basis for psychological containment and growth. Merry (2002) related this containing and supportive therapeutic setting to the support and development of an authentic self where conditions of worth were absent and the client could receive care and support without having to *be* or *feel* a certain way to become accepted. Howe (1993) elaborated on the social component of the development of an authentic self in stating

*“if we can begin to understand how the self forms as the individual grows in an environment of other people, we might appreciate **what** clients need from counselling relationships and **why** they need it. The clue lies in understanding*

the link between the formation of the self and the kind of experiences adults seek when they are distressed, hurt or confused”.(Howe 1993, p. 12).

The containment, acceptance and support a therapeutic relationship could offer sadly remained absent for the participants in the present study. It was however vitally important to recognise this deficit not only in the present research, but also to see the research study’s applicability for future treatment initiatives with regards individuals living with obsessions and compulsions. By recognising the skills and qualities a therapeutic connection could offer individuals in distress, it remains a hope that these skills could be used to relieve distress for individuals in similar circumstance.

Within the present study participants reported finding comfort and belonging within support groups. It appeared a support group could allow freedom to “just be” alongside a sense of safety from the outside world. Hall and Cheston (2002) carried out a study within a drop-in centre (through the use of observations and semi-structured interviews) and found participants (individuals living with psychological difficulties) reported the drop-in centre as a safe place which protected and insulated against the perceived stigma about mental illness in the outside world. Participants in their study stated how society as a whole had denied them opportunities but within the drop-in centre, the participants reported feeling normal and accepted. Clare, Rowlands and Quin (2008) carried out a two-year long IPA study (via email) focusing on the experiences of individuals (living with dementia) who were part of the Dementia Advocacy and Support International (DASNI) group. Findings from their study suggest group belonging offered participants a collective strength despite challenges and upheavals they faced and helped to ameliorate loneliness and fear in the face of illness. A culture of shared understanding and mutual support was evident between the participants as they offered vital information to one another about the development of dementia, about what to expect and to know the group members were there to help if needed. This appeared to ring

true for participants in the present study as well when they were amongst others who were accepting and sharing ideas about how to live successfully with obsessions and compulsions. This also appeared to ring true for Haslam, Jetton, Postnes and Haslam (2009) who reported on group belonging offering positive returns through companionship, security, the formation of emotional bonds, and a stimulating context for collective learning. Tajfel and Turner (1979) described how individuals made sense of themselves through group belonging. It appeared Tajfel and Turner recognised how low status groups had to adapt in order to negate any negative impact on the self esteem of the group members and described how permeable boundaries could allow members to migrate to other groups or non-permeable boundaries (such as the presence of enduring difficulties as presented within the existing study with its focus on the experience of obsessions and compulsions) necessitated the group members being creative in rejecting the negative stereotypes associated with their group. This creativity appeared within the present study where moments of shared humour (within a support group for individuals living with obsessions and compulsions) were described for example joking about self harm (Isiah) or the cherished sense of freedom the group brought to group members where they could all just be themselves without fear of rejection or discrimination (Barbara). Participants relayed how they formed close bonds and friendships with individuals with similar mental distress (either as partners or as friends) and almost gravitated towards one another (Scarlet, Diane). It appeared essential to recognise the impact of group belonging in both the protection and support it offered to the participants and how living with obsessions and compulsions were cohesive elements in their support groups and friendships. Outside of the social groups these components (obsessions and compulsions) identified the participants as outsiders and as being different to the norm, and belonging to a low status group which necessitated hiding their distress or being very selective about how much information they shared and with whom.

The difference between physical and psychological distress

Within the present study many participants referred to the difference between how readily physical illness was received in society as opposed to their perceptions of scorn and distaste regarding mental distress. It appeared the status of having a physical ailment could allow participants recognition and validity whereas in their estimations psychological distress did not bestow the same result. Jane spoke of her guilt in not having cancer as she desperately hoped for her obsessions and compulsions to be accepted and treated as valid and yet she appeared guilty for even considering a comparison between her distress and that of cancer patients. Similarly Nigel described watching a television programme featuring burns victims and described his attempts to use the burns victims as a means of shocking himself out of feeling sorry for his lot. It appeared for Barbara and Tom physical distress was much more readily understood and accepted as it was visually recognised such as a broken arm or leg and was also understood to pass after a short period of time whereas obsessions and compulsions were phantom-like, invisible to the naked eye and were long term. It could be the participants' negative views necessitated coping strategies such as linking the presence of obsessions and compulsions to brain- or chemical imbalances as it could prove helpful in removing blame for the causality of psychological distress. Medical terminologies and explanations appeared to carry much weight and could be useful in explaining to others that obsessions and compulsions were real and were part of recognisable conditions, not the figments of the participants' imaginations.

Pescosolido et al., (2010) carried out a study to determine if calling mental illness a brain "disorder" could diminish public stigma. Through two surveys, spaced ten years apart, Pescosolido used vignettes based on the perceptions of mental illness and help seeking behaviours. It appeared a huge increase in the biological understanding of mental illness had occurred in the time period between the two studies (from 6 % to 13% increase) but no

significant change in public stigma was recorded. It appeared participants in the Pescosolido study were hesitant to live close to, work with or engage with someone living with mental illness for fear of the individual being dangerous or violent.

The participants in the present study (as a whole) appeared to also relate to Phelan (2005) who described how medical underpinnings of mental distress had been employed by many activist groups in de-stigmatizing behaviours previously discriminated against. By offering a valid explanation such as chemical changes or genetic underpinnings of distress, individuals living with psychological (mental) distress could be freed from blame for its cause. Deacon and Baird (2009) reported how the National Alliance of Mental Illness (NAMI) described mental illnesses as “*biologically based brain disorders. They cannot be overcome through ‘will power’ and are not related to a person’s ‘character’ or ‘intelligence’*” (NAMI, 2006). It appeared Deacon and Baird understood that genetic- or brain explanations as causative elements for mental distress could imply individuals living with this particular distress were not in control of the distress or its cause, leading to decreases in stigma. Conversely Deacon and Baird reported how the chemical imbalance causality was linked to understanding depressed individuals would have a poorer prognosis and all psychosocial interventions could be dismissed as ineffectual. There were many factors which could have affected the outcomes of the Deacon and Baird study, including the fact that respondents were knowledgeable psychology students familiar with a variety of psychology models, including the bio-psycho-social model and might have chosen answers which would reflect their understanding of this particular model as a well known causative model in mental distress. Lam and Salkovskis (2007) studied the causative elements for mental distress through the use of a video showing an individual panicking and asked respondents to judge whether a genetic-, biological-, psychological, or unknown cause could result in the character in the video self harming and / or harming others. Respondents in Lam and Salkovskis’ study implied biological causes (of

mental distress) could be related to harmful behaviours and did not improve existing negative views about mental illness. The writers encouraged therapists to focus on instilling hope for recovery through avoiding deterministic approaches such as exclusive biological underpinnings of mental distress. Findings in the Lam and Salkovskis study could have been affected by the use of self report measures alone.

Genetics and the understanding of mental distress

The understanding of mental distress as purely genetic appeared to bring with it many controversies. In the present study genetic components such as chemical imbalances or hormonal changes were put forward by the participants to explain causality for obsessions and compulsions. It appeared however strong polar positions existed within the mental health fields which could explain why mental distress and its treatment remained patchy (as experienced and reported by the participants in the present study).

Weiner (1986 and 1996 in Phelan, 2005) drew attention to the importance of attribution theory (Heider, 1958 in Tajfel and Fraser, 1978) as judgements about the causes for a certain phenomenon or outcome, could affect emotions, expectations and behaviours towards the person in question. Corrigan (2000) linked attribution theory to the stigma associated with mental illness and described how it could be possible to negate stigma if the illness could be linked to medical underpinnings as opposed to negligent behaviours. Nelkin and Lindee (1995 in Phelan, 2005) warned against the use of genetic essentialism as it could infer a sense of permanence and abnormality from the everyday person. Nelkin and Lindee proposed that by using a genetic reasoning for mental distress causality could imply that a person living with mental distress would be deemed permanently different from others, his or her behaviour would be pre-determined by the genetic heritage and the individual and any offspring would be doomed to their fate as victims of a bad genetic inheritance. Phelan

(2005) carried out a total of 1241 telephone interviews aimed at identifying causative elements of mental distress and reported how respondents appeared to believe a genetic component to mental illness would increase levels of deviance. It would also seem stigma levels aimed at individuals living with mental illness (and its so called genetic underpinnings) would not increase with regard the individual himself, but would be increased towards the offspring and siblings of the individual in question and respondents reported requiring increased social distance from these offspring and siblings. These findings could act as a damning nail in the coffin of individuals such as the participants in the present study as it could remove any validity and recognition of their efforts to lead normal lives (despite their struggles with obsessions and compulsions) as their genetic heritage could almost act as a dehumanising factor not only for the individuals involved but also for their extended families. It could be the vignettes used in Phelan's study impacted on results as they were focused on serious mental distress and results for more moderate mental distress could be different. Equally the vignettes tested hypothetical situations which could have elicited different results from real life situations.

Thankfully proponents existed who spoke against the exclusive application of genetic inheritance as a damning factor for individuals living with mental distress. Kendler (2005) described how psychiatry (his profession) was fundamentally aimed at alleviating human distress and proposed it could include technological advances and improvements but should never exclude or avoid the individuals needing support and care. Kendler appeared to acknowledge the Cartesian dualism present in the treatment of mental distress and rejected any notion of figuratively splitting of an individual patient into biological and mental components. He ascribed a new way of looking at mental health concerns by stating individuals were tied in body and mind together and "*the mental and the biological became different ways of viewing/ and/ or different levels of analysis of the mind-brain system*"

(Kendler, 2005, p. 434). Kendler proposed roles for thoughts, feelings and impulses in being part of an individual's experience and opposed a very narrow approach which would only focus on the role of biology or propose biology to be at the base for all elements of experience. He urged for a clinical understanding of mental distress to include a plurality which could include different types of information (including subjective accounts) which could work towards a better understanding of distress in all its complexity. Kendell (2001) echoed the urge for a focus on a person rather than a series of symptoms and described his mental distress as "*neither minds nor bodies develop illnesses. Only people (or, in a wider context, organisms) do so, and when they do both mind and body, psyche and soma are usually involved*" (Kendell, 2001, p. 491). Hansen (2006) also rejected the current mental health culture as based upon biological understandings of mental distress and included his opposition of recognised materials and guides including the DSM –IV (Diagnostic and Statistical Manual for Mental Disorders, American Psychiatric Association, 2004) and the exclusive use of empirically supported treatments. Hansen called for a return to Humanistic ideals of "holism, growth, and subjectivity which he believed had become eclipsed by reductionism, psychopathology, and scientific objectivity in modern treatment approaches" (Hansen, 2006, p. 5). Hansen appeared greatly influenced by Szasz (1960) who posited a struggle when noticing the same application of rules when judging mental- and physical distress. Szasz described how in speaking about physical illness there were indicators of normal and abnormal physical states whereas if implications of "normal" and "abnormal" were applied in a mental health context there were no concept of what these words would imply as mental illness was a pattern of behaviour in society expressing its distaste with a particular behaviour at a particular time. According to Szasz psychiatric diagnoses were constructed socially, not discovered (Szasz 1970, in Hansen 2006). Szasz stated individual beliefs could not be explained in the same fashion as to which symptoms of physical illness

could be. He reported how, when a patient relayed information about physical distress he or she could focus on symptoms or signs tied to specific anatomical areas whereas when mental distress was explained an individual could refer to his sense of himself, others and the world. This conception of mental illness appeared to tie it again to a social context. It appeared imperative when focusing on the present study to recognise the world in which the participants were received. If it was true that genetic essentialism prevailed, any subjective experience of mental distress would become irrelevant and ignored. The main purpose of this study was to focus on the individual participant experiences and to highlight their meanings and interpretations. It was true to recognise the genetic components to mental difficulties but equally was completely unfair to focus on only genetic components when focusing on people's personal experiences such as was the participants in the present study.

