

*“The Only Way I Was Going to Be
Lovable.”*

A Grounded Theory of Young People’s
Experiences of Body Dysmorphic
Disorder.

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1. Abstract

Body dysmorphic disorder (BDD) is characterised by a distressing preoccupation with perceived defects or flaws in one's appearance. BDD most typically emerges in adolescence (Gunstad & Phillips, 2003; Phillips, Menard & Fay, 2006) and is estimated to affect 2.2% of the UK adolescent population (Veale, Gledhill, Christodoulou, & Hodson 2016). There is a dearth of research into children's and young people's (CYP's) lived experiences of BDD, particularly in relation to educational contexts (Mataix-Cols et al., 2015).

Using Constructivist Grounded Theory methodology (Charmaz, 2014), interview data from 10 young people (YP) between the ages of 16 and 25 were analysed.

The emergent theory that, *Appearance-based identity becomes the focus of adolescent identity formation in young people's experiences of BDD, informed by relational experiences of shame and low self-worth* encompassed four key themes, namely: (1) *Appearance-based identity is informed by and informs relationships in young people's experiences of BDD*; (2) *Characteristics of BDD are expressions of shame and low self-worth*; (3) *Shame-based educational experiences trigger and perpetuate BDD*; and (4) *Lack of understanding of BDD deepens shame and leads to stagnation of identity formation*. These findings informed the development of a psychological model of BDD in young people: *The Shame-Identity Model of BDD in Young People*.

Psychoanalytic conceptualisations, both of shame and of BDD, in addition to the literature on adolescent identity development, are drawn upon in the Discussion. Implications for Educational Psychology (EP) practice and the practice of other educational professionals are discussed.

2. Introduction

This chapter offers an overview of children's and young people's (CYP's) mental health in the UK, introduces the research area, and establishes my reflexive¹ research position.

2.1 Background

Recent guidance from the Department of Health (*Future in Mind*, 2015) and Public Health England (*Five Year Forward View for Mental Health*, 2016) has emphasised the importance of the promotion and support of CYP's social, emotional, and mental health (SEMH) in the UK. To deliver on this vision, the government has legislated for parity of esteem between physical and mental health. A recent government green paper entitled, *Transforming Children and Young People's Mental Health Provision* (Department for Health; Department for Education, 2017) acknowledges that mental health and wellbeing are vital to CYP's ability to thrive and achieve. It also recognises that CYP with mental health difficulties face unequal chances in their lives, citing this as "*one of the burning injustices of our times*" (Department for Health; Department for Education, 2017, p. 3).

Relevant to this study, improved services were pledged for eating disorders in the green paper, with an additional £30 million of investment and 70 new or enhanced community eating disorder teams. BDD, the focus of this study, has high rates of comorbidity with eating disorders (EDs). For example, in one study (Ruffolo, Phillips, Menard, Fay &

¹ In the reflexive position, I, as researcher, turned the lens on to myself, noticing my own inner and outer reactions to the participants' stories, manner of speaking, body language etc. I reflected on how I was making sense of my interpretations, and pondered on why I may be interpreting certain aspects in certain ways.

Weisberg, 2006) 32.5% of 200 individuals diagnosed with BDD had a comorbid lifetime ED. Furthermore, BDD is more prevalent than EDs (Dyl, Kittler, Phillips & Hunt, 2006), yet, is less publicly understood and more difficult to diagnose (Phillips, 2004; Grant & Phillips, 2004). Indeed, in the cross-agency local transformation plans (NHS England, 2016), BDD is not mentioned, while EDs are extensively referred to. Similarly, the green paper cites ED statistics but fails to mention BDD. There can be a high degree of diagnostic overshadowing² within EDs and BDD, with BDD often failing to be recognised and screened for within an ED diagnosis (Grant, Kim, & Eckert, 2002). Further exploration of overlapping experiences on the body image struggles continuum, including how diagnoses like EDs and BDD may intersect and conflate, appears in the Discussion chapter.

The *Five-Year Forward View for Mental Health* (2016) championed the bringing together of physical and mental health. In response, *Better Mental Health for All: A Public Health Approach to Mental Health Improvement* (Faculty of Public Health, 2016) offered service users' perspectives on what integrated care might look like. The case for tackling inequalities between physical and mental health had previously been made in the government commissioned report, *Whole Person Care* (Royal College of Psychiatrists, RCP, 2013), which stated, "*There must also be widespread recognition of the social and cultural factors affecting mental health ... social policy on poverty, employment, violence, parenting, and body image issues, to name but a few, are just as important for achieving parity as efforts to reform healthcare.*" (RCP, 2013, p.59)

Body image related mental health difficulties appear to be a growing concern in CYP, and an increasing occurrence in education settings. Childline delivered 2,239 counselling

² Diagnostic overshadowing describes the phenomenon whereby clinical professionals wrongly presume symptoms are related to/are a consequence of a pre-diagnosed condition.

sessions related to body image in 2016/2017; a 20% increase on the previous year (NSPCC, 2017). Over a third of adolescent boys and almost half of girls in the UK have reported dieting to change their body shape or lose weight (All Party Parliamentary Group on Body Image, 2012). One Sweden-based study reported that one in four seven-year-old girls in its sample ($n=411$) had tried to lose weight at least once (Westerberg-Jacobson et al., 2012).

On the extreme end of the body image struggles continuum is BDD, which most typically occurs in adolescence (Bjornsson et al., 2013; Gunstad & Phillips, 2003; Phillips et al., 2006). BDD is characterised by a distressing preoccupation with perceived defects or flaws in one's appearance, which are either not visible to the outside eye or are attributable to normal human variation (American Psychiatric Association [APA], 2013). In one of the larger studies of individuals diagnosed with BDD ($n=188$), the mean age at onset was 16 years (range = 4-43 years), with BDD beginning before the age of 18 in 70% of cases (Phillips & Diaz, 1997). BDD is estimated to affect 2.2% of the UK adolescent population (Veale, et al., 2016) and has one of the highest suicide rates associated with any mental health diagnosis (Phillips & Menard, 2006; Phillips et al., 2006; Veale et al., 2016).

There are two systems of classification for so-termed psychiatric conditions: (1) the International Classification of Diseases (ICD-10/11) (World Health Organisation [WHO], 1994/2019 *in preparation*); and (2) the Diagnostic and Statistical Manual (DSM-5) (APA, 2013). Each has multiple editions, demonstrating that categorisation in psychiatry is subject to revision, dispute, and contestations. Many ethical considerations surround these debates (Greenberg, 2013). BDD is classified under the umbrella of obsessive compulsive and related disorders (OCRDs) in the Diagnostic and Statistical Manual of Mental Disorders – 5th Edition (DSM-V) (APA, 2013). The main preoccupation with appearance is classified as obsessional, leading both to repetitive and avoidance behaviours (Phillips, 2002; Greenberg & Wilhelm,

2011). BDD was classified as a hypochondrial disorder in ICD-10. According to one of the UK's leading experts on BDD (in conversation with myself in November 2018), many specialist clinicians in the UK view this as inaccurate; hence the predominant use of the DSM classification of BDD in the UK.

Research suggests individuals with a BDD diagnosis are typically distressed by up to three body parts simultaneously, with one usually causing the most distress (Khemlani-Patel, 2001; Neziroglu, Khemlani-Patel, & Yaryura-Tobias, 2006a)³. One study found that people diagnosed with BDD have a lifetime average of four preoccupations (Phillips, McElroy, Keck, Pope & Hudson, 1993). They can become preoccupied with their perceived defect(s) to such an extent that they experience significant emotional distress, including feelings of depression, anxiety, and suicidality (Phillips et al., 2006). A history of suicidal ideation primarily owing to BDD has been found in 45%-70% of individuals with this diagnosis in cohorts studied in cross-sectional/retrospective studies (Perugi et al., 1997; Phillips et al., 2005). The rate of past suicide attempts in adults with this diagnosis has been reported as 22-24% (Veale et al., 1996; Phillips & Diaz, 1997). In one study, which included both adults ($n=164$) and adolescents ($n=36$), 80.6% of the adolescents had a history of suicidal ideation, and 44.4% had attempted suicide (Phillips et al., 2006).

Reported cases of BDD in CYP suggest the clinical features of BDD are generally similar to those in adults (Albertini & Phillips, 1999; Braddock, 1982; Cotterill, 1981). Symptom severity has been found to be a predictor of poorer psychosocial functioning (Phillips, Quinn & Stout, 2008). The appearance preoccupations can make it difficult to attend school, socialise, and even leave the house, sometimes for many months or even years (Phillips et al,

³ The number of body parts involved is not an element of the diagnostic criteria for BDD in DSM-V (i.e., a person can meet the diagnostic criteria if solely focused on one body part).

2006). In one study, 15% of a sample of 33 adolescents (Phillips & Albertini, 1999) had dropped out of school permanently due to BDD-related distress. Comorbidity with other diagnoses has been found to be typical, with a mean of more than two lifetime comorbidities (Gunstad & Phillips, 2003). Major depressive disorder, social phobia, and obsessive compulsive disorder (OCD) have been reported to be the most common in adult studies (Gunstad & Phillips, 2003; Phillips & Diaz, 1997; Veale et al., 1996; Zimmerman & Mattia, 1998). A range of other current and lifetime comorbidities have been reported, including dysthymia disorder, eating disorders, and substance use disorders (Grant, Kim & Crow, 2001; Grant, Menard, Pagano, Fay & Phillips, 2005; Gunstad & Phillips, 2003; Nierenberg et al., 2002; Phillips & Diaz, 1997; Zimmerman & Mattia, 1998).

BDD is commonly under- or mis-diagnosed for a variety of reasons (Buhlmann, 2011; Buhlmann, Reese, Renauld & Wilhelm, 2008). For example, people who experience BDD do not necessarily voice their appearance-related distress unless specifically asked, due to feelings of shame and embarrassment (Conroy et al., 2008; Grant, Kim & Crow, 2001). Furthermore, clinicians may not assess for BDD if anorexia nervosa seems more relevant or pressing due to physical health needs. Arguably, this may be related to the hierarchical approach to diagnosis in the DSM and ICD (Grant & Phillips, 2004).

There is a slowly growing body of research exploring the lived experience of adults diagnosed with BDD. However, there is a dearth of research into the lived experience of young people (YP) and their families (Phillips et al., 2006).

2.2 Reasons for interest in the research area

My interest in this research area was the result of: (1) personal, historic experience of BDD; (2) involvement with the Body Dysmorphic Disorder Foundation as a trustee of the charity (www.bddfoundation.org); and (3) experience of working with CYP with body dysmorphic tendencies through the BDD Foundation, my previous position as a school counsellor, and my current position as a Trainee Educational Psychologist (TEP). My personal and professional experience was strongly suggestive of a scarcity of available resources for CYP experiencing BDD, in addition to a lack of awareness and understanding of BDD both in educational settings and the wider public arena. Indeed, the preliminary literature review demonstrates a paucity of in-depth, qualitative research into BDD in CYP. Two of the UK's leading experts on BDD, clinical psychologists at the BDD and OCD-Related Disorders Clinic for CYP at the Michael Rutter Centre at the Maudsley Hospital in London, acknowledged (in a conversation with myself in July 2018) there is a lack of understanding of, and support for, BDD in CYP both in the UK and internationally.

2.3 Historical context

It is perplexing that such a relatively common mental health struggle has gone unrecognised and under-supported for so long. One potential reason is that, until the 1990s, systematic empirical research studies had not been carried out to elucidate BDD's clinical features, prevalence, potential causes, and other characteristics. However, BDD was first described in 1886 by an Italian physician, Enrico Morselli. He described dysmorphophobia as a subjective feeling of ugliness or physical defect, which the person feels is noticeable to others, although

the appearance is within normal limits (Morselli, *published* 2001). French psychiatrist, Pierre Janet (1903), then described a woman who was housebound for five years due to acute shame in relation to her body. Later, Sigmund Freud (and, subsequently, Brunswick) described arguably the most famous case of BDD: The *Wolf Man*, who was preoccupied by perceived defects of his nose (Mahony, 1984).

Dysmorphophobia was first introduced under atypical somatoform disorders in DSM-III in 1980 (APA, 1980). In 1987, it was given independent diagnostic status in the DSM-III revision (APA, 1987) as a disorder of irrational conviction. In DSM-IV (APA, 2000), the diagnostic label became BDD and was placed under the category of somatoform disorders. In DSM-V, it retained its name but moved to the category of OCDs.

As may be evident from this unfolding discourse, the issue of the diagnostic criteria of BDD is a contentious one. One could view this, in a positivist sense, as the history of BDD being a history of mistakes (e.g., under-diagnosis, mistaken diagnosis, wrongful overshadowing, etc.) which the DSM and ICD have progressively attempted to correct. However, I view this rather differently: As forms of distress representing experiences which are partially a result of social and cultural factors or 'vectors' (Hacking, 1998) that bring certain groupings into visibility, and then take them away again. Thus, I suggest that the way in which BDD has been classified over time may have been dependent on the social and cultural vectors of each time period.

2.3.1 National and local context

Norman Lamb, then Care and Support Minister, and the previous coalition government, introduced the legal right for NHS patients in England to choose their mental healthcare

provider for outpatient treatment. This legal right came into force on 1st April 2014 and was referred to as Patient Choice.

The way this change in law was interpreted is outlined in *Choice in Mental Health* (NHS Improvement, April 2016). A recent Patient Choice survey conducted by Singh, Urbanski and Veale (*in preparation*, 2019), in which researchers emailed a Freedom of Information request to all clinical commissioning groups (CCGs) in England in June 2017, sought to uncover the degree of Patient Choice in the treatment of BDD in England. This survey followed heightened concern that those with a BDD diagnosis were not receiving adequate, timely, and appropriate treatment. 169 self-report responses were received. Based on the responses, 34% of the 169 CCGs were deemed to be compliant with Patient Choice. Central London was the only London-based CCG who claimed compliance, though they were unable to clarify how funding for BDD treatment and care was agreed upon. 61% of respondents were classified as noncompliant. 6% of responses were classified as unsure (i.e., it was unclear from the response whether Patient Choice was adhered to for BDD).

2.3.2 Local services

National Institute for Clinical Excellence (NICE) guidelines for BDD (2005) recommend BDD-specific cognitive behavioural therapy (CBT) with exposure response prevention (ERP) and high-dose selective serotonin reuptake inhibitors (SSRIs). There is one specialist BDD service for CYP in London; the Michael Rutter Centre at the Maudsley Hospital, which offers BDD-specific CBT for CYP with a diagnosis of BDD. Other centres which offer specialist outpatient and/or inpatient treatment for BDD in the London and Greater London area, which are non-specific to CYP but treat CYP are: (1) Southgate Priory; (2) Nightingale Hospital; (3) London

Centre; (4) Body Image Clinic; (5) OCD/BDD service at the South West London and Saint George's Mental Health Trust; and (6) the Anxiety Disorders Residential Unit at the Bethlem Royal Hospital.

2.4 Researcher's position

My researcher position has been strongly influenced by critical discourses of the current dominant biological (i.e., within-person) models in psychiatry and clinical psychology, including: (1) The *Power Threat Meaning Framework* (Johnstone et al., 2018) which offers an alternative paradigm to the current diagnostic system; (2) the lack of reliability and validity of psychiatric diagnoses (Bentall, 2004; Burstow, 2015; Johnstone, 2014; Read & Dillon, 2013); and (3) the questioning of the scientific foundations of psychiatric medications (Goldacre, 2015; Moncrieff, 2008; Whittaker, 2010). This position informed: (1) recruitment criteria decisions (e.g. welcoming those who self-identified with the label of BDD, but who did not have a diagnosis, to also take part); (2) the structure and content of interview questions; (3) the non-pathologising language used; and (4) aspects of the way in which data were analysed, as further outlined in the Methodology chapter. These perspectives, alongside the systemic and psychodynamic insights offered through the Tavistock Clinic, characterised my researcher position and interpretation of study findings.

This study was also influenced by an emancipatory tradition within educational psychology, which campaigns for social justice, equal opportunities, inclusion, and ethical practice (Billington, 2000). One aim of this study was to raise awareness about effective EP practice for young people (YP) who self-identity with, or have a formal diagnosis of, BDD and improve outcomes for these YP and their families.

Further details about the researcher's position are given in the Methodology chapter.

2.5 Role of the Educational Psychologist (EP)

It has been suggested that due to the recent government austerity agenda and associated budget cuts, accompanied by heightened awareness of needs and associated demands for services, it is becoming increasingly difficult for specialist mental health services to provide adequate support for CYP experiencing mental health difficulties (Young Minds, 2016). Frith (2016) reported that opportunities for early intervention are often missed, and parents' and professionals' attempts to gain specialist support for CYP with mental health needs are regularly unsuccessful, with only 25% of referrals resulting in support from the Child and Adolescent Mental Health Service (CAMHS). EPs are, arguably, ideally placed to offer SEMH support in schools and other educational environments (Bozic, 1999). In addition to a good understanding of mental health needs, EPs also understand needs within an educational context; therefore, making them better placed, in some cases, to offer therapeutic interventions than their colleagues from other branches of psychology (Atkinson, Corban & Templeton, 2011). Despite this, mental health legislation aimed at schools seems to imply a limited role for EPs (Department for Education, 2014; 2016, Department for Health; Department for Education, 2017).

There is a growing interest in both evidence-based practice (Kennedy & Monsen, 2016) and practice-based evidence (Fox, 2011) in EP work, alongside the growing popularity of person-centred work and planning (Woods, 2016), placing the CYP's experiences at the centre of strategies and interventions; the zeitgeist of modern EP practice. Conducting research constitutes one of the five core activities of EPs (Division for Education and Child

Psychology [DECP], 2002). This evidence-based research is frequently conducted to assist vulnerable children (Crinson, 1999). It was hoped the theory emerging from this study would serve to broaden EPs' understanding of BDD, thus enhancing practice with this population.

2.6 Chapter summary

This chapter provided a context and rationale for this study. In the following chapter, the preliminary literature review is presented.

3. Preliminary literature review

Consistent with the Constructivist Grounded Theory (CGT) methodology, a targeted literature review was conducted after data collection and analysis (Charmaz, 2014). A preliminary search was also carried out to establish context and avoid duplication (Chiovitti & Piran, 2003; Dunne, 2011). The purpose of this preliminary review was to obtain an overview of the current knowledge base of CYP's experiences of BDD and identify gaps in the research to inform the research questions (Birks & Mills, 2015).

3.1 Search strategy for preliminary literature review

EBSCO, which encompasses a selection of databases, was used to include medical, educational and psychological journals, using a sensitive search strategy designed to capture different spellings and terms. It combined the following keywords: "body dysmorphic disorder" or "body dysmorphia" or "dysmorphophobia" or "BDD" or "perceived ugliness" or "imagined ugliness" AND "school" or "sixth form" or "college" or "classroom" or "university". The following limiters were put in place: "subject — body dysmorphic disorder"; "subject — body image"; "source type — academic journals"; "peer reviewed"; "language — English".

Review inclusion criteria were:

- 1) Participants with a primary diagnosis of BDD/sub-threshold BDD (or, pre-1987, a diagnosis of dysmorphophobia);
- 2) Paper included participants aged below 26 years (in keeping with the 0-25 age range of the EP remit);

- 3) Findings related to general BDD symptomatology, as opposed to unrelated features (e.g., smoking);
- 4) Findings were not specific to cosmetic surgery patients only;
- 5) Focused on lived experience, as opposed to medication/neurology; and
- 6) Full paper was available in English.

3.2 Results

The systematic Boolean/phrase literature search yielded a total of 46 unique title references, of which 20 were rejected following a review of the title and abstract, using the inclusion criteria (see Appendix One), leaving 26 papers for inclusion. A hand-search yielded an additional four relevant articles, carried out by reading the abstracts and reference lists of articles cited in the 26 inclusion articles, and by running the same original search terms through Google Scholar. A discussion with two leading experts in the field (a psychiatrist and a CBT therapist both specialised in BDD) led to the identification of two additional papers (Albertini & Phillips, 1999; Veale et al., 2016), and a discussion with a leading BDD specialist based at the Maudsley led to the identification of two further papers (Krebs, Turner, Heyman & Mataix-Cols, 2012; Mataix-Cols et al., 2015), thereby totalling 34 included papers. The Critical Appraisal Skills Programme (CASP, 2016), a critical-appraisal research tool, was used to assess each paper's aims, sampling, study design, data collection, data analysis and findings (see Appendix Two). The strengths and limitations which arose from the critical appraisal of each article were reviewed in relation to these aspects; the most salient of which are highlighted in this review. The CASP also supported me to ascertain how the papers were thematically and methodologically related, thus informing how this review was structured.

3.3 Overview of relevant literature

3.3.1 Prevalence rates

12 papers considered the prevalence rates of BDD in CYP up to age 25. A recent systematic review estimated the weighted prevalence of BDD in the UK to be 2.2% in UK adolescents and 3.3% in UK student populations (Veale et al., 2016).

Reported prevalence rates of BDD for CYP ranged between 1.7% (Mayville, Katz, Gibson & Cabral, 1999) and 5.8% (Taqui et al., 2008). Two studies reported no difference in prevalence rates between males and females (Ahamed et al., 2016; Schneider, Mond, Turner & Hudson 2017). Four studies found higher levels of BDD concerns in females than males (Bartsch, 2007; Boroughs, et al., 2010; Mayville et al., 1999; Taqui et al., 2008). Two studies concluded older adolescents were more likely to have BDD symptoms than younger adolescents (Dlagnikova & van Niekerk, 2015; Schneider et al., 2017). There was a difference in relation to ethnic background in three studies: (1) Boroughs, Krawczyk, & Thompson (2010) identified female Caucasians and Latinas as reporting more symptoms than those of African descent; (2) Bartsch (2007) demonstrated lower prevalence rates among students of Asian backgrounds; and (3) Mayville et al. (1999) reported Africans of both genders were less dissatisfied with their appearance than Caucasians, Asians, and Hispanics. Since UK-based papers did not break findings down by ethnicity, it is unclear whether there are ethnicity-based differences in the experiences of BDD within the UK population.

The most commonly cited foci of appearance concern in these studies were: (1) skin (Ahamed et al., 2016; Taqui et al., 2008); (2) body fat (Ahamed et al., 2016; Taqui et al., 2008);

(3) head hair (Taqui et al., 2008); (4) nose (Taqui et al., 2008); (5) teeth (Taqui et al., 2008); (6) general head/face area (Cansever, Uzun, Donmez, & Ozsahin, 2003); and (7) hips (Cansever et al., 2003). Related experiences cited within these papers included: (1) past mental health service use (Schneider et al., 2017); (2) anxiety (Ahamed et al., 2016; Bohne et al., 2002b; Schneider et al., 2017); (3) depression (Bartsch, 2007; Bohne, Keuthen, Wilhelm, Deckersbach & Jenike 2002a; Bohne et al., 2002b; Schneider et al., 2017); (4) OCD (Bohne et al., 2002a; Bohne et al., 2002b; Schneider et al., 2017); (5) eating disorders (Schneider et al., 2017); (6) low self-esteem (Bartsch, 2007; Bohne et al., 2002a; Bohne et al., 2002b; Boroughs et al., 2010); (7) life dissatisfaction and poor quality of life (Bartsch, 2007; Schneider et al., 2017b); and (8) skin picking (Bohne et al., 2002a; Bohne et al., 2002b).

3.3.2 BDD-related behaviours

Seven papers investigated BDD symptomatology. Damercheli, Kakavand and Jalali (2017) explored the relationship between social anxiety and BDD in female students at a university in Iran. 1,000 students answered questionnaires, including the Social Phobia Inventory (SPIN) (Connor et al., 2000). 280 students were selected as the final sample, discerning those with the highest anxiety and BDD scores. Results suggested that fear of positive and negative evaluation (appearance-related evaluation by others) together mediated the relationship between social anxiety and BDD. 60 incomplete questionnaires were put aside and not included in the results, raising questions around inclusivity and the breadth of experiences captured.

Mastro, Zimmer-Gembeck, Webb, Farrell and Waters (2016) investigated 387 young adolescents' (aged 10-13) appearance anxiety and BDD symptoms in Australia, including

social difficulties, self-perceptions, and comorbidities. The Appearance Anxiety Inventory (AAI) (Veale et al., 2014) was used as an indicator of BDD symptoms. Young adolescents reporting high appearance anxiety were compared to their same-age peers on social, self-perceptual, and comorbid dysfunction. 35 adolescents, 89% of whom were girls, had high appearance anxiety symptoms and reported significant deficits in self-reported measures of social functioning, self-competence, and rejection sensitivity. They also experienced more symptoms of depression and social anxiety and reported more extreme weight management behaviours. The relatively low response rate of students across all schools was an important limitation.

In further research (Calogero, Park, Rahemtulla, & Williams, 2010), the extent to which interpersonal concerns of rejection based on appearance (i.e., Appearance Rejection Sensitivity [RS]) served as an indicator of risk for excessive body image concerns was examined among 106 British students. Appearance-RS uniquely predicted a greater degree of BDD symptoms and acceptance of cosmetic surgery.

In a small sample of $n=54$, Pecorari et al. (2010) investigated whether students from a single university in Turin with BDD traits who had requested cosmetic surgery differed from those without BDD traits, in relation to self-esteem, personality, and quality of life. Measures included: (1) the Health-Related Quality of Life questionnaire (HRQL) (Juniper, 1997); and (2) the Rosenberg Self-Esteem Scale (RSE) (Rosenberg, 1965). They concluded lower self-esteem, higher harm avoidance, and lower self-directedness were found in: (1) those who were worried about how they look; (2) those with interference in their social life due to this worry; and (3) those who spent more than three hours per day thinking about their appearance. It is important to note correlation does not prove causality in this, or indeed, in any case.

Kaymak, Taner and Simsek (2009) evaluated BDD symptoms in Turkish university students with skin diseases. A total of 107 outpatients diagnosed with any skin disease, and a control sample of 109 age-and-sex-matched healthy subjects, both recruited from the student body of the same university, completed the Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, Mock & Erbaugh, 1961) and the Body Dysmorphic Symptoms Scale (BDSS) (Ramos et al., 2016). Higher scores were found on the BDSS in the group with skin diseases compared to the healthy controls. It is unclear to what extent these were perceived defects or objective skin diseases, as the study was based on self-report.

Woodie and Fromuth (2009) examined whether hyper-competitiveness was a moderator between BDD symptoms and gender roles in 345 college students in the Netherlands. Significant positive correlations were found between BDD symptoms and hyper-competitiveness in both males and females. The study was limited by its homogenous sample (primarily Caucasian women, 18-20 years old), which was drawn from a pool of psychology students. Thus, the findings may not extend to a more culturally- or educationally-diverse group.

In a seminal study by Phillips et al. (2006), the clinical features of BDD in adolescents ($n=36$) and adults ($n=164$) with this diagnosis in the United States (US) were investigated. Adolescents were found to be preoccupied with numerous aspects of their appearance, most often their skin, hair, and stomach. Among the adolescents: (1) 94.3% reported moderate, severe, or extreme distress due to BDD; (2) 80.6% had a history of suicidal ideation; and (3) 44.4% had attempted suicide. Adolescents experienced high rates of impairment in school, work, and other aspects of psychosocial functioning. They also had significantly more delusional beliefs about their appearance than adults with BDD, as well as a higher lifetime

rate of suicide attempts. This study included significantly fewer adolescents ($n= 36$) than adults ($n=164$), an obvious limitation.

Phillips et al.'s 2006 study was an update to research conducted by Phillips and Albertini (1999), which found 94% of 33 US adolescents aged 6-17 years (female $n=30$, male $n=3$) with a diagnosis of BDD reported impairment in social functioning, and 85% reported impairment in academic or job functioning, due to BDD. 39% had experienced psychiatric hospitalisations, and 21% had made a suicide attempt. 36% had received surgical, dermatological, or dental treatment, with a poor outcome in all cases. 68% of these 33 CYP spent more than three hours a day thinking about their perceived defect; some said it was virtually all they thought about. The most common BDD-related behaviour reported was camouflage (94%) (e.g., covering the perceived defect with clothes, makeup, or a hat). 85% reported excessively checking their appearance in mirrors or other reflective surfaces, and nearly half reported dieting. 39% reported compulsively picking at their skin to improve its appearance. 94% reported social interference due to embarrassment and shame related to their appearance, and 85% reported their appearance obsessions and behaviours interfered significantly with their academic performance. In addition to the 39% who temporarily missed school due to hospitalisation, an additional 18% dropped out of school temporarily, and 15% dropped out permanently due to BDD symptoms.

3.3.3 Development of scales

Two studies particularly considered the development and utilisation of scales related to BDD. He et al. (2017) composed a 34-item matrix named the Body Image Concern Scale (BICS), which targeted body image concerns, and trialled it with 328 male and 365 female Chinese

university students. Six latent factors were identified as part of an exploratory factor analysis: (1) social avoidance; (2) appearance dissatisfaction; (3) preoccupation with reassurance; (4) perceived distress/discrimination; (5) defect hiding; and (6) embarrassment in public. Females scored significantly higher than males on the following factors: (1) appearance dissatisfaction; (2) preoccupation with reassurance; and (3) defect hiding, thus correlating with the findings of Bartsch (2007); Boroughs, et al. (2010); Mayville et al. (1999); and Taqui et al. (2008). The results would require replication in a broader population of CYP before they could be considered generalisable.

In 2004, Cash, Phillips, Santos and Hrabosky developed the Body Image Disturbance Questionnaire (BIDQ). The participants were 220 college women and 75 college men in the US, who completed an online survey containing this new assessment. For both sexes, BDD was found to be correlated with depression, social anxiety and eating disturbances. Greater body image disturbances were observed in females than males, among heavier than lighter females, and among White than African-American females, correlating with the findings of Boroughs et al. (2010) and Mayville et al. (1999).

3.3.4 Muscle dysmorphia

Three papers focused specifically on muscle dysmorphia (MD), which is classified as a subtype of BDD in DSM-V (APA, 2013). Menees, Grieve, Mienaltowski and Pope (2013) examined the relationship between the critical comments which 118 college-aged men in the US recalled others making about their bodies and their current level of MD symptoms. Participants were asked to complete the MD Questionnaire (MDQ) (Grieve & Shacklette, 2012). No significant differences were found in the MD symptoms between participants who did and did not recall

comments about their bodies. However, a significant relationship was found between the severity of the comment and the severity of MD symptoms, whilst more negative reactions to the critical comment were also associated with more MD symptoms. There was very little variability in the participants' ages, races, and education levels, thus potentially limiting the generalisability of these findings.

Chandler, Grieve, Derryberry and Pegg (2009) examined how MD relates to trait anxiety and obsessive compulsive symptoms. A sample of 97 college-aged men from the US completed the MD Inventory (MDI) (Derogatis, 1984) and the Drive for Muscularity Scale (DMS) (McCreary, Sasse, Saucier & Dorsch, 2004), among other scales focused on body image attitudes and anxiety. Results showed trait anxiety and obsessive compulsive symptoms demonstrated strong relationships with social-physique anxiety and overall MD symptomology. Anxiety-related variables accounted for 77% of the variance in MD symptoms. Again, correlation does not prove causation here, nor in the following study.

Finally, Ebbeck, Watkins, Concepcion, Cardinal and Hammermeister (2009) explored the nature of the relationship between MD symptoms and self-concept, as well as the negative affect variables in 183 female and 103 male college students (aged 18+) from the US. Those with low perceived body attractiveness and high social-physique anxiety were more likely to struggle with MD symptoms.

3.3.5 Intrusive thoughts

One study considered intrusive thoughts/mental intrusions in BDD, which have been defined as discrete, untimely, and unexpected conscious cognitive products that can be experienced as thoughts, images, sensations, or impulses (Clark & Purdon, 1993). In this study (Giraldo-

O'Meara & Belloch, 2017), a sample of 410 undergraduate university students in Spain completed a 54-item version of the Appearance Intrusions Questionnaire (AIQ) (Giraldo-O'Meara & Belloch, 2017), designed to assess intrusive thoughts related to appearance defects (AITs). Up to 90% of participants experienced AITs. Only non-clinical samples were used, which may limit the generalisability of these findings to the non-clinical population.

3.3.6 Response to CBT treatment

One paper (Mataix-Cols et al., 2015) reported on an age-appropriate CBT protocol for adolescents in a pilot randomised controlled trial. 30 adolescents between the ages of 12-18 were included in the study. The CBT group showed a greater improvement in BDD symptomatology relative to the control group at post-treatment and two-month follow-up. Nearly 60% of the CYP were found to either be inconsistently attending school or not attending school at all due to BDD-related distress. Almost half desired cosmetic procedures. The findings of this paper triangulate with the findings of an earlier case series by Krebs et al. (2012), in which six adolescents with a diagnosis of BDD received a course of CBT; with an overall 44% percent reduction in symptoms post-treatment across participants. Avoidance (e.g. mirror avoidance) and compulsive behaviours (e.g. excessive bathing) had been evident across all six young people pre-treatment.

3.3.7 Single-case studies

Six of the papers were single-case studies. In the earliest (Braddock, 1982) a 17-year-old female diagnosed with dysmorphophobia (as classified at that time) was distressed by the

appearance of her forehead and desired cosmetic surgery. Following behavioural therapy, the YP displayed increased assertiveness with her peers but continued to be distressed by the appearance of her forehead. Braddock highlighted the importance of early intervention in her conclusion.

In a single-case study by Burrows, Slavec, Nangle and O'Grady (2013), the two-year treatment of a 14-year-old female from the US with a diagnosis of BDD and major depressive disorder is described. School attendance was found to increase following twice-weekly sessions of exposure with response prevention (ERP), medication (fluoxetine), and a brief hospitalisation. In another case study, Adebayo, Gureje and Nuhu (2012) explored BDD presenting as depression in a 17-year-old Nigerian boy. The authors concluded a high level of suspicion of BDD is necessary in patients presenting with medically unexplained physical complaints and depression.

One paper describes the case of a 17-year-old female with a diagnosis of primary BDD and comorbid OCD and major depressive disorder (Thein-An, Merricks, Nadeau, Ramos & Storch, 2017). Despite significant reductions in ritual engagement⁴, the YP's symptoms relapsed to baseline after returning home from her inpatient treatment (CBT). Another paper was comprised of four case studies (Phillips, Atala & Albertini, 1995) of adolescents with respective diagnoses of BDD. The cases included two 17-year-old females, one 16-year-old male, and one 16-year-old female. Each of the YP experienced appearance-related preoccupations which were distressing, time-consuming, and reported to be uncontrollable. Normal daily-life functioning was impaired, and there were high levels of school absence, psychiatric hospitalisation, suicidal ideation, and suicide attempts. All four YP reported a

⁴ Ritual engagement describes repetitious actions which are undertaken in an attempt to soothe and reduce anxiety.

decrease in symptoms following a course of SSRIs. It is important to note that other ameliorating factors, independent of the effects of medication, were not specifically considered; these may have contributed to a reduction in the observed distress.

In the most recent case study (Thungana, Moxley & Lachman, 2018), a 15-year old African female, who was admitted to an inpatient psychiatric unit in South Africa for treatment of psychotic symptoms, was poorly responsive to standard treatments. The YP had missed a significant amount of school, had active suicidal ideation, had socially isolated herself, and was distressed by her so-perceived yellow teeth; covering her mouth with her hand whenever she spoke. She was also distressed by her so-perceived large breasts and attempted to lose weight to reduce their size.

3.3.8 Experiences in school, including school-based interventions

Ogedegbe and Coker (2016) investigated the impact of a health programme in Nigeria on a sample of $n=200$ secondary school students with low self-esteem who also scored highly on the Negative Self Inventory Scale (Agbu, 2011) which the authors took as a measure of BDD. Participants were divided into experimental and control groups. Results showed the health programme had a significant impact on the students with low self-esteem and 'BDD', as compared to the students who did not participate in the programme. This study was carried out in a few selected schools only, using self-completing instruments, thus limiting its potential generalisability. The use of the Negative Self Inventory Scale as a measure of BDD is also questionable; it is neither widely used nor scientifically validated for this purpose.

Weingarden, Curley, Renshaw and Wilhelm (2017) explored patient-identified events in the development of BDD in the US, including school-based events, thus representing a

relevant sample for inclusion in this review. 37.6% attributed the development of their BDD to a triggering event, of which bullying experiences were the most commonly described. Participants who specifically attributed their BDD development to a bullying experience had poorer psychosocial outcomes, as compared to those who attributed their BDD development to another triggering event. This study was limited by its lack of a control or comparison group.

3.4 Identified gaps in the literature

This preliminary literature review revealed a dearth of qualitative research into the lived experience of BDD in CYP. The studies which explored CYP's lived experiences were either single-case studies largely focused on the role of medication and/or specific treatment programmes, or solely used a range of scientifically-validated assessments to gather experiences. None asked open, exploratory questions about CYP's experiences with BDD, posed in-depth questions about school experiences, or sought to explain the nuances of CYP's experiences. Furthermore, the existing research appears to reflect a de-contextualisation that hints at an individualisation and medicalisation of the phenomena that has come to be classified as BDD. I believe it is reasonable to pose questions about causality and treatment that lie outside of the body and individual psyche. In understanding BDD as a phenomenon, and therefore, supporting individuals, it may be important, even necessary, to explore how the personal may also be political in the experience of BDD.

The current study aimed to address knowledge gaps and exploration omissions by raising a CGT of YP's lived experiences of BDD in the home, educational setting, and wider societal context.

3.5 Chapter summary

This chapter outlined the preliminary literature review and highlighted gaps in existing research into CYP's experiences of BDD. The research purpose and aims, research questions and methodology are outlined in the following chapter.

4. Methodology

This chapter outlines the theoretical stance and methodological approach taken for this study.

4.1 Research purpose and aims

The purpose of this research was to derive a theory of YP's experiences of BDD. It aimed to answer the following questions:

1. What informs and perpetuates YPs' experiences of BDD, including in the home and education settings?
2. How do educational experiences inform the emergence and experience of BDD?
3. Does BDD impact a YP's experience of education and, if so, how?

This research had both exploratory and explanatory elements:

- **Exploratory:** To explore the experiences of YP who had been given and/or self-identified with the label of BDD and analyse what facilitated and/or hindered the experience and support of these YP in educational settings.
- **Explanatory:** To understand and provide an explanation of the experience of BDD in YP in the form of a theory.

This research also had an emancipatory element. I considered participants may experience feelings of empowerment as a result of talking about their experiences which, until now, have largely been absent from the literature. Validation and acknowledgment of YP's experiences of BDD appears to be both professionally and societally lacking. I conjectured that sharing their experiences may result in participants feeling their experience of BDD was worthy of attention and recognition; and may invite a certain level of catharsis. Indeed, all participants thanked me for conducting the study and shared their relief at being able to share their experiences. Parents expressed their gratitude, also. I hoped this research might raise the profile of the population of YP who experience BDD, not only in the scientific literature, but also, more fundamentally, in professional and public awareness.

4.2 Researcher's position: epistemology and ontology

The current research falls within a critical realist ontology and a social constructivist and symbolic interactionist epistemological position.

The constructivist approach acknowledges the crucial role of the individual, concluding knowledge cannot exist without individuals to construct it (Martin, 2006). Individuals construct their world in a unique way, depending on their cultural and societal background, their developmental history, and the social forces acting upon them. For social constructivists (Bruner, 1961; Dewey, 1929; Piaget, 1980; Vygotsky, 1962;1978), knowledge and understanding are human products, which are socially and culturally constructed in an active manner (Ernest, 1999). Therefore, knowledge is a result of one's interactions with others in the environment (Schunk, 2012). Particularly pertinent to this study is social constructivism, which has implications for the construction of identity and how this might be

subjectively experienced within the social world (Burr, 2015; Davies & Harre, 1990; Lafrance, 2009; O'Grady, 2005). Researchers have broadened this to include the body, its functions, and its dysfunctions (Stoppard, 2000; Ussher, 2011; Yardley, 1997).

Critical realism (Bhaskar, Archer, Collier, Lawson & Norrie, 1998) overlaps with constructivist approaches. It assumes there is a reality, but the way it is interpreted and experienced is affected by contextual factors, such as political factors, cultural context, and personal history. Some constructivists would posit the world is only our knowledge of it, while some critical realists would argue there is a world independent of our knowledge. This research sits within and between these positions, as this study is based on the following assumptions:

- BDD exists, but only because: (1) we (i.e., society and individuals) say it exists; (2) certain conditions, informed by dynamics of threat and power (Johnstone et al., 2018), have engendered the behaviours and experiences that have come to be classified as BDD; (3) the set of experiences comprising BDD have been defined as such.
- It is possible to posit a Grounded Theory based on the collected data, since there are possible underpinnings of BDD outside of YP's knowledge (and power) of their experience of BDD (Johnstone et al., 2018). However, any theory posited by myself as a researcher will inevitably be a construction informed by my own history, experiences, etc.

From the perspective of social constructivism (Szasz, 1961), psychiatric diagnoses could be viewed as constructions developed as a result of social and cultural influences, rather than examples of objective reality. This draws attention to the implicit essentialism of traditional psychiatric diagnoses, referring to the way in which diagnostic categories are viewed within the medical model as coherent, stable, and universal essences, e.g. the implication that BDD

has a genetic component or is caused by aberrant biology. Within the dominant medical model, presenting difficulties are typically seen as symptoms of an underlying biological and pathological process operating within the individual (i.e., a within-person view) (Beresford, Nettle & Perring, 2010).

From the perspective of critical realism (Bentall, 1999), psychiatric diagnoses may also be viewed as constructions; the difference is this approach does not assume the study of psychopathology should give way to discursive practices⁵ alone. Rather, by studying the social and political contexts within which diagnoses like BDD emerge, we can begin to replace biased or misleading concepts with more useful concepts, both scientifically and clinically. Thus, we can conceptualise and provide new theories, such as those offered in this thesis and in the *Power Threat Meaning Framework* (Johnstone et al., 2018), as further explored in the Discussion chapter.

Social constructivism and critical realism acknowledge that knowledge in the human sciences is historically, socially, and culturally bound. This contrasts with the dominant medical view of psychiatric diagnosis that mental illnesses are largely a-historical and a-cultural and are not strongly subject to changes in social norms. Importantly, when distress and behaviours are constructed as emerging from dysfunction within individuals, solutions tend to be offered at the individual level. Thus, NICE guidelines suggest CBT and high doses of SSRIs as treatments for BDD (NICE, 2005). This study hopes to further elucidate the systemic factors underpinning the experience of BDD in YP.

⁵ Discursive practices refer to the linguistic and socio-cultural characteristics of recurring episodes of face-to-face interaction; episodes that have social and cultural significance to a community of speakers.

In my view, diagnostic labels such as BDD are not an inevitable fact of human psychology or biology. Rather, there are alternative ways of defining or conceiving of the phenomenon (Johnstone et al., 2018). Indeed, there can be significant ramifications of conceiving of human distress as diagnosable pathologies (e.g., offering medications with unknown long-term effects). Thus, the most crucial question would not be whether BDD exists but, rather, how we can understand YP's experiences of BDD and support them in forging identities for themselves beyond their struggles. I acknowledge that another researcher may have constructed another Grounded Theory from the same data. Therefore, the findings are imbued with my interpretations, which themselves have been informed by my experiences.

The social constructivist and critical realist perspectives align, to a degree, with symbolic interactionism, the major theoretical perspective associated with Grounded Theory (Charmaz, 2014). Symbolic interactionism is a theoretical perspective that views self, situation, and society as constructed by human actions. The underlying assumption is that symbols and language play a crucial role in forming our actions and meanings. Interpretation and action are viewed as reciprocal processes, each affecting the other (Blumer, 1969; Dewey, 1934; James, 1950; Mead, 1934). Symbolic interactionists do not deny the existence of social structures; rather, they postulate that people both construct and reproduce them. They recognise human beings can name themselves, think about themselves, talk to themselves, imagine themselves acting in various ways, love or hate themselves, and feel ashamed or proud of themselves. Humans can, in fact, act towards themselves in all the ways they can act towards others. Thus, humans have a motivating inner life, alongside a collective life of symbols and knowledge that helps explain their external actions. Symbolic interactionists assert that meaning can be generated by examining interpretations people give to their experiences (Hollway & Jefferson, 2008), a core focus of this study.

Symbolic interactionists emphasise the distinction between the self-as-process and the self-as-object. This is particularly relevant to the experience of BDD, given that a key aspect is the objectification of aspects of the physical body (Veale, 2004). Attention is drawn to social identities typically having profound implications for claims to a personal identity (Stokes & Hewitt, 1976), another emergent theme of this study, as further explored in the Discussion chapter. Some symbolic interactionists would view the social self as being implicit in the experience of the personal self, and vice-versa. In BDD, part of the YP's experience of the personal self would appear to be determined by how they believe the self is perceived by others, i.e. the perceived social self.

4.3 Research methodology: a Constructivist Grounded Theory approach

4.3.1 Rationale for Grounded Theory

The methodological approach chosen for this research was constructivist Grounded Theory (CGT), a contemporary revision of Glaser and Strauss' (1967) original Grounded Theory (GT). The development of GT occurred at a time (during the 1960s) when qualitative research was dominated by a prevailing positivistic paradigm. It highlighted the inherent restrictions of positivist approaches in developing new interpretations of phenomena (Denzin & Lincoln, 2011) and placed emphasis on deriving theory from the research data using an inductive approach (Glaser & Strauss, 1967).

GT can be adopted by *“any epistemological perspective that is appropriate to the data and the ontological stance of the researcher”* (Holton, 2009, p.269). It is characterised by the constant comparison method, which aims to iteratively develop codes, categories and themes

through data analysis; and by theoretical sampling, which involves the identification and selection of rich data sources to explain the social phenomenon investigated (Charmaz, 2014). GT involves the progressive identification and integration of categories of meaning, resulting in a theory that provides an explanatory framework with which to understand the phenomenon under investigation. Different approaches have emerged within GT, including the CGT approach, developed by Charmaz (2014). Further description of CGT is offered in the next section.

I considered other qualitative methods of data analysis, including ethnography. Following supported reflection and a discussion with an expert ethnographer, I understood that deriving a general theory could not be met via this methodology within the given timeframes. In addition, ethical concerns related to subjecting YP who struggle with appearance-focused distress to extended observation rendered this approach, both ethically and practically, unfeasible.

I considered thematic analysis (TA) (Braun & Clarke, 2006), an approach which enables the researcher to identify and analyse themes in the data. I felt GT would provide a greater level of interpretation to search for an explanation of YP's experiences of BDD. I also considered interpretive phenomenological analysis (IPA), which studies how people make sense of their lived experiences (Smith, Flowers & Larkin, 2009; Starks & Brown Trinidad, 2007). This methodology would have enabled me to explore how individual YP view and experience BDD in their lives. However, IPA would not have sufficiently taken the wider societal context into account for my ontological and epistemological stance, nor would it have allowed me to connect and interpret what YP say about their experiences to provide a theory.

4.3.2 Constructivist Grounded Theory (CGT)

The constructivist approach to GT has historically been built on theories of social justice with a focus on *“furthering equitable distribution of resources, fairness, and eradication of oppression”* (Charmaz, 2005, p.203). Whereas traditional Objectivist Grounded Theory (OGT) (Glaser & Strauss, 1967) seeks to identify and conceptualise a core concern, CGT typically presents a theoretical product of a more diffuse nature, in keeping with the ontological relativism of multiple realities (Martin, 2006). While OGT aims to erase the social context underlying the data, CGT emphasises the importance of context and reflexivity of researcher interpretations, and the social context within which the data gathering process takes place. Thus, CGT results in an analytic interpretation of participants’ experiences and the processes which constitute how these experiences are structured.

From the outset of this study, I acknowledged, in line with the social constructivist position, that any resultant theory would be an interpretation, as I did not conceive it was possible to analyse data independently of my experiences, opinions, and values. I also acknowledged the impact of society on my personal constructions, alongside how human beings act towards things based on the meaning these things have for them (i.e., symbolic interactionism). Researchers *“are not passive receptacles into which data are poured”* (Charmaz, 2014, p.27) and cannot, therefore, claim either scientific neutrality or authority. I tangentially held in mind that my experiences (e.g. my historical diagnosis of BDD) may, in fact, enhance my sensitivity towards participants’ experiences and the data collected (Denzin & Lincoln, 2011).

4.4 Ethical considerations

4.4.1 Regulatory approvals

An ethics application was reviewed and approved by my research supervisor and the Research Ethics Committee of the Tavistock and Portman NHS Trust in June 2018 (see Appendix Four). The research complied with the British Psychological Society (BPS) *Code of Ethics and Conduct* (BPS, 2009) and the *Standards of Conduct, Performance and Ethics for Practitioner Psychologists* (Health Care Professions Council [HCPC], 2008). I sought and was granted permission from the BDD Foundation and OCD Action to use their membership lists for recruitment purposes, and from the Michael Rutter Centre at the Maudsley to send emails to YP who had consented to be contacted for research purposes.

4.4.2 Consent

I provided participants with detailed, written information about the study at least two weeks' prior to taking part, via an information sheet (BPS, 2009, 1.3: 1) (Appendix Five). Prior to signing a written consent form, potential participants were informed they would be at liberty to withdraw at any time (BPS, 2009, 1.4: 2). This action encompassed the additional aim of rebalancing the power differential between myself and the participants, particularly in recognition that a significant proportion of YP who experience BDD have reported experiences of relational disempowerment (Didie et al., 2006). I obtained written, voluntary, and informed consent from participants prior to participation (BPS, 2009, 1.2: 2) (Appendix Six). Confidentiality was protected by attributing anonymised, unique identifiers to each

participant and ascribing each with a pseudonym. Any data collected was anonymised and retained in an electronic file (BPS, 2009, 1.2:4).

At the outset, I made participants aware of the limits of confidentiality (BPS, 2009, 1.2:5), such as in the case of disclosures that suggested intended harm to self or others; research suggests a strong propensity towards self-harm and suicidal ideation in YP who experience BDD (Phillips & Albertini, 1999). I made participants aware that a small study, such as this one, would carry greater risks in terms of participant identification, but every effort would be taken to ensure anonymity.

I am a trustee of the BDD Foundation, through which, at least in part, participants were recruited. My official position is secretary, which involves keeping and disseminating minutes of meetings, producing literature, and co-facilitating support groups. If a participant had come forward who was closely known to me, careful consideration would have been given to potential researcher bias, or the possibility that the existing relationship may impact negatively on the participant or the research process. While I had briefly met a couple of research participants in the past (e.g., at BDD Foundation conferences), the relationship was not deemed intimate enough to make researcher bias a concern (Asselin, 2003).

4.4.3 Vulnerability and signposting

YP who identify as struggling with BDD are likely to be vulnerable. Both they and their families are likely to experience, or have historically experienced, multiple stressors, including psychiatric input, outpatient and/or inpatient treatment, depression, anxiety, and social anxiety. I signposted participants to the support offered by the BDD Foundation, OCD Action, and other organisations whenever appropriate, such as when participants expressed feeling

as though they were lacking support, that they had never met anyone else struggling with BDD and wished to (in this case, signposting was to support groups), and when they expressed current experiences of anxiety, depression, and hopelessness. I also signposted to leaflets/additional literature from other charities/organisations, as required. The conduction of this research led to me visit the Papyrus office (the UK's leading charity for young suicide) in London in March 2019 to obtain materials and information; this meeting has resulted in a link being forged between Papyrus and the BDD Foundation.

4.5 Reliability and validity issues

The principles of reliability, validity, and generalisation are treated very differently within qualitative research methodology. Creswell (2009 p.190) notes that qualitative validity *“means that the researcher checks for the accuracy of the findings by employing certain procedures”*. To this end, I engaged in systematic data checking and confirmation (i.e., checking new codes against previously ascribed codes), with a continual return to the research questions. I also engaged in the process of iteration (cycling between interpretation and collection of data) throughout, repeatedly re-examining my interpretations and ascription of codes considering further data collected. This helped to ensure a continual monitoring of both analysis and interpretation (Morse, Barrett, Mayan, Olson & Spiers 2002). Both early (open) and advanced (focused and theoretical) codes were brought to research supervision to confirm my interpretations made sense within the presenting data.

4.5.1 Trustworthiness

Positivists (e.g. Comte, 1975) have long questioned the trustworthiness of qualitative research, largely because positivist concepts of reliability and validity cannot be addressed in the same way as in quantitative research. Lincoln and Guba (1985) offer a view on how reliability and validity based principles can be met in qualitative research. They first introduced the concept of trustworthiness to provide a more applicable construct to qualitative research methods, instead of reliability and, arguably to a lesser extent, validity. They propose four components are inherent in the establishment of trustworthiness: (1) credibility; (2) transferability; (3) dependability; and (4) confirmability of findings.

Credibility is concerned with confidence in the truth of the research findings. This can be achieved by spending enough time in the field (Lincoln & Guba, 1985) and seeking negative cases (or codes) and alternative explanations (Robson, 2011). I conducted in-depth interviews while continuing to be immersed in my work as a trustee of the BDD Foundation. In addition, I kept reflections in the form of memos. I also took time to identify negative cases to consider how these might inform/alter the emergent theory.

Second, transferability implies the applicability of findings in other contexts (Lincoln & Guba, 1985). This was sought by utilising a semi-structured interview schedule, which could be used in other contexts, and eliciting rich accounts and descriptions from research participants to enhance the possibility of the findings' relevance to other contexts (e.g., older or younger YP; YP experiencing OCD; YP experiencing BDD and/or OCD in inpatient settings).

Third, I ensured procedures were consistent and could be repeated (Lincoln & Guba, 1985) to increase dependability. The use of detailed memos was supportive to this end, comprising an audit trail of research activity (Corbin & Strauss, 2008). The coding and analysis

of the interview transcripts was supported by the MAXqda software. This aimed to increase the level of transparency by documenting all data at each stage of the data analysis, as presented in the Appendices.

Last, confirmability was aimed for through the maintenance of a degree of neutrality (Lincoln & Guba, 1985); although I acknowledged this neutrality did not negate researcher influence and/or bias. Rather, I aimed for a degree of in-the-moment neutrality (e.g., not responding to accounts of suicide attempts with shock or overly nuanced emotional displays). I reflexively considered researcher bias in research supervision and within the memos (see Appendices Seven and Eight). This led me to explicitly state my assumptions throughout the research process and reflect on how these assumptions impacted the emergent codes and theory.

4.6 Research strategy

4.6.1 Research sampling: recruitment

I aimed to recruit 6-10 UK-based research participants⁶ aged 13-25 years who self-identified as having a historic or current experience of BDD. I chose this age range both because BDD typically emerges in adolescence, and to reflect the age remit of the EP (recently extended to 25 years). Therefore, I hoped to capture an range of experiences both at early and later stages of BDD.

Those who self-identified as having BDD were included. Research has shown BDD is often either misdiagnosed or diagnosed many years after onset (Zimmerman & Mattia, 1998);

⁶ To provide the potential for data sufficiency.

thus, YP may experience BDD who have not yet been diagnosed. In addition, I conjectured the inclusion of both groups would enrich the data in terms of having an experience of a distressing preoccupation with a perceived defect both inside and outside the context of a psychiatric diagnosis. Importantly, both YP who have been diagnosed with BDD and YP who self-identify as struggling with BDD require understanding and support. Those with a self-deemed historic experience were permitted inclusion, due to their potential insights related to moving through, and possibly assimilating, to a greater or lesser degree, their experiences.

CGT prompts the researcher to look for data where they are likely to find it (Charmaz, 2014). An email was sent out to all members of the BDD Foundation and OCD Action, inviting YP to take part. The Michael Rutter Centre at the Maudsley Hospital also agreed to disseminate the informational email. It was made clear within this email that this research was not affiliated with any support or advice offered by these organisations; any decision to take part/not take part would not affect a YP's affiliation/support.

When YP expressed an interest in taking part in the study, I asked them what support was available to them (familial and professional) to assess possible sources of containment. I made it clear they could contact me after the interview also, e.g. if the interview was emotionally challenging for them. I also asked whether they felt able to travel to the Tavistock for the interview and if they had someone who could accompany them if they wished. Two participants came with a supporter; who waited in the waiting room or local cafe while the interview took place.

YP gave their own consent. While three CYP under the age of 16 indicated their interest in participating, at that time their experiences of BDD made it unfeasible for them to travel to London to be interviewed. For this reason, and possibly others, the research

requirements (including the use of face-to-face interviews) may have excluded both CYP experiencing acute BDD, and younger participants in the early stages of their BDD experience.

No potentially-interested participant was rejected based on their gender or ethnic status. Consent was sought in line with the Helsinki declaration of ethical standards (World Medical Association, 1964: 2013).

Inclusion criteria for participants were:

- A YP who had a BDD diagnosis or self-identified as struggling with BDD or had struggled with BDD historically;
- Aged 13-25 years; and
- Fluent in both written and verbal English.

Exclusion criteria were:

- A YP who was currently receiving inpatient treatment, as vulnerability and risk levels might have been too high; and truly voluntary, informed consent would have been more difficult to assume, particularly if the YP was being treated under a section of the Mental Health Act 1983 (Hamilton, 1983);
- A YP who was on the SEN Register for severe communication difficulties;
- A YP who was using illegal substances at the time of interview or had used these substances within the last three months; and
- A YP with a primary diagnosis of psychosis/schizophrenia, as bodily sensations/hallucinations may have overlapped with BDD symptomatology; thus, potentially heightening distress beyond that for which support could be offered as part of this study.

All 10 YP who met the criteria and could travel to the Tavistock were permitted to take part in the research, following signatories on the consent forms (see Appendix Six). Due to the

small sample size, and for reasons of confidentiality and anonymity, a limited amount of information in relation to the participants' identities is disclosed. I removed parts of the transcripts that could compromise the participants' identities (e.g., names of towns/therapists/peers).

Self-Identified Gender	Age at Time of Interview	Ascribed Pseudonym
A (Female)	24	Angela
B (Female)	22	Beth
C (Female)	22	Catherine
D (Female)	25	Dion
E (Male)	16	Edward
F (Female)	18	Fiona
G (Female)	24	Gill
H (Female)	22	Hattie
I (Female)	18	Ingrid
J (Male)	22	John

Table 1: Research participants' gender, identifiers, ages, and ascribed pseudonyms

Of these participants, nine identified as white-British and one as Caribbean. Two were attending secondary school, two were attending university, four were working and two were neither in education nor employment due to BDD.

4.7 Interview schedule

I used semi-structured, intensive interviews to collect data. Intensive interviewing methods are a good fit with CGT methodology, as they are open-ended, yet directed, and allow emergent themes to surface (Charmaz, 2014). Intensive interviewing focuses on the topic, while providing an open space wherein participants' experiences can be shared.

Semi-structured interviews can be used with most versions of GT (Willig, 2013). I felt intensive, semi-structured interviews would be the most useful and ethical approach for this study, particularly given their allowance for participant-led foci around the core topics being discussed.

I considered alternative data-collection methods, including questionnaires and focus groups. Questionnaires have a propensity to omit the complexity of participants' experiences (Yardley, 2000); the use of focus groups was dismissed for similar reasons. Furthermore, a group context may have reduced the desire/ability of YP to attend and may have inhibited the sharing of personal accounts and experiences (Smith, 2008). I conjectured providing YP with the opportunity to tell their story face-to-face would enhance the emancipatory experience.

I discussed the proposed schedule with my research supervisor to determine whether all questions were open, non-judgmental, and exploratory in nature. His feedback was incorporated into the rewording and refocussing of the interview schedule. I refined the structure to aim for interviews lasting no longer than 75 minutes, so as not to overburden participants (Guest, MacQueen and Namey, 2012).

The content and structure of the interview was determined by questions which would afford an opportunity to address all research aims. I took time to ensure the questions were

simply worded and without the use of any jargon or medical-model language⁷. I sequenced potentially emotionally-charged topics in the middle of the interview, so as not to overwhelm participants at the outset or leave them with the memory of a difficult emotion/event at the end.

The initial question invited the YP to reflect on a personal object/piece of artwork, etc. they had brought with them, which they felt said something about their experience of BDD. The final question prompted the YP to share anything further which they felt had not been covered. Thus, the interview both opened and closed in a person-centred manner. I hoped this would be empowering and would place the locus of control with the participant, in recognition of the pre-existing power differential between myself as interviewer (i.e., researcher) and themselves as interviewees (i.e., participants) (Gubrium & Koro-Ljungberg, 2005). I also hoped this would increase the trustworthiness of the study by enabling participants to talk about topics of interest outside of my suppositions and preconceptions. Some of the objects brought along by participants were photographs, poems, pieces of artwork, and voice recordings.

In line with social constructivist thinking, I used the interview schedule questions as a guide only, employing flexible discernment and allowing myself to be led by the participants' verbal and nonverbal responses.

As the interview process unfolded, some early themes emerged. These themes were then woven into the interview schedule to further elucidate the emergent open and focused codes. Thus, the interview schedule was not static; rather, it was reviewed and amended throughout the interview process, both in the moment and between interviews.

⁷ For example, I refrained from using words like 'illness' and 'unwell', rather using phrases like, '...during the time you were distressed about your nose....'

Interviews took place in a private room at the Tavistock and Portman Centre and lasted between 38-72 minutes. I requested a room at the Tavistock which had been assessed as private, devoid of too much traffic/noise, and comfortable/amenable for a one-on-one interview. I checked with participants regarding whether they would like the light to be switched on or left off, in recognition of the possible distressing effects of strong lighting on those who experience BDD (Wilhelm, Otto, Lohr & Deckersbach, 1999).

4.7.1 Core qualities of the interviewer

I took time before the commencement of each interview to build rapport with the participants, chatting about their journey to put them at ease. Throughout each interview, I aimed to use the participants' language as much as possible, particularly when reflecting their answers back to them and making additional prompts (Moriarty, 2011). If I noticed the YP was still in a stage of uncertainty about the nature of their difficulties, I waited for them to use the term BDD before I did so.

I aimed to communicate genuine interest and respond non-judgmentally to whatever was shared and thus maintain neutrality (Hollway and Jefferson, 2008). As participants "*free-associated*" (Hollway and Jefferson, 2008, p. 296) to pieces of art/music/etc. they had brought to the interview, themes that did not originally appear to be relevant to me were explored for their contribution to an enhanced understanding of participants' experiences.

I regularly paused the interview process to explore a statement or topic, using open-ended invitations, such as, "*What does that mean to you?*" and, "*Can you tell me more about*

that?". I also aimed to remain vigilant towards potential defences⁸, in both myself and participants, within the interviews. I would sometimes probe sensitively while, at other times, would relinquish a topic participants appeared to be defended against. I posed further probing questions and statements sensitively and tentatively to elucidate participants' direct experiences, as opposed to making possible assumptions about these experiences.

4.8 Data transcription

The way recorded audio data are converted into written text can have a bearing on data analysis (Cohen, Manion & Morrison, 2007). There are two main approaches: (1) naturalism, in which every expression is transcribed in fine detail; and (2) denaturalism, in which any distinctive sounds are removed (Oliver, Serovich & Mason, 2005). The denaturalised system is most commonly used in CGT research (Charmaz, 2014) and removes stutters, pauses, and nonverbal or involuntary vocalisations. In line with this typicality, I selected a denaturalised system for this study for ease of reading, coding, and analysis.

The way in which spoken language is transcribed (e.g., where punctuation is added, where paragraph breaks are made etc.) can have an impact on the meaning conveyed, and, therefore, on the later data analysis. To consolidate this impact to a single source (i.e., one person) and ensure I did not miss out on the kinds of understandings that can develop as tapes were transcribed (Tilley, 2003, p.770), I transcribed all recordings myself, as opposed to outsourcing the process. Please see Appendix Seven for a sample section of transcript.

⁸ The psychoanalytic conceptualisation of defences describes unconscious psychological strategies used to deny, manipulate, or distort reality to defend against feelings of anxiety and uncomfortable impulses.

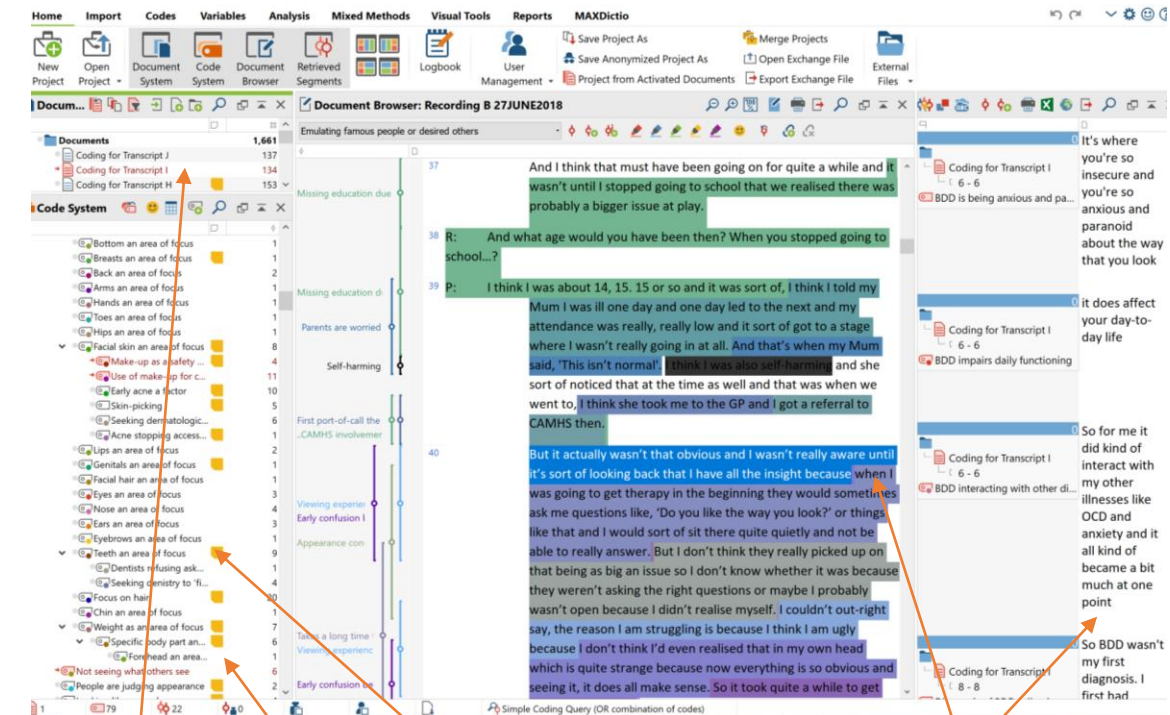
4.9 Computer-assisted qualitative data analysis software (CAQDAS): MAXqda

MAXqda-18 was used to analyse the data. MAXqda is a specific computer-assisted qualitative data analysis software (CAQDAS) that supports a systematic approach to conducting CGT. Codes, memos, and folders can be created with relative ease, and it is possible to colour-code text to support grouping and analysis.

I found MAXqda-18 to be a useful tool for transcription and code storage, as well as analysis of data, particularly when using the following features:

- **Search function:** Enables previously-ascribed themes to be found and integrated;
- **Segment-retrieval function:** Enables the user to see repeating themes in single transcripts and across selected transcripts;
- **Memo-writing function:** Enables the linking of memos to all types of codes and text;
- **Visual tools:** Provides data-sufficiency evidence; and
- **Interactive quote matrix:** Enables rapid finding of quotes linked to specific codes.

Figure 1 indicates the basic features of the programme:



Memos

Document Management System

Containing interview transcript files.

Coding System

Activated codes are displayed in the Retrieved Segments window.

Text Browser

Containing the coded transcript (coloured text and bars indicate ascribed codes).

Figure 1: Basic features of MAXqda

4.10 Data analysis

This section presents the method of data analysis involving iterative cycling between data collection, reading/re-reading transcripts, and replaying audio recordings. Reflexive processing was conducted simultaneously, i.e., considering my thoughts, reflections and researcher position in relation to the data being analysed. I used three phases of coding for

this study, in line with Charmaz's (2014) recommendations: (1) open; (2) focused; and (3) theoretical.

4.11 Stages of data analysis

4.11.1 Open coding

Initially, I became familiar with the data (Charmaz 2014) by listening to the audio recording of each interview at least three times, transcribing interviews with diligence, and reading through the transcripts of each interview on a minimum of five separate sittings.

Then, I identified initial conceptual labels by examining fragments of data to discern the key concepts they contained. A descriptive code was then assigned to text fragments. Rather than systematically fragmenting text according to lines, sentences, phrases, words, etc., I took an open stance of fragmentation, according to the subject matter contained within these fragments. Some fragments were single words, some were partial sentences, some were complete sentences, and others were sections of text longer than one sentence.

Reflexivity was extensively drawn upon in each stage of coding; and took a particular form in the open coding stage. I continuously asked myself how and why I was ascribing certain open codes to fragments of text and took great care not to overlay my judgments and assumptions onto these open codes. This was achieved by coding for action as opposed to meaning and using 'in vivo' codes as described in the following paragraph. This reflexivity shifted at the focused and theoretical coding stage. At this juncture, I began to consider the meanings, and how my experiences and assumptions informed my interpretations of these

meanings, the young people may be trying to communicate, directly and subliminally, through their narratives.

Some of the open codes were ‘in vivo’ codes, in which the title of the code was taken from the direct statement of a participant. This supported the theory to remain grounded in the data. Some examples were: (1) *“body is not you”*; (2) *“body feels wrong”*; (3) *“looking like a non-human”*; (4) *“BDD is like having two minds in the head”*; (5) *“can’t inflict appearance on others”*; (6) *“shame keeps you captive”*; and (7) *“BDD is like a monster”*.

An example of open coding is given in Figure 2 via a screenshot of MAXqda:

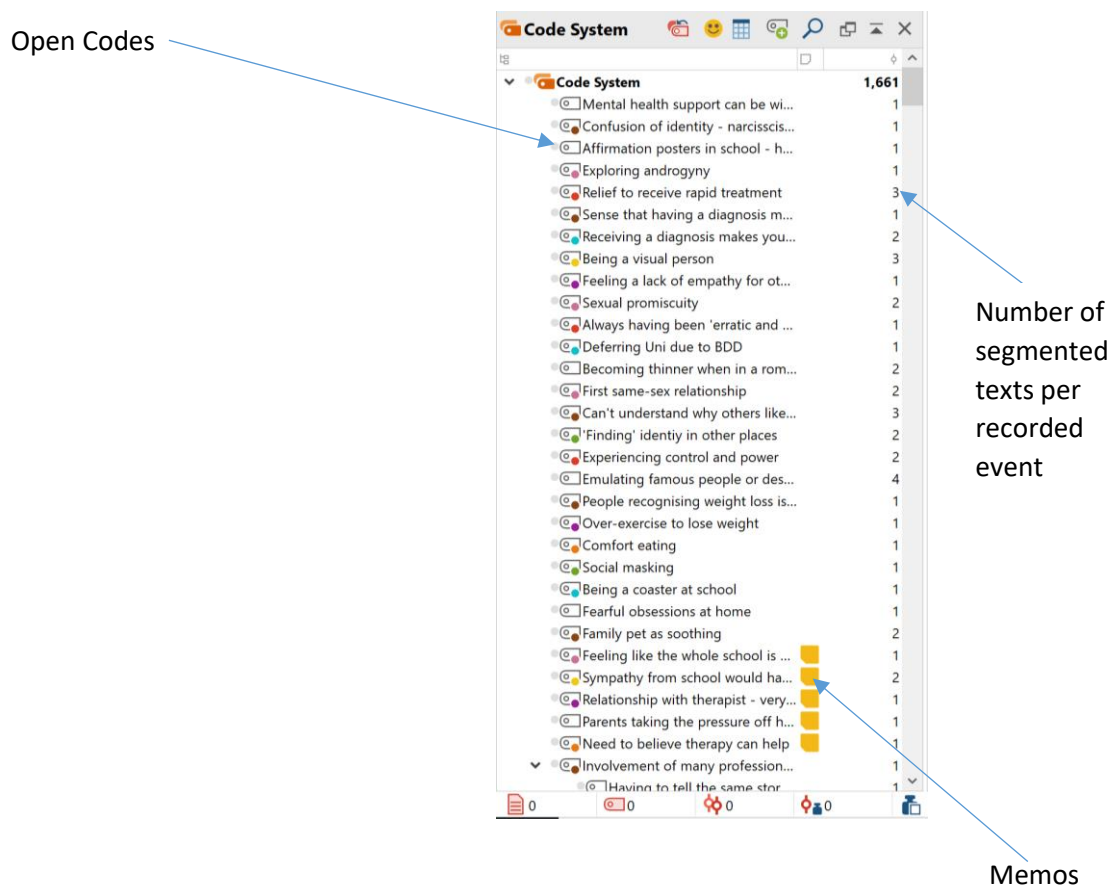


Figure 2: Open-coding example, MAXqda

The following is an example piece of the transcript and the open codes ascribed to it (Table 2):

Transcript section	Ascribed Open Codes
<i>"I think my brother and sister would sort of point it out (the YP's bellybutton) in the kind of teasing way you do in the bath and stuff, when we were very small, and I just had a very strong sense that it was something I needed to hide."</i> (Gill)	Having a perceived defect pointed out by siblings' teasing.
	Hiding perceived defect/experience from others.

Table 2: Example of open coding

4.11.2 Focused coding

In this next stage, which took place alongside the open-coding phase, I began to make links between open codes to group together concepts into broad categories. This involved continuously comparing pieces of coded text against other pieces of coded texts, and open codes against other open codes. This let me to bring connections together under more abstract and higher-order conceptual categories (Corbin & Strauss, 2008; Charmaz, 2014), using memos to document my reasoning. This stage of focused coding aimed to glean an understanding of the central phenomena in the data (Robson, 2011). Numerous open codes comprised the 19 focused codes raised, as demonstrated in Figure 3.

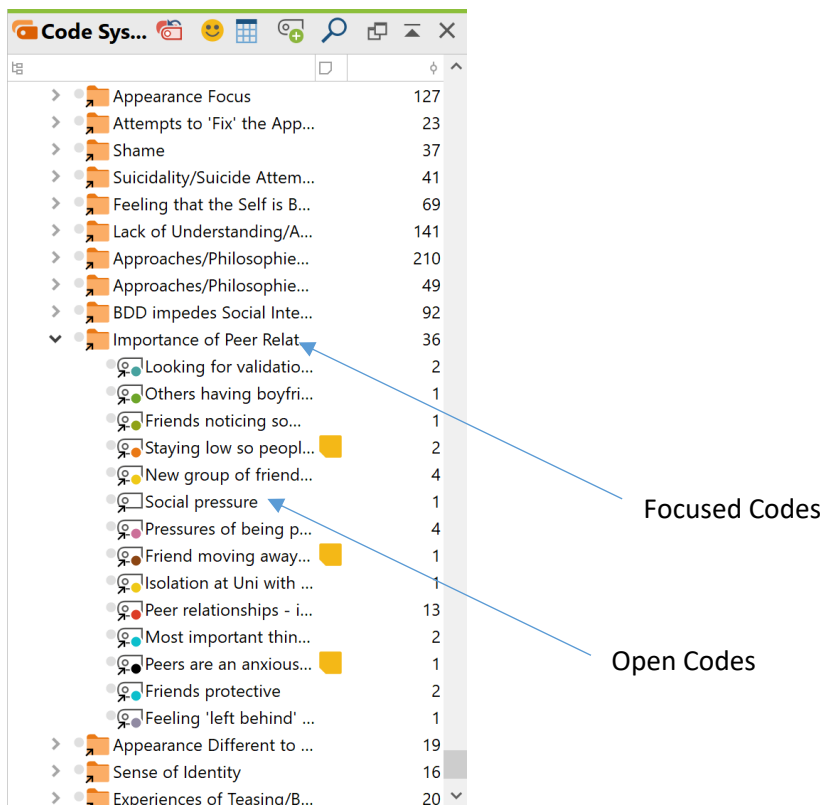


Figure 3: Focused coding example, MAXqda

The two open codes ascribed to the text segment in Table 2 formed part of the following focused codes:

Open Codes	Focused Codes
Having a perceived defect pointed out by a sibling/teasing	Experiences of teasing/bullying
Hiding perceived defect/experience from others	Shame

Table 3: Worked example of focused coding

4.11.3 Theoretical coding and grounding of theory

At this stage, I examined possible relationships between substantive categories (Charmaz, 2014). I came away from the computer, wrote focused codes (and a key selection of open codes) onto Post-It notes, and manoeuvred them into different groups over a period of around five weeks. I felt it was important to return to these physical conceptual maps daily over this period to check previous thinking against current thinking and discern any alternative groupings/possibilities. The process necessitated a continual return to the interview transcripts to check and amend the way open codes had been assigned. When I found myself becoming lost in the data (i.e., unable to see the wood for the trees), I stepped away, returning with fresh eyes at a later hour or date. I used memos to support and document my thinking.

To return to the example, the following open-to-focused codes became part of the following theoretical categories (Table 4):

Open Codes	Focused Code	Theoretical Category
Having a perceived defect pointed out by a sibling/teasing	Experiences of teasing/bullying	Appearance-based identity is informed by and informs relationships in young people's experiences of BDD
Hiding perceived defect/experience from others	Shame	Lack of understanding of BDD deepens shame and leads to stagnation of identity formation

Table 4: Worked example of theoretical coding

This process raised four theoretical codes (Charmaz, 2014). These theoretical codes supported the emergence of a conceptual description of an overarching, core conceptual category: *Appearance-based identity becomes the focus of adolescent identity formation in BDD, informed by relational experiences of shame and low self-worth*. Sample coded segments of text are given in Appendix 10 (a full list is available on request). A list of all focused and open codes is given in Appendix 12.

4.12 Theoretical sampling

Theoretical sampling prompts the researcher to retrace their steps or take a new path when ideas and categories emerge to “*elaborate and refine categories in your emerging theory*” (Charmaz, 2014, p. 192).

To continuously re-evaluate and compare emergent codes and fill any theoretical gaps, I reviewed and made subtle amendments to the interview schedule after individual interviews (see Appendix Three). I also conducted additional recruitment for male participants to further explore an emergent theme of ‘maleness, BDD, and increased experiences of shame’ within the *characteristics of BDD* focused code, as only one male came forward in the initial recruitment process⁹. Furthermore, I re-considered the emergent conceptual categories after each interview and each round of coding. Lastly, I repeatedly went back to the transcripts of each participant to check, qualify, and elaborate the boundaries of the emergent codes, including the specification of relationships between focused codes. Figure 4 offers a visual representation of this process.

⁹ This is noteworthy, given the equal prevalence rate of BDD in males and females.

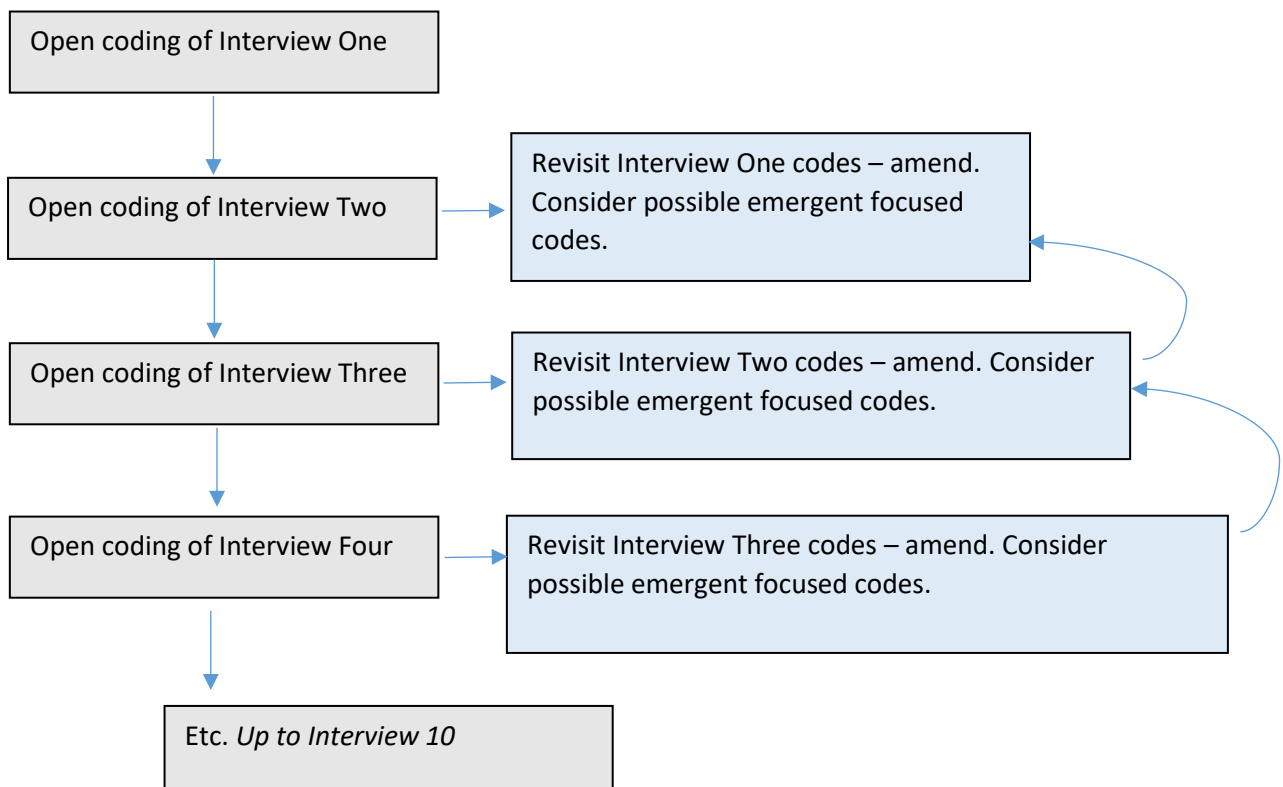


Figure 4: Coding process

4.13 Memos

Memo writing provides the researcher with material to ponder, explore, revise, and sort; constituting a crucial method in GT. It prompts the researcher to analyse their data and codes early in the research process, keeps them involved in the analysis, and helps increase the level of abstraction of their ideas (Charmaz, 2014). Glaser (1978) advised researchers to stop and write ideas as memos whenever they occur. I kept a notebook on my person throughout the study's duration for this purpose. I kept both early memos and advanced memos. I used early memos to: (1) explore and fill out qualitative codes; and (2) direct and focus further data collection. I used advanced memos to: (1) trace and categorise data, including identifying links between codes; (2) describe how theoretical categories emerged and changed; and (3)

identify the beliefs and assumptions that supported each theoretical category. Example memos are given in Appendix Nine.

Freewriting was used within memos, as described by Charmaz (2014). This process aims to get one's ideas onto paper as quickly and fully as one can, relinquishing any focus on grammar, etc. Focused freewriting supported me in times of immobilisation. See Table 5 for a memo example using freewriting:

Open Code	Example Text Segments	Freewriting Memo
Fear of being unlovable/being alone.	<p><i>"I just remember always having a sense in my head that I had really sticking-out ears, like elfish ears, and my belly button is weird, and I felt no one would ever love me because of these things, and I was different."</i> (Gill)</p> <p><i>"How can anyone love me?"</i> (Catherine)</p>	<p>This seems to be key. The sense that the self might be unlovable perhaps leads to ways to make the self more lovable. Society upholds a view that looking a certain way can increase our lovability, thus the person assumes they can become more lovable by changing the way they look. The problem is, as the appearance feature is 'fixed', the core sense of unlovability remains, thus the BDD moves on to another feature. Can treatments that fail to address the core sense and fear of unlovability ever be truly successful?</p> <p>This links with identity - the self as unlovable. Where did this decision that the self is unlovable spring from? Does</p>

		<p>this connect with family trauma and trauma of other kinds (i.e., teasing/bullying experiences in school)?</p> <p>BDD isn't about hating the appearance, it seems; rather, it is about hating who the person thinks they are.</p>
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Table 5: Example freewrite memos

4.14 Negative case analysis

Negative case analysis, a GT technique (Morse, 2010), involves the researcher actively looking for information that contradicts the emergent key concepts. The following negative cases emerged during the data analysis stage of this study:

- Two participants felt relational experiences of shame in the context of family relationships were not connected in any way to their experience of BDD, thus contradicting the theoretical code – *Appearance-based identity is informed by and informs relationships in young people's experiences of BDD.*
- One participant did not mention that BDD had impeded her access to education or work, thus contradicting the theoretical code – *Educational experiences trigger and are affected by BDD.*
- One participant had not experienced disordered eating related to her experience of BDD, thus contradicting the focused code – *Disordered eating linked to BDD.*

I explored data that demonstrated sharp contrasts with the major emergent patterns and compared them to the major patterns to further elucidate both, using memos to document my thinking. The negative cases informed the development of theory in the following ways:

Participant(s)	Negative case(s)	Reflections
Beth and Hattie.	Overtly stated there had been no family relationship difficulties or early traumas.	<p>One participant shared that her mother had been diagnosed with a life-threatening physical illness (which could be conceived of as a family trauma), and shared teasing experiences she did not feel overly affected by.</p> <p>The other participant shared that she had viewed others being bullied by her peer group, which affected her.</p> <p>Therefore, it would appear both participants had some difficult early-life experiences; the difference was they did not perceive these as being linked to their experience of BDD.</p>
Dion.	No impact on school or work attendance mentioned.	One participant did not mention academic pressures at school. She was currently self-employed. Therefore, it is possible academic pressures may increase BDD-related school and work absence. Self-employment could be hypothesised to make BDD-related experiences easier to manage for some YP.
Hattie	Disordered eating not part of the BDD experience.	Appearance focus for this participant was on her hair, which was not alterable through alteration of her weight. Therefore, disordered eating may be more typically linked to BDD in YP when the

		focus of appearance is alterable through eating behaviours.
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Table 6: Negative cases informing the GT

4.15 Theoretical saturation/sufficiency

The aim of GT research is to reach theoretical saturation (Glaser, 1992). This refers to a point in the data analysis when no new meaningful data emerges. Dey (1999) added to this idea with the notion of sufficiency, as opposed to saturation, as it is challenging to reach true data saturation in real-world research studies. Sufficiency does not necessitate data sources to be exhausted to make claims that most of the analysis is theoretically saturated.

In order to reach sufficiency in all areas, one additional male participant (John) was interviewed to further elucidate the theme of shame in relation to maleness and BDD, taking the number from nine to ten participants. Fewer new codes were added as the study progressed, alongside an increase in repetitive data; no new conceptual categories were emerging, and no new information was being added within these categories. At this point, I acknowledged theoretical sufficiency (Dey, 1999) was achieved. To view a table indicating the number of new open codes ascribed to each interview, see Appendix 11. This demonstrates fewer new open codes were ascribed to each participant as the study progressed.

4.16 Chapter summary

This chapter outlined the ontological and epistemological stance taken for this study, the purpose and design of the study, and an account of the methods applied. Chapter Five will outline the research findings.

5. Research findings

In this chapter, the findings of the CGT analysis are presented.

5.1 Aims

The overarching aim of this study was to develop a CGT of YPs' experiences of BDD. CGT methodology was used to analyse the data from 10 YP who self-identified or had been clinically diagnosed as experiencing BDD. The study explored how YP conceptualised their experiences of BDD, and what they found helpful and unhelpful in the home, educational and wider societal context.

5.2 Overarching theory

"The shame will always keep you captive." (Dion)

The CGT presented here proposes YP's experiences of BDD are complex and multifaceted, revolving around a core sense of shame (also described by the YP as worthlessness, perceived badness of the self and unlovability), which is then projected onto a perceived defect, around which adolescent identity formation then becomes focused. I summarised this as the central theoretical category: *Appearance-based identity becomes the focus of adolescent identity formation in young people's experiences of BDD, informed by relational experiences of shame and low self-worth.* The study findings and emergent theory formed the basis of a newly

proposed model, the *Shame-Identity Model of BDD in Young People*, as outlined in Figure 5. A more detailed discourse of this model will be offered in the Discussion chapter.

Four main theoretical categories comprised the central category. These were each comprised of numerous focused codes, which themselves were comprised of multiple open codes (see Figures 5 and 6, and Table 7).

I turn to psychologist Silvan Tomkins to open this section of the thesis:

“Though terror speaks of life and death and distress makes the world a vale of tears, yet shame strikes deepest into the heart of man. While terror and distress hurt, they are wounds inflicted from the outside, which penetrate the smooth surface of the ego; but shame is felt as an inner torment, a sickness of the soul. It does not matter whether the humiliated one has been shamed by derisive laughter or whether he mocks himself. In either event, he feels himself naked, defeated, alienated, lacking in dignity or worth.” (Tomkins, 1963a, p.118)

Shame-Identity Model of BDD in Young People

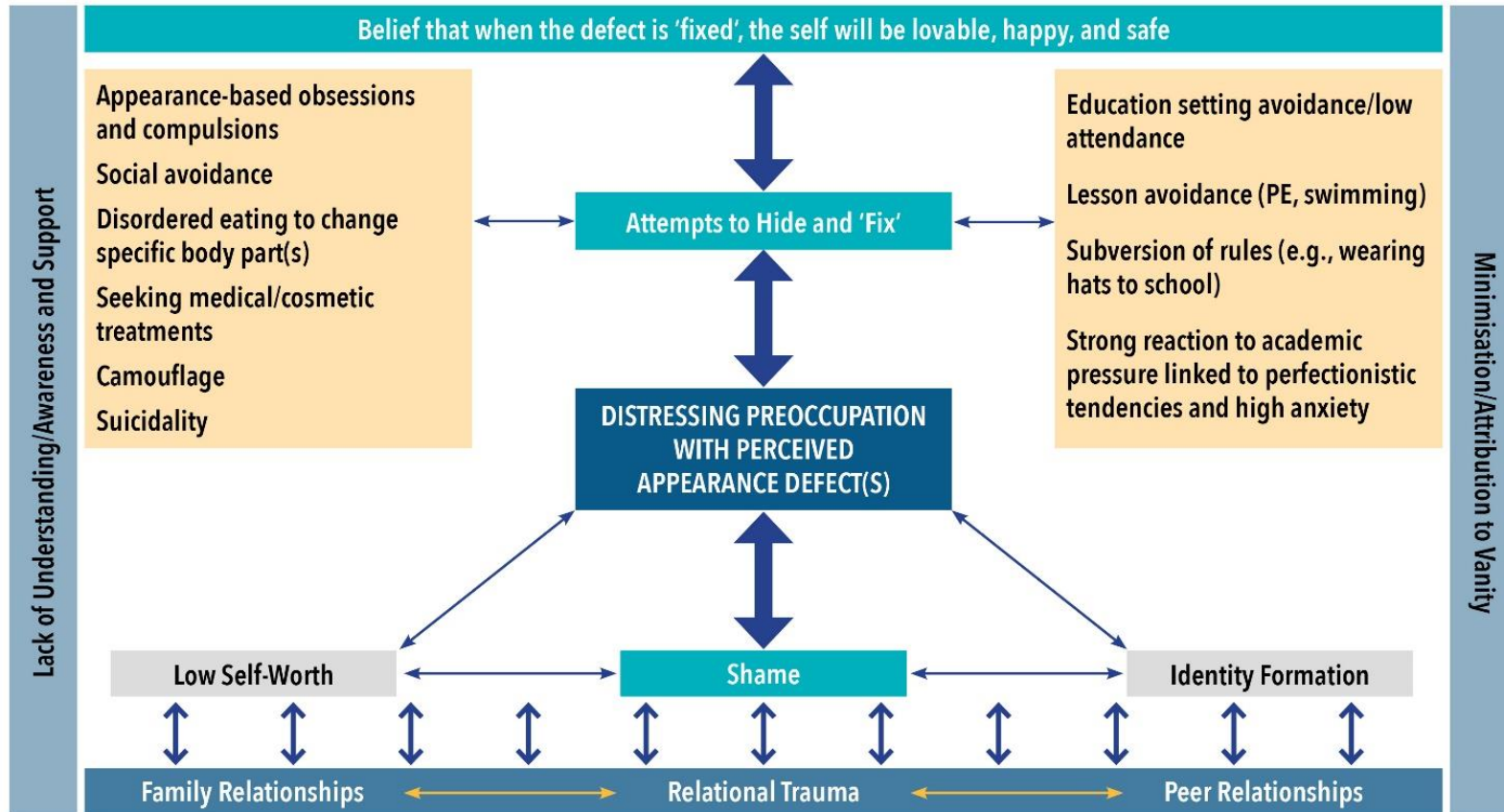


Figure 5: Shame-Identity Model of BDD in Young People

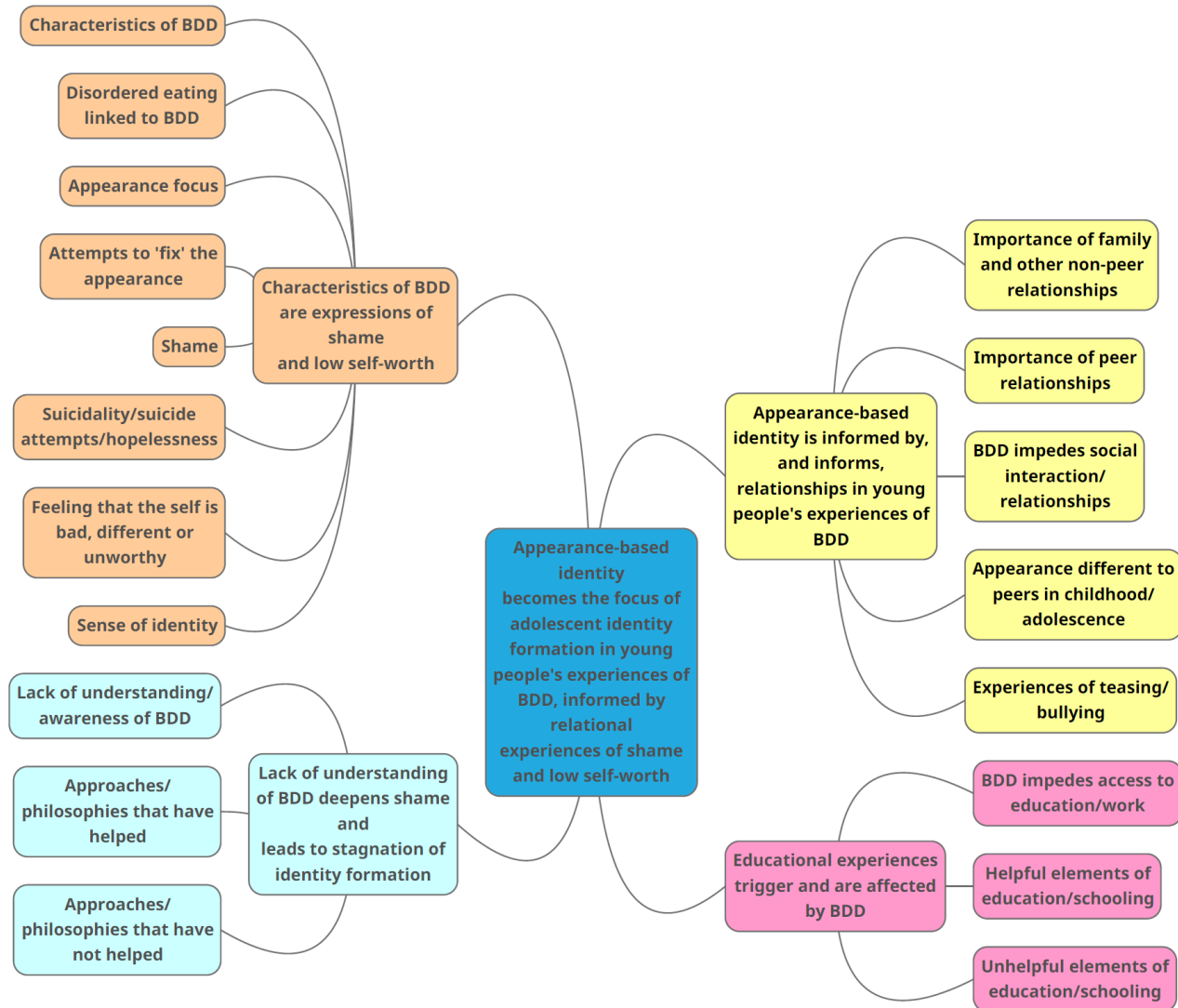


Figure 6: Mind map of open, focused, and theoretical codes

Central Category: Appearance-based identity becomes the focus of adolescent identity formation in young people's experiences of BDD, informed by relational experiences of shame and low self-worth

Theoretical categories	Focused codes	Number of open codes	Participants
Appearance-based identity is informed by and informs relationships in young people's experiences of BDD	Importance of family and other non-peer relationships	23	ALL
	Importance of peer relationships	18	ALL
	BDD impedes social interaction/relationships	28	ALL
	Appearance is different from peers in childhood/adolescence	6	Angela, Catherine, Edward, Fiona, Hattie
	Experiences of teasing/bullying	10	Angela, Beth, Catherine, Edward, Fiona, Gill, Hattie, Ingrid, John
	Characteristics of BDD are expressions of shame and low self-worth	Characteristics of BDD	78
	Disordered eating linked to BDD	16	Angela, Beth, Catherine, Dion, Edward, Fiona, Ingrid, John
	Appearance focus	42	ALL

	Attempts to fix the appearance	8	ALL
	Shame	19	Angela, Beth, Catherine, Dion, Edward, Fiona, Gill, John
	Suicidality/suicide attempts/hopelessness	14	ALL
	Feeling the self is bad, different, or unworthy	28	Angela, Beth, Catherine, Dion, Edward, Fiona, Gill, Ingrid, John
	Sense of identity	12	ALL
Shame-based educational experiences trigger and perpetuate BDD	BDD impedes access to education/work	18	Angela, Beth, Catherine, Edward, Fiona, Gill, Hattie, Ingrid, John
	Helpful elements of education/schooling	38	ALL
	Unhelpful elements of education/schooling	51	ALL
Lack of understanding of BDD deepens shame and leads to stagnation of identity formation	Lack of understanding/awareness of BDD	39	ALL
	Approaches/philosophies that have helped	76	ALL
	Approaches/philosophies that have not helped	32	ALL

Table 7: Focused and theoretical codes

5.3 Detailed analysis

The following four sections outline how the conceptual theoretical categories informed the CGT.

5.3.1 Theoretical Category One: Appearance-based identity is informed by and informs relationships in young people's experiences of BDD

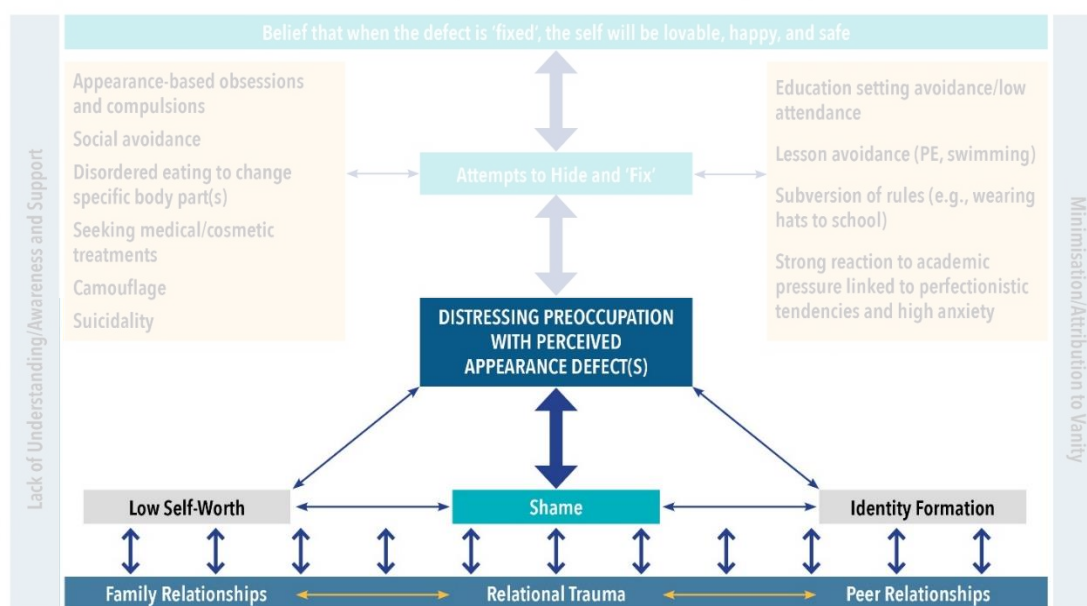


Figure 7: Section of Shame-Identity Model of BDD in Young People as informed by theoretical category one

The current findings uphold findings of previous (non BDD-related) studies; that identity is necessarily formed in relationships with others (Cooper, Grotevant & Condon, 1983; Cote, 1996; Marcia, 1967). Most of the participants' experiences of shame appeared to have emerged in the context of family and/or peer relationships. The relationships these participants had with their family members and peers appeared to have informed their felt sense of self; their sense of identity.

5.3.1.1 Importance of family and other non-peer relationships

All participants talked about the impact of various relationships on their experience of BDD, including relationships with family, peers, therapeutic staff, and educational staff. They also spoke about the impact these relationships had on the development and experience of their distressing preoccupation with their appearance.

Shame in the context of difficult familial experiences was spoken about by eight participants, including fractious relationships with parents. Fiona explained, there were *“issues within my family anyway, like with my Dad and stuff... I didn’t get along with my Dad at all, whatsoever... I’d have constant fights when I came home”*. This was prior to her distressing preoccupation with her perceived defects. Some participants talked about not getting along with their parents, nor receiving emotional support from them, including during peer-related bullying experiences (e.g., *“I’ve been very bullied and did not receive much support from my Mum and Dad.”* [Catherine]).

Two participants felt they had received a lack of affirmation from their parents, and two experienced their parents mocking their appearance. A couple of participants explained appearance was lauded as being important by their parents, in comparison to other traits (e.g., *“I feel like, for me and my family, looks were a big thing, and something that would be talked about... comparing me to my cousin, for example. That, for me, was probably an early kind of trigger, as well.”* [Ingrid]). Experiences of appearance being important to their families and/or peers seemed to highlight the appearance-based aspect of their identity more prominently than other aspects of their personhood (i.e., personality, creativity, intelligence,

etc.). I hypothesise this may be part of the reason why the YP themselves came to place such an emphasis on appearance; thus, losing sight of the value of other aspects of their identity.

Seven participants mentioned a lack of communication between family members, including *"...there being a lot of stress in the family, and a lot of anger, and not really very much communication between anybody, or expression of love between anybody"* (Gill). Three participants shared a parent was currently or had historically struggled with mental health issues, including hoarding (Gill), alcoholism (Catherine and Dion), and/or narcissism (Catherine). One participant's mother had experienced frequent low moods (John). Two participants mentioned domestic violence. Dion described parental infidelity as a factor in her BDD, as it made her feel she was *"not good enough"* for her father. Gill explained, in relation to her difficult family situation, *"at that age, you just have no concept of what's not acceptable for someone your age to be seeing or be living like or experiencing, and so you just ultimately blame it on yourself."*

Two participants talked about having siblings with mental health difficulties. Edward's brother missed school for a couple of years due to *"anxieties and stuff"*, and John's brother struggled with drug addiction. Catherine described her grandmother having mental health difficulties, and that her behaviour would *"add fuel to the fire"* of the difficulties in her family home. These experiences suggest BDD may be informed by transgenerational experiences and patterns.

Importantly, two participants felt their BDD was not linked in any way to their familial experiences. As Beth explained, *"I am very close to my family and my Mum, and I have that kind of support."* (See negative case analysis in Table 6).

5.3.1.2 Importance of peer relationships

The task of 'belonging' in adolescent identity formation came through strongly in every interview. Some participants spoke about social pressure within their peer group being linked to their experience of BDD, including the need to fit in (e.g., *"I think it was the moving into the new friendship group. This social pressure. Kids are mean. At 12 years old, kids are nasty, and so it was very much like that, feeling like I had to fit in."* [Fiona]). Four participants spoke about the pressures of being part of the in-group, explaining how difficult it was to be *"cool in general"* (Hattie). Hattie added, *"The people I hung out with were kind of like the popular girls, and I... watched them bully others... even though it wasn't directed at me, I was kind of aware of, like, people being critical to others."*

For Fiona, moving to a new group of friends was a direct trigger for her BDD, as this highlighted appearance as a salient element of her identity: *"...from first year to second year (secondary school)... I got involved in a new group of friends, and it was the first time I sort of cared about my appearance."* Others touched on this theme in the context of transitioning from primary to secondary school, and/or their experiences of secondary school:

- *"I think probably that transition of going from primary... to secondary school, where there's so many more people. That probably, like... led me to engage in these behaviours, like camouflage¹⁰."* (Angela)
- *"I feel like the transition from primary school to high school was a big thing for me, effectively for the worst."* (Ingrid)
- *"I'd say... secondary school... I really didn't like."* (Dion)

¹⁰ Camouflage in the context of BDD describes using cosmetics, clothing, etc. to cover up and hide perceived appearance defects.

- *“I went to an all-girls school, so I’m just surrounded by teenage girls. Not the ideal environment.”* (Hattie)
- *“I don't think there is help in a grounded way, especially in secondary school... it all sort of feels a bit gimmicky.”* (John)

The transition to university in the context of peer relationships was mentioned by four participants. Gill felt going to university meant it was *“the first time that I suddenly was without people around me that make me feel like I’m a good person in some ways. So, then I thought, ‘I am just nothing’... it’s a very strong point in my memory of when it got really bad.”* For Hattie, the transition to university was the *“final push”* towards recovery, despite finding it *“very scary to live in halls”* initially. John had retracted his plan to go to university, because he felt so distraught about his appearance and believed he would not be able to manage emotionally nor fit in. Perceptions of the self as an unworthy person came across poignantly. Participants described how difficult it was for them to imagine why their peers might like them or want to include them in their social group.

Participants cited peer relationships as being important in multiple ways, including close friends being aware of their struggle with BDD and being able to talk to and connect with them (e.g., *“I think what was one of the most important things for me... to be able to just be with people and talk to them.”* [Gill]). Having new friends after a transition to university was cited as important for their recovery by two participants, as was rekindling friendships after a period of absence from school and being *“able to go out for the first time and enjoy my independence”* (Ingrid).

A couple of participants talked about being able to forget their BDD-related worries while socialising, as *“just being immersed with all these people just makes you forget about everything”* (Hattie). A few participants found it particularly helpful to have reassurances from

peers while struggling or in a crisis. John had found it helpful, though difficult, to be confronted by peers and invited to watch a documentary about BDD while he was struggling: “...my friends... they started piecing together things that I'd been saying about my lips and my nose or my hair, and they found the ‘Ugly Me’ documentary.” Hattie described her two best friends as being her “bodyguards” when people asked her why she had been absent from school due to her BDD.

5.3.1.3 BDD impedes social interaction/relationships

“Everything I did kind of somehow led back to, ‘I’ve got this big secret (the perceived defect), and no one can know and it’s very shameful.’” (Gill)

Two participants shared that peers had spread rumours about why they had been absent from school. Understandably, this compounded the shame they already felt. For Beth, one rumour claimed she had “gotten pregnant and had a child”, while another was that she was “off partying in Europe.” Fiona experienced a rumour that she “had something wrong with my bladder” because she left lessons to go to the toilet so regularly to mirror-check. She added she had “just let that one go”, as she preferred people to assume she had a bladder infection, rather than think she was “vain” or struggling with BDD. Two participants talked about experiencing a backlash after telling their friends about their struggles. Dion experienced a close friend disclosing she had been making herself vomit “in front of, literally, my whole school year” after she has confided in this friend about her experience of bulimia.

Most participants spoke about anxiety related to social relationships. Hattie had been formally diagnosed with social anxiety prior to her BDD diagnosis. Participants talked about

feeling as though they had nothing to offer in social relationships. Gill explained, *"I just became more and more socially anxious, and I just... I dreaded even walking along the road with somebody, because I felt that I wouldn't have anything to say, that I would just feel completely embarrassed and blank, basically."* Participants shared experiences of social anxiety in education settings (e.g., *"I remember specifically, the thought of being in lecture halls and seminars with other people was just so overwhelming. I just had to avoid that altogether."* [Angela]). John explained he was constantly questioning, *"Why does everyone respond to me so well if I always feel like a bit of a fraud?"*

Social paranoia was a prevalent code across participants, which expressed itself in such statements as, *"comparing and seeing people looking at me, which makes me extremely uncomfortable most of the time"* (Edward). It was not unusual for some participants to regularly engage in *"scanning the area and sort of listening to what other kids were saying, and if they were talking about me, or assuming that if they laughed, they were laughing at me"* (Beth). For Ingrid, *"it got to the point where I couldn't go outside, in case people looked at me and judged me"*.

Participants' avoidance of social situations appeared to have been related to this social paranoia. Most participants had missed family and/or peer occasions because of their perceived defect(s). Catherine described her experience of having to attend a family wedding as causing her to be *"so stressed out that I smashed a mirror, and then I just decided I wasn't going, couldn't go; it was too much. It hurt me too much, and then the thought of going there and feeling like everyone was looking at me."*

One participant (Beth) spoke directly about people-pleasing tendencies in the context of social relationships. Others alluded to it. Catherine shared she had allowed her friend to give her a tattoo, even though she was not trained, because she had wanted to please her.

People-pleasing tendencies led to fawning/submitting¹¹-type peer interactions for some of the participants; thus, potentially adding further evidence to underlying feelings of unworthiness and possible relational trauma.

5.3.1.4 Experiences of teasing/bullying

Bullying and teasing in the context of peer relationships was spoken about by five participants as an aspect of their BDD experience. Gill described it as *“the nail in the coffin”* of her appearance-focused distress. Most of these participants experienced appearance-focused teasing within an education setting. For Catherine, *“it all started when I was about eight or nine, and I used to breathe in because the other kids started making fun out of me for being chubby.”* Angela was teased for being tall and would experience subjectively hurtful comments like, *“What’s the weather like up there?”* Ingrid experienced teasing for being pale, which led to a distressing preoccupation with her skin. Angela described her experiences of bullying as being *“...definitely a catalyst, the bullying, and I think that sort of triggered the self-focused element of BDD.”* John explained he had forgotten his close friends would tease him about his nose, until they reminded him some years later: *“I actually didn’t remember until only a few months ago, when he told me that they would always make fun of my nose. And I had no memory of that, which, I suppose, I blocked it out... it was almost so horrible that I can’t remember it at the hands of really good friends.”*

¹¹ Fawning/submitting refers to laying aside one’s needs and desires for another’s needs and desires, in order to maintain a relational connection.

5.3.2 Theoretical Category Two: Characteristics of BDD are expressions of shame and low self-worth

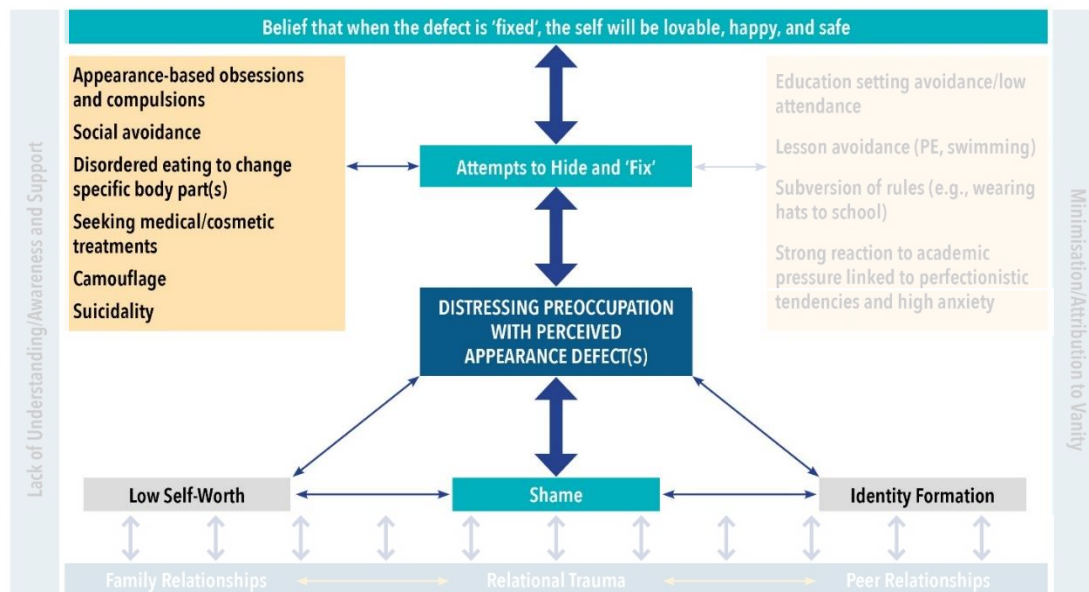


Figure 8: Section of Shame-Identity Model of BDD in Young People, as informed by theoretical category two

Each of the characteristics of BDD were described by the participants as an attempt to protect, amend, and make sense of a fractured identity, and/or to remove and/or soothe feelings of shame. Participants talked about engaging in appearance-focused compulsions to remove their sense of shame and amend their physical appearance, and thus, their core identity, from a ‘bad’ person to a ‘good’ person, who was acceptable to the self and others and worthy of attention and love. As Dion so poignantly described, *“I think that was how it really stemmed, that idea of not being good enough, not feeling like I’m enough, and I think that spiralled into how I visually saw myself.”*

5.3.2.1 Characteristics of BDD

Participants mentioned the following characteristics of their experience of BDD (Table 8):

Characteristics (Open Codes)	Participants Who Mentioned This Characteristic
1. BDD being linked to (i.e., following/preceding) other psychiatric diagnoses and/or psychiatric experiences	ALL
2. Safety behaviours ¹² (related to the appearance defect[s])	ALL
3. Impairment in daily functioning	ALL
4. Social anxiety	ALL
5. Feelings of hopelessness	ALL
6. Area of appearance focus moving	ALL
7. Seeing something different to what others see, in terms of appearance	ALL
8. Experience of aspects of the appearance as defective/ugly	ALL
9. Attempts to fix the perceived defect(s)	ALL
10. Obsessive and/or compulsive behaviours	ALL
11. Significant gap between onset and diagnosis	Angela, Beth, Dion, Edward, Fiona, Gill, Hattie, Ingrid, John
12. Anxiety and depression	Angela, Beth, Catherine, Edward, Fiona, Gill, Hattie, Ingrid, John
13. Use of camouflage, including makeup and clothing	Angela, Beth, Catherine, Edward, Fiona, Gill, Hattie, Ingrid
14. Broader feelings of not being good enough and of being different and/or unworthy	Angela, Beth, Catherine, Dion, Edward, Fiona, Gill, Ingrid, John
15. Seeking cosmetic surgery/dentistry/dermatology	Angela, Beth, Catherine, Dion, Fiona, Gill, Hattie, Ingrid, John
16. Suicidality	Angela, Beth, Dion, Edward, Fiona, Gill, Ingrid, John
17. Mirror-checking	Angela, Beth, Catherine, Dion, Fiona, Hattie, Ingrid
18. Undergoing cosmetic/dermatological/dentistry procedures	Angela, Catherine, Dion, Edward, Hattie, Gill, Ingrid
19. Using do-it-yourself procedures and products at home to fix the perceived defect	Angela, Beth, Edward, Fiona, Hattie, Ingrid, John

¹² Safety behaviours refer to compulsions undertaken to soothe anxiety and/or protect against rejection, e.g. using camouflage.

20. Social paranoia	Angela, Beth, Catherine, Dion, Edward, Ingrid, John
21. Believing the self/their life would be better if the appearance changed/the defect was 'fixed'	Angela, Beth, Catherine, Dion, Fiona, Ingrid, John
22. Surgery/cosmetic procedures not helpful long-term	Angela, Catherine, Dion, Edward, Gill, Ingrid
23. Experiencing distress at night	Angela, Beth, Catherine, Edward, Fiona
24. Feelings of exhaustion	Beth, Catherine, Edward, John
25. Experiencing BDD as episodic	Beth, Catherine, Edward, John
26. Initially believing it isn't BDD; the self is simply ugly	Angela, Beth, Fiona, John
27. Researching cosmetic procedures online	Beth, Edward, Ingrid, John
28. Mirror (and reflective surface) avoidance and/or mirror-checking	Catherine, Dion, Edward
29. Suicide attempts	Angela, Fiona, Ingrid
30. Feelings of anger	Catherine, Fiona, Ingrid
31. Overall perfectionism	Beth, Hattie, Ingrid
32. BDD particularly difficult during the summer months	Angela, Catherine, Ingrid
33. Use of alcohol and/or drugs to make distress more manageable	Fiona, Gill, John
34. Sensory experiences/feelings of physical pain	Catherine, Gill, John
35. Believing the body is not the self/does not fit	Angela, Catherine
36. Not able to see changes in own appearance (i.e., feeling that the self is the same weight after losing weight)	Catherine, Dion
37. Experiencing the body as a prison	Angela, Gill
38. BDD linked with a sense of being out of control	Catherine, Ingrid
39. BDD experienced as a persecutory voice	Beth

Table 8: Characteristics of BDD cited by participants

The use of camouflage was a characteristic of BDD spoken about by eight participants. One participant (Hattie) talked about wearing the same clothes every day, while two participants

talked about wearing excessive clothing to hide aspects of their appearance. Five participants talked about using makeup to cover their facial skin, often using many layers and multiple products. Fiona would use *"lots of makeup on my skin, like four foundations... so much makeup."* Angela would also wear her makeup to bed, in case someone might walk in/a fire alarm may go off. Participants spoke about being unable to leave the house without their makeup on and feeling *"...very, very distressed if I was asked to take it off"* (Gill).

Another preoccupation-based behaviour, shared by three participants, was skin-picking as an attempt to remove perceived blemishes. Beth explained she would *"always get tricked to skin pick whenever I was looking in the mirror... and then I would try and cover it with makeup because the skin picking made it worse"*. Fiona explained she was *"desperately, like...trying to clear my skin, and then picking. Like, so much picking, all the time...."* For these participants, it appeared picking their skin was an attempt to remove their perceived defect to ameliorate the sense of shame they felt.

Experiencing aspects of their appearance as being ugly/repulsive had a very strong impact for all participants; they described perceiving themselves as a *"monster"*, an *"alien"*, and a *"non-human"*. As Catherine described it, *"I'm not saying I'm Quasimodo or the Elephant Man, but at times, in my head, that's how I see myself."* All participants, in some way and to some degree, spoke about that belief that if their perceived defect were to be fixed, they would be a more acceptable and lovable human being, and would no longer experience any difficulties. Fiona put it in the following way: *"I do still think if my skin was clear, then I wouldn't have any problems."* There was a deep sense that if their appearance defects were to be fixed, the participants would perceive their identity as a person who was lovable and good.

A few participants talked about experiencing a disconnect between their bodies and their felt sense of self. For example, Angela described feeling uncertain about how far certain

parts of her body extended out in space, explaining, *"It's almost as though it's not you from a point onwards."* Catherine described her sense that *"...my head doesn't match my body. It doesn't fit. It's not supposed to be on my body"*. Gill explained she *"...felt completely trapped in my own body"*, while Angela shared her sense that *"you're in there somewhere, but... your external is just like... it's just like a prison, almost"*.

Some participants described sensory experiences related to their BDD, including feelings of physical pain. Gill expressed her frustration about this aspect of her experience, as she felt it had not been understood nor validated by professionals: *"...my sense of what I think is BDD is that I have kind of a lot of sensations in my body and just a lot of kind of pain. So, I just... I don't feel I've really been helped to understand that. So, I'm quite frustrated."* Frustration at the lack of people's understanding appeared to lead participants to believe they must be abnormal in some way; as they were unable to find people, including specialist professionals, who could understand their experiences. In part, this may be why BDD support groups were cited as being helpful by two participants (e.g., Hattie explained these support groups *"definitely lifted me up"*).

Gill explained she used alcohol throughout her university years to numb her uncomfortable physical sensations related to BDD. Catherine smoked tobacco to soothe her anxiety, while Fiona found the daily use of marijuana to be relieving: *"It made me calmer, and it made me think deeper about things, and it made me reason a lot more."* John used both alcohol and drugs to soothe his feelings of social anxiety: *"...I've always been kind of erratic and manic, sort of. I would drink too much and take too many drugs to kind of feel more confident."* Use of these substances appeared to provide participants with a temporary sense of an altered identity; that is, a person who was more relaxed, less socially anxious, and more

interesting to be around. They also appeared to numb the YP's feelings of shame and unworthiness, albeit momentarily.

5.3.2.2 Shame and sense of identity (related to diagnosis)

"I think I have always had a lot of shame." (Beth)

Receiving a BDD diagnosis was something most participants found difficult to talk to family and friends about. Seven participants described feeling as though the label of BDD did not apply to them initially, since they believed they truly had appearance defects. Angela remembered *"looking it up (BDD), and I, at first, it's like I'm sure many other people feel; I was like, 'No, this isn't me. I'm just ugly.'"* The concept of BDD was particularly difficult for participants with slight physical anomalies to assimilate into their understanding, especially for participants who had experienced acne. As Fiona explained, *"...people are telling me that I'm seeing something that other people don't see, and I was so angry about that because, like, 'You guys don't know; my skin is genuinely really bad.'"* This was complicated by participants spending significant amounts of time covering their blemishes with cosmetics. Therefore, they felt others were unaware of how bad their skin was. Some participants were afraid of mentioning BDD to others, in case their perceived ugliness would be confirmed, as explained by Dion: *"...the fear of people's opinions, and what they would say... I think I always had this fear of, okay, if I actually put this out there, people will affirm it, and they will say, 'Well, you actually are ugly, so you're correct.'"*

Participants talked about the challenges of waiting a long time for a BDD diagnosis. Part of this challenge was feeling the self must be abnormal, as nobody seemed to understand

what was occurring. The following ages were cited by participants in terms of first manifestations of BDD and initial BDD diagnosis, if they had received one (Table 9):

Participant	Age of First Manifestations of BDD	Age of Diagnosis
Angela	8	18
Beth	13	17
Catherine	6	No formal diagnosis
Dion	13	20
Edward	11	14
Fiona	13/14	15/16
Gill	3/4	20
Hattie	10	14
Ingrid	10/11	16
John	8	22

Table 9: Age of first manifestations of BDD, and age of diagnosis by participant

For those nine participants who had received a formal diagnosis, there was an average of 7.2 years between onset of struggle and diagnosis. The main reasons for this time lapse were: (1) receiving other diagnostic labels/diagnostic overshadowing; (2) minimisation of distress by others; (3) lack of professional understanding; (4) feelings of shame leading to hiding one's compulsions and obsessions; (5) believing the perceived defects were real; and (6) believing physical treatments (e.g., dermatology), not psychiatric treatments, were required.

5.3.2.3 Appearance focus

The sense of diagnosis-related confusion seemed to be heightened by the experience of BDD moving from one appearance focus to another. Catherine described it in the following way: *“My stomach has always been an issue, but it's kind of like I had a basket. I had a BDD basket, and, at first, I picked up my belly... and then I picked up this awful hair, and then I picked up this awful forehead... then it was my eyes... they are not right... eventually, my basket was full, and everything was, you know, it was like a grey cloud that just came over.”* Hattie similarly explained, *“The acne kind of calmed down, so then that was quite early on after my diagnosis. So, the BDD kind of moved to other things, so my hair, facial features, and clothes.”*

The following areas of appearance distress were cited by participants in this study (Table 10):

Body Part	Number of Participants	Number of Codes	Participants Who Mentioned This Body Part
Facial skin	7	44	Angela, Beth, Catherine, Gill, Fiona, Hattie, Ingrid
Head Hair	6	18	Angela, Beth, Catherine, Fiona, Hattie, Ingrid, John
Weight	6	13	Angela, Beth, Catherine, Dion, Edward, Fiona, John
Teeth	5	14	Angela, Beth, Catherine, Dion, Edward, Ingrid
Stomach	3	9	Catherine, Edward, Gill
Nose	3	3	Beth, Catherine, Ingrid, John
Eyes	2	3	Catherine, Dion
Ears	2	3	Catherine, Gill

Lips	1	1	Catherine, John
Body skin	1	2	Ingrid
Back	1	2	Catherine
Legs	1	2	Catherine
Genitals	1	1	Catherine
Hips	1	1	Catherine
Chin	1	1	Catherine
Arms	1	1	Catherine
Hands	1	1	Catherine
Toes	1	1	Catherine
Facial hair	1	1	Catherine
Breasts	1	1	Catherine
Eyebrows	1	1	Catherine
Buttocks	1	1	Catherine

Table 10: Areas of appearance concern by number of participants

The most common areas were similar to those found in two adult studies (Phillips & Diaz, 1997; Phillips et al., 2005) (cumulative number, $n=507$ participants), with skin and head hair being the most prevalent in both. The graph below refers to the results of this present study.

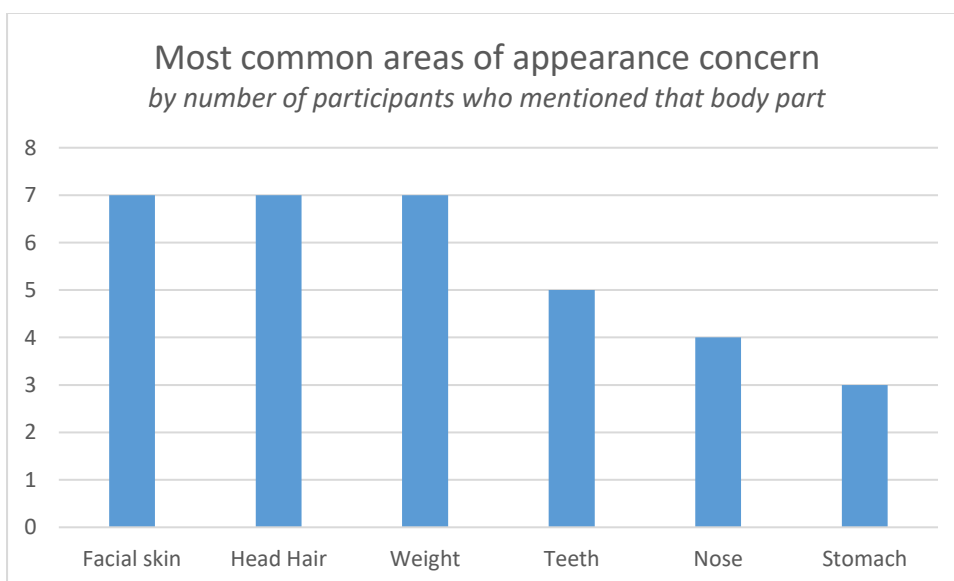


Figure 9: Six most common areas of appearance concern by number of participants

Participants talked about engaging in repetitious mirror-checking (five participants), avoiding mirrors for fear of catching sight of their perceived defects (three participants), and using certain safe mirrors (two participants). Safe mirrors were described by participants as mirrors they felt they could trust more than other mirrors. This seemed to relate to the location of the mirror (e.g., safe mirrors mostly seemed to be at home, and unsafe mirrors to be mostly in public places, like the school toilets). This possibly suggests these YP felt safer and better able to trust their reflection when there was a reduced possibility of this reflection being seen by others. BDD, therefore, would seem to be related to how one believes others see the self.

One participant (Edward) would run home from school each time he needed to use the toilet to avoid seeing his reflection: *“I just don't really go to the toilets in the school whatsoever because then there are mirrors everywhere... I'll literally, you know, just like sprint home.”* Other reflective surfaces, such as cutlery, were also mentioned by Edward. He would hide them for fear of catching his reflection in them: *“I kept moving things... and, like, hiding things that, like, showed reflections and stuff... I didn't want to make a big fuss of it.”* This notion of not wanting to make *“a big fuss”* was described in different ways by some of the other participants. This appeared to be related to participants feeling they were not important/worthy enough to warrant the concern of others.

5.3.2.4 Suicidality/suicide attempts/hopelessness

For nine participants, suicidality and/or hopelessness was a feature of their experience of BDD. Three reported, during the interview, that they had made suicide attempts, and each of these three had made more than one attempt. Fiona's two suicide attempts were prompted by feeling coerced into returning to school before she felt she was ready. Participants who

spoke about feeling suicidal cited reasons such as: (1) feeling life was pointless; (2) wanting cosmetic surgery and being unable to get it; (3) feeling like things were not going to get any better; (4) fear of others judging their appearance; (5) feeling as though there was no point in trying when one could take 'the easy way out'; and (6) believing nobody cared about them. As Gill observed, *"It was kind of the first time it dawned on me that if I didn't do anything, if I just stopped and lay there in bed, that nothing would happen; no one would care. Yeah, there was just black, and there was no point in living, really, because that's what life was."* The sense of life not being worth living if one does not belong and/or is not cared for by others was a strong narrative across participants' interviews.

Feelings of depression and anxiety were shared, to some degree, by all participants. For some, this included panic attacks. For Catherine, these were severe enough to raise concerns about possible epilepsy. For some participants, their depression became overwhelming, rendering them unable to get out of bed in the morning or leave the house. According to Ingrid, *"Even getting out of bed was a task for me; the thought of getting out of bed and having to face the day made me physically sick."* Three participants had been prescribed medication specifically for depression and anxiety. For Angela, her dual diagnosis of anxiety and depression seemed to impede a diagnosis of BDD, as clinicians were not looking into why she was anxious and depressed: *"I remember that, even up until that point... looking over the GP's shoulder at the notes she was making; the title was always 'depression with anxiety'... so, I was like, oh, maybe I'm just depressed and anxious, and BDD isn't the thing."* Feelings of depression and anxiety were typically cited by participants as being related to their perceived appearance defect(s), while some participants talked about feelings of depression and anxiety being present before their appearance-focused preoccupations. For most participants, it also seemed they blamed their perceived appearance defect for their feelings

of anxiety, depression, and shame. There was a sense that, once the perceived defect was fixed, the YP expected to feel better, as previously described.

5.3.2.5 Disordered eating linked to BDD

Nine of the 10 participants described disordered eating as being related to their experience of BDD in some way. For the majority, these aberrant eating behaviours were engaged in to alter a specific body part (e.g., the shape of their face).

Frustration induced by diagnostic overshadowing with disordered eating was cited by four participants. Edward captured this frustration poignantly: *"...people think, kind of like, there's only one issue. Let's sort out one issue at a time... they were just like, 'So, you want to be lighter?' and stuff like that, but it wasn't just about weight; it wasn't just about numbers...it wasn't just about that, but they were the questions I got asked."* Participants described their eating behaviours being just one of the many ways they attempted to alter specific body parts, and how misunderstood they felt when diagnostic labels such as anorexia were ascribed to them without further questioning why they engaged in certain eating behaviours. Edward and John, the two male participants in the study, found the label of anorexia to be particularly shameful and difficult to talk about with their family members and peers.

5.3.2.6 Attempts to 'fix' the appearance

Participants spoke about using a variety of methods to 'fix' their perceived defect(s) to remove the deep sense of shame they felt. Ingrid explained how she *"used to push my nose down as hard as I could because I didn't want it to grow, and I didn't want it to get big"* and

“push my teeth against the frame of my bed, hoping they would push back.” Four participants sought dentistry for their perceived defect(s), and all received it. Two participants sought and received braces. Dion explained, *“I remember writing in my diaries... if only I had my teeth done or if I had different-coloured hair or if I had different-coloured eyes, you know, I'd be more happy with myself.”* Teeth-whitening was also engaged in by two participants, and Angela had her teeth shaved, in addition to inquiring about veneers. Ingrid explained she had been through a *“conveyor belt”* of treatments: *“I've gone through fake tans, dyeing my hair, hair extensions, eyelash extensions, microblading my eyebrows and my teeth; I had braces when I was 15. My parents paid for them because, obviously, they weren't bad enough to get them off the NHS, so I got my parents to pay, you know, quite a lot of money for me to get my teeth straightened and whitened. So, it's been quite a conveyor belt of things I've gone through.”* Fiona described her experience of the appearance-focused distress moving from one body part to another becoming a *“vicious cycle... getting worse and worse”*.

Edward shared his experience of putting weights on his stomach to flatten it. To remove his moles, he would *“chop them off and stuff, which is extremely painful.”* Hattie would trim her own hair in an attempt to fix it, while other participants talked about dyeing their hair. John had sought and received drugs for halting/reversing hair loss.

Dermatological interventions had been sought by four participants, and all had received them. This included dermatological consultations, microdermabrasion, facials, antibiotics, and skin-planing¹³. The purchase of over-the-counter dermatological treatments was also typical, as described by Fiona: *“I've tried absolutely every antiviral, antibiotic product under the sun.”* Some participants would spend time each day researching procedures on the

¹³ A procedure in which dead skin cells and small hairs are removed from the top layer of the skin.

internet. As Beth described it, *“I would be shut up in my room quite a lot, and I’d often be online, doing things like researching plastic surgery, going on social media, comparing myself.”*

Catherine spoke about having various tattoos and piercings. She explained, *“I get tattoos, and I feel good about myself for a little bit.”* She explained getting Botox injections had also boosted her confidence for a short while. As this sense of feeling better about her appearance was short-lived, she added, *“I won’t do it anymore.”* Gill explained she had undergone surgery on her bellybutton and Angela had *“done a couple of, like, not too invasive, like, cosmetic procedures”*. The physical treatments participants engaged in had not reduced their feelings of low self-worth, depression, anxiety, and shame in the long-term, as the core sense of unlovability they felt remained, thenceforth projected onto another perceived defect. As Beth explained, *“I was just, sort of, a bad person deep down.”*

5.3.2.7 Feeling the self is bad/different/unworthy

Each of the participants spoke about or strongly alluded to feelings of inadequacy/low self-esteem which were broader than their perceived appearance defects. Beth explained, *“My sort of big fear is that I’m unlovable, and I will always be alone.”* Gill shared, *“I guess I tried to think of different things, like, that I could do, and I felt that that’s the only way I was going to be loveable¹⁴; otherwise, I wouldn’t be.”* Gill later added, *“I just felt very... just terrible about myself, and I didn’t feel like I had anything to offer anyone and would just stay in my room a lot. I was just very, very, very lonely.”*

¹⁴ It was from this quote that the partial title of this thesis was derived.

For some participants, the feeling of not being good enough led to attempts to try out alternative identities. John described experimenting with different personas by watching film actors and members of the public and taking on their manner of dressing, speaking, etc. to assume their identity: *“He was beautiful: Mixed-race skin, gorgeous lips. He was the tiny and athletic and lithe that I'd always wanted to be, and he had a really good dress sense, and it was just like all of my focus went onto him, and I was, like... I would buy all the kind of clothes he would wear; I started listening to all the music he was listening to... it was, like, another obsession.”* For those participants who talked about this theme it seemed, in some way, that the ‘fixed’ perceived appearance defect epitomised their idealised self-identity.

5.3.3 Theoretical Category Three: Educational experiences trigger and are affected by BDD

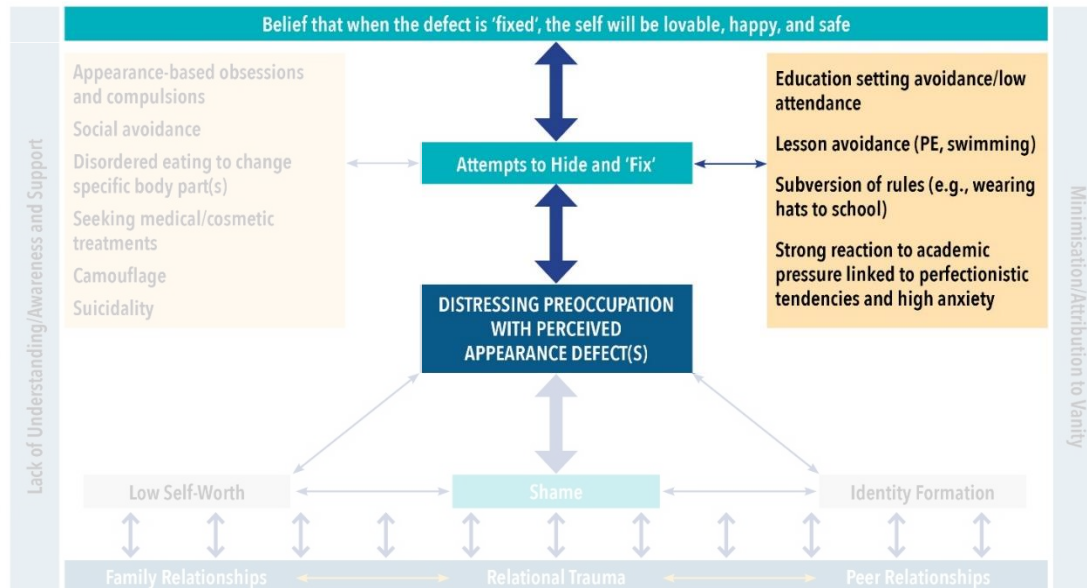


Figure 10: Section of Shame-Identity Model of BDD in Young People as informed by theoretical category three

The findings of this study suggest participants yearned to be understood, validated, and empathised with in the educational setting. They hoped, within their educational setting, to

avoid further experiences of shame and to have their identity recognised, esteemed, and bolstered. Some participants seemed to feel as though they had lost their individual identity after transitioning to secondary school (becoming just one of a large crowd), in addition to experiencing increased academic pressure and social pressure from peers. It appeared that the formation of these participants' identities was being informed by relationships with peers and educational staff, in addition to familial relationships.

5.3.3.1 Missed education

These findings suggest YP experiencing BDD may miss a significant amount of education (Table 11).

Participant	Overview of Missed Education
Angela	Missed numerous university lectures and seminars. At one point, stopped going to university altogether.
Beth	Missed most of five years of school (going in only for the odd day, with attendance increasing to 30-40% in sixth form). Currently, low attendance at university (is gradually improving).
Catherine	No mention of missed school. Intermittent missed work days and changing jobs frequently, due to BDD.
Dion	No mention of missed school.
Edward	Regularly skipped Fridays at school (due to PE). Averaging 69-72% for GCSE years. Absent from school for multiple weeks during inpatient hospitalisations.
Fiona	Regularly didn't come into school until lunchtime (due to getting ready). Attendance regularly dropped as low as 12%. Described being " <i>hardly there</i> " for GCSE years.
Gill	Often arrived late for school, due to appearance-focused behaviours beforehand. Missed majority of lectures and seminars at university.
Hattie	Stopped going to school altogether at the age of 12/13. Raised attendance to 40% for GCSE year. Often skipped PE.

Ingrid	Stopped going to school in year eight. Rarely went to school thereafter. Did not sit any GCSEs.
John	Retracted his plans to go to university due to appearance-focused distress.

Table 11: Overview of missed education for each participant

Reasons cited for missing education related to BDD included: (1) taking a long time to get ready in the morning; (2) depression (including finding it difficult to get out of bed); (3) anxiety (particularly social anxiety); (4) eating challenges (e.g., feeling weak due to not eating enough); (5) feeling overwhelmed by BDD; and (6) being “*hungover*” (Gill) (due to drinking a lot of alcohol to numb BDD-related feelings and bodily sensations). As Beth described it: *“And then I think the BDD would just get the better of me... the BDD was always there... I would be sort of sitting there and having this voice, you know, saying, 'you are disgusting; people are staring at you; you're ugly; you need to leave' and things like that, and I couldn't really take that for so long.”* This sense of feeling the self was disgusting, which I hypothesised was linked to a core feeling of shame, seemed to be the underlying reason participants missed education.

Academic pressure from both parents and school staff was an early emergent code, and three participants talked about going to academically pressuring schools. For each of these participants, the academic pressure seemed to grow, starting in year seven (e.g., *“I did quite like year seven, maybe that first term. I had a small friendship group, and I was doing well academically, but it was definitely a pressurising, highly academic, 'trying to get to Cambridge or Oxford' kind of school. So, that did make me quite stressed, on top of how I was feeling.”* [Hattie]). Some participants cited the academic pressure imposed both by others and the self as one of the reasons it was difficult to attend education.

5.3.3.2 Unhelpful elements of education/schooling

Two participants spoke about the struggle experienced by their parents when trying to get them to school each morning. For Ingrid, her parents *“were so frustrated and so angry, and it got to the point where they just... they gave up. They couldn't do any more. They couldn't force me, even though they tried.”* Beth talked about her internal battle of wanting to go to school but feeling unable to, despite the patience and support of her mother: *“I'd just turn around and get my mum to drive me home, and then I would say, 'No, no, I want to go to school,' and we would do a loop, back and forth, sort of 10 times each morning.”* Participants also expressed feelings of guilt resulting from the impact their BDD had on their parents, which appeared to further deepen their sense of shame, e.g. *“That decade was so turbulent for me and my family. And I love them so much and to put them through the stuff I did...”* (tails off, looking upset) (Angela).

Three participants spoke about finding it difficult to concentrate on schoolwork, due to their BDD. Edward *“found GCSE year really hard because you're meant to be, like, focusing on working hard and stuff like that, and I could revise at home, no problem. Because at least at home, I knew no one was watching me.”* Catherine explained, *“I have trouble concentrating, because my head's like a whirlwind”*. Gill shared, *“...just focusing my eyes on a page and reading a whole sentence; I find it very difficult”* due to the appearance-related preoccupations she was experiencing. Some participants engaged in compulsions to alleviate their anxiety and improve their concentration. Edward would *“...sneak out of school, run home, brush my teeth, and come back... without it, I feel... I don't know... I just feel really irritable, and I can't concentrate.”*

Two participants felt the initial trigger of their BDD had partially been in the educational context. For Angela, it was having a school photo taken. For Fiona, it was the general school environment, alongside difficulties with her father.

Disconcertingly, seven participants spoke about being punished in educational settings due to their BDD-related behaviours. Edward received a *"few detentions"*, due to his BDD-related behaviours, and described his sense that one of his teachers *"hated"* him because of these behaviours. He felt his teachers *"saw it as me not trying... 'he's just bunking the lessons'... they started to be a bit mean to me... it must have seemed like I was just, you know, at home, just messing around."* Angela also received a detention related to her BDD. These punishments are hypothesised to have further compounded participants' sense of shame and feelings of being both misunderstood and rejected.

Participants shared that the pressure to attend school on top of their BDD-related struggles was too much to cope with at times. Beth explained, *"What was difficult was, on top of the anxiety of the BDD worries and stuff, like, that it was, 'You're not at school; you should be at school.' I think they arranged for me to come in and meet with the school welfare officer and said that I was playing truant, and I said, 'I'm not; I'm mentally unwell.'"* Beth later shared she had been *"threatened"* with exclusion due to her low attendance, *"and that was quite difficult because I felt like I was being punished, and I was sort of thinking, there is nothing I can do. I want to be at school, and they were sort of threatening me and saying, 'Well, if you don't come in, you need to go (to be excluded).'"* Ingrid's parents were almost taken to court over her high level of absenteeism. She explained, *"I just felt like everyone's kind of against me."*

Some participants talked about being singled out by teachers. Fiona shared, *"...every lesson, I'd get, like, angry emails from the... teacher, telling me off for, like, missing my lessons,*

and then the ... teacher would just have such low expectations of me. They just made me feel so shit.” Experiences such as these understandably led some participants to feel *“quite awkward around the teachers because I felt like they thought I was truanting or didn’t want to be there or was a bad person... and was just skipping lessons.”* (Beth). Ingrid explained when her BDD started, *“...it was like the whole school was against me, and it was very much very overwhelming.”*

Particularly difficult lessons cited by some participants were PE and swimming. Reasons were linked to the fear of: (1) removing clothing; (2) wearing shorts and short-sleeved tops; (3) getting their hair wet; (4) putting the hair up; and (5) smudging makeup. Three participants would skip school specifically on the days they had PE and/or swimming. Gill explained, *“I remember being about seven years old... and not wanting to get changed for PE in front of people. So, every year, that became a problem, ongoing, weekly, which gave me a lot to think about and worry about.”* Two participants appreciated not having to go to PE and swimming lessons and being able to use the periods as study time for other subjects. They highlighted the importance of not making assumptions about why they did not want to attend swimming and PE. For example, Hattie was afraid of going swimming for fear of getting her hair wet, and she was resistant to participating in PE as this would mean having to tie her hair up. It had nothing to do with exposing parts of her body, as may have been presumed.

Five participants shared their incredulity that educational professionals had never asked them for the reasons behind their behaviours. Angela explained, *“It’s funny how that was instantly seen as, like, ‘Oh... you’re being awkward; you need to be punished.’ Like, I would’ve loved someone to be, like, ‘Why do you, like, always forget your PE kit? Why do you hate PE? Why are you doing so well in all of your other subjects, but you hate PE?’. And maybe*

if someone did do that, they could've got something out of me earlier than 18." Gill explained, *"I was never asked anything about why I might be behaving the way I was."*

Two participants shared their fears about being left behind by their peers, both socially and academically, due to the amount of school they had missed. Four participants talked about having missed exams due to BDD and/or having found exams particularly stressful (e.g., *"I guess I only just got through the GCSEs; I was just on my last tether the whole time."* [Hattie]). Edward found it difficult to ask for missed work from peers: *"You feel a bit embarrassed, continuously going back to your friend to rely on and ask, 'Can I have this?'... and then they'd ask, 'Why weren't you in?'"* Fiona spoke about how difficult it was for her to imagine a life beyond school: *"I just was so intent on such a small picture for so long. All that mattered to me was what they (her peers) thought of me, and how I was looking at school, and what I was doing, and I wasn't thinking about anything beyond school. Only this year, I have thought about my life beyond school properly."* Conceiving of an identity beyond their school years seemed to be difficult for each of the younger (pre-aged 20) participants of this study.

Three participants shared their opinion that the whole school system needed to change to better support mental health. Hattie explained, *"It was just very... it was just quite pressurising, I guess, extremely. So, I don't know what they could have done really, like, individually. I guess they'd have to change the whole school system, and what drives it."*

5.3.3.3 Helpful elements of education/schooling

Participants were asked about any elements of their education and/or education settings that had been helpful during their experience with BDD. A few participants explained that, in terms

of keeping up with schoolwork during absences, they appreciated schoolwork being sent home and missed schoolwork being placed on an online portal to negate them having to ask their peers. One participant appreciated extended deadlines, three participants found it helpful to sit exams in a separate room, and one participant found it a relief to receive exam results alone. A few participants felt part-time schooling and/or a flexible timetable would have been beneficial and found college/university easier than secondary school for this reason.

Six participants shared that individual teachers were helpful and supportive. This appeared to have been invaluable, such as for Edward: *"She's my favourite teacher, easily, and I can talk to her about lots of things, which is nice. But she was like, 'Are you okay? I noticed that you always have a blazer on, and you just have your arms crossed normally,' and I was like, 'Yeah, yeah. I'm fine,' and then she kind of just kept on talking to me because I'm pretty sure she knew that something was going on, to a point where she was just like, 'Are you okay? I have noticed that you haven't been in,' and this and that."* Fiona described her form tutor as *"like, literally, my second mum. I go out for coffee and stuff with her, and she texts me about school, and a lot of the time, when I'm not in in the morning. So, she'll just text me... she has my back, so I use her as a support system."* Having a key adult to validate their identity beyond their struggles appeared to help participants perceive a broader identity for themselves and reduce feelings of being misunderstood and ashamed.

Participants cited the following as particularly helpful, in terms of support from individual teachers: (1) knowing about BDD/knowing why they had been absent from school; (2) allowing the YP to approach them for support in their own time, while making it clear they were available; (3) gently inquiring about specific behaviours (e.g., refusal to take the blazer off in lessons); (4) providing a point of contact during absences; (5) thinking outside the box

(e.g., one teacher texted the YP to collect their GCSE results once the other pupils had left); (6) being non-judgemental; (7) not publicly questioning unusual behaviours (like leaving the classroom to mirror-check); and (8) conveying a genuinely caring attitude. Catherine explained *“there were some teachers I absolutely fell in love with”*, due to how kindly they treated her.

Three participants spoke about how helpful it was to have open lines of communication between their parents and the school, particularly in relation to absence. Two participants explained it was easier not to be asked by peers why they had been away.

Each of the participants who had moved on to college and/or university described finding the college and university setting easier than the secondary school setting, due to: (1) gaps between lessons; (2) being able to be absent without punishment; (3) better mental health services onsite, and (4) older peers being more open about mental health struggles. Hattie, who was at university at the time of the interview, explained, *“People know that I'm on anti-depressants, and I've had a history of anxiety. And that's it, and that's kind of the same with everyone. People are like, 'Yeah, I'm also on antis', you know, 'I've got a bit of history with OCD,' and leave it at that.”* In contrast, aspects of university participants found difficult included: (1) finding it anxiety provoking to live in halls with unknown peers; (2) feeling lonely; (3) university counselling services being too generalised; (i.e., having no specialism in BDD); and (4) regularly using alcohol to cope with their anxieties.

5.3.4 Theoretical Category Four: Lack of understanding of BDD deepens shame and leads to stagnation of identity formation

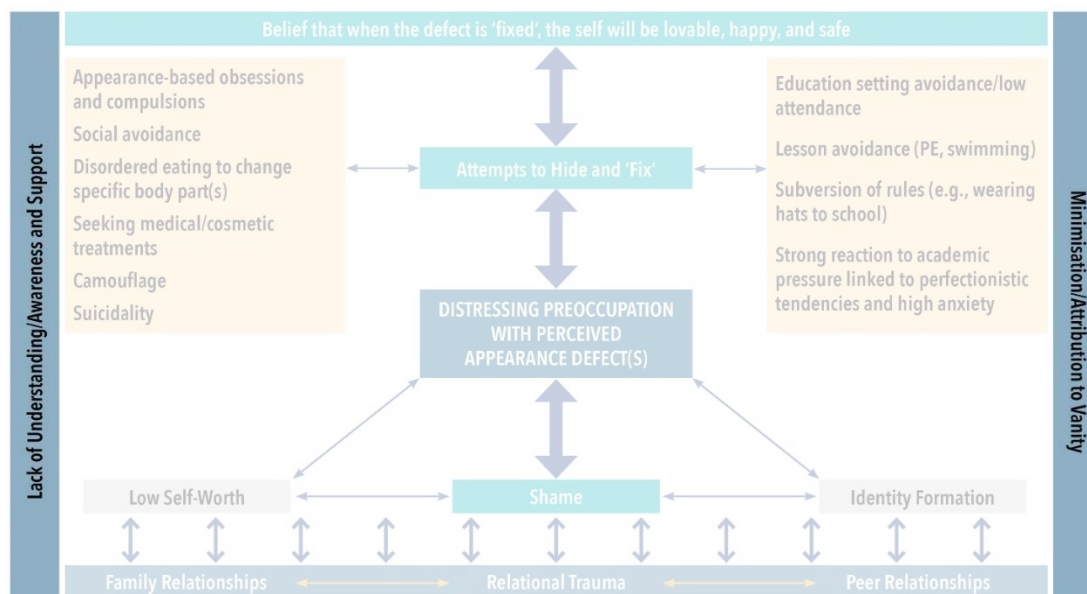


Figure 11: Section of Shame-Identity Model of BDD in Young People as informed by theoretical category four

Experiences like minimisation, attributing BDD to vanity, and punishing a person for their BDD-related behaviours were cited as increasing experiences of shame and further impacting participants' self-concept, sense of identity, and self-esteem. Typically, this appeared to lead to participants becoming increasingly preoccupied by, and focused on, fixing their perceived defect(s) to be accepted and to belong, so they would no longer be seen (as they perceived it) to be *“abnormal”*, *“vain”*, or *“selfish”*.

5.3.4.1 Lack of understanding/awareness of BDD

All 10 participants spoke in some way about other peoples' misconceptions about BDD. This included the supposition that BDD is linked to vanity, particularly in the context of the societal normalisation of adolescents' focus on physical appearance. As Ingrid explained, *“I think it*

came across as me being vain, and I don't think they really got it at first. It's quite hard to understand. I'm a teenage girl, you know; I'm going to go through those phases, like experimenting with my hair, and etc. So, in a sense, it is normal, but it's not." A few participants described BDD as the direct opposite to vanity. Angela explained, "They think it's something to do with vanity or narcissism or something but, oh, gosh, that couldn't be further from the truth, I don't think." Being perceived as being vain was a significant source of shame for these YP. In some cases, it led them to question whether they were indeed vain or narcissistic, despite having intense feelings of disgust and hatred for themselves. As John put it, "I'm on this little cusp of being an absolute narcissist, and someone who absolutely hates themselves."

Participants highlighted other shame-inducing misconceptions made by others: (1) BDD is caused by social media; (2) BDD always results from bullying experiences; (3) People with BDD are selfish; (4) BDD only affects one aspect of a person's life; (5) BDD is only related to dissatisfaction about appearance; and (6) BDD isn't a serious mental health problem. Participants spoke about others (including family members, peers, GPs, clinicians, and teachers) minimising and trying to normalise their distress, which left them feeling invalidated, shamed, and misunderstood. Gill explained, "I said that I felt worried, that it was disgusting and that I would never be able to be like other people. Why couldn't I just be, like, have a normal bellybutton, and she (her mother)... I can't really remember what she said, but I have a kind of a sense, a memory sense that she was quite like, 'Oh, don't worry. Everyone's different, and everyone's got different kinds of bellybuttons', but I didn't feel like I was being really listened to in that because I felt that it was much more of a big deal."

Hearing minimising messages from GPs seemed to result in a delayed diagnosis for some participants. John described trying to obtain clinical support for BDD as being like "jumping up against a glass wall", due to the lack of understanding and awareness among

GPs. Dion was told by her GP, *“Maybe it's just your monthly cycle. You could be just very emotional, and before that time, you know, women do experience... they start to feel a bit uncomfortable with their appearance and things before that, because of their hormones”* which led the GP to advise Dion to *“take Evening Oil of Primrose.”* Other professionals were also cited as lacking understanding, including social workers, mental health workers, and school-based counsellors. Ingrid recalled *“being ... in school, and this lady, who I think was part of social services... said, ‘You're old enough to put an alarm on.’ You know, she just didn't understand at all, and that comment really stuck with me, saying that you're old enough to get yourself out of bed and get ready, and I thought, ‘It's just not like that.’”*

Perhaps due to, or worsened by, a lack of awareness and understanding, all participants described feeling confused about, and ashamed of, their BDD-related experiences. Six participants talked about receiving other psychiatric labels before their BDD diagnosis. Five participants described receiving a BDD diagnosis as a relief, even if they experienced an initial stage of denial (which Fiona described as *“vicious”* denial). Dion explained, *“I think I was quite relieved because I finally knew what it was. Yes, because if you're like, all of these years, I'm thinking I'm crazy, you know.”* Similarly, Gill described her relief at *“having a kind of a name to put on something, which made me feel, to some extent, a bit less disgusting than I had believed myself to be.”* Catherine described how she *“sat there in my bedroom, and I cried when I looked it up and actually read about it, because it just described my life, and then, all of a sudden, I realised... there is something wrong with me, and I'm not just selfish.”* Participants typically first heard the term BDD via family members, GPs, or clinicians, or by conducting a Google search about their distress. For Beth, *“I think one day, I typed in, ‘I'm so ugly, I want to die,’ or something like that onto Google, and that's when things about BDD sort of came up, obviously.”*

Due to the lack of awareness and understanding, participants spoke about finding it difficult to share their experiences of BDD with others. In fact, each of them expressed gratitude and relief in some way for being able to share their story in detail with me, as some had not had the opportunity to do before in such depth, thereby highlighting the emancipatory element of this research.

Participants expressed their frustration when others did not understand why they were so distressed about their appearance. Edward explained, *"They try to help you, and they say stuff like, 'You look fine, and it doesn't matter,' which, to me, personally, really annoyed me, because they don't understand."* Ingrid *"felt kind of helpless and a bit useless and just quite angry, I think, and annoyed that no one really understood what I was going through."* Three participants described a sense of isolation, due to having to keep their experience of BDD largely to themselves. Gill explained, *"When you're suffering in such a way where you feel that you can't even tell your family how you're feeling, or friends, or you haven't told people for the whole time you have been alive, it's... you feel very disconnected from people."*

To some degree, all participants described finding BDD difficult and shameful to talk about. Despite having been diagnosed with BDD some years ago, Angela explained, *"There is still a bit of shame, I think, in saying I've got BDD, and I'm much more comfortable saying something like... I have mental health problems; I've got an eating disorder, I've got depression, I don't know."* Three participants explained BDD is a particularly difficult thing to talk about during puberty, due to assumptions that adolescents are generally overly interested in their appearance, as previously described.

5.3.4.2 Approaches/philosophies that have not helped

In this section, findings are presented in table form due to the large amount of data collected. Many of the themes within this material have, in fact, been presented in depth in other sections. Table 12 lists approaches/philosophies, including respective sample quotes, participants felt had not helped in relation to their experiences with BDD.

Unhelpful Approaches/Philosophies	Example Quote	Number of Open Codes	Participants
Punishment at school, due to BDD behaviours	<i>"The only things I got in trouble for at school were my uniform not being correct, makeup and being late...And actually, all of these things I got in trouble for, were as a result of me feeling anxious and disgusted with myself."</i> (Gill)	16	Angela, Beth, Edward, Fiona, Gill, Hattie, Ingrid
Ascribing BDD to vanity	<i>"Well, for some people it might come across as quite vain but it's actually the complete opposite."</i> (Ingrid)	13	Angela, Beth, Catherine, Edward, Fiona, Gill, Ingrid, John
Skin-picking to fix the skin	<i>"There is the skin picking... I would do it to almost get rid of blemishes or marks or whatever which obviously then makes more marks and, you know, breaking the skin causing redness."</i> (Beth)	5	Angela, Beth, Fiona

Taking a within-person view of BDD	<i>"...she felt the issue was more to do with me than the family."</i> (Beth)	5	Beth
High parental expectations	<i>"He expects his children... he wanted me to be a doctor; he wanted me to be this; he wanted me to be that."</i> (Catherine)	4	Catherine, Ingrid
Ascribing BDD to puberty	<i>"I kind of credited all these other (BDD-related) feelings with puberty like being an emotional... like literally an emotional wreck. I thought that was just puberty."</i> (Edward)	4	Edward, Gill, Ingrid
Involvement of many professionals	<i>"I just remember lots of people and having to explain how I felt and my situation over and over again to different strangers, and it just got tiresome."</i> (Ingrid)	2	Ingrid
Lack of sensitivity when approaching BDD	<i>"I would never tell anyone anything and would never complain about anything, so it would need to be an approach that really is going to capture those people."</i> (Gill)	2	Gill
Receiving non-specific BDD therapy	<i>"I think, sometimes, mental health can be a little bit like, 'Come to this warm room and have a cup of tea and everything's going to be alright,' and that's not how it works."</i> (John)	2	Gill, John
Using many products on the skin	<i>"I was just putting myself in a vicious cycle of drying out my skin and caking it with makeup, and</i>	2	Angela, Beth,

	<i>then it would get worse... it just kind of started tumbling down.”</i> (Fiona)		Fiona, Hattie
Parents taking YP for physical treatments	<i>“I was 15, and I got braces, and a funny thing is, my teeth have moved, which defeated the whole point, kind of... which just affirms that it is a mental thing, because I still didn’t feel good about myself.”</i> (Dion)	2	Dion, Edward, Fiona, Ingrid
Catastrophising	<i>“I like to think of the worst-case scenario, like, ‘This is going to happen; that’s going to happen,’ and it got to the point where my anxiety would just then take over, and I would just shut down.”</i> (Ingrid)	2	Beth, Ingrid
Drinking alcohol or using marijuana to numb feelings	<i>“I was hungover from drinking loads, and that’s pretty much all I was doing for those years.”</i> (Gill)	2	Fiona, Gill, John
Not getting enough sleep	<i>“At school time, I wouldn’t sleep ‘til 3AM, and then I have to get up at 6AM and never... just get barely any sleep, day after day, and it would be so horrible.”</i> (Fiona)	2	Fiona
Avoiding showers ¹⁵	<i>“It’s like, I went through a point when... if I was inside, I was like, ‘well, if I don’t need to see people,</i>	2	Edward

¹⁵ Avoiding showers was identified as being unhelpful, as it made the YP even more reluctant to go out, leading to a vicious cycle of staying home.

	<i>then I don't really need to shower that much'." (Edward)</i>		
Comparing appearance to media figures	<i>"I'm obsessive about films and actors and performers, and I think a lot of the stress has come about by consuming so much visually, and then thinking... 'Why am I not dressed like that? Why does my life not feel like that?'" (John)</i>	2	Beth, John
Parents trying to convince the YP they have BDD before they are ready	<i>"Especially my mum. She went to all the BDD conferences and would, like, bring me books on BDD, and I was like, 'I don't know what you are talking about at all. That's not what I have. You are wasting your time.'" (Fiona)</i>	1	Fiona
Forcing a return to school before the YP is ready	<i>"...it got to the night before school, and I was like, there's absolutely no way I can do this... and I overdosed then, that night before school... I was in the hospital for like four days, and then on the fourth day, my dad was, like, 'So, are you ready to go to school tomorrow?' and I was, like, 'No'... and so, I had the next day off, and then I realised that, like, I was going to have to go straight back to school, and I just so wasn't ready, and then I did it again (took an overdose), like,</i>	1	Fiona

	<i>literally, two days after, so I was back in hospital..." (Fiona)</i>		
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Table 12: Approaches/philosophies that did not help participants, with example quotes

5.3.4.3 Approaches/philosophies that have helped

Table 13 lists approaches/philosophies participants felt had helped their experiences with BDD, including respective example quotes.

Helpful Approach/Philosophy	Example Quote	Number of Open Codes	Participants
Making steps towards recovery	<i>"...just, like, fighting it, really." (Hattie)</i>	30	ALL
Pastoral support at school	<i>"There were some teachers who were very sympathetic. There were two teachers who I really got along with. They were really nice and would always email me about work." (Fiona)</i>	23	Angela, Beth, Catherine, Edward, Fiona, Hattie
Having specialised BDD therapy (including attending BDD support groups)	<i>"I had an intense kind of therapy, where they actually travelled to my house and stayed in a hotel nearby... which was very, very exhausting, but, I think, quite rewarding at the same time." (Ingrid)</i>	22	Angela, Beth, Edward, Gill, Fiona, Hattie, Ingrid

Having a formal diagnosis and/or resonating with the label of BDD	<i>"...to have sort of a reason, a bit of rationale as to why I was behaving the way I did. I felt like it (the diagnosis) was just something we all needed, so, yeah, that was a relief in that sense."</i> (Angela)	11	Angela, Beth, Catherine, Dion, Gill, Hattie, Ingrid
Having future hopes/goals	<i>"I just want to get over all of this... not just put it behind me but actually resolve my issues, properly sort myself out, brush myself off, and carry on... so, yeah, actually get better. Then, hopefully, finish A-levels, go to college, start a family..."</i> (Edward)	8	Angela, Beth, Dion, Edward, Fiona, Hattie
GP as the first port-of-call (although some experienced a lack of understanding from GPs initially)	<i>"I think she took me to the GP, and I got a referral to CAMHS then."</i> (Beth)	7	Angela, Beth, Catherine, Edward, Fiona, Hattie, John
Romantic relationships	<i>"...he was... really lovely, and he made me feel beautiful and nice, and you shouldn't need someone else to tell you you're beautiful to feel beautiful, but I did."</i> (Fiona)	7	Fiona, Gill, Hattie
Sharing experience with friends	<i>"I had a good friend at the time... she was really encouraging."</i> (Dion)	6	Dion, Gill, Hattie, John

Spirituality	<i>"...so, now I'm doing some meditation, and someone is taking me through some meditation practices. So, I'm really excited to see what could come from that and just... more exploration of those things, I have found most helpful so far." (Gill)</i>	5	Dion, Gill
Trying different treatment approaches	<i>"...she was like, 'Okay, yeah, counselling and come back in a couple of weeks; try mindfulness, come back in a couple of weeks; maybe we'll try sertraline, come back in a couple weeks. Now, we'll refer you to IAPT¹⁶.'" (Angela)</i>	4	Angela, Gill
Improving relationship with and understanding from parents	<i>"I feel like it did take several years for them to kind of understand... in that sense, I'm quite lucky. Because now, in the present, they do understand my mentality, and they do get it. So, if I'm feeling some sort of way, they are quite sympathetic." (Ingrid)</i>	4	Edward, Fiona, Ingrid
Putting one's mental health first, including having a gap year after exams	<i>"Because the way I see it, you can take your A-levels at any time, but your mental stuff will stay with you forever. So,</i>	3	Fiona, Hattie

¹⁶ Improving Access to Psychological Therapies (IAPT).

	<i>you've got to sort that out before you put on anything else."</i> (Fiona)		
Looking at experiences objectively (through maturity)	<i>"...growing up and being able to look at your experiences more objectively."</i> (Angela)	3	Angela, Edward
Reading books about others' experiences of BDD	<i>"When I read that book¹⁷... it was like a gentle way of easing me into understanding it (BDD)."</i> (Gill)	3	Gill
Exercise	<i>"Exercise helps me a lot. So, if I'm feeling really low, I've got to get moving because if I sit at home in bed, I'm going to feel worse, and it spirals out of control."</i> (Dion)	3	Dion, Gill
Facing one's fears	<i>"I feel that going on ITV was one, and I also think putting my story on YouTube was another, because that really frightened me."</i> (Dion)	3	Beth, Dion, Ingrid, John
Parents removing pressure	<i>"I feel, like, my family... taking a lot of pressure off me."</i> (Ingrid)	1	Ingrid
Believing therapy can help	<i>"I feel like the first step to recovery and treatment just has to start with you. You have to be in the right mindset. You have to actually believe, 'This will help me.'"</i> (Ingrid)	1	Ingrid, John

¹⁷ 'Reflections on BDD: Stories of Courage, Determination, and Hope'. Schnackenberg & Petro (Eds) (2016).

Psychoeducation	<i>"I think, as well, in therapy, the psychoeducational side of things...has always been really helpful for me." (Angela)</i>	1	Angela
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Table 13: Approaches/philosophies that helped participants, with example quotes

The approaches and philosophies participants found helpful and unhelpful have implications for EP practice, and the practice of other educational professionals, as outlined in the Discussion chapter. They are summarised in a leaflet I created for educational professionals as a result of these findings, which can be found in Appendix 13. The following areas comprise the headings in this leaflet:

- 1) Offer pastoral support
- 2) Ensure a joined-up approach between professionals
- 3) Validate appearance-related distress
- 4) Address BDD-related behaviours with interventions, not punishment
- 5) Support peer relationships
- 6) Liaise with parents, carers, and other family members
- 7) Recognise that physical treatments are not beneficial for BDD
- 8) Be aware of perfectionistic tendencies and high anxiety levels
- 9) Offer alternatives to communal showers/toilets
- 10) Allow time off from school to attend therapy sessions
- 11) Avoid a forced return to school before the YP feels ready
- 12) Offer educational amendments (e.g., timetable amendments)
- 13) Include BDD in the PSHE curriculum
- 14) Value the whole child/YP

5.4 Chapter summary

The findings outlined in this chapter suggest a significant aspect of YP's experience of BDD is shame. Therefore, a second literature review was conducted to explore shame in the context of BDD, as outlined in the following chapter.

6. Second literature review

In keeping with CGT methodology, a second literature review was conducted based on the theoretical code and supporting focused codes. The following theme was reviewed: *Shame in the context of BDD* with the intention of also drawing upon the literature on adolescent identity formation in the Discussion. Adult studies were included in this review, as the preliminary literature review found the YP-specific research to be lacking. Furthermore, the features of BDD in YP have been found to be similar to those in adult populations (Albertini & Phillips, 1999; Braddock, 1982; Cotterill, 1981).

6.1 Search strategy for second literature review

EBSCO (a selection of databases) was used to encompass medical, educational and psychological journals. It was searched with a sensitive search strategy, designed to capture different spellings and terms used. It combined the following keywords (AB – Abstract): “body dysmorphic disorder” or “body dysmorphia” or “BDD” or “imagined ugliness” or “body dysmorphophobia” AND “shame”. The following limiters were put into place: “language-English” and “source type – academic journal”.

Review inclusion criteria were:

- 1) Focused on the impact or perpetuation of shame in BDD;
- 2) Focus not exclusively on gender differences and/or sexuality; and
- 3) Focus not exclusively on outcomes of medication and/or specific treatment(s).

6.2 Results

The systematic Boolean/phrase literature search yielded a total of 11 unique title references, of which five were rejected, following a review of the abstract, using the inclusion criteria, leaving six papers for inclusion. A hand-search of papers, carried out in the same way as in the initial literature review, yielded three additional relevant papers, totalling nine papers for inclusion. For a table of excluded papers, please see Appendix 14. For the table of included papers (CASP¹⁸, 2016; used here particularly to document and ascertain links between findings and theoretical postulations) please see Appendix 15.

6.3 Overview of relevant literature

6.3.1 Psychoanalytic perspectives on BDD and shame

Thomas Fuchs (2002), psychiatrist and philosopher, draws on the ideas of French phenomenologist Maurice Merleau-Ponty (1962), including lived bodiliness (one's lived relation to the world as mediated and experienced by the body; one's embodied being-in-the-world) and the corporeal body (the anatomical object of physiology; a living-object organism). The lived and corporeal body are conjectured to be closely connected to the interpersonal sphere, alongside the notion that the body only becomes an object when it is seen by others¹⁹.

¹⁸ *Critical Appraisal Skills Programme*. Please see description of the CASP in 3.2, within the Methodology chapter.

¹⁹ This is linked to Sartre's notion of 'the gaze' (1963).

Fuchs argues that once the body is grasped by the another's gaze, it bears the imprint of another. In other words, the gaze of another corporealises the lived body. In this way, the mirror represents the other's perspective on the body. As psychologist and psychoanalyst Alessandra Lemma (2009) hypothesises (based on her clinical work with adults with a diagnosis of BDD), if the touch-gaze relationship is not affirming in infancy, the infant may grow up to seek the affirming gaze in other available mirrors, which might include actual mirrors and/or others' faces.

Fuchs asserts shame is immediately related to another's gaze. Thus, we may say shame is the "*incorporated gaze of the other*" (Fuchs, 2002, p. 228), which takes up memory in the body as an implicit memory. Emerging alongside this incorporated gaze is the sense that the person no longer *is* the lived body; rather, the person *has* the corporealised (objectified) body, and therefore, must exert actions to deal with it. These conjectures echo Foucault's ideas of biopower (e.g., the seizing of things, time, the body, etc.) to exert a modern form of power over society (Foucault & Ewald, 2003). One could argue these ideas were, in fact, originally articulated as double-consciousness in Simone de Beauvoir's *The Second Sex* (1949): The notion that the oppressed sees the self as though through the eyes of the oppressor.

Fuchs conjectures BDD is closely connected with shame, with a core trait being the felt sense of being stared at, derided, and rejected, which may result in "*paranoid ideas of reference*" (2002, p. 234). The person with BDD is unable to "*neutralise*" (2002, p. 235) the gaze of another. Rather, the person experiencing BDD continues to see themselves through the so-perceived contemptuous other's eyes. This is linked to a strong insufficiency of self-esteem. Fuchs hypothesises that this sense of insufficiency may be linked to one's emergent sexuality, explaining why BDD most typically emerges in the adolescent years when, as

Lemma (2009) describes it, the body most strongly presents itself to the psyche, prompted by physical sexual maturity.

Lemma's (2009) views closely echo those of Fuchs, while focusing more extensively on the early caregiving attachment relationship. Lemma argues that, in healthy development, the experience of the infant being looked at by the mother is predominantly a benign experience. In the process of being seen and finding receptiveness and understanding in the eyes of the caregiver, the experience of the self is validated. Lemma describes how it is, in part, through identifying with the image the (m)other has of him that the child develops a sense of himself. In Lemma's experience of working with people diagnosed with BDD, three qualities of the mother-as-mirror have been characteristic:

- 1.) The mother was felt to have provided a blank or one-way mirror; opaque and hard to read.
- 2.) The mother was felt to have been actively distorting; looking at the infant with hateful eyes.
- 3.) The mother may have been inappropriately, narcissistically invested in the appearance of the infant's body.

Each of these experiences are conjectured to lead to corporealized (body-related) shame, which is particularly projected onto perceived appearance defect(s). According to Lemma's postulations, this takes place in the context of an identification with an abnormal superego²⁰

²⁰ The superego is the ethical component of the personality and provides the moral standards by which the ego operates.

that lures the self into believing that an ideal ego can exist. Therefore, this ideal ego is relentlessly sought after.

Also taking a psychoanalytic perspective, Parker (2014) describes how, in BDD, shame inflates body hatred to the point of outweighing body love. She suggests intense experiences of shame are common to all people struggling with BDD; both generating and maintaining the BDD experience. She suggests, in adolescence the perceived defect (or, more broadly, the body) is experienced as the enemy which is responsible for a core sense of worthlessness and abnormality. Linked with Lemma's (2009) ideas of the touch-gaze relationship, Parker draws upon object relations theory (Klein, 1946) and, specifically, Winnicott's (1971) theory of mirroring, to make sense of BDD's possible early underpinnings. According to Winnicott, during the mirror phase of development, the infant sees themselves mirrored in the mother's face. A mother who is unable to take pleasure in the infant may provide a one-way or blank mirror (Lemma, 2009), thereby contributing to the infant's experience of their body as undesirable.

Parker also draws upon Fonagy's (Fonagy, Jurist & Target, 2002) ideas of mentalisation²¹, wherein the factors that inhibit the development of a sense of self as a subject, which is central to the evolution of shame, are explained. Parker suggests that early mirroring in the primary attachment relationship may be inadequate in BDD, and, therefore, the person may come to experience the self as a physical entity without psychological meaning. Indeed, Fonagy et al. (2002) have coined the term 'unmentalised shame' for shame which remains unmediated by any sense of distance between feelings and realities; an intense and prevailing sense of intractable humiliation (a trauma). In agreement with

²¹ Mentalisation, which is dependent on mirroring, is the process by which we realise that having a mind mediates our own and others' experiences of the world.

Lemma's (2009) and Fuch's (2002) conceptualisations, Parker describes the person experiencing BDD as being driven by the early onset of the dynamics of shame, and always, therefore, striving towards an impossible aesthetic ideal to remove this sense of shame.

6.3.2 Perspectives on functional and evolutionary contexts of BDD

In their discussion paper, Veale and Gilbert (2014) consider the functional and evolutionary contexts of BDD. They pronounce people with BDD as being "*very sensitive to shame*" (p.151). They describe threat sensitivity as an innate human characteristic, developed from early learning and conditioning. They suggest emotionally-conditioned memories of threat can fuel rumination, which, in BDD, becomes focused on body shame. The threat system in BDD is linked to appearance, wherein the aesthetic element of the identity becomes the salient domain of monitoring and judgment. Therefore, physical appearance is argued to be one of the most common dimensions of shame (Veale & Gilbert, 2014). The threat-sensitive attention process, which is a monitor for appearance sensitivity, is suggested to be involved in BDD in some way, particularly because people with this diagnosis have frequently had social experiences characterised by being shamed, humiliated, and/or rejected.

Veale and Gilbert (2014) highlight the capacity to experience oneself as an object as paving the way for negative evaluations of the self and the experience of shame; thus BDD "*depends upon viewing the 'self' as an object and defining identity through one's appearance*" (p.154). They conclude by conjecturing, "*a key message to someone with BDD is that the way their brain has been shaped is an evolutionary problem of being human and internal threats and that BDD symptoms are designed to keep them safe from perceived social exclusion or*

rejection.” (Veale & Gilbert, 2014, p.157) The rationale for offering compassion-focused therapy is outlined in this paper.

6.3.3 Studies on shame comparing BDD and other obsessive compulsive and related disorders

Three papers compared experiences of shame in BDD and other so-diagnosed OCRDs. They include a focus on body shame, which describes the evaluation of oneself as unworthy, due to the perception of bodily defects and body-relevant implicit shame (involuntary associations of body shame in memories that are not available to the conscious mind for self-report). It has been suggested elsewhere that internal body shame arises in response to internal repugnance of one’s appearance and may be closely related to self-disgust (Cororve and Gleaves, 2001).

Clerkin, Teachman, Smith and Buhlmann (2014) used the Implicit Association Test (IAT; Greenwald, McGhee & Schwartz, 1998) to glean involuntary associations in memory to feelings of shame. They found people diagnosed with BDD ($n=30$) had greater measures of body-relevant implicit shame than people diagnosed with OCD ($n=30$), people diagnosed with social anxiety disorder (SAD) ($n=29$), and healthy controls (HCs). Thus, body shame seemed to be particularly prominent in BDD, compared to other groups, though some null findings in the SAD group render the findings less reliable. These findings echo those of a review of 110 studies on OCRDs conducted by Weingarden and Renshaw (2015), the conclusions of which suggest body shame is inherent in BDD specifically, in comparison to other OCRDs.

Weingarden, Renshaw, Wilhelm, Tangney and DiMauro (2016) used Path Analysis²² to examine whether anxiety and shame were risk factors for people diagnosed with BDD ($n=114$), OCD ($n=114$), and HCs ($n=133$). They found the path from shame to depression was significant in the BDD group and non-significant in the OCD and HC group. They conjectured when individuals diagnosed with BDD judge their appearance to be defective, they may extend this judgement to suppose they are broadly worthless and thus experience consequent feelings of shame and depression. Shame was significantly and similarly associated with suicide risk and functional impairment in both the BDD and OCD groups (Weingarden et al., 2016). Weingarden and colleagues advise taking measures of shame at the beginning of treatment for BDD. This study was cross-sectional in design, thus limiting the researchers' ability to make causal conclusions about shame and anxiety as early risk factors for outcomes.

6.3.4 Studies on shame comparing BDD to eating disorders

One paper (Kollej, Brunhoeber, Rauh, de Zwaan & Martin, 2012) compared general shame and body shame on two versions of the Differential Emotions Scale ([DES]; Izard, 1977; 2001) across 33 healthy controls (HCs), 31 individuals diagnosed with BDD, 32 individuals diagnosed with anorexia nervosa, and 34 individuals diagnosed with bulimia nervosa. The BDD group reported greater general and body shame than HCs with large effects, and similar levels of general and body shame to the eating disorder (ED) groups. The BDD group reported more psychosocial impairment due to appearance, more mirror avoidance, more compulsive

²² Path analysis is used to describe the directed dependencies among a set of variables. It is an extension of the regression model.

checking, and more camouflaging than both the ED and HC groups, which is in line with previous research findings by Rosen and Ramirez (1998) and Hrabosky et al. (2009). Kollei et al. (2012) concluded individuals with BDD appear to experience greater impairment due to their appearance concerns than individuals with EDs. Given that individuals with comorbid eating disorders and BDD diagnoses were excluded, the results cannot be related to individuals with this comorbidity. This comorbidity is not untypical (Ruffolo et al., 2006).

6.3.5 Studies on shame in BDD specifically

Finally, Weingarden, Renshaw, Davidson and Wilhelm (2017) examined associations between body and general shame with BDD phenomenology and depression severity, suicide risk, and functional impairment. They found body shame was more strongly related to phenomenology (i.e., symptoms such as mirror-checking), whereas general shame was more strongly related to psychosocial outcomes (e.g., functional impairment) associated within BDD. The distinct roles of body shame and general shame in BDD are consistent with findings in ED research (for a review, see Goss & Allan 2009). In both BDD and ED groups, shame appears to be more strongly related to adverse psychosocial outcomes compared to body shame. This suggests when a person's shame extends from a focus on the body to a wider focus on one's self as worthless and/or defective, the risk for depression, suicidality, and functional impairment increases (Parker, 2014; Weingarden et al., 2017).

6.4 Summary of the second literature review

The experience of BDD may be rooted in early shaming experiences (as early as the primary caregiving relationship), within which the person becomes entrenched in the sense of the self as a shamed object, as opposed to a self with psychological bearings (Lemma, 2009; Parker, 2014). This may lead to internal shame, describing self-generated criticism and negative self-evaluation. One aspect the papers included in this review do not appear to take significantly into account is how this all takes place in a broader political and societal arena of appearance marginalisation and homogenisation. This will be further discussed in the following chapter.

The internal shame experienced would appear to be projected onto the body (i.e., body shame); possibly, since this is where society suggests it may belong (i.e. the societal notion that the 'imperfect' body is intrinsically shameful). The person may then closely monitor themselves through their appearance to keep themselves safe and negate social rejection (Veale & Gilbert, 2014). The body shame, which is projected onto perceived defect(s), may then ignite BDD-related experiences and behaviours. These behaviours appear to sit alongside a broader sense of shame related to the individual's personhood and may lead to increasingly lower self-esteem and heightened hopelessness.

6.5 Chapter summary

This chapter summarised the second literature review. In the following chapter, I shall describe how the literature informed the *Shame-Identity Model of BDD in Young People*, in addition to outlining implications for EP practice, possible future research, limitations of this study and a reflective statement.

7. Discussion

This final chapter provides a commentary on the CGT in relation to the research questions, literature review, proposed *Shame Identity Model of BDD in Young People*, and other theoretical links.

This discussion also draws upon the *Power Threat Meaning Framework* (PTMF) (Johnstone et al., 2018), which offers a conceptual alternative to traditional models of mental health and distress based on psychiatric diagnoses. Published by a division of the British Psychological Society, the PTMF involved the work of senior psychologists, other mental health professionals, and service user campaigners across a five-year time period. It argues that mental health diagnosis is part of a continuum of oppression and marginalisation, and that there are other ways of conceptualising human suffering and emotional distress.

7.1 Statement of findings

The purpose of this study was to raise a CGT of the lived experience of CYP who self-identify with and/or have a diagnosis of BDD. As outlined in the Findings chapter, the CGT conjectures: *Appearance-based identity becomes the focus of adolescent identity formation in young people's experiences of BDD, informed by relational experiences of shame and low self-worth.* This finding shall henceforth be elaborated on in relation to the research questions and existing literature.

Other diagnoses shall be considered in relation to shame and identity, particularly those highlighted by participants in this study as being either diagnoses additionally received or commonly diagnosed pre, post, or alongside the diagnosis of BDD. As described in the

opening chapter, I conceptualise diagnostic labels as being socially constructed and existing on a broad continuum. Therefore, research conducted with people diagnosed with OCD (which comes under the same category as BDD in DSM-V), for example, may also elucidate possible aspects of the BDD experience, particularly where BDD-specific research in these areas is lacking.

7.2 Introduction to the topic of shame

Shame has been considered central to the experience of BDD since its earliest clinical descriptions (Janet & Raymond, 1903). Shame has been described as a sense of smallness, worthlessness, and powerless in a given situation (Schoore, 1998). It has also been conceptualised as an attachment emotion (Lewis, 1971) and as the primary social emotion (Scheff, 1988). Kohut observed a characteristic of the human infant is to eagerly look for the satisfaction of the *“need of the budding self for the joyful response of the mirroring self-object”* (Kohut, 1977 p. 788). The primary caregiver has been described as this mirroring self-object (Kohut, 1977, Lemma, 2009). Face-to-face encounters that are expected by the infant to elicit joy, but do not, can become the principal context for shame experiences (Izard, 1997; 2001). This relates to Erikson’s (1950) description of shame as being rooted in a visual, nonverbal affect.

For the infant, during moments of shame (e.g., when the expected joy in the face of the primary caregiver is absent and/or is transposed with contempt and/or disgust), looking at the primary caregiver can become *“like smiling at a stranger”* (Tomkins, 1963b p.123). Expecting an exchange of psycho-biologically-attuned, shared positive affect, the infant instead experiences a facially-expressed misattunement, triggering a shock-induced deflation

(Schore, 2002). The infant is, thus, propelled into a low arousal state they cannot yet autoregulate. Therefore, shame represents a rapid transition from a pre-existing, high-arousal, positive state to a low-arousal, negative state (a decrescendo [Stern, 1985]). Physiologically, this represents a shift from sympathetic to parasympathetic predominant activity, induced through vagal activity (a dorsal-vagal response [Porges, 1995; Schore, 1998]). With this comes the slowing of the heartrate, and the sense of time slowing down, which may magnify anything occurring during the state of shame. Given that shame has been described as a largely visual experience, it is perhaps unsurprising that, for some YP, it is the visual aspects of the self and their perceived appearance to another that become magnified.

Like Erikson (1950), Schore (1998; 2002) describes shame as being visually based. Shame would appear to split the self into the observer and the observed, with the observer witnessing and criticising the part being observed. This can lead to hypervigilant scanning in the service of self-protection; in turn, amplifying the extreme feelings of self-consciousness that are characteristic of BDD (Veale & Gilbert, 2014). As the shame becomes internalised, the presence of another is no longer required. The person, thus, becomes both the persecutor and the victim of their experience (Karpman, 1968), i.e. both the 'seer of the self' and the 'seen'.

Shame has the propensity to spin an image of isolation out into the future (Schore, 1998), which may contribute to the intense anxiety experienced. Perceived defects carrying attached shame can become a potent source of intrusive, repetitive thoughts (Schore, 1998), another core feature of BDD. In BDD, the YP expects to be rejected and socially isolated, unless they can do something to ameliorate this (Parker, 2014). Based on the findings of this study, I suggest YP experiencing BDD attempt to fix aspects of their appearance, in part, to

protect themselves against future experiences of isolation and rejection (i.e., to keep themselves safe).

Schore (1991) describes body shame as always coexisting with a deeper shame of oneself. He conjectures if the deeper shame is not addressed, no amount of body/physical alterations will be satisfactory. This relates directly to the surface level changes attempted in BDD through the fixing of the perceived defect(s). Since the deeper sense of shame remains, the fixing is futile, and BDD moves to another perceived defect, a phenomenon described by all 10 participants of this study.

Like trauma, shame has been described as timeless; as always experienced as happening right now (Schore, 1991; 1998). It is possible that the body-based sensations described by some of the participants of this study, as characteristic of BDD, may be physiological expressions of shame itself.

7.3 Research question one: What informs and perpetuates YP's experiences of BDD, including in the home and education settings?

7.3.1 The experience of the physical appearance as the most salient element of one's identity in adolescence informs and perpetuates YP's experiences of BDD in the home and education settings.

BDD most typically develops in adolescence, a critical stage in the development of identity (Marcia 1967; Marcia, 1991; Meeus, 1996; Waterman, 1993). In the modern Western world, adolescents arguably seem to be seeking their identities in a society within which appearance ideals are becoming increasingly narrow, prescriptive, and extolled as synonymous with

success, happiness, and lovability. This phenomenon is arguably relatable to the power dimension of the *Power Threat Meaning Framework* (PTMF) (Johnstone et al., 2018). In the PTMF, the operation of power (e.g., biological/embodied; coercive; legal; economic/material; ideological; social/cultural; and interpersonal), including possible re-traumatisation by mental health services themselves, is proposed to be a key aspect of human emotional distress/suffering. The fundamental question posed within this aspect is: “*How has power operated in your life?*” (Johnstone et al, 2018, p. 9).

An element of this power is the enduring consequence of Cartesian dualism²³, the presentation of biology as an independent source of behaviour and emotional distress, as opposed to an aspect of our being that is continuously shaped by social action. Thus, mental health conditions in the prevailing medical model are viewed as ‘all in the brain’ and/or ‘all in the mind’. This, in turn, facilitates a view of BDD as an illness or psychological condition with symptoms, rather than the lived experience of a person who is situated within a social and political sphere.

Societal notions of the optimal appearance of different body parts may be particularly compelling for adolescents, as identity formation is a key characteristic of this life stage. Adolescence is a stage in which identity strategies are trialled and challenged, and infantile identifications become identity (Kroger, 2004; Marcia, 1989). Adolescents may construct imaginary representations of themselves, based on societal discourses, that are not directly accessible to the conscience (Guichard & Hutteau, 2001; Santisi, Magnano, Hichy, & Ramaci, 2014; Wigfield & Wagner, 2005). The findings of this study suggest these imaginary representations in BDD are an idealised self in the form of an idealised body part or parts, in

²³ Descartes’ assertion that the immaterial mind and the material body are two completely different types of substances; which interact causally.

line with a YP's objectives, beliefs, and convictions (Marcia, 1991; Wigfield & Wagner, 2005). It seems plausible that these convictions are assimilated from societal notions of lovability and beauty, including via family members and peers (Bissell & Rask, 2010; Moradi, Dirks & Matteson, 2005).

Numerous studies have demonstrated self-perceived appearance can impact the dimensions of identity development in adolescence²⁴. The YP in this study appeared to have assumed the notion of self-as-object, as opposed to a self with psychological bearings (Parker, 2014; Veale, 2004). Thus, in answer to the question, *"How has power operated in your life?"* in the PTMF, the YP experiencing BDD might respond, *"I have been exposed to (or, possibly, saturated in) the message that my appearance is the most salient aspect of my identity. My body is an object, which is manipulatable by my will and effort, and my personality, talents, etc. are not the aspects of my personhood that will make me a worthy and lovable human being; my appearance alone can accomplish this. The shame I feel is because my appearance is defective, according to the societal standards I have internalised. If I fix my defects, the sense of shame I feel will reduce or vanish."*

Alongside this internalisation of the societal myth that physical attractiveness is somehow equitable with lovability, participants also appeared to have internalised the societal message that vanity is similarly abhorrent to ugliness. Therefore, these young people seemed to be caught within an irreconcilable dilemma. There was a sense that to be 'beautiful' (and to make efforts towards obtaining this 'beauty') is societally laudable while being perceived as vain can lead to societal rejection. This 'catch-22' appeared to layer

²⁴ (Andrew et al., 2016; Garn et al., 2016; Hodder & Coleman, 2008; Koff et al., 1990; Lau et al., 2004; Marsh et al., 2002; Nelson et al., 2018; O'Dea et al., 2006; O'Dea & Abraham, 1999; Strauman & Glenberg, 1994; Sweeney & Zionts, 1989; Thomas et al., 2000; Verstuyf et al., 2014).

additional shame and confusion onto these young people's experience of BDD and to further inhibit them from sharing their perceptions and feelings with others; for fear they would draw attention to their perceived defect while simultaneously being perceived as vain for caring so much about their appearance.

The YP in this study yearned to fix and/or change their appearance to become a worthy person (i.e., to remove feelings of shame, to fit in, and to embody their ideal self). The characteristics of their experience of BDD (e.g., camouflaging, seeking surgery, etc.) then appeared to be attempts to hide or fix the identity they felt to be unacceptable. Indeed, appearance-based self-discrepancies have been found to exist between 'actual self' and 'ideal self' in individuals diagnosed with BDD (Veale, Kinderman, Riley & Lambrou 2003). Moreover, self-discrepancy theory posits discrepancies can lead to negative affect, including feelings of shame (Higgins, 1987). The findings of this study suggest experiences of shame underpin, perpetuate, and result from the experience of BDD in YP, as outlined in the following sections of this chapter.

7.3.2 Early experiences of shame inform and perpetuate YP's experiences of BDD in the home and education settings.

Descriptions of difficult early life relational experiences were present in most participants' narratives. These relationships would have taken place within the power structures and societal notions of the appearance ideals already described. This aspect may represent the threat facet of the PTMF; the kinds of threats the negative operation of power may pose to the individual, group, and community. I suggest that in BDD, relational experiences of shame (Fuchs, 2002; Lemma, 2009) become a threat to the person's sense of lovability. This felt sense

of shame may then be projected onto the appearance and, specifically, a perceived defect, in a bid to remove and resolve this feeling of shame and remove the threat of rejection.

Relational experiences of shame can occur in the primary attachment relationship and may affect the security of the attachment (Stern, 1985). Some theorists have conjectured that somatoform disorders, the classification under which BDD was situated in DSM-III and DSM-IV, represent care-seeking behaviour on the part of individuals experiencing insecure attachment relationships (Bass & Murphy, 1995; Stuart & Noyes, 1999). Studies have found associations between insecure attachment styles and reports of somatic symptoms (Ciechanowski, Walker, Katon, & Russo 2002; Waldinger, Schulz, Barsky & Ahern., 2006). Links have also been identified between the risk of developing muscle dysmorphia (a subtype of BDD) and having an insecure-avoidant attachment style (Fabris, Longobardi, Prino & Settanni 2017). Furthermore, correlations have been drawn between avoidant attachment styles and clinical levels of body image concerns (Cheng & Mallinckrodt, 2009; Koskina & Giovazolias, 2010; McKinley & Randa, 2005; Troisi et al., 2006).

Most participants of this study felt invalidating familial experiences had both led to and perpetuated their experience of BDD in some way. There is a dearth of research into familial factors, including the impact of these factors (i.e., their perceived threat on the emotional and psychological life of the individual) on identity formation in BDD. Research by Didie et al. (2006) found that of 75 subjects (69.3% female) with a diagnosis of BDD who completed the Childhood Trauma Questionnaire: 78.7% reported a history of childhood maltreatment, 68% reported a history of childhood emotional neglect; 56% reported a history of childhood emotional abuse; 34.7% reported a history of childhood physical abuse; 33.3% reported a history of childhood physical neglect; 28% reported a history of childhood sexual abuse; and 40% reported a history of severe maltreatment. The severity of sexual abuse was

found to be significantly associated with BDD severity. A history of attempted suicide was related to historic emotional, physical, and sexual abuse.

In research by Neziroglu, Khemlani-Patel and Yaryura-Tobias (2006b), which included 50 people with a diagnosis of BDD, 38% reported some form of abuse during childhood (28% reported emotional abuse; 22% reported sexual abuse; 14% reported physical abuse; and 16% reported multiple forms of abuse). Findings of the current study suggest adverse childhood experiences may be common among YP experiencing BDD, although the sample was small, and direct measures or questions of adversity were not taken or posed. As Gill put it, *"I do think a lot of what's manifested as what I think is body dysmorphia really came from the early child experiences (including parental mental health difficulties and a perceived lack of affection between family members)."*

Participants in the present study candidly shared their experience of themselves as intrinsically bad and unworthy. It appeared they had internalised the outward threat of being unlovable, thus, projecting this threat onto their perceived appearance defect; an objectified body part, situated within an objectified body. Gilbert's Model of Shame (1997, 1998, 2003, 2014), which draws upon the work of Cooley (1902), Kohut (1977) and Bowlby (1969), suggests that, following shaming experiences, it can be a common human experience to experience the self, or a part of the self, as the bad object (Klein, 1946).

Psychoanalyst Melanie Klein postulated the infant splits all objects, of which people are one, into either ideally good or wholly bad objects. This splitting occurs because the infant is not yet able to conceptualise two possibilities simultaneously (i.e., that an object can have both good and bad qualities). As a result, the infant sees only part-objects. It sees the 'all good' or the 'all bad' in every object he perceives. To keep himself safe, the infant aims for a

total union with the good objects, and a total annihilation of the bad objects, as well as a total annihilation of the bad parts of the self.

Until the infant moves through the developmental stage of individuation²⁵ (Winnicott, 1970), Klein (1946) conjectures that they continue splitting objects and seeking dissolution of the bad parts of the self. From the findings of this study, I suggest that, upon reaching adolescence, the YP who has not fully achieved the developmental stage of individuation may perceive the self as the bad object among the good objects (e.g., the family members and/or peers) to which they yearn to belong. In BDD, the perceived appearance defect becomes the bad object specifically, and the idealised body part becomes the means by which connection and belongingness is hoped to be achieved. The safety behaviours (e.g., mirror-checking, skin-picking, camouflage, etc.) could be viewed, in this way, as the transitional objects from bad self to good, individuated self (Winnicott, 1964) and as an attempt to remove the threat of being unloved and/or rejected. It has been suggested that appearance-based teasing and familial focus on appearance deepens the sense of the perceived defect as the bad object and, thus, impacts the YP's developing self-concept and sense of identity (Gleason, Alexander & Somers, 2000; Rickert, Hased, Hendon & Cunniff, 1996).

Participants described familial focus on physical appearance and comparison with their siblings' and, in one case their cousins', appearance as leading to shame and resultant identity-related distress. Some participants either explicitly talked about, or alluded to, receiving the message during childhood/adolescence from family members, peers, and society, that appearance comprised a significant part of their identity and was an important measure of their self-worth. This corroborates with Lemma's (2009) suggestion that the

²⁵ The developmental stage of individuation describes the embodied (i.e., felt) understanding of the infant as being separate from his caregiver(s).

mother-as-mirror may be inappropriately, narcissistically invested in the appearance of the child's body in BDD; perhaps, since the mother (and/or father, grandmother etc.) herself, embroiled within power and threat dynamics, assimilated the belief that appearance is the most salient measure of lovability.

Similarly, within peer relationships, three of this study's participants spoke about the pressures of being part of the in-group, in terms of appearance being highlighted, focused on, and, therefore, magnified. As Fiona described it, *"Half the pressure was because I was in this group; it was sort of, like, the bee's knees."* Neziroglu, Roberts and Yaryura-Tobias (2004) describe individuals with a BDD diagnosis as regularly reporting being in the attractive crowd in school, as well as having early dating success and other childhood and adolescent experiences wherein the importance of appearance was highlighted and exaggerated.

7.3.3 Peer-related experiences of shame inform and perpetuate YP's experiences of BDD in the home and education settings.

Participants of this study shared their experiences of peer judgment/teasing/bullying in relation to their appearance, including their weight, the shape of their nose, their skin tone, and their height. These experiences appear to have posed a threat to their identity and lovability. In a 2018 survey conducted by YMCA England and Wales, more than half (55%) of the 1,006 CYP (11-16-year-olds) who were surveyed reported being bullied about the way they looked. 60% of these CYP had attempted to change their appearance following the bullying they received.

Adolescents' aversive peer experiences have been found to have unique roles in predicting emotional maladjustment (London, Downey, Bonica, & Paltin, 2007; McDonald,

Bowker, Rubin, Laursen & Duchene, 2010). Participants in the current study expressed strong feelings of rejection within their peer groups, alongside pervasive feelings of non-belonging. One study ($n=2510$; BDD group $n=45$) found YP diagnosed with BDD are more likely to have experienced appearance-related teasing than the general population (40% versus 15.6% [Buhlmann et al., 2011]) and to remember the incident more vividly and as more traumatic. In a study by Webb et al. (2015), BDD symptoms were higher when adolescents ($n=188$, 54.8% female) self-reported more appearance-related teasing and higher social anxiety. Interestingly, appearance teasing by cross-sex peers, rather than same-sex peers, was uniquely associated with elevated BDD symptoms. These associations were found to be partially-mediated by appearance-based rejection sensitivity²⁶ (Park, 2007).

The phenomenon of appearance-based rejection sensitivity relates to the meaning facet of the PTMF; the central role of meaning, as produced with societal and cultural discourses and primed by evolved and acquired bodily responses, in shaping the operation, experience, and expression of power, threat, and our responses to threat. The YP's experiences of peer rejection within the current study did not appear to be the decisive factor in their resultant distressing preoccupation with an aspect of their appearance. Rather, it was the meaning the YP attributed to these experiences that led to their attempts to fix aspects of their appearance. These meanings arguably make sense, given the societal, familial and educational reality within which these YP were situated.

While some participants in the current study experienced appearance-based bullying directly, others merely witnessed it happening to others. In both instances, participants shared a realisation (i.e., meaning) that appearance was a key way their identity could be

²⁶ Appearance-based rejection sensitivity describes a personality-processing system characterised by anxious concerns and expectations of being rejected based on one's perceived physical attractiveness.

decided upon and declared by others (Fuchs, 2002). When people are confronted with an appearance-related trigger, such as another person making a comment about their appearance, a dysfunctional mode of processing may be activated (Neziroglu, Khemlani-Patel & Veale, 2008). Attention can shift inwards, and the person may begin to process their felt sense of self as an aesthetic object²⁷. What follows can be an involvement in comparing an internalised, mostly negative, image of the appearance to the internal image of the desired appearance. A repeated comparison may then be set in motion that renders the internal image of the self unstable, leaving the person uncertain of how they look. Therefore, any perceived defects are experienced as magnified, due to the selective attention paid to these defects, and to time slowing down, due to the experience of shame (Schore, 1998).

In numerous theories (e.g., cognitive models of depression, attachment theory, and rejection-sensitivity theory [Beck, 2008; Bowlby 1988; Downey, Lebolt, Rincón & Freitas, 1997]), early social adversity, such as peer teasing, peer exclusion, and parental abuse, has been conjectured to lead to selective information processing. In a study of university students ($n=237$), appearance-based teasing by peers, and fear of negative evaluation, were associated with more self-reported symptoms of BDD (Lavell, Zimmer-Gembeck, Farrell & Webb, 2014), thus corroborating with the findings of the present study. The present study goes a step further by highlighting the importance of the meaning YP attribute to social adversity. If the meaning the YP attributes is that they are intrinsically unworthy and unlovable, they may go on to attempt to fix this unlovability, potentially by attempting to fix an aspect of their appearance.

²⁷ This relates to the symbolic interactionist supposition that human beings perceive themselves as both subject and object.

7.3.4 Mistrust within relationships inform and perpetuate YP's experiences of BDD in the home and education settings.

Participants spoke about experiencing a sense of mistrust and disbelief when people told them they could not see their perceived defect²⁸. According to Erikson (1968, p.65), a basic sense of trust with others is the *"first component of mental vitality"*. This allows an individual to take chances, explore options, and, eventually, make an identity commitment. It is through these trusting relationships with others that the YP learns to trust themselves, as well as *"proving oneself to be trustworthy"* (Erikson, 1968, p128). The findings of the present study suggest a distressing preoccupation with an appearance defect both delays this basic sense of trust and is a response to it. As Schore (1996) points out, repeated and pervasive early experiences of shame render the ability to trust both others and the self extremely challenging.

Lack of trust can lead to experiences of isolation and shame, thus becoming a self-amplifying cycle. While there has not been any direct research into experiences of isolation in people diagnosed with BDD, adolescents who have higher levels of relational victimisation have reported more loneliness and depressive symptoms than their age-matched peers (Zimmer-Gembeck, Trevaskis, Nesdale & Downey, 2014). The findings of this study strongly suggest social isolation may be a key aspect of YP's experiences of BDD, which corroborates with findings of other studies (Frare, Perugi, Ruffolo & Toni, 2002; Phillips, 1991). Socially isolating themselves seemed to further compound participants' distressing preoccupation with their perceived defects; another self-amplifying cycle.

²⁸ As Catherine described it, *"...you end up hating people because you feel that people are lying to you. So, like, people feel sorry for me... that's the only reason that someone would say something nice, is because they feel sorry for me."*

Social paranoia was related to experiences of social anxiety for most participants. I suggest these YP were not perceiving an absent threat, as other studies have suggested (e.g., Buhlmann & Wilhelm, 2004). Rather, the YP may have been projecting a broader societal threat onto these social situations, informed by societal power dynamics.

It has been suggested that individuals diagnosed with BDD may selectively attend to emotional stimuli (Buhlmann et al., 2002a) and interpret ambiguous social situations as threatening, compared to individuals diagnosed with OCD, and healthy controls (Buhlmann et al., 2002b). It has also been suggested that individuals diagnosed with BDD may have difficulties identifying the emotional expressions of others (Buhlmann et al., 2004) and rate more expressions as contemptuous (Buhlmann & Wilhelm, 2004), thus assuming others are looking at them disapprovingly. I assert it is equally possible and highly plausible that shame-based relational experiences and the experience of BDD itself may lead to the perception of threat in emotional expressions, etc., thus leading to an assumed meaning that others are disgusted by the self.

All participants expressed a sense that a current aspect of their appearance was outside the norm²⁹, which they then blamed for experiences of social adversity. It has been suggested the transgression of societal norms can result in social shame (Johnstone et al., 2018). It seems a pervasive sense of social shame due to perceived appearance differences directly underpinned the experience of BDD in some way and to some degree for all participants of this study. This also appeared to reduce their sense of belonging.

Belonging becomes particularly important to identity formation in adolescence. During this time, the ability to establish and maintain positive peer relationships is related to

²⁹ A norm can be defined as “*that which is socially worthy, statistically average, scientifically healthy, and personally desirable*” (Rose, 1999, p.76).

higher levels of sociability, perceived competence, and self-esteem, as well as reduced anxiousness, hostility, and depression (Buhrmester, 1990). To belong, adolescents may strive to look like their peers, since appearance differences are a potential source of teasing and social rejection (Cash, 1995). Some participants in this study felt their appearance was different to their peers prior to struggling with BDD. Participants talked about being significantly taller than their peers, being the first to have acne, and going through puberty early. These differences seemed to lead to fears of not fitting in/belonging, being teased (including actual, related experiences of teasing), and being somehow a bad person, or even a non-person. Participants used words like “alien”, “monster”, “Martian”, and “hideous” to describe how they thought they looked. Angela had once been convinced she was conceived via artificial means, given her so-perceived aberrant appearance. This relates to Festinger’s (1954) social comparison theory, which suggests human beings have an innate drive to evaluate themselves by comparing themselves to others. The disparity between desired others and the perceived self typically results in behaviour intended to eliminate the perceived discrepancy.

7.3.5 An underlying sense of oneself as an ‘appearance object’ and unlovable informs and perpetuate YP’s experiences of BDD in the home and education settings.

The sense of one’s lovability being related to one’s appearance was very strong for each of the participants in this study. This impinged on romantic relationships for some³⁰. For a few

³⁰ Catherine described ending up “in such a place where you’re literally just looking at everyone else all the time. You’re feeling sorry for your boyfriend because they’re even bothering to be with you. You’re not you anymore; you are literally just a nervous wreck, and you end up being someone that they don’t want to be with because you’re not you anymore.”

participants, the experience of BDD was largely focused around their desire to have a romantic relationship, and their distress that their perceived defect may prevent them from ever having such a relationship (i.e., a threat).

Participants seemed to feel their appearance was their identity, and they had no other means of, or reason for, being lovable. Thus, as previously described, they seemed to experience themselves as an object, as opposed to a self with a personality, talents, preferences, something to offer the world, etc. A strong focus on the self as an object has been related to Piaget's (1965) definition of *egocentrism*: A failure to distinguish the self from the non-self. Egocentrism has been described as a characteristic of cognitive functioning that occurs whenever a CYP is beginning to cope with a novel domain (i.e., finding the self as an aesthetic object among other objects) and when assimilation and accommodation of this domain are out-of-step, a typical concomitant of disequilibrium (Flavell, Miller & Miller, 1985). It has been conjectured that egocentrism resurges in early adolescence, when the adolescent becomes increasingly occupied with assimilating multiple possible perspectives on the self; one of these perspectives is one's own. Piaget suggests the task is then to assimilate and coordinate the perspectives of others and locate one's own ego in respect to them. Failure to do so has been suggested to lead to confusion of the ego (Piaget 1965).

Elkind's theory of imaginary audiences (1967; 1985) is the most widely cited application of Piaget's analysis of egocentrism to adolescence, wherein the adolescent may behave as if they are the focus of attention from a projected audience who shares their preoccupations and concerns. I suggest this behaviour of the adolescent is neither pathological nor the sole result of egocentrism. Rather, the adolescent may behave as if they are the focus of attention from an audience who shares their preoccupations and concerns because they are such a focus. I suggest we can only understand BDD as a pathology if we

agree that wider society is not disproportionately preoccupied with appearance perfection, nor equates this perfection with lovability. I posit the meaning given to the actual, not simply perceived, threat by the YP is a perfectly logical and legitimate one. This appears to lead to a tendency towards conformity (e.g., *“just being, like, cool, in general, and not, you know, hanging out with the non-cool children.”* [Hattie]). This desire for conformity and loss of autonomy (Plant & Ryan, 1985) is arguably a direct result of relational disempowerment; the power aspect of the PTMF.

7.3.6 A distressing preoccupation with the mirror informs and perpetuates YP’s experiences of BDD in the home and education settings.

It seems the mirror may represent the societal gaze on the self in YP experiencing BDD. Adults diagnosed with BDD have reported spending up to six hours at a time stuck in front of the mirror (Veale & Riley, 2001). Indeed, mirror-gazing can go together with complex rituals and safety behaviours in a specific order, although this typically fails to achieve any reduction in anxiety (Rachman, 1974; Veale, 1993). Participants in the present study seemed to experience a spiralling of their anxiety in response to mirror-gazing and appearance-focused rituals. Despite knowing these behaviours typically increased their anxiety, they described feeling compelled to check the mirror to ascertain how they looked, often with the hope they would not look as bad as they felt themselves to be (Veale & Riley, 2001).

Participants also described using the mirror to help them to hide or fix their perceived defect. Lemma (2009) conjectured that if the desiring gaze of another is absent in infancy, the person may later search for the loving gaze in whichever mirrors are available. These mirrors could be other people, or reflective surfaces, such as actual mirrors. Rather than finding the

loving gaze they are seeking, people whose infantile experiences were rooted in shame are likely to find 'more of the same'. This may be partially due to a confirmation bias within the psyche, and partially because we tend to seek out relationships and experiences that will facilitate a resolution of early, unresolved experiences (Freud, 1914).

I suggest the YP experiencing BDD looks in the mirror and sees a reflection of the shame they feel internally, which has been projected onto them from the outside, including through family members, peers, and wider societal discourse. Hence, their anxiety and distress increases. Participants talked about safe and unsafe mirrors in this study, with the safe mirrors most typically existing in the home environment. This suggests YP with BDD may perceive the mirror as the perspective of another's gaze upon the self, thereby finding public mirrors more distressing than private mirrors. In turn, this suggests the threat is perceived as being 'out there' in society, rather than solely within a person's own psyche.

7.3.7 Lack of awareness and understanding of BDD perpetuates the shame underlying the experience of BDD and can delay diagnosis.

Most participants in this study had not heard of BDD before they received a diagnosis. Some were diagnosed with other psychiatric labels before receiving a BDD diagnosis. Research suggests adults with BDD have at least one comorbid diagnosis (Gunstad & Phillips, 2003). Extensive studies into the experiences of CYP are yet to be conducted. For some participants, the lack of clarity about what they were dealing with was confusing, shaming, and frustrating.

YP may not have the cognitive or emotional resources to make sense of their situation without blaming themselves (Johnstone et al., 2018). Predominantly, participants in this study spoke about or strongly alluded to feelings of shame, rather than guilt, as being related to

their appearance-based struggles and wider experiences. For many, receiving a label of BDD was eventually a relief, as it allowed them to imagine that perhaps they were not as ugly as they believed themselves to be. Conversely, the label of BDD itself induced feelings of shame in some participants, including those who had experienced some relief after receiving the diagnosis. This mostly appeared to be linked to other people's ignorance of, and misconceptions related to, BDD; particularly that BDD is related to vanity in some way.

The phenomenon of experiencing a received psychiatric diagnosis as both a relief (e.g., having a name for one's distress, having one's experience validated, feeling less alone, receiving access to specialised treatments and resources) and with feelings of hopelessness, exclusion, shame, and disempowerment is not a new one (Johnstone, 2014). There remains a lack of an alternative position between the medical model (i.e., 'You are sick, and you have an illness') and the moral model (i.e., 'You are a bad person, and it is your fault') (Harper, 2013; Lafrance, 2009; Pitt, Kilbride & Welford, 2009), characterised as the 'brain or blame' dichotomy (Boyle, 2013). Therefore, psychiatric diagnosis may represent both salvation and damnation for those who receive them (Leeming, Boyle & Macdonald, 2009; Johnstone et al., 2018). The findings of this study suggest BDD itself is a "bid for salvation"; a desire to remove one's ugliness to become lovable, safe, and whole.

Participants spoke about how much easier their experience with BDD might have been if wider members of society had heard of BDD and understood it (e.g., "*...if we're in a society where everyone knew what BDD was, and they would just go, 'Okay, cool, I get it.'*" [Angela]). For this reason, four of the participants had courageously publicly shared their experiences via the media to raise awareness of BDD³¹. Despite finding it incredibly challenging, these

³¹ Regarding her media appearances, Beth explained, "*People always say, 'Why would you want to do that?', and I hate doing it. Obviously, it's really difficult to do, but the reason I do it is because I had never heard of it*

participants experienced some positive outcomes as a result of media appearances, such as receiving messages of support from others, and feeling as though they were helping other YP experiencing BDD. Therefore, providing YP with opportunities to share their stories and support others, while ensuring specialised psychosocial support is in place, may be highly beneficial. Indeed, providing help and support to others has been found to support mental health and wellbeing (Borgonovi, 2008; Thoits & Hewitt, 2001), while sharing one's story can have emancipatory effects (Johnstone et al., 2018; Longden, Corstens, Escher & Romme, 2012), thus, perhaps, supporting the YP to forge an esteemed identity for themselves.

Participants shared their belief that their experience of BDD could have been less difficult and shaming if it had been recognised and validated at an earlier stage. This was particularly evident within participants' narratives related to disordered eating. Numerous participants received eating disorder diagnoses before, alongside, or after their BDD diagnosis. The extent to which disordered eating was linked to BDD for all but one of the research participants was an elucidating finding of this study. Currently, a diagnosis of BDD is not made if disordered eating and a focus on weight/shape are the main areas of presenting concern, according to DSM-V and ICD-10 criteria. However, participants spoke emphatically about how their attempts to lose weight were directly linked to fixing their perceived defect, and that this was typically missed by professionals.

Participants explained that professionals had assumed their aberrant eating behaviours to be directly related to a wish to lose overall weight from the body³², whereas participants were typically focused on changing specific aspects of their appearance. Exploring

(BDD), and if I had heard of it before, I might not have gone through that couple of years of, sort of, just not knowing... and that's why I do the media awareness because I think if it just helps one person like me, then that's worth it."

³² i.e., to see the number on the bathroom scales go down.

why YP wish to lose weight/are restricting their food intake/are purging will be an important step forwards, as opposed to making the assumptions these participants were subjected to.

Feelings of hopelessness and suicidality were also often missed, due to assumptions that the YP were experiencing normal adolescent concerns about their appearance. For three of these participants, their feelings of hopelessness led to suicide attempts. Large-scale prevalence studies of suicidal ideation and attempts in CYP with a BDD diagnosis have yet to be conducted but have been cited as 67% suicidal ideation and 44.4% suicide attempts ($n=33$) (Albertini & Phillips, 1999) in a small study.

All participants spoke about their distressing preoccupation being minimised by others. They added that most people, including medical and mental health professionals, failed to realise the extent of their hopelessness and distress, leading to further shame and an increased propensity to hide their experiences from others. Greater openness, vigilance, and screening for suicidality in YP experiencing a distressing preoccupation with perceived defects in their appearance is clearly warranted. This may be even more vital than it is for the adult BDD population, as adults do not appear to be exposed to the same shame-inducing assumptions as the population of YP experiencing BDD may be (e.g., the YP is simply going through a normal adolescent stage of being concerned about their appearance).

7.3.8 Increasing understanding and awareness alleviates the experience of BDD in both the home and education settings.

The approaches and attitudes that most helped the participants of this study share a common theme: Being treated by others with understanding, compassion, dignity, respect, and non-judgement. This is succinctly epitomised by the overall message of the *Power Threat Meaning*

Framework (Johnstone et al., 2018): *“You are experiencing a normal reaction to abnormal circumstances. Anyone else who had been through the same events might have ended up reacting in the same way. However, these survival strategies may no longer be needed or useful. With the right kind of support, you may be able to leave them behind”* (Johnstone et al., 2018, p. 18). A core aspect of these abnormal circumstances is that we live in a culture wherein ideals of individualism, competition, materialism, consumerism, choice, and commodification of the body have taken centre-stage, as previously described.

The list of approaches/philosophies participants felt did not help them also have a common theme: Assumptions that the physical appearance is a measure of worth and is changeable/fixable, underpinned by shaming experiences. For example, participants spoke about their parents taking them to dentistry and dermatology appointments to relieve their distress. This appeared to confirm there was indeed a defect to be treated, particularly when dentists/dermatologists provided these treatments, thus compounding their sense of shame.

Screening for BDD whenever YP are presenting in a high state of distress to physical health and cosmetic professionals, regardless of whether there is an actual presence of blemishes, uneven teeth, etc., would therefore seem to be highly important. In one study of 268 adults seeking dermatological treatment, 11.9% met the diagnostic criteria for BDD (Phillips, Dufresne Jr, Wilkel & Vittorio, 2000). In a study of 200 adults with a diagnosis of BDD, physical treatments were sought by 71% and received by 64% (Crerand, Phillips, Menard & Fay, 2005). These treatments did not improve the experience of BDD for people in these studies, in line with the findings of the present study. Parents may be attempting to help their child by taking them along to the dermatologist, for example, in the hope this may reduce their distress. Supporting parents to find alternative ways to respond to their child’s pleas for dermatology/dentistry/etc. would, thus, be an important step forward.

The findings of the present study suggest seeking dermatological treatments in BDD can go alongside the presence of actual skin conditions, such as acne. An individual is exempt from a diagnosis of BDD if a visible difference or defect is present. In most BDD prevalence studies to date, individuals with moderate or severe acne have been excluded (Uzun et al., 2003). However, individuals who have more than a slight physical anomaly may have levels of distress and preoccupation that fulfil BDD criteria. Bowe, Leyden, Crerand, Sarwer and Margolis (2007) screened for BDD symptoms among 128 individuals ages 16-35 with acne across a spectrum of acne severity. They found rates of BDD ranged from 14.1% to 21.1%.

Acne was described as a feature of their BDD by half the participants in the present study. Previous studies have found the impact acne has on an individual's quality of life has very little to do with the acne severity (e.g. Mallon et al., 1999). Thus, I emphasise the importance of taking acne-related distress in YP seriously, regardless of the severity of the condition of the YP's skin.

All participants of the study spoke about their attempts to fix their appearance, including the use of professional and do-it-yourself procedures. In a study conducted by Veale (2000), 16% of adults ($n=25$) with BDD who were questioned cited a worsening of their appearance-related distress after their cosmetic procedure. Nine participants were so dissatisfied with the outcomes of their surgery that they went on to perform do-it-yourself procedures at home. The findings of the present study demonstrated that cosmetic procedures and treatments did not have lasting positive outcomes in the context of BDD for these YP, and that these YP also engaged in do-it-yourself procedures at home. This study's *Shame-Identity Model of BDD in Young People*, therefore, conjectures that appearance-related changes do not soothe the experience of BDD; as the core sense of appearance-as-identity remains, as does the underlying experience of shame, typically projected onto

another appearance feature. More broadly, the power structures and threats operational within society remain, also.

7.4 Research questions two and three: How do educational experiences inform the emergence and experience of BDD? Does BDD impact a YP's experience of education, and if so, how?

Each of the areas already covered are relevant to YP experiencing BDD in educational settings. They elucidate some of the reasons why most participants in this study experienced significant disruption to their education.

7.4.1. Lack of understanding of BDD in educational settings compounds feelings of shame and leads to negative experiences with education and absenteeism.

7.4.1.1 The transition from primary to secondary school is particularly challenging and may negatively impact on young people's experiences of BDD.

The transition from primary to secondary school is an important part of the developmental process for adolescents (Aikins, Biermann & Parker, 2005). This transition can be challenging both socially and emotionally for some adolescents, as they must adapt to new social and organisational structures (Frey, Hirschstein, Edstrom & Snell, 2009; Pereira & Pooley, 2007). Pupils have reported a reduced sense of belonging and connectedness in secondary school, relative to primary school (Pereira & Pooley 2007). For the participants in this study who spoke about secondary education, this was perceived as the most difficult aspect of their

educational experience. Three participants partially attributed the trigger of their BDD to their transition to secondary school. The underlying reason for this trigger appeared to be: (1) increased pressure to be part of an in-group (relating to the power aspect of the PTMF); (2) experiences of peer-related and educational-staff-related shame (relating to the power and threat aspects of the PTMF); (3) a reduced sense of belonging (relating to the threat and meaning aspects of the PTMF); and (4) less support to deal with emotionally distressing experiences (relating to the power and threat aspects of the PTMF). In many cases, these experiences led to BDD-related absences from school, which were at their highest during the secondary school years for each of these participants. Therefore, additional support/screening/vigilance around possible BDD-related experiences/behaviours for secondary-aged pupils seems to be important. These behaviours may include: (1) absenteeism; (2) repeated lateness; (3) use of camouflage (e.g., makeup, refusal to remove hats/jumpers/etc.); (4) refusal of/distress related to school photographs; (5) missed PE and swimming lessons; (6) avoidance of school toilets and showers; (7) leaving lessons frequently to mirror-check/skin-pick/engage in other appearance-related compulsive behaviours; and (8) social paranoia.

Experiences of being punished for BDD-related behaviours in secondary-school settings were a disconcerting finding of this study. This can be related directly to the power aspect of the PTMF. Participants shared feelings of blame and shaming experiences within the educational setting. These experiences had palpable overtones of power imbalance and dominance. It was clear these experiences of shame further isolated these YP, making it even more challenging for them to attend school. It also seemed to result in a higher propensity to hide their distress from others.

Power is the fundamental dynamic of social structure (Smail, 2005). Abuse of the power imbalance in schools in the context of mental health struggles has received little attention in research literature. For example, the preponderance of research into adolescent bullying has focused on peer-to-peer bullying. When teachers are mentioned, their perceptions of bullying and classroom management strategies are typically the focus of the study, not their treatment of the pupils (e.g., Twemlow & Fonagy, 2005; Twemlow, Fonagy, Sacc, & Brethour, 2006). YP experiencing mental health struggles like BDD are likely to be more vulnerable to such bullying, in part because the power imbalance will arguably be greater and perhaps more obvious. Gill described people in authority, like educational professionals, as being *“very, very terrifying.”*

7.4.1.2 Academic pressure increases anxiety, which heightens BDD-related distress.

High amounts of academic pressure were cited as being anxiety-inducing by many of the participants in this study. It was striking how many of the participants' attendance fell particularly low during exams, when pressure was at its strongest. It was also remarkable how many participants went to selective and/or grammar schools and/or were high achievers academically (mentioned by seven of the 10 participants).

There does not appear to have been any direct research on the correlations between academic pressure or academic self-concept and BDD to date. According to a review of 67 articles on paediatric OCD, which comes under the same category as BDD in DSM-V, school avoidance, school refusal, and academic difficulties are common in the OCD-diagnosed population (Geller et al., 1998). Often, CYP diagnosed with OCD will repeat an academic year, change schools, or drop out of school (Knölker, 1987). In early research by Honjo et al. (1989)

($n=61$ CYP with a diagnosis of OCD), researchers found school-related stress played a role in the onset, exacerbation, and maintenance of obsessive compulsive symptoms. In later research by Piacentini, Bergman, Keller and McCracken (2002), almost 50% of 151 CYP diagnosed with OCD experienced substantial related challenges in the school setting, including concentration difficulties in class and failing to complete homework.

Compulsive behaviours have been found to frequently evoke feelings of shame, with many CYP tending to hide their compulsions from educational staff (Fischer-Terworth, 2010), perhaps due to the power differential and pervasive feelings of shame. For example, CYP with obsessive compulsive behaviours may hide their compulsions by excusing themselves to go to the lavatory or performing their compulsions during breaks (Adams, 2004). Research including CYP diagnosed with OCD has found if compulsions are suppressed all day at school, CYP frequently engage in a ritualising frenzy when they return home (Adams, 2004). While further research on BDD specifically is needed, the findings of this study suggest YP with a BDD diagnosis may also suppress and/or hide their compulsions in the school environment, potentially leading to heightened distress, increased shame, and more compulsive behaviours at home.

7.4.1.3 Helpful approaches to BDD in education are underpinned by key, attuned adults who are willing to have open, non-judgmental discussions with young people about their experiences and make timetable/provision adaptations.

The findings of this study have led to the compilation of a list of approaches/philosophies in educational settings which participants did or did not find helpful. This has been reproduced

as a leaflet, which has been signed off by the BDD Foundation for use in education settings (Appendix 13).

It is arguably more challenging to develop secure pupil-teacher relationships in secondary schools, as YP spend less time with a single teacher. However, pupil-teacher relationships are important to secondary school pupils (Learner & Kruger, 1997; Wentzel, 1997). Secure pupil-teacher relationships are more likely to occur when teachers are involved with, sensitive towards, and have frequent positive interactions with CYP (Howes & Hamilton, 1992; Howes & Smith, 1995). Participants in this study cited relationships with key teachers as significantly important to feeling able to cope in the secondary-school environment in particular. Alongside support with developing positive peer relationships, and targeted psychosocial interventions, this would appear to be central to enabling YP experiencing BDD to continue to access education.

The recent green paper on CYP mental health (Department of Education; Department of Health, 2017, p.10) recognises that *“school staff play an essential role in early identification (of mental health difficulties)... and are able to encourage coordination between children and young people’s mental health services and school staff, which is important for specific diagnoses.”* Several of this study’s participants noted their teachers noticed worrisome behaviours, but few questioned the YP about these. Rather, teachers typically made assumptions about why they might be behaving in a certain way (e.g., assuming they were refusing to wear their PE kit to subvert school rules).

7.5 Implications for EPs and other educational professionals

The findings and emergent GT of this study have the following suggested implications for EPs and other educational professionals. (For more information, please see the Leaflet for Educational Professionals in Appendix 13). Educational professionals may wish to:

- Provide key, attuned adults in the educational setting who check in with the YP regularly;
- Support attendance and/or send work home in a sensitive manner (e.g., via email, to negate the YP having to ask their peers);
- Ensure close liaison between home and school, particularly regarding school absences;
- Refrain from punishing YP for their BDD-related behaviours, including making assumptions about the YP's behaviours;
- Provide a sensitively-planned timetable, which may involve alternatives for swimming and PE lessons, and the provision of a separate room for exams;
- Provide additional support for the transition from primary to secondary school, and additional support/vigilance in the secondary-school environment for possible BDD-related triggers and behaviours;
- Be vigilant and provide support for adverse peer experiences, including bullying experiences;
- Refrain from making assumptions about any aberrant eating behaviours and ask open, curious questions about such behaviours;

- Consider the provision of individual toilet and shower facilities, perhaps without the presence of mirrors;
- Consider excusing the YP from having school photographs taken;
- Carefully consider the functions and outcomes of any camouflage used by the YP, including potentially increased social vulnerability; and
- Liaise closely with any providers of BDD-specific therapy, as any exposure tasks and the reduction of safety behaviours will also possibly need to take place in the educational environment.

7.6 Implications for young people and their families

The findings and emergent GT of this study have the following implications and important considerations for YP experiencing BDD, as well as their families:

- Keeping the educational setting informed of the reasons for a YP's absence;
- Holding in mind that taking YP for physical assessments/procedures related to their perceived defect (e.g., dentistry, dermatology, and cosmetic surgery) is unlikely to have positive outcomes and may add evidence to the YP's belief that there is indeed a defect present;
- That aberrant eating behaviours do not necessarily mean the YP is trying to lose overall body weight;
- That GPs and other medical professionals may not have heard of/may not know much about BDD and may say something that causes the YP to feel misunderstood. It may, therefore, be helpful to take the *GP Information Card*

About OCD and BDD to any GP visits which can be found at:

<https://www.ocdaction.org.uk/sites/default/files/pdf->

[precompiled/ocdbdd_gp_card.pdf](https://www.ocdaction.org.uk/sites/default/files/pdf-precompiled/ocdbdd_gp_card.pdf);

- That educational professionals may not have heard of BDD. Therefore, providing them with the leaflet in Appendix 13 may be beneficial: www.bddfoundation.org/resources/bdd-leaflets;
- Refraining from pressurising YