An evaluation of a specialist service model for treating Body Dysmorphic Disorder (BDD): application of the National Institute for Health and Clinical Excellence Guidelines for BDD (NICE, 2006).

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A thesis submitted in part fulfilment of the requirements of
The University of Derby
College of Health & Social Care

For the degree of Doctor in Health & Social Care Practice
(Cognitive Behavioural Psychotherapy)

Module 8DP001

Date: 14th August 2019

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#### ABSTRACT

Body dysmorphic disorder (BDD) is still poorly recognised with a dearth of research into treatment. This is the only known study to date to evaluate the implementation of the National Institute for Health and Clinical Excellence (NICE) guidelines recommended treatment for BDD in clinical practice as well as providing qualitative data of both patients and clinicians (NICE, 2006).

#### Aim:

The study aims to evaluate current recommended treatments for Body Dysmorphic Disorder utilised in a specialist service for BDD. In addition the study elicits the experiences of patients receiving treatment and the clinicians providing the treatment. This provides a basis to assess if refinements are to be made to treatment protocols for BDD in this specialist service.

#### Methods:

A mixed methods approach was employed with quantitative data from patients treated for BDD collated from the Trust's database and examined with intention to treat analysis. Thematic Analysis (TA) was used to analyse data from semi-structured interviews conducted with clinical staff and patients to elicit their experiences of respectively providing and receiving treatment.

# Findings:

The clinical data indicated impairment in patients' functioning plus high risks and substance misuse. Treatment outcomes of NICE recommended CBT and medication (Selective Serotonergic Reuptake Inhibitors and augmentation) produced significant improvements in BDD symptoms in patients with severe symptoms at baseline. Patients also showed significant improvements in depression and overall functioning. However despite improvements symptoms were not completely eliminated and one group treated by the service (Level 6 outpatients) showed minimal to no improvement on all symptom measures. Both clinician and patient participants expressed dissatisfaction with the lack of sufficient knowledge and expertise for treating BDD. Both groups also placed high value on the therapeutic relationship. However clinicians interviewed indicated a higher dissatisfaction with current treatment options for BDD than patients.

# Conclusions:

The experiences of patients provided a different perspective to the findings in the quantitative phase. Their view of improvements was based on their functioning and overall quality of life. Clinicians' perspectives provided insight into other options for treatment which are lacking and could provide substantial support for current recommendations. Given the evidence base for recommended treatments is still limited, it is essential to include qualitative data in evaluating effectiveness of treatment and in developing services that respond to patient needs and choice.

#### **ACKNOWLEDGEMENTS**

This study would not have been possible without the participation of the patients and staff at the OCD/BDD Service. My deepest gratitude for all your help and giving your time to make this happen. I would like to thank Dr Lynne Drummond and Mrs Sharon Clenaghan for supporting my project and helping me through the bureaucratic process.

I am especially thankful to my director of studies, Dr Dzintra Stalmeisters and my supervisor Dr Michael Townend for their support and offering their vast experience and knowledge to guide me through the years of the doctorate and the final thesis. I greatly appreciate your time and patience in supervising me whether in person, telephone or Skype and emails. Your comments, feedback and insights were invaluable.

I would like to express my heartfelt gratitude to my devoted husband, Suren Govender for his unwavering support and encouragement. Thank you for your insights, helping work out my time scales and proofreading. Finally, thank you to my little ones Rishan, Natasha and Darshan who had to sacrifice time spent together so I could complete this thesis.

#### LIST OF ABBREVIATIONS

AM Anxiety Management

BAPRAS British Association of Plastic, Reconstructive and

Aesthetic Surgeons

BDD Body Dysmorphic Disorder

BDD-YBOCS Yale-Brown Obsessive-Compulsive Scale modified for

Body Dysmorphic Disorder

BDI Beck's Depression Inventory

BNF British National Formulary

BT Behaviour Therapy

BSI Brief Symptom Inventory

CASP Critical Appraisal Skills Programme

CT Cognitive Therapy

CBT Cognitive Behavioural Therapy

DSM Diagnostic and Statistical Manual of Mental Disorders

ECT Electroconvulsive Therapy

EMDR Eye Movement Desensitisation and Reprocessing

HRA Health Research Authority NHS

ICD International Classification of Diseases

MADRS Montgomery-Asberg Depression Rating Scale

MHRA Medicines and Healthcare products Regulatory Agency

MI Minimally Invasive Procedures

NICE National Institute for Health and Clinical Excellence

NICE was renamed the National Institute for Health and

Care Excellence on 1 April 2013

NCCMH National Collaborating Centre for Mental Health

OCD Obsessive Compulsive Disorder

PIP Poly Implant Prostheses

SDS Sheehan's Disability Scale

SRI Serotonergic Reuptake Inhibitor

SSRI Selective Serotonergic Reuptake Inhibitor

WHO World Health Organisation

YBOCS Yale-Brown Obsessive-Compulsive Scale

#### LIST OF TERMS

Augmentation In the context of pharmacological management of

psychiatric disorders, this refers to the combination of two or more medications to achieve better treatment results.

Boolean A term referring to searching on the web with the use of

"and" "or" operators between two words or values

(Cambridge University Press, 2019).

CE Marking Conformité Européene (European conformity) CE

marking on a product is a manufacturer's declaration that the product complies with the essential requirements of the relevant European health, safety and environmental

protection legislation (Gov.uk, 2012).

Digital natives Those born into the digital world and having grown up

using digital devices such as mobile phones, Internet,

computers (Prensky, 2001).

Emotional regulation A process of identifying and responding to emotional

experiences (Diefenbach, Tolin, Meunier et al., 2008).

Generation Y People born between 1980 and 1994.

Generation Z This is the newest generation to be named and were born

between 1995 and 2015.

Participant Is someone who takes part in research (Health Research

Authority, 2017).

Rhinoplasty Refers to plastic surgery performed on the nose.

pansexual groups that may not have an overall term to

describe their sexual orientation (Math, Seshadri, 2013).

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# **CHAPTER 1**

# INTRODUCTION TO THE STUDY

# 1.1. Overview of the chapter

This chapter begins with a brief outline of the main symptoms and presentation of body dysmorphic disorder (BDD). It then goes on to explain some of the reasons for the study as well as the earlier understanding of BDD and how it is positioned in contemporary society. This is followed by a journey through the development of the National Institute for Health and Clinical Excellence Guidelines for Obsessive Compulsive Disorder (OCD) and BDD describing the background to the inclusion of BDD in the guidelines (NICE, 2006). Furthermore it considers how these guidelines have influenced the recognition and treatment for BDD. This chapter will briefly explore implications of BDD within society. This will be further illustrated in view of more recent political changes driven by the financial effects of body image concerns. This chapter concludes with a description of the aims and objectives of the study.

#### 1.2. Outline of BDD

## 1.2.1 Definition

Body dysmorphic disorder (BDD) is described as excessive and persistent preoccupation with appearance and specific body parts accompanied by marked distress. Both the Diagnostic and Statistical Manual of Mental Disorders (DSM-V, 2013) and the International Classification of Diseases (ICD-11, 2018) describe the main criteria similarly. The DSM-V (2013) and ICD-11 (2018) categorises BDD under a new section titled obsessive compulsive and/or related disorders (Appendices A; B).

# 1.2.2 Epidemiology

Unfortunately there are no prevalence studies of BDD in the UK. However there have been prevalence studies conducted in the US and Germany. A nationwide study was conducted in the US which administered the BDD interview schedule to 2,048 participants (Koran, Abujaoude, Large et al., 2008). It was found that 2.4% (49) met the DSM IV criteria. Two German studies, showed a prevalence of 1.7% in a sample of 2552 (Rief, Buhlmann, Wilhelm et al., 2006). An updated study in

Germany showed a prevalence of 1.8% (45) in a sample of 2510 (Buhlmann, Glaesmer, Mewes et al., 2010). A community survey of 673 participants was conducted in Florence, Italy, which focused on somatoform disorders (Faravelli et al., 1997). The findings indicated a 1-year incidence of 0.7% for BDD. A study conducted amongst a University student sample of 395 in South Africa indicated an incidence rate of 5.1% (Dlagnikova, van Niekerk, 2015). These studies indicate this condition is far from being a rare disorder and given its debilitating nature, it demands more attention.

#### 1.2.2a Gender Prevalence

With regards to gender prevalence, findings are varied. Some studies have shown a higher rate of BDD in females whilst others have found BDD to be as common in males as in females (Koran et al., 2008; Rief et al., 2006; Phillips, 1996; Phillips et al., 2001; Tyagi, Govender, Drummond, 2012). However treatment outcome studies generally show a higher proportion of females in the samples than males. Possibly the disorder is more readily recognised in females or that it is more socially acceptable for females to present with concerns about their appearance. This is another area needing more research.

## 1.2.2b Ethnicity

From using global search engines it appears studies into ethnicity and BDD are very limited and there are no known cross-cultural studies published thus far. Most of the literature concerns body image in a broader context rather than solely BDD. Just one study was found regarding BDD in an ethnic diverse population sample of 1041 participants at an American University (Boroughs, Krawczyk, Thompson, 2010). The study reported that incidence of BDD in Caucasian Americans was above the prevalence of the total sample whereas the estimated occurrence was lower for Latinos, Asian Americans and African Americans.

## 1.2.2c Sexual Orientation

A study into BDD prevalence in different sexual orientation groups found that lesbian or sexual minority females had the highest scores on measures of BDD compared to heterosexuals and gay or sexual minority males (Boroughs et al., 2010). Heterosexual males had the lowest rates of BDD symptoms whilst heterosexual

females and gay men had similar levels of BDD symptoms. At the time of this study there was no epidemiological literature found on transgender populations.

Epidemiology studies conducted at dermatology clinics show rates of 12% to 14% of patients screening positive for BDD (Phillips et al., 2000; Conrado, Hounie, Diniz et al., 2010). Similarly studies of patients presenting for cosmetic surgery showed 7% to 15% met the criteria for BDD (Sarwer, Wadden, Pertschuk et al., 1998; Aouizerate, Pujol, Grabot et al., 2003).

#### 1.2.3 Presentation of BDD

Due to the shame and embarrassment most people with BDD experience, they are rarely forthcoming about their concerns (Phillips, 2005). It has also been reported that individuals may have had the problem for an average duration of 10-15 years before diagnosis (Veale et al., 1996; Phillips and Diaz, 1997). Often they are misdiagnosed due to presenting with symptoms similar to other disorders (Phillips, 2000). Additionally sufferers of BDD often have comorbid depression (Phillips, 1998; Phillips, 1999; Phillips, Coles, Menard, Yen, Fay, 2005). Furthermore due to their belief that the problem is a physical rather than psychological one, most people with BDD will seek out cosmetic surgery rather than mental health services (Phillips, Dufresne, Wilkel et al., 2000; Conrado, Hounie, Diniz et al., 2010; Sarwer, Pertschuk, Wadden, et al., 1998; Aouizerate, Pujol, Grabot et al., 2003).

People with BDD are often preoccupied with their perceived flaw to the exclusion of most other aspects of their lives (Phillips, Quinn and Stout, 2008; Phillips, Menard, Fay et al., 2005). The preoccupation results in extensive "safety behaviours" to attempt to reduce their distress (Phillips, 2005). Safety behaviours are described as "actions that aim to prevent catastrophe in a feared situation and reduce harm" (Salkovskis, 1985). These actions take the form of using camouflage such as wigs, copious amounts of makeup, hats, scarves, sunglasses; avoidance of social situations; adopting mannerisms which the individual believes will draw attention away from their flaw (Phillips, 2004; Veale et al.,1996).

# 1.2.4 Areas of Preoccupation

Individuals with BDD may be preoccupied with any feature but it is commonly found that concern tends to be skin, nose and hair (Phillips, Grant, Siniscalchi et al., 2001; Phillips, 1986). The focus tends to be on features more apparent to others although preoccupation can be of any area of the body. Also multiple features are often of concern to varying degrees (Phillips, 2004).

With regard to areas of concern a study into gender differences in BDD showed males and females presented with more similarities than differences (Tyagi et al., 2013). The only statistically significant differences were in preoccupation with breasts, hips, skin (face and body) and hair (face and body, except head). These findings were similar to results in an earlier study on gender differences (Philips, Diaz, 1997).

However one form of BDD called muscle dysmorphia tends to affect males more than females (Pope et al., 1997; Pope et al., 2000). The individual is preoccupied with concerns about their muscular development being insufficient (APA, 2013). Studies have shown that sufferers of muscle dysmorphia have higher incidence of substance misuse, particularly anabolic steroids (Leone, Sedory, Gray, 2005). They are also found to have a higher risk of suicide and have a poorer quality of life compared to those with other forms of BDD (Pope et al., 2000; Phillips, 2005).

Ethnicity and culture may have an influence on features of concern for example; eyelids were a common concern amongst a Japanese sample which is less common in studies of Western populations (Ishigooka, Iwao, Suzuki et al., 1998).

## 1.2.5 Functional impairment

Physical appearance and body image is of interest to most individuals, however in BDD this is a major concern which is taken to extremes. Behaviours to attempt to cope with their distress are time-consuming, interfere with daily activities and have a significant impact on the individual's functioning (Phillips, Quinn, Stout, 2008). In severe cases the individual can become housebound (Phillips, McElroy, Keck et al.,

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1993; Phillips, Didie, Menard et al., 2006). Studies report consistently high levels of unemployment, single marital status, and hospitalisation (Phillips, Menard, Fay et al., 2005).

### 1.2.6 Risk factors

There is a high risk of suicidality related to BDD with reported rates of 70% to 80% experiencing suicidal ideation, with 24% to 28% attempting suicide (Phillips et al., 2005; Phillips, 2007). The numbers of completed suicides are not clear but a study in a dermatology clinic described a series of 16 BDD cases of completed suicides (Cotterill, Cunliffe, 1997).

In addition to risks to self in BDD, literature highlights the limited attention given to risks to others especially healthcare professionals, despite the evidence (Lucas, 2002). A survey regarding BDD in cosmetic surgery settings was carried out on members of the American Society for Aesthetic Plastic Surgery (ASAPS) (Sarwer, 2002). Findings indicated 40 percent reported being threatened, mainly by litigation and some physically (Sarwer, 2002). In a similar study a survey of dermatologic surgeons indicated that 12 percent of surgeons reported threats of litigation or physical violence (Sarwer, Spitzer, Sobanko, et al., 2015). Furthermore cases of violence perpetrated against cosmetic surgeons in Russia and the United States drew attention to BDD in the media on an international level (Amos, 2015; Dolgin, 2015).

One also needs to consider the risks BDD sufferers may pose to children in their care (NICE, 2006: 10.1.5.3; 10.1.5.4). A global literature search has not revealed any known published studies about risks to children living with a parent suffering from BDD. Although from clinical practice and anecdotal evidence from colleagues, child protection and safeguarding issues have been raised in some patients with BDD. Risk assessments highlighted concerns of neglect and placing children at risk due to the patients' preoccupation with their appearance. In addition, this raises the question of what the psychological impact may be of growing up in an environment where one's care-giver is consumed by their appearance concerns. Given the sensitive nature of the subject, it may be difficult for researchers to design a study

into these factors. Studies that have been found following a search for risks to children have been focused on risk factors for *developing* BDD (Albertini, Phillips, 1999; Buhlmann, Marques, Wilhelm, 2012). Indeed studies into general risk factors in BDD are very limited, requiring more attention.

In addition to the above risks, there is one that is more particular to BDD than any other psychiatric disorder. "DIY surgery" or self-inflicted surgery refers to people attempting to make changes to their physical features by themselves (Veale, 2000). Self-inflicted surgery is a damaging and shocking measure of the level of frustration and distress the individual with BDD experiences in relation to their perceived flaw (Phillips et al., 2005; Phillips, et al., 2006). This should not be confused with self-harming behaviour as the psychological process is quite different (Veale, 2000; Favazza, Rosenthal, 1993; Chapman, Gratz, Brown, 2006).

# 1.3 History of BDD

Recognised as far back as the 1800s, Italian psychiatrist Enrico Morselli first devised the term dysmorphophobia in 1891, which he described as a:

"Subjective feeling of ugliness or physical defect which the patient feels is noticeable to others, although the appearance is within normal limits. The dysmorphophobic patient is really miserable in the middle of his daily routines, everywhere and at anytime, he is caught by the doubt of deformity." (Jerome, 2001:103).

Dysmorphophobia was further described in Kraepelin's works (1909 – 1915). The most well-known case of BDD was named the "Wolf Man" who was engrossed by imagined flaws of his nose (Freud, 1959; Brunswick, 1971).

Dysmorphophobia first appeared in the Diagnostic and Statistical Manual of Mental Disorders (DSM III) in 1980. There were no accompanying diagnostic criteria and it was cited as an example of an "atypical somatoform disorder". The DSM III-R (1987) first used the term "Body Dysmorphic Disorder" as a diagnosis. BDD was categorised under somatoform disorders in the DSM-IV (1994) and under

hypochondriacal disorder in the International Classification of Diseases (ICD-10) in 1992. In both diagnostic manuals the main criteria is described as excessive preoccupation with appearance and specific body parts accompanied by marked distress.

A more recent shift has seen the DSM V and ICD-11 classified BDD under Obsessive Compulsive and related disorders (APA, 2013; WHO, 2018). Furthermore repetitive behaviour, degrees of insight and muscle dysmorphia was included in diagnostic criteria, which helps to differentiate BDD from disorders with similar symptoms (Krebs, Fernández de la Cruz, Mataix-Cols, 2017).

# 1.4. Motivation for the study

My experience of treating patients with BDD and witnessing the devastating impact the disorder has on their lives as well as their loved ones inspired this study. Before working in the specialist service for OCD/BDD, it was rare to see patients with BDD in my clinical practice. Even during the first years of working in the specialist service patients with BDD were still a minority, with referrals for BDD few and far between and skills in treating this disorder were still developing with limited literature available on effective treatments (Phillips, 2000).

The turning point for me was treating a young female patient who was referred by a surgeon who had already performed reconstructive surgery on her. The patient had only been seen in dermatology settings until she caused the first serious damage to herself and required reconstructive surgery. This brought her to the attention of a mental health professional. The initial surgery had been a success, however due to her psychological difficulties the patient could not cope with the healing process and caused herself further damage. This resulted in her requiring major surgical procedures on a more complex level. However the surgeons felt the risk was too great to operate again until she was psychologically stable.

Working with this case which was BDD in its extreme was a compelling experience. My interest in BDD was firmly rooted and set me on this path to contribute to

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increasing awareness of this illness and ensuring people with BDD get the most effective treatment at the earliest stage.

Despite the NICE guidelines for OCD/BDD highlighting the need for early recognition of BDD and the most appropriate treatment pathways, there is still a lack of understanding of the disorder, even within mental health services (NICE, 2006; Phillips, 2000). This is further demonstrated in six studies conducted in mental health settings, including inpatient facilities, which screened adult and adolescent patients for BDD. The results of these studies are presented in Table 1 indicating the number of patients found to have BDD. Interestingly, none of these patients had a previous diagnosis of BDD recorded in their medical records. One might infer that these patients did not disclose their BDD symptoms to healthcare professionals previously possibly due to embarrassment but also that the healthcare professionals may not have routinely screened for BDD in their assessment (Phillips, 2005; Phillips et al., 2008; Veale et al., 2015).

Table 1: Screening for BDD in mental health settings

Author	Sample	Diagnosed with BDD
Phillips et al., (1996)	80	11
Zimmerman, Mattia (1998)	500	16
Grant et al.,(2001)	122	16
Dyl et al., (2006)	208	14
Conroy et al., (2008)	100	16
Veale et al., (2015)	432	25

Furthermore the specialist service conducted a survey of NHS Health Care Trusts across London and the rest of the UK to explore the care pathway for identifying and treating BDD. Out of the eight NHS Trusts that responded, there were only two that were able to demonstrate a service pathway for BDD although this was specifically linked to Dermatology clinics rather than stand-alone specialist services. This instilled in me the desire to contribute to increasing awareness and recognition of this debilitating illness and to explore interventions and treatments.

This brought my focus to the specialist service for OCD/BDD and the treatments provided. The NICE guidelines for OCD and BDD provided much needed direction for recognition and treatment of BDD (NICE, 2006). The NICE guidelines for OCD/BDD (2006) recommend five simple questions to help healthcare professionals assess for BDD (Appendix C). This is an element of "recommended good practice based on the clinical experience of the Guideline Development Group" (NICE, 2006). These questions could help to identify at risk individuals and could improve the care pathway for early intervention. The healthcare professional does not need to be an expert in BDD to ask these questions.

However the guidelines have probably made the most impact on services already treating BDD, although these services are limited. There is one consortium of NHS England funded specialist services mainly based in London i.e. South West London and St George's Mental Health NHS Trust (SWLSTG), The Maudsley, The Bethlem and access to two inpatient beds at The Priory in North London with the OCD service in Queen Elizabeth II Hospital in Welwyn Garden City providing specialist psychopharmacological treatment. These services with limited resources provide assessment and treatment to patients across the United Kingdom.

There is also a dearth of research into the disorder plus its treatment. The main literature describing treatment for BDD has come from US studies on treatment outcomes, which includes psychological, pharmacological as well as cosmetic surgery interventions. The treatment studies will be discussed in further detail in the literature review chapter.

For the most part mental health and healthcare services do not regularly consider BDD when conducting initial assessments or consultations (Phillips, 2000; Phillips, 2006; Phillips et. al., 2008). The specialist service aims to collaborate with other services on a national level to address this disparity. Using the stepped care model as a basis to redefine the operational structure, the service was commissioned with specific focus on OCD and BDD (Figure 1). The service operates mainly on steps 5 and 6 although consultation, training and supervision are provided from steps 1 to 4 (Fig. 1). The service is cited by NICE as a model for putting the recommendations into practice.

Figure 1. \*The Stepped Care Model (OCD/BDD NICE guidelines, 2006) \*This model

is adapted to show only treatment as related to adults as the service does not treat children and adolescents.

		Who is responsible	What is the focus?	What do they do?	
		for care?			
		Step 6	OCD or BDD with	Reassess, discuss options, care	
		Inpatient care or	risk to life, severe	coordination, SSRI or	
		intensive treatment	self-neglect or	clomipramine, CBT (including	
		programmes	severe distress or	ERP), or combination of SSRI or	
			disability	clomipramine and CBT	
				(including ERP), augmentation	
				strategies, consider admission	
				or special living arrangements	
	Sto	ep 5	OCD or BDD with	Reassess, discuss options.	
	Ми	ultidisciplinary care	significant	SSRI or clomipramine, CBT	
	wit	h expertise in	comorbidity, or more	(including ERP), or combination	
	00	CD/BDD	severely impaired	of SSRI or clomipramine and CBT	
			functioning	(Including ERP); consider care	
			and/or treatment	coordination, augmentation	
			resistance, partial	strategies, admission, and social	
			response or relapse	care.	
	Step	<b>4</b>	OCD or BDD with	Assess and review, discuss options.	1
	Mult	idisciplinary care in	comorbidity or poor	CBT (including ERP), SSRI, alternative	
	prim	ary or secondary care	response to initial	SSRI or clomipramine, combined	
			treatment	treatments.	
	Step 3 GP, primary care team,		Management and	Assess and review, discuss options. Brief	:
			initial treatment of	individual CBT (including ERP) with self-help	
	prima	ary care mental health	OCD or BDD	materials (for OCD), individual or group CBT	
	worker, family support team			(including ERP), SSRI, or consider combi	ned
				treatments; consider involving the family/o	carers
				in ERP.	
	Step 2		Recognition and	Detect, educate, discuss treatment option	ıs,
	GP, practice nurses, school health advisers, health visitors, general health settings (including hospitals)		assessment	signpost voluntary support organisations,	
				provide support to individuals/families/	
				work/schools, or refer to any of the approp	priate
				levels	
Step 1			Awareness and	Provide, seek and share information about OCD	
Individuals, public organisations, NHS			Recognition	or	
				BDD and its impact on individuals and	
				families/carers.	
			I		

# 1.5. Background to NICE (2006) guidelines for OCD/BDD

The re-classification of BDD in the DSM V (2013) has been long awaited. Indeed it was long overdue as BDD was categorised under somatoform disorders but treatment was more aligned with OCD. BDD was still classified under hypochondriacal disorder in the International Classification of Diseases (ICD-10, 1992). However the revision of the ICD-10 (1992) and release of the ICD11 (2018) has brought about the hoped for consensus in the classification of BDD (Veale, Matsunaga, 2014).

One may ask why BDD has been included in the OCD spectrum disorders? Why not align with a disorder that is concerned with body image, such as eating disorders? BDD and eating disorders share similar clinical presentation, in particular, concerns about body shape, disturbed body image, behaviours such as over-exercising and camouflaging (Kittler et al., 2007; Hrabosky, et al., 2009). However it is the differences that set these two disorders apart. In studies comparing BDD and eating disorders it was found that patients with eating disorders were preoccupied with weight (Kittler et al., 2007; Rosen et al., 1998). Even if the focus is on a part of the body such as the waist or stomach, the main concern is the weight around that area. In contrast in patients with BDD the concern is the body part and less or no concern about weight. Psychologically the two groups differ as well with patients with BDD having more negative self-perception and poorer self-confidence as well as more impaired functioning in all areas of their lives due to concerns about appearance. Patients with eating disorders scored higher on psychological symptoms on the Brief Symptom Inventory (BSI) than patients with BDD. The BSI is concerned with psychological symptoms in all areas

The main difference however is the recommended pharmacological as well as psychological treatments for both these disorders, which take divergent paths (Didie et al., 2010; Ipser, Sander, Stein, 2009; Phillips, et al., 2008; Yager, Devlin, Halmi et al., 2006). This comes back to the pairing of BDD with OCD in the NICE guidelines. The similarities between OCD and BDD are documented more than other disorders that BDD may share symptoms with such as: social phobia, somatoform disorder or

eating disorder (Phillips, McElroy, Hudson, et al., 1995; Phillips, Pinto, Menard, et al., 2007; Chosak, Marques, Greenberg, et al., 2008). According to the literature there are a total of 11 studies comparing BDD and OCD and three comparing BDD and eating disorders (Phillips, et al., 2010). In perusing the literature just one study was found that discussed the relationship between social anxiety and BDD (Fang, Hofmann, 2010). No studies were found to compare BDD with any other disorder including somatoform disorder which it was previously categorised under in the DSM IV and the ICD-10 (APA, 1994; WHO, 1992; Phillips, et al., 2010).

Direct comparative studies into OCD and BDD were conducted using the Yale-Brown Obsessive-Compulsive Scale (YBOCS) and a modified version for BDD (BDD-YBOCS) (Goodman et al., 1989; Phillips et al., 1997). The symptoms of intrusive thoughts and compulsive behaviours which are shared between these two disorders did not show any significant difference on the scales (Phillips, et al. 1998; Phillips, et al. 2007). This indicates there are key similarities between OCD and BDD symptoms (Table 2). However in BDD there is a difference in the meaning attributed to the thoughts and compulsions. With BDD the focus is on negative self-perception but compulsions do not necessarily follow the same pattern of reducing anxiety as it usually does in OCD (Veale, et al. 2001).

Table 2: Similarities and differences between BDD and OCD.

# Similarities between BDD and OCD Difference

# Intrusive unwanted thoughts

- Thoughts are anxiety –causing.
- Repetitive behaviours in response to thoughts have a compulsive quality e.g. application of make-up, checking particular feature.
- Reassurance-seeking from others and by using behaviours such as checking.
   (Phillips, et. al., 2007).

# Differences between BDD and OCD

- Poorer insight than OCD sufferers (Phillips et al. 2007; Eisen, Phillips, Coles, et al., 2004; Phillips et al., 2006; Mancuso, Knoesen, Castle, 2010).
- Compulsive behaviour has more emotional regulation function rather than the anxiety reduction role in OCD (Jacofsky, Santos, Khemlani-Patel, et al., 2016; Diefenbach, Tolin, Meunier et al., 2008).

Although the research into pharmacological treatments for BDD is limited, the evidence thus far has shown the same treatments for OCD and BDD have proved effective, in particular treatment with SRI/SSRI medication (Hollander, Allen, Kwon, et al., 1999; Phillips, Albertini, Rasmussen, 2002; Phillips, 2006). Similarly psychological treatments namely CBT has been shown to be efficacious for both OCD and BDD (Williams, Hadjistavropoulos, Sharpe, 2006; Ipser et al., 2009). This seemingly completes the circle bringing OCD and BDD together under the one guideline. Those championing the cause of BDD welcomed the guidelines for bringing BDD into focus (BDD Foundation, 2013; OCD Action).

This is definitely a step forward for BDD although an in-depth perusal of the NICE guidelines shows BDD very much in the shadow of OCD. Indeed the NICE guidelines references 67 papers relating to BDD compared with 643 regarding OCD (NICE, 2006). There are firm foundations for the treatment of OCD as evidenced in the numerous research studies available. Conversely for BDD there are no definitive psychological treatment models and no conclusive evidence pharmacological interventions. There is currently no medication specifically licensed for treatment of BDD (FDA, 1998; MHRA, 2004). Incidentally the evidence update of the NICE guidelines for OCD/BDD reported on 16 papers, all regarding only OCD (NICE, 2013).

From a perusal of the literature, there appears to have been only three studies that have directly compared BDD and OCD: Phillips et al., (1998); Frare, Perugi, Ruffolo et al., (2004) and Phillips et al., (2007). The differences between these disorders have implications for treatment approaches, especially with regards to poorer insight in individuals with BDD. Studies have shown that 2% of individuals with OCD have a delusional or absent degree of insight as compared with 27% - 60% of individuals with BDD (Phillips, et al., 2007; Eisen, et al., 2004; Phillips, et al., 2006; Mancuso et al., 2010).

Clinical practice working in the specialist OCD/BDD service has provided first-hand experience of the difference in the degree of insight between these two disorders. Engaging patients with BDD in treatment requires a different approach than with patients with OCD as they may be less likely to believe their symptoms are

psychological in nature. Instead they see the problem as a physical one (Phillips, Dufresne, Wilkel, et al., 2000; Conrado, Hounie, Diniz, et al., 2010; Sarwer, Wadden, Pertschuk, et al, 1998; Aouizerate, Pujol, Grabot et al., 2003). This brings into question the use of NICE guidelines for two disorders which appear very similar (Table 2) but without sufficient research evidence for treatments for BDD. Can the treatments shown to be effective for OCD also be used for BDD?

#### 1.6. BDD in the social context

One could question whether BDD is a media cultivated disorder given that as a society we are constantly bombarded with images in every forum of what is considered the physical appearance to aspire to. The cosmetic industry earns billions in revenue based on the desires of both men and women striving for that elusive perfect look. The United States is the largest cosmetic market with revenue of 53.7 billion US dollars in 2011 and an estimated 62.46 billion US dollars for 2016 (Statista.com, 2011). A breakdown of the cosmetic sales according to product type showed 35.3% was skincare in 2014 (Statista.com, 2014).

In addition more availability to cosmetic surgery with competitive marketing has shown an increase of people seeking surgical procedures. In 2015 there were 51,140 people in the UK seeking cosmetic surgery, indicating a rise of 12.6% from 2014 (BAAPS, 2015). The role of the media in this increase can be queried again with television programmes such as *Extreme Makeover, Ten Years Younger and Cosmetic Surgery Live* being aired to a public mesmerised by the possibilities of new technologies offering enhanced beauty. A survey investigated how much 42 patients seeking cosmetic surgery for the first time were influenced by plastic surgery television shows. The findings indicated that four out of five patients stated they were influenced to seek cosmetic surgery by television programmes and almost a third described the degree of influence to be "very much" or "moderately" (Crockett Pruzinsky, Persing, 2007).

However a literature review regarding the motivation for seeking cosmetic surgery determined that factors such as body image, bullying, BDD, education and culture are predictors in the decision to have cosmetic surgery (Haas, Champion, Secor,

2008). Furthermore BDD has been documented in patients since the 1800s as mentioned in the history of BDD. At the time psychoanalysis was a strong influence on treatment for example the case of the "Wolfman" and the focus was on analysis of dreams and familial relationship dynamics (Freud, 1959; Brunswick, 1971). Thus BDD is not a new concept and media and society's responses to image promotion cannot be held solely responsible despite the impact it may have on people with BDD. Therefore we have to explore further into the psychological and biological domains bearing in mind that BDD sufferers do respond to psychological and pharmacological interventions (Phillips, 2005).

# 1.7. Economic and political implications of BDD

Body image concerns have been marginalised for a long time. However the medical scandal of the Poly Implant Prostheses (PIP) breast implants failures brought body image problems including BDD into sharp focus (Keogh, 2012). This incident then led to body image concerns being raised in parliament (APPG, 2012). Organisations such The British Association of Aesthetic Plastic Surgeons (BAAPS) followed suit by announcing their intention to fund long term research into recognition and treatment of body image disorders including BDD and highlighting the possible effects of unregulated advertising of cosmetic surgery (BAAPS, 2012). The Department of Health (DoH) is also reviewing cosmetic procedures in the UK including advertising that may be considered to influence or impact on body image concerns (DoH, 2013). The Scottish Government has also set up a committee to address concerns about cosmetic surgery (Scottish Government, 2015). A major development in recognising body image concerns was the recent guidance published by the General Medical Council (GMC) on 12<sup>th</sup> April 2016 for doctors who provide cosmetic interventions, both surgical and non-surgical. One of the key aims is to ensure the psychological needs of the patient. The guidance came into effect on 1st June 2016.

These developments for body image concerns including BDD are long overdue. However one has to question whether the interest in BDD and body image would have been raised if the economic implications had not been so high. In October 2012 the cost to the NHS for consultations and scans for women who had faulty breast implants was estimated at £850,000 and expected to rise by a further £901,000

following surgery (Smith, 2012). Although 95% of the implants were carried out by private practice, the NHS had to step in to address the problem (Horton, 2012). Where the media has played a role in promoting the ideal appearance, it has ironically also been useful to bring attention to body image problems with the focus on the cosmetic surgery industry following the PIP scandal. The increased scrutiny highlighted quality issues of implants by the Silimed brand that has had their CE (Conformité Européene) Marking suspended whilst the MHRA investigates (BAAPS, 2015). In addition the Trilucent implants an alternative to silicone have also been found to be defective and recalled due to adverse physical symptoms experienced (Rizkalla, Webb, Chuo et al., 2002).

Unfortunately the drive to clamp down on unnecessary cosmetic procedures may have a bearing on how patients with BDD are identified and provided with the appropriate treatment (Nassab, 2015). Patients may be reluctant to engage with psychological or psychiatric services when they have been refused the treatment of their choice which is cosmetic surgery (Crerand, Franklin, Sarwer, 2006). It is also important to note that refusal to perform a procedure will not deter the often desperate BDD sufferer who will continue to seek surgery even incurring substantial debts and risking poor procedures (Phillips, 2005). "Shopping" abroad for cosmetic surgery has become a more regular occurrence which often places more demand on healthcare services (BAAPS, 2015).

A survey into patients seen by NHS plastic surgeons following problems with cosmetic surgery conducted outside the UK indicated a total of 215 patients presented to NHS (British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS), 2011). This was reported by 62 of the consultants who responded to the survey. Out of these patients, 145 (74%) required treatment for post-operative complications and 50 (26%) expressed dissatisfaction or concerns with appearance.

In addition to the pressure on NHS resources, there are the wider implications of the impact of BDD in society. The correlation with severe BDD symptoms and impaired functioning is described as a common feature (Phillips et al., 2005). The consequential lack of involvement in work, social spheres and general contribution to

society results in more demands on the welfare system and a larger number of individuals without a supportive social network (Phillips et al., 2008). The duration of the disorder is often several years before any treatment is sought during which time the individual with BDD has often had long periods of isolation and limited activities (Veale et al., 1996; Phillips et al., 1997). This makes it more difficult to rebuild their lives and can lead to further psychological distress with the realisation that a large part of their lives is lost to the disorder.

# 1.8. Aims and objectives

#### 1.8.1. Aims

The aims of the research will be:

- To explore and evaluate the application of the NICE guidelines in treating BDD within the context of a specialist service.
- To elicit and explore the experiences of clinicians treating patients with BDD and patients receiving treatment for BDD.
- To identify and refine where applicable treatment protocols to improve effectiveness.

## 1.8.2. Objectives

- To identify interventions used by the specialist service in assessing and treating BDD.
- To analyse and quantify clinical outcome from the specialist service.
- To report patterns found in patients' and clinical staff experiences.
- To identify areas of effectiveness and those requiring improvement.
- Synthesis of findings.

#### 1.9 Research Questions

Do the implementations of the NICE guidelines for BDD contribute to clinical effectiveness?

How do patients with BDD respond to and experience treatment that has been recommended by the NICE (2006) guidelines for BDD?

What are the views of clinicians treating patients with BDD using the NICE (2006) guidelines as a frame of reference?

# 1.10 Summary

It is abundantly clear that BDD is a debilitating disorder for the individual but also for their families (Phillips, 1991). Additionally the current social fascination with appearance and body image ideals projected across mass media has highlighted the increased difficulties for people with BDD as this reinforces their perceived flaws. There is a limited knowledge base for the many facets of the disorder including epidemiology studies.

Since its inception the vision of the service has been for clinical excellence and patient satisfaction. This study plans to determine the treatment outcomes the service achieves in applying the NICE (2006) guidelines for BDD and what the experiences of patients and clinicians have been. In addition, the study aims to highlight factors that may be obstacles to providing the best treatment. Participants will have the opportunity to describe what they felt worked best and aspects they felt were less helpful. This could provide key indicators for the best ways to engage patients in treatment and interventions to enable continued progress following treatment. In addition, interventions found to be beneficial and not highlighted in the NICE guidelines, may serve to refine the treatment protocol for BDD for this service to possibly bridge the gaps that cause some interventions to be unsuccessful or result in dropouts and disengagement (NICE, 2006).

The next chapter will review the literature including studies used as an evidence base for the development of the NICE guidelines for OCD/BDD (2006).

# **CHAPTER 2**

# LITERATURE REVIEW

# 2.1. Purpose of the literature review

The purpose of reviewing the published literature is to offer a theoretical foundation for the study. The chapter provides a comprehensive discussion of the background to the development of the NICE (2006) guidelines for OCD/BDD by evaluating the literature published globally. This gives credence to this study, illustrating the scarcity of research on treatment of BDD whilst providing the rationale for using a mixed methods design in this study. This in turn identifies key issues that contribute to the understanding of the data and findings presented in this study.

# 2.2. Process of reviewing the literature

A critical review of the literature was conducted by determining its purpose in line with the research questions of the study. Literature was evaluated according to relevance for the study (Table 3). Each source was read critically and data extracted regarding key concepts; strengths and limitations; arguments presented; credibility. This approach is in keeping with the critical stance taken in this study. The data was analysed and sources were organised according to patterns and themes. A table was used to consider how publications related to each other and formed the basis of the structure of the critical review (Graph 3). Gaps in the literature were identified and prominent authors were noted.

The literature review aims to explore and appraise the main types of interventions used to treat BDD. To date there have been three meta-analysis (Williams et al., 2006; Ipser et al., 2009; Harrison, et al., 2016). However one of these studies only describes randomised controlled trials of cognitive behavioural psychotherapy (CBT) (Harrison et al., 2016). In addition there is one literature review of treatments for BDD, focusing only on CBT (Prazeres, Nascimento, Fontenelle, 2013).

There are just two long-term follow up studies (McKay, 1999; Veale, Miles, Anson, 2015). The most striking feature of the literature review was there were so few papers available on treatments of BDD in comparison to other mental disorders that have dedicated NICE guidelines (e.g. NICE guidelines for depression, 2010). OCD, which shares the NICE guidelines with BDD have a far greater number of treatment

outcome studies than BDD (NICE, 2006). Although attempting to take different approaches, the metaanalysis and literature reviews have limited studies to work with thus the ability to provide new information is restricted.

The process of conducting the literature search involved using the databases listed in Appendix D. Boolean terms were avoided to allow for a more specific array of papers to be identified relating to BDD. As not all search engines use the same Boolean rules, it is best not to use these operator words unless one knows exactly what the search is for e.g. the full title of a paper that was manually identified (Winder, 2007). Although literature reviewers for the Cochrane library use Boolean terms specific to each database, this was not practical with regards to available resources in this study (Higgins, Cochrane, 2011). To allow for linguistic differences in spelling of words, abbreviations were used and Americanised versions of words were added to the search terms.

Studies were also identified by a manual search in the references of published papers and books on BDD. The published treatment outcome studies are evaluated and results compared to examine the most effective interventions. This establishes a basis for evaluating the implementation of the NICE (2006) guidelines for OCD/BDD. One of the limitations of this literature review is that only published studies were evaluated. Although a search for unpublished studies was carried out via databases and manual searches of books and papers, just one was identified: Chandler, Benson (2015). The review process involved a global search however the majority of studies are from the United States. Indeed one particular author (Phillips) is one of the world's leading experts on BDD and has contributed a significant amount to the available literature on BDD thus is used as a reference extensively through this study.

Although this is a critical review of the literature, a systematic approach was taken to ensure transparency and to address limitations. Furthermore the Critical appraisal skills programme (CASP) was used to identify the most relevant papers for this study (Critical appraisal skills programme, 2018).

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# 2.2.1 Selection of studies

Papers were considered eligible if they met the inclusion criteria in Table 3.

Table 3: Eligibility criteria for selection of studies

INCLUSION CRITERIA	EXCLUSION CRITERIA
i) BDD was first included in the DSMIII-R as a diagnosis with criteria in 1987 and in the ICD-10 in 1992. Thus all papers regarding treatment outcomes of BDD from 1987 to current were considered relevant.	Articles prior to 1987 were excluded as the diagnostic criteria for BDD was unclear. Editorials and letters were excluded using the CASP criteria.
ii) All treatment related papers on BDD published in English.	Non-English publications were excluded if the databases did not provide an automatic translation application, as translation of papers was not possible due to resource constraints.
iii) All published treatment outcome studies of adult BDD sufferers and adolescents with BDD who were provided with the same treatment.	
iv) Articles where BDD is the primary diagnosis according to all versions of the DSM (APA, 1987; 1994; 2000; 2013) or the ICD (WHO, 1992; 1999; 2018).  v) All papers with clearly stated ethical approval.	Body Integrity Identity Disorder (BIID) and olfactory reference syndrome.

From the 140 published articles perused, 45 studies were identified as relevant (Appendix D). Studies that were reproduced elsewhere were considered as one article. Out of the relevant articles, there were 13 randomized controlled trials, eight

on cognitive behavioural therapy (CBT), four on medications and one on computerized interpretation bias modification.

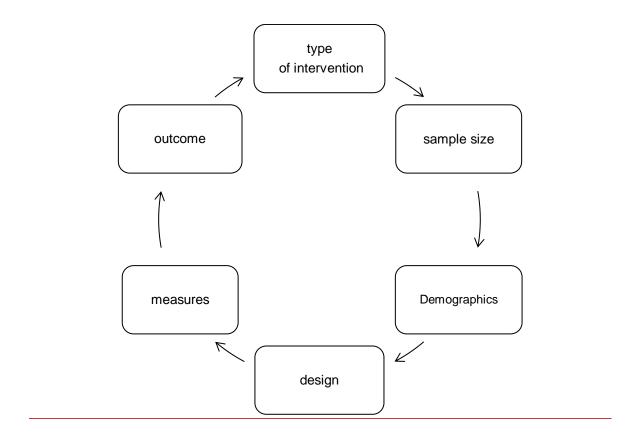
Table 4: Excluded studies

Number of excluded studies (N=96)	Reason for exclusion
2	Letters to editors
4	Children and adolescent studies
7	Review studies
15	BDD not the main diagnosis
68	Descriptive, non-interventional studies

#### 2.3 Data Extraction

The three main treatments were: psychological interventions, pharmacotherapy and medical procedures. The main psychological treatment was cognitive behavioural therapy (CBT) which included studies focusing only on exposure and response prevention (behavioural treatment); only cognitive therapy and both group and individual therapy. There was one additional treatment study using a cognitive modification approach. Pharmacological treatment studies are limited and the main medications used were Serotonergic Reuptake Inhibitor (SRI) and Selective Serotonergic Reuptake Inhibitor agents (SSRI). Medical procedures included electroconvulsive therapy (ECT), cosmetic surgery and minimally invasive procedures such as Botox and dental treatments. Variable types extracted from each paper are illustrated in Fig. 2.

Figure 2: Data extracted from each paper



The studies are presented in chronological order in Appendix E (Psychological interventions), Appendix F (Pharmacotherapy), Appendix G (Medical procedures). This provides an overview of the specific data which can then be cross referenced with the discussion of the main treatments and the contribution these papers have made to this study. Signposting to the treatment studies will be noted as Appendix label followed by numerical listing of the paper e.g. Appendix E: 1.

### 2.4 Overview of the development of the NICE guidelines for OCD/BDD

The NICE organisation describes a set of core principles which underlies the development of all their guidelines (NICE, 2018; Appendix X). The guidance for OCD/BDD has a well-documented description of the methods used to develop the guideline. There is little doubt that all available information for OCD has been included and the guidance is extremely thorough in all respects for OCD. However this seems less so for BDD.

Granted, the evidence base for BDD is not as prolific as OCD. The literature available regarding BDD at the time the guidelines were published were less than 70 papers with over 600 for OCD. However there are other aspects for BDD which appear to have been overlooked such as the section describing the impact of OCD on family and carers (NICE, 2006: 3.5). Unfortunately similar information for carers and family of BDD sufferers was not provided. Perhaps this is due to there not being representatives from carers or families of sufferers with BDD being included although a representative for OCD carers and families was on the panel. Could it have been assumed that it was sufficient representation to cover both disorders? In addition there were no patient representatives for BDD to contribute alongside the two patient representatives for OCD (NICE, 2006: pg. 6-7).

Having experience of working with both OCD and BDD sufferers, including within an inpatient setting, it is clear these patients do not present in the same way and their experiences are vastly different including the impact on their families and carers. One has to question whether it is fully representative of both disorders to have only patients with OCD contributing to the guidelines and similarly for carers/family members. Perhaps there may have been more parity between the representation of OCD and BDD if there were personal accounts from family/carers of BDD sufferers included as well. There were four accounts from family/carers of OCD sufferers and three from patients with OCD but just one from a patient with BDD (NICE, 2006: pg.47-72). This dearth of patient accounts is one of the driving factors for using mixed methods in this study. A recent publication of personal accounts of patients with BDD or their loved ones is the first of its kind to offer insight into their experiences (Schnackenberg, Petro, 2016). The positive reception given to this book highlights the need for more studies offering qualitative data which hold more meaning to sufferers of BDD and their carers as well as offering greater insight to the general public (BDD foundation conference, 2016).

The NICE guidelines for OCD/BDD (2006) were updated in September 2013 which included new treatment studies for OCD. There were no new studies included on BDD regarding treatment despite there being new studies available (NICE, 2013).

#### 2.5 Overview of the main treatments for BDD

With increased media exposure of body image concerns, BDD has drawn more attention in recent years (APPG, 2012; BAAPS, 2012; DoH, 2013; GMC, 2016). This has prompted more research and policy development into psychological treatments for body image concerns. However BDD has still not been the main focus of research until more recent media attention on the effect of cosmetic surgery and emergence of BDD concerns. The link between BDD and cosmetic procedures/surgery needs to be highlighted and is therefore included within this section on treatment.

## 2.6 Psychological treatments

Psychological treatments make up the bulk of the evidence base for managing BDD (Appendix D). Of this, CBT-based studies are in the majority. In addition, single publications were found on Eye Movement Desensitization and Reprocessing (EMDR); Psychodynamic Psychotherapy and Cognitive interpretation bias modification training within the time period investigated. The findings of the studies are displayed in (Appendix E).

#### 2.6.1 Cognitive Behavioural Therapy

CBT is the first line treatment recommended by the NICE guidelines (2006) for BDD. Studies have used different formats e.g. CBT, CT, BT and delivered individually or in a group setting (Khemlani-Patel, Neziroglu, Mancusi, 2011; Veale, 1996). This section depicting CBT treatments for BDD patients is divided into a review of treatment studies (n=4); case studies (n=3); RCTs (n=7); comparative studies (n=1) and variations of standard CBT treatment interventions (n=8). One of the RCTs is also a comparative study but since RCTs are the gold standard for research, it seemed more appropriate to include the study under that subsection.

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#### 2.6.1a Treatment Studies

Two of the treatment studies were of BT and two were CBT based. Retrospective studies are often criticised for providing inferior evidence compared to prospective studies. This is mainly due to factors such as convenience sampling; selection bias; higher possibility of misclassification and recall bias (Sedgwick, 2014). However retrospective studies can be more appropriate when sample sizes are small and a disorder may be considered rare or is not easily recognised, as with BDD (Vassar, Holzmann, 2013). This also supports the use of retrospective data analysis in this study to evaluate the outcomes of treatment.

A retrospective case note study on the outcome of BT for a sample of patients with BDD, showed improvement in 15 cases but 28% (n=6) were unimproved (Appendix E:5). It was also reported that patients with BDD did not respond as well to BT as patients with other disorders treated over the same time period. One of the recommendations was for future research to test whether adding CT to the treatment for BDD could lead to further improvement (Gomez-Perez, Marks, Gutierrez-Fisac, 1994). The study also found that patients who previously had cosmetic surgery had a poorer outcome.

Although at the time of its publication the study had the largest sample of patients with BDD (n=30), one would have expected a bigger sample considering patients were treated over a period of 19 years (Gomez-Perez et al., 1994). Unfortunately the authors do not discuss the reasons for the low referral rate of BDD patients which would have provided useful comparative information. Most of the studies discussed in this section had small sample sizes but although this may be a seen as a limitation, it is also indicative of the nature of the disorder with BDD sufferers having difficulty seeking help.

In recent years there has been increased public awareness of BDD due to media focus and celebrities talking about their experiences (Reuman, 2011; Lupkin, 2016; Wiseman, 2016). However people are still reluctant to seek psychological help for BDD (Vulink, Rosenberg, Plooij, et al., 2008; Ghadakzadeh, Ghazipour, Khajeddin, et al., 2011). Onset of BDD is described in a number of studies to be in early teens

and diagnosed usually by age 16 (Phillips, Menard, Fay, Weisberg, 2005; Phillips, et al., 2006). Yet as found in the BDD specialist service and the literature, sufferers of BDD usually have the problem for many years before seeking help (Veale et al., 1996; Phillips, Diaz, 1997).

Another aspect of the study by Gomez-Perez, et al., (1994) was that all participants had co-morbid disorders and social avoidance. The presence of comorbid disorders in BDD sufferers is given little attention even though this could have consequences for treatment (Baer, Jenike, 1992). However a study investigating CBT for individuals with BDD and comorbid Axis I and Axis II disorders, demonstrated the effectiveness of CBT for BDD despite additional diagnoses (Neziroglu, McKay, Todaro, et al., 1996; Appendix E: 8). There was no relationship found between number of personality disorders detected in subjects and the treatment outcome for BDD. Unfortunately the study lacked valid measures for depression and functionality relevant to evaluate the overall effectiveness of the treatment, particularly as both are factors to consider in BDD (Phillips, 1999; Phillips, et al., 2005; Phillips et al., 2008).

In a rare longitudinal study evaluating a BT and maintenance programme (relapse prevention and management) for BDD, patients (N=10) also had co-morbid anxiety and depression (McKay, Todaro, Neziroglu, et al., 1997). Findings indicated patients generally improved on BDD and depression symptoms, yet those in the maintenance group (N=5) continued to improve on measures of anxiety and depression post treatment and longer term (McKay, 1999).

However the study did not have a control group and the sample was small which restricts conclusions about efficacy. There was limited demographic data and additional information on the clinical presentation of the subjects. Information about the age range of patients, the gender distribution and education level was provided but no information was provided on marital status, ethnicity or employment. Similarly clinical information was presented on areas of BDD concern but no mention is made of comorbid disorders, impact of BDD on levels of functioning, suicidality, previous treatment, concurrent medication or any previous nonpsychiatric treatments such as cosmetic surgery. Despite these limitations, the paper contributes findings which

suggest that BT can provide a clinically meaningful decrease in BDD symptoms. It also highlights the importance of relapse prevention to possibly reduce the number of patients who require further episodes of treatment. This would help to lessen the burden on an already strained NHS in the UK (Bell, Jarvie, 2015).

A further study into the effectiveness of CBT examined the treatment outcomes of 13 patients which consisted of group treatment and additional individual treatment for three patients with higher symptom severity (Wilhelm, Otto, Lohr, et al., 1999). The subjects showed significant reductions in BDD symptoms on Y-BOCSBDD (Appendix E: 11).

The authors note that due to the pressures by the organisations commissioning their services, group CBT was considered the more economically viable option (Wilhelm et al., 1999). However it is heartening to note that where indicated due to severity of patients' presentation, the authors nevertheless conducted additional individual therapy. The results from the group treatment were similar to those found in individual treatment (Veale, 1996) with regards to reduction in symptoms. This was also found in an audit of group treatment of BDD conducted in the BDD specialist service (Chandler, et al., 2015, unpublished). There was no exclusion criteria based on comorbidity which allows for generalisation, despite the small sample size. It would have been useful if the authors had used measures of functionality to identify if any changes occurred following treatment, considering their description of the impact of BDD on the participant's lifestyle (Wilhelm et al., 1999).

Despite the positive results from the longitudinal BT study, there still remained a fairly large percentage that were unimproved in the other studies (Gomez-Perez et al., 1994; Neziroglu, et al., 1996; Wilhelm, et al., 1999). There were also inconsistent findings in the two BT studies with one reporting a much lower response rate (Gomez-Perez et al., 1994). One of the recommendations was for future research to test whether adding CT to the treatment for BDD could lead to further improvement (Gomez-Perez et al., 1994).

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#### 2.6.1b Case Studies

There were three case studies found all using different elements of CBT and also a variety of frequency and lengths of treatment. Similarly to the BT studies previously reviewed, the CT only treatment studies also showed some improvements but including BT was considered for added benefit. Efforts were made to compensate for the small sample sizes by ensuring gender groups were equally represented, demographic details were gathered and subjects were included if they had comorbid disorders. Unfortunately despite the small sizes of samples in these case studies, none included qualitative data on the patients' experiences. This would have provided more clarity to understand the outcomes.

In a study of five patients treated with ERP and CT, treatment was of varying length with some patients having intensive therapy five times per week and others having weekly sessions (Neziroglu et al., 1993). Although improvements were reported, the findings would have had more merit if they were compared and explained with regards to differences in severity and reasons for different lengths of treatment. The overvalued ideation (OVI) scores were reported however not all the BDD-YBOCS scores were stated. Also since it was a small sample size it was conceivable to have included an account of patient's experiences to further explain the findings.

The second case study examined the role of CT in treating BDD (Geremia, Neziroglu, 2001). Results indicated that CT resulted in statistically significant reductions in BDD symptoms in two out of four subjects (Geremia, et al., 2001). The rationale for some aspects of the design was not clarified such as assigning patients to separate groups of different duration for data gathering. Furthermore one of the patients who was reported to have significant reductions in BDD symptoms after treatment attempted suicide following a derogatory comment made by a psychiatric patient at the day programme. The improvement therefore has to be viewed with caution as the patient's perception of themselves was clearly still extremely fragile. It can therefore be argued that the benefit of adding in behavioural techniques may help to prepare patients for eventualities such as this and provide a firmer foundation for the reduction of BDD symptoms (Veale et al., 2010).

Still if using CT initially to engage the patient could increase compliance and produce some symptom reduction, it may be easier for the patient to participate in the more difficult behavioural exercises (Geremia et al., 2001). This may possibly explain the reports that subjects spontaneously exposed themselves to social situations as their BDD symptoms improved. Follow up was only of short duration (3-5 weeks post treatment) thus long term effects of the treatment could not be determined.

In contrast, a single case study explored treatment of BDD using only BT (Rabinowitz, Neziroglu, Roberts, 2007). Pre-treatment the subject had BDD symptoms within the extremely severe range and depression symptoms within the severe range. Intensive treatment was conducted 5 days per week over 6 weeks. The patient also participated in group therapy once per week. This intensity of treatment is unusual but the authors believed this to be necessary due to the severity of the patient's presentation and impairment in functioning.

Following treatment the patient's scores on Y-BOCSBDD dropped to moderate range and depression scores dropped to mild range. After one year of treatment the patient is continuing to have treatment twice weekly for 45 minute sessions to maintain the improvements he made. The patient was also on medication but the dosage of one medication was reduced during therapy and the other reduced and stopped without any adverse effects on symptoms. The level of intervention required prompts the question of whether the patient could have benefitted more from inpatient admission and whether that could have reduced the duration of the treatment.

Currently there are no known studies examining inpatient treatment for BDD specifically but a study into inpatient treatment of OCD and BDD using CBT and medication revealed 42% reduction in symptoms at the end of treatment which is on average four months with a maximum of six months consisting of a combination of individual and group therapy (Drummond, Fineberg, Heyman, et al., 2008). Unfortunately the results were not independently reported for BDD. Also there are few inpatient facilities of this type available for treatment of BDD both in the UK and the USA (BDD Foundation, 2013; BDD Alliance, 2016).

# 2.6.1c Comparative study

In the first known study to compare CT and BT in treating BDD, participants (n=17) were assigned alternately to either CT or BT groups to determine whether there was benefit from adding in CT to BT in a combined approach following a treatment protocol (Khemlani-Patel et al., 2011). The CT group had treatment for 12 weeks followed by BT forming a combined treatment whilst the BT group had 24 sessions of only BT. Both treatments were found to be as effective in reducing BDD symptoms. However the sample was small; lacked a control group and blind assessment. The combined treatment of CT and BT was again no more significantly effective than BT alone (Appendix E: 15). This was an unexpected result as their hypothesis was that a combined treatment of CT and BT would result in significantly greater improvements than BT alone (Khemlani-Patel et al., 2011).

A longer duration of treatment may show different outcomes particularly in functioning and quality of life as the onset of BDD may be many years before seeking treatment (Veale et al., 1996; Phillips, Diaz, 1997). Therefore a short course of treatment is insufficient time to address the overall impact of the disorder (Khemlani-Patel et al., 2011). This study addresses pertinent issues relating to the clinical presentation and treatment of BDD and makes recommendations for treatment of BDD beyond CBT to a more holistic approach including support for employment and training to improve social skills.

### 2.6.1d Randomised controlled trials (RCT) of CBT

From the literature reviewed there are seven RCTs of CBT treatments for BDD to date. All the trials presented encouraging results for the effectiveness of CBT.

The first two RCTs were focused only on female participants (Rosen, Saltzberg, Srebnik, 1989 Appendix E: 2; Rosen, Reiter, Orosan, 1995 Appendix E: 6). Interestingly none of the patients dropped out in either study, considering it is often difficult to engage BDD sufferers in therapy (Marquesa, Weingarden, LeBlanca, et al., 2011). In the second study a cancellation policy was used if any member of the group was unable to attend (Rosen, et al., 1995). This may have served as an

incentive using peer encouragement to attend each session. There is no indication if this or a similar incentive was also used in the first study. Although the results of both studies were promising, the findings were limited by the samples being exclusively female. This restricts the generalisability of the results of both studies, given the similarities in incidence and areas of preoccupation in both genders (Phillips et al., 1997; Tyagi et al., 2013). In addition the studies' findings are weakened by the predominant focus on body image concerns such as weight, size and body shape rather than BDD symptoms (Rosen, et al., 1989; Rosen, et al., 1995).

Following on from this earlier work, a RCT randomly assigned patients (n=19) to CBT (n=9) or no treatment waiting list control group (n=10) for 12 weekly sessions and excluded patients whose primary concern was weight and body shape (Veale, Gournay, Dryden, et al., 1996; Appendix E: 7). The results were promising yet generalisability was limited by the high proportion of females (90%) similar to the previous RCTs as well as the small sample size and exclusion of delusional patients. Considering the incidence of delusionality in patients with BDD tends to be relatively high to the extent this criterion has been added to the DSM V and ICD 11 diagnostic criteria for BDD, these patients should be represented in the sample (Phillips, 2006; APA 2013; WHO, 2018). In addition there was no indication of the presence of concurrent psychotropic medication plus a lack of follow up ratings.

There seemed to be a hiatus at this point in the CBT treatment studies on BDD with no further publications until more recently. A possible reason for this may be that experts in the field were considering different approaches to applying CBT to address inconsistencies with treatment outcomes. This is borne out in the more recent publications of CBT treatment trials. A treatment manual was developed expanding on standard treatment for BDD by adding in five flexible "modules" of CBT selected according to need (Wilhelm, Phillips, Fama, et al., 2011). The treatment was developed by bringing together the different proposed CBT models and neurocognitive studies (Wilhelm et al., 2010; Veale et al., 1996; Wilhelm, Neziroglu, 2002; Deckersbach, Savage, Phillips, et al., 2000; Feusner, Townsend, Bystritsky, et al., 2007; Feusner, Moody, Hembacher, et al., 2010). This is an innovative approach bringing together the elements of CBT to devise a treatment package that addresses the complex presentation of BDD. This is achieved by providing individualised

treatment regimes for additional symptoms that often co-exist with BDD such as skin-picking, hair plucking, muscularity or weight concerns and mood management. There was also a module on psychoeducation for those considering cosmetic surgery.

This approach was then tested in a pilot study which showed improvements in BDD symptoms to the subclinical range (Wilhelm et al., 2011; Appendix E: 16). This pilot study was followed up with a RCT using the modular CBT treatment (CBT-BDD) manual (Appendix E: 20; Wilhelm, Phillips, Didie, et al., 2013). At the end of 24 weeks the combined sample of treatment completers showed an average 55% decrease in BDD-YBOCS scores indicating 83% of the treatment completers were responders. The results of this study are unfortunately weakened by a lack of alternative treatment to compare efficacy especially given that the waiting list participants also showed improvements. Despite the limitations this paper describes a more comprehensive form of CBT treatment aimed at individualised care for different aspects of BDD as well as more global factors such as such as risk, motivation and patient satisfaction.

In the initial study patient feedback was collated and themes reported (Wilhelm et al., 2011). In the RCT reasons were provided for patients dropping out of treatment and direct quotes from patients were included. This was the only study to provide patients' comments on experiences of completing treatment. All the comments were positive plus reasons reported for patients dropping out of treatment were not directly related to the treatment itself (Wilhelm, Phillips, Steketee, 2013).

This is encouraging as there are often non-completers and non-responders in CBT studies, the reasons for which are rarely reported or discussed in the literature (Appendix E). For the purpose of improving treatment options for BDD sufferers positive responses need to be examined as much as negative ones to ascertain, from the patient's perspective, what works and what is less helpful. In recent years incorporating qualitative information into studies is more commonplace as the importance of patient experience has been identified as a factor in improving effectiveness of service delivery (Boiko, Campbell, Elmore, et al., 2015; Weich, Fenton, Bhui, et al., 2018).

In a further shift from standard CBT, a RCT was conducted to investigate the effectiveness of using Metacognitive therapy (MCT) to treat BDD (Rabiei, Mulkens, Kalantari, et al., 2012). MCT is based on a theory to treat generalised anxiety disorder but was broadened into a general treatment approach (Wells, Matthews, 1994; Wells, 2000). This is the only study on MCT for treating BDD (Appendix E: 17). Metacognition refers to beliefs about thinking (Moses, Baird, 1998). Metacognitive therapy focuses on these beliefs which are considered to regulate thought processes and causes a pattern of response which maintains negative emotions, images or other intrusions (Wells, 2000).

The use of the Thought Fusion Instrument (TFI) provided a measure of improvement in the symptoms of cognitive fusion which is described as a fusion of internal events with past experiences which impact on behaviour patterns (Hayes, Strosahl, Wilson, 1999; Feusner, Yaryura-Tobias, Saxena, 2008; Neziroglu, 2010). This belief structure is often seen in BDD presentation and examining this was a useful contribution to the understanding of how therapy can impact on these belief structures (Cooper, Osman, 2007). Patient satisfaction was reported as moderate to high. Considering the limited qualitative information available in studies on BDD, it would have been valuable to have patients' quotes reported. Nevertheless this study makes an important contribution to the body of knowledge about BDD treatment as no other literature on MCT and BDD was found.

Likewise comparative studies for BDD were not available until relatively recently when CBT was compared to anxiety management (AM) (Veale, Anson, Miles, et al., 2014; Appendix E: 19). The trial also reported on the outcome on delusionality and depression with treatment including imagery rescripting for distressing memories associated with the onset of BDD and habit reversal for skin picking. Unfortunately due to the discrepancy in the end points between the two treatment groups, the study could not conclude that CBT had greater efficacy than AM (Veale et al., 2014). In an exploratory study these patients were followed up from one to four years post treatment (Veale, Miles, Anson, 2015). Most of the patients were able to maintain their gains in follow up with 11 (28.2%) in full remission. One of the findings was that patients who did not maintain the 30% improvement had more symptoms of

depression than those who did. However the findings have to be treated with caution as there were also ten patients who had received further psychological treatment after the initial study. Due to the retrospective design of the follow up study, the improvements cannot be conclusively linked to the initial CBT treatment.

Generally the findings provide evidence for CBT in its combined format for treating BDD supporting the NICE guidelines' recommendations (NICE, 2006). Still from the studies reviewed and literature on BDD there are patients who do not respond to treatment with CBT or who drop out of treatment early on (Marquesa et al., 2011). Some of the problem areas are: difficulty engaging patients in therapy, dropout rates, also motivation to change which is an important factor in ensuring engagement with CBT especially as the interventions are difficult (Folke, von Bahr, Assadi-Talaremi, et al., 2012). Participants with comorbid disorders were included in all studies but some neglected to provide measures to determine changes in symptoms such as depression as well as levels of functioning which tends to be most commonly associated with BDD (Nierenberg, Phillips, Petersen, et al., 2002; Phillips et al., 2008). A combination of approaches appears to be beneficial and adjustments made to the standard treatments have shown positive impact (Wilhelm et al., 2011; Rabiei et al., 2012). However only two studies reported on patients' experiences which would have given validity to positive outcomes in the other studies. The continued search for a treatment modality that works best has seen adaptations of standard CBT for BDD in the last few years.

### 2.6.1e Adapting CBT treatment

This section illustrates eight studies which have a basis in CBT and have been adapted or augmented to address some of the problem areas described above (Fig. 3). There is one study of each intervention apart from imagery rescripting and internet based CBT which have two studies each.

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# Behavioural and interpretative methods

A case study of a university student with BDD found that although improvements were made in ERP, the patient became resistant to further exposure interventions and therapy became stagnant (Watts, 1990). Interpretative intervention was then introduced which takes the form of psychoanalytic treatment with the theory of the patient's resistance to becoming an adult. Further ERP was conducted thereafter and the patient was also provided with cognitive interventions to enable him to challenge his thinking patterns and develop an acceptance of his physical appearance. Unfortunately there were no measures of symptomatology but then again, using a variety of psychotherapeutic methods does not lend itself easily to scientific measurement. The gains obtained with the use of ERP were clearly described. However with the addition of interpretative methods the patient was helped to overcome obstacles in traditional behavioural treatment and make additional progress.

The literature often describes behavioural treatments as challenging (Hartmann, Greenberg, Wilhelm, 2016; Wilhelm, et al., 2013). There are times in clinical practice when a patient's progress appears to plateau and continuing along the same track does not generate further improvement. One can question whether the addition of other interventions can be helpful in overcoming obstacles to progress. The nature of the treatments presented in this case study, although useful in this one case, make it difficult to replicate in a large scale study as it is an individualised treatment package for specific circumstances. It cannot be seen as generalisable although it is thought-provoking for the concept of individualised packages of treatment.

# Culturally adapted CBT

Cultural influences and ethnicity is another area of very limited study in BDD (1.2.2b, pg. 11). An important issue in treating and engaging people with BDD from different ethnic backgrounds was addressed in this case study (Weingarden, Marques, Fang,

et al., 2011). Incorporating ethnic identity and cultural backgrounds in treatment appeared instrumental in the subjects' improvements. The results should also be considered in context of the use of medication. Subject A had a lower baseline score than Subject B and improved to no symptoms on medication however whilst Subject B was of higher severity and not on medication, he also improved to subclinical symptoms. The limitations of the study are having just 2 patients which make generalising findings very restricted. The authors also acknowledge that they were unable to control for confounding variables such as the impact of the therapist with regards to ethnicity and the therapeutic relationship (Weingarden, et al., 2011).

This topic is largely neglected in the literature and this is the only known paper to discuss CBT for BDD from a cultural perspective. This is especially relevant where people have experienced actual discrimination and this may further impact on their perception of themselves. Ethnically appropriate physical features may be focused upon as a source of concern if the individual has difficulties with their ethnic identity (Ishigooka, et al., 1998).

# • Inference based therapy (IBT)

According to the IBT approach, obsessions are doubts which are internally generated with an idiosyncratic reasoning process causing the individual to be unsure of their own senses and logical thinking (O'Connor, Ecker, Lahoud, et al., 2012). IBT focuses on the reasoning process (inferential confusion) which creates the doubt and aims to change this to restore a more functional perception (O'Connor, Aardema, 2011). IBT was developed to enhance the cognitive approach for patients with BDD presenting with high OVI (Taillon, O'Connor, Dupuis et al., 2013).

A study exploring the use of IBT for BDD showed significant improvement in BDD symptoms from baseline to post treatment (Taillon et al., 2013). There was also reduction in depression symptoms and OVI. However the Inferential Confusion Questionnaire (ICQ) showed no significant difference from pre to post treatment. Considering the concept of inferential confusion is the focus of IBT, the lack of meaningful change does not support the intervention's hypothesis. Although the

authors attempt to explain the lack of change, their conclusion is that the ICQ needs to be modified to measure inferential reasoning in BDD.

Although this study produced some improvements in BDD symptoms which were maintained at six month follow up, it was not proven superior to CBT from comparison of effect sizes (Taillon et al., 2013). Interventions such as IBT attempt to provide a different approach to some of the more complex aspects of BDD such as OVI. Although this is commendable, it may be more beneficial to develop a clearer understanding of BDD in all its complexity to inform development of the most effective treatment methods. As yet there is no definitive model to understand the mechanism of BDD although there are both psychological and medical conceptual models proposed as an explanation of BDD (Veale et al., 1996; Neziroglu et al., 2004; Feusner et al., 2008).

#### Internet based CBT for BDD

There are CBT based internet treatments already established for depression and anxiety disorders including OCD (Beating the blues; Fearfighter), however it has not been widely explored for BDD. Internet based CBT is an innovative, cost effective and widely accessible means of providing psychological treatment (Gratzer, Khalid-Khan, 2016). NHS England has approved the use of BDD-NET as one of the 14 digital products being evaluated (NICE, 2019).

There have been recent innovations in investigating internet use to treat BDD (Enander, Ivanov, Andersson, et al., 2014; Gentile, La Lima, Flygare, et al., 2019; Appendix E: 24; 25). The findings of both studies were promising with significant improvement from baseline to post treatment with further gains made at 3 month follow up.

Dropout rates were low in the first study with just one patient who disengaged (Enander, et al., 2014). In the second study seven dropped out which is in keeping with most of the psychological treatment studies reviewed (Gentile, et al., 2019; Appendix E). However in both studies participants also reported the treatment elicited adverse reactions especially in the initial part of treatment with new

symptoms and deterioration of symptoms being most experienced (48% and 25% respectively; Enander, et al., 2014; Gentile, et al., 2019). Nevertheless overall patient satisfaction indicated the majority of the patients were pleased to very pleased with the treatments. The findings are promising for further controlled studies to be carried out. However some basic information was lacking in these studies such as the ease of use of the program; assessing the ability of patients to use technology; whether the age of participants has any bearing on technological skill. Also in the global study the majority of participants were from Western countries with easy access to technology and all spoke English. These are factors to be considered if further studies are planned. Also of note was the level of severity which was in the moderate range and patients were all self-referred which usually has more positive implications for motivation to change (Mataix-Cols, Cameron, Gega, et al., 2006).

## Acceptance-based exposure therapy

Similar to IBT, acceptance based treatment attempts to redress areas within CBT where patients show low response or drop out of treatment (Linde, Rück, Bjureberg, et al., 2015). In contrast to IBT however, the focus is primarily on the behavioural intervention of exposure rather than cognitive treatment. A pilot study evaluated the addition of psychoeducation and acceptance and defusion into exposure interventions (Linde, et al., 2015; Appendix E: 21). The acceptance and defusion aspects involve being aware of unpleasant emotions, thoughts or physical sensations without avoiding them or engaging in the misgivings created, but continuing with everyday activities. The aim is to develop a willingness to allow for and observe these experiences from a different perspective. Results showed clinically significant improvement in BDD maintained at six month follow-up. But most interesting was the dropout rate was just two patients. One of those was reported to have improved after two sessions and discontinued treatment and the other cited practical difficulties in attending the sessions (Linde et al., 2015). Given that exposure is already an established treatment method, there is no conclusive indication for the use of acceptance-based treatment (McKay et al., 1997; Khemlani-Patel et al. 2011). Nevertheless it is the low attrition rate rather than symptom reduction that appears significant in this study. An intervention that can assist in reducing dropouts warrants further investigation in controlled studies of CBT.

Although the authors report feedback from patients this aspect of the study would have been more useful had patients' experiences been recounted (Linde et al., 2011: pg. 15). This is a further validation for the need for qualitative studies in treatment for BDD.

# • Imagery Rescripting (ImR)

Studies into the characteristics of BDD have uncovered a phenomenon in sufferers of BDD where they experience not just thoughts but negative images of their appearance (Osman, Cooper, Hackmann, et al., 2004). Furthermore BDD sufferers also describe more aversive memories relating to appearance e.g. bullying, derogatory comments, than non-BDD sufferers (Buhlmann et al., 2007; Buhlmann, 2011). ImR has been used as an intervention alongside CBT (Rabiei et al., 2012; Veale, et al., 1996; Wilhelm, et al., 2013). A study was conducted to investigate the efficacy of ImR as a standalone treatment for patients with BDD linked to aversive past experiences (Willson, Veale, Freeston, 2015; Appendix E: 22). One of the striking aspects of this study is how quickly improvements occurred in those patients who responded. The efficiency of just one session resulting in change is of interest especially as BDD is considered a condition that is difficult to treat and takes several sessions to see any improvement (Cotterill, 1996; Wilhelm, et al., 1999; McKay 1999).

However three of the patients had previous CBT and two of those were responders to ImR. Despite the CBT being at least six months prior to the assessment for the study, improvements following CBT have been shown to continue into follow up at six or even 12 months post treatment (Gomez-Perez et al., 1994; McKay et al., 1997; Wilhelm et al., 2011). Therefore it is difficult to ascertain whether there was some influence from the previous treatment. On the other hand from the two patients who did not respond, one also had previous CBT. It is also a small sample from which findings cannot be generalised. Therefore this study does not provide conclusive evidence of the efficacy of ImR, although it is an interesting concept and should be further investigated.

Further study in the use of imagery rescripting was included in cognitive therapy to treat BDD where all patients in the sample had intrusive images relating to aversive memories (Ritter, Stangier, 2016, Appendix E: 23). Although improvements were reported, again the sample was small and there was no control group. However unlike the previous study, details of the patients who did not respond to ImR are provided, which is an important aspect to consider when wanting to replicate this research (Willson et al., 2015). The authors acknowledge that improvements could have been affected by other factors such as therapeutic alliance and as it was included in a package of cognitive therapy, it is difficult to assess the impact of ImR on its own (Ritter et al., 2016).

These are the first studies to explore the use of ImR in BDD. Both studies raise queries for including this element as an intervention in CBT for BDD. The improvements shown may contribute to individualising treatment programmes for BDD in patients with a specific presentation.

# Summary of adapted studies

These studies used the basis of CBT to varying degrees with some adding and enhancing the field of CBT for BDD whilst others had a more tenuous connection (Fig. 3). From the six studies reviewed, two factors which could prove especially useful for future development in BDD treatment are internet based interventions and adapting treatment to be culturally sensitive. These aspects can be more widely beneficial to patients with BDD. However from the other studies, it appears that various interventions were trialed to test out theories of effectiveness (Watts, 1990; Taillon et al., 2013; Linde et al., 2015; Ritter et al., 2016; Willson et al., 2015). Although there were interesting findings which could possibly help in reducing attrition rates and lack of response, these studies have little to add to improve on CBT for BDD apart from where individual or specific circumstances may warrant these.

# 2.6.2 Additional psychological treatments

Three additional psychological treatments of BDD were found in the literature. None of these are recommended in the NICE guidelines (2006) for treating BDD however with the limited body of knowledge available other avenues can still offer some insights.

# 2.6.2a Psychodynamic therapy

A case study using psychodynamic psychotherapy to treat a patient with BDD centred on the formulation of the patient's relationship with her father (Bloch, Glue, 1988). Through the therapeutic process, the patient was able to develop a positive transference and worked towards addressing her interpersonal difficulties and poor self-esteem (Bloch, et al., 1988). The paper has merit in describing the context in which psychodynamic psychotherapy could potentially be useful in treating BDD. In particular, cases where underlying family difficulties may play a part. However this is just one case where progress was found and the authors cite other studies reporting failed attempts to treat patients with BDD using psychodynamic psychotherapy (Bloch, et al., 1988; Beary, Cobb, 1981; Brotman, Jemke, 1984). Unfortunately there are no measures to rate the level of severity of symptoms at baseline, post treatment or follow up but measuring outcomes is associated with a CBT model rather than a Psychodynamic one. Although the emphasis is currently on measurable outcomes, there may still be potential benefit of Psychodynamic psychotherapy in specific cases (Department of Health, 2011).

# 2.6.2b Eye Movement Desensitization and Reprocessing (EMDR)

At a time when EMDR was still only a recent development and was mainly used to treat Posttraumatic Stress Disorder (PTSD) a trial was conducted to treat BDD using EMDR (Brown, McGoldrick, Buchanan, 1997).

A common factor in six of the seven patients who responded to treatment was the presence of intense intrusive imagery which is often experienced in PTSD (APA, 2000). Five patients reported the onset of BDD to follow on from a casual comment made about the individual's appearance. The suggestion is that this experience

carried the intensity of a traumatic event with accompanying intrusive imagery (Brown et al., 1997). However not everyone subjected to chance remarks about their appearance will develop BDD. The authors consider that this perception may be influenced by the patient's personality but do not elaborate further. Improvements were reported over a short series of treatments; between one and three sessions which was also found in the Imagery rescripting study (Willson et al., 2015).

The rapid response rate makes this a possible option to consider especially in BDD cases where there have been traumatic experiences (Veale et al., 2010). Unfortunately there are clinical and demographic aspects either unreported or lacking in clarity. There were no measures of symptom severity reported therefore there is no indication of how improvement was measured or what level of severity patients were at pre- treatment. It is also unclear who treated the patients and what their experience was in treating BDD. The authors express their surprise at the positive results obtained and recommend more rigorous studies are conducted into the use of EMDR in treating BDD.

### 2.6.2c Modifying interpretation biases

The use of technology in treatment has been a growing field and may prove an accessible and appealing medium for BDD sufferers (Enander, et al., 2014; Hedman, 2014). A study evaluating the use of computerized treatment to reduce social evaluation and appearance-related interpretation biases in BDD was conducted with a sample of university students and community members (Summers, Cougle, 2016; Appendix E: 25). The findings indicated improvements in BDD symptoms for those participants with higher pretreatment scores (Summers, et al., 2016). Participants were in the mild range of pretreatment scores and it is questionable whether they had appearance concerns rather than a diagnosis of BDD. There were also no improvements on depression and anxiety symptoms. The study provides some additional information of interpretation biases in BDD however has little to add to treatment options especially for patients with moderate to severe BDD.

# **2.6.3 Summary**

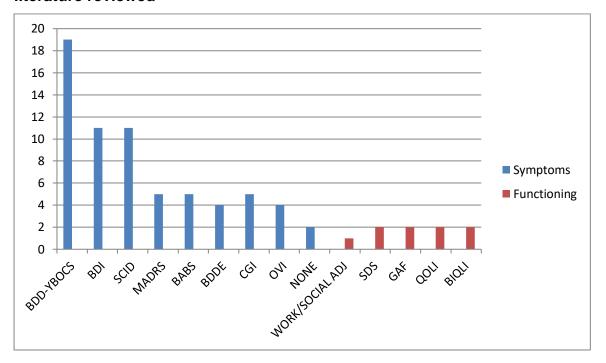
There is undoubtedly some evidence from the literature reviewed that CBT is the most effective psychological treatment for BDD which is supported by findings in metaanalysis and literature reviews (Williams et al., 2006; Ipser et al., 2009; Prazeres, et al., 2013; Harrison, et al., 2016).

However studies reviewed indicate there are still improvements to be made and there are still patients who do not respond to CBT or drop out of treatment (Appendix E). Limitations in most studies included small samples sizes and generally a higher proportion of females than males. Other issues also need to be addressed such as ethnic diversity and the need for the models of treatment to be adapted accordingly which has shown effectiveness in case studies (Weingarden et al., 2011).

Several studies reviewed also explore variations on the standard CBT treatment in an attempt to remedy the shortcomings of traditional CBT. Internet based CBT for BDD produced results that appear promising as an alternative, cost effective and more accessible method of delivering CBT. Furthermore with onset of BDD being in adolescence, use of technology will be more appealing to the younger generation of BDD sufferers who are digital natives (Prensky, 2001). Treatments such as Metacognitive therapy show some promising results and may be an alternative to standard CBT for those patients unable to engage in the behavioural component of CBT. However none of the studies presented conclusive evidence for the addition of interventions or variations to standard treatment. Apart from ImR, all the adaptations in treatment were one-off studies. More attention should be given to enhancing the CBT model by considering a holistic view of the patient rather than what appears to be trials of novel interventions.

One of the restrictions in reviewing the available literature is the use of a variety of different measures which makes outcomes across different studies difficult to compare (Graph 1). The BDD-YBOCS was used in 18 out of 24 papers reviewed; the BDI was used in 11 papers and the SCID in 10 papers. There was no consistency in the use of measures. Just eight studies used measures to rate patients' levels of functioning and again there was no consistency with five different measures being used. Three measures were used in two studies each and two measures were used in one study each.

Graph 1: Measures of symptoms plus functioning: frequency scales used in literature reviewed



A significant theme emerging from the literature review is the sense that treatment for BDD is trial and error. It is recognised that CBT although found to be effective, does not lead to complete remission of BDD symptoms (Phillips, Grant, Siniscalchi, et al., 2005). However the reasons for this are not being fully explored to enable a well-informed decision of how to proceed with treatment options to best treat BDD. Instead it could be suggested that researchers want to be the first to create a new improved version of CBT to treat BDD based on some of the one-off studies reviewed (Watts, 1990; Taillon et al., 2013; Linde et al., 2015). Although it is vital to provide effective treatment to people with BDD and any research into treatment efficacy is welcome, it is clear that BDD is still not sufficiently understood for a clear treatment model to be developed (Phillips, 1991).

### 2.7 Pharmacological treatment

There is currently no medication specifically licensed for treatment of BDD (FDA, 1998; MHRA, 2004). Only a few studies have been conducted into pharmacological treatment for BDD but none have been designed to obtain FDA or MHRA approval

(Phillips et al., 2008). The findings of the studies are in Appendix F. There are four RCTs, four open label trials, two case studies and one retrospective case note study. The focus in the literature has been mainly on Serotonergic Reuptake Inhibitor (SRI) and Selective Serotonergic Reuptake Inhibitor agents (SSRI) for treating BDD (NICE, 2006). There have also been investigations into augmentation of SSRI medication with dopamine blockades (antipsychotics) which have produced mixed results (Williams et al., 2006; Ipser et al., 2009).

# 2.7.1a Serotonergic Reuptake Inhibitor (SRI) and Selective Serotonergic Reuptake Inhibitor agents (SSRI)

One of the criteria for the OCD/BDD specialist service is that patients need to have been offered two trials of SSRI medication alongside CBT before being referred.

"No RCTs have been conducted that compare an SRI or any other medication with CBT or a combination of the two. There are a few case reports of combination treatments highlighted in the psychological interventions but they do not assist in guiding clinical practice" (NICE, 2006: 7.3.13 pg. 189).

Nevertheless given the high levels of distress and often comorbid conditions experienced by patients with BDD cared for by the service, the majority usually require SRI or SSRIs to enable them to engage in therapy. There is one study on an SRI and four on SSRIs included in this study (Appendix F).

The first RCT investigating pharmacological treatment of BDD compared SRIs Clomipramine with Desipramine (Hollander, et al., 1999). Apart from general support, therapy was not provided thus allowing for a clearer indication of the medications' effectiveness. Participants (n=22) also had at least one comorbid disorder but this was reported to have no influence on treatment outcome similar to findings in psychological treatments (Neziroglu, et al., 1996; Wilhelm, et al., 2011). Despite the high dropout rate, this study provides a holistic view of the effectiveness of Clomipramine in treating BDD.

Apart from the improvement in BDD symptoms, this trial produced findings particularly significant to inform clinical practice: firstly the delusional patients

showed equivalent and additional progress compared to nondelusional patients. This could mean patients with a delusional level of BDD may not require adjunctive antipsychotic medication. Considering the adverse effects and long term physical consequences of taking antipsychotics this would be a much preferred option for best practice (British National Formulary, 2009; NICE, 2014). Secondly improvements in functional impairment in a condition where patients are usually severely disabled gives hope that their quality of life can be improved (Frare, et al., 2004; Phillips et al., 2006). Clomipramine was well tolerated and drop outs were not due to side effects.

One of the limitations was a lack of placebo control which would have provided an efficacy standard against which to measure the treatment effect. Although, using another similar medication as an active control protects the double-blind. There was also no maintenance phase after the crossover which could result in participants carrying over the effects of the previous medication. This is often found in pharmacological interventions using a crossover design (Maclure, Mittleman, 2000).

Despite the promising findings there have been no further investigations into the use of Clomipramine for BDD. However this paper paved the way to encourage further research and more rigorous RCTs of pharmacotherapy for BDD.

The first SSRI studied in a RCT was Fluoxetine (Phillips, Albertini, Rasmussen, 2002; Appendix F: 3). Delusional patients showed improvement in BDD symptoms to the same extent as nondelusional patients with fluoxetine, similar to previous study findings (Hollander et al., 1999). The time to noticed effect with Fluoxetine was slow despite the rapid increase in dosage; still the medication was well tolerated. Patients were excluded if they had previous medication from two weeks to six months prior to the trial depending on the agent. However six participants were concurrently receiving non-CBT based psychotherapy which started prior to the trial. Three of these patients were in the treatment group and three in the placebo group. The reasons for including these patients are not further elaborated and no separate data is provided on these patients to describe the impact of receiving therapy with medication or placebo. The results therefore may not be a true reflection of the effectiveness of Fluoxetine.

The generalisability of the findings of this study is restricted by the exclusion of patients with suicidal ideation although this was in accordance with FDA regulations (FDA, 1998). Mild cases were also excluded to avoid results being skewed with possible responses to placebo which have been found in other studies (Coryell, Noyes, 1988; Wilcox, Cohn, Linden, et al., 1992). Nevertheless further investigation is warranted into patients with mild symptoms as a means to prevent worsening of the condition and aid in early intervention. This is especially given that people with BDD tend to present for treatment after a long duration of the disorder when the condition has deteriorated (Veale et al., 1996; Phillips, Diaz, 1997).

The RCT of Escitalopram was the first prospective study on relapse prevention in BDD (Phillips et al., 2016). As with previous studies, BDD symptoms and functional impairment showed significant improvement. The striking results were the significant difference in time to relapse which was longer in the treatment group compared to the placebo group (Appendix F: 11). Given the OCD/BDD service routinely follows up patients for a year post treatment, relapse prevention is an important aspect of the work undertaken with each patient.

Studies in open label trials of Citalopram and Escitalopram produced similar results (Phillips et al., 2003; Phillips, 2006). With both Citalopram and Escitalopram the time to response was similar to Clomipramine. Both agents produced significant improvement in BDD symptoms from baseline and significant improvement in functional impairment and quality of life. In addition significant improvements were found in BDD delusionality as well. These studies although not rigorous RCTs, still contribute to the possible effectiveness of SSRIs.

### 2.7.1b Treatment with Serotonin Norepinephrine Reuptake Inhibitor (SNRI)

The NICE guidelines states that most antidepressants, including venlafaxine should not normally be used to treat BDD without comorbidity (NICE, 2006). There have been two studies using Venlafaxine for treating BDD:

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In the first case study full remission was reported however the stated improvement was unable to be tracked as there were no measures described (Amâncio, Magalhães, Santos, et al., 2002). Additionally previous treatment was psychotherapy but no indication was given of what type of psychotherapy it was (Amâncio, et al., 2002). There was no discussion regarding other factors that could have played a part in improvements. Therefore no conclusive evidence for the use of Venlafaxine can be made from this paper.

A second study used an open label trial where participants (n=10) had previous trials of SSRIs which were unsuccessful in treating their symptoms (Allen, Hadley, Kaplan et al., 2008). No psychotherapy of any type was provided. Venlafaxine showed effectiveness in reducing BDD symptoms from four weeks of the trial on less than optimum levels of Venlafaxine. This shows a link between drug trials with SRIs and SSRIs previously described which indicate improvements early on before optimum levels of medication were reached. However there were no significant improvements on any of the other measures of symptom severity including functionality and BDD delusional symptoms. Given these are vital symptoms to be addressed as well as the primary BDD symptoms, Venlafaxine does not appear to compare well to the SRI and SSRI medication reviewed.

### 2.7.2 Dopamine blockade (antipsychotic) medication

Augmentation with antipsychotics has been shown to be effective in treating OCD (NICE, 2006). Thus as the search for effective treatments for BDD continues, the adjunctive use of antipsychotic medication has become the next level to explore. The NICE guidelines included four studies on the use of antipsychotic medication for treating BDD (NICE, 2006). Three of these trials were deemed relevant for this study (Appendix F: 2, 7, 8). The one case report which was excluded was a letter to the editor which describes a patient with a primary diagnosis of bipolar disorder and depression with psychotic features (auditory hallucinations) and BDD symptoms successfully treated with Olanzapine. Using the CASP guidelines, this did not meet the criteria for inclusion in this study (CASP, 2018). There was a study included which was published after the NICE guidelines (2006) and the NICE guidelines update (2013) (Appendix F: 10).

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Just one investigation was a placebo-controlled double-blind RCT using Pimozide to augment fluoxetine for treatment of BDD (Phillips, 2005a). It appears the motivation for using Pimozide was that it was used in studies previously, showing efficacy for BDD (Riding, Munro, 1975; Munro, Chmara, 1982). The results of the study were not promising (Appendix F: 6). Since then it has been found that Pimozide prescribed with fluoxetine can lead to bradycardia and is not recommended for concurrent use (Stahl, 2009). "Following reports of sudden unexplained death, an ECG is recommended before treatment" (British National Formulary, 2011:4.2.1, pg. 233). The additional information about Pimozide's interactions and high levels of toxicity may have been unknown at the time of these studies. This paper highlights the need for a considered approach before embarking on drug treatment trials especially where the mechanism of a drug is questionable.

The outcomes of other augmentation studies have been inconsistent and studies with a robust design are sparse (Phillips et al., 2001; Ipser, et al., 2009). A chart review of augmentation of SRIs with antipsychotics showed 15.4% effectiveness in trials whilst a study using Olanzapine to augment Fluoxetine resulted in minimal to no response (Phillips et al., 2001; Phillips, 2005b, Appendix F: 7). Contradictory to this are case reports which describe successful outcomes with the use of Olanzapine (Grant, Kim, Crow, 2001; Nakaaki, et al., 2008). Similarly a case report using Aripiprazole produced a positive outcome (Uzun, Ozdemir, 2010). However single case reports are limited with regard to clinical implications as findings are not fully representative of the population.

However these single case results may bear more credence supported by the most recent retrospective case note study comparing a group given antipsychotic augmentation with a non-augmented treatment group (Rashid et al., 2015; Appendix F:10). Although a breakdown is given of the number of patients prescribed a particular antipsychotic this is not followed up by linking the improved or the non-responsive patients to the medication. Therefore although the results are promising it would have been more useful to know which medication produced positive results and which drew no response.

Investigations into the efficacy of buspirone augmentation appear to be more promising (Phillips et al., 1996a, Appendix F: 2; Phillips et al., 2001). Both these studies reported positive results for Buspirone with minimal side effects and it is generally well tolerated. This data, while preliminary, suggests that buspirone augmentation of SRIs may be useful for BDD and warrant further investigation in a controlled trial.

The OCD/BDD specialist service offers antipsychotic medication to augment SSRIs when considered necessary. This is usually due to the level of severity of the patients' BDD symptoms and presence of co-morbid disorders. In addition most patients have had two or more trials of SSRI medication alongside CBT. The current circumstances regarding augmentation studies give the impression that it is very much trial and error with no clarity as to what will be most beneficial. The evidence in the literature for the use of antipsychotic augmentation is insufficient to determine if this will be a beneficial course for patients who do not respond to SSRIs (Williams et al., 2006; Ipser et al., 2009, Phillips et al., 2001, Phillips et al., 2006). Nonetheless a notable finding across studies with positive response was early improvements to symptoms before optimal dosage was reached (Phillips et al., 2001). This suggests treatment could be more cost effective and of a shorter duration if an appropriate psychotropic agent was identified specifically for treatment of BDD. At the time of writing there is no evidence base for augmentation with a dopamine blockade.

#### **2.7.3 Summary**

Apart from Fluoxetine, all the trials of SRI, SSRIs and SNRI described a short time to response. All the trials reported the main symptoms of concern being successfully treated. The improvement in BDD symptoms is of course the primary focus but the additional impairment in functioning that often accompanies BDD is an important factor to be addressed. Most of these studies demonstrated improvements in functioning and quality of life. There was a mixed result for response levels of delusionality with different SSRIs which warrants further investigation.

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It was encouraging that there were no reported drop outs due to side effects in the medication trials of SSRI/SRI as these are the main agents showing any effectiveness. However despite noteworthy findings trials have not been replicated to produce a sound pharmacological evidence base for treating BDD. There seems little impetus in pursuing this form of treatment apart from one off trials. In addition the small sample sizes and high ratio of females to males restrict the generalisability of the findings. There also still remains a significant percentage of patients who have no or limited response to SSRIs/SRIs (Phillips, Albertini, Siniscalchi, et al., 2001).

There are a number of deficiencies in the area of pharmacotherapy for BDD. The majority of studies have been case series or open label trials with just four randomised controlled trials (Ipser, et al., 2009). Most studies employed a full range of valid and reliable measures; however none included patient satisfaction questionnaires to determine the patients' views of treatment which would be especially relevant given the physical effects of medication. One study provided the patients' perspective although this resembled a brief case description rather than a report on the patient's experiences in their own words (Phillips et al., 2016). This emphasises the relevance of this study's design to provide a true reflection of the patients' perspective alongside quantitative treatment data.

Further research replicating studies with large samples is needed. No direct comparative studies have been done with other treatments which have been shown to be effective, such as CBT. Research into a comparison is necessary to understand the relationship between these treatments. This could better inform future directions in treatment strategies of BDD.

Pharmacological studies are usually in accordance with the Food and Drug Administration regulations (1998) [FDA] or regulations by the Medicines and Healthcare products Regulatory Agency (2004) [MHRA] but as no medication is currently licenced for treating BDD, the studies seem to be experimental. Thus far no drug trial has been designed to obtain FDA or MHRA approval for BDD and yet NICE guidelines have included medication recommendations based on a handful of studies. Due to the high prevalence of comorbid disorders with BDD, especially

depression the medication of choice is usually a SSRI (Phillips, 1998; Phillips, 1999; Phillips, Coles, Menard, et al., 2005). Furthermore BDD has been classified under OCD spectrum disorders which show a response to SRI and SSRI medication. Therefore the initial course of pharmacotherapy for BDD will tend to follow the prescribing guidelines for disorders in this category. Thus the pharmacological treatments for BDD do not appear to be aimed at addressing the unique nature of the disorder but rather to treat those symptoms found in other disorders under the same classification. Again this highlights the need to establish a clearer understanding of the mechanism of BDD to better inform treatment.

#### 2.8 Medical treatment

The inclusion of medical treatments is highly relevant for the study of BDD as there is a higher proportion of people with BDD who present to medical rather than mental health settings (Conrado, et al., 2010; Aouizerate, et al., 2003; Naylor, Parsonage, McDaid, et al., 2012).

Seven studies were found to be relevant focusing on medical interventions and outcomes in patients with BDD. There are no RCTs in this area and just one study is prospective by design. Risks of physical injury due to self-inflicted or "DIY" surgery was also highlighted in one paper and described in another (Veale, 2000; Phillips, 2001). There are two studies into long term follow up of BDD patients following cosmetic surgery. Results and details of the studies are in Appendix G.

# 2.8.1 Cosmetic surgery and minimally invasive (MI) procedures

Despite the literature suggesting cosmetic surgery is contraindicated for patients suffering with BDD both surgery and MI procedures in BDD cannot be ignored (Sarwer, et al., 2003; Mulkens, et al., 2006; Sarwer, et al., 2008; Biraben-Gotzamanis, et al., 2009). In the current climate of mass media promoting the ideal body image and increased access to cosmetic and MI procedures, more people are opting for cosmetic procedures (Grabe, Ward, Hyde, 2008; BAAPS, 2015). The recognition that some people requesting cosmetic procedures may have

psychological disorders has been slow in emerging but finally serious attention is being given to this issue (DoH, 2013; Scottish Government, 2015; GMC, 2016).

There is a more sizable research base on the psychological aspects of cosmetic surgery than expected (Sarwer, et al., 1998; Hasan, 2000; Grossbart, et al., 2003). A theoretical model regarding body image and cosmetic surgery has been developed to consider the psychological aspects of cosmetic surgery Sarwer, Pertschuk. Wadden, et al., 1998). The premise is that the physical reality of one's appearance is the basis for one's body image and can influence perceptions, behaviours and the choice to seek cosmetic surgery (Sarwer et al., 1998). This is not focused on BDD specifically but could provide insights to inform a model of BDD.

A study specifically investigating outcomes of cosmetic surgery and self-inflicted or "DIY" surgery indicated a mixed response to surgery (Veale, 2000). Some participants (n=6) reported satisfaction however from this group they also had additional procedures or became preoccupied with other features thus suggesting the BDD symptoms remained clinically significant (Appendix G:1). Satisfaction rating decreased with repeated procedures whilst BDD symptoms measured by preoccupation levels increased as well as levels of impairment.

Patients in the sample who reported self-inflicted surgery after they were unable to have surgery due to surgeon's refusal or costs involved all expressed being unhappy at the results. A selection bias of treatment failures limits the credibility of the findings (Veale, 2000). On the other hand, people who overcome BDD following satisfaction with cosmetic surgery are unlikely to seek mental health care for BDD (NICE, 2006). There were also a number of different procedures for different features which obscures the measure of success. A single procedure focusing on a particular feature in a large sample would provide more informative results.

The retrospective nature of the data is described as a limitation however a prospective study with BDD patients undergoing cosmetic surgery raises ethical implications of surgeons operating on patients they are aware have BDD (Veale, 2000; Freedman, 1987). The study also lacks any valid and reliable measures which limits the accuracy of the data regarding symptom severity and effect of treatment.

Despite these weaknesses, this study brings into focus the need for further investigation into cosmetic surgery on patients with BDD and highlights risks involved which are specific to BDD.

A large scale study evaluating the outcomes of cosmetic surgery/MI procedures indicated that severity of BDD symptoms was not changed following procedures (Phillips, Grant, Siniscalchi, et al., 2001). Although it was a large sample the participants were part of a research program specialising in BDD which limits generalisability (Phillips, et al., 2001). There may also be a bias towards participants who did not improve following cosmetic procedures which was also discussed in the previous study.

# Rhinoplasty

Two studies specifically examining outcomes of rhinoplasty had similar findings (Veale, Haro, Lambrou, 2003; Felix, de Brito, Nahas, et al., 2014, Appendix G: 3, 8)). Post-surgery differences in a sample of non-BDD patients and patients with minimal symptoms of BDD indicated that there is a group of patients in the subclinical or mild BDD range that improve with cosmetic rhinoplasty (Veale, et al., 2003). This is an interesting finding as it raises the question of whether this is a valid treatment for patients with BDD at these levels of symptomology, in particular for rhinoplasty.

A further study of rhinoplasty in patients diagnosed with mild or moderate BDD indicated similar positive results (Appendix G: 8; Felix, et al., 2014). Unfortunately it is unclear whether the patients were appropriately diagnosed with BDD using a reliable diagnostic tool (Crerand, Phillips, 2014). In addition the study reports that patients had actual nasal defects from mild to marked deformity. This in itself would call into question their diagnosis of BDD (APA, 2013; WHO, 2018). In addition the results report at 1 year follow up 21 patients experienced preoccupation with their perceived flaw between 1-3 hours per day and 10 for three or more hours per day. Although the findings indicate an improvement from baseline, there were still patients in the sample who continued to be preoccupied by their feature (Appendix G: 8; Crerand et al., 2014). However an interesting aspect of this study is the ethnicity of most of the participants who were described as of African descent making this the

only study without an overrepresentation of Caucasian subjects. Although the role of ethnicity in the degree of satisfaction was acknowledged, there was no further examination of ethnicity in this study but this needs further investigation.

## Longer Term Follow Up

Longitudinal studies in treatment of BDD are rare but there have been two such studies in cosmetic surgery for BDD. Patients consenting to be followed up five years after they had requested cosmetic surgery indicated that the majority of the BDD group who received surgery did not improve (Tignol, Biraben-Gotzamanis, Martin-Guehl, et al., 2007; Appendix G:5). Although cosmetic surgery appears inadvisable in BDD based on the lack of improvement over time contradiction was found in the patients' reports of satisfaction in the procedures despite the lack of change in BDD symptoms. The study raises interesting points for further investigation. In particular the emergence of BDD in previously non-BDD patients following cosmetic surgery needs further investigation to identify the possible propensity of patients seeking cosmetic surgery to develop BDD. This could provide valuable insights for cosmetic surgeons to identify and screen for vulnerability to BDD. Additionally there was one subject who had a complete recovery from BDD following the surgery. There appears to be a very small proportion of BDD sufferers who respond to cosmetic treatment. The reasons for this need further exploration.

The second follow up study examined shorter versus longer term outcomes in people with BDD who have surgery or other cosmetic procedures (Crerand, Menard, Phillips, 2010; Appendix G: 6). Although short-term improvement in appearance and/or preoccupation was reported this was not sustained, however there were 15 patients who perceived long term improvements overall on BDD symptoms but this was not further explored (Crerand, et al., 2010; Appendix G: 6). It would be interesting to note what led to their responses – if there were differences in their clinical presentation or if they had psychological or pharmacological treatment in the intervening years to treat BDD. Also notable was that rhinoplasty was the most common procedure received by the participants overall. With the previous studies on rhinoplasty showing remarkable results, it would have been useful to have further

data into the responses of this group of participants (Veale et al., 2003; Felix et al., 2014).

The advantage of the cross sectional design was having a wide range of participants who provided data across different age groups as the sample also included adolescents. However a longitudinal design may have provided more specific information regarding changes over time to achieve more conclusive findings for outcomes. The retrospective nature of the study has to allow for differences over time but variables such as suicidality, functioning and depression were considered over lifetime without correlating this with time frames for surgery or other procedures. In addition since a measure of depression was not done at the time of follow up, the presence of depression could influence patients' perceptions and affect the results.

The reasons for not receiving surgery compared to other cosmetic procedures were explored indicating cost being the main reason the participants cited for not having surgical procedures. The doctors' refusal was the second reason which appears contradictory as findings indicated surgical treatment was significantly less likely to be refused than any other cosmetic intervention (16 refused out of a total of 148 procedures requested). It is suggested that surgeons may not be aware of the diagnosis or not consider surgery as contraindicated (Sarwer, 2002). Unfortunately no data was obtained from surgeons as to their reasons for refusal.

It is not clear whether participants who showed no change or were worse at follow up were offered other treatments or if these patients were signposted to other services for treatment which raises ethical considerations of a duty of care. Although there are areas which need further exploration, this paper investigated cosmetic surgery in BDD more thoroughly than any other study. The paper also addresses limitations from the first study (Crerand, et al., 2005). There are no other large scale studies of long term outcomes and the comparison of procedures over short and long term. The study also included other appearance enhancing procedures such as Botox and cosmetic dental procedures, which tends to be overlooked in most studies.

#### 2.8.2 Other medical treatments for BDD

With the increasing exploration of pathophysiological models to understand BDD it was relevant to include medical interventions in the literature review (Feusner, Yaryura-Tobias, Saxena, 2008; Feusner et al., 2011). The search revealed the use of electroconvulsive treatment (ECT) to treat BDD although thus far the literature on the use of ECT in BDD is sparse and consists of one case study, a report on a case series and an editorial letter (Rapinesi, Serata, Del Casale, et al., 2013; Phillips, 2005a; Carroll, Yendrek, Degroot, et al., 1994).

The case series reported no response to ECT in eight cases of BDD treated (Phillips, 2005a). Conversely an editorial letter described a case of major depression and psychosis with BDD who responded positively to ECT. Similarly a case study on the use of ECT in a patient with major depression, delusionality and BDD showed improvements where all other treatments had been tried unsuccessfully including CBT, SSRIs and augmentation with antipsychotics (Rapinesi, et al., 2013; Appendix G:7). However the BDD symptoms appear to be a comorbidity rather than the primary diagnosis and there are no measures of BDD symptom severity described. Furthermore the description of the patient's symptoms fits more closely with muscle dysmorphia (APA, 2013; WHO, 2018). The description of aggression and unprovoked violence also raises questions about possible substance misuse, especially anabolic steroids which is noted to be of high incidence in sufferers of muscle dysmorphia (Leone, Sedory, Gray, 2005). Depression and delusionality may have exacerbated BDD symptoms. Therefore once the depression and delusionality abated, the BDD symptoms may have improved rather than being treated in its own right (Phillips et al., 2008; Phillips et al., 2005a). There is no conclusive evidence from this study for the use of ECT in treating BDD.

The conclusion regarding the use of ECT at this time appears to be that it is beneficial when there is major depression with co-morbid BDD (Phillips et al., 2008). However this may be related to ECT resulting in improvement in the depression symptoms which then has a positive effect on the BDD symptom severity (Phillips, 2005a). But there is no evidence for the treatment of BDD with ECT at this time (Phillips et al., 2008; Phillips et al., 2005a).

## 2.8.3 Summary

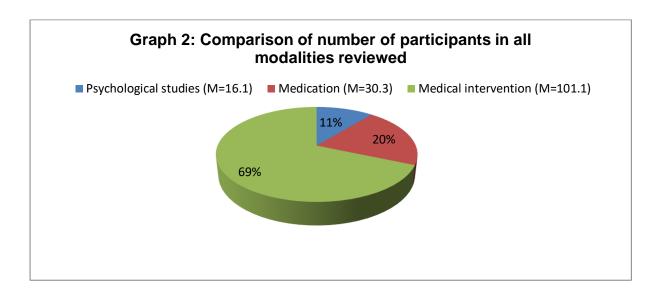
Although most of the studies unequivocally suggest that cosmetic surgery is not an effective treatment strategy for BDD, a small percentage of patients with BDD responded favourably to cosmetic surgery in most of these studies (Crerand et al., 2010; Veale et al., 2003; Felix et al., 2014). Regrettably none of the studies offered any further exploration of these phenomena. Further investigation into this may yield important insights which could influence treatment options for BDD across different levels of severity.

At the current time, however the literature is largely in agreement that cosmetic surgery should be avoided in patients with BDD and could lead to worsening of symptoms (Phillips, 2001; Crerand, et al., 2005; Tignol et al., 2007; Crerand, et al., 2010). There seems to be a bias towards failure in cosmetic procedures rather than objectively exploring treatment successes as well as failures. This approach seems to be geared towards proving cosmetic procedures are not beneficial for BDD patients which could narrow the options for exploring treatment for BDD. Although the trend is towards reducing unnecessary cosmetic procedures for people with BDD, there may be a group of people with BDD who can benefit from cosmetic procedures which needs to be explored. Not to do so may be denying a cohort of people with BDD the option to experience a remission from the disorder and improvement in functioning leading to a better quality of life.

#### 2.9 Discussion

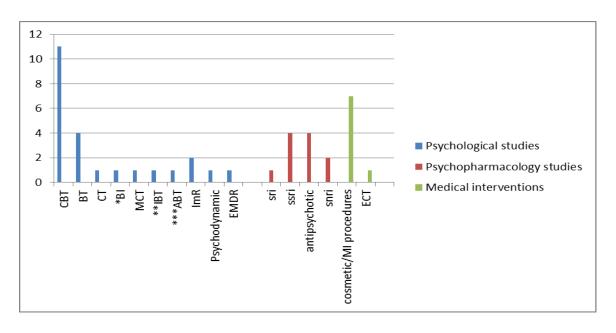
Bringing together all three modalities of treatment studies reviewed, the general consensus in the literature appears to be that CBT is an effective psychological treatment for BDD whilst SSRI agents have a growing body of evidence for efficacy (Ipser et al., 2009). Studies indicate better outcomes with CBT than pharmacotherapy with improvements maintained over longer periods (Williams et al., 2006). The views regarding the use of cosmetic surgery also draws a consensus but it is contrary to those expressed for psychological and pharmacological treatments. The prognosis for BDD patients receiving cosmetic surgery appears to be poor and although improvements are made, these are short term and not maintained over the longer term (Phillips, et al., 2010).

However it has been noted that some patients with BDD experience remission from their symptoms following cosmetic surgery (Veale et al., 2003; Crerand et al., 2010; Felix et al., 2014 Appendix G: 6, 8).). Although this has only been found in a small number of patients, it is still worthy of further exploration. In addition reviewing all three modalities of treatment indicates the greater likelihood of patients with BDD being seen initially by medical or surgical teams rather than mental health services (Sarwer, et al., 1998; Aouizerate, et al., 2003). A comparison of the number of participants across the three treatment modalities reviewed in the literature is a stark illustration of this tendency (Graph 2).



The largest sample sizes in published studies were of medical interventions, in particular, cosmetic surgery studies. This may be unsurprising given the high prevalence of people with BDD who attend cosmetic surgery and dermatology clinics (Sarwer, et al., 1998; Phillips et al., 2000; Aouizerate, et al., 2003; Conrado, et al., 2010). This also indicates the need for closer links between mental health services and general health care (DoH, 2011a).

Graph 3: Illustration of number of studies in three main treatment modalities



\*BI Behavioural interpretive intervention

With regards to specific treatments, after CBT the second highest number of studies is of cosmetic surgery/ MI procedures (Graph 3). Perhaps this reflects researchers' concerns about the current appeal of cosmetic surgery and people with BDD who may be drawn to seeking surgical rather than psychological help (BAAPS, 2015).

A model describing the psychology of cosmetic surgery proposes the physical reality of appearance is a key aspect determining perception and behaviour (Sarwer et al., 1998). In bringing together psychology and cosmetic surgery there may be new directions to be investigated. This may appear controversial in light of most recommendations for patients with BDD to steer clear of cosmetic surgery but the questions beg to be asked- what would the outcomes be for BDD treated with psychological therapy in conjunction with surgery? What would the impact be on long term outcome?

Although it is more likely that any link between psychological therapies and cosmetic surgery will be aimed at screening patients preoperatively for BDD and refusing surgery to patients with BDD symptoms. The NICE guidelines make recommendations for individuals with suspected or diagnosed BDD seeking cosmetic surgery to have specialist mental health assessment for BDD (NICE,

<sup>\*\*</sup>IBT Inference based therapy

<sup>\*\*\*</sup>ABT Acceptance based treatment

2006). This would appear to be the most appropriate course of action and to signpost the patient to alternative recommended treatments such as CBT or medication. It is hopeful that with the GMC guidelines for doctors offering cosmetic interventions highlighting psychological needs of patients, this will promote recognition of BDD symptoms (GMC, 2016).

Nevertheless one of the challenges of treating BDD is the difficulty in engaging patients in psychological treatment early on (Phillips, et al., 1993). One of the recurrent themes across studies was a description of the long duration of the disorder (M=11 years) prior to psychological treatment being sought (Gomez-Perez et. al. 1994; Veale et al., 1996; Phillips, Diaz, 1997). Clinical evidence from the specialist BDD service also indicates this trend. This is an aspect of BDD that should be studied further, especially to promote early intervention. Engaging patients with BDD in psychological treatment is made particularly difficult when there is limited insight (Phillips, et al., 1993).

Augmentation of SSRIs with antipsychotic medication to attempt to address this clinical presentation is still an area of limited research with only two studies showing any promise of improvements with augmentation (Phillips, 1996; Rashid et al., 2015). It is concerning that despite the lack of sufficient evidence augmentation of SSRI medication with an antipsychotic is recommended for treating BDD in the NICE guidelines (NICE, 2006: 7.4.2.8, pg. 191).

In addition one of the main deficiencies of the studies reviewed is a lack of comprehensive qualitative data. Randomized controlled trials (RCTs) and quantitative studies have an important place in the assessment of the efficacy of treatments. However the focus is restricted to whether an intervention has a statistically significant effect. Thus a large amount of vital information goes unexplored. There is a lack of clarity to understand why interventions are successful or not and the reasons for the effect of the treatment. More importantly quantitative studies do not address the participants' experiences of the intervention and do not include the clinicians' experiences of providing an intervention. Although published studies suggest CBT is effective in treating BDD and in reducing the risk of relapse as well as producing patient satisfaction little is understood about patients'

experiences of CBT and reasons for non-response in some subjects (Greenberg, Wilhelm, 2011).

CBT lends itself to quantitative study and thus is more likely to generate more published work. The short term nature of the intervention can be an obstacle in treating BDD where the presentation is generally multifaceted. Some of the studies highlight this as an area to be considered as longer treatment may be more beneficial and acceptable to patients (Veale, et al., 1996; Khemlani-Patel, et al., 2011). Unfortunately resource constraints and pressures from funding organisations have an influence on the length and duration of treatment provided (Wilhelm, et al., 1999; Rabiei, et al., 2012). The emphasis is increasingly on cost effectiveness in health care provision and the search for interventions that show improvement within a short period of time (Mojtabai, 2005). Therefore CBT has been the focus of application across a number of disorders and in a variety of forms (Beck, 1997).

One of the advantages of CBT is the malleable nature of its application e.g. internet CBT (Cuijpers, van Straten, Andersson, 2008; Andersson, Enander, Andren, et al. 2012). The attraction of internet–based treatment is the increased accessibility of CBT for patients who may not engage with psychological treatment otherwise (Enander et al., 2014; Hedman, 2014). However there is the risk that by considering CBT as the "magic wand" for all disorders, other beneficial interventions may be overlooked to the detriment of best practice in patient care. Equally from the literature reviewed on CBT outcome studies, 11 out of 21 studies reported dropouts and non-responders (Appendix E). Thus CBT is not a one size fits all treatment and highlights the need for further exploration of reasons for treatment failure and dropout. On the other hand, CBT has still shown more promise than other interventions for BDD but further research is need to make this a more robust treatment option.

This literature review only considered published works in English unless translation was available, which is a limitation for the study. One has to bear in mind that just because a paper is published, that does not make it good evidence. Also the focus in most scientific journals tends to be on RCTs or quantitative studies where there are significant findings (Egger, Davey-Smith, Altman, 2001). Therefore interventions

which may not easily lend themselves to these methods may be lost such as Art Psychotherapy and Psychodynamic Psychotherapy. Also although there may appear to be gaps in information provided in studies, one has to consider the published work may not represent the original full work of the author/s as the published work has to adhere to publication guidelines regarding word count etc. But the reader can only evaluate what is made available. This may also be a restriction for NICE guidelines which is a useful guide to evidence-based treatments but can only include evidence from studies that have been published (NICE, 2006).

In addition to the previous discussion, the process of conducting the literature review has ultimately revealed several patterns:

- There is at present a lack of sufficient robust studies into treatment for BDD.
- There are several domains in which treatment studies are being conducted and there is no integration between them.
- Although there are several proposed models to understand the processes of BDD there is still no definitive model of BDD.
- At the time of writing there are no qualitative studies on BDD.

# Chapter 3:

## **METHODOLOGY**

#### 3.1. Introduction

This chapter describes the approach and methods used to evaluate the application of the NICE guidelines in treating BDD within the context of a specialist service. It will highlight the theoretical underpinnings that drive the particular design chosen for the study as well as clarify the rationale for the design and methods used.

The study uses a mixed methods approach in order to provide a more complete understanding of the practical application of the NICE guidelines for BDD. The aim is to explore different types of data: descriptive data from analysis of standardized measures, as well as accounts of participants' lived experiences acquired through semi-structured interviews. The qualitative data enriches the value of the quantitative data in considering how to refine treatment protocols where appropriate to improve effectiveness. The techniques used in analysis of the data are discussed and limitations highlighted. To ensure that the validity and credibility of the study is of the highest standard, the process will be described with as much transparency as possible.

Ethical considerations in undertaking this study will be discussed especially with regards to the participants interviewed. This chapter will conclude with a critique of the methods to identify strengths and limitations.

## 3.2. Theoretical perspectives

The philosophical underpinning creates a foundation on which the design and methods of a study are based (Scotland, 2012).

Two opposite methodological paradigms come together in this study:

- Positivism/ Post-positivism which uses quantitative methods to analyse data to support a hypothesis (Creswell, 2003).
- Interpretivism, which is on the other end of the continuum, uses qualitative methods to gather detailed information about participants' experiences (Creswell, 1994).

Bringing these approaches together in a mixed methods design offers multifaceted perspectives for a more complete understanding of the treatment outcomes.

## Positivism and Post-positivism

The principle of positivism recognizes only that which can be scientifically proven by measurement and observation (Morgan, Smircich, 1980). However positivism was criticised for the stance that an absolute truth can be obtained through only observation and measurement, leading to the rise of the post-positivist movement (Popper, 1963). Post-positivism takes a more pragmatic view, by recognising that observation is not without errors and will be influenced by the researcher's own experiences, views, culture etc. (Trochim, 2006). Nevertheless, post-positivists still pursue observable and measurable data but causal relationships are sought, often using participants' perspectives. Furthermore theories are tested to improve on them (Popper, 1959; Creswell, 2009).

## Interpretivism

The theory of interpretivism is that reality is a social product. It cannot be understood without including the perceptions and meanings given to particular social processes by the individuals of that social group (Orlikowski, Baroudi, 1991). Social sciences require a different approach than physical sciences which tend to be independent of the person (Bhattacherjee, 2012). In social science research the influence of the human element which includes researchers, cannot be denied (Weber, 2011). In contrast to positivism, the paradigm of interpretivism or phenomenology attempts to understand phenomena through accessing the subjective meanings given to them (Orlikowski et al., 1991).

Given that the post-positivist stance also acknowledges the need to include human experience, using both these paradigms was most fitting.

## 3.3 Methodological context

#### 3.3.1 Ontology

This study will be carried out from a critical realist ontological position. Critical realism accepts the existence of reality that can be measured but also acknowledges the influence of human perception and cognition plus subjective experience in shaping that reality (Yeung, 1997; Bhaskar, 1998).

Critical realism identifies and analyses the psychological and social systems which make up the natural world (Bhaskar, 1998; Houston, 2001). BDD is influenced by our social reality, in particular, the idealised appearance and image coveted by society and promoted by mass media. It is argued that social reality exists collectively, because it is ideas, views, expectations shared by people (Searle, 1996). In this vein the social reality of BDD needs individual's perceptions and views to be untangled from the perceived views of society, then acknowledged and explored. Considering BDD is still largely misunderstood and underdeveloped it is essential to obtain patient experiences and perceptions to develop a clearer understanding of the disorder (Phillips, 2008). This could inform the way forward regarding engagement and treatment plus possible ways of prevention. Furthermore the views of the clinicians involved in treating these patients will provide an added facet towards understanding how patients respond to treatments. Given the research questions (pg. 29:1.9) it was most appropriate for this study to be situated along the critical realism continuum. This position determines what is able to be measured or what is knowable as well as on the other end of the continuum, the influence of human experiences.

## 3.3.2 Epistemology

The epistemological stance of this study follows both post-positivism and interpretivism involving a mixed methods approach which is consistent with critical realist ontology. Using both qualitative and quantitative methods is becoming more widely recognized for the valuable contributions each makes in research (Curry, Nembhard, Bradley, 2009).

Thus quantitative methods lend itself to this approach as it can be used to mathematically verify knowledge obtained. However this study leans more towards the principles of post-positivism coming from a critical realist perspective. It is therefore important to use multiple measures and methods of observation to obtain a deeper understanding and reduce the margin of error. This method of evaluating practice is associated with a CBT approach and the medical model (Bakker, 2008).

CBT and medication are the main treatments recommended by the NICE (2006) guidelines for BDD and are provided by the specialist service. The focus in CBT tends to be on obtaining scientific evidence that interventions are efficacious by

using validated measurement instruments (Bakker, 2008). Similarly in the medical model a range of validated symptom-led scales are used to assess response rates and calculate outcomes. The service uses both therapist-rated and patient-rated standardized measures to assess severity of clinical symptoms. This approach enables clinicians to have a clearer framework for evaluating the treatments and interventions they provide and identify areas which may not be as effective. This is the clinical context, however taking a broader view, there are pressures on the National Health Service (NHS) to provide evidence-based treatments and show costeffectiveness and rapid through-put (DoH, 2015). The Trust's Quality Account (2015/2016) is in keeping with the requirements set out by the DoH to ensure compliance (DoH, 2015). Thus it is in the best interests of the service to provide measurable outcomes and a clearly mapped pathway of the patient's progress through the service. Historically within this particular Trust there has been termination of some specialist services following service review by local commissioning bodies with one of the reasons quoted as a lack of measurable outcomes.

To ensure this service evaluation was as comprehensive as possible, it was essential to explore the element of human experience. Interpretivism is a leading approach in qualitative research and pertains to the subjective nature of an individual's perceptions of the world and the resulting internal mental representations (Ratner, 2008). Furthermore by eliciting patients' and clinicians' experiences, it is bringing forward an element that surpasses policies and procedures of governmental and Trust targets. The fundamental reason for providing the service is to improve people's lives, thus it follows that their experience is central to any evaluation of the service for future improvements. This approach allows for additional information to be obtained and could offer different reasons for treatment outcomes which will enhance the understanding of the disorder and influence choice of interventions to treat it.

These opposite epistemological positions complement each other as they can balance out areas that may be lacking in each method providing a more complete approach.

#### 3.4 Method

This study uses different research design elements within a case study approach (Appendix H). Case study can incorporate both quantitative and qualitative data collection in an in-depth exploration of phenomena with single or collective cases (Yin, 2009; Creswell, 2003). A convergent parallel design was most fitting as it provides straightforward procedures to collect and synthesise results in a mixed method study (Cresswell, 2015). Additionally the data collected from the three strands were complementary in nature which suits the use of the convergent parallel design to interface the different sets of data.

The quantitative aspect involves survey research methods which are used to obtain data from participants that are representative of a population (Williams, 2007). As an analytic element it is used to identify; measure then evaluate effects of treatment on patients. This is used in designing outcome studies which investigate the end result of treatments or interventions (Jefford, Stockler, Tattersall, 2003). Outcomes research is pivotal in providing evidence-based treatments whilst allowing for quality of care to be evaluated and improved (Agency for Healthcare Research and Quality (AHRQ), 2015). The quantitative data analysis satisfies the post-positivist stance taken in this study for objective, scientific data regarding clinical outcomes, symptoms of severity and demographic illustrations.

However qualitative methods can also be considered scientific in the process of seeking to answer specific questions plus using rigorous procedures in collecting and analysing data (Mack, Woodsong, Macqueen et al., 2005). Furthermore qualitative methods extend beyond this, as the analysis in this study illustrates, in the iterative process of data analysis as well as the interpretive approach to data gathered considering meanings participants ascribe to their experience. This brings together the underpinning paradigms the study is driven by thereby providing a comprehensive understanding of the research area. The study design incorporates both methods in a three phase process of data collection and analysis which is illustrated in the flow diagram in Appendix H.

## 3.5 Data Analysis

Quantitative data is stored and analysed on a Statistical Package for Social Sciences (SPSS v25) file. Descriptive statistics will be generated for the clinical data using paired t-tests. Thematic analysis (TA) is the method adopted for the process of the qualitative data analysis which will be used to contextualise the quantitative data. Qualitative data was gathered using semi-structured interviews which were audio recorded to ensure accuracy in transcription (5.2.1, pg. 130). Qualitative analysis involves coding the data, categorising and eliciting themes supported by extracts from the transcripts. Adopting a manual approach to data analysis was considered most appropriate, as it allows for the iterative and creative process of the researcher's interpretation of the data. Although software for qualitative analysis is useful in organising and categorising data, it can restrict this process (Welsh, 2002).

## 3.6 Thematic Analysis

Thematic analysis (TA) focuses on identifying, analyzing and generating patterns or themes across datasets whilst describing data in rich detail (Braun, Clarke, 2006). Although the process of TA was described in texts on qualitative analysis, there were no definitive models for its use (Miles, Huberman, 1994; Boyatzis, 1998). Providing a framework for clarifying TA as a standalone method of qualitative analysis helped to address the undefined way that TA was generally described in the literature (Braun et al., 2006). Still despite its wide-spread use there is a lack of literature on TA which leads to queries about the credibility of this as a separate method (Nowell, Norris, White, Moules, 2017). However proponents of TA argue that through applying rigour and transparency, the trustworthiness and credibility of TA can be produced (Braun, et al. 2006; Alhojailan, 2012; Nowell, et al. 2017).

Triangulation is significant in studies such as this which uses a combination of methods and different data sources (Patton, 1999). Participants in this study were from three different groups: outpatients, inpatients and clinicians who provided different perspectives that could be compared for similarities and variances. This provided a more comprehensive analysis of the data (Mays, Pope, 2000).

## 3.7 Choosing Thematic analysis

TA forms the basis of qualitative analysis for most types of approaches (Holloway, Todres, 2003). Given TA is a method of analysis rather than being tied to a philosophical underpinning it provides the flexibility to use it with different methodologies (Braun, Clarke, 2006). This is particularly useful in areas of healthcare that are lacking in research as is described in this study. It fits the aims of this study as it can be used to report the experiences of the participants and meanings they ascribe to their experiences from a critical realist perspective (Willig, 1999). In this study TA allows for the use of a framework that is considered most appropriate to develop the links between themes and the research questions.

Other approaches were considered for the study such as interpretative phenomenological analysis (IPA) and grounded theory (GT). TA shares the similarity of generating themes with both these approaches but their analysis is guided either by their underpinning methodology or to generate a theory (Glaser, Strauss, 1967). Therefore as these approaches did not fit the aims and objectives of this study, TA was considered most appropriate.

#### 3.7.1 Reporting thematic analysis of data

The flexible nature of thematic analysis means it can be used with a critical realist framework (Braun et al., 2006). However it is essential to be explicit about the theoretical framework one is using and to ensure analysis is consistent with this as it could easily become vague and unstructured (Holloway et al., 2003).

Thematic analysis goes beyond descriptive reporting to examine and interpret underlying meanings, views and beliefs (Braun et al., 2006). Furthermore in developing themes, the researcher actively engages in interpretation of the data content (Patton, 2002). It is proposed that reporting in the first person can be used to acknowledge the importance of the part played by the researcher in analyzing and interpreting the data (Foster, Parker, 1995). However in this study the analysis was reported explicitly as the researcher's interpretation which felt more suitable and demonstrates authenticity. Furthermore the approach produces a report remaining true to the theoretical underpinnings of the study. It is postulated that TA satisfies the process of discovery emphasized in positivism/post-positivism by use of coding and generating themes but also allows for those themes to be further explored fulfilling

the Interpretivism positon (Boyatzis, 1998). Advocates of TA clearly seek to establish TA as a standalone analytical method which has much to offer in qualitative analysis rather than just descriptive data especially as it forms the basis for most qualitative methods (Boyatzis, 1998; Aronson, 1994; Attride-Stirling, 2001; Braun et al., 2006). By reporting the data with the richness and depth allowed by using TA this study also supports this position.

"The extracts in thematic analysis are illustrative of the analytic points the researcher makes about the data, and should be used to illustrate/support an analysis that goes beyond their specific content, to make sense of the data, and tell the reader what it does or might mean." (Braun et al., 2006: 80)

## 3.7.2 Thematic Analysis using the Six-Phase Process

Analyzing the body of data and identifying codes then categories and generating themes is a cyclic process (Figure 4, pg. 91). Analysis followed an inductive process forming generalisations based on observations and meanings that the researcher ascribed to the data.

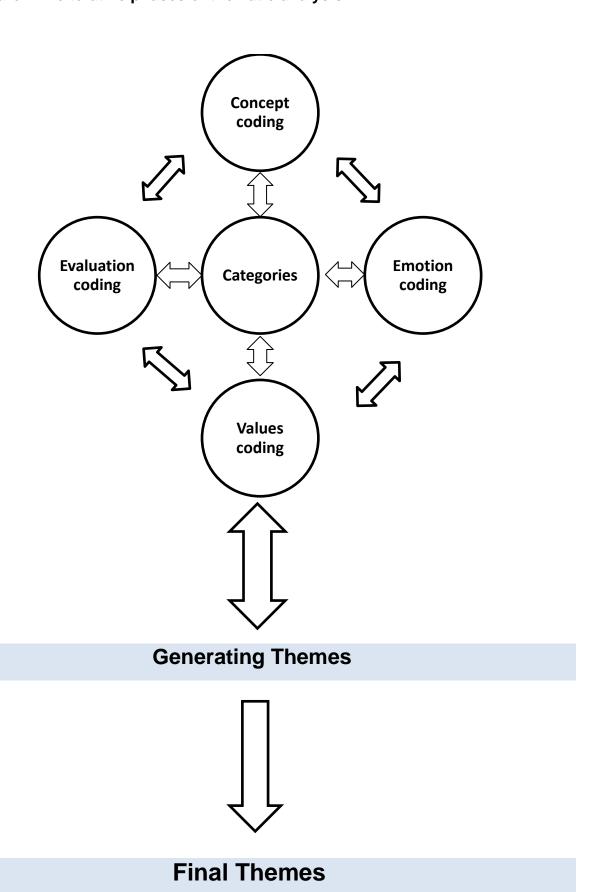
For the purposes of transparency the process is described in detail in the following subsections. The TA approach used in this study follows the six-phase process developed by Braun et al. (2006). This was chosen for the structure and clarity it provides; moreover it is the only publication providing a clearly defined process of conducting thematic analysis without relating it to theoretical paradigms (Braun, Clarke, 2014).

The body of data is in the form of transcripts providing vast amounts of information which need to be organised for relevance. Although the process is described in sequential steps, it is an iterative process revealing additional data to add to the analysis thus ensuring rigour and validity.

- Familiarisation with the data: Data gathered from semi-structured interviews
  were transcribed verbatim and read several times, to become closely familiar
  with its content.
- Coding: This phase involved identifying significant features of the data considered relevant to addressing the research questions. This required assigning labels or codes to the transcripts, then collating all the codes and

- related data extracts for further analysis. A number of coding methods were considered and initially explored until the most appropriate methods were found that were most suitable in relation to the aims of the study (Fig. 4).
- 3. Searching for themes: In this phase the collated data are further explored to identify patterns or possible themes. Data is then collated that may pertain to potential themes which are then further examined to determine the relevance of each potential theme.
- 4. Reviewing themes: The potential themes are checked against the information in the body of data to ensure they are representative and that they address the research questions. This phase involves developing themes and may result in discarding, changing or combining themes.
- 5. **Defining and naming themes**: In this phase each theme is analysed in greater detail and clarified with a title.
- 6. **Writing up**: In this final phase, the detailed analysis is interwoven with extracts from the data and contextualised with reference to relevant literature.

Figure 4: Reiterative phases of thematic analysis



## 3.8 Coding

The route taken to *arrive* at a coding method is an integral part of the analysis which needs to be detailed, in particular, for transparency and future replication (Morgan, Krueger, 1997).

The process of coding is summed up by Strauss:

Any researcher who wishes to become proficient at doing qualitative analysis must learn to code well and easily. The excellence of the research rests in large part on the excellence of the coding.

(Strauss: 1987, pg. 27).

Choosing coding methods started with perusing available research on thematic analysis which was found to be limited despite TA's wide usage (Boyatzis, 1998; Braun et al., 2006). In order to get a broader view of coding, the focus was changed to include all publications on coding in qualitative analysis. Coming from a post-positivist / interpretivist stance the choice of coding methods was based on meeting both the needs for clarity in the process plus integration of interpretations and reflections in addressing the aims of the study. In addition demonstrating the cyclic nature of coding, the transcripts needed to be read and initial impressions noted in order to identify which coding methods were most appropriate. This process was repeated until the most suitable coding methods were identified (Patton, 2015; Saldana, 2016).

Although there is no definitive method for coding, guidance was considered according to what methods met the needs of the study most appropriately (Blair, 2015). Several approaches were found useful however a coding manual which provided a comprehensive and clear description of coding methods was chosen to be most appropriate (Saldana, 2016). This was most suitable to link in with the aims of the study and the underpinning theoretical stance of post-positivism and interpretivism (Boyatzis, 1998). Other coding models considered were found to be too restrictive as these were linked to a theoretical framework rather than a standalone coding process (Taylor, Gibbs, 2010; Boyatzis, 1998; Charmaz, Mitchell 2001).

## 3.8.1 Coding methods

The coding methods followed a heuristic, cyclical pathway used tend to overlap as they represent factors that are interrelated with regards to the research questions. The first wave of coding used all methods simultaneously, providing an overview from which initial impressions were noted highlighting key words or phrases (Fig. 4). The second analysis used each coding method to process specific information, however other areas were noted separately, as this process could not occur in complete isolation. Once a detailed picture started to emerge, codes were grouped into possible categories. Given the different phases of the study, using a number of coding methods ensured that the most amount of information could be drawn out of the body of data as possible.

#### 3.8.1a Elemental methods

Elemental coding methods provide a basic overview of the entire body of data on which to build and include the researcher's interpretations (Saldana, 2008).

## Concept coding

Concept coding represents suggested broader meanings or ideas stimulating reflection which is particularly relevant for the aims of this study (Saldana, 2016). There is an overlap with process coding as it also includes processes and uses gerunds (ing) words denoting action taking place on a number of levels from daily observable activities to more experiential processes such as coping or adapting (Charmaz et al., 2001). Processes also capture actions that occur over time thus it was a useful method to identify changes that patient participants described over the course of treatment (Saldana, 2003).

#### 3.8.1b Affective methods

This method interprets the experiences of participants to convey the subjective qualities of the data such as emotions and values. In addition this method also considers the qualities of programs or policies and in this study this relates to treatment guidelines (Saldana, 2016).

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## Evaluation coding

This method was an obvious choice for an evaluation study and the method is closely linked to the aims of the study. Evaluation coding is used to make a judgement, about the use of policies, guidelines or programs which in this study relates to the NICE guidelines for OCD/BDD. It goes beyond this to consider how to make improvements and implications for future developments (Patton, 2015).

## Emotion coding

This coding process was especially useful to highlight experiences, feelings and perceived emotions whilst also taking the researcher's perceptions into consideration (Smith, Flower, Larkin, 2009). Codes can be gleaned from language used but also interpretations of participants' mood (Saldana, 2016; Goleman, 1995).

## Values Coding

Values coding conveys participant beliefs, principles, attitudes and perspectives from their experiences. This includes their view of themselves, others, objects as well as ideas. It is particularly valid for use in studies such as this concerning interpersonal and intrapersonal experiences using a case study approach (Gable, Wolf, 1993; LeCompte, Preissle, 1993).

#### 3.9 Categories

Creating categories precedes the development of themes as the analytic process generates large amounts of codes which need to be classified. Categories organise findings from participants' accounts by providing an explicit description of the content. The process of categorisation consists of three components: Origination, verification and nomination (Constas, 1992).

Origination: This refers to the source of the categories which could be participants, the researcher or literature on similar works. In this study patient participants could not be involved in this process for reasons described elsewhere (3.17, pg.107) but clinician participants could contribute and through presentations disseminating the early findings to the team, possible categories were discussed and their feedback was considered in the analysis.

However as the study involves an interpretive element, the researcher's analysis of the data was the main source of the categories. This introduces bias as the findings will be influenced by the views, perceptions and experiences of the researcher. Nevertheless, this is acknowledged as part of the process of analysing qualitative data (Smith et al., 2009; Vaismoradi, Jones, Turunen, et al., 2016).

*Verification:* In order to support the categories developed this study used referential sources from studies that have similarities.

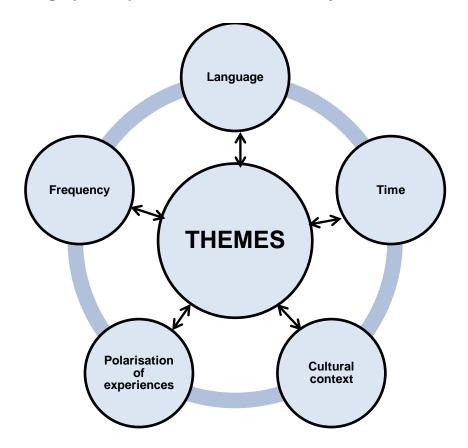
*Nomination*: This is the process of assigning labels to categories which in this study uses the interpretive position as well as participants as a source.

#### 3.10 Themes

Themes are constructs or concepts which capture key elements in the dataset, not necessarily the number of times it has been identified but how significant it is to the research question (Braun, et al, 2006). Themes are considered to be the underlying meanings interpreted from the data along with idiographic experiences of participants. Although generating themes is an essential part of qualitative research, there are limited studies that clarify the process of identifying themes (Ryan, Bernard, 2003; Braun, et al., 2006). This is possibly due to the diverse ways of generating themes in different qualitative studies particularly where the study is driven by a particular theoretical stance (Vaismoradi et al., 2016).

There are different procedures to identify themes but for this study the approach illustrated in Figure 5, (pg. 95) was considered most useful to meet the aims of the study whilst tapping into the most relevant idiographic experiences of the participants to provide information in rich detail (Smith, Osborn, 2003; Smith et al., 2009; Vaismoradi et al., 2016).

Figure 5: Idiographic experiential factors to identify themes



Language use: Consider the potency of the words used regarding emotive content, delivery- hesitancy or difficulty in expressing themselves, stopping and starting responses.

Frequency: Repetition of ideas, words or views.

Cultural context: Identify the social context, perceptions according to age, gender, and ethnicity.

Time: Critical events during the period investigated.

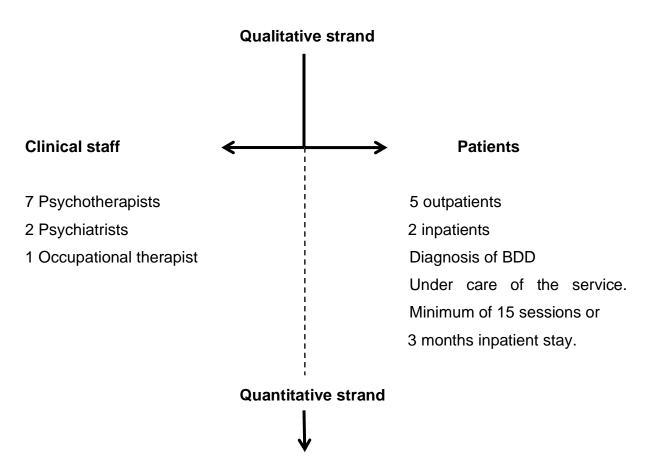
Polarisation of experiences: Pros and cons of a situation, dichotomy expressed in perceptions of experiences. (Smith et al., 2009)

Arriving at themes is an iterative process and requires reviewing codes then amending or accepting themes to reach the final selection (Fig. 4; Fig. 5). When describing the themes, using excerpts from participants' interviews supports the interpretation (Halldorson, 2009; Ryan, et al, 2003).

## 3.11 Participants

Two groups of individuals were invited to participate in this study based on prior working knowledge of the staff and the patient group under their care (Fig. 6). One group comprised qualified clinical staff (N= 10; psychiatrists, cognitive behavioural psychotherapists and occupational therapists) responsible for devising treatment programmes and providing treatment to patients. The other group were patients under care of the service who have a diagnosis of BDD (N=7). The total patient sample is illustrated in Table 6 (pg.118).

Figure 6: Participant recruitment and sample



Database of local outpatients from 1st April 2006 (N=31)
National inpatients (N=13) and national outpatients (N=4) from 1st April 2007.

Staff were informed at the team meeting of the study and invited to participate. They were also asked to inform patients of the study and provide the patient information sheets to patients. Given the difficulty often experienced engaging patients who have BDD, it was deemed most appropriate for the clinician responsible for their care to invite them to participate. In this way the patient could consider participating without the potentially anxiety-provoking situation of meeting with a new person (i.e. the investigator) to discuss it. Also given the sometimes tenuous nature of their engagement, it was felt that being approached by someone new about the study could jeopardise their engagement. This is in keeping with the ethical principle of beneficence to protect patients' well-being (United States, 1978).

In addition the quantitative sample comprised a total of 48 referrals. A breakdown of the number of patients in different levels of the service is given in Table 5. These patients were accepted by the service as meeting the diagnostic criteria for BDD over a specific time period. Regional outpatients were included from 1st April 2006 and national inpatients and national outpatients from 1st April 2007. These are the dates that the respective services were operationalised as models for implementing the NICE (2006) guidance for OCD/BDD. National outpatients are provided with treatment by the specialist service in their geographical area depending on their individual circumstances, although they fall within level 6 of the NICE guidelines (2006). Patients are accepted from the age of 18; there is no upper age limit.

Table 5: Number of patients referred on Level 5 and 6 of the stepped care model (NICE, 2006)

Service Type	NICE (2006) Level	N (48)	Percent	
	_			
Regional outpatients	5	31	64.6	
National community	6	4	8.3	
National inpatients	6	13	27.1	

#### 3.11a Inclusion criteria

To ensure ethical recruitment in fulfilling the principle of non-maleficence only patients that were currently under care of the service were invited to participate in the qualitative strand of the study (Beauchamp, Childress, 2001). This included patients who completed treatment and were in follow up and those who completed an adequate trial of treatment, which is 15 sessions or 3 months inpatient stay. At that stage of treatment patients would have completed sufficient therapy to enable them to continue to practice the techniques and "be their own therapist" if they choose to discontinue formal sessions or if they wished to be discharged from the inpatient ward.

For the quantitative data all the referrals of patients accepted for treatment were included in analysis. Dropouts and missing data was included as intention to treat analysis with the last known score on measures carried forward.

#### 3.11b Exclusion criteria

For the semi-structured interviews, patients were excluded if they were actively suicidal, psychotic or regularly abusing drugs or alcohol. This suitability was determined by the patient's responsible clinician in inviting patients to participate in the study. The sample of clinicians excludes staff, students and ancillary staff not responsible for devising treatment and care programmes for patients.

## 3.12 Sampling

Bringing together quantitative and qualitative methods in this study has its own challenges especially in determining the process of sample selection. The patient samples for both the quantitative and qualitative strands of analysis were obtained from the same database. In addition a sample of clinicians was used in the third phase of the study to provide additional qualitative data. The samples were not equal in size (Fig. 6). Sample sizes in qualitative methods tend to be smaller than quantitative samples as the emphasis is on the deeper understanding of the experiences of a particular group rather than generalising findings to the population (Patton, 2002). The analysis in the three phases, generated data which was then merged and compared using a convergent mixed methods parallel design (Appendix H). The findings were then discussed in relation to the aims of the study (Chpt. 7).

## 3.12a Quantitative sample Phase 1

Quantitative studies emphasise the generalisability of findings requiring large samples of a given population (Palinkas, Horwitz, Green, et al., 2015). Non-random sampling was used in the collection of quantitative data to ensure the largest sample of patients relevant for the study could be obtained (3.11a, b).

#### Power considerations

The general guidance for sampling is to obtain the largest sample possible to be able to detect small but significant changes which could be generalised to the population (Moher, Dulberg, Wells, 1994). However there is call for less focus on sample size as this may mean important trials are unpublished and knowledge lost especially in subjects with a dearth of information, which is the case with BDD (Schulz, Grimes, 2005). Furthermore in retrospective studies such as this a power calculation is not relevant as all cases meeting the inclusion criteria in the database will be used. Instead the confidence intervals from the statistical tests should prove more useful as well as transparency in describing the process leading to the sample selection (Schulz, Grimes, 2005; Dancey, Reidy, 2004).

#### 3.12b Qualitative sample Phase 2 and Phase 3

Qualitative methods focus on the depth of understanding of the data which in contrast to quantitative methods can be generated by a smaller sample (Patton, 2002). Purposeful sampling was used to identify the participants for the qualitative component of this study (Fig. 6; Table 6). This is a technique used to select a sample that will provide the most relevant information in a short timespan when there are limited resources at one's disposal (Patton, 2002). The samples identified and selected have a particular experience relating to the subject of study i.e. either as a patient or as a clinician providing treatment (Cresswell, Plano Clark, 2011). It is also important that the individuals included in the sample are willing to participate and provide a reflective account of their experiences (Bernard, 2002; Spradley, 1979).

Recognising that patients and therapists have a different experience of the therapeutic dynamic, meant that it was necessary to obtain data from both groups to fully explore the treatment experience (Wright, Davis Vanderbilt, 1994). The therapeutic relationship, especially in CBT is geared towards the patient achieving behaviour changes therefore although the therapy is collaborative in nature, there is a power difference with the therapist in the position of greater control (Wright, Davis, 1994; Beck, Rush, Shaw, Emery, 1979; Orlinsky et al., 1994). Therefore obtaining views from patient and therapist allowed for aspects of therapy, such as the therapeutic relationship to be explored from both perspectives and is linked to the study's aims (Frank, 1985; Strupp, 1988).

#### 3.13 Data collection

Clinical information regarding severity and outcome was extracted from databases. Clinical and demographic data was collated; analysed and interpreted using validated scales which are administered routinely at assessments and reviews. In addition the patients' level of functioning is also rated to provide a comprehensive view of the impact of the psychopathology on the patient's life and to establish whether there were any changes in their functioning following treatment. Data collected was analysed to determine changes in clinical symptoms of BDD.

#### 3.14 Semi-structured interviews

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Semi-structured interviews are often used in qualitative research to aid in exploring views and experiences of the participants regarding a particular topic (Edwards, Holland, 2013). Using semi-structured interviews in this study fits in with the nature of the data needed- as it is a service evaluation, the interview schedule was aimed at obtaining the most relevant data to address the research questions (Appendices O, P).

Patients with BDD are often hesitant to meet others even those with BDD for fear of being judged therefore semi-structured interviews appeared the most sensitive way to engage them in the study (Phillips, 1991). The benefit is that it provided a clear format and direction to ensure relevant data was obtained but also allowed for respondents to elaborate on their lived experience. Given it allows greater flexibility; it also aids in building rapport and supports the exploration of the participant's views beyond the constructed questions (Smith, 2008). Even so it was difficult to persuade some patients to have a face to face meeting and they would only agree to telephone participation. In accordance with the principles of beneficence and justice, these participants' requests were respected (United States, 1978; Beauchamp and Childress, 2001). Research comparing telephone and face to face interviewing found that there was no significant difference between data obtained (Herzog, Rodgers, 1988; Sweet, 2002). Telephone interviews are mainly used in qualitative studies using small samples and TA in particular allows for flexibility in methods of data collection (Carr, Worth, 2001; Reid, Flowers, Larkin, 2005). In addition as the service is both regional and national, interviewing patients face to face was not always practical.

The investigator allowed 30 to 40 minutes for the interviews as denoted on the information sheets. However this required flexibility with regards to the needs of the participant. The majority of interviews took 20-30 minutes, but some took 15 minutes and others needed more time; taking more than an hour. Some of the difficulties with using semi-structured interviews are that the investigator's control over the interview can be reduced (Smith, 2008). This meant that interviews had to be ended when the participants did not provide any further information despite prompting. In contrast,

some interviews took longer as responses had to be explored further and participants needed prompting or support to express their views.

Patient semi-structured interviews: Interviews were conducted on the hospital site in the team's interview rooms or by telephone. The interviews included checks for signs of distress when considered necessary from the patient's response or non-verbal cues such as silence or change in tone of voice or expression. The patient's responsible clinician was informed of the interview. Two face to face interviews were conducted and five were by telephone.

Clinician semi-structured interviews: The clinicians working in the Community OCD/BDD Service are based in community sites in boroughs across the Trust. Therefore for practicality reasons interviews were conducted either by telephone or on the hospital site in the team's interview rooms. Three interviews were conducted face to face and seven by telephone.

**Transcribing:** Digital audio recordings were made of the interviews and to ensure accuracy, transcripts were compared to the recordings and amendments made where needed. All interviews were transcribed by the investigator and follow the same format providing consistency.

#### 3.15 Measures

These questionnaires are routinely administered from assessment through to the end of treatment and are collated and stored on the Trust's database.

There are two self-reporting measures:

Beck's Depression Inventory (BDI) (Beck, Ward, Mendelson et al., 1961) is a 21-question multiple-choice instrument for measuring the severity of depression. The questions are scored from 0 to 3 with a total scoring range of 0 to 63. The BDI is reported to have been structured into groups of symptoms from clinical observations (Beck, Steer, Garbin, 1988).

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The BDI has been extensively used since its development and has been established as a reliable measure in both clinical and non-clinical studies (Richter, Werner, Heerlein et al., 1998; Blumberry, Oliver, McClure, 1978; Beck, Steer, 1984). Reviews of the BDI describe variability of scores, even over the course of a day, however this would be in keeping with symptoms of depression and it is acknowledged that the BDI is highly sensitive to changes in symptoms (APA, 2013; WHO, 2018; Richter et al., 1998).

A weakness of the BDI lies in its inception, when it was tested on predominantly Caucasian samples in the United States (Dozois, Covin, 2004; Richter et al. 1998). Therefore it falls short in representing other population groups and considering cultural differences which have a bearing on how depression is perceived (Dozois et al., 2004; Falicov, 2003). It is also plausible that some patients may not be candid in rating their symptoms which could reduce its reliability (Stehouwer, 1987). There is also criticism in the literature that some of the items such as "crying" may have different connotations for males which could lead to gender bias (Barroso, Sandelowski, 2001). Bearing in mind its limitations, the BDI is still an appropriate choice of measure, particularly as it reflects changes in symptoms with psychotherapeutic treatment (Demyttenaere, De Fruyt, 2003). Overall it is simple in its structure, easy to score, gives a comprehensive rating of symptoms and can be completed in a short amount of time which makes it more user-friendly for patients (Dozois et al., 2004). Therefore it was considered the most appropriate measure for patients in the care of this service.

Sheehan's Disability Scale (SDS) (Sheehan, 1983), is a five item measure used to assess the extent that symptoms result in functional impairment in three interrelated domains: work/school; social/leisure; family life. The first three items are rated on a visual analog scale ranging from 0 to 10 with a high score indicating severe impairment. The last two items ask about how many days the respondent missed work or study and how many days were unproductive due to their symptoms (Rush, First, Blacker, 2008). Scores over 5 on each item are considered to indicate significant functional impairment (Rush, et al., 2008).

The SDS is a simple plus basic scale but it is the simplicity and ease of use that make it an appealing patient-rated measure. It also enables clinicians to have a clear indication of the level of functioning in the most significant areas of a patient's life. In addition the reliability and validity of the SDS has been positively evaluated in different populations (Arbuckle, Frye, Brecher et al., 2007; Coles, Coon, DeMuro et al., 2014).

There are two scales administered by therapists:

Yale Brown Obsessive Compulsive Scale Modified for Body Dysmorphic Disorder (BDD-YBOCS) (Phillips, Hollander, 1997). This is a 12-item semi-structured instrument designed to rate severity of body dysmorphic disorder symptoms in the week prior to the assessment. It has been modified from the extensively used Yale Brown Obsessive-Compulsive Scale (YBOCS) for measuring OCD symptoms due to similarities shared between these disorders (Goodman et al., 1989a, b; Phillips et al., 2010).

The BDD-YBOCS has been widely used in studies on BDD (Wilhelm et al., 1999; Phillips et al., 2002; Phillips et al., 2003; Wilhelm et al., 2011). From the 43 studies reviewed 31 studies used the BDD-YBOCS across three different types of modalities (Appendices E, F, and G). The first five questions assess the preoccupation with appearance–related concerns and the second five items measure involvement in behaviours linked to appearance concerns. There are two additional questions on the BDD-YBOCS; one which is designed to give an indication of insight and the other of avoidance due to BDD symptoms. A cut off score of 20 is used to indicate the presence of BDD (Phillips, 2006).

Validity and reliability reviews of the BDD-YBOCS are very limited with the main study evaluating the scale conducted by one of its designers which could indicate bias (Phillips et al., 1997; Phillips et al., 2014). However it has also been found to maintain validity and accuracy across different languages and cultures (de Brito, Sabino Neto, de Oliveira et al., 2015). One of the areas it falls short on is rating overvalued ideation which has been found to be a leading factor in treatment failure (Phillips et al., 2001; Eisen et al., 2004). Instead the Brown's Assessment of Beliefs

Scale (BABS) is used to assess insight and overvalued ideation (Eisen, Rasmussen Phillips, et al., 2001). This makes it more cumbersome as it involves having to use two scales which clinicians have to be trained to do. In addition, there is training for clinicians to use the YBOCS but none for the BDD-YBOCS which calls reliability into question (Eisen, et al., 2001; Goodman et al., 1989a, b).

Montgomery-Asberg Depression Rating Scale (MADRS) (Montgomery, Asberg, 1979). A 10-item measurement tool conducted as a semi-structured interview, to assess the range and severity of symptoms of depression on a scale from 0 to 6 with higher rating indicating greater severity in symptoms.

Originally developed to assess the effect of antidepressant medication on symptoms of depression, the scale is a useful adjunct to the BDI given the treatment focus of CBT and medication for BDD in the service (Demyttenaere et al., 2003; Bech, 2006). Studies on sensitivity of the MADRS indicate good performance in differentiating between patients who did or did not respond to treatment and between levels of severity (Montgomery et al., 1979; Kearns, Cruickshank, McGuigan et al., 1982, Bowling, 2005). Good inter-rater reliability and validity has been shown in a number of studies (Montgomery et al., 1979; Davidson, Turnbull, Strickland, et al., 2006; Takahashi, Tomita, Higuchi et al., 2004).

Although developed as a semi-structured interview tool, the rating relies on the clinician's assessment of the patient's reported symptoms. Hence it could be considered that the scale is not unbiased. Further research has suggested that development of a structured interview guide will improve inter-rater reliability thus making the scale's reliability and validity more robust even across different language domains (Williams, Kobak, 2008) Takahashi, et al., 2004).

#### 3.16 Challenges in using mixed methods

As previously discussed both TA and quantitative methods have strengths and limitations but combining them reveals another level of understanding of the data. This study will build on gaps in the literature by using a mixed methods approach which allows for more comprehensive gathering of data. Quantitative research allows

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for large amounts of data to be collected and analysed and results to be generalised to the larger population (Cresswell, 2015). However quantitative methods do not explore the experience of participants which is better served by using qualitative methods (Creswell, 2015).

A difficulty with mixed methods design is that it requires more time commitment due to the multiple strategies used to analyse and integrate data (Bazeley, 2004). Conducting individual interviews were also more time consuming although using telephone interviews reduced travel time. Using semi-structured interviews, gave voice to the participants in the study which will provide a more vibrant context for the numerical results of the quantitative analysis (Smith, 2008). Personal accounts are also more appealing to readers (Cresswell, 2015). Similarly using semi-structured interviews with clinicians enabled them to express their views more openly whilst reducing bias as responses were not influenced by the presence of other team members.

In addition this is the first known study written in English to give a detailed account of clinicians' perspectives of treating BDD within a psychological and pharmacological model. This will add to the knowledge of the treatment aspects especially with regards to areas clinicians feel are lacking and require further development. Bringing together both the methods will make the information more accessible to both clinicians and the general public.

#### 3.17 Quality assurance of the research

This study incorporates the four main principles for establishing the quality of qualitative research (Yardley, 2000; Smith et al., 2009). In order to ensure sensitivity to the context a clear understanding of the existing literature on BDD and its treatment was required along with in-depth exploration of the meanings of their views and experiences from the data gathered from respondents (Yardley, 2000). The principle of sensitivity was vital in conducting the interviews which required engaging the participant, building rapport and recognising any distress or unease which also adheres to the professional code of conduct (BABCP, 2010).

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Principles of commitment and fidelity were displayed by care and attention to the participants during data collection and with the analysis of the data (Yardley, 2000; Smith et al., 2009). The fidelity of the data can sometimes be difficult to ensure if participants do not wish to have further involvement. Therefore the interviews in this study are transcribed from audio recordings and the (HCP) respondents who agreed, were sent copies to verify the content whilst most did not feel it necessary. It was also considered to not be beneficial to the patient participants to share the interpretation of the transcripts with them as this could impact on their relationship with their therapist and/ or cause disturbance in the therapeutic process. This is in accordance with the ethical principle of non-maleficence to ensure the participants' well-being.

Transparency and coherence is the third principle involving the clear description of the processes involved, from design through to analysis, in conducting the study both for participants and for future research (Smith et al., 2009). Quotes in participants' own words are included to provide a context for the emerging themes and to support findings and interpretations. The researcher provides clear explanations of the transcribing process and the style of interpretation used to ensure findings are considered within this framework and also to ensure the fidelity of the data (3.7.1, pg. 91; 5.2.1, pg.130).

The fourth principle regarding impact and importance highlights the purpose of the study which is to be beneficial to patients with BDD and clinical staff treating the disorder (Yardley, 2000; Smith et al., 2009). The study was conducted with these principles as guidance; bearing in mind that the needs of the participants are the priority.

#### 3.18 Ethics

A service evaluation is described as "designed and conducted solely to define or judge current care" (Health Research Authority, 2017). In this type of project the standards of care provided are considered but it does not involve undertaking any treatment or intervention. Existing data is collated and analysed; although input from patients may be involved e.g. in this study patients were invited to participate in

semi-structured interviews to provide their experience of the treatment and help determine what interventions were most effective.

As this study was deemed a service evaluation, NHS Research Ethics Committee review was not required.

However ethics approval was sought and obtained from:

- The College of Health and Social Care Research Ethics Committee at the University of Derby (Appendix I).
- Approval and registration was obtained from the South West London & St
  George's NHS Mental Health Trust Quality Governance department. The
  department approves and registers audits but there is no separate department
  for service evaluations so these are registered alongside audits. Hence the
  wording in the standard approval correspondence received (Appendix J).

The ethical considerations significant to this study require an adherence to the British Association of Behavioural and Cognitive Psychotherapy (BABCP, 2010) professional code of conduct as well as the South West London and St George's NHS Mental Health Trust's policies on consent, confidentiality and clinical governance.

The principles that form the foundations of biomedical ethics have been widely discussed in the literature (International Council of Nurses, 1996; Beauchamp, Childress, 2001; Polit, et al. 2004). There is a consensus as to the main principles which should guide research, including beneficence, non-maleficence, justice and autonomy. These principles underpin the non-consequentialist ethical theory of deontology which is embraced from a patient-centred position in this study (Pieper, 2008). The description of patient-centred deontology stipulates that individuals are not to be treated as a means to an end (Kant, 1785). As observed in the literature, deontologists tend to be more considerate of the costs to participants (Schlenker, Forsyth, 1977).

The principle of beneficence requires that any research that is carried out ensures that participants' decisions are respected and they are protected from harm and their well-being is ensured (United States, 1978). Furthermore the principle of fidelity

concerned with building trust between the researcher and the participant is most important to enable participants to feel comfortable in discussing their views and experiences (Parahoo, 1997). This also involved using the principles of CBT in engaging the participants and being sensitive to their concerns and needs.

In accordance with these principles, the ethical basis in conducting this study focused on ensuring the appropriate procedure was followed for participant interviews. The purpose was not just to obtain information from participants but to safeguard them with regards to their informed consent, voluntary participation and confidentiality. This responsibility to ensure the wellbeing of participants during the study is required by the principles of non-maleficence and beneficence. The investigator's independent position is clearly explained to participants as duty bound to protect the interests of the participants and having no influence on treatment provided or on staff management.

#### **3.18.1 Consent**

To fulfil the principles of non-maleficence and autonomy all participants in this study were fully informed in writing and verbally about the purpose, methods and how the research findings will be used. No incentives were offered for participation. Participation was subject to consent for any data and information they provided to be used. Participants were provided with written information on what their contribution will involve (Appendices M, N). Further information or clarification was provided to participants if requested as was explained in the participant information sheet. This enabled participants to make an informed choice based on all the information being provided thus ensuring an autonomous decision and no harm from any omission or commission (Appelbaum, 2007). As detailed in the information sheets, participation was voluntary and they were also able to withdraw their consent at any time prior to the data being analysed without the need for any explanation and without prejudice.

The principle of non-maleficence requires a commitment to protect participants from harm. In this type of study it is important to ensure participant's needs and well-being are the first priority. Therefore patients were identified and invited by their responsible clinician to participate depending on the clinician's assessment of the

patient's mental state and risk status. The responsible clinician gave their patients the information sheets and consent forms.

For the clinicians' feedback, information sheets and consent forms were provided by the study investigator to participate in the service evaluation. All data was anonymised or pseudonyms used and none of the patients or clinicians will be identifiable in the report of the findings. Participants were informed that they can refuse to answer any question and can request that the recording of interviews be stopped and the interview terminated at any time. Permission for recording was included in the consent form (Appendices M, N).

## 3.18.2 Confidentiality

In accordance with the principle of non-maleficence, anonymity of respondents is respected (Beauchamp et al., 2001). No identifying details of patients and clinicians were used in the research study. Participants were informed of the confidentiality of information they supply in writing and verbally. The participant was also made aware of exceptions to this. The exceptions are if the participant provides information regarding issues of risk either to them or to others. This information would have to be relayed to the necessary parties to manage appropriately. Patients are provided with details of the Trust's confidentiality policy as standard procedure for all patients offered assessment or screening by the service.

Data provided by clinicians was anonymised and stored on a separate Trust database developed specifically for the purpose of this study and only accessible to the investigator. This data will be stored for two years and then destroyed securely according to Trust policy following the conclusion of the study. This is also in keeping with the principles of the Data Protection Act (1998).

#### 3.18.3 First do no harm

In clinical research non-maleficence requires disclosure to subjects any possible risks that participation may involve (Lawrence, 2007). In addition the principle of beneficence requires making an effort to secure their well-being (United States,

1978). To uphold this principle in the course of the semi- structured interview, if the participant became distressed or wanted the recording stopped for any reason, the interview was stopped and the participant was given time to discuss their concerns or upset.

As agreed with the specialist service, for patient participants, their therapist was available if they wished to discuss any concerns with them. Interviews as far as practicable were arranged for when their therapist was available for face to face or telephone consultation. The participant was asked if they wished for their GP or other health care professional to be contacted following the interview. In debriefing following the interview, it was clarified whether they still agreed to have their responses included in the study or if there was any information they did not want to be used.

As it is a national service, for practical reasons some participants were not able to travel to the hospital. In conjunction with the principle of justice, it was unfair to exclude them on geographical grounds; therefore their interviews were conducted by telephone.

In clinical research non-maleficence requires disclosure to subjects any possible risks that participation may involve (Lawrence, 2007). In addition the principle of beneficence requires making an effort to secure their well-being (United States, 1978). For patient participants, prior to the interview their responsible clinician was asked about any current concerns about the patient being interviewed. If there were any concerns from the clinician, the plan was for their clinician to inform the patient that the interview will be postponed or cancelled as appropriate and for the clinician to explain their concerns.

If the responsible clinician did not have any concerns, the investigator also clarified with the patient when contacted if they wished to go ahead with the interview at that time. If the patient voiced any concerns they had the option to rearrange the interview or withdraw their participation. Similarly if the clinician participant was upset in any way by the interview they had the option to discuss their concerns with their supervisor/line manager or anyone else they wanted to consult.

Following the interviews the participating patients and clinicians were offered a debriefing session. This was to identify if any emotional distress was caused by the interview process; to answer any questions; to ensure the participant was emotionally settled before ending the session. If any distress was noted, an action plan was to be established to ensure the appropriate support was available for the participant. They were given a debriefing sheet with the investigator's contact details if they wished to discuss any aspect of the interview at a later date (Appendix Q).

Patients were advised that if they had any queries regarding their treatment, they could contact the professionals involved in their care. With regard to identifying risks in the patient group, the plan was to alert the professionals responsible for their care. Clinicians with any queries outside of the study remit would have been directed to their line manager or supervisor. The participant information sheets include these provisions (Appendices K, L).

The study was conducted in a non-discriminatory manner in conjunction with the ethical principle of justice, in particular the response to each participant's needs. Translated information was available for patients if needed and a translator would have been provided if required for patient interviews. The team base is equipped for people with physical disabilities to ensure accessibility. This is also in keeping with the BABCP standards of conduct, performance and ethics (BABCP, 2010).

## 3.18.4 Benefits of the study

The second principle of beneficence refers to the benefit of research to the participants as well as to society (United States, 1978). In this study participants had the opportunity to voice their opinion on treatment received and treatment provided—what they felt worked best and aspects they felt were less helpful. Although there may not be any specific benefit for each individual, the information they provided could offer some direction as to the best ways of engaging patients in treatment and highlighting interventions that will enable them to continue to progress at the conclusion of treatment.

Findings from the study once published will add to the body of knowledge regarding BDD. This will be helpful in developing a general awareness of the disorder in society and promoting treatment methods for BDD that have been found to be most beneficial. This satisfies the principle of beneficence where the study findings may lead to improving knowledge and interventions to have longer term benefits for larger society (United States, 1978). In addition this upholds the principle of fidelity in maintaining the highest standards of care and professional conduct acting in the best interests of the patient (BABCP, 2010).

## 3.18.5 Dissemination of findings

A continuation of the second principle of beneficence was to ensure the aims and objectives of the study, in addition to being beneficial, will also make a valuable contribution to both the body of knowledge and the service (United States, 1978). The researcher has an ethical responsibility to ensure findings from the study are available to other health care professionals to increase the development of knowledge in this field (Singh and Singh, 2007; Fernandez, Kodish, Weijer, 2003). This is especially relevant regarding BDD considering the dearth of research available. In addition there is the responsibility to the participants who provided the information to offer them the opportunity to view the findings (United States, 1978; Fernandez, et al., 2003). In this study, the aim is to disseminate the results of the study through presentations and publications and to make copies of the findings available to participants upon publication if they wish.

#### 3.19 Limitations

The small sample size of the quantitative data may be considered to limit generalisability as does the focus on just one service. Nevertheless from studies reviewed the average sample size for pharmacotherapy studies was M=32.6 and for psychological therapies M= 16.12.

There is also growing support for the use of smaller samples in qualitative studies (Smith et al., 2003; Reid et al., 2005). Although findings appear to be less transferrable to the population, data from smaller samples can be interpreted to a

greater depth without the detail becoming lost in vast quantities of information (Smith et al., 2009). In addition as treatment resources for BDD are very limited this study will produce preliminary findings to add to the research base and provide the opportunity to develop further research projects.

Although there may appear to be a selection bias in using both inpatient and outpatient groups as they differ in factors which could influence outcome, these groups are not being compared as they received treatment on different levels of the NICE (2006) guidelines.

## 3.20 Summary

TA provides an experiential aspect to the study and in so doing also brings a greater understanding of the quantitative data. This can be used to inform how to refine the application of the NICE (2006) guidelines to address concerns, needs and shortcomings as well as to reinforce areas of strength and excellence revealed through the analysis of the data. In addition providing a clear and transparent process of thematic analysis also adds to the knowledge base for qualitative research as literature on TA is also limited (Braun et al., 2006; Ryan et al., 2003; Vaismoradi et al., 2016).

Findings from the study are presented in the subsequent chapters. These are separated into quantitative results (Phase 1) and qualitative findings (Phase 2 and 3) using TA. The chapters flow from descriptive statistical data into a deeper interpretation of the patients' and health care professionals' (HCPs') views which are then merged to compare and contrast themes in the final chapter.

Chapter 4:
Phase 1
ANALYSIS OF
QUANTITATIVE DATA

#### 4.1 Introduction

This chapter is presented in two parts. The first provides a description of the total patient participants. The second reports the results from analysis of patients' measures pre- and post- treatment.

# 4.2 Patient participant characteristics

Patient participants are divided into three groups from the quantitative data collected: Outpatients treated at level 5 of the NICE guidelines (2006); national service inpatients and national service outpatients treated at level 6 of the NICE guidelines (2006). Table 6 describes the patient participants.

Outpatients in the national service treated at level 6 (L6 national outpatients) may have symptoms of similar severity as the inpatients however usually differ with regards to need for 24-hour nursing care. They were provided with intensive treatment, often in their own homes comprising several consecutive days of therapy which included supporting their local service to manage their care. However some patients have been treated as "outpatients" who were actually admitted to an acute inpatient setting elsewhere and it was deemed more beneficial for therapists to treat the patient there rather than admit them to this unit. This may be due to their level of risk, their distress at being moved from a familiar environment or being far from their support network.

The sample of patients who participated in the semi-structured interviews is included in the quantitative data analysis but will also be described separately to provide a context for the information gathered from the interviews (Tables 10 and 18).

Table 6: Sociodemographic characteristics of patient participants by group and combined

	Outpar (N=3		Inpatie (N=1		outpa	ational atients =4)	Total Sa (N=4	_
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Age at assessment	34.68	12.39	34.77	9.56	39.7	20.8	35.13	12.30
	R= 18-6	3	R= 18-	50	R= 24-70	)		
Onset age	15.68	6.12	17.0	6.05	14.0	4.32	15.90	5.930
	N	%	N	%	N	%	N	%
Gender								
Male	11	35.5	7	53.8	2	50.0	20	41.7
Female	20	64.5	6	46.2	2	50.0	28	58.3
Employment								
Unemployed	14	45.2	10	76.9	3	75.0	29	60.4
Employed	12	38.7	1	7.7	0	0.0	13	27.1
Student	4	12.9	2	15.4	0	0.0	4	8.3
Retired	1	3.2	0	0.0	1	25.0	2	4.2
Ethnicity								
White	26	83.9	12	92.3	4	100.0	42	87.5
Black	1	3.2	0	0.0	0	0.0	1	2.1
Asian	2	6.5	1	7.7	0	0.0	3	6.3
Other incl. Chinese	1	3.2	0	0.0	0	0.0	1	2.1
Mixed	1	3.2	0	0.0	0	0.0	1	2.1
Accommodation								
Living alone	13	41.9	3	23.1	1	25.0	17	35.4
With parents	14	45.2	8	61.5	1	25.0	23	47.9
Supported housing	0	0.0	0	0.0	1	25.0	1	2.1
With spouse/partner	4	12.9	2	15.4	1	25.0	7	14.6
Marital								
Single	25	80.6	11	84.6	3	75.0	39	81.3
Married	2	6.5	1	7.7	1	25.0	4	8.3
Partner	2	6.5	1	7.7	0	0.0	3	6.3
Widow/Widower	1	3.2	0	0.0	0	0.0	1	2.1
Divorced	1	3.2	0	0.0	0	0.0	1	2.1
Children								
None	27	87.1	12	92.3	4	100.0	43	89.6
Parent	2	6.5	1	7.7	0	0.0	3	6.3
Single parent	2	6.5	0	0.0	0	0.0	2	4.2

# 4.2.1 Sociodemographic findings

A total of 48 participants were included in the study. The data indicated a larger percentage of females than males presenting with BDD in the service (Table 6). The participants were predominantly Caucasian, ranging in age from 18-70 years old with an average onset age of 15 and range of 10- 45 years. The average duration of BDD was 19.23 years in keeping with studies indicating long duration before seeking treatment ((Veale et al., 1996; Phillips, et al., 1997). English was the first language for all patients.

Areas of note were the high rate of unemployed participants; single status and no children. There was also a majority of participants living with their parents. These findings are consistent with the literature indicating the disabling impact of BDD on the individual's functioning (Phillips, et al., 2005; Phillips et al., 2008).

#### 4.3 Clinical factors

At assessment patients provided detailed descriptions of the features they are concerned about by completing the Body Dissatisfaction Checklist (Appendix Z.v).

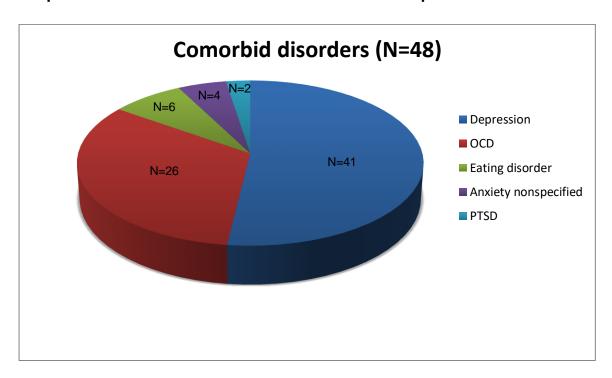
Table 7: Most common areas of preoccupation

Feature	Incidence in total sample
	(N= 48)
Skin	20
Whole face	15
Nose	14
Eyes	9
Whole body	8
Hair on head/baldness	8
Breasts	7

Features that were more noticeable tended to be areas of preoccupation (Table 7). These results shared similarities with findings in research studies (1.2.4 pg. 20; Phillips, et al., 2001; Phillips, 1986). Patients in the sample often indicated more than

one area of preoccupation and this could sometimes change in the course of treatment with additional areas becoming the focus. The data also revealed that five patients had previous cosmetic surgery and four performed self-inflicted surgery which is an indication of the extreme measures patients with BDD will go to alleviate their distress (Veale, 2000; Phillips et al., 2005; Phillips, et al., 2006).

Findings of note were the high risk profiles with 30 patients indicating suicide risk with suicidal ideation or previous suicide attempts (Appendix U). Alongside this were 29 instances of misuse of alcohol and illicit substances (Appendix U). There was also a high comorbidity rate (Graph 4). These findings are in keeping with the literature reports on clinical features of BDD (Conrado et al., 2010; Phillips et al., 2006; Grant et al., 2001).



**Graph 4: Incidence of comorbid disorders in the sample** 

Comorbid depression was present in 85% of the sample followed by 54% with OCD. There were also 33% of patients with more than 2 comorbid disorders in the sample. Additional disorders occurring singly in the sample were: hoarding; personality disorder (unspecified); Asperger's Syndrome; schizophrenia and bipolar disorder.

The medication regime usually consisted of a SSRI and augmentation with a dopamine blockade. From the available data collated, the most common medication used was Fluoxetine whilst Aripiprazole was the most common augmentation

prescribed (Appendix V). Given the limited research studies into pharmacological treatment for BDD, the guidelines concluded that there is no evidence for either SSRIs or augmentation with dopamine blockades in BDD however they suggest the similarities between BDD and OCD warrant trials with this medication as they have been shown to be effective in OCD (NICE, 2006: 6.13.7, pg.173). This is concerning as pharmacological treatments for BDD seem to be a trial and error exercise. Indeed following the trial of Pimozide this medication was found to have concerning health effects (Phillips, 2005a). Given the lack of clear direction in the NICE guidelines (2006) for pharmacological treatments, evidence was sourced from any available research studies to support prescribing practices in the service (Appendix F, Appendix V).

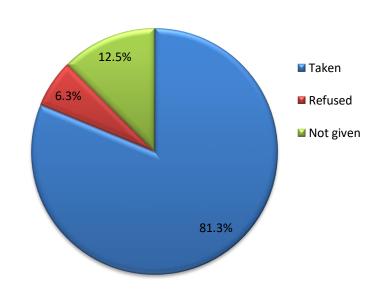
One of the shortcomings identified in the literature was that patients do not always engage in treatment and there is a relatively high dropout rate. From the total of 48 participants, 10 (20.8%) dropped out of treatment before the 15 sessions or three months admission. Four of the non-completers were outpatients, three were inpatients and three were L6 national outpatients. Reasons for dropout were obtained where possible which could help in reviewing strategies for engagement (Table 8).

Table 8: Reasons for dropout where provided:

Outpatients	2 disengaged as felt therapy too difficult
	1 relapsed into use of illicit substances
Inpatients	1 requested discharge as felt was coping better after 2 month admission
	1 relapsed into alcohol abuse
L6 national	1 disengaged as felt therapy too difficult
outpatients	1 relapsed into use of illicit substances
	1 discharged to CMHT due to self-harming, violent behaviour

## 4.4 Analysis of interventions provided

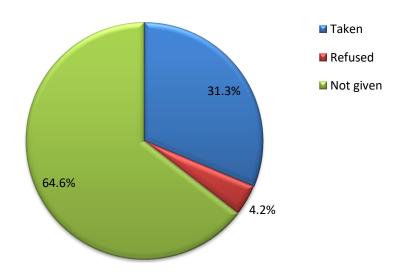
The expectation of the service as per referral criteria and in accordance with the stepped care model is that patients are provided with CBT prior to being referred to the specialist service (Fig. 1; NICE, 2006). However the recognition and expertise to treat BDD is still lacking amongst healthcare professionals and patients are accepted for treatment when it is clear they will not be able to access the appropriate treatment elsewhere.



**Graph 5: Treatment with SSRIs for BDD (N=48)** 

Treatment with an SSRI was accepted by 81.3% (N=39) of patient participants which was offered in line with the NICE guidelines (2006). A further 12.5% of patients were not offered SSRIs (N=6) and 6.3% (N=3) refused to be prescribed SSRIs (Graph 5). The reasons for refusal where available were: concerns about physical effects of medication on skin; concerns about side-effects. As previously stated, there are no medications currently licenced for treatment of BDD (FDA, 1998; (MHRA, 2004). A breakdown of medications prescribed is provided in Appendix V.

Graph 6: Augmentation with Dopamine blockades for BDD (N=48)



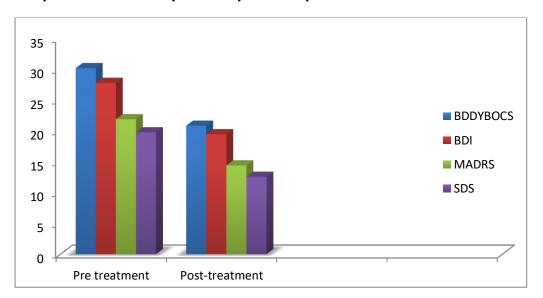
Augmentation studies are even more limited and success rates are variable (Appendix F). Augmentation with dopamine blockades were provided in lower doses than for psychotic disorders and were taken by 31.3% (N=15) of patients and 4.2% (N=2) refused (Graph 6). The majority of patients (64.6%, N=31) were not given augmentation as the team did not think it would be clinically beneficial. The team usually opt for trials with other SSRIs and psychological interventions instead. Once again the question arises, where is the evidence base to suggest the use of augmentation is warranted for treatment of BDD? Out of four studies two studies showed some responders (Rashid et al. 2015; Phillips et al., 1996a). However findings in these studies were inconsistent as the same augmentation used in two different studies showed no response in one and possible response in the other (Phillips, 2005b; Rashid et al., 2015). Clarity was lacking in the study regarding response to specific medications (Rashid et al., 2015).

Table 9: Treatment outcomes for level 5 and level 6 inpatients and national outpatients

Patient group	Treatment	BDD-YBOCS		BDI		MADRS		SDS	
	phase	Mean	SD	Mean	SD	Mean	SD	Mean	SD
L5 Outpatients (N=31)	Baseline	30.19	4.28	27.81	12.34	21.90	8.94	19.77	7.80
	Post treatment	20.84	10.41	19.45	12.09	14.39	9.69	12.55	9.85
	пеаппет	p=0.001		<i>p</i> =0.001		p=0.00°	1	<i>p</i> =0.001	I
L6 Inpatients (N=13)	Baseline	36.08	3.12	33.85	12.53	29.15	10.09	27.62	2.78
	Post	23.23	10.02	19.69	12.14	18.00	10.80	18.92	10.01
	treatment	<i>p</i> =0.001		<i>p</i> =0.016	3	p=0.005	5	<i>p</i> = 0.01	2
L6 National Outpatients (N=4)	Baseline	28.00	14.8	27.00	12.57	21.75	9.10	24.75	5.73
	Post	23.25	13.3	25.75	11.44	19.00	6.16	23.00	9.02
	treatment	<i>p</i> =0.362		p= 0.391		<i>p</i> =0.391		<i>p</i> = 0.391	
Total sample	Baseline	31.60	6.02	29.38	12.45	23.85	9.64	22.31	7.45
(N=48)	Post treatment	21.38 p=0.001	10.3	20.04 p=0.001	11.93	15.75 p=0.002	9.78 2	15.15 p=0.001	10.31

# 4.5 Treatment outcomes

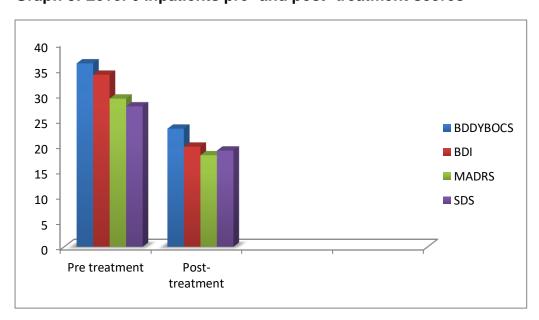
Patients in the L5 outpatient group showed significant improvements from baseline on measures of BDD, depression and functioning (Table 9; Graph 7).



**Graph 7: Level 5 Outpatients pre- and post- treatment scores** 

The outpatient group improved by 31% on the BDD symptom measure; 30% on BDI; 34% on MADRS; 36.5% on SDS.

L6 inpatients showed significant improvement in BDD symptoms from baseline and a trend towards significant improvements in depression and functioning (Graph 8).

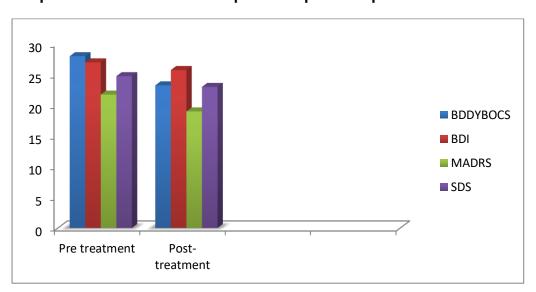


Graph 8: Level 6 Inpatients pre- and post- treatment scores

The inpatient group showed a response rate of 35% on BDD symptom measures; 41% on BDI; 38% on MADRS and 31% on SDS.

Despite the improvements, BDD symptoms for all groups remained within the moderate level of severity with depression ranging between mild and moderate and functioning from mild to moderate impairment. However given this is a specialist service and patients referred are at the more severe end of the spectrum, this result is in keeping with their levels of severity. Still the qualitative data may provide additional insights into the outcomes on measures of severity.

A finding of particular note was L6 national outpatients only showed a 5 point improvement on BDD symptom measures overall and between 1.25 and 2.75 points on measures of depression and functioning (Graph 9).



Graph 9: Level 6 National outpatients' pre- and post- treatment scores

The L6 national outpatient group showed minimal improvements on all measures. The BDD-YBOCS indicated 16% improvement on the BDD symptom measure; 4.6% on BDI; 12% on MADRS; 7% on SDS.

This finding may have implications for treatment in this service category as the outcomes for patients in this level did not reach significance on any measures of symptoms. In addition three patients in this service category dropped out of treatment (Table 8, pg.121). The reasons for the lack of responders in this group are not clear and there were no participants from this service level in the qualitative phase of the study. However given it is a small number of patients, examining the individual demographics and scores on measures may shed some light on this (Table 9, pg.124; Appendix W).

All patients in this group indicated high risk behaviour: one had suicidal ideation, three had previous suicidal attempts. All had more than two additional comorbid disorders (Appendix W). They had all been prescribed SSRI medication although one was non-compliant with medication. None had augmentation to their medication regime. Three showed marked levels of impairments in social, work, home management spheres. These factors combined with symptom severity may have contributed to difficulty gaining benefit from the outpatient national treatment (Table 9, pg.126; Graph 9).

The nature of treatment for this group tends to be:

- Providing an intensive series of treatment days in collaboration with local services.
- The patient is expected to continue to practice skills and techniques learnt with support from their local mental health service.
- Follow up from specialist service.

These patients may be falling in the gap where the specialist service does not have the resources to provide ongoing treatment on a national level to patients who do not meet the inpatient criteria for admission. Nevertheless they have developed a system of disseminating skills and collaborating with local mental health services to provide treatment in areas nationally where there is no access to specialist BDD services. However this group needs further investigation to evaluate effectiveness of the service provision in its current form.

Level 6 inpatients had a greater baseline severity than L5 outpatients as was expected (4.2, pg. 121). However the inpatient group showed greater improvements on all measures compared to outpatients apart from measures of functioning which may be attributed to greater impairments in functioning at baseline for the inpatient group (Table 9). The qualitative data may give an indication of the reasons for the disparity between these groups' responses.

#### 4.6 Discussion

This chapter provides an interesting insight into the population of patients with BDD who present to specialist services. Several points emerged from the sociodemographic breakdown. The ethnicity of patients with BDD is an area with very limited research. Patients were predominantly Caucasian despite being based in a locality with ethnic diversity and also having a national component to the service. Questions arising from this are whether people from minority ethnic groups do not have access to services; are they more reluctant to use mental health services or are methods of engagement used not effective? Furthermore, without people being aware of the disorder, including within health care services, it is less likely to be recognised or have treatment offered.

The findings are consistent with literature descriptions of the young onset age of BDD with long duration of the condition (Phillips, et al., 2006; Veale et al., 1996). This also highlights the need for developing the awareness of BDD so that it is not a hidden disorder. One of the findings of concern is the high risk profiles of the patients in the sample (Appendix U). This shows similarities to reports on risk behaviour in BDD (1.2.6, pg. 21; Phillips et al., 2005; Phillips, 2007; Cotterill, et al., 1997). Given BDD is not easily recognised, risk prevalence may be greater than reported and is another area needing further investigation.

In addition findings indicated 40% of patients had a history of misusing alcohol or illicit substances (Appendix U). Interestingly when examining reasons for dropout three of the eight patients who responded indicated relapse into alcohol or drug use (Table 8, pg.121). Self-medicating with alcohol and illicit substances may have developed to cope with the anxieties generated by BDD (Grant, Menard, Pagano, et al., 2005). This again points to the need for earlier intervention as long term sufferers of BDD tend to have comorbid disorders and be more impaired with their functioning (Phillips, et al., 2008). Examining the experiences from patients' interviews in Phase 2 of this study may provide further insights for the findings in this phase.

# **Chapter 5:**

# **Phase 2: Thematic analysis**

How patients with BDD respond to and experience treatment that has been recommended by the NICE (2006) guidelines for OCD/BDD.

#### 5.1 Introduction

This chapter unfolds with a description of the data management plus the process and method of analysis including coding followed by a depiction of the patient participants (Appendix R). For clarity and transparency the coding process is demonstrated in Table 11 (pg.135) and an excerpt from a patient's transcript demonstrates the coding process (Appendix S). For clarity a list of the superordinate and subordinate themes extracted from the patients' interviews is illustrated in Figure 7. The focal point of this chapter is the exploration of each superordinate and subordinate theme supported by patients' quotes with further interpretation by the author. The data in this study was reported in keeping with the critical realist framework analysing both manifest and latent content. The manner in which the findings were reported was chosen to demonstrate authenticity in the interpretation of the data (3.7.1, pg. 91). Using TA from a critical realist approach enables the interpretation of experiences and meaning whilst acknowledging the researcher's bias (Vaismoradi et al., 2016). The chapter concludes with a discussion of the findings in relation to literature.

## **5.2 Data Management**

### **5.2.1 Transcription**

The way that data is transcribed can strongly influence how participants are portrayed and perceived (Oliver, Serovich, Mason, 2005). Audio recordings of the interviews were transcribed using a more denaturalised approach which aims to be a verbatim portrayal of the interview contents (MacLean, 2004). However the precision of reporting is focused on meanings, views and experiences expressed rather than filler words (i.e. "um, er") (Oliver, et al., 2005). Nevertheless given that supporters of naturalised transcribing argue these could be useful to provide additional information about the participant's affect, filler words were excluded unless they illustrated meaning or the tone of the response (Schegloff, 1997). By focusing on content of dialogue, it can limit misunderstanding or misrepresentation of the participant's response (Billig, 1999a).

Choosing this method of transcribing is linked to the nature of the research question which focuses on experiences and perceptions for the purpose of evaluating

interventions recommended and to contribute to the body of knowledge. Also this method is more allied with the underpinning theoretical framework and the use of TA which requires richness and depth in analysis but not to the extent of interpreting every mannerism or involuntary vocalisation.

Transcripts were prepared for analysis by numbering each line to allow for cross-referencing. Where any comments could possibly identify an individual or third party, these were removed and denoted by closed brackets ([ ]). Initial analysis involved an overview of each transcript with notes made in the margins about salient comments or words used. The transcripts were then re-read and specific information was identified by using coding strategies (3.8, pg. 94) that address the research questions (Saldana, 2016).

## 5.2.2 Data Analysis

Data gleaned from participants' accounts called for organisation and structure. This was found in a heuristic approach which helped to assimilate the data into a more coherent format (Smith, et al., 2009). The notes were used to develop lists of the information. The lists were then interpreted for each case to propose an impression of how the participant made sense of their experience. A search was made across all the transcripts for common words or ways of describing an experience (Fig. 8, 9). Notes from each transcript were then compared and codes were assigned. This process was repeated until codes were exhausted. The codes were then categorised and emergent themes identified.

#### Superordinate themes

Superordinate themes indicate the prevalence of dominant ideas or patterns across the dataset following analysis to refine themes (Smith, et al, 2009).

## Subordinate themes

Subordinate themes refer to recurrent patterns identified in more than half the sample that give structure to the more complex overarching superordinate theme by providing patterns of meaning (Braun, et al, 2006).

The process of arriving at the final themes was a journey in itself. Thematic analysis also provides an interpretive view of the data rather than being purely descriptive (Braun, et al., 2006). The initial analysis was too intellectualised with little of the

actual feelings and experiences reported and used "therapist- language" which was a familiar medium for the researcher. Putting this aside, transcripts were re-read and notes made for each case again. Themes were identified and evidence sought in quotes. Themes were discarded several times before arriving at the core themes. Although the process is a search for patterns, it is also seeking to identify deviations and idiosyncrasies which may give added insights. Once this was clear, the superordinate and subordinate themes all seemed to flow together in a coherent structure.

Where themes existed in more than half the sample, these were taken further with lesser themes discarded or considered for subordinate themes. In addition themes were identified that highlighted a significant experience for participants that related to the research question.

Although for the purpose of transparency and accuracy it would have been ideal to involve patients in the analysis, following discussion with the clinicians responsible for the patient participants, it was not deemed appropriate to present the transcripts to the patients. Patients generally found it anxiety-provoking being interviewed in the first instance with most opting for telephone rather than face-to-face interviews. It was considered that for some patients, the fragility of their engagement may be jeopardised. This is an area that can be explored in future studies.

#### 5.3 Patient characteristics

Sociodemographic and clinical characteristics of the patient sample are shown in Appendix R. Using pseudonyms felt more personalised rather than assigning a value to each participant. It helps to maintain the essence of the analysis in focusing on their idiographic experiences. The researcher is denoted by 'R'.

The sample was predominantly female and all were Caucasian. The mean age was 31 (R=18-49) with mean onset age of 14 (R=12-16). The average duration of BDD symptoms was 17 years. The impact on functioning is striking with the majority of the patients in the sample unemployed, living with their parents and single. In addition five patients had more than two comorbid disorders; three used substances; five indicated high risk profiles; one had cosmetic surgery and one self-inflicted surgery.

All patients received SSRI medication with two receiving more than two trials of SSRIs and two received augmentation.

The individual pre- and post- treatment scores of participants on clinical measures of symptom severity are presented in Table 10.

Table 10: Clinical scores on measures for qualitative sample

Patients	Treatment phase	BDD- YBOCS	BDI	MADRS	SDS	Comment
Alice	Baseline	37	38	14	20	BDD symptoms reduced
	Post treatment	16	16	10	9	by 52.5%. Overall functioning shows mild impairment.
Betty	Baseline	38	43	33	28	BDD symptoms reduced by 45%. Overall
	Post treatment	20	10	21	11	functioning shows mild impairment.
Cathy	Baseline	34	31	20	30	BDD symptoms reduced by 60%. Overall
	Post treatment	10	4	8	0	functioning shows no impairment.
Dan	Baseline	26	20	24	13	Reduction of BDD and depression symptoms to
	Post treatment	1	2	4	0	non-clinical range. Overall functioning shows no impairment.
Eve	Baseline	28	17	12	17	BDD symptoms reduced to almost subclinical
	Post treatment	8	9	6	5	range. Overall functioning shows minimal impairment.
Fred	Baseline	38	30	25	27	A 7.5% reduction in BDD symptoms, still within
	Post treatment	35	16	27	15	severe range. Overall functioning shows moderate impairment.
Gail	Baseline	28	34	24	26	A reduction of 22.5% in BDD symptoms. Overall
	Post treatment	19	25	12	18	functioning shows moderate impairment.

From the seven patients in the sample, one made complete recovery, three had mild BDD symptoms, two had moderate BDD symptoms and one remained in the severe

range. A >40% decrease in BDD-YBOCS scores corresponded to significant improvements in functioning measured by the SDS. Most of the patients had depression ratings that corresponded with their level of BDD symptoms (Table 10).

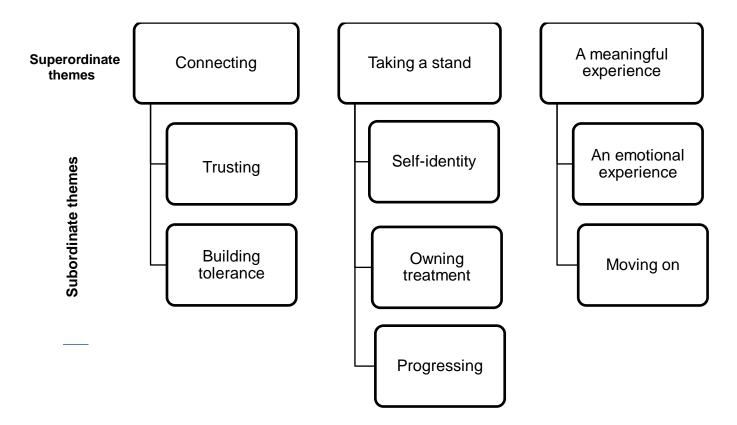
Table 11: Process of coding, categorising and identifying themes from patient transcripts

Feeling listened to Trusting Feeling valued Habituation Telepositing  Relationships Connecting with other Interactions Community	s
Trusting Feeling valued Habituation Interactions	
Feeling valued Interactions Habituation	
Habituation	
Toloroting	
Tolerating Community	
Nurturing	
Feeling understood	
Socialising	
Being part of a community	
Appreciation	
Being accepted	
Having options	
Being judged	
Negative views of self	
Difficult being with others	
Isolated	
Being grateful	
Emotions, personal experience Emotional intensity Meaningful experience	9
Despair	_
Detached Endings	
Resisting	
Too much to tolerate Collaborating	
Feeling pushed	
Overwhelmed	
Loss of independence	
Not taking responsibility	
Barriers	
Not buying it	
Feeling put upon	
It's not working	
Learning	
Can't cope	
Moving on	
Progress Fighting back Taking a stand	
Potential	
Not giving up Empowering	
Building resilience	
Being in control Learning	
Overcoming	
Facing things	
Persevering	
Achievement	
Personal growth	
Developing skills	
Learning	
Processing therapy	
Understanding	
- Chaorotanang	

#### 5.4 Themes

Three superordinate themes were identified and are listed in Figure 7 with their associated subordinate themes. The themes identified indicated patterns of experiences from engagement through to the end of therapy.

Figure 7: An outline of superordinate and subordinate themes from patient transcripts



# Superordinate theme 1

## 5.5. Connecting

One of the difficulties described by participants is feeling alienated from the rest of society. This is usually linked with fear of rejection and avoidance. Not only does this impact on social relationships but also engaging with healthcare professionals (Veale, 1996; Phillips et al, 2008). Patterns identified in the subordinate themes relate to the process of engaging with treatment.

#### **Subordinate themes**

## 5.5.1 Trusting

For patients the process of engaging in treatment meant developing trust in the therapist as well as themselves and others (Ryan and Deci, 2000). The therapeutic relationship forms a vital part of treatment (Strupp, 1988; Greenhalgh, Heath, 2010). The initial stage of engagement in treatment is critical, in particular for patients with BDD who find it difficult due to the nature of the disorder (Wilhelm, et al., 2013; Crerand, et al., 2006; Marquesa, et al., 2011). A common theme running through the patients' accounts is of their interactions with their therapist and the bearing this had on their experience.

Alice's account illustrates her experience of building trust in the therapist which enables her to trust herself and finally extends to other people.

**Alice:** "My therapist was very supportive but did not let me get away with not doing my homework.

The aim was to help me move away from coping strategies I had developed to deal with my feelings of shame and disgust. For e.g. I always showered in the dark. The coping strategies served as a constant reminder that I thought my body was disgusting and never gave me or others the chance to challenge these thoughts. It is hard to express the gratitude I feel to my therapist and the BDD service.

The therapeutic relationship features highly in her account and appears to set a foundation for the progress that follows. She describes feeling supported but also being reminded of taking responsibility in her treatment. Support seems instrumental in helping her to follow through into the most difficult part of the process, to trust herself to overcome the fears.

In Fred's response however, there appears a dichotomy in his views of the therapy and the therapeutic relationship.

**R**: "Would you recommend others to have this type of treatment if they had BDD? **Fred**: "Yes, although it doesn't miraculously take away all problems -what does?- it

helps someone like me who's thoughts are mixed and unsure to then be put on the correct pathway for recovery.

**R**: "Are there any other aspects about your treatment that you would like to tell me about?"

**Fred**: "None in particular except that my therapist shown real and genuine desire to see me improve and live a more fulfilled life."

Fred's account gives an impression of unrealistic expectations "miraculous"; a solution for "all" problems. Although he goes on to deny that to be the case ("what does?") it seems he is saying what he thinks the researcher (R) wants to hear. Fred expresses uncertainty about the treatment and although he describes it being helpful, his use of language indicates he felt he was not really making a choice. He appears to believe that his therapist is working in his best interests but he does not seem to have fully bought into the treatment.

On the other hand Eve's responses in the interview were limited but she became more animated when talking about working with her therapist.

R: "What do you think was the most helpful part of the treatment?"

**Eve**: "Face-to-face sessions with [therapist] gave me the opportunity to talk through things that I have always been unable to talk about and to explore new ways of thinking and controlling my anxieties."

Here Eve expresses how trusting her therapist enables her to reveal more about herself. This is especially significant to Eve as she has not felt able to do so before. More importantly by making a choice to take this step, she is asserting her autonomy in bringing about change.

There is a similar strand in this excerpt from Gail which gives an impression of enduring a painful experience over most of her life.

**Gail**: "I know, I have had BDD since I was a child and suffered all my life with negative thoughts and had many forms of counselling and cognitive therapy to try to support me but sadly the treatment didn't work and wish I had of been offered this treatment many years ago because people don't understand how to cope with it."

Gail's experience of how others responded to her made her own struggle with BDD more difficult. There is a sense of regret and loss for all the years when her difficulties were not understood. Her account is tinged with relief that she has finally found people who recognise what her needs are and provide treatment that works for her.

## 5.5.2 Building tolerance

Being exposed to social situations was part of the interventions used in treatment. Four patients expressed their discomfort and distress of being in public and with other people, particularly fearing negative evaluation. However they also describe the experience of growing tolerance to the situation and what that came to mean to them.

Betty's account resonates with conflicting emotions. On one hand she feels vulnerable being forced to endure closeness to others. On the other hand she also awakens to her need to be part of the group. There is a sense of resentment of being in a situation out of her control but this gives way to feeling more relaxed as part of the community, no longer needing to hide away.

**Betty**: "Just being in the inpatient environment was a good exposure for my BDD as being around people was a difficulty at the time."

R: "What was the difficulty for you?"

Betty: "Just having to leave my room and people seeing me."

R: "What do you think was the most helpful part of the treatment?

"I think the most helpful part of treatment was the communal environment..."

**R**: "Which aspects did you feel were not helpful?

**Betty:** "I suppose the time limit on inpatienting but I understand why it is what it is, but given the chance I would have stayed a little longer to try and complete my final exposure tasks."

Betty's initial distress has been overtaken by the greater need for creating bonds with others showing a direct link between learning to tolerate and establishing a connection. At the end of treatment the conflicting feelings arise again but from a different perspective. She is now torn between wanting to hold on to the safety of the

ward community and having to face the world outside. There is a reversal from resenting the intrusion of others to wanting to cling onto the familiarity of the community she has come to feel accepted by. Betty also appears uncertain of being fully prepared to face the outside world. Treatment has become the safety net but she also recognises part of the recovery process is learning to trust herself to be able to put this into practice outside of the ward.

There is a similar conflict displayed in Cathy's responses which indicated intense feelings of fear and alienation around other people.

R: "Which aspects did you feel were not helpful?"

Cathy: "It was difficult being on the ward."

R: "What was difficult?"

Cathy: "Being around other people when I hadn't even been going out... but I guess

it also helped with the exposure."

Similar to Betty, there is a sense of resentment of being "forced" into being in close proximity to other people. However this was in a more controlled environment than being in public places, which she seems to reflect on. Cathy is able to consider the benefits of the situation and used it to help her being around people.

Alice also found therapy tasks difficult initially and the language she uses signifies the intensity of her experience.

Alice: "Sometimes I found the homework exercises very upsetting but gradually I have become less fearful and the disgust with my appearance has decreased. It also felt good to learn to do things in a more "normal" way and I had a chance to discover that the earth would not swallow me up and others would not run screaming if they saw my body."

As a social being with a need to share a bond with others, Alice felt that she would be rejected. However in her description of tolerating the anxiety and recognising the deprecating views of herself are her own, she is taking the next step of allowing others into her life. She can understand that her previous way of functioning was not

in keeping with the average person ("normal"). She takes enjoyment from reconnecting with the outside world and starting to trust that others will not always reject her which is described as a monumental step. Her account sounds exaggerated but for Alice this is based on her own extreme reaction to her appearance.

This strength of response is a common pattern in patients' experiences as seen in the following extract:

R: "What do you think was the most helpful part of the treatment?"

**Dan:** "Think about something else instead of being absorbed by this idea that people are staring at you and the fact that we just talked about other people, their lives. You know, they're not necessarily concerned with you. They've got their own lives to deal with. It helps to shift the perspective."

Part of treatment was going out to public places which highlighted anxiety Dan's experience of being negatively evaluated by others. His use of the word "absorbed" describes the intensity of feeling and gives an impression that the anxiety takes over completely. He goes on to explain how he experienced the process of change. This happens with beginning to see others as individuals as well, rather than merely agents of negativity towards him. Dan has moved beyond tolerating the anxiety of being with others and is immersed into the world around him.

### Superordinate theme 2

## 5.6 Taking a stand

The themes previously described flow into the next phase of treatment: developing a stronger sense of self. Self-determination theory (Deci and Ryan, 1985) explores how people develop, what motivates them and how they maintain a healthy state. The theory also considers the intrinsic and extrinsic factors that play a role in this process (Ryan et al., 2000). The treatment offered by this service is focused on supporting patients' development of autonomy and intrinsic motivation.

# 5.6.1 Self-identity

The concept of personal self is of having a clear, unitary awareness of who one is (Baumeister, 1998). One develops a sense of self through interactions with significant people in one's life as well as experiences of the world. These experiences influence the perceptions of oneself and the development of a sense of self that guides one's behaviour and views (Harter, 1999).

Patients expressed their sense of self in a number of ways which also gave an indication of how they viewed and engaged with therapy.

Fred's account shows a stance being taken.

**Fred:** "I felt many methods of targeting my BDD were attempted to see which one would be most effective for me."

The reference to BDD as "my" denotes BDD is seen as a part of the self. Treatment on the other hand is described from a passive stance rather than a collaborator. Treatment is expressed as something that was done to the patient which gives an impression of resistance to letting go of this "part" of the self despite the difficulties the disorder causes.

Cathy also expresses having doubts when she started treatment. It is evident how intensely Cathy felt about her face and detached from accepting her face as part of herself.

R: "How do you feel about the treatment you received for BDD?"

Cathy: "I was not sure treatment could ever change the way I feel about my face. I felt that I didn't want this face. But things have changed for me with the treatment."

R: "In what way?"

**Cathy:** "I could still see things I wanted to change but I have moved away from the idea of not looking like me, which is a positive thing."

However in contrast to Fred's account, Cathy uses the word ("my") in a different context expressing an ownership of the treatment. The outcome is more progressive with an experience of change within herself.

She admits to still having thoughts about changing her appearance but the intensity and meaning has altered. Her experience of progress is reflected in her acceptance of herself and being able to assimilate her physical appearance as part of herself. There is a sense of becoming a "whole" person with a merging of mind and body. The result is an altered perception of herself along with a sense of accepting and being more comfortable with who she is.

At the other end of the scale, Dan epitomises the superordinate theme of taking a stand especially in his view of how appearance is portrayed generally in the media and what he believes is best for him.

**Dan:** "When I came into the sessions, I came with the idea that looks are everything. I believe aesthetics have become very important in the magazines and TV. You just have to see TV, now we getting a bit like America, we have to get the really good-looking people on TV, who get the majority of jobs, so I think it is putting pressure on people to conform to this sort of beautiful image. For me because of the sessions, whether other people think it's right or wrong. I believe I have got my idea of what I want to have done under control. This is where it stops for me and that's it really."

He has revised his sense of what he identifies with and has a new outlook on his previous view of wanting more plastic surgery ("what I want to have done...)". Dan's sense of confidence is palpable in dismissing what other people may think about his appearance. He clearly and strongly defines his stance.

The patient's accounts indicate positions along a continuum- from Fred who is ambivalent and resistant to change, Cathy who is initially struggling to engage but has progressed and Dan who is using therapy as effectively as he can. This leads on to the next aspect of the therapy process – to consider how patterns of engagement could impact on outcome.

#### **5.6.2 Owning treatment**

Delivering CBT is based on collaborative working with patients (BABCP, 2010). Patients need to be committed and willing to take responsibility for their treatment; however this is the best or ideal case scenario because patients may experience a variety of complicating factors which make it difficult for them to engage as effectively. Therefore CBT is not for everyone (RCPSYCH, 2018). Studies indicate

those patients who take responsibility for their progress rather than expecting their therapist to do so are more likely to make improvements and carry this forward to longer-term benefit (Delsignore, 2008).

The patients participating in this study describe varying degrees of ownership for their treatment. In keeping with findings in the literature, the accounts of patients who took more responsibility show a greater sense of achievement and a more positive outlook for their future.

Betty's remarks indicate ownership and involvement in her therapy.

**Betty:** "I think the most helpful part of treatment was the communal environment, and also the emotional support from therapists and their help in creating set exposure tasks useful to me."

Betty used professional support provided but also took the initiative to consider aspects which can help her, such as the setting in which therapy was provided. The communal environment signifies an ongoing exposure exercise for someone with BDD but Betty views this as an opportunity to help herself.

Similarly Eve takes the initiative to seek out self-help and from the use of words "I" and "my", the emphasis in this extract is on her responsibility to progress.

**Eve:** "The books I bought were also very helpful, following advice, on BDD and on assertiveness. My own notes are also helpful."

Her notes help her reflect on the process of therapy which is from her own perspective rather than the clinicians involved in her care.

This theme follows on in Dan's account where he demonstrates responsibility for his improvement whilst using support effectively.

**Dan:** There are things that I found worked better for me. Simple things, you know, where you try to listen, listen to the things that are happening around you.... It also helped that after doing the exposure with you, we would come back and talk it over.

Dan took an active role in trying different interventions and deciding what he felt was most beneficial. Repetition of the word "listen" emphasises the focus on this skill that he has developed. Being actively involved in the process of reflection helped Dan to consolidate his learning experience.

Taking ownership of the treatment feeds into the next subordinate theme which describes the outcome of developing autonomy.

# **5.6.3 Progressing**

A central principle of CBT as described in 5.5.2 is to help patients become more autonomous which is shown to be most beneficial in aiding and maintaining progress (Ryan, Deci, 2008). Patients demonstrate a greater sense of achievement. Their comments invoke strong images of their struggle and their triumph.

Alice offers a powerful depiction of how she sees herself taking control of her life and overcoming the disorder.

Alice: "I can push aside the bullying thoughts of BDD. For the first time in years I also feel hopeful. BDD is a bully and a prison and now I am breaking away."

Therapy was a catalyst in making change happen. Alice acknowledges her own effort in creating a happier and healthier state of being. There is a sense of freedom and release with new purpose and an optimistic view of life.

In a similar way Dan talks about how he used therapy to help himself.

R: "Which aspects did you feel were not helpful?"

**Dan:** "I don't think there's anything I didn't find helpful, because, you know, just talking about things obviously helped but when you came up with ideas of what I could try and do, you try and try them and you know if it works for you or not. In the process of trying them, you know, it's still a helpful process."

Dan places emphasis on the guided aspect of the therapy and the efforts he made as can be seen in the repetitive use of the word "try". He has used the treatment as intended; to develop his own coping skills and find his own way forward.

Likewise Gail describes moving away from BDD and the benefits of making these changes.

**Gail:** "When you have something like BDD you live in a bubble and get so caught up in rituals and checking, thinking you are helping yourself by carrying out these rituals but for only short term relief and then it comes back more intense, but in fact carrying out the different programmes makes you see things differently and working through and facing things does make things in the long term more manageable."

From Gail's account, one gets the sense of being isolated and consumed by the disorder. She describes the distorted view of people with BDD who are caught up in destructive patterns. She sees this from another perspective now and despite how difficult it can be, she sees that dealing with the problem is the only way for sustained improvement. She gives the impression of determination and a strong sense of commitment to overcome her difficulties.

Cathy's words "feel safer" signifies how dangerous she saw the world. Feeling safe has meant avoiding being outside of her comfort zone and especially strangers, finding it difficult to trust that others will not harm her.

**R:** What was the most helpful part of treatment?

**Cathy:** "Doing the exposure programme with my therapist. Going out, to shops and public places I would have avoided before."

"I can go out, feel safer."

Cathy shows a drive to triumph over the fear and take back control: "I can go out". This brings her underlying resilience to the fore. She will not be defined by her fear and the difficulties she has faced.

### Superordinate theme 3

### 5.7 A meaningful experience

This set of themes relates to the experience of the journey through therapy. For most patients therapy is a significant experience in their lives. The decision to seek therapy is often filled with anxieties and preconceptions until they have a clearer idea of the therapy process. Therapy often involves challenging their behaviour and exploring aspects of themselves which can evoke intense emotions (Beck, 2011).

# 5.7.1 An emotional experience

The process of engaging with a therapist itself can evoke intense emotions. Alongside this is then working on the most difficult and fear provoking situations they can imagine. This demands a great deal of belief in themselves as well as the therapy (Beck, 2011).

The following excerpt demonstrates the overwhelming emotion experienced by the patient recounting her journey from addressing her problems through to achieving change.

**Alice**: "The coping strategies served as a constant reminder that I thought my body was disgusting and never gave me or others the chance to challenge these thoughts." (Pause) **R**: **Are you okay?** 

Alice: "Yeah...Sorry." R: That's ok, take your time. (Participant pauses.)

R: Are you ok to continue or do you want to stop here?

Alice: "I'm ok, sorry. ...I have become less fearful and the disgust with my appearance has decreased."

"The therapy has saved my life and remade it."

The intensity of negative feeling Alice experienced towards herself seems to overwhelm her when she recalls views of herself. The language used is intense: "disgusting" illustrating how extreme her self-view was. There is a lack of assimilation of her appearance into her identity. This lack of connection means her physical self is almost alien to her yet she is unable to get away from it which led to a sense of desolation and despair. Yet she describes a transformation through the course of therapy, leading to a new beginning and a different perspective.

Fred's experience was overwhelming as well but related to his experience of the therapy techniques.

**Fred:** "I felt that at times the treatment felt too much, especially with the regular exposures. Although it was very beneficial to my treatment and helped a lot, maybe if there were other less intense ways to introduce me into regular exposures it would have helped me gradually adjust more to the exposures.

... to fully change one's mindset is a challenging and daunting task. It became a bit off putting on occasion but I wanted to improve."

Fred's experience of the interventions being too difficult is one expressed in the literature by patients who disengage from treatment (Folke, et al, 2012). There is no question that therapy is arduous especially when the problem has been ongoing for several years with severe impact on functioning. Fred finds addressing dysfunctional patterns of behaviour very difficult as these have been developed over the course of years as a strategy of "coping," although it keeps him within the boundaries of the disorder. Fred expresses a dichotomy in his feelings about therapy whilst his expectations or possibly his view of the therapist's expectations are unrealistic- "fully change one's mindset..." which sets the scene for a lack of full commitment to the treatment. This pattern runs through most of Fred's responses.

Betty expresses her frustration at the loss of independence and a feeling of lack of control.

R: Which aspects did you feel were not helpful?

**Betty:** "I also found being given my medication by staff instead of self-administering frustrating, but then again I do understand why they might have to do it this way."

**R**: What would you have liked to be different in the treatment?

**Betty**: "I can't really think of anything but if really nitpick I would have liked less focus on drug treatments."

R: Why do you feel that way?

**Betty**: "I went through a lot of changes of medication and side effects during my stay. Other than that I found the treatment really helpful."

There is also a sense of resistance to medication as a treatment option as she continues to discuss her feelings about this. The feeling of loss of control continues into her further comments.

### 5.7.2 Moving on

The ending of treatment is a very meaningful experience in the patient's care. This is the culmination of all that has happened throughout treatment whether progress is made or not (Weddington & Cavenar, 1979). The process of ending therapy in CBT is introduced from the initial meeting with ongoing encouragement to take responsibility for their treatment. This is in keeping with preparing the patient to become their own therapist (Beck, 1995).

This excerpt from Gail is indicative of her embracing the approach and putting it into practice for a positive outcome.

**Gail**: It was hard at times but worth persevering. I have managed to do things I thought would never be possible for me, like going on holiday and sitting on a beach.

**R**: Are there any other aspects I have not asked about regarding your treatment that you would like to tell me about?

**Gail**: "All I would say is I still have moments and things that I find difficult to face but I have the tools now to help myself and will do so if I am in the right place mentally, and as my therapist said you will have a blip now and then and that's normal refocus and carry on."

Gail's experience is filled with evidence of her growth and progress. Her account shows a sense of achievement enabling her to have a better quality of life. Still she remains realistic about the course of the disorder and recognises there may be challenges ahead but she is better equipped to deal with that. Her outlook shows the potential for the improvements to be sustained beyond therapy.

The patient's views of their lives post-treatment is testament to how they see their development and learning as part of their way forward. In Dan's view he sees himself re-joining different spheres in his life and leaving the BDD persona behind.

Dan: "It's also helped me with socialising, in social and work situations.

I used to get stuck at mirrors, shop windows, it was always detrimental to me, it never helped. I don't have that anymore. I probably look at mirrors like everyone else, probably less, look at my appearance, I'm a bit scruffy (laughs). I probably don't look in the mirror as much as I should now!"

Dan is able to laugh at himself now rather than having self-deprecating thoughts. His sense of self is more solid as someone who has grown and is instrumental in determining his own way forward seen in repetitive use of "I".

In reflecting on their experience, patients illustrated the contrast between their initial and end of treatment perspectives.

Alice: "Before starting therapy I was filled with disgust and shame about the way I looked. ... I feel like a different person and am happy for the first time in a long time... For the first time in years I also feel hopeful."

This contrast is vividly described by Alice giving an image of movement along a continuum from extreme self-loathing to acceptance of herself. The repetition of "first time" indicates the awakening of a new self-awareness.

An exploration of the content of the patients' interviews highlighted key interventions which may have influenced their experiences of treatment and is described in Table 12.

**Table 12: Experience of specific interventions** 

Interventions that were experienced as helpful	Aspects of treatment experienced as unhelpful
Number who expressed this (N)	Number who expressed this (N)
Exposure, eliminating safety	Particular theoretical concepts (N=1)
behaviours (N= 6)	
Attentional refocusing	Time limited treatment
(N=2)	(N=1)
Cognitive restructuring	Medication
(N=5)	(N=1)
Emotional support	Cognitive restructuring
(N=3)	(N=1)
Psychoeducation	
(N=3)	
Activities of daily living	
(N=4)	

Out of seven patients, five stated that they did not find any aspect of treatment to be unhelpful. Two described what they felt was not beneficial. These factors were theoretical concepts of CBT for BDD; time limit to in-patient admission; medication and cognitive strategies. Interestingly the two patients who described aspects they felt were unhelpful showed the least amount of improvement on BDD symptom measures as well as measures of depression and overall

functioning. From the analysis of these cases (Fred, Gail) detailed previously in this chapter their limited improvement raises further questions for investigation.

The patients expressed how they used different interventions to help them make changes which they felt led to their improvement. Despite behavioural tasks being described as difficult, it was clearly considered most instrumental in assisting change and also leading to altered perspectives supported by cognitive interventions. Activities of daily living skills were also considered an important factor in improving quality of life.

Both respondents, who received inpatient treatment, expressed finding the ward environment difficult but again the exposure aspect of being in a communal setting was considered helpful.

### **5.8 Discussion of Findings**

This was a fascinating exploration of patients' experiences in their journey from starting treatment to beyond. One of the vital elements identified was developing trust. Patients acknowledged the importance of trusting in their therapist but also in themselves. Particularly when interventions are difficult to tolerate, trusting that the therapist will support them through it is an important part of maintaining engagement and could play a part in positive outcome (Bohart, Elliott, Greenberg and Watson, 2002). The literature also suggests that patients who feel understanding and empathy from their therapist are more likely to engage fully in the treatment (Lambert, Barley, 2002).

BDD sufferers endure an extremely disabling impact on their lives so treatment is geared to improving symptoms of BDD as well as overall functioning. The emotions flowing across these accounts range from intense fears, dread and anguish to joy and strength but also resistance and feeling overwhelmed. The majority of patients described improvements and benefits from treatment. However there were patients who made limited progress and found treatment difficult. Patterns found in their accounts mainly indicated less collaboration resulting in limited responsibility accepted for treatment; difficulty tolerating the interventions and not being fully committed to treatment. Although this sounds as though all the responsibility for treatment is resting with the patient, therapists initially shoulder the majority of this

whilst preparing the patient to become more accountable to themselves through learning the skills they need to become their own therapist (BABCP, 2010). However for some patients this process did not fully occur which indicates that other approaches could be useful where CBT and medication have not enabled progress (RCPSYCH, 2018). Further research is required into alternatives when patients find it difficult to engage in CBT e.g. motivational interviewing techniques (Miller, Rollnick, 2002; Wilhelm, et al., 2013).

However BDD treatment options are still limited as there is both a lack of research and knowledge about BDD (Phillips, 2000). This is further illustrated by patients' reporting their experience of BDD not being understood and difficulty accessing appropriate treatment. Patients express their frustration and sense of loss for years spent trying to find treatment but also gratitude for finally receiving treatment that addresses the BDD. Gratitude has two strands – the first is recognising the positive interactions of others to benefit oneself and the other is of a more general nature regarding what is meaningful in one's life (Armenta, Fritz, Lyubomirsky, 2016). Patients were grateful for treatment they received but they could also recognise the part they played in making change happen. Gratitude can play a role in encouraging people to make constructive changes by motivating them to behave more benevolently and reduce destructive behaviour patterns (Emmons, Mishra, 2011; Bono, Emmons, Mccullough, 2012). It is linked with experiencing "positive psychological states, much like contentment, pride, and hope" (Giacomo, et al., 2012: Chpt. 33: pg. 560.)

A number of positive emotional and social outcomes, such as increased feelings of connectedness and greater perceived social support can arise from the feelings of appreciation (Wood, Maltby, Gillett, et al., 2008; Giacomo, et al., 2012). Developing a connection with others was a key part of patients' experiences of progress. Gratitude served as a key indicator of the change in perception of patients' relationships with others where they regarded their therapists as the source of helping to improve their quality of life which then extended to others in their network for example, fellow patients on the inpatient ward and recognising the value of connecting with others.

A thought-provoking exploration of identity shows patients experiencing significant personal growth over the course of treatment. Their comments reflect their sense of

strength and confidence in how they see themselves. This seems to be a critical factor in their progress. Those patients who experienced significant improvements described a greater level of self-esteem and confidence than those who expressed difficulty engaging in the treatment. The development of a sense of self appears as a product of the therapeutic process rather than an aspect specifically targeted in treatment.

It was important to minimise misinterpretation of data, therefore significant statements were identified in context of the entire interview and coded according to what the patient appeared to emphasise. The aim was to avoid interpreting data to fit categories or coding types. Instead larger extracts were quoted as examples to provide a context for statements coded so that patients' experiences were not misinterpreted e.g. where they used humour or irony. The analysis was an iterative process through which codes and themes were considered several times and either kept or discarded before finally being written up.

The overall conclusion is that treatment was largely well-received and although patients found the techniques difficult, in some cases they were able to use these to extremely good effect. From their accounts it also appears that these improvements are sustainable as they have the tools to continue to address difficult events in their lives post–treatment. However it also highlighted areas for development in the current treatment recommendations particularly for patients who find the techniques too difficult or are unable to use the treatment when there may be complicating factors such as co-morbid disorders.

# **Chapter 6:**

Phase 3: Thematic analysis

How clinicians treating patients with BDD experience the application of the NICE (2006) guidelines for OCD/BDD within the context of a specialist service.

#### **6.1 Introduction**

This chapter is the third phase of analysis focusing on findings from clinician's experiences of providing treatment for BDD. The analysis process has been described in the previous chapter (5.2) but additional information will be explained concerning this sample. As the team is small, the description of the clinical staff who participated in the study will be brief to maintain anonymity. To promote transparency, the process of coding and arriving at themes is displayed in Table 14. Superordinate and subordinate themes extracted from the interviews are illustrated in Figure 8. An excerpt from a HCP's transcript providing an example of the process involved in coding is included in Appendix T. As in chapter 5, each superordinate and subordinate theme is described and interpreted supported by quotes from participants.

Language is the participants medium to express meaning and experience (Widdicombe, Wooffitt, 1995). It is argued that how language is interpreted cannot be separated from the researcher's perceptions and own experiences in the process of analysis (Trochim, 2006). Therefore as previously explained the approach taken to report data reflects the researcher's interpretation (3.7.1., pg. 91).

#### 6.2 Data analysis

As in patients' interviews, audio recordings were made to ensure accuracy. The difference with the samples was that clinicians could be approached to verify transcripts. Early on in the interview process, it was deemed necessary to provide an additional reassurance to clinicians to address any concerns that their knowledge of the NICE guidelines was being evaluated. This was noted following the first participant's comments about not having read the guidelines lately. A standard statement was therefore relayed at the start of each interview:

"This interview is designed to gather your experiences and views as clinicians in treating patients with BDD using the NICE guidelines. This is not a test of your knowledge or expertise".

#### 6.3 Clinician participants

The sample of clinical staff (N=10) responsible for treatment were interviewed for the qualitative aspect of the study (Fig. 6). English was the first language for all but one

of the staff members but the individual was fluent in English and comfortable being interviewed in this medium. The clinicians' experience in this field ranged from 5 to 25 years. Four worked in the outpatient service, two worked across both in- and outpatient services and four worked with the inpatient service.

Given the size of the team is small; a more detailed description of the clinicians would not be possible without compromising confidentiality and anonymity. Table 13 describes the service provision for step 5 and 6 of the NICE guidelines (2006) also described in Fig 2. The clinicians will be referred to as (health care professional) HCP and denoted by a number to preserve anonymity. Also due to the male: female ratio being very small the gender neutral "they" will be used.

Table 13: Provision of Stepped care model (NICE, 2006)

Feature of model	Step 5	Step 6
Focus of care	Outpatient (Regional)	Inpatient (National)
Duration	20-30 sessions	Average 4 months – maximum 6 months
Method of delivery	1:1 face to face	1:1 face to face; group; 24 hour nursing care
Treatment offered	CBT, medication, EMDR, Family work	CBT, medication, EMDR, family work, OT.
Level of severity	YBOCSBDD>20	YBOCSBDD >30
Treatment provided by	CBT, medical staff.	CBT, nurses, OT, medical staff
How service is accessed	IAPT, CMHT referrals	CMHT referrals only

The main difference in service provision relates to the level of severity (Fig 2, pg. 22). Patients at step 6 require 24 hour nursing care due to the severity of their disorder causing them significant functional impairment; risks to themselves or others and /or complications due to co-morbidities. Service criteria also require that patients at step 5 and 6 will already have had previous CBT and medication. Inpatients have the benefit of additional support through the communal environment and group activities together with nursing care for ongoing assistance.

Table 14: Process of coding, categorising and identifying themes from HCP transcripts

Codes	Categories	Emergent themes
Organisational requirements Organisational restrictions Pressures of organisation	Organisational aspects Service requirements Clinical provision	Providing clinical service Service delivery
Lack of resources		
Time constraints		
Guidelines		
Policies		
Compliance with guidelines		
Misunderstanding		
Misdiagnosing		
Signposting appropriately		
Health care professionals lack of knowledge		
Not referring		
Service provision		
Clinical work		
Not comprehensive		
Limited public awareness		
Not sensitive to patient experience Restrictions		
Meeting service delivery aims		
Lack of opportunity for learning	Performance objectives	Clinical role identity
Holistic view	Belief in treatment	Olimbal fold identity
Patient-centred	Values, principles	
Clinical role	Valado, principios	
Job satisfaction		
Training, support		
Values, principles		
Knowledge		
Frustration		
Dedication		
Commitment		
Dissonance		
Passion		
Belief in treatment model		
Dissatisfied		
Inadequate treatment options		
Lack of research		
Helplessness		
Demoralising		
Confusing		
Fulfilling	Derecived nations experiences	Patient care
Engagement Patient care	Perceived patient experiences Therapeutic relationship	Patient care
Choice	Providing clinical care	
Collaboration	1 Toviding diffical care	
Feeling safe		
Listening		
Acceptance		
Challenging		
Therapeutic alliance		
Therapeutic limitations		
Lack of early intervention		
Difficulty in tolerating treatment		

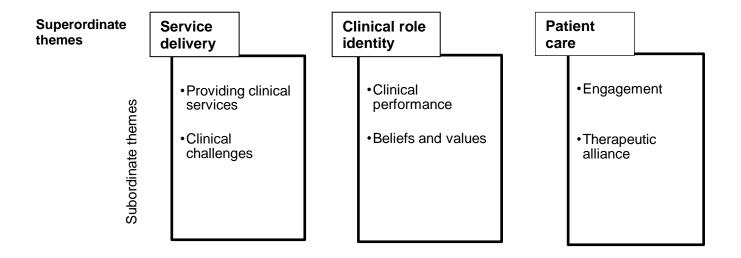
Contributing factors	
Incorporating other interventions	
Carers or family involvement	
Limited cognitive shift	
Empathy	
Supportive	
Unrealistic expectations	
Patient response	
Improving functioning	
Improving quality of life	

#### 6.4 Themes

Three superordinate themes were identified from the clinicians' transcripts with four subordinate themes associated with them.

These are illustrated in Fig. 8.

Figure 8: Summary of superordinate and subordinate themes from clinician interviews



### Superordinate theme 1

# 6.5 Service delivery

Clinicians practicing in this specialist service are required to have sound knowledge and expertise of BDD. In addition they provide training, supervision and consultation to other healthcare professionals in assessment and treatment of BDD. Furthermore given the dual nature of the specialist unit both the NHS Trust's and NHS England's requirements need to be met in delivering the service (Table 13). Treatment delivery follows the NICE (2006) guidelines stepped care model and the Service is cited as an example of translating theory into practice on the NICE guidelines website (Figure 1; NICE, 2009; Drummond et al., 2008; Boschen et al., 2008).

#### Subordinate themes

### 6.5.1 Providing clinical services

The service provides specialist consultation/supervision as required at each level of severity in the stepped-care model. Although focus in assessment and treatment is, as previously described at level 5 and 6 (Table 13).

HCPs generally indicated positive views of following the NICE (2006) guidelines in providing clinical services for BDD. However there are also suggestions of dissatisfaction plus doubt that the guidelines are comprehensive enough. This is illustrated in the following excerpt from HCP10. The initial statements feel apologetic about their limited experience which may be a precursor to the uncertainty expressed.

R: "What do you think about current guidelines for treating BDD?

HCP10: "I don't have an awful lot of experience to be honest, because I haven't

been here for too long. The guidelines seem to work pretty well from what I can tell. I don't really have any positive or negative thoughts about it."

R: "How do you feel about following the NICE guidelines?"

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**HCP10:** "Fine. It's good having the guidance there. I think without it could feel quite overwhelming. It gives us more confidence in using the treatments and things like that."

They go on to describe feeling reassured by having the guidance but an indication of how challenging the HCP finds it working with this disorder is expressed with the "overwhelming" feeling.

The sentiment of being reassured by the guidance is echoed in HCP7's comments but also tinged with some doubt as to relevance for BDD opposed to OCD. However the HCP acknowledges this is the only evidence-based guidance for BDD at present.

R: "What do you think about current NICE guidelines for treating BDD?"

**HCP7:** "They've been well thought through, and they are helpful in guiding what treatment is appropriate for BDD by taking you through the different pathways. I don't know if they're as helpful for people with BDD than OCD but I don't know what other type of help is out there."

R: "How do you feel about following the NICE guidelines?"

**HCP7:** "It's helpful to know that there is evidenced based treatment. And it lets you know that there's a strategy around the disorder. So, I do find them helpful as a quidance."

Some of the views of providing a service based on the sole guidance available for BDD shows a concern that there is insufficient evidence-based research of BDD to make the guidelines as comprehensive as they could be.

HCP6's comments echo this.

R: "What do you think about current guidelines for treating BDD?"

**HCP6:** "There is a relative lack of good quality, adequately powered research in BDD. Despite this the current guidance does seem to cover the main therapeutic interventions of CBT and psychopharmacological intervention."

Similarly HCP4 and HCP1 expressed this concern:

R: "What do you think about current NICE guidelines for treatment of BDD?"

**HCP4**:"I think the guidelines are helpful but not all patients fit into the recommendations.

**R:** "How do you feel about following the NICE guidelines?"

**HCP4**: "I try to follow them but the complexity of patients with BDD means we need to use other interventions."

HCP4 recognises that the guidelines provide some recommendations but cannot be used as a protocol of treatment as patients require a needs-led package of care.

This is mirrored in HCP1's comment.

R: "What do you think about current NICE guidelines for treatment of BDD?"

**HCP1:** "I think it's quite good, the only problem that it doesn't take into account is that most of these people have associated conditions, like personality disorders and such."

There is a sense that HCP6, HCP4 and HCP1 are appreciative of having guidance. However all three voice concerns that the guidelines are not comprehensive enough particularly when comorbidities with additional needs are present.

Furthermore some HCPs seem especially affected by the difficulties patients with BDD have in using the treatments recommended. The response of HCP2 expresses dissatisfaction with the use of the guidelines despite reluctantly admitting that medication helped ("...to an extent..."). The emphasis is on the lack of benefit as shown in repeated statements to this effect ("...never really changed..."; "...didn't make any huge progress, by no means"; "...she didn't feel like she made any difference").

#### R: "What do you think was most beneficial in treating patients with BDD?

**HCP2:** For one lady who had BDD on our ward awhile back, I would say it was the medication, because it got her to a position where she could start to do the CBT. She

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did the exposure work but still felt very anxious after it, and that never really changed for her. So, medication helped with her, to an extent, to engage with the CBT and OT work. But she didn't make any huge progress, by no means. There was some difference, but she didn't feel like she made any difference".

The HCP's perception of how the patient responded generated strong emotions in the HCP and contributes to the sense of frustration and helplessness.

Similarly HCP8's impassioned views show dissatisfaction with the guidelines informing service delivery.

R: "What do you think about current NICE guidelines for treating BDD?"

HCP8: "I don't pay too much attention to them to be honest. I have read them a while ago. They recommend CBT, but they're not very specific about what to do. And they're lumped with OCD. I think BDD needs its own NICE guidelines independent of OCD. The evidence for medication is different. And also the specific CBT methods are different. There are some similarities, but there's very little research out there. I would say they're vague and they don't influence my practice massively.

R: "How do you feel about following the NICE guidelines?"

**HCP8:** "I do follow them, and as a team, we do follow them. But because they are vague, I feel indifferent."

The use of the word "lumped" to describe the combined guidelines shows frustration and the feeling that BDD is disregarded as a serious condition. The HCP responds to the guidelines by not paying them "too much attention". The HCP feels BDD needs consideration in its own right but instead has been subsumed into the guidance without allowing for ways BDD differs from OCD. Feeling "indifferent" is not a true reflection as the preceding comments indicate strong feelings of discontent. Although when seen in context – it is a way of conceding that the team has to follow the guidance as the service model is based on the NICE (2006) guidelines but as a clinician they do not feel it informs their way of working.

There are no clear evidence-based alternatives if the patient does not benefit from the recommended treatments. This could lead to HCPs experiencing frustration and helplessness found in the extracts quoted. Despite generally expressed views that the guidelines are helpful, one gets the increasing sense that in practice the clinicians find the guidance inadequate to inform clinical service provision for BDD.

### 6.5.2 Clinical challenges

The specialist service was re-modelled in accordance with the NICE stepped care model to ensure that patients throughout the spectrum of OCD/BDD symptoms receive optimal evidenced-based treatment (Drummond et al 2008; Boschen et al., 2008). This has been easier met for OCD with the service producing numerous research articles and presentations on standard and novel approaches to treating OCD over a number of years (Govender et al., 2006; Turner, Drummond, Mukhopadhyay et al., 2007; Boschen et al., 2008; Boschen et al., 2010; Drummond et al., 2012). On the other hand, the focus on BDD is markedly limited within the service (Tyagi et al., 2013; Govender et al., 2017).

One of the challenges highlighted is the limited referrals of patients with BDD. This HCP emphasises the need for health care professionals to be more aware of BDD.

**HCP7:** "If you're in the profession and you know about it, that's fine, but if you're not; I don't think people in general know a lot about BDD. So, for example if health professionals could know more about them, then they would know the right things to ask people, in terms of their symptoms and directing them accordingly."

The lack of awareness generally and within health care is one of the reasons people with BDD are misdiagnosed and the disorder goes unrecognised (Phillips, 2008). This perspective is expressed in the following excerpts:

R: "How do you feel about following the NICE guidelines?"

**HCP1**: "Maybe I don't treat enough patients with BDD to really know. In the past year, I only treated 1 patient with BDD.

**R**: "Is there anything that I haven't asked you about treatment provided by the service for BDD that you would like to discuss?"

**HCP1**: "...we have very few that manage to get here to be treated by us. So the only cases of BDD that were getting to us were the ones that needed 24 hours care, that felt they wouldn't cope".

The HCP expresses a feeling of helpless in trying to provide a service for BDD patients. The words "few...manage; only cases...getting to us" emphasis this feeling that there is an abyss between the patients and the service. Those who are referred have declined further into the course of the disorder with so much impairment in some cases that their needs require inpatient admission with nursing care.

HCP6 also voices this view expressing concern that the stepped care model may actually cause a delay for these patients who need specialist help.

R: "How do you feel about following these guidelines?"

**HCP6**: "In general they make sense but I am concerned about a few patients who are extremely ill from the start and who have to wait to proceed through the steppedcare model whereas they may be best served by moving rapidly into more specialised services."

Where the appropriate treatment is not available, the patient care pathway does not indicate a clear process for patients to advance through to access a suitable service.

HCP8 also expresses concerns about the limited number of referrals and links this to limited awareness.

**R:** "Is there anything that I haven't asked you, about treatment for BDD provided by the service that you would like to discuss?

HCP8: "We're not getting as many referrals at the moment, it's really reduced. ...I don't think people in the CMHTs recognised BDD as something they would ask about when assessing patients. ...So, it's could be there are people out there with BDD, undiagnosed, untreated and suffering. And that's down to public awareness, GP awareness and I think we need to be doing more at that level. ...But because we've been understaffed, we haven't gone out and sought any extra referrals. I think we could put together a pack on how to treat BDD, like a type of manual. We advised referrers for our group to use those screening questions from NICE, if they were unsure. So, the feedback was that was really helpful for some people to have those pointers. Our service is known, and we have BDD in our title, so I would have thought that professionals in our trust know about us, so I don't know why our referral rate has dropped. There may be just a lot of people misdiagnosed."

From the HCP's experience, providing information on how to screen for BDD has helped referrers identify symptoms. HCP8 expresses a sense of helplessness at

being unable to help "...those people out there with BDD, undiagnosed, untreated and suffering." However there is also recognition that more could be done to promote awareness and disseminate knowledge but resource constraints make this challenging. The HCP is reduced to working on the assumption that people will know where to refer as "...we have BDD in our title."

One of the factors to ensure people with BDD receive the help they need is early intervention which could promote better prognosis and a better quality of life. Given the onset of BDD symptoms tends to be adolescence, it follows that this is a crucial phase when information should be made available (Phillips, 2008).

HCP4 emphasises imparting knowledge to young people to promote early intervention.

**R:** "If given the opportunity, how would you improve on the NICE guidelines for BDD?"

**HCP4:** "I haven't read them recently, but I would want to catch it earlier. So more education in schools, more of an acknowledgment of how the current media, social media and TV have massive impact on younger people's views of their appearance."

HCP4 also considers the influence of the media and a generation that has grown up in the age of social media. In addition to direct interpersonal communication, Generation Y and Z view relationships in terms of virtual communication (Subrahmanya, Greenfield, 2008; Bolton, Parasuraman, Hoefnagel et al., 2013; Buzzetto-Hollywood, Alade, 2018). This needs to be recognised for possible implications for teens with BDD to avoid interacting in the tangible social arena (Czincz, Hechanova, 2009).

A similar thread runs through HCP7's views, highlighting earlier intervention.

**R:** "If given the opportunity, how would you improve on the NICE guidelines for BDD?"

**HCP7:** "I would want the NICE guidelines to work for younger people. I think strategies that help earlier on in life, with boys and girls, with BDD, self-esteem and development in adolescence should be the focus. For me, if you're an adult who's

already got the disorder, you've kind of missed the boat. So, things like self-confidence classes, and promoting more self-awareness, at a time where people are more vulnerable would be something I would like to improve on."

There is an indication of feeling that more could be done and wanting to be instrumental in this with the use of "I" rather than a general statement of areas to be improved on. The HCP sees BDD as more difficult to address once the patient is an adult as the more malleable developmental stages have passed.

Additional challenges are found in trying to provide interventions which are specific to the disorder whilst working within organisational policies. HCP1 described feeling unsupported by the organisation in aspects of their clinical work.

R: "What do you think was least beneficial in treating patients with BDD?"

HCP1: "The inability of the NHS to provide proper tools to work, like mirrors. So, we were unable to apply part of the CBT type treatment. We had all these plastic ones that were so distorted, I was afraid to look in them (exclaims). We tried to bring some better ones, but were told that we couldn't use them, as they would be unsafe to use with patients."

The idiosyncratic nature of the disorder requires specific tools however in accordance with Trust's health and safety protocols, glass mirrors are not allowed in clinical areas. The HCP expresses frustration at these restrictions. From the HCP's response, one senses the ridiculousness of the situation when plastic mirrors reflect a distorted image making it more anxiety-provoking for patients who already have a distorted view of themselves.

The unique nature of the service based on the NICE guidelines (2006) also poses a challenge when HCPs consider the recommended treatment does not meet the individual needs of the patient.

R: "Is there anything that I haven't asked you about treatment provided by the service for BDD that you would like to discuss?"

HCP2: "There was another BDD patient that the treatment worked really well for. So, it goes to show if you do have someone that is driven and engages with the model, they can progress. And she reached the top of her hierarchy. But for me, I'll always remember the other person that really struggled with the suggestions and found it all too extreme for her. So, perhaps it is about accepting where the patient is at and finding out what they can and can't do. And maybe further down the line, they might be able to push their boundaries and challenge it. When dealing with someone's appearance, I think the exposure practice that we do for BDD patients' touches such a raw nerve, that we should be a bit more sensitive to that. This particular patient had other diagnoses that impacted on how she engaged with the model, like depression and personality traits that made things more complicated. But I think most BDD patients would have found the suggested exposures quite difficult."

HCP2 recalls a patient who progressed with treatment giving credence to the effectiveness of the treatment guidelines. However the HCP finds the experience of working with a patient who did not benefit from treatment more profound. The language used to describe how the HCP perceived the patients' experience e.g. "touches such a raw nerve" indicates the intensity of the HCP's experience. The HCP is frustrated, feeling the patient is not really being heard and the treatment protocols expected to be followed not sufficiently taking complicating factors into account.

Even for those HCPs who seem more signed up to the treatment guidelines, they still question aspects of the approach meeting patient's needs and the lack of sufficient research in treating BDD.

**R**: "Do you think that there's anything that you've used in treating BDD that hasn't been beneficial?"

**HCP3:** "There have been patients who were unable to deal with certain types of CBT due to becoming increasingly dependent and not being able to tolerate the stress of the therapy."

"It almost reaches that level of severity to the point that a person has lost insight completely. And I think that that can be quite difficult to work with. So someone might see disconfirmation around them, but that still wouldn't change the rigidity they believe how they see themselves. And they are able to function, but their anxiety levels don't go down and they don't habituate because it's such a fixed belief that they hold and it's not likely to change. I think that is something the CBT literature and training could talk more about. The delusional nature of it, people not habituating, anxiety not going down and is that because of emotional dysregulation, distress intolerance, is it their rigid beliefs always driving their anxiety and it doesn't change? It's not to say CBT doesn't work, but to say that it is an area for development."

The HCP's initial response places more responsibility for treatment effectiveness with the patient yet recognises the process is stressful. As they continue to reflect on their experience, they begin to question why interventions are not always effective. By the conclusion of this response, the strength of conviction is reduced with recognition that some factors in BDD are not being addressed by the current treatment guidelines: "it is an area for development". Once again the concern is raised about insufficient research and training.

### Superordinate theme 2

# 6.6 Clinical role identity

It is important to explore the clinicians' role identity regarding their clinical functions especially since the team has diverse expertise (Blake, Ashforth, Harrison et al., 2008). A strong role identity has been linked to values and beliefs that influence the clinician's performance of their roles and interaction with other team members and patients (Gilburt, 2016). This pattern has been observed through the responses of the HCPs which could have implications for patient outcomes which will be discussed in the synthesis chapter.

#### 6.6.1 Beliefs and values

HCPs interviewed expressed varying degrees of confidence in the treatments for BDD and the treatment guidelines. Their responses indicated their values regarding patient care and their beliefs about how to provide the best treatment.

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This excerpt from HCP3's interview shows a passionate belief in the treatments provided and seems defensive to any suggestion of lack of benefit.

**R**: "Do you think that there's anything that you've used in treating BDD that hasn't been beneficial?"

**HCP3:** "Every treatment we do has been useful; it's just a matter of if the patient is able to maintain it."

"Patients that are able to tolerate their stress and regulate their emotions are able to engage better with the standard CBT therapy and get the most from it."

"To me, it's less about the CBT technique and process and more about the individual and how they're able to engage with the therapy itself. These are more client factors rather that CBT factors."

The HCP describes CBT almost beyond reproach with the patient needing to fit in with it. One of the essential performance objectives is to follow a patient-centred approach. However from HCP3's response, the strength of belief in the technical aspects of the clinical intervention has overshadowed the principles of practicing collaborative working.

HCP9 on the other hand seems less embedded in the approach and expresses a need to adapt treatment to engage patients.

R: "What do you think was most beneficial in treating patients with BDD?"

**HCP9:** "When people are very fixed in their beliefs with BDD, it's good to work on a motivational level to improve on their quality of life. I would work more on the motivational and recovery side of things, rather than pushing people too far with exposure treatment in the first instance. To get a good formulation, gauge someone's motivation and to do a good piece of cognitive work before going into exposure side of things is really beneficial for me."

The HCP is flexible with their approach which is: "...beneficial for me" indicating a sense of feeling comfortable with this approach. Despite the service demands for showing improvements at specified stages in treatment the HCP prefers to work alongside patients "...rather than pushing people too far..."

HCP8 also considers the guidelines for BDD need more clarity as it seems to be overshadowed by OCD. The HCP also expresses their view on media influences which they see as promoting the ideal appearance.

# R: "If given the opportunity, how would you improve on the NICE guidelines for BDD?"

HCP8: "I would have separate guidelines as a first. The treatment that IAPT offers should specify what could be offered at each step. And to have clearer guidelines on medication. I don't think it's completely clear on what there is evidence for." "Also, more public awareness about BDD, maybe steps 1 and 2. Just labelling it. There's a lot on telly about beautiful bodies and surgery etc. but I don't hear about BDD in the media. In an ideal world, there would be more awareness about BDD as a separate condition and what it involves and the treatment available for it."

Again lack of awareness and insufficient research is highlighted. HCP8 also reiterates their call for separate guidance for BDD.

Despite their concerns, the HCPs also express their dedication to the service and their belief in the therapeutic approach. HCP5 expresses a fervent belief in using CBT as a whole approach rather than separating the cognitive and behavioural aspects.

# R: "If given the opportunity, how would you improve on the NICE guidelines for BDD?"

HCP5: "I'm unconvinced that long term cognitive therapy in isolation would be helpful, for instance, unless it was also accompanied by some robust exposure work. I think it's a profoundly under researched condition, but because of the presentation of the client it's easier to do less difficult therapy. When you're asking people to put a spot on their face, and go out with it on their face, I think it's really difficult for patients, but I also think that it's very important at the same time. When I've attended workshops in the past, it's been quite clear that people who've worked with patients specifically with BDD -that cognitive therapy on its own, isn't going to cut the cake. I think therapist tend to go with the easy option because it makes them anxious because the patient gets so anxious. And I also think a lot of therapist in essence

don't want to get their hands dirty. I think to them, therapy is talking therapy and getting your hands dirty is something that they struggle with. But I really feel that that doesn't help the client."

The HCP recognises how difficult the behavioural techniques can be for patients but also with commitment it shows positive results. Interestingly the HCP observes that therapists may avoid techniques such as ERP as it raises patients' anxiety levels. Therapists need to recognise their own unease and address this in order to help patients tolerate then manage anxiety. Otherwise they are merely colluding with the patient's safety behaviours or avoidance.

# 6.6.2 Clinical performance

In carrying out their clinical roles, team members have to meet their professional and organisational requirements (BABCP, GMC, HCPC, SWLSTG). In addition the service identifies specific treatment objectives for clinical staff and these are evaluated in their supervision (individual and peer group); case reviews; ward rounds and annual reports. Being a specialist service offers a unique position to provide longer-term treatment, however there are still expectations that therapy should not exceed 30 sessions. Clinicians are expected to provide evidence for therapy to continue when 20 sessions has been reached. This also applies to inpatient admission with a maximum stay of 6 months. Regular reviews are held at specified intervals in treatment to ascertain engagement and progress. Although a degree of autonomy is expected from clinicians, there are also clear service boundaries within which to operate (SWLSTG, 2010).

Linking the values and beliefs expressed by HCPs with the emotional content of their responses gave a fascinating insight into how they see their role within the team whilst trying to meet the clinical objectives of the service.

HCP2 displays flexibility in considering the patients' care in holistic terms.

**HCP2**: "So, this BDD patient would come to [ ]. Some of which will have an ERP basis to it and we used a CBT approach. We also used meaningful engagement and activity. Other strategies such as distraction, looking at activity scheduling, developing interests and roles and how they spent their time. I haven't personally

worked with families, but we would try to include them as much as possible in their treatment, because sometimes people can get family to collude with their BDD. And I think there is a need for the family to be involved because of the understanding of the disorder."

HCP2 takes a more holistic approach although still remaining true to the recommended treatment. The emphasis is on collaboration and "meaningful engagement" rather than offering a treatment option that the patient has to comply with. In this extract, the HCP is clearly integrating the concept of being patient-centred into the treatment approach. Taking this position resonates more with HCP2 than focusing on patient's outcomes with standard recommended interventions such as ERP.

It is explicit in the NICE documentation that recommendations are for guidance to promote best practice rather than to replace professionals' clinical judgement (NICE 2018). Although the HCPs interviewed conveyed this in their responses on practice, they also voiced frustration with limited clinical options available for treating BDD, as seen in the following extract:

**HCP2**: "From my little experience from the two BDD patients we've had here, one patient didn't find the exposure particularly useful and the manner in which the treatment was done. And I personally, I found the work I was trying to do with her quite challenging. I don't think it fits quite as well as it does with OCD. ...but there is no other recommendations in terms of treatment, as far as I know."

R: "What do you think was least beneficial in treating patients with BDD?"

**HCP2**: "With the ERP approach, I think sometimes it can be too challenging and sometimes, what we were suggesting for the patients was too much. Maybe that's something to learn from."

This extract reveals a lack of assurance about the effectiveness of treatment options. They express feeling there are insufficient opportunities to develop experience as few patients with BDD are coming through to the service. There is also a sense of dissonance – the HCP is aware of what the treatment recommendations are and puts them into practice but is aware this may not always be the right fit for patients

with BDD. Repetition of "I" indicates the personal impact on the HCP in trying to work within this model and the frustration that there are no other options. They describe feeling the guidelines are more suited to OCD but do not adequately fulfil needs for BDD patients. Furthermore the service model putting it into practice does not take this into account.

In this extract HCP5 also comments on the guidelines being more comprehensive for OCD with less clarity for BDD. The HCP states they find BDD more difficult to treat than OCD and would welcome more detailed guidance for treatment options.

**R:** "If given the opportunity, how would you improve on the NICE guidelines for BDD?"

HCP5: "Clearer evidence-base on what really does help. So just breaking things down a little bit more, with the use of CBT and medication. Certainly, with the guidelines for OCD, they are quite specific about ERP. I personally think that BDD is a difficult condition to treat, more difficult than OCD. I think the guidelines should be more explicit about what helps and what definitely doesn't help in terms of CBT."

The HCPs' responses generally indicate they feel a need to adjust their approach to engage patients or to offer something different using their core skills rather than following the recommended treatment.

HCP8 also considers the guidelines for BDD need more clarity as it seems to be overshadowed by OCD. The HCP also expresses their view on media influences which they see as promoting the ideal appearance.

# R: "If given the opportunity, how would you improve on the NICE guidelines for BDD?"

HCP8: "I would have separate guidelines as a first. The treatment that IAPT offers should specify what could be offered at each step. And to have clearer guidelines on medication. I don't think it's completely clear on what there is evidence for." "Also, more public awareness about BDD, maybe steps 1 and 2. Just labelling it. There's a lot on telly about beautiful bodies and surgery etc. but I don't hear about

BDD in the media. In an ideal world, there would be more awareness about BDD as a separate condition and what it involves and the treatment available for it."

Again lack of awareness and insufficient research is highlighted. HCP8 also reiterates their call for separate guidance for BDD.

Despite their concerns, the HCPs also express their dedication to the service and their belief in the therapeutic approach. HCP5 expresses a fervent belief in using CBT as a whole approach rather than separating the cognitive and behavioural aspects.

# R: "If given the opportunity, how would you improve on the NICE guidelines for BDD?"

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The HCP recognises how difficult the behavioural techniques can be for patients but also with commitment it shows positive results. Interestingly the HCP observes that therapists may avoid techniques such as ERP as it raises patients' anxiety levels. Therapists need to recognise their own unease and address this in order to help patients tolerate then manage anxiety. Otherwise they are merely colluding with the patient's safety behaviours or avoidance.

### Superordinate theme 3

#### 6.7 Patient care

The main purpose of this study is to understand and evaluate patient care for BDD not just in providing treatment but in ensuring positive patient experience. The NHS and NHS England actively promote patient centred care to support patient choice, collaborative working practices and integrated care. However these intentions will only be effective for patients with BDD if the disorder is more widely understood and treated otherwise they will remain on the periphery of having the best care available.

# 6.7.1 Engagement

Clinicians' responses indicated patient care to be a major theme with engagement a vital component. Apart from the general CBT skills in engaging patients, working with patients with BDD requires more specific principles including dealing with past experiences of healthcare; validation; not responding to discussions of appearance (Linehan, 1993; Veale et al., 2010).

An excerpt from HCP10's interview demonstrates their view of the engagement process.

**R:** "Is there anything that I haven't asked you about treatment provided by the service for BDD that you would like to discuss?"

HCP10: "Not really, just to say that when it works, it works really well. I think people struggle a little bit to get going in the beginning with BDD treatment, because it can be quite hard to get them engaged with the treatment. Engaging can be difficult in a sense that it takes longer, so you need that time available to work with them. I've found the Theory A Theory B works quite well with helping them with engagement. Particularly validation, because one of the biggest problems with dealing with patients with BDD is that they often feel like they're not being believed. Especially, if they've been through a couple of courses of treatment, they feel as if their physical symptoms aren't being recognised. So I found that by validating their physical symptoms, not just trying to change their interpretation or understanding of them,

helped with their anxiety. So by encouraging them and letting them know they are being believed, not just trying to change their view point, helps to get them on-board with the treatment by testing different theories and ideas. So, when it works, it works well."

The HCP emphasises the necessity of time needed in this phase of engagement. They also use specific interventions for BDD in this process and demonstrate a belief in the value of the approach for engaging patients with BDD with the repetition of "...it works well." The HCP describes validation and dealing with past experiences as a precursor to developing a therapeutic alliance.

A similar pattern is found in HCP1's account:

R: "What do you think was most beneficial in treating patients with BDD?

**HCP1:** "Challenging the behaviours and beliefs of how people are accepted and offering them unconditional positive regard throughout the therapy. That contributed by helping them engage and they felt safe, and able to move on and apply techniques to help them take risks."

The HCP's approach encompasses the principles of therapy whilst also being patient- centred. The extract demonstrates an empathic, supportive approach with the focus being on trust as a key for patients to engage with treatment. Feeling "safe" and taking "risks" can only be achieved if the individual trusts the therapist's guidance.

HCP5 highlights the need for a dynamic and flexible approach to engage patients.

R: "What do you think was least beneficial in treating patients with BDD?"

**HCP5:** "I think new technology is interesting with BDD, as I was working with a client, who would look at various pictures of themselves on Facebook and Snapchat. And they had 100's of pictures that they would go over day in and day out, trying to change and alter the look of. So what was helpful for this client, was saying 'I'm actually going to stop using these social media programs and stop the comparison there'. Whether that is partial avoidance, is open to conjecture. It's almost like a

client who has an alcohol problem and saying to them, why don't you go into the pub 3 times a week, to test that exposure. So to me, it has that sort of quality about it. It is like an addiction. So, for this client who stopped using the social media programs, it was actually really effective. But there's another side of me that says maybe for clients to lead a normal life, we should be teaching them to use these platforms, but just in a better way."

The HCP recognises that patients with BDD tend to be within the generation of digital natives. Thus engaging patients needs to involve adapting to changes in their needs and their ways of learning. The HCP also expresses the difference in treatment with BDD where exposure treatments are not as appropriate as it may be for OCD.

### 6.7.2 Therapeutic alliance

Once patients are engaged in therapy, developing a strong therapeutic alliance is the next essential step which establishes a mutually agreed path through treatment. A well-established therapeutic alliance can contribute to maintaining collaboration and engagement in often challenging interventions (Goldfried, Davila, 2005). Furthermore it is thought to lead to better outcomes and prevent dropouts in conditions that are considered difficult to treat (Klein, Schwartz, Santiago, et al., 2003).

Developing the therapeutic alliance is also emphasised in HCP8's account.

**HCP8:** "Forming a therapeutic alliance is crucial and overcoming any kind of blocks in that alliance. Maybe even more so than OCD, because often the person feels they're justified in behaving the way that they do, because the defect to them seems so real. A patient that I'm currently working with has said that she feels quite patronised, belittled and she didn't feel like her efforts were being truly recognised. So, shifting that block so that we can work together is crucial."

People with BDD often describe feeling misunderstood and not taken seriously as patients' accounts attest to (Refer 5.5.1 pg. 136). The therapists in this service initially help patients heal from these previous experiences concentrating on the therapeutic alliance before interventions. The HCP reiterates the importance of

removing obstacles to therapy where not forming a therapeutic alliance could be a major stumbling block.

Here HCP7 shows how using the therapeutic alliance allows them to tap into the deeper needs of the patient in a holistic way rather than merely following the treatment guidelines.

R: "What do you think was most beneficial in treating patients with BDD?"

HCP7: "Lots of work on self-esteem, before trying to do the exposure work. In my experience, people tend to have a negative self-image and that really does tend to dominate, not only things around their appearance, but can also affect other aspects of their lives like their status in life and how they compare themselves to other people. It's more than just their appearance. CBT work and stuff around self-esteem and being able to nurture and look after themselves and experience pleasure with that, I've found quite useful. Not just doing an exposure in a social situation and helping with self-belief. That doesn't also feel like a nurturing thing. It can feel more like a testing and trying, rather than a nurturing type of treatment."

This variation to the standard recommended treatment shows a considered response to the patients' needs with use of therapeutic skills beyond techniques for BDDspecified interventions.

HCP4 also highlights the advantage of having more clinical time with patients which this service model allows to a greater degree than other services.

**R:** "Is there anything that I haven't asked you about treatment provided by the service for BDD that you would like to discuss?"

HCP4: "BDD, more so than maybe any other disorder is more about the therapeutic relationship. It's about the trust and the longevity, so making sure that you have a longer period to work with people. I don't think it would work in IAPT or any other similar type therapies. Because we have an inpatient unit, we have plenty of time to work with patients. Working in a shorter term therapy setting, I don't think is as affective, because you need that longer time to build up a relationship, and trust,

which I think is massively important when it comes to treatment for people with BDD."

The repeated reference to the therapeutic relationship and developing trust highlights how vital the HCP views this for treating BDD. However this takes time which the HCP points out is limited in most therapeutic settings.

Developing the therapeutic alliance with patients is described as crucial by the HCPs but it is also recognised that patients face difficulties in accessing the appropriate care for BDD due to the limited understanding of the disorder. HCP5 admits that even as a specialist in the disorder, they consider their understanding of BDD to be only reasonable with much to be done to develop the body of knowledge and awareness of BDD generally.

HCP5: "I think we as clinicians have a better understanding, but not necessarily a good understanding of BDD, because of the work that we do. I think I have a good understanding of OCD and I think I have a fair understanding of BDD. So, when I think about clinicians in other areas who don't have the specialist expertise, knowledge and access to training, I think there's a huge amount of work to be done out there for BDD clients and the diagnosis of it. And even the recognition of it alone."

The HCP considers that limited understanding of BDD generally amongst clinicians can result in patients having negative experiences of healthcare professionals which make developing the therapeutic alliance more challenging.

#### **6.8 Discussion of Findings**

The accounts from clinicians interviewed provided a valuable insight into their perspectives and feelings about their experiences in the service. Views expressed show the passion for their work and belief that they can make a difference. However with regards to the NICE guidelines, there is a sense of dissatisfaction that it is adequate for BDD. This is not surprising given at the time of publication there were only three RCTs of CBT for BDD with a combined total of available data from two of those studies (N=36) which formed the CBT evidence-base in the NICE guidelines

for BDD (NICE, 2006). There have been a further seven RCTS conducted on CBT for BDD which were described in a metaanalysis but there have been no further reviews of the NICE guidelines for BDD (Harrison et al., 2016). The responses of the HCPs raises the question of the impact of establishing the service model based on the NICE (2006) guidelines. A dichotomy exists as they see no difficulties in accepting provision of the service according to NICE (2006) guidelines for OCD but it see it as not sufficiently robust for BDD. The overall impression is that clinicians are resigned to there being at least *some* guidance available for BDD given the limited knowledge and evidence-based research available.

However there is also frustration and helplessness voiced in many of the HCPs' comments which can be rooted in the lack of a substantial evidence-based body of knowledge for BDD. Clinicians have nothing to draw on when recommended interventions are not working. Instead they turn to generic interventions or those used in other disorders such as mindfulness, motivational interviewing and working on self-esteem etc. Furthermore HCPs reported that in some instances, using goals focused on daily living skills allowed the patient to feel some sense of achievement especially when they found the CBT interventions difficult. Occupational therapy could benefit patients in improving functioning yet this is neglected in the NICE guidelines for BDD mainly because there is no published research into occupational therapy for BDD.

The gap in knowledge of BDD is clearly recognised with literature calling for research into improving on CBT as well as the understanding of the development and maintenance of the disorder (Veale, Miles, Anson, 2015; Krebs, et al., 2017). This is also illustrated in the findings from the literature review as previously described (2.4 pg. 39). Additionally research indicates some benefits for SSRIs but also the limited number of trials and lack of understanding of the neurophysiological aspects of BDD means the evidence is still relatively weak (Phillips et al., 2008; Ipser et al., 2009).

The inadequate understanding of BDD makes it more difficult to provide the treatment that patients need in a timely manner. There are a limited number of health care professionals with the expertise to assess and treat BDD. However not all have the opportunity to disseminate their knowledge and skills, therefore training for BDD is limited which means restricted injection of new ideas, approaches or interventions

into the available training. Therefore most health care professionals do not have the opportunity to develop even basic skills in recognising BDD (Phillips et al., 2008; Veale et al., 2015). The impact of this is that referrals to appropriate services are not forthcoming as reported by the HCPs in this study. Added to this the lack of understanding could lead to adverse patient experience, disengaging from services, worsening patients' conditions eventually resulting in more profound needs with significant impact on carers/families and further demands on resources.

Although the stepped care model was designed to improve access in practice, patients with BDD who may not have access to appropriate treatment in the initial steps have little recourse than to proceed through each step and multiple services before accessing specialist care. That is if they remain engaged through this process which is less likely due to the nature of the disorder (Veale et al., 1996; Phillips et al., 1997).

One of the advantages of multidisciplinary (MDTs) working is the different perspectives each person brings to the team. Given all the members of the team have core professions, in addition to their role in providing CBT or medical management, this enables delivery of holistic care (Mental Health Commission, 2006). MDTs also provide opportunities to use these alternate views to initiate change and strive for improvement. However operational support is also required to allow for this to happen. Yet from the expressions of frustration found in clinicians' accounts some seem to feel there is little control over operational factors and no support to address shortcomings in recommended treatments along with restrictions which pose challenges to achieve the desired outcomes. It is understood that providing a clinical service within the NHS has requirements based on organisational operational policies and procedures (NHS England, 2018). However there are procedures to assess the impact policies have on service delivery, although from HCPs' reports it appears this does not always translate into practice thus not accommodating specific needs of this group (SWLSTG, 2016). Despite the frustrations described by clinicians, there is a shared culture in the team of providing a needs-led service regardless of the organisational demands (Ovretveit, 1993). There is a strong sense consensus in providing the best care for the patients even with organisational restrictions, limited knowledge base and treatment guidance.

HCPs generally demonstrated a commitment and belief in the treatment modalities which promotes the unity of the team members.

A factor conspicuous by its absence was any reference to outcome measures. Possibly this was not considered as relevant in decision-making regarding treatment instead it seems clinicians evaluated patients' progress in terms of the patients' experiences. However outcome measures were regularly completed and provide objective measures of symptoms used in the Unit's reports and research undertakings therefore the clinicians do value the data obtained. However they do not discuss this in their personal accounts thus may see outcome measures as a service requirement to evaluate effectiveness which relates to the value-for-money requirements of commissioners. One of the factors that give CBT stronger appeal is the measurable nature of the treatment targets (Bakker, 2008). CBT has been shown in researching findings to be a cost-effectiveness treatment across disorders and in comparison to medication which has prompted funding into CBT services including development of IAPT services in 2008 (NHS England, 2018; Myhr, Payne, 2006). Unfortunately there has been less attention given to early intervention for BDD which HCPs interviewed highlighted a need for, particularly increasing awareness in teenagers as this is the usual phase of onset (Phillips et al., 2006).

Working with younger adults also raises the aspect of social media which HCPs note could have an additional impact on treatment of young adults with BDD. This is not addressed in the NICE guidelines (NICE, 2006). Yet there are generations (generation X and Y) who have been born into the digital age with a different view of relationship contexts with face-to-face social interactions competing with on-line communication and social networks based in social media platforms (Cabral, 2011). For a young person with BDD, opting for online communication would be an easy option as the generation sees social media networks as a norm (Subrahmanya, et al., 2008). It could be seen as beneficial in providing social acceptance and inclusion whereas direct contact would raise anxiety leading to avoidance and isolation (Subrahmanya, et al., 2008). Furthermore internet and computer based treatments which have been trialed for BDD may be a way to engage younger people early on (Enander et al., 2014; Summers et al., 2016). Still there is the need for real world interactions which require social skills which may be underdeveloped if interactions have mainly been in a virtual setting (Cabral, 2011).

With the digital age comes more availability to media images and information which HCPs discussed in their interviews. Although the media may be vilified for portraying appearance ideals and images to aspire to, the media can play an important role in promoting the awareness of BDD. A recent media report that Superdrug launched Botox clinics prompted a response by Professor Stephen Powis, medical director of NHS England, which was relayed in the media. This resulted in Superdrug granting that customers will be screened for BDD (Levine, 2019). The media can therefore be instrumental in bringing public attention to BDD and influencing options available for assessment, recognition and treatment.

The main themes that stood out in the HCPs interviews were the frustration at lack of evidence based research and knowledge of BDD plus the dedication to patient care and developing therapeutic alliance. Working with patients suffering the debilitating effects of BDD can be an intensely felt experience as seen in some of the HCPs responses especially regarding shortcomings in treatment.

# Chapter 7:

# **SYNTHESIS OF FINDINGS**

#### 7.1 Introduction

The aims of the study were described in 1.8.1 pg. 27, achieving the following:

- Evaluation of applying NICE (2006) guidelines in treating BDD within a specialist service.
- Eliciting and interpreting experiences of patients and clinicians respectively receiving and providing treatment for BDD.

#### This chapter will present:

- Summary of findings from the three phases.
- Discussion of synthesised findings followed by links to literature.
- Strengths and limitations of the study.
- Recommendations for future research.
- Recommendations for refining policies and treatment protocols.
- Dissemination strategies

#### 7.2 Summary of Findings

### 7.2.1 Phase 1: Quantitative Analysis

Key patterns identified were:

- Limited alleviation of BDD symptoms for some patients found on standardised measures.
- Impact on quality of life- work, relationships, independence.
- Limited diversity in ethnic representation of patients referred.

#### 7.2.2 Phase 2: Patient Interviews

Key themes identified related to:

- Engagement in treatment and using techniques effectively. NICE (2006) guidelines recommended treatments do not fit everyone with BDD.
- Lack of early access to appropriate treatment, adverse experiences in healthcare from lack of understanding, knowledge plus skills in recognising and treating BDD.

#### 7.2.3 Phase 3: Health Care Professional Interviews

Key themes identified were:

- Lack of sufficient evidence-based research resulting in treatment options for BDD not comprehensive enough, lacking alternatives when patients' symptoms not improving.
- Tensions within the organisation related to inflexible policies and procedures.
- Efficiency of patients' pathway through the stepped-care model.

### 7.3 Discussion of Synthesised Findings

Synthesis of findings from the three phases produced the following focal points:

- A predetermined package of treatment vs needs-led care.
- Implications of deficiency in knowledge and understanding of BDD.

#### 7.3.1 A Predetermined Package of Treatment vs Needs-Led Care

This specialist service evolved to implement the NICE (2006) guidelines as a means to both provide a specialist service but also to survive in the face of service reviews and funding cuts. The inpatient service was presented to NHS England following threats of closure due to lack of funding from local CCG bodies. In following the guidance, the service was commissioned by NHS England and together with two other specialist services at different locations formed a consortium working with this model.

Given the inception of this service and the framework that treatment is provided within, tensions arise when the package of treatment does not work. Interviews with clinicians indicated difficulties with parameters of treatment guidelines. Healthcare professionals express commitment to the therapeutic model but consider interventions for BDD to be insufficient especially when patients find the interventions too difficult to tolerate. There are no clear alternative recommendations for BDD apart from further trials of the same interventions. This creates conflict between the organisations' objectives and the professional's view of what is in the best interests of the patients. Clinicians emphasised the individual needs of patients, reverting to their foundation skills and knowledge to look at alternatives to engage patients and ease symptoms. Still half of the clinicians interviewed reported that they

did not deviate from the NICE (2006) guidelines. Clinicians may decide to remain within these confines as this is the only evidenced-based recommendations available for BDD and it seems the safer option than to attempt any novel approaches especially when patients' present with complexity, severe symptoms and risks. Added to this, clinicians reported that despite it being a specialist service for BDD, their opportunity to gain experience treating the disorder is limited due to low referral rates. This may influence their decisions on treatment if they feel less confident in treating BDD. This is also borne out in responses from patients who found the interventions difficult and would have welcomed alternative treatment options.

A complicating factor is that the outpatient service is commissioned by local funding agencies and has more flexibility with referral criteria, reports on measures and interventions used whilst the inpatient service is funded by NHS England with strict criteria regarding referrals, treatment, outcomes measures and duration of treatment. This could raise tensions amongst team members where there are differing views of patients' needs. The clinician participants from the outpatient service reported using a host of alternative interventions alongside CBT such as other medications; augmentation; EMDR, family work, mindfulness, motivational interviewing, schema therapy, solution focused interventions; daily activities and living skills. However the impact of this is not formally measured as this does not fall within service directives.

The interviews with patients may explain results from outcome measures. For those patients interviewed BDD ratings indicate improvements but not complete alleviation of symptoms in all cases. There is also a discrepancy between scores on measures and the patients' perceptions of their level of progress. Patients describe their progress in terms of their living skills, social interactions and quality of life. This correlates with sociodemographic findings from phase 1 which shows the disabling effects of the disorder on patients' functioning. The service is based on a framework of treatment and care which works well for OCD but for BDD this treatment package is inadequate to meet their specific needs.

#### 7.3.2 Implications of Deficiency in Knowledge and Understanding of BDD.

With the lack of research regarding development; neurophysiological mechanisms; maintenance factors, even a definitive model of BDD, establishing treatment options is still in its infancy with a sense of trial and error for many of the interventions for BDD. The evidence-based research used by NICE for the BDD guidelines was very limited which weakens its credibility (Tables 15, 16). Furthermore they have not been reviewed despite publication of other studies. Ultimately deficiencies in understanding BDD are at the root of difficulties in addressing needs of patients with effective treatments.

Nevertheless professionals promoting the need for advancements in understanding and treating BDD have been instrumental in raising the profile of the disorder and its inclusion in OCD spectrum disorders is seen as a means to ensure it is not lost within diagnostic manuals. Given the similarities between OCD and BDD (Table 2) as compared to other disorders, further support for recognition was inclusion of BDD in the NICE guidelines (NICE, 2006). Opinion is divided on whether this is the best option with most HCPs interviewed stating that they believe BDD should have separate guidance. This arises from experience of treating the disorder with recommended treatments which are used effectively for OCD but have more inconsistent results for BDD. On one hand the NICE guidelines were considered by clinicians interviewed as generally helpful and for those patients who respond well to treatment they reported significant impact on their quality of life. On the other hand for those patients who are unable to find benefit in recommended treatment, there are no signposts of what to offer. The clinicians have to concede there are no other services or treatment options for BDD.

This again underlines the deficiencies in understanding and treating BDD which has the impact of patients being misdiagnosed or symptoms not being recognised early on. Health care professionals reported that referrals for BDD were scarce and patients attested to this by their experiences of not being offered the appropriate specialist treatment earlier. The duration of the condition was therefore found to be lengthy which has a detrimental effect on functioning as seen in the quantitative findings. This may also lead to obstacles to treatment where patients resort to using substances to cope with the BDD symptoms, which is another factor with little research (Grant, et al., 2005).

Unfortunately there is only a small cohort of healthcare professionals worldwide who have expertise in BDD. The literature review bears this out with most of the published research conducted by the same authors even across treatment modalities (Appendices E, F, G). From patient and clinician interviews their experiences echo this concern with both groups expressing the need for more awareness of the disorder.

# 7.4 Discussion of Findings Linked to Literature

A metaanalysis of CBT RCTs for BDD discussed their findings in relation to the NICE guidance (Harrison et al., 2016). However there are currently no known studies into the effectiveness of using the NICE (2006) guidelines for BDD. A common element in literature on BDD is a description of it being an under researched condition (Phillips, 2000; Williams et al., 2006; Ipser et al., 2009; Harrison et al., 2016).

# 7.4.1 Predetermined Package of Treatment vs Patient Needs

This study's findings raise concerns about having NICE guidelines for a disorder where evidence-based treatment is so limited. It is acknowledged in treatment studies that at post treatment, patients with BDD continue to experience clinical symptoms (Marquesa et al., 2011; Phillips et al., 2013). However the guidelines do not provide recommendations for other interventions nor is there guidance on patient presentation that may benefit from a recommended medication regime (Harrison et al., 2016).

Some studies into additional interventions have shown promise however they have not been explored in further studies nor have they been included in treatment options (Rabiei et al, 2012; Wilhelm et al., 2013; Enander et al., 2014; Summers et al., 2016). CBT has been described as the most effective psychological treatment for BDD based on the available research which indicates improvements in symptoms following therapy (Williams et al., 2006, Ipser et al., 2009; Harrison et al., 2016). Apart from one study comparing CBT with anxiety management, there are no other comparative studies in controlled trials (Veale et al., 2014). Thus CBT appears most effective by default. Also the nature of CBT lends itself more readily to being measured thus is presented in a format more readily accepted for publication.

Despite these shortcomings the NICE (2006) guidelines does serve to address patients' needs to some degree in providing the opportunity to receive treatment that to date is the most evidence-based available (Wilhelm et al., 2013). Although there is a lack of expertise in BDD, the guidelines provide some direction for healthcare professionals to use CBT skills and trial medication regimes to provide for the needs of patients who would otherwise have no options available (Harrison et al., 2016). Nevertheless, this raises questions of whether there could be alternatives to the NICE (2006) guidelines which will be discussed in recommendations for future directions.

# 7.4.2 Deficiency in Knowledge and Understanding of BDD

This deficiency is a common observation described in the literature on BDD (Williams et al., 2006; Ipser et al., 2009; Harrison et al., 2016). Yet the root of this difficulty is unknown considering this is not a new disorder (Morselli, 1891 in Jerome, 2001:103).

# Questions arising from this are:

- Is the lack of wider research into BDD due to perceptions of low prevalence and low impact?
- Do general assessments and consultations in mental health or other health care settings that people with BDD present at include screening for BDD symptoms?

#### Perceptions of Prevalence and impact of BDD

From prevalence studies in the US and Germany it is estimated that from 1.7% to 2.9% of the general population is affected by BDD (Rief, et al., 2006; Koran, et al., 2008; Buhlmann, et al., 2010). In the absence of epidemiological studies of BDD in the UK, this number could be higher. On the other hand disorders such as schizophrenia has a worldwide prevalence rate of approximately 0.28% yet has a much higher profile due to the considered burden of the condition (Charlson, Ferrari, Santomauro, et al., 2018). Furthermore other body image disorders such as anorexia and bulimia have an estimated prevalence of between 0.1% and 1% across age

groups and genders still there is more awareness and recognition of these disorders (Hoek, van Hoeken, 2003).

Clinical presentation of patients with BDD at severe levels can result in inability to meet self-care needs and becoming housebound. This places intense stress on carers to help maintain the individual's functioning (Phillips, 2007; Dunnai, Labusechagne, Castle et al., 2010; Phillips, 2015). The individual is unable to make any positive contribution to society as they are isolated from any social interactions, work or study (Phillips et al., 2008; Veale, et al. 2010). In addition where they have sought cosmetic surgery inappropriately, this results in a burden of cost and drain on healthcare resources to rectify failed surgical procedures or having to address repeated attempts to have further surgery (Phillips, 2015). Most alarming is the high risks of harm BDD sufferers pose to themselves particularly performing self-inflicted surgery and suicide risk (Cotterill, et al., 1997; Veale et al., 2010; Phillips 2015; Lupkin, 2016). Despite the significant impact of BDD on the sufferer, their carers and society in general, there is still a meagre knowledge base.

An additional aspect found in the course of this study was the uneven representation of ethnic groups in the sample. There is minimal research into ethnicity and BDD but studies have shown ethnicity and culture may play a part in symptom presentation and may have implications for treatment (Ishigooka et al., 1998; Boroughs, et al. 2010; Weingarden, et al., 2011).

#### Do healthcare professionals routinely screen for BDD?

Screening questions for BDD is not part of routine practice in assessments by mental health practitioners (Grant et al., 2001; Conroy et al., 2008; Phillips, 2009). This has also been observed from clinical experience and responses of both patients and healthcare professionals.

One of the main reasons for this could be the lack of training in recognising and assessing for BDD in the undergraduate training curriculum for healthcare professionals. In recent years there have been attempts to redress this with a BDD module incorporated into CPD online training on the RCPsych website (Ellison,

Veale, 2016). Also treatments manuals have been published (Veale et al., 2010; Wilhelm et al., 2013). These are progressive steps in increasing awareness and knowledge however this has not reached everyone.

One of the areas to consider is the role of pharmacology sponsors in promoting dissemination of knowledge about disorders (Mosher, Gosden, Beder, 2004). With disorders such as schizophrenia where there is an understanding of the biological mechanism and a clear role for pharmacotherapeutic treatment pharmaceutical companies have played a significant role in education (Angell, 2000). Though this has triggered a critical appraisal of the agenda of pharmaceutical companies in the literature including the view that obtaining funding for research can be hindered if companies do not see it as a profitable venture (Angell, Relman, 2001; Gosden, 2001; Lexchin, 2005). For researchers seeking funding for BDD projects, this will pose a difficulty as the main evidence-based treatment options at present are psychological (NICE, 2006). This provides limited incentives for the corporate sector producing health related products to promote research into BDD. In contrast treatments that require pharmaceutical, biotechnological or other technological devices have generated much support from organisations that have financial interests in promoting these products, even patient organisations who may seek funding from the corporate sector to continue to operate, resulting in conflicts of interest (Mandeville, 2019).

Supporters for psychological therapies described the usual practice for GPs seeing patients with depression or anxiety disorders was to prescribe medication but with the introduction of stepped care models and IAPT services there are more treatment options available (Layard, 2006; NHS England, 2016; NCCMH, 2018). This has come about with the increasing recognition of the need for other treatments as mental health disorders have a far–reaching impact on society as a whole (NHS Confederation, 2014; NHS England, 2016; NCCMH, 2018). Unfortunately it seems that focus on BDD has only been prompted by high-profile media reports on scandals in the cosmetic surgery industry where there are financial implications involved as previously discussed (1.7, pg. 25).

The nature of the presentation of BDD contributes to the difficulty healthcare professionals have in recognising it as a clinical diagnosis (Conroy et al., 2008). BDD symptoms can easily be mistaken for a generally occurring experience of dissatisfaction with appearance, especially for teenagers, (Fitts, Gibson, Redding, et al., 1989; Trekels, Eggermont, 2017). These concerns have prompted a movement more recently to include confidence building material as part of the school curriculum (Be Real, 2019; The Telegraph, 2017). Reports on appearance related concerns state that 37% of females experience appearance dissatisfaction whilst 26% of males are dissatisfied with their appearance (Government Equalities Office, 2014). However it is defining the difference between dissatisfaction and a diagnosis of BDD that requires specific knowledge (Philips, et al., 2006; Phillips et al., 2008).

# 7.5 Strengths and limitations of the study

The study has a number of strengths and limitations regarding methods and literature review as well as the researcher's perspectives.

#### 7.5.1 Methods

Using a mixed methods approach provided multiple sources of data which allowed for different aspects of the service to be evaluated. Although quantitative methods are more commonly used in mental health research, incorporating a qualitative method provided a context for the descriptive findings from the quantitative phase of the study (Powell, Single, Lloyd, 1996). This allowed for a more in-depth exploration of factors that affect the patients' quality of life such as impairments in levels of functioning and relationship-building. Although literature describes the disabling nature of BDD the lack of qualitative research on BDD does not allow for this concept to be fully explored (Phillips et al., 2000; Phillips et al., 2005; Phillips et al., 2008). Therefore using qualitative methods in this study provides new perspectives and possible directions for treatment investigation.

In addition, providing insights into clinicians' perspectives and experiences which are lacking in the literature highlights areas of deficits in resources available for BDD sufferers. NHS England promotes the use of clinician's expertise in service development yet the literature searched is mostly devoid of any discussion of

clinicians' experiences of treating BDD which this study serves to redress by including clinicians in the qualitative analysis.

"There should be even greater emphasis put on people's experience and how experts-by-experience can be seen as real assets to design and develop services." (NHS England, 2016:18)

The availability of data from both patient and clinician rated standardised measures allowed for a more robust evaluation of the outcomes of treatments. Unfortunately not all the medication names prescribed for patients in the quantitative dataset were available which limits the information on the overall number of different medications used. Also treatment outcome findings cannot give an indication of whether CBT or medication was the most effective intervention instead it is attributed to CBT in conjunction with medication. Additionally although some clinicians reported using interventions not detailed in the NICE (2006) guidelines such as EMDR, family work, activities of daily living skills, these were not recorded in a formal way on outcome measures. Although the SDS provides a holistic measure of impairment, there are no objective measures to determine whether these specific interventions contributed to outcomes. On the other hand, the qualitative data provides some insights into the impact of some of these interventions. A limiting factor may be that patient participants were either treatment completers and discharged or in follow up, which would impact on their perspectives compared to patients who were non-completers.

Using thematic analysis also promotes its use as a standalone qualitative method with significant contribution to make in terms of the depth and richness of data that can be obtained using this approach. In addition thematic analysis in this type of study provides clarity in identifying strong patterns for areas to be further investigated.

#### 7.5.2 Sampling

Still this approach faced some limitations particularly in sampling. The relatively small sample size could be seen as a limiting factor however the analysis produced a wide range of perspectives and the common patterns that emerged indicated that saturation was reached. Still patients who chose to participate may have presented a bias towards a group who are more engaged and responded more favourably to treatment, as it is generally considered difficult to engage patients who have BDD

(Phillips et al., 2008; Veale et al., 2010). Conversely some patients may have agreed to participate as they had their own agenda to communicate their dissatisfaction, which is an area researchers are promoting as well as studies on patient satisfaction (Coyle, Williams, 1999).

Due to resource and time constraints, the researcher was unable to recruit participants across the specialist service consortium which would have offered a more comprehensive view of the implementation of the NICE (2006) guidelines. In addition as one of the centres also provides treatment for children and adolescents, this would have provided much needed insights into BDD in young people. Also although there was no upper age limit for patients invited to participate there were no participants over 49 years old, which provided less representation of older adults. However examining the quantitative sample provided an explanation as patients over the age of 50 were outliers and none were under care of the service at the time of the study. Key findings from the appearance satisfaction survey indicated that body satisfaction is at its highest in the 50-64 age groups which is perhaps a reason for lower presentation of BDD in older adults (Government Equalities Office, 2014).

#### 7.5.3 Literature review

From the outset, it was clear that availability of literature on BDD was scarce (Veale et al., 2010). The study includes a comprehensive appraisal of the available literature on treatment however no published studies in other languages were included which poses a limitation. Often healthcare professionals conducting studies in their clinical settings may wish to disseminate their findings but if the sample is small it is often rejected by publications (Sullivan, 2015).

#### 7.5.4 Researcher's influence

Subjectivists maintain that research is influenced by the researcher's biases from the outset (Hunt, 1993). Certainly in this study the topic of focus was chosen due to the researcher's particular interest. However this may not necessarily be considered bias where the researcher is transparent regarding the motivation for the study, preconceptions and explanation of the method of interpretation used (Malterud, 1993).

The influence of being interviewed by a peer can be beneficial as clinicians identify with the researcher as a fellow clinician and feel safe to express emotion-laden views (Chew-Graham, May, Perry, 2002). However given the researcher was known to have specialist interest and expertise in the subject this generated a concern of being judged (6.2, pg. 156). The researcher's clinical experience in the setting may also have an influence on patient participants' responses as they may consider the researcher to have a better understanding of BDD and may be more comfortable expressing their experiences. On the other hand although it was made explicit that their participation would not affect their treatment in any way, they may have concerns with being judged and be more considered in their responses (Chew-Graham, et al., 2002).

#### 7.6 Recommendations for future research

The study highlighted the following areas for future development:

- Development of a definitive psychological, biological and social model for BDD.
- Research into treatment options.
- Education and awareness of BDD.

# 7.6.1 Development of a definitive psychological, biological and social model for BDD

Several psychological and physiological theories relating to development and maintenance of BDD have been proposed but there are still discrepancies and factors that require further investigation (Veale et al., 1996; Deckersbach, et al., 2000; Wilhelm et al., 2002; Feusner, et al., 2007; Feusner, et al., 2010; Wilhelm et al., 2010). The focus needs to be on the onset of the disorder which tends to be in adolescence (Phillips, 2005). Patient participants shared their view and the consequences of not receiving treatment earlier on in the course of the disorder. Although not discussed in this study as the service caters for an adult population, the guidelines also relate to children and adolescents but research on this population is minimal and is confined to single case studies or case series (Phillips, Didie, Menard et al., 2006).

There needs to be further exploration of how body image develops in adolescence and factors that may disrupt the normal process that could lead to developing BDD (Phillips, 2005). Social factors such as ethnicity and culture also need to be included in this search to understand the development of the disorder. Progress in establishing a definitive model of BDD will offer more avenues to explore regarding treatment.

#### 7.6.2 Research into treatment options

The literature review provides a clear indication of the limited research available on treatment for BDD. Research comparing treatments is minimal with just two studies comparing treatment modalities (Khemlani-Patel, et al., 2011; Veale et al., 2014). Despite the literature describing the impact of BDD on functioning, there are no studies into other interventions such as Occupational therapy for BDD or Art therapy (Armitage, 2016; Berner, 2015).

Given the limited understanding of the disorder, every avenue should be explored even possibly controversial ones such as cosmetic surgery. A study on rhinoplasty for BDD showed improvements including at follow up. Although it was a small cohort compared to the studies showing no improvement or worsening of symptoms with cosmetic surgery, further examination of this group is warranted as it may provide information on particular characteristics of the patient group that influenced outcome (Felix et al., 2014).

Treatment with medication documented in this study indicated the numbers of patients receiving SSRI and augmentation which gave some understanding of how the medication recommendations in the NICE guidelines were implemented (NICE, 2006). Data on specific medications used was not available for all patients in the sample; nevertheless the breakdown could point to directions for future research into medications that appear more favoured (Appendix V). Fluoxetine was the most prescribed SSRI and is described in the literature as a preferred first option SSRI for BDD (NICE, 2006; Phillips, Hollander, 2008). In addition Clomipramine and Sertraline were both the second most prescribed SSRIs from available data yet research is limited to non-existent with Fluoxetine and Clomipramine described in two case reports and no known studies of Sertraline in treating BDD (Hollander

Liebowitz, Winchel, et al., 1989; Phillips, 1991). At the time of writing there are no known studies comparing SSRIs with other treatments found to be effective such as CBT. The link between guidelines recommending these pharmacological treatments for BDD with available evidence is tenuous at best. The question arising from this is why are these medications not being further investigated?

The literature suggests SSRIs decrease preoccupation with appearance; reduce distress and promote improved psychosocial functioning (Phillips et al., 2008). However a metaanalysis finding suggests CBT is more efficacious than medication (Williams et al., 2006). Without direct comparisons however, there is no conclusive evidence for this. Therefore considering the improvements described from taking SSRIs it would appear that relieving patients' physical symptoms and increasing ability to actively control levels of preoccupation would help them to engage in psychological interventions such as CBT which work towards addressing cognitive aspects as well as behavioural patterns that maintain the disorder. Furthermore if the level of distress is reduced, the patient is more able to use problem-solving and their support networks to return to an improved level of functioning. However in this study's sample with the high rate of comorbid disorders present, especially depression (N=41, 85%), it is unclear whether the medication relieved symptoms of BDD or as the symptoms of depression abated, the BDD symptoms were more amenable to change with the psychological therapy. Depression is the most commonly found comorbid disorder in BDD sufferers which if left untreated will impact on level of engagement and result in a range of physical symptoms (Phillips et al., 2005). Patients need to be cognitively stable in order to engage in psychological therapy; therefore a transdiagnostic approach may be needed (Phillips et al., 2008). A guery arises of whether these patients are receiving adequate treatment for depression initially and if this could help them to address their BDD in earlier steps rather than being stepped up to specialist services.

However to fully understanding how SSRIs are able to influence treatment outcomes further studies into their use alongside psychological therapies; holistic interventions such as those used in Occupational Therapy and family work will provide much needed advances in treating BDD. Also conducting long-term follow ups of patients will provide an indication of the sustainability of particular treatment strategies.

Innovations in mental health such as the role of digital technology in treatment is an area to explore especially as the onset of BDD tends to be in adolescence and young adults for whom this platform is an area of social interaction and connectivity (Phillips et al., 2005; Gould, Munfakh, Lubell et al. 2002). NHS England in conjunction with NICE have developed a five year plan to assess digital therapy products for IAPT services (NHS England, 2017). One of the approved products is BDD-NET a digitally enabled therapy for individuals to access remotely (Gentile, et al., 2019). The concept is based on a study aimed at increasing access to psychological therapy for BDD on a global scale which would be ideal given the limited resources available for treating BDD (Enander, et al., 2014; Gentile, et al., 2019). However a concern would be the nature and quality of the therapeutic relationship with an online treatment forum which has limited therapist contact. From the qualitative findings in this study both patient and clinician participants valued the therapeutic relationship above all interventions. It was this aspect of therapy that secured patients' engagement plus increased their motivation to actively use difficult interventions. For patients with moderate to severe symptoms of BDD, digital CBT would require a high level of self-motivation. Yet with the occurrence of comorbidities the level of engagement with online treatment is questionable (Phillips et al., 2005; Graph 4, pg. 120).

With a limited number of professionals who currently have expertise in treating BDD, another question arises of how therapists will be trained and how their performance will be monitored in supporting patients using this therapy program. In addition there are issues such as patients in more deprived areas of the globe having access to the necessary technology; internet speed; software compatibility; language and cultural factors – all these need to be considered. Would there also be a danger of the program being a false sense of reality with patients developing a sense of confidence within a virtual field without in vivo reality testing? Yet this could provide an opportunity to develop an alternative graded step for patients who find the real-life exposure too overwhelming to tolerate (5.7.1, pg.147). Also with technology able to provide easier and faster access to appropriate services, this could be a way to provide early intervention for those patients facing the onset of the disorder. There will undoubtedly be setbacks and troubleshooting needed before this form of therapy delivery is fully functional on a global scale but it may signify a new way forward.

#### 7.6.3 Education and awareness of BDD

Appearance and body image has been recognised as an important factor in ensuring mental health and wellbeing (Burrowes, 2015). Although the promotion of body confidence is welcome advancement, the document held no mention of BDD but had repeated reference to eating disorders. This is not to detract from promoting awareness and recognition of eating disorders instead it is vital that equal focus should be on BDD. Often these disorders overlap but the eating disorder may be more easily recognised and BDD symptoms assumed to be part of the eating disorder (Grant, Phillips, 2004).

Awareness of BDD is primarily lacking but the media could play a large part in disseminating research findings especially with the popularity of reality television shows (Mazzeo, Trace, Mitchell, et al., 2007). At present the literature is focused on researching possible adverse effects of the media on appearance and body image (Tiggemann, Slater, 2004; Grabe, Hyde, 2009). Yet TV shows such as the Gok Wan's reality series have highlighted body and appearance concerns with the presenter taking further steps to promote education on appearance and self-confidence in schools (The Telegraph, 2009). These types of media platforms can provide opportunities to highlight signs and symptoms of BDD so that it is more recognisable in early stages.

Alongside this there was a clear theme identified in this study amongst clinicians and patients interviewed that there are insufficient professionals who understand and can treat BDD. Therefore there needs to be training in BDD from specialist services at all levels of the stepped care model so that healthcare professionals are able to recognise and offer treatment early on as well as be aware of referring patients on to specialist care more rapidly. Some of the clinicians interviewed reported that closer working with primary care services such as IAPT have led to establishment of CBT groups for BDD which allows for greater access to treatment for patients. There needs to be more forums for dissemination of information as well as bringing together other disciplines such as Occupational therapists, Social workers, Art therapists who can offer a more holistic view of the patient as well as alternative treatment options to explore.

# 7.7 Recommendations for refining policies and treatment protocols

The themes highlighted by the study findings as well as existing literature clearly indicate the scope for further development in policies and treatment protocols. The following were the main considerations for refinement:

- Service treatment protocols
- NICE guidelines for OCD and BDD (2006)
- NHS Trust operational policies
- Wider policy recommendations

#### 7.7.1 Service treatment protocols

Further investigation is recommended into effectiveness of treatment for L6 national outpatients. From the literature reviewed, the findings appear to be CBT as a combined treatment is more effective but due to the practicality, time plus resources of providing outpatient treatment to patients based in locations nationally, it is mainly a behavioural component that is used in treatment. This works well for the OCD patients but from the findings, it clearly does not suit the patients with BDD. It is likely the lack of resources to provide treatment is the main difficulty as without the local services having skills and expertise to continue treatment, there may be little response from patients. The theory behind providing "outreach" treatment in the patient's locality is innovative but unless the resources are available to put into practice this is not feasible. Ideally HCPs in different regions should be identified who will be trained in recognising and treating BDD and could be the expert for that region. Therefore when referrals from that region come through the specialist service can set up a treatment plan and work with the local services and local expert HCP to implement treatment.

#### 7.7.2 NICE guidelines for OCD and BDD (2006)

The NICE (2006) guidelines are considered a valuable resource in clinical treatment decisions, yet for BDD it does not have a sound evidence-base (Hurwitz, 2001). Including BDD under OCD spectrum disorders in the DSMV (2013) and ICD11 (2018) as well as including BDD in the NICE (2006) guidelines alongside OCD has been discussed and debated in the literature with consensus that the diagnostic classification of BDD is well-placed. (Harrison, de la Cruz, Enander, et al., 2016;

Phillips, Wilhelm, Koran et al., 2010; Grant, et al., 2004; Phillips, Pinto, Menard et al., 2007). However although there is some evidence for recommendations made by the NICE (2006) guidelines there are reservations about how comprehensive this is given the limited research evidence for treating BDD (Harrison, et al., 2016). This was also remarked upon by the clinicians who participated in the study. With their experience of treating both disorders in the same setting their views were that BDD should have separate guidelines or recommendations for treatment.

There are areas lacking for BDD in the key principles for developing the NICE guidelines (Appendix X; 2.4, pg. 39). Where evidence based research of a disorder is insufficient, it is not endorsed to develop clinical practice guidelines (Field, Lohr, 1992). Instead consensus recommendations can be formalised based on available research findings; clinicians' experience and expertise; qualitative information from patient responses and views of interventions (Trickey, Harvey, Wilcock, et al., 1998; al., 2014). Development Diamond, Dagna, Hyman, et of recommendations for BDD could be an area of future development but may require a large scale multi-centre study of the implementation of the NICE (2006) guidelines to endorse the need for this.

#### 7.7.3 NHS operational policies

One of the obstacles described by clinicians interviewed was inflexibility in some aspects of practice due to Trust policies. Although it is a blanket policy system for the Trust's operation, there are additional policies to allow for systems to be reviewed (SWLSTG, 2016). It would be beneficial for the application of the operational policy for specialist services to be reviewed in light of clinicians' views, and agreed compromises to be established. The department has previously argued against a specific infection control policy requiring handwashing posters and antibacterial hand gel dispensers in the Unit as it was contraindicated for patients with OCD to be exposed to this. This was agreed by the Trust; therefore similar consideration should be given to BDD sufferers where there are specific requirements e.g. the use of mirrors for BDD interventions.

In addition it is recommended to include basic screening questions for BDD (Fig. 1) in the routine assessment process in CMHTs and healthcare settings where people with BDD are more likely to present (Phillips, 2005; Phillips et al., 2008; Veale et al.,

2015). Furthermore the NICE Quality and Outcomes Framework (QOF) report on anxiety and depression highlighted social anxiety as the most common presentation of anxiety disorders. However given the propensity for people with BDD to be misdiagnosed, including BDD screening as a QOF indicator may provide incentives for GPs to recognise and diagnose BDD (Phillips, 2000; Fang et al., 2010; NICE, 2015).

#### 7.7.4 Wider policy recommendations

As described in the literature and supported by comments from patients and clinicians, it is clear that early intervention to prevent the longer term implications of BDD will be the most logical step. Although the causes of BDD are still not fully understood, there are links made from clinical presentations indicating common factors which may have a bearing on the development of the disorder. Peer pressures; bullying; adverse early experiences are among the contributing factors described in literature on development of BDD (Phillips, 1991; Veale et al., 2010).

#### 7.7.4a Recommendations for education

With the recognition of the disabling impact of conditions such as BDD there needs to be a stronger drive to promote awareness and early intervention especially in schools where the problem initially manifests and can be addressed before becoming a fully-fledged disorder (NICE, 2006; NCCMH, 2018). Including topics in the curriculum about self-esteem, confidence and resilience-building can help teenagers to make sense of their development and experiences. In addition experts in the field can be invited to talk in schools to provide the basic information about BDD, plus signs and symptoms of the disorder which parents/carers and teachers could identify, with a clear pathway to access appropriate services.

However there still needs to be a pathway developed for young people to access help if they feel they are vulnerable to developing the disorder. Key stakeholders such as school nurses, education welfare officers, paediatricians, GPs and parents need the necessary information to be able to recognise BDD and services need to be in place to intervene at the onset. Here again the necessary skills and understanding of the disorder is needed in child care services.

Furthermore with the use of social media platforms as a norm among the digital native generation, there are additional avenues of stressors on young people that have to be accounted for. Recognising that the use of technology is a part of their culture means adapting teaching policies to incorporate promoting safer and appropriate use of social media (Subrahmanya, et al., 2008).

# 7.7.4b Recommendations for physical healthcare services

In addition one of the quality, innovation, productivity and prevention (QIPP) challenges for the NHS is to have more integration between physical health care and mental health services (DoH, 2011, 3.26-3.30 pg. 23; DoH, 2010). The role of body image especially in young people is cited by the DoH as one of the targets for the "no health without mental health" campaign (DoH, 2011, 3.12, pg.19). With the high rate of presentation of BDD cases in physical health settings it would be a logical step to adjust operational policies to bring these sectors together for closer working. This could create an improved pathway of care for BDD sufferers therefore patients can access appropriate services earlier on. With the NHS and DoH looking for new improved ways of working this interface between health sectors would allow for more dynamic use of clinical resources (NHS England, 2017).

From research and reports it is recommended for good practice that the psychological needs of patients attending departments such as maxillofacial surgery, dermatology, plastic surgery, are addressed to support the medical team (Naylor, Parsonage, McDaid, et al., 2012; NHS England, 2015). Research also suggests CBT as a beneficial adjunct to medical treatment for patients with head and neck cancer. Due to the location of the cancer and the effects of treatment on social interaction, patients with head and neck cancer are at particular risk of psychological problems, particularly social anxiety and depression (NICE, 2004; Patterson, Fay, Exley, et al., 2018).

#### 7.8 Dissemination

The opportunity to contribute to the knowledge base and field of study is directly related to the dissemination strategies used (Boddy, 2011). Communicating findings has been ongoing throughout the process of completing this study. However the

approach taken was not only to present findings but to promote implementation of strategies in clinical practice (Bero, Grilli, Grimshaw, 1998).

There are ethical considerations of ensuring findings are made available to the field of study and particularly where research involves qualitative data there is a responsibility to ensure the stories of the participants are heard in a responsible manner ensuring ethical principles are upheld (Boddy, 2011).

The dissemination practice for research findings was challenged in the following quote:

'Research is of no use unless it gets to the people who need to use it' Professor Chris Whitty, Chief Scientific Adviser for the Department of Health, (NIHR: 2016).

#### 7.8.1 Dissemination activities to date

At the time of writing the findings from this study have been presented to the staff in the specialist service. This included the clinical lead, ward manager and outpatient team manager who have treatment and service management responsibilities.

Masterclass presentations on BDD were provided for the Trust and primary care staff covering the region of South West London. This was aimed at promoting awareness of BDD, its recognition, assessment and treatment. Further to this, presentations were given on BDD at the Institute Of Trichologists; IAPT services in Wandsworth and Merton; one day lectures on BDD at University of Derby; Maxillofacial surgery and Orthodontics St George's Hospital. Aspects of findings and information on BDD were also presented at the British College of Aesthetic medicine in 2017.

From the quantitative data analysis and collaboration with colleagues a poster presentation on gender differences was produced and accepted at the Annual Meeting of the American Psychiatric Association and was subsequently published in the Journal of Obsessive-Compulsive and Related Disorders (Tyagi et al.,2013).

One of the most exciting opportunities to transfer research findings into practice came from establishing a screening initiative for BDD in a maxillofacial surgery department. The findings from the screening service were presented at the 2016 Psychodermatology conference at the Royal College of Physicians. The presentation was subsequently published in the British Journal of Dermatology (Govender et al., 2017).

#### 7.8.2 Future dissemination strategy

The NIHR dissemination plan template was useful as a guide to plan future dissemination strategies. Plans for future dissemination are illustrated in Appendix Y.

#### 7.8.3 Looking back, the way forward

Throughout the course of this study, the shortcomings in services provided for people with BDD have been highlighted: from limited education and training to lack of recognition and treatment.

Therefore the stepped process will involve bringing together stakeholders from multidisciplinary backgrounds from education, children and adolescent services, health care and mental health as well as parent and patient groups who can provide input into how to address the lack of awareness of BDD and its development. Early intervention is an important aspect of addressing the development of BDD. Information needs to be provided in schools to target the most vulnerable group – adolescents where the initial onset occurs (Phillips, et al., 2006). Given the initial onset is in adolescence it will be beneficial to consider the use of social media platforms and technology to engage this population (Bolton et al., 2013). Furthermore with the focus on celebrities and media, developing links with celebrities can be a way forward in increasing exposure of BDD to the general public. Celebrities such as Gok Wan and Alan Carr have publicly described their own experiences with BDD and body image difficulties (Wan, 2010; Carr, 2008).

Developing a global network with others interested in BDD, such as Dr Katharine Phillips and Prof. David Veale, will be a step forward to work towards a common goal of increasing awareness and recognition of the disorder. This could provide a forum for working towards bridging the gaps in the treatment currently provided for patients

with BDD. The BDD foundation provides a forum for patients and carers to find support and information but there needs to be an increased awareness amongst health care professionals.

During the course of my Doctorate I identified the need for an in-house psychological service from the pilot project I established to provide screening for BDD to patients at the Oral and Maxillofacial Surgery Unit. This was part of a service development initiative to establish joint working between mental health and the health care service. Most patients were not receiving mental health assessment or treatment and the Oral and Maxillofacial surgery team did not have direct access to psychological services. The findings from this initiative clearly indicate more joint working is needed with physical health care services (Govender et al., 2017).

From this study it is clear that BDD is not recognised until patients have been significantly impaired by the disorder (Table 6). This needs to be addressed by developing links with health care professionals such as GPs; primary care nurses; Liaison Psychiatry services and providing the basic assessment tools to identify patients who possibly have BDD. This does not require an expert in BDD but the use of the questions in the NICE guidelines within the usual consultation or assessment process (NICE, 2006; Appendix C).

This study has proven to be the culmination of the years of working towards understanding this disorder and finding a way forward to promote others' understanding and recognition of BDD. This has been the first step in identifying gaps in the literature and in the provision of services to people with BDD and formulating a future plan to address these.

#### 7.9 Summary

This chapter brought together findings from each phase of the study identifying key themes in how participants experience and perceive treatment and the model of care. Through exploring commonalities as well as outliers, obstacles to treatment and areas of deficiency were identified with ways to improve the knowledge base along with clinical practice. The study design and limitations were discussed and

contributed to indicators for future research and practice recommendations. The synthesis highlighted the necessity for greater investment in promoting education, research and treatment of BDD. This chapter concludes with a description of the dissemination activities to date and the strategy to continue this process.

# **Chapter 8**

# **CONCLUSION**

#### 8.1 Overview

This chapter presents the conclusion of this study which includes a final reflection.

The purpose of this study was to evaluate the implementation of the NICE (2006) guidelines in the treatment of BDD in a specialist service. The aims and objectives (1.8.1 pg. 32) of this study were achieved as discussed in Chapter 7 (7.1, pg. 186; 7.3, pg. 187).

Furthermore this study makes a valuable original contribution to the limited body of knowledge about BDD as it is the first known study to provide:

- Evaluation of implementing NICE (2006) guidelines for BDD in practice.
- In depth exploration of qualitative data of clinicians' experiences in treating BDD.
- Interpretation of qualitative data regarding patients' experience of the package of treatment for BDD provided in this specialist service.

# 8.2 Contribution to knowledge

### 8.2.1 Application of the NICE (2006) guidelines for BDD

To date this is the only known study evaluating the use of the NICE guidelines for BDD in practice (NICE, 2006). The guidelines are a useful adjunct to clinical decision-making but to ensure the recommendations remain relevant and most effective for the service evaluating the implementation of the recommendations provides that context.

# 8.2.2 Clinicians' experiences of treating BDD

The clinicians' perspective in this study provides a unique insight into the provision of the service using the NICE guidelines for BDD (NICE, 2006). The view from the interaction with patients is generally lacking in the literature. From current research there seems to be a trend to find new approaches and interventions to treat BDD (2.6.1). However this study focuses back to the individuals involved in the treatment i.e. the clinician and the patient. In so doing valuable information was obtained about

the multiple approaches and flexible nature of treatments utilised by therapists. In particular the emphasis from clinicians was on engagement, developing a therapeutic alliance and repairing any ruptures in the alliance to ensure the best outcomes. Furthermore the clinicians' perspective provided a direction for recommendations for refinements in current treatment protocols as well as future research. This study therefore provides an original contribution to the knowledge base for BDD from an overlooked perspective.

#### 8.2.3 Patients' experience of treatment for BDD in a specialist service.

This study provides a clear pattern of themes indicating the most beneficial aspects of treatment as experienced by the patient. However given that not all patients respond to NICE recommended treatments, obtaining the patients' perspective contributes an insight into what patients' value most in treatment. Of particular note is identifying what may lead to disengagement or lack of response. Considering both patients and clinicians placed a high value on the therapeutic relationship, this may be the key to better understand the needs of this group of patients. In addition this revealed the views of patients regarding the challenging nature of the CBT interventions used and possible ways to improve the engagement in this process by using other interventions and therapeutic skills. The literature reviewed has focused mainly on quantifying treatment responses. By providing a rich analysis of patients' responses, this study adds a further layer to the current understanding of BDD.

#### 8.3 Research Objectives

The research objectives (1.8.2 pg. 34) have been systematically achieved through the three phases of the analysis. This study identified interventions used by the specialist service for treating BDD which are mainly CBT and medication as recommended by the NICE guidelines (NICE, 2006). However in addition the individual clinicians also tailored treatment to suit the individual patient by using interventions such as improving daily living skills and family work. Although these interventions were not formally rated to allow for a comparison, this identified factors for future research.

Clinical outcomes were analysed indicating significant improvements in the total sample in both BDD and depression symptoms along with overall functioning.

However analysis of each level of the sample indicated some patients were not responding to treatment (Table 9, pg.124). Following on from the quantitative analysis the second and third phases of the study sought to provide a context for the findings. The synthesis of the study findings discussed areas of effectiveness and those requiring refinement.

# Salient points

The qualitative data provided an interesting dichotomy of responses between the two groups of participants. Clinicians voiced more frustrations and helplessness especially with the limitations in understanding BDD and treatment options (HCP8: 6.5.1 pg. 160; HCP1: 6.5.2 pg. 164; 6.8; pg. 180).

Patients on the other hand seemed to have fewer expectations of treatment with some exceedingly grateful for the treatment received which sadly suggests the lack of positive experiences prior to their treatment (Alice; Gail: 5.5.1, pg.137). However there were some patients participants who experienced difficulty with the treatment including not seeing it as a collaborative approach which reflected in their outcome scores on objective measures and may provide direction for engagement approaches such as using motivational interviewing techniques (Fred: 5.5.1 pg.137; 5.6.1 pg. 142; 5.7.1 pg.147).

It is clear from the views expressed as well as available literature that in order to improve quality of life for BDD sufferers, there is a need for additional treatment strategies to address functioning in other spheres (1.2.5 pg.19; Frare et al., 2004; Phillips et al., 2006). Vital activities of daily life such as education/occupation, family relationships, home management and social and leisure activities are perceived as inadequately addressed within the structured CBT and medication treatment strategies recommended (6.6.1; 6.7.1). Anecdotal evidence and studies using a more individualised approach suggest a more comprehensive package of treatment will be beneficial for BDD sufferers (Wilhelm et al., 2013; Khemlani-Patel et al., 2011; MHC, 2006).

Treatment guidelines need to be viewed in an objective and critical way to ensure best practice. Also not all stakeholders were included in the panel contributing to the NICE guidelines for OCD/BDD (2006). It would have been beneficial to have views from dermatologists, cosmetic or plastic surgeons especially as the majority of

patients with BDD tend to present at these settings (Sarwer, et al., 1998; Aouizerate, et al., 2003; Conrado, et al., 2010).

### 8.3.1 Reflexivity

Reflexivity involves the researcher having awareness of their own beliefs and personal constructs and how these influence the research topic and the representation of the data (Etherington, 2004). Following the semi-structured interviews with patients and clinicians, I felt it would be beneficial to describe my own reactions and interpretations of the participants' experiences. This transparency also allows an insight into how the interpretations were made and draws in the reader to consider their experience of the participants' comments (Etherington, 2004). This links in with the epistemological positions adopted for this study, which recognise the influence of the researcher (Trochim, 2006; Weber, 2011). In addition given the stance taken with providing my interpretation of the data, this reflection provides an additional context for the reporting of the qualitative data (3.7.1., pg. 91; 6.1.).

#### Reflections on qualitative data from patient participants

Experiences described by patients who have struggled to find appropriate treatment left me saddened e.g. Gail who reported having had a lifetime of suffering with BDD.

Listening to the comments of patients regarding their experiences made me feel a mixture of responses. This also influenced the coding process of searching for other instances of these experiences which I found in most of the transcripts. The loss of all those years due to a lack of appropriate help and a limited understanding of the disorder gave further impetus to my drive to educate the general public and healthcare professionals about BDD.

On the other hand descriptions of how much they have gained from treatment gave me a sense of elation e.g. Alice: "The therapy has saved my life and remade it." This gave me the evidence to validate the treatments provided. This also influenced the analysis of the transcripts to find other instances where patients did not feel the treatment helped them which inspires me to continue to improve on interventions and look for alternatives.

#### Reflections on qualitative data from clinician participants

Although we work towards helping people get better, we learn more about becoming better clinicians from those who we have not been able to help. I had a sense of the frustration and helplessness described by clinicians which I could relate to. This influenced my analysis of the data in ensuring that these comments were not overlooked as it gave a voice to the clinicians. It is one of the motivating factors for this study and to identify the gaps in the service and evidence-base for treating BDD.

However I felt annoyed when I found the views of one of the HCPs to be too inflexible and defensive rather than being objective about the shortcomings in the treatment (HCP3). This made me think that they were putting their role first rather than the patients' care and not in keeping with the principles of CBT. I therefore analysed the data with this in mind to identify any other instances where this was the case but found it was the opposite with patient-centred care and collaboration at the forefront of clinicians' views. I re-read the HCP3's transcript and considered the HCP's comments in a more objective way so that I gave a more balanced interpretation of the comments. This made me more cognisant of the influence of my own reactions in analysing the data.

#### 8.4 Final reflection

The doctoral process has been a tremendous learning and growth experience from reflecting on the motivation for my interest in this subject to the immersion in the qualitative data. Prior to this study, my research experience had been restricted to pursuing quantitative studies and my initial stance came from a positivist outlook. This was mainly due to a culture of producing outcomes research that would be more readily accepted by journals. However reflecting on my own experiences of treating patients with BDD, I felt it imperative to explore the experiences of patients and clinicians which I believed would provide direction for future developments for BDD. Having an awareness of my own bias being a CBT practitioner and having a strong belief in this model, my choice of transcript excerpts to include in the appendices was in keeping with the critical stance taken throughout this study. I felt it was important to recognise when services were not meeting needs in order to generate improvements. Merely sharing results of when it has been beneficial as evidence for effectiveness would be defeating the purpose of evaluating service

provision as few lessons can be learnt to promote development. Given the movement towards qualitative research is growing this avenue proved exceptional in providing a deeper understanding of the experiences of both patients and clinicians and areas for improvement. Seemingly a supporter for the misunderstood and underrepresented, my choice of TA as a method of analysis is fitting as it is also an area needing further research and acknowledgment despite it being a basis for almost all qualitative methods (Braun et al., 2006).

Over the course of preparing this thesis I noticed the development in my writing style becoming more concise and refined with the ability to incorporate the critical stance in a more seamless way. I also discovered a great deal of satisfaction in the process of writing and imparting my thoughts and ideas. During the doctoral journey, life circumstances resulted in needing to have a break from study. Furthermore due to family responsibilities I decided to resign from my post. However I was able to continue my research with an honorary contract and although initially the bureaucratic process presented difficulties and delays, it also provided me with a new perspective on the service. I am fortunate to able to continue to work with patients with BDD as an independent CBT practitioner and continue to have links with the service. Interestingly having separated from the service provided me with a different perspective which gave more credence to the critical stance taken in the study.

Throughout this doctoral journey, supervision was the anchor that helped me stay on track and overcome setbacks. I found the doctoral path a lonely one with the isolation of distance learning providing little opportunity in later stages to engage in sharing of ideas and concerns or stimulating debates. However I also realised my passion for the subject and my resilience in the face of difficult personal life events and changes in my professional identity. Finally I am proud of all I have achieved and look forward to building on the foundations I have established.

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# **APPENDICES**

# Appendix A: Diagnostic Criteria for Body Dysmorphic Disorder (ICD 11, WHO 2018)

### 6B21 Body dysmorphic disorder

## **Description**

Body Dysmorphic Disorder is characterized by persistent preoccupation with one or more perceived defects or flaws in appearance that are either unnoticeable or only slightly noticeable to others. Individuals experience excessive self-consciousness, often with ideas of reference (i.e., the conviction that people are taking notice, judging, or talking about the perceived defect or flaw). In response to their preoccupation, individuals engage in repetitive and excessive behaviours that include repeated examination of the appearance or severity of the perceived defect or flaw, excessive attempts to camouflage or alter the perceived defect, or marked avoidance of social situations or triggers that increase distress about the perceived defect or flaw. The symptoms are sufficiently severe to result in significant distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning.

#### **Exclusions**

- Anorexia Nervosa (6B80)
- Bodily distress disorder (6C20)
- Concern about body appearance (QD30-QD3Z)

# Appendix B: Diagnostic Criteria for Body Dysmorphic Disorder

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(American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders (DSM-5®), American Psychiatric Publishing, 2013).

# Appendix C: Recommended questions to identify individuals with BDD symptoms (NICE, 2006: 10.4.2.2, pg. 230)

- Do you worry a lot about the way you look and wish you could think about it less?
- What specific concerns do you have about your appearance?
- On a typical day, how many hours a day is your appearance on your mind?
   (More than 1 hour a day is considered excessive)
- What effect does it have on your life?
- Does it make it hard to do your work or be with friends?

## Appendix D: Overview of the literature search

# DATA BASES

Pubmed Refseek

Psychlnfo Academic Index

Science Direct iSeek

Medline Biclefeld Academic S Eng

Researchgate SSRN
EBSCO host Scopus
The Cochrane Library SciELO
The British Library Embase



#### SEARCH TERMS

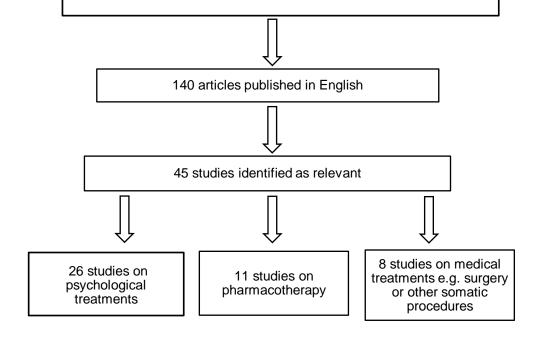
Body dysmorphic disorder, dysmorphophobia, body image disorder, muscle dysmorphia, somatoform disorder, BDD.

Psychological treatments for BDD, cognitive behavioural/behavioral therapy, psychotherapy, EMDR, cognitive therapy, behavioural/behavioral therapy, psychoanalysis, psychodynamic therapy, CBT, CT, BT, Internet, computerised treatment.

Pharmacological treatments for BDD, medication for BDD, SSRI, antipsychotics, dopamine blockades, SNRIs, MAOIs, augmentation for BDD.

Medical treatment of BDD, physical interventions for BDD, somatic treatment for BDD.

Cosmetic surgery for BDD, aesthetic procedures for BDD.



# Appendix E: Psychological treatment of patients with BDD

First Author and year	Intervention	Sample (n)	Gender	Age	Design	Measures	Outcomes
1. Bloch, et al. (1988)	Psychodynamic therapy. Once weekly sessions for 20 months.	1	Female	20	Case study	None reported	According to the authors the patient showed some improvement in her functioning.
2. Rosen, et al. (1989)	CBT in groups; Minimal treatment control group Six 2 hour sessions	23	Females only	M=19 SD=1.15	RCT	-Body Shape Questionnaire -Bulimia Test (BULIT) -Body Dissatisfaction Scale of the Eating Disorders Inventory -Body image behavior questionnaire	Improvements were shown in all aspects of body image perception for the CBT group: size overestimation, p=0.004; Body Shape Questionnaire, p=0.005; Body Dissatisfaction Scale, p=0.009; and reports of behavioral avoidance, p< 0.0001.
3. Watts (1990)	Behavioural and interpretive intervention 36 sessions	1	Male	20	Case study	None reported	Behavioral therapy produced some improvement with further progress using interpretive methods. This allowed for more behavioural work to be done and additional improvement.
4. Neziroglu, et al. (1993)	Exposure and response prevention (ERP) and Cognitive therapy	(5) 4 completed	2 Males, 3 Females	16-33 M=24.6	Case series	-Overvalued Ideation Scale (OVI) -Modified Yale Brown Obsessive Compulsive Scale (BDD-YBOCS) for BDD	Four patients showed improvement, one patient disengaged. One patient had 12 weeks intensive treatment, showing the most improvement at follow up. Four patients showed at least a 2 point drop in the OVI post treatment.
5. Gomez-Perez et al., (1994)	Behaviour therapy (ERP) M= 14 hours of therapy over M=13 weeks.	(30) 21 completed	15 males, 15 females	M=26	Retrospective case series	-Main problem severity -Fear Questionnaire (FQ) -Work adjustment and Social adjustment - Intensity of belief in a body defect	Nine patients (43%) showed much improvement in the main problem severity with six (28%) slightly improved and six (28%) showing no improvement. Follow up at 1-3 months (N=17): nine patients were much improved with six slightly improved and two with no improvement. At 6-12 months follow up (N=10): eight (80%) patients showed much improvement and two (20%) slight improvement.

(Appendix E contd.) 6. Rosen, et al. (1995)	Group CBT Eight 2 hour sessions	54	Females only	20-61 (M=36.5, SD=9.5)	RCT	- Semi-structured interview Body Dysmorphic Disorder Examination (BDDE) - Body Shape Questionnaire - Multidimensional Body Self- Relations Questionnaire (MBSRQ) - Appearance Evaluation scale - Brief Symptom Inventory - Rosenberg Self-Esteem Scale.	Out of 27 subjects in the CBT treatment group 22 (81.5%) showed clinical improvement at post treatment and 20 at four and a half months follow-up compared to the no treatment control. The main effect for the treatment group was significant: F=20.01, p = 0.000. MANOVA indicated: Significant improvement over time in treatment group from baseline to post treatment and follow-up: p=0.000.
7. Veale, et al. (1996)	Individual CBT 12 weeks (12 sessions)	19	17 Females 2 Males	M=36.7, SD=13.7	RCT	<ul> <li>Semi-structured interview BDDE</li> <li>BDD-YBOCS</li> <li>MADRS</li> <li>Social phobia and anxiety inventory</li> <li>Hospital Anxiety and Depression Inventory</li> <li>Derriford Scales</li> </ul>	Seven out of nine in treatment group no or subclinical BDD symptoms at end of treatment. Participants showed a 50% reduction in symptoms on main outcome measure (YBOCS-BDD). All subjects on waiting list showed clinical level of BDD symptoms throughout.
8. Neziroglu et al. (1996)	CBT (Daily 90min sessions over 4 weeks= 20 sessions)	17	10 females 7 males	15 to 45 (M=25.1, SD=10.3)	Prospective cohort study.	-Structured Clinical Interview for DSM-III-R Personality Disorders (SCID-II) -BDD-YBOCS.	70.6% (n=12) showed an improvement of more than 50%. Significant difference on BDD-YBOCS across all subjects from pre to post treatment t=6.40, p < 0.001.
9. McKay et al. (1997)	Exposure and response prevention (behavioural therapy) and maintenance. 6 weeks, 5 sessions per week, 90 minutes.	10	4 males 6 females	21-45 (M= 31.2, SD=4.7)	Prospective cohort study. Following treatment subjects randomly assigned to maintenance program or control.	-Structured Clinical Interview for DSM-III-R (SCID) -Behavioral Avoidance Test (BAT)BDD-YBOCSBeck Depression Inventory (BDI)Beck Anxiety Inventory (BAI).	All participants showed improvements on all measures: BDD-YBOCS: t = 5.48, p < 0.001, BAT: t= 7.12, p < 0.001, BDI: t= 4.12, p < 0.01 and BAI:t = 2.76, p < 0.05. All patients remained BDD symptom free at 6 month follow up although control group had higher levels of anxiety and depression than the maintenance group.
10. Brown et al. (1997)	Eye Movement Desensitization and Reprocessing (EMDR)	7	5 females 2 males	From adolescence to forties. Not specified	Case series	Defined by Diagnostic and Statistical Manual of Mental Disorders 4th Edition, (DSM- IV) Specific measure not stated.	Improvement reported in six out of seven cases.

(Appendix E contd.) 11. Wilhelm et al. (1999)	Group CBT, 12 weekly, 90 minutes. Three patients also seen individually.	(13) 11 completed	10 females, 3 males	18-48 (M=30.62 SD=10.95)	Case series	- SCID. -BDD-YBOCS. - BDI.	Significant reductions in BDD symptoms overall. BDD-YBOCS: reduction of M=9.6 points on the BDD-YBOCS and M=11.3 points on the BDI. t=3.94, p<0.01. Results remained significant when three patients receiving additional individual therapy were removed: BDD-YBOCS: t=3.58, p<0.01. Depression scores showed improvement.
12. Geremia et al. (2001)	Cognitive Therapy (CT)	4	2 males and 2 females	25-35 (M=31.5, SD = 4.5)	Single subject multiple baseline design	-BDDE -BDD-YBOCS. - BDI. -BSS -OVI -BAI	One discontinued therapy. Three showed decreased BDD symptomatology with significant difference from baseline to post-treatment ( $p < 0.05$ ). The difference from baseline to follow-up was also significant ( $p < 0.05$ ).
13. Rabinowitz et al. (2007)	Exposure and response prevention (behavioural therapy)	1	male	23	Case study	-BDD-YBOCS. - BDI.	Baseline score on BDD-YBOCS= 32, severe level. After treatment reduced to 20, moderate level. BDI scores also decreased from 48 (severe symptoms) to 19 (mild symptoms).
14. Weingarden et al. (2011)	Culturally adapted CBT. 22 individual sessions	2	2 males	30 and 40	Case studies	- SCID -BDD-YBOCS -Clinical Global Impression Scale (CGI) - BDI-II -The Brown Assessment of Beliefs Scale (BABS)	One improved to having no BDD symptoms and the other improved to subclinical symptoms on BDD-YBOCS.
15. Khemlani- Patel et al. (2011)	CBT for BDD- comparison of CT versus Behaviour therapy (BT) and CBT vs BT. Individual therapy 12 sessions CT 12 sessions BT Total of 24 sessions three times per week for 90 minutes.	(17) 10 completed	7 males and 3 females	M=32.40, SD= 10.52	Prospective cohort study. Group 1 CT and CBT. Group 2 BT.	-BDDE -SCID -BDD-YBOCS -Quality of Life Inventory (QOLI) -Social Avoidance and Distress Scale -Defect Related Beliefs Test -The University of Rhode Island Change Index -OVI -BSS - BDI-II - BAI	Results for CT vs BT indicate that all participants improved significantly on Y-BOCS BDD: [F(1,8) = 14.028, p = 0.006]. CBT vs BT showed significant gains on BDD symptoms overall: [F(1,8) = 16.846, p =0.003]. Improvements were found regardless of whether treatment was CT, BT or CBT. Improvement of CT/ CBT group from baseline to post treatment on YBOCSBDD was 48% (M= 13.6) and 37% (M=10.6) for BT group.

(Appendix E contd.)							
16. Wilhelm et al. (2011)	CBT- 18 or 22 individual therapy sessions of 60minutes, twice weekly for 4 weeks then once weekly.	12	7 females 5 males	M= 32.2 SD=4.6	Prospective cohort study. Random assignment to 18 or 22 session groups. Intention to treat analysis	- SCID - BDD-YBOCS - CGI - BDI-II - BABS - Client Satisfaction Inventory (CSI)	Those completing treatment (n=10) showed mean percentage decrease of 53% on BDD-YBOCS with significant difference from baseline: t =6.08, p <0.001. The significance was maintained for intention to treat: mean reduction of 47.1% on BDD-YBOCS: t =5.41, p <0.001 CGI. Nine provided follow up data at 3 and 6 months which showed improvements to be maintained. According to the CGI 80% of the completers remained stable.
17. Rabiei et al. (2012)	Metacognitive Therapy 8 weekly individual sessions	20	18 females, 2 males	16 -37 (M = 25.2, SD =6.5)	RCT waiting list control	Defined by Diagnostic and Statistical Manual of Mental Disorders 4th Edition, (DSM-IV) Specific measure not stated.     -BDD-YBOCS     -Thought Fusion Instrument (TFI)     -Patients' satisfaction	Post treatment 70% of sample scored 20 or under (mild to subclinical symptoms) on YBOCS BDD. All the patients in the wait-list control group remained at clinical levels. At follow-up, it was 60% in the treatment group with mild to subclinical symptoms and no change in the control group.
18. Taillon, et al., (2013)	Inference based therapy 20 weekly one hour sessions	(13) 10 completed	Not reported	20-54 (M=34.1 SD=9.1)	Open label, uncontrolled clinical trial	-BDD-YBOCS - BDI-II - BAI - OVI - Inferential Confusion Questionnaire - Expanded Version (ICQ-EV)	The post treatment score showed M= 13.4 (p<0.001) improvement of BDD symptoms. Significant reduction in depressive symptoms and overvalued ideation. There was no significant change in the BAI and ICQ.
19. Veale, et al., (2014)	CBT vs anxiety management (AM) 12 weeks	(46) 39 completed	19 males 27 females	25.0-36.5 M=30.0	Single blind RCT	-BDD-YBOCS - CGI - BABS - MADRS - Appearance Anxiety Inventory (AAI) - Patient Health Questionnaire (PHQ) - Generalised Anxiety Disorder-7 (GAD-7) - Body Image Quality of Life Inventory (BIQLI)	CBT significantly better than AM at 12 weeks on BDD symptoms. At 12 weeks 48% in the CBT group were responders with an increase to 52% at 16 weeks and maintained at 1 month follow up. The AM group showed 12% responders at 12 weeks and this was maintained at 1 month follow up.

(Appendix E contd.) 20. Wilhelm, et al., (2013)	Modular CBT (CBT-BDD) or 12 week waitlist control	(36) 29 completed	61% female, 39% male	M=34.8	RCT	-SCID-I/P - SCIDII - BDD-YBOCS - BABS - BDI-II - Sheehan Disability Scale (SDS) -CSI	17 randomised to CBT-BDD, and 19 randomised to waitlist. By week 12, CBT-BDD participants showed 50% were responders, compared to 12% of participants on waitlist (p = 0.026).
21. Linde, et al., (2015)	Acceptance based exposure therapy 12 weeks group and 8 weekly individual sessions.	(21) 19 completed	13 females, 8 males	18-44 M=27.3	Prospective cohort study	-BDD-YBOCS -SDS - MADRS -Quality of life Inventory (QOLI) -Acceptance and Action Questionnaire (AAQ-II) -Credibility Scale	At post treatment 68% of completers showed a significant improvement in BDD symptoms.
22. Willson, et al., (2015)	Imagery rescripting Single session	6	4 females, 2 males	19-35 M=25.6	Single case experimental deisgn	- SCID - BDD-YBOCS - BDI	Four participants showed clinically significant improvement in BDD symptoms. At 6 month follow up the overall improvement for the four responders ranged from 57%-81% reduction in scores on the BDD-YBOCS. Two non-responders showed none to minimal improvement.
23. Ritter et al. (2016)	Imagery rescripting	6	5 females, 1 male	18-48 M=29.5	Case series	- SCID - Body dysmorphic disorder diagnostic module (BDDDM) - BDD-YBOCS -Body dysmorphic symptoms inventory (FKS: Fragebogen korperdysmorpher symptom) - BDI-II -Semi-structured interview	Four participants were responders. The whole group showed a significant decrease in BDD symptoms of 19% after imagery rescripting. Treatment responders showed a decrease in BDD symptoms of 24% post treatment (p<0.001). There was a further 12% reduction at follow up showing a significant improvement from baseline to follow up (p<0.001).

(Appendix E contd.) 24. Enander et al. (2014)	Internet based CBT 12 weeks	(23) 22 completed	16 females, 7 males	M=30.3	Uncontrolled clinical trial	- BDD-YBOCS - CGI - Global Assessment of Functioning (GAF) - Body Dysmorphic Dimensional Scale (BDD-D) - Montgomery-Åsberg Depression Rating Scale, self-report (MADRS-S) - Skin Picking Scale Revised (SPS-R) - BIQLI	Using ≥30% decrease on the BDD-YBOCS as a response rating, 82% of completers were responders post treatment. The mean decrease from baseline to post treatment was 51%.
25. Summers, et al. (2016)	Computerised Treatment Modifying interpretation bias	(40) 38 completed	30 females, 8 males.	M=19.79	Randomised Trial	- BDD-YBOCS - SCID - Depression Anxiety Stress Scales (DASS -21) - Word Sentence Association Paradigm (WSAP)	IBM group indicated a 35% improvement on BDD symptoms whilst the placebo control group showed a 20% improvement. Depression and anxiety measures indicated minimal changes for both groups.
26. Gentile, et al (2019)	Internet based CBT 12 weeks global	(32) 25 completed			Uncontrolled clinical trial	- MADRS-S - BDDQ; - Dysmorphic Concerns Questionnaire (DCQ) - Alcohol Use Disorders Identification Test (AUDIT) -Drug Use Disorders Identification Test (DUDIT) - BDD-YBOCS - Columbia Suicide Severity Rating Scale (C-SSRS) - BABS - CGI-S - GAF - SCID for OCD & related disorders - Mini-International Neuropsychiatric Interview	Improvement baseline to week 6 p<0.001. Further improvements were seen at post-treatment p<0.001. Maintained at 3 months follow up. Significant improvement in depressive symptoms.

# Appendix F: Pharmacotherapy for patients diagnosed with BDD

First Author and	Intervention	Sample (n)	Gender	Age	Design	Measures	Outcomes
1. Hollander et al., (1999)	Length of trial: 16 weeks Clomipramine vs Desipramine (SRI) (Clomipramine) Dose M= 138mg/day (SD=87) (Desipramine) Dose M= 147mg/day (SD= 80)	(40) 18 completed	23 males, 17 females	18-65 (M=34.5)	RCT, double blind crossover, 16 weeks	- Structured Clinical Interview for DSM-IV (SCID) - Y-BOCSBDD - National Institute of Mental Health Global Obsessive-Compulsive Scale (BDD-NIMH) - Clinical Global Impression scale (CGI) adapted for BDD - Hamilton Depression Rating Scale (HAM-D) - Social Avoidance and Distress Scale - Fear of Negative Evaluation Scale - Fixity of Beliefs Questionnaire modified for BDD - Schneier Disability Scale	Both medications showed an improvement in symptoms but Clomipramine treatment resulted in significantly greater reduction on Y-BOCSBDD: M=16.2 (SD 8.5) than Desipramine treatment: M= 20.7 (SD 7.7) p = 0.003. Clomipramine had a response rate of 65% compared to 35% for Desipramine.
2. Phillips et al., (1996a)	Length of trial: 8 weeks. Buspirone	13	6 males, 7 females	21-47 (M=31.9)	Open label trial	-SCID -CGI -Semi-structured interviews	Six (46%) patients improved. Three reduced dosage or stopped taking Buspirone resulting in increased symptom severity. One resumed the higher dose and improved again. Response time was M=6.4 weeks (range 5-9 weeks)
3. Phillips et al., (2002)	Length of trial: 12 weeks. Fluoxetine Dosage from 40 to 80 mg a day	(67) 60 completed	46 females and 21 males	18-65 M=32.1	RCT placebo control	-Y-BOCSBDD -CGI - BABS - BDD Diagnostic Module based on DSM-IV criteria - SCID-P - BDD Form Semi-structured instrument for clinical characteristics of BDD (unpublished Phillips, 1992) - Electrocardiogram (ECG), Physical examination and standard blood tests and drug screening.	Fluoxetine was significantly more effective than placebo on the Y-BOCSBDD after 12 weeks of treatment. The baseline for the fluoxetine group was M= 31.5 (SD= 5.6) reducing to M=21.0 (SD=9.8) at 12 weeks, which represented a 33% reduction on the main outcome measure.18 (53%) of subjects responded to fluoxetine compared to 6 (18%) response to placebo.
						9	274

(Appendix F contd.) 4. Amâncio et al., (2002)	Length of trial: 6 months. Venlafaxine	1	Female	39	Case study	None	Patient was reported to be asymptomatic 30 days after starting Venlafaxine 75mg twice daily. Followup at six months showed the patient to remain asymptomatic.
5. Phillips et al., (2003)	Length of trial: 12 weeks. Citalopram	15	73.3% females, 26.7% Males	M=29.3, (SD=11.9)	Case series	- YBOCS BDD -CGI -BABS -Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) - Global Assessment of Functioning (GAF)	73.3% (N=11) of subjects responded to treatment. The YBOCSBDD showed an improvement of M=15.4 from baseline to completion. The CGI, showed 40% (N=6) of subjects were very much improved, and 26.7% (N=4) were much improved. There was also significant improvement in psychosocial functioning and mental health-related quality of life.
6. Phillips, (2005a)	Length of trial: 8 weeks. Pimozide Dose at endpoint: M=1.7mg/day (SD=1.0) Equivalent dose for placebo: M=5.0mg/day (SD=3.4)	28	Not reported	M=17.7	RCT placebo- controlled, double-blind, parallel-group	-Y-BOCSBDD -CGI -HAM-D -SCID -Brief Psychiatric Rating Scale	Pimozide was not more efficacious than placebo for body dysmorphic disorder severity or on any other measure. Out of 11 subjects, two (18.2%) responded to Pimozide and three (17.6%) in the placebo group (n=17) were responders.
7. Phillips, (2005b)	Length of trial: 8 weeks. Olanzapine Dose at endpoint: M=4.6 mg/day (SD=3.3) Range: 2.5-15mg/day	6	3 females, 3 males	M=29.3 (SD=11.9)	Open label trial	-Y-BOCSBDD -CGI	Olanzapine showed minimal improvement of BDD symptoms on the CGI in two patients and unchanged in four.
8. Phillips, (2006)	Length of trial: 12 weeks Escitalopram Dose: M= 28mg/day (SD=6.5) Range 10-30mg/day	(15) 14 completed	7 females, 8 males	18–65 M= 37.6 (SD= 8.8)	Open label trial	-Y-BOCSBDD -CGI -HAM-D -SCID -BABS -Global Assessment of Functioning	On intention to treat analysis 73% (n=11) of subjects were responders. Y-BOCSBDD $F = 15.9 < 0.001$ .

						(GAF) -Social and Occupational Functioning Assessment Scale - Longitudinal Interval Follow-up Evaluation (LIFE) - Short Form Heath Survey -Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q)	
9. Allen, et al., (2008)	Length of trial:12-16 weeks Venlafaxine (SNRI) dose: minimum of 150mg/day and maximum of 225mg/day maintained at this dose for 8 weeks.	(17) 11 completed	2 males, 15 females	20-50 (M= 29.7)	Open label trial	-Y-BOCSBDD -CGI - BABS -Overvalued Idea Scale -Schneier Disability ScaleBody Dysmorphic Disorder Examination Self Report (BDDE-SR) - BDI-II - BAI	64% response rate. Y-BOCSBDD score reduced by ≥33% (n=5).
10. Rashid, et al., (2015)	Length of trial: varied. Adjunctive antipsychotic: Quetiapine, (n=7) Aripiprazole, (n=6) Risperidone, (n=6) Olanzapine, (n=1) Amisulpride. (n=1)	(32) 18 responders	males 34%, females 66%	Not reported	Retrospective Case note study	-Y-BOCSBDD	Group 1: n=11 no antipsychotics given. Five patients (45%) improved, five disengaged and one showed no response. Group 2: antipsychotics given (n=21) 13 (62%) improved. Two disengaged, six did not show response.
11. Phillips, et al., (2016)	Escitalopram vs Placebo Phase 1: Length of trial: 14 weeks Escitalopram  Phase 2: Length of trial: 6 months Escitalopram or placebo	N=100 Phase 1 N=100 74 completed Phase 2 N= 58	Phase 1 64 females, 36 males Phase 2 40 females, 18 males	Total group M= 33.5	RCT Phase 1:open label trial  Phase 2: double blind placebo controlled trial	-Y-BOCSBDD -CGI -BABS -Quality of Life Enjoyment and Satisfaction Questionnaire (Q- LES-Q) -HAM-D -Range of Impaired Functioning Tool -Psychiatric Status Rating Scale for BDD	Phase 1: 81.1% improvement on BDD symptoms for 74 completers. $p$ <0.0001 on Y-BOCSBDD, BABS, Q-LES-Q, HAM-D, Impaired Functioning Tool.  Phase 2 outcome for 28 subjects randomised to continuing escitalopram, showed further significant improvement on Y-BOCSBDD with M=4.1 points reduction on scores ( $p$ <0.036).  Relapse rates: escitalopram treated group 18% by end of 6 months compared with relapse rate of 40% for placebo group ( $p$ =0.049).

# Appendix G:

# **Medical interventions in BDD\***

First Author and year	Intervention	Sample (n)	Gender	Age	Design	Measures	Reported Outcomes
1.Veale, (2000)	Cosmetic surgery and "DIY" surgery	29 Non-BDD n=23 BDD n= 6	88% female, 12% male	22-63 (M= 36)	Retrospective cohort study	No measures reported	Satisfaction with surgery n= 6. DIY surgery n= 9. All dissatisfied.
2.Phillips, et al., (2001)	Cosmetic surgery and MI procedures	289 with BDD 250 adults 39 adolescents /children	Adults: 131 females, 119 males. Adolescents 34 females, 5 males.	18-80 M=33.0 (SD=10.3) 6-17 M=14.7 (SD=2.5)	Retrospective cohort study	-Y-BOCSBDD -SCID -BABS -Schedule for Affective Disorders and Schizophrenia for School- Age Children-Present and Lifetime Version (K- SADS-PL):	66% (n=165) received cosmetic procedures. 484 treatments received. No change in BDD symptoms in 326 (72%) of treatments received. 68.7% (46) of treatments showed no improvement or worsening of BDD symptoms. Children/adolescents: 56.3% (n=9) received procedure. No changes in BDD severity or preoccupation/
3.Veale, et al., (2003)	Rhinoplasty	29 subjects 23: non-BDD 6: 'possible BDD'	22 females, 7 males	M=38 (SD= 12.77)	Retrospective cohort study	-Body Dysmorphic Disorder Questionnaire (BDDQ) -Hospital Anxiety and Depression Scale (HADS) Y-BOCSBDD -Nose imperfection was rated by the patient on an 8-point scale -Patient satisfaction questionnaire -Rhinoplasty Questionnaire	Follow up post-surgery: 3 months n=2 'possible BDD'. 9 months n= 0 rated as 'possible BDD'.

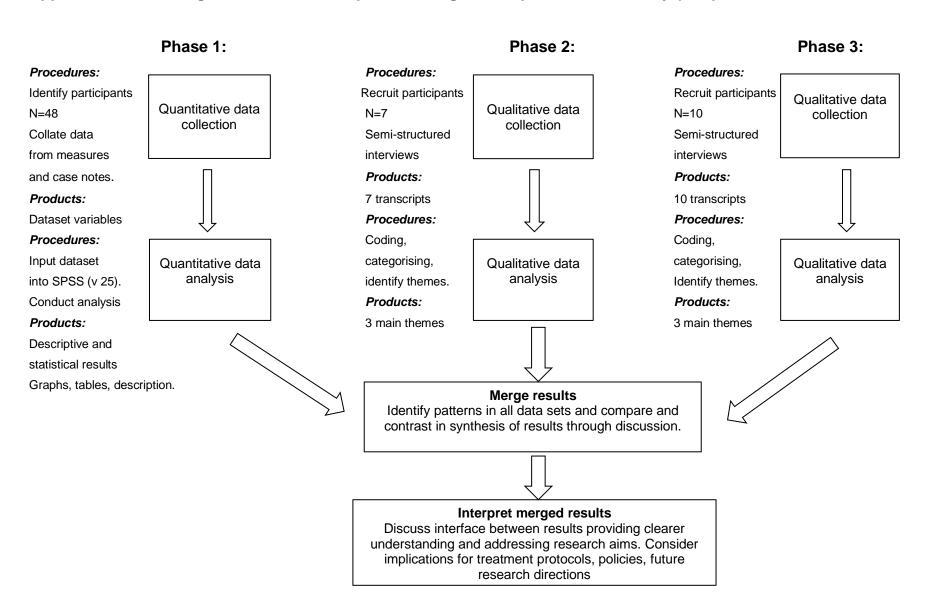
(Appendix G contd.) 4.Crerand, et al., (2005)	Dermatology, cosmetic surgery	200 BDD	68.5% female, 31.5% male	14-64 M=32.6 (SD=12.1)	Retrospective cohort study	-BDD Form -CGI -SCID-DSMIV -BDD-YBOCS -BABS -Medical outcomes study -Quality of life enjoyment and satisfaction Questionnaire -Social adjustment Scale self-report	N=128 patients underwent nonpsychiatric medical treatment. 91.0% showed no improvement in BDD symptoms. 3.6% showed improvement and 5.4% indicated worsening of BDD symptoms. Four subjects (2.0%) reported the medical treatment triggered the onset of BDD.
5.Tignol et al., (2007)	Cosmetic surgery	(30) 24 followed up 10 BDD 14 non-BDD	10 BDD: 8 female, 2 male 14 non-BDD: 13 female, 1 male	BDD: M=42.5 (SD = 11.6). Non-BDD: M=51.9 (SD = 7.6).	Prospective cohort study	-SCID-BDD Module -Sheehan Disability Scale (SDS) -MINI International Neuropsychiatric Interview (M.I.N.I.)	N=7 BDD patients underwent cosmetic surgery. Follow up n=6 remained at clinical range of BDD. N=8 of the 14 non-BDD underwent cosmetic surgery. Follow up n=3 met diagnosis for BDD.
6.Crerand, et al., (2010)	Dermatology, cosmetic surgery	200	137 females, 63 males	M= 32.61	Retrospective naturalistic, cohort study, cross- sectional.	BDD Form CGI SCID-NP BDD-YBOCS BABS	N=87 procedures Long term: Y-BOCSBDD: surgery received (n=42): M=24.7(SD=11.1). Not received (n=158): M=28.4 (SD=9.7) Short term improvement= 43.4% (n=37) Long term = 2.3% (n=2) Long term, no change or worse: 97.7% (n=85). Non-surgical/MI procedures: Long term = 4.0% (n=13)
7.Rapinesi, et al., (2013)	Electroconvulsive therapy (ECT) 6 sessions ECT over 2 weeks. Average length of seizures was 62 seconds. Seizures > 25 seconds was defined as a therapeutic level.	1	Male	24	Case report	No measures reported	The patient's mood, anxiety symptoms and delusional symptoms improved. At six months follow up patient not preoccupied with perceived flaws.

8.Felix, et al., (2014)	Rhinoplasty	31	All female	M=31.7, SD=10.0	Prospective cohort study	-Body Dysmorphic Disorder Examination (BDDE)
----------------------------	-------------	----	------------	-----------------	--------------------------	--

25 (80.6%) of the sample showed complete remission of the BDD symptoms at 1 year follow up with 28 (90.3%) reporting satisfaction with the rhinoplasty results.

<sup>\*</sup>All participants were diagnosed with BDD unless stated otherwise.

# Appendix H: A convergent mixed methods parallel design of the phases of the study (Adapted from Creswell, et al., 2011).



# Appendix I: University ethics approval

RE: Ethics form resubmission

Fri 05/02/2016 12:34

Dear Anusha

Thank you for your amended documents and information/confirmation of service evaluation. I can confirm you are able to proceed with your project and wish you every success.

Please note if any changes to the study described in the application or to the supporting documentation is necessary you are required to make a resubmission to the College of Health and Social Care Research Ethics Committee.

Also, for the committee's records, can you please notify the secretary when your study has been completed.

Yours sincerely,

Lorraine Henshaw

Chair College of Health and Social Care Research Ethics Committee College of Health and Social Care University of Derby Kedleston Road Derby DE22 1GB

01332 591776

# Appendix J: Organisation registration of study and ethics approval

Wed 21/10/2015 14:55

Registration of Study

Dear Anusha

Thank you for registering your audit\* which has been approved by your supervisor.

Please send me the audit tool you intend to use before starting to collect any data. This is to ensure that there is no duplication of work or missed opportunities for joint projects.

Please note it is important you have a consultant/ team manager to supervise the audit so they can ensure that any recommendations from the audit can be turned into actions and I am pleased that Dr. Lynne Drummond has agreed to supervise this project.

Please ensure you send me the audit report, along with any action plans once the audit has been completed. This should include a date for re-audit and details of where the audit report has been discussed (ie local team meeting). An audit report template is available on InSite <a href="http://insite.xswlstg-tr.nhs.uk/Clinical/ClinicalGovernance/Pages/Clinical-Audit-Resources.aspx">http://insite.xswlstg-tr.nhs.uk/ClinicalGovernance/Pages/Clinical-Audit-Resources.aspx</a> I will then be happy to send you a Certificate of Completion.

Thanks for your interest. Good luck!

Kind Regards,

Maggie

Clinical Effectiveness Manager and Quality Improvement

T: 020 3513 5881 M: 07739322275 F: 0208 772 5519

E: Maggie.Conway@swlstg-tr.nhs.uk

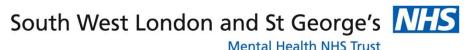
A: Quality Governance

South West London and St George's Mental Health NHS Trust Ground Floor, West Wing, Building 15, Springfield University Hospital 61 Glenburnie Road, London SW17 7DJ

<sup>\*</sup>Wording explained 3.17, pg. 107

#### Appendix K: Information sheet for patient participants





NATIONAL and TRUSTWIDE OCD and BDD SERVICES

MORRISON BUILDING 9E

SPRINGFIELD UNIVERSITY HOSPITAL

61 GLENBURNIE ROAD

LONDON

SW17 7DJ

Telephone: 020 3513 6961

Fax: 020 3513 6965

Out of Hours Crisis Line:0800 028 8000

Dear

#### **INFORMATION SHEET FOR PARTICIPANTS (Patients)**

Service Evaluation Title: An evaluation of a specialist service model for treating Body Dysmorphic Disorder (BDD): application of the National Institute for Health and Clinical Excellence (NICE, 2006) Guidelines for BDD.

#### Invitation and brief summary

I would like to invite you to be involved in this service evaluation which is part fulfilment of my Doctorate. Before you decide whether you want to take part, it is important for you to understand why the service evaluation is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if anything is unclear or if you would like more information. Thank you for reading this.

#### What is the purpose of the service evaluation?

This service evaluation is to evaluate treatments and obtain patients' experiences of treatments received in this specialist service for Body Dysmorphic Disorder. The research into treatments for BDD is limited and this service evaluation aims to contribute towards the understanding of what treatments patients find most beneficial.

#### What will participation involve?

As you are aware the data from the questionnaires you have completed during the course of your treatment is stored anonymously on our database. This information will be used to evaluate the treatment we have provided and help us to make changes where needed so that we can provide the best service possible to our patients. All information is anonymised, pseudonyms will be used if quotes are reported and no identifiable details will be presented in the report.

In addition you will be invited to participate in an interview which will comprise of seven questions and will take between 30-40 minutes. It is intended as an opportunity for you to express your views on the treatments you have received for BDD and what your experience has been. The interview will be audio recorded to ensure the accuracy of the data.

#### Benefits/ Risks

Although the service evaluation may not have any direct benefit for you, the information you provide will be used to help improve the services for treating patients suffering from BDD. It will also be useful with providing help to people in the early stages of the disorder to prevent their condition becoming worse.

If during the course of the interview, you become distressed for any reason, the interview will be stopped. You will be given time to discuss your concerns or upset and your therapist will be available if you wish to discuss this further with them.

You will be asked if you wish for your GP or other health care professional to be contacted. You will be asked if you still wish to have your responses included in the service evaluation or if there is any information you do not want to be used.

If you have any queries regarding your current treatment you will need to direct these to the professionals involved in your care.

#### Confidentiality

All information you provide will be held in confidence within the limitations of the investigator's professional duty of care.

As part of the presentation of results, your own words may be used in text form in publication. This will be anonymised, so that you cannot be identified from what you said.

All of the service evaluation data including audio recordings will be stored in electronic format on a secure IT system in keeping with the Data Protection Act (1998) and the Trust's data protection policy at South West London and St George's Trust OCD/BDD Service for 2 years and will then be securely destroyed.

#### Please note that:

- You need not answer questions that you do not wish to.
- All the information will be anonymised. It should not be possible to identify anyone from my reports on this service evaluation.

It is your choice whether to take part or not. If you decide to take part you are still free to withdraw up to when the data is analysed which will be 3 months after your interview. You can contact me by emailing or by telephone and withdraw without giving a reason and without prejudice. If you withdraw from the service evaluation all data will be withdrawn and destroyed. If you decide to take part please keep this information sheet and sign and return the consent forms in the envelope provided.

Thank you for your time.

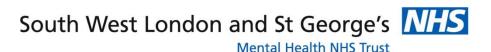
Anusha Govender Cognitive Behavioural Psychotherapist Doctoral Student in Health and Social Care Practice

(email:A.Govender1@unimail.derby.ac.uk)

Version 2 13/12/15

## **Appendix L: Information sheet for clinician participants**





NATIONAL and TRUSTWIDE OCD and BDD SERVICES
MORRISON BUILDING 9E
SPRINGFIELD UNIVERSITY HOSPITAL
61 GLENBURNIE ROAD
LONDON
SW17 7DJ

Telephone: 020 3513 6961

Fax: 020 3513 6965

Out of Hours Crisis Line:0800 028 8000

Dear

#### **INFORMATION SHEET FOR PARTICIPANTS (Clinicians)**

Service Evaluation Title: An evaluation of a specialist service model for treating Body Dysmorphic Disorder (BDD): application of the National Institute for Health and Clinical Excellence (NICE, 2006) Guidelines for BDD.

#### **Invitation and brief summary**

I would like to invite you to be involved in this service evaluation which is part fulfilment of my Doctorate. Before you decide whether you want to take part, it is important for you to understand why the service evaluation is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if anything is unclear or if you would like more information. Thank you for reading this.

### What is the purpose of the service evaluation?

This service evaluation is to obtain clinicians' (psychotherapists, psychiatrists and occupational therapists) views of implementing the NICE recommended treatments in this specialist service for Body Dysmorphic Disorder. The research into treatments for BDD is limited and this service evaluation aims to contribute towards the understanding of what treatments are most efficacious. This service evaluation will also obtain patients' experiences of treatments received in this service for BDD.

#### What will participation involve?

Participating in a semi-structured interview which will comprise of seven questions and will take between 30-40 minutes. It is intended as an opportunity for you to express your views on the treatments you have provided for BDD and what contributions it may have to your service. All information is anonymised, pseudonyms will be used if quotes are reported and no identifiable details will be presented in the report.

If you have any queries outside of the service evaluation remit you will be directed to your line manager or supervisor.

#### Confidentiality

All information you provide will be held in confidence within the limitations of the investigator's professional duty of care.

As part of the presentation of results, your own words may be used in text form. This will be anonymised, so that you cannot be identified from what you said. The interview will be audio recorded to ensure the accuracy of the data.

All of the service evaluation data will be stored in electronic format on a secure IT system in keeping with the Data Protection Act (1998) and the Trust's data protection policy at South West London and St George's Trust OCD/BDD Service for 2 years and will then be securely destroyed. Please note that:

- You need not answer questions that you do not wish to
- Your name will be removed from the information and anonymised. It should not be possible to identify anyone from my reports on this service evaluation.

It is your choice whether to take part or not. If you decide to take part you are still free to withdraw up to when the data is analysed which will be 3 months after your interview. You can contact me by emailing or by telephone and withdraw without giving a reason and without prejudice. If you withdraw from the service evaluation all data will be withdrawn and destroyed. If you decide to take part please keep this information sheet and sign and return the consent forms.

Thank you for your time.

Anusha Govender Cognitive Behavioural Psychotherapist Doctoral Student in Health and Social Care Practice

(email: A.Govender1@unimail.derby.ac.uk)

Version 2 13/12/15

#### **Appendix M: Consent form for patient participants**



# South West London and St George's Mental Health NHS Trust

NATIONAL and TRUSTWIDE OCD and BDD SERVICES MORRISON BUILDING 9E

SPRINGFIELD UNIVERSITY HOSPITAL 61 GLENBURNIE ROAD LONDON SW17 7DJ

Telephone: 020 3513 6961

Fax: 020 3513 6965

Out of Hours Crisis Line:0800 028 8000

Participant Identification Number for this trial:

# **CONSENT FORM (Patients)**

Title of Project: An evaluation of a specialist service model for treating Body Dysmorphic Disorder (BDD): application of the National Institute for Health and Clinical Excellence (NICE, 2006) Guidelines for BDD.

Please tick box

1. I confirm that I have read the information sheet dated 13/12/15 (version 2) for the above service evaluation. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw until data is analysed without giving any reason, without my medical care or legal rights being affected.

3. I understand that where it is relevant to my taking part in this service evaluation, sections of my medical notes, specifically questionnaire responses will be looked at by the chief investigator (Anusha Govender). I give permission for this individual to have access to my records.

4. I understand that where it is relevant to my taking part in this service evaluation, an audio record will be made and will only be used by the chief investigator (Anusha Govender) for the purpose of the service evaluation. I give permission for this individual to audio record my interview.						
	•	be quoted anonymously or by use of a ce evaluation results and give permiss				
	II information I providuestigator's professi	de will be held in confidence within the onal duty of care.	е			
7. I agree to take pa	rt in the above servi	ce evaluation.				
Name of Participant	 Date	 Signature				
Name of Person taking consent	 Date	Signature				

### **Appendix N: Consent form for clinician participants**



# South West London and St George's Mental Health NHS Trust

NATIONAL and TRUSTWIDE OCD and BDD SERVICES

MORRISON BUILDING 9E

SPRINGFIELD UNIVERSITY HOSPITAL

61 GLENBURNIE ROAD

LONDON

SW17 7DJ

Telephone: 020 3513 6961

Fax: 020 3513 6965

Out of Hours Crisis Line:0800 028 8000

Participant Identification Number for this trial:

Name of Investigator: Anusha Govender

### **CONSENT FORM (Clinicians)**

Title of Project: An evaluation of a specialist service model for treating Body Dysmorphic Disorder (BDD): application of the National Institute for Health and Clinical Excellence (NICE, 2006) Guidelines for BDD.

Please tick box

1. I confirm that I have read the information sheet dated 13/12/15 (version 2) for the above service evaluation. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw up until data is analysed without giving any reason and without any prejudice.

3. I understand that where it is relevant to my taking part in this service evaluation, an audio record will be made and will only be used by the chief investigator

(Anusha Govender) for	the purpose of the serv	rice evaluation. I give permission fo	r
this individual to audio	record my interview.		
		oted anonymously or by use of a ation results and give permission fo	r
5. I understand that all limitations of the investigator's pro	•	Il be held in confidence within the	
6. I agree to take part i	n the above service eva	luation.	
Name of Participant		Signature	
Name of Person taking consent	Date	Signature	

### Appendix O: Semi-structured interview schedule for patient participants



## South West London and St George's MHS

Mental Health NHS Trust

NATIONAL and TRUSTWIDE OCD and BDD SERVICES
MORRISON BUILDING 9E
SPRINGFIELD UNIVERSITY HOSPITAL
61 GLENBURNIE ROAD
LONDON
SW17 7DJ

Telephone: 020 3513 6961 Fax: 020 3513 6965

Out of Hours Crisis Line:0800 028 8000

### SEMI-STRUCTURED INTERVIEW SCHEDULE- Patients

Interview length: 30-40 minutes

Date: Time:

### Introduction:

Thank you for agreeing to take part in an interview for this service evaluation. I would like to assure you that you will remain completely anonymous and no records of the interview will have your name or identifying details on them. With your consent I would like to audio record this interview. The main reason is to have an accurate account of your views and experiences which will also aid in the analysis of the data.

### Semi-structured interview questions

- 1. What was the main treatment/s you received from this service for BDD?
- 2. How do you feel about the treatment you received for BDD?
- 3. What do you think was the most helpful part of the treatment?
- 4. Which aspects did you feel were not helpful?
- 5. Would you recommend others to have this type of treatment if they had BDD?
- 6. What would you have liked to be different in the treatment?
- 7. Are there any other aspects I have not asked about regarding your treatment that you would like to tell me about?

Thank you for your patience and for sharing your views and experiences. Version 2 13/12/15

### Appendix P: Semi-structured interview schedule for clinician participants



## South West London and St George's **WHS**



Mental Health NHS Trust

NATIONAL and TRUSTWIDE OCD and BDD SERVICES MORRISON BUILDING 9E SPRINGFIELD UNIVERSITY HOSPITAL 61 GLENBURNIE ROAD LONDON SW17 7DJ

Telephone: 020 3513 6961

Fax: 020 3513 6965

Out of Hours Crisis Line:0800 028 8000

#### SEMI-STRUCTURED INTERVIEW SCHEDULE- Clinicians

Interview length: 30-40 minutes

Date: Time:

#### Introduction:

Thank you for agreeing to take part in an interview for this service evaluation.

I would like to assure you that you will remain completely anonymous and no records of the interview will have your name or identifying details on them.

With your consent I would like to audio record this interview. The main reason is to have an accurate account of your views and experiences which will also aid in the analysis of the data.

### Semi-structured interview questions

- 1. What do you think about current guidelines for treating BDD?
- 2. How do you feel about following these guidelines?
- 3. Which interventions if any, have you used outside of these guidelines?
- 4. What do you think was most beneficial in treating patients with BDD?
- 5. What do you think was least beneficial in their treatment?
- 6. If given the opportunity how would you improve on the NICE (2006) guidelines for BDD?
- 7. Are there any other factors that I have not asked about regarding treatment provided by the service for BDD that you wish to describe?

Thank you for your patience and for sharing your views and experiences. Version 1 21/09/15

### Appendix Q: Debriefing information for both groups of participants



# South West London and St George's Mental Health NHS Trust

NATIONAL and TRUSTWIDE OCD and BDD SERVICES

MORRISON BUILDING 9E

SPRINGFIELD UNIVERSITY HOSPITAL

61 GLENBURNIE ROAD

LONDON

SW17 7DJ

Telephone: 020 3513 6961

Fax: 020 3513 6965

Out of Hours Crisis Line:0800 028 8000

Dear

### **Debriefing sheet**

Thank you for contributing as a participant in the present service evaluation.

This service evaluation is aimed at determining what standards of care the service achieves in applying the NICE (2006) guidelines for BDD. In addition the service evaluation also explores the experiences of patients suffering with BDD and perspectives of clinicians applying the NICE (2006) guidelines in the specialist service.

This service evaluation could provide direction as to the best ways of engaging patients in treatment and highlighting interventions that will enable them to continue to progress even after treatment is ended. Additionally, as there are very limited resources available for treating BDD, the findings from this service evaluation will lead to further research opportunities into early intervention and treatment of BDD to be spread across other services.

Again, thank you for your time and co-operation in this service evaluation. If you have any questions regarding this service evaluation, please feel free to ask the investigator.

If you wish to contact the investigator at a later time, these are my contact details:

Anusha Govender (email: A.Govender1@unimail.derby.ac.uk or telephone: 0203 513 6961).

Thanks again for your participation.

Anusha Govender

Cognitive Behavioural Psychotherapist

Doctoral Student in Health and Social Care Practice

## Appendix R: Characteristics of the qualitative patient sample

Patient identification*	Alice	Betty	Cathy	Dan	Eve	Fred	Gail
Level of care	Level 5 outpatient	Level 6 inpatient	Level 6 inpatient	Level 5 outpatient	Level 5 outpatient	Level 5 outpatient	Level 5 outpatient
Gender	Female	Female	Female	Male	Female	Male	Female
Age	18	23	27	49	37	20	45
Ethnicity	White	White	White	White	White	White	White
Marital status	Single	Single	Single	Single	Married	Single	Partner
Children	None	None	None	None	None	None	Yes
Employment	Unemployed- student	Unemployed	Unemployed- student	Employed	Employed	Unemployed- student	Employed
Accommodation	Living with parents	Living with parents	Living with parents	Living alone	Living with spouse	Living with parents	Living with partner
Onset age	15	16	14	14	15	12	12
Comorbid disorders	OCD, Depression	Depression, eating disorder	Depression, eating disorder, PTSD	OCD, depression	Depression	Depression	OCD, depression
Drug/Alcohol use	Alcohol	None	Alcohol	None	Drug use	None	None

(Appendix R contd.)							Suicidal
Risk behaviour	Suicide attempt DSH cutting, overdosing.	Suicidal ideation DSH: Cutting	Suicide attempt DSH cutting overdosing	None	Suicidal ideation Self-inflicted surgery	None	ideation
Cosmetic surgery	None	None	None	Cosmetic procedures and surgery (3)	None	None	None
Medication	**SSRI Not given augmentation	Fluoxetine 60mg, Clomipramine 150mg, Escitalopram Augmentation given	SSRI Not given augmentation	Citalopram 20mg Not given augmentation	SSRI Not given augmentation	Fluoxetine 40mg	Paroxetine 40mg, Sertraline 200mg Augmentation: Risperidone

<sup>\*</sup>Patients are given pseudonyms to anonymise data and maintain confidentiality.
\*\*Names of medication and dosage are provided where available.

### Appendix S: Example of coding process for TA: excerpt from patient participant's transcript

Fred		Passive, use of same	Lack of ownership
1.	R: What was the main treatment/s <u>you received</u> from this service for BDD?	wording as R	Detached, disconnected
2.	Fred: "I received a range of strategies and explanations used to aid understanding and	} Listing, lack emotive	Telling me what thinks I
3.	control over negative thoughts about my appearance. R: (Such as) These included	content	want to hear?
4.	Theory A and B, the vicious flower model, attention refocusing, relaxation techniques,		May be reading from review
5.	exposure therapy, pendulum diagram, weekly sessions, regular exposures for	Passive recipient	report?? These are listed in
6.	habituation."	Treatment not seen as	report as interventions
		collaborative.	used.
7.	R: So how do you feel about the treatment you received from this service for	"My bdd"	BDD Part of self-
	BDD?	Language diff from	Lack of ownership, passivity
8.	Fred: "I felt many methods of targeting my BDD were attempted to see which one would	describing treatment.	in receiving treatment.
9.	be most effective for me." (R: Mmm, how did that work for you?)	Not entirely convinced	
10.	Fred: "Overall I made big improvements regarding going out but still had some anxiety	-conflicting statements	
11.	present regarding my appearance although not as severe as before. It's less likely to		
12.	deter me from going out."	Use of same wording	
		again	Almost as though it's a test-
13.	R: What do you think was the most helpful part of the treatment?	S	disconnected from own
14.	Fred: "I think the regular exposure was the most beneficial, practice wise, especially	Disconnected,	experience.
15.	when accompanied with attention refocusing which aided in dealing with	detached	-sounds like reciting from
16.	exposures by occupying thoughts." (R: I see, anything else that was helpful?)		textbook
17.	Fred: "In terms of helping me understand the disorder, the habituation and vicious flower		
18.	model aided understanding of the stages and consequences of my BDD and why	Initially- engagement	Use of other interventions
19.	it would be beneficial to deal with it sooner rather than later. The hierarchy was	Language more	for engagement
20.	also helpful in realising milestones that show my progress and what should be	emotive not using	
21.	the next target to obtain."	same wording as R	But eager to please and say
	<del></del>	here.	the right thing
22.	R: Which aspects did you feel were not helpful?		
23.	Fred: "Well, I felt the theory A and B concept was the weaker of the explanations as it's	Unrealistic	
24.	guite difficult for someone with BDD to initially come to terms with. (R: Hmm, I	expectations	
25.	can see that could be difficult) Also to fully change ones mindset is a	Resistance, barriers	
26.	challenging and daunting task. R: How did you cope with that?		
27.	It became a bit off putting on occasion but I wanted to improve.		
	. —		

ppendix S contd.)		
AG: Would you have liked anything to be different in the treatment?  I felt that at times the treatment felt too much, especially with the regular exposures.  AG: Exposure exercises can be difficult because it initially raises your anxiety. What did you feel could be different?  Although it was very beneficial to my treatment and helped a lot, maybe if there were other less intense ways to introduce me into regular exposures it would have helped me gradually adjust more to the exposures.	ERP –difficult, too much	Difficult, overwhelmed Resistance. Treatment done to him rather than actively engaged.

### Appendix T: Example of coding process for TA: excerpt from HCP's transcript

### HCP2

### 20. R: What do you think was most beneficial in treating patients with BDD?

- 21. HCP: "For one lady who had BDD on our ward awhile back, I would say it was the medication,
- 22. because it got her to a position where she could start to do the CBT. She did the exposure work but
- 23. still felt very anxious after it, and that never really changed for her. So, medication helped with her,
- 24. to an extent, to engage with the CBT and OT work. But she didn't make any huge progress, by no
- 25. means. There was some difference, but she didn't feel like she made any difference.

### 26. R: What do you think was least beneficial in treating patients with BDD?

- 27. With the ERP approach, I think sometimes it can be too challenging and sometimes, what we were
- 28. suggesting for the patients was too much. Maybe that's something to learn from. We were getting
- 29. this patient to do extreme things, like walk around with coloured make-up on her face, or her
- 30. eyebrows not done. I know that's what we had to do as the treatment model, but for someone with
- 31. BDD, it seemed very emotive for them. So they felt like, you're wanting them to go that step a little
- 32, too far, I think with OCD it's easier to take people further and pull people back. Whereas with BDD.
- 33. that particular patient found that really difficult. So, when us as therapists are questioning, if we
- 34. would do that ourselves, we have to ask should we be asking that of patients to push it that far. But
- 35. then again, the evidence says if we don't, the relapse is higher.

### 36. R: If given the opportunity, how would you improve on the NICE guidelines for BDD?

- 37. I would put OT in there for a start, because I don't think OT is in the NICE guidelines. But I do think
- 38. there is a <u>role for OT</u> in there, <u>for building confidence</u>, <u>self-esteem work and all of the meaningful</u>
- 39. <u>engagement and activity.</u> And also, I think that there needs to be more of a <u>distinction between</u>
- 40. BDD and OCD.

Medication- as per guidelines – to help engage in cbt but again not seeing as beneficial.

Emphasis on lack of benefit.

Expressing more that unhappy with compared to what is satisfied with.

Expecting too much from patients. Learning opportunity.

Treatment model- needs to fit the patient rather than trying to fit patient into model.

Not feeling comfortable with treatment methods, not convinced of benefit.

But nothing else available, so *confused* as to what to do in patients' best interests. Lack of representation of other interventions and treatment options. Separate guidelines for BDD.

-Frustration-Confusion Dissonance-Not buving into treatment model Demoralising Work satisfaction? Helplessness Interpretation of patient's experience Too difficult Expectations not realistic for patient to achieve ERP too extreme to use as would in OCD More complex treatment not taking this into account. Patient's needs not being met Sticking to quidelines rather than tailoring treatment to patients needs Not sensitive to patient experience

Appendix U: Risk profiles and substance use of total patient sample

Risk behaviour	No. of patients (N)	Substances used	No. of patients (N)
Self-harm overdosing	13	Alcohol	16
Self–harm Cutting	15	Cannabis	8
Violence towards others	5	Cocaine	3
Suicidal ideation	19	LSD	1
Suicidal attempts	11	Heroin	1
Self-surgery	4		

Self-surgery is included due to the risk of serious injury patients pose to themselves. A high proportion of patients had a history of self-harm (58%) and an even higher percentage indicated suicide risk (62.5%). More than half the patient sample (54%) indicated use of substances with some patients using more than one illicit substance.

Appendix V: Comparison of medications prescribed by the service for patients with BDD and total of research studies on these medications to treat BDD

Medication	Patients prescribed	Research studies
	(N)	
Fluoxetine	14	1
Citalopram	4	1
Sertaline	5	none
Clomipramine	5	1
Paroxetine	2	none
Escitalopram	2	2
Dopamine blockades (Augmer	ntation)	
Aripiprazole	6	1
Risperidone	4	1
Olanzapine	3	2
Buspirone	1	1
Amisulpride	1	1

Appendix W: Level 6 national outpatient demographics and clinical factors

Variables	Patient 1	Patient 2	Patient 3	Patient 4
Age	70	24	37	28
Duration (years)	58	14	17	14
Employment	Retired (medical grounds)	Unemployed	Unemployed	Unemployed
Marital Status	Married	Single	Single	Single
Dependents	None	None	None	None
Accommodation	Living with spouse	Supported accommodation	Living alone	Living with parents
OCD	Present	Present	Absent	Present
Depression	Present	Absent	Present	Present
Anxiety disorder unspecified	Present	Absent	Absent	Absent
Asperger's Syndrome	Absent	Present	Absent	Absent
Self-harm	Absent	Present	Present	Present
Overdose	Absent	Absent	Present	Present
Cutting	Absent	Present	Absent	Present
Suicide: Ideation (I)	Present (I)	Present (A)	Present (A)	Present (A)
Attempt (A)				
Violent	Absent	Present	Absent	Absent
Alcohol misuse	Absent	Absent	Present	Absent
Cannabis	Absent	Absent	Present	Absent
Cocaine	Absent	Absent	Present	Absent
LSD	Absent	Absent	Present	Absent
Heroin	Absent	Absent	Present	Absent

## **Appendix X: Key principles for developing NICE guidelines** (NICE, 2018:1.4 pg. 14-15).

NICE develops guidelines according to the following core principles:

- Guidance is based on the best available evidence of what works, and what it costs.
- Guidance is developed by independent and unbiased committees of experts.
- All our committees include at least 2 lay members (people with personal experience of using health or care services, including carers, or from a community affected by the guideline).
- Regular consultation allows organisations and individuals to comment on our recommendations.
- Once published, all NICE guidance is regularly checked, and updated in the light of new evidence or intelligence if necessary.
- We are committed to advancing equality of opportunity and ensuring that the social value judgements we make reflect the values of society.
- We ensure that our processes, methods and policies remain up-to-date.

### Appendix Y: Strategy for dissemination

Aim of	Methods of	Target group	Strategy of
dissemination	dissemination	g	dissemination
Developing	Written	Service users	*Producing easy to read
awareness and	information	and carers,	leaflets to promote
providing	Imormation	Primary care	recognition of
education.		staff.	_
Promotion of		Stair.	symptoms/treatment
			options and advice on
routine screening			who to approach for
for BDD and early			help and support.
recognition of			Providing information
symptoms.			and simple screening
			recommendations for
			GPs to use in
			consultations.
Promoting interest	Presentation	Health care	Conference
in BDD research		professionals	submissions-
and strategies to		and service	posters/oral
overcome		users	presentations/symposia:
obstacles.			BABCP
			Psychodermatology
			BCAM
			BDD Foundation
To contribute to	Publications	Wider	Journal articles. Peer
body of knowledge.		professional	reviewed journals have
To aid in future		and scientific	a national and
research ventures.		groups.	international range to
			reach a wide audience.
Provision of training	Lectures,	Health care	To continue presenting
and skills based	workshops.	professionals	the BDD lecture at
learning.			University of Derby.
			Presentation at
			academic meeting at
			SWLSTG.
		1	

			To promote introduction
			of a BDD lecture at St
			George's Medical
			School through
			networking with
			psychiatry lecturers.
			Providing workshops
			and training in
			collaboration with
			colleagues- at the time
			of writing Dr Tyagi at
			Queen's Square, UCL is
			developing an OCD-
			spectrum service.
To generate	Network building	NHS Trusts,	Proving information on
interest and		independent	my field of expertise;
collaboration in		practitioners,	proposals of projects;
BDD awareness,		independent	collaboration in
research, training		healthcare	research.
and service		companies	
development.			
	1	1	l l

\*An additional aim is to incorporate patients' accounts or comments in the leaflets but this is dependent on their willingness to participate and ethical considerations will need to be addressed: consent, confidentiality, clear and transparent objectives in use of the material and target groups.

### **Appendix Yii**

Content removed due to copyright reasons.

Measures routinely used by the service to identify symptom severity

Appendix Z.i: Content removed due to copyright reasons.

Appendix Z.ii: Content removed due to copyright reasons.

Appendix Z.iii: Content removed due to copyright reasons.

Appendix Z.iv: Content removed due to copyright reasons.

Appendix Z.v: Content removed due to copyright reasons.