Cognitive dissonance

Festinger (1957) developed the theory of cognitive dissonance. He purported how individuals were usually consistent in thought and behaviour but at times decisions presented themselves where an individual would find a personal inconsistency and would try to rationalise and make sense of this inconsistency. The inconsistencies could cause psychological discomfort and levels of which were reported to depend on the personal significance of the subject to the individual concerned. For example a smoker could become aware of the negative health consequences of smoking but could rationalise that it offered a sense of social belonging which was more important than possible future ill health. Cooper (1999, in Harmon-Jones and Mills, 1999) highlighted the benefit of Festinger's theory in that *"knowledge of the environment and knowledge of one's own behaviours, attitudes, and emotions were represented cognitively and that it was the relationship among the cognitive representations that prompted motivation"* (Cooper, 1999, p.150). Steele (1988, in Aaronson, Blanton and Cooper, 1995) reported how cognitive dissonance would directly

affect the individual's self concept and as a result the individual would have to protect this valued component of self (by rationalizing). Participants in the present study appeared to struggle with many conflicting beliefs and ideas with relation to living with obsessions and compulsions. It seemed the obsessions and compulsions were a part of themselves they could not extract or remove and sat at the core of many conflicting experiences. It seemed living with obsessions and compulsions could be described as i) both unrelenting and nearly resolved (Allan); ii) a lens through which to see the world or only a small component of a life focused on a variety of other subjects and experiences (Isiah); iii) the causative element in confusing relationships with loved ones which included feeling very loving and also very angry feelings towards close family members (Nigel). The dissonance appeared to also relate to the furtherance of research as the research interview was said to instil a discriminatory label (by focusing on obsessions and compulsions) or to offer a useful discussion validating recognised distress (Isiah). It appeared living with obsessions and compulsions related to feeling free (within an OCD group context) or feeling unconsciously controlled; and finally, obsessions and compulsions were said to offer useful parenting skills which could be removed and lost through psychological therapy as opposed to tolerating the long-term distress it was reported to cause for the individual living with the obsessions and compulsions (Barbara).

It seemed in accordance with Steele, Spencer and Lynch (1993) the participants saw themselves as less acceptable and their distress as shameful and secretive. From the Analysis section in this research report it became clear how the participants were greatly affected by the public perceptions of their distress and appeared to each have a negative sense of self. Cognitive dissonance appeared to relate to the causation of the distress such as Nigel who related the corrosive comments, made by his mother, which he believed were the initial cause for his distress. Nigel appeared to feel rejected and angry at his mother but equally hankered

after a close relationship with her and the rest of his family. Cognitive dissonance also seemed to relate to the management of obsessions and compulsions as Allan related how he managed his distress through the use of meditation and yoga but equally noted how his wife noticed how the obsessions and compulsions encroached on their relationship long before Allan became aware. It appeared it was important for Allan to mention his continued progress and improvement and yet at another level his distress seemed to continue unabated and unacknowledged. Cognitive dissonance also appeared related to the stigma associated with mental distress and in particular with living with obsessions and compulsions such as when Isiah mentioned his appreciation of an interview focused on this specific topic only to at a later point in the interview relay his severe anger and frustration at being “labelled OCD” and needing a diagnosis confirmation to participate in the research study. It appeared in general terms the participants were fighting to make sense of who they were and what place the obsessions and compulsions played in their lives.

Individual needs and the role of Counselling Psychology in meeting these needs

Many principles and guidelines existed within the field of Counselling Psychology practice (as based within humanistic counselling) to support individuals living with internal conflict such as cognitive dissonance as described within the participant field in the present study. Merry (2002) described how an individual could be understood to have internalised conditions of worth and could try to be the same as others and live in accordance to their rules and prescriptions in order to feel loved and cared for. The individual in this context was said to fear abandonment and would hide parts of the self which were incongruent to others' requirements. Merry proposed that individuals could hide or ignore parts of themselves which could cause discrimination or at worst rejection by others, and a conditioned self could emerge. Cooper (1999) described how the individual could be understood to identify with the denied or distorted parts of his self concept and use this to build an alternate self. Merry

described the self as “ *not an entity, rather it is a constellation of perceptions and experiences, together with the values attached to those perceptions and experiences...since we are continually experiencing ourselves and the world around us,...is the property of the self as fluid, dynamic and open to reorganisation*” (Merry, 2002, p. 33). Merry called on Rogers’ personality theory (Rogers, 1951 in Merry 2002) which encouraged any attempt to understand an individual, to focus on the individual’s context and the meaning the individual made of his experience. Rogers noted how an individual’s self concept could be built through interactions within a specific context and how values could be built as a result of the series of interactions with other individuals within the world. Rogers proposed that, if an individual came across relevant information about his self concept, which the individual disagreed with, he or she could choose to ignore it or could attempt to change it so it could fit the individual’s accepted picture of him-or herself. If it were impossible to find a means of integrating the disagreeable information into the self concept, anxiety and distress could arise (similar to Festinger’s theory of cognitive dissonance, 1957). Mearns and Thorne (1999) described how a counsellor (or indeed a Counselling Psychologist) working in the person-centred approach, would be able to support the development of a self concept within the client through offering unconditional acceptance. It was possible to build a relationship where the client could remove the conditions of worth and learn not to depend on others’ views of him-or herself as a basis for a self concept. The counsellor could facilitate the client to heal him-or herself and could support a journey described by Rogers as “*freedom to be oneself is a frighteningly responsible freedom, and an individual moves toward it cautiously, fearfully, and with almost no confidence at first*” (Rogers, 1961, p. 171). Howe (1993) similarly described how the psychological practitioner could create an environment conducive to change where the client could experience acceptance and trust. The practitioner was described as a port in a storm or a secure base where the client could safely explore his or her vulnerabilities and experiment

with new ideas and concepts without fear of abandonment. The participants in the present study appeared fearful of divulging their distress to friends and family and many had negative experiences of psychological therapy. It could be a therapeutic context such as described by Merry, Howe and Rogers could facilitate a development of a secure self despite the many insecurities living with obsessions and compulsions appeared to create.

Secondary gain

Fishbain (1994) commented on the presence of secondary gain as a psychological component to living with chronic pain. Despite his research having been focused primarily on physical illness (chronic pain) the usefulness of the concept of secondary gain remained in the present study. Fishbain recalled Freud (1962, in Fishbain, 1994) describing how secondary gain was understood as a social or interpersonal gain as the result of illness. In more recent research this finding remained as echoed by Kwan and Friel (2002) and Ferrari and Kwan (2001). Secondary gain was contrasted with primary gain which was described as an intrapersonal defense to decrease anxiety (Fishbain, 1994). Both primary and secondary gain was said to lie outside of conscious awareness. Fishbain also referred to Fordyce (1976, in Fishbain, 1994) who described a variety of reinforcers for secondary gain, otherwise understood to be gains from the environment. It appeared a person could, for example, adopt a sick role within a family and gain extra care and attention and could avoid all social and civil responsibility. Bienoff (1946, in Fishbain, 1994) proposed that if an individual found secondary gains there were also secondary losses present. These could include the economic loss of unemployment, loss of supportive family relationships and the presence of social stigma due to long term disability. Within the present study secondary gain appeared to resonate for some of the participants' management of their obsessions and compulsions. It appeared by choosing not to address obsessions and compulsions (by accepting practical help with locking doors after group meetings) Barbara was able to feel more in control. It was as

she could rely on the help and support of her husband (in particular) to keep her obsessions at bay. Some of the participants appeared to gain in attention and care (such as Scarlet whose friends rallied round when she was struggling) but almost all of the participants saw equal if not bigger secondary losses as a result of their experiences of obsessions and compulsions, including loss of employment (Tom, Nigel, Scarlet, Jane, Barbara). Scarlet experienced a loss of family relationships as she related to “being too much to handle or to put up with” (as a result of the obsessions and compulsions), similar losses were reported by Nigel (whose family described his as a layabout). Many of the participants lived isolated lives where they would venture out only if necessary (Tom, Nigel) and for all participants stigma of mental distress prevailed.

Fishbain (1994) called into question whether all patients could be understood to unconsciously develop secondary gain behaviours and questioned whether it could be possible some patients were actively making decisions to adopt a social role where they could receive secondary gains. King (1994) appeared to recognise that despite an individual possibly gaining in some respects (from secondary gain) he or she would still live with a physical ailment which could cause much distress. King called on practitioners to take a non-judgemental view of their patients in recognising that the situation of illness and disability could cause much fear and turmoil and even if secondary gain could be understood to be a conscious choice, only very limited options were available to the individual (who would continue to live with physical illness at the very least). This finding appears to directly relate to the present study where the participants seemed to continue to struggle with obsessions and compulsions despite some secondary gains. It also appeared they remained fearful of discrimination and reprisal and once again these fears reinforced their very narrow and limited lives.

Very importantly the psychological component to distress needed to be recognised and addressed. It seems findings such as Kwan and Friel (2001) who proposed medical doctors as somatizers who looked for organic (physical) causes of distress, before considering any psychological links to patients' distress, often ignoring and denying the possible benefit of psychological contact, offered evidence of how psychological distress could be last on the list to be addressed. Individual difference appears to remain paramount when discussing and acknowledging psychological distress. Van Egmond (2005) described two diverging reactions to identifying with the sick role as one of his patients showed great improvement once underlying depression was recognised and validated, whilst a second patient was said to have an internal need to destroy herself and even after acquiring a sickness pension, continued with self loathing and numerous suicide attempts. In the present study there were also very divergent meanings and understandings of living with obsessions and compulsions. As it offered validity and a viable understanding of the participants' distress, it also placed them inside a group of people (those living with psychological distress) which they did not want to form part of.

Limitations of the research

This research offered a snap shot of eight people's experiences, perhaps other themes present alongside greater details but limited scope within the confines of the study with regards to time to explore themes. The study was not trying to create any rules but it might be that other participants might have flagged up different interpretations. Qualitative research focused on the subjective in depth experience which could co-exist alongside nomothetic data, both adding to existing knowledge. As interviews were conducted over the internet (Skype), telephone as well as face to face, the quality of some of the interactions were limited as it proved challenging to build rapport without a face to face conversation. Some sound

difficulties were experienced in one of the interviews limiting (only partially) what could be transcribed successfully.

Yardley (2000; in Smith, Flowers and Larkin, 2009) described four guiding principles to ensure qualitative studies consistently offered valid and rigorous contributions. These four guiding principles were stated as sensitivity to context, commitment and rigour, transparency and coherence and impact and importance. These criteria were fulfilled within this study in the following manner.

Sensitivity to context

Sensitivity to context was established through the use of IPA as method for analysis which focuses on eliciting particular and specific materials of each participant, within their particular lived worlds and contexts. In choosing to use IPA, homogeneity of the participant group was essential, a requirement which was fulfilled by the choice of concerns studied as these were understood to closely relate with regards presentation of obsessions and compulsions, familiarity, underlying cognitive structures as well as responses to treatment regimes and development across the lifespan of the psychological distress incurred. By incorporating inclusion criteria it was possible to limit the study to participants who lived with obsessions and compulsions and it was possible to create a piece of work focusing on this homogenous group rather than include participants who might live with psychological distress but such which could be of a different nature and might dilute the applicability and usefulness of describing this study as focusing on the lived experience of obsessions and compulsions. By interviewing participants with a diagnosis of either OCD or BDD the study made use of informed and experienced people who had knowledge and information about the chosen subject, highlighting their applicability for this specific and sensitive topic rather than using individuals who had no specialised knowledge or experience to contribute. Sensitivity

to context was also achieved through creating a safe and secure interview setting where all research interview questions were posed from an empathic and supportive stance focusing on the elicitation of in depth experiential materials which were explored and interpreted within the analysis section and which set the basis for discussion. By reading and re-reading participant accounts any and all themes and extracts within this study were based on the participants' first person experiences and perceptions. Verbatim extracts ensured analysis and discussion as applicable to participant data in its truest form and cemented its role in acting as a guiding light with the themes and sub themes identified. Any and all claims made relate to the participants' experiences with regards living with obsessions and compulsions and could be verified by reading transcripts provided. As a double hermeneutic great care and consideration was taken in interpreting the participants' interpretations and perceptions in order to acknowledge individual participant accounts alongside shared perceptions. Through recognising and presenting existing research in the field of research focused on obsessions and compulsions, (both quantitative-and qualitative studies), within the critical review and across this study, this study recognises the importance of context particularly as few qualitative studies appeared to have been published eliciting subjective accounts, hence necessitating further phenomenological exploration alongside questionnaire and scan-based studies already in existence. Within the discussion section any findings were substantiated with further literature review as appropriate. This study has made a series of original contributions which were further explored and substantiated in the discussion section.

Commitment and rigour

All research interviews were carried out with commitment to in-depth analysis as focused on participant materials. Through the research process great care and consideration was placed on the choice of questions and prompts used and the setting of a safe and secure context within which to explore the research schedule. Questions posed were focused on

establishing rapport but equally to elicit in depth perceptions from each of the homogenous group of participants chosen. The interview questions remained focused on the phenomenology and interpretation of subjective experience with particular focus on the iterative and individual accounts of all participants but also situating these accounts within a wider context with themes and perceptions which could perhaps cross over contexts and inform and contribute to other areas of experiential research. The researcher has shown committed action throughout the planning and execution of the research study by staying close to the participant perceptions and ensuring their comfort throughout the planning and completion of research interviews. Only through close examination of participant descriptions was a double hermeneutic possible where the researcher could re-interpret participant materials whilst maintaining individual voices in the transcripts. The analysis and discussion sections paid particular attention not only to participant perceptions and experiences but focused on what participants appeared to feel was important and how these important points could possibly relate as themes across transcripts studied. Great care was taken in the choice and balanced use of participant reflections so as to represent all participant voices.

Transparency and coherence

Detailed descriptions were explicated within the methods section, paying close attention to the planning, construction and execution of the research study. By providing this information transparency of process was ensured. All written research materials were available within the methods section and appendices of the study to remove any ambiguity with regards the focus and aims of the study and how it came to fruition. Information detailing the analysis process was provided to show progress from individual transcripts to the whole of the homogenous group of participants interviewed. Tables were used to represent the research schedule and the participant demographics to bring clarity and context

to the participant group chosen and the use of appropriate and carefully chosen questions relating to the area of research pertaining to subjective experience. Within the appendices the researcher included her own reflections taken from her research diary. These reflections alongside the document written as a reflection on the research process offer a clear and frank description of the researcher's own processes with regards carrying out the research study.

Impact and importance

Within this study particular attention was paid to what the participants found important and noteworthy and as a result a number of original contributions were identified and noted within the discussion section. Particular salient points related to i) the impact of feeling powerless and stigmatised by living with obsessions and compulsions and the ensuing cognitive dissonance experienced and reported by participants, ii) the strength and volatility of reflected appraisals with regard self stigma and symbolic interactionism, iii) the role of seeking and requiring acknowledgement of psychological distress which appeared invisible to the naked eye, iv) the function of having a diagnosis of psychological distress pertaining to living with obsessions and compulsions in offering containment and belonging or scrutiny and discrimination, v) the essential role of community- or group belonging where participants felt they fitted in and could be free to act unreservedly, vi) the great sense of empathy and care participants felt for others who were living with psychological distress and their hopes and desperation to receive support and care themselves, vii) the recognition of failings of medical and mental health professionals in offering appropriate information and containment to participants and the need for further education and training to facilitate apparent gaps in recognition of distress related to obsessions and compulsions and its effects, viii) the role of misconceptions acting as deterrents to psychological therapy and ix) the need for psychological professionals to build trustworthy relationships and to present environments where hesitant clients could feel safe to explore their concerns.

Suggestions

Ongoing research was necessary to focus on subjective experience as a means of informing practice. It might be useful to reflect on the medicalization of illness and the medical terminology used frequently within psychological distress. These medical terms need to be married with subjective experiences and stay close to the individual's understanding or meaning making processes in order to remain useful for psychological practice. Different types of knowledge existed, including quantitative- and qualitative data. The latter relied on subjective interviews bringing detailed lived experience to the fore. As clinicians we do not experience the same distress our clients do and might need to call on their experiences to inform practice and to find ways of supporting and alleviating distress. By listening and accurately interpreting distress, we acknowledge and validate the clients but also could recognise the shortcomings within our practice which might affect socially averse clients (such as these participants) to come forward for psychological therapy and to form a trusting relationship. Qualitative research on the experience of distress as related to the lived experience of individuals living with obsessions and compulsions appeared currently very limited. Two recent research papers might form part of a new wave of subjective enquiry, these being Brooks (2011), Olson, Vera and Perez (2007) and Murphy and Perera-Delcourt (2012). Brooks described an ethnographic experience of living with OCD, highlighting the disparity between an outer and inner identity whilst Olson et al. called for greater education for clinicians, families and individuals living with OCD to address disparities between diagnosis and treatment regimes. Murphy and Perera-Delcourt identified internalised stigma and feelings of personal failure as related to living with OCD. There appeared to be some cross over within this research regarding the findings of Murphy and Perera-Delcourt in acknowledging personal stigma and sense of failure but equally the cognitive dissonance and

dynamic patterns of distress (within individuals living with obsessions and compulsions) appear to need further exploration in future qualitative studies.

Implications of these findings for future research

Ongoing qualitative exploration was necessary to bring to the fore the experiences of people living with mental distress. It was necessary to recognise within such research the diversity of concerns but also shared themes in order to build more cohesive and supportive practice to support these individuals.

Implications of these findings for policy-making, training and practice

It was proposed that psychological training and policy –making could benefit from focusing on the individual’s experience. It would be a fallacy to state that each individual should be wholly considered and their needs met at all times but equally it might be possible to build policy and training programmes bearing in mind the meaning making participants employ in their daily lives. For individual clients within psychological therapy it might be important to make use of detailed formulation and care planning so as to include the diversity and dynamic nature of the client’s experience of distress. This could perhaps relate to the participants in this study who would describe their experiences as resolved but equally would show great distress and dissonance throughout their inter-and intrapersonal relationships. Most importantly the variety of experience should also remain centre stage in any therapeutic work so as to avoid homogenising distress. It was very important to recognise due to the internalised stigma as described within this research, to bear in mind how it could possibly act as deterrent for therapeutic attendance. By acknowledging participants (and quite possibly future clients) would struggle with their reflected perceptions of what obsessions and compulsions could be understood to be like and equally such as the participants within this study, might present with cognitive dissonance with regards to management of obsessions

and compulsions, particular care should be taken to create a supportive and encouraging therapeutic relationship.

Study evaluation/critique

One of the advantages of one-on-one interviews remained the control the participant had in directing the flow and content of information, however one of the disadvantages might be the intensity and intrusiveness of some of the materials or areas discussed. It might be important to create a dynamic within the interview where the privacy and autonomy of the participant remained centre stage, in recognising the participant's concerns about the researcher's motivations and reasons for doing the particular research.

The study was limited due to a difficulty in obtaining completed contact and consent forms from diagnosing clinicians. As the study rested on the confirmation of diagnosis of participants prior to participation, it seemed to delay the pace of research interviews and ultimately resulted in the exclusion of prospective participants. It might be that offering clinicians the option to confirm diagnosis by email might be a quicker option to follow in future studies. During the later stages of recruitment this became possible through making amendments in the ethical permissions to obtain confirmation of diagnosis and indeed sped up the process considerably. It might be that prospective participants lived with co-morbid difficulties which inhibited participation. It might be important to bear in mind any other psychological concerns which could impact on participation prior to developing any follow up studies. The consent form stated a recorded interview would take place and as it did not clarify the interviews would be sound recorded, it might be prospective participants were concerned about being filmed and did not come forward to participate. It might be useful to be much clearer in the use of language in all forms related to participation in future projects. It appeared considerably challenging to build rapport over Skype and telephone interviews

and it might be important to consider interview options for future studies as participants might feel comfortable to participate over the telephone or via Skype but this would take place in the absence of visual cues or body language which might inform a face to face interview. Technical problems appeared to exist in the use of technology for the interviews and made the transcription considerably difficult. It might be important to consider alternative recording devices than the digital recorders used in this study to ensure sound quality.

Prior to interview the participants were asked to provide pictures or photographs from happy times or very important stages in their lives (as pertaining to obsessions and compulsions and as used by Silver and Reavy (2010) in their narrative analysis of BDD). None of the participants acted upon this request. One participant offered to send pictures but it did unfortunately not take place whilst another participant was happy to share poetry and other written materials instead of the pictures requested. It might be this request was too challenging in view of eliciting strong emotional reactions or memories of challenges in the participants' lives.

Some of the participants appeared confused as to the focus of research and it might be important to clarify that research was not offering therapeutic intervention. The focus and aim of the study was made clear in all written materials but it might be beneficial to repeat the forms on a number of occasions so as to exclude any misunderstandings. Many participants were cautious as a diagnosis confirmation was sought prior to participation. It was important to note the difficult relationships participants had had up until that point in obtaining diagnoses and the role these played in their lives (if at all), as part of the initial discussions prior to interview.

Conclusions

Within this study three main themes were explored as situated within the participant data. These were focused on i) the participants' understandings surrounding having control or their distress exerting control over them, ii) the sense of self and relationships as related to living with obsessions and compulsions and iii) the participants' thoughts surrounding cognitive dissonance and change, embodying aspects of recovery and maintenance of the distress in question. It appeared regardless of the specific condition, all the participants experienced distress surrounding the impact and lack of control within their lives as affected by the psychological struggles. It seemed many had formed coping strategies in order to contain or distract but in broad terms the participants described instances of being consumed and overtaken by their obsessions and compulsions in an unrelenting fashion. It appeared participants would internalise the lack of control as failure, adding to already negative self concepts. Participants described challenging relationships where their distress was often misunderstood or unacknowledged, in part due to self reliance and the participants' habits of living with the distress without others' knowledge, but equally as a result of the misconceptions surrounding mental distress, its causes and its impact. This could also be true of medical professionals involved in the participants' care as the knowledge and understanding of the conditions in question appeared limited at best. Due to the apparent lack of support from the mental health field, it seemed the validity of the two conditions were often drawn into question, as the distress was often invisible to the naked eye participants made many comparisons with the preference for physical observable distress as opposed to mental illness. A controversial and opposing finding has to be mentioned in that having a diagnosis (related to living with obsessions and compulsions) was seen to infer validity and a means of distancing from overt responsibility to successfully address the psychological distress in question. By knowing the distress was caused by factors outside of the participants' immediate control, they could in some part create compassion for themselves

rather than feeling to blame for its existence in the first place. Participants appeared to see themselves as outsiders, only belonging with others with similar concerns. It seemed these in-groups offered comfort, acceptance and freedom where the participants could be themselves without fear of being misunderstood or judged. It was important to mention how participants would rename their distress for outsiders as the “disorders” were perceived as un-understandable by those not living with it themselves. By using these different terminologies, participants appeared to create some distance between themselves and the stigma associated and perceived in living with mental distress. Many of the participants appeared torn between feeling they could contain their difficulties or feeling totally overwhelmed by their experiences, equally they seemed to struggle with concepts surrounding living with and accepting the conditions as opposed to being healed or expected to be healed by interventions offered. These and other concepts of dissonance were resident across the three main themes as it highlighted the dynamic experiences and constant efforts in the participants trying to contain and understand their difficulties but feeling unable from one day to the next to come to clear conclusions as to how to move forward or integrate the obsessions and compulsions within their lives. It appeared by remaining open for these dissonant experiences, psychologists could form closer understandings of clients’ distress and by acknowledging the lack of clear answers or singular coping strategies, we could support the diversity of needs present in those struggling to live with mental distress. It was important to explore subjective data as a form of data equally important to, but different from quantitative data, each forming a necessary part in creating a broader understanding of mental distress and improved interventions to assist clients. It might be, through an integration of quantitative and qualitative data, possible to follow in the footsteps of Larkin, Eatough and Osbourn (2011), who proposed phenomenologically- based research to inform existing cognitive science studies. Larkin et al. recognised the important contribution phenomenologically- based

studies (in particular those making use of IPA) could make through its focus on situated knowledge exploring the participants' individual contexts and experiences. Larkin called for ongoing conversations between proponents from both sides of the psychology paradigm in order to increase discussions of integrated knowledge such as which this study hopes to contribute.

Critical appraisal of research process

One of the aspects of the research process which remained with me was time. This related to the time it took to gather sufficient participants, to transcribe and analyse transcripts and to complete the research process as a whole. I feel almost a love- hate relationship with time as I noticed throughout the research process this hollow feeling in my stomach because of having no time at all or feeling I want to spend my time in having a life outside of sitting at my computer writing the research study. I noticed throughout the research process how little control I had over the process itself and how I was at the behest of kind participants choosing to overcome their internal demons in order to talk about their fears and struggles. And yet at times I couldn't stop feeling angry at the unreturned forms or the ignored emails to clinicians and prospective participants the like. I recognise this feeling was intensified as after the time period for attracting participants had lapsed, I was contacted by at least six individuals eagerly wanting to take part and I had to turn them away. I notice how throughout the research process I wanted to almost kick myself for setting up a study where participants as a result of their distress, would struggle to participate! Many of the participants lived with complex distress which would make social encounters especially difficult. I have thought how I could have designed the study differently to accommodate for this distress but so far have not found another more useful setup than the semi-structured interviews I chose.

I am reminded of the hours it took to complete the NHS ethical application and the comments from the head of the board thinking I was perhaps a bit silly to apply to the NHS to seek only eight participants, I felt my little study was seen as innocuous enough to grant permission for but equally I was annoyed at the great amount of effort it took to find a supportive NHS Trust, present to their research committee, to get the ball rolling, only to find discrimination from the NHS ethical board to which I presented. It made me rethink the

importance of bringing qualitative research to the fore if a body as large as the NHS still hankered after large quantitative studies alone.

Perhaps the hardest aspect of time was waiting for contact and consent forms to be returned by prospective participants or the diagnosis confirmation sheets returned by diagnosing clinicians. I was surprised at the lack of care and effort on the part of some of the clinicians involved, even after telephone discussions and copies of consent forms were posted to them, to not return the forms, meaning a prospective participant could not take part. I must add the delight and surprise when other clinicians were openly supportive and encouraging of the research. I felt at times I did not have a clue where to start in the design or practical aspects of the study but found gracious and supportive clinicians and other trainees in similar positions as myself, very generous with their time. I remember feeling like a stalker in that I would wait patiently for at least a week or so to elapse before I contacted prospective participants or clinicians through email or the telephone. I felt so scared I was perhaps making them more anxious by phoning or leaving messages. Sadly many prospective participants never returned their forms or answered emails leaving me guessing. I remember meeting with my supervisors when it seemed I might not have sufficient participants and creating a plan B, C and D in case I had to defend the lack of participants. I felt so powerless in having to let the process unfold and hope for the best rather than have a study which I could contain and guide. I remember how I contacted many different charities, support- and volunteer groups through the internet, the post, telephone calls and how I wanted to make sure I did not miss any possible link to prospective participants.

I am reminded of individuals who tried to make use of the research for their own benefit, such as the counsellor who was very annoyed at me for talking to her son (a prospective participant) in the same way as which I had done to all the prospective participants only to find she wanted me to be more empathic. I remember her telephone call

where she told me that she could have helped my study so much and now I would never have her son's participation. I felt so angry at her trying to hijack the research and make me feel guilty for not offering her son a counselling session (instead of the research I was offering!).

One aspect of the recruitment that will remain with me, was the desperate emails from prospective participants. Their distress of years of no help and support and their struggle to choose to participate or not, opening the door to their struggles in a recorded interview, was a great eye opener. The courage and determination of individuals to actualise and become the best they could be will always remain with me and act as an inspiration. I am reminded of attending a support group during the recruitment process. When I entered the room I realised I was being vetted not only as researcher but as psychologist in training responsible for all the group members' positive and negative experiences of therapy for their distress. I understand how challenging it was for the group to invite me to talk to them but equally recognise that as the evening's meeting went on, I had to leave as soon as possible as the discussions became quite heated in the participants mentioning perceived failures by psychological professionals. I hastily made my exit thinking it was a wasted journey, another long day with a late night rail journey back to Wolverhampton. I was surprised when the facilitator of the support group agreed to participate. I now understand how the research participation could mean a means for individuals to air their grievances or to have the therapy they never had. I realise in stark contrast the very boxed way in which I expected the research to progress as I thought the public would also be knowledgeable about research and would not have biases or extraneous reasons blocking participation. Another aspect for which I had not accounted was participants living with co-morbidities of the two diagnoses in question. Initially I hoped to interview just such participants but chose to split the two conditions as I could not be sure which difficulty was a causative element in distress.

Humour formed a huge part of the research process, I remember interviewing a participant in her home, only to be interrupted by her daughter and the dog coming in for a coffee. Once we got going again (me nervously recording on two Dictaphones to ensure it worked!) her husband returned from his jog only to sit down in the middle of our interview as if he was watching a television interview! Another very funny incident occurred when a prospective participant very eagerly sent me her postal address only to find she resided in the USA! We had emailed back and forth about the study and I made sure to answer any of her queries only to find she could not participate as the study was limited to people living within the UK. Only in hindsight can I laugh at moments such as this whereas at the time I was desperate to find sufficient participants and cried at the loss of another possible interview.

It has been a rocky process with regards to research supervision as the university lost three permanent members of staff during my first year of study. Two of the members were my research supervisors and I felt devastated after having created and discussed the ideas for the research with people whom I believed would be there as supportive supervisors, only to find I had to find two new supervisors and hope the ideas would still work with a new team. Luckily I found two very supportive and empathic, experienced supervisors who guided me through the second year of the research. Unfortunately I lost another supervisor along the way due to ill health and another new team member stepped in. Again I was fortunate as this was a very experienced, passionate supervisor but under all this we were privy to the stresses and strains inherent in working at the university and knew how each lecturer was given huge amounts of research supervision across not only the Doctorate but also in the undergraduate programmes. I felt I struggled with trying to be compassionate for the staff members and feeling I needed support and guidance when it was not forthcoming. I am grateful for these staff members helping through emails, tutorials and quick words in the corridor, I could never

thank them enough for their tireless passion or research, especially if my area of work was not their first interest or desired method.

I recognise anxiety and sadness I experienced during telephone and Skype interviews as I was unable to make face to face contact with the participants it felt at times difficult to elicit useful material from an interview. I felt like I was struggling, sometimes expecting nothing from participants, believing they had nothing to say, only to find when I listened back to the interviews there was much distress, conflict and fruitful experience. I feel as if I was hoping for an idealised research process where all the participants would be available for face to face interviews within a short period of time, in the locality where I lived and then all the interviews would be completed in a short period of time. Sadly this was not the case and the eventual interviews were spread out over a period of almost a year. I hated the transcription, especially when technical difficulties made the audio track impossible to decipher. I was so annoyed with myself for not realising these difficulties could impact so badly on the sound quality and the true words of the participants could not be heard. I also regret not stating in the invitation to participate that interviews would be sound recorded. Instead I mentioned only that interviews would be recorded and looking back, I believe some prospective participants might have feared being filmed-a disastrous mistake on my part in inviting people who live with BDD or OCD who might feel anxious already due to perceived physical compulsions.

One of the frustrations I experienced related to not being able to include all the diversity of themes as expressed by participants. Due to time and work limits, I had to focus on the most potent and present themes. This does not exclude the participants' other experiences however these would have to be included in other pieces of work, which at present remains impossible. I recognise as I embarked on this study I had lofty ideas about the amount of representation I could include in the research discussion and now realise how a

study based around a narrower more specific idea could still do justice to the participants' experiences but it means that some parts of the transcripts have to be excluded.

In re-examining the interviews I recognised how at times I responded positively to a particular interview and dreaded transcribing others. I wondered if my own personal views of the participants might have encroached upon the analysis of the data and recognised possible reasons for my reactions. I noticed how the distress the participants described would at times feel unbearable for me, and I wanted to "do something" to relieve the distress. Equally I recognised how I might have felt participants were stating both positive and negative components of their experience, almost creating a double standard in their rendition where they felt at once successful in containing their distress and being consumed thereby. I recognised how potent distress was as it could become absorbed through a telephone or Skype interview and this made me reflect on the courage and determination of the participants in living with their individual distress (as described) on a permanent basis.

I recognised throughout the research process I wanted to ensure the participants' voices were heard. As a result I remained anxious in ensuring I did not follow my own biases but listened closely to the participants' experiences. The reason for following qualitative and especially Interpretative Phenomenological Analysis (Smith, Flowers & Larkin, 2009) in this research has allowed for participants' subjective impressions and opinions and I hope this will offer a starting point for further similar research. As I was listening to the interviews I recognised how much the participants felt they had lost as a result of stigma, being misunderstood or equally by remaining quiet about their distress no help was forthcoming. It felt it was very important to highlight not only their experiences but also to start breaking down the taboos of mental illness in general. I was inspired by other qualitative papers focusing on the experience of mental distress related to living with Obsessive Compulsive Disorder (OCD), including Brooks (2011), an ethnographic study reporting on the experience

of living with OCD, as well as Olson, Vera & Perez (2007) who studied the lives of adults living with OCD and the necessity for education regarding OCD for both clinicians and individuals living with mental distress. These papers identified themes prevalent to experience and offered me a starting point for my own research. I was also inspired by Deegan (1995) who spoke of her own experience as a mental health practitioner living with schizophrenia and called upon mental health professionals to focus on subjective experience in research so as to remain focused on the individual's journey rather than become side tracked by diagnoses and diagnosis descriptors. Sadly I did not come across any qualitative studies focusing on the experience of living with Body Dysmorphic Disorder and as I spoke to participants it became clear how many felt isolated and underrepresented within not only their immediate communities but equally within the mental health community. As a result it felt even more important to start a qualitative research study which would highlight experience and hopefully offer tentative explorations of what it was like living with BDD or OCD. By reading other qualitative research papers I felt inspired and encouraged to focus on subjective accounts of experience. I hope I have done the participants' justice, who, as diverse as they were, each had the right to be heard and understood.

Word count: 2442

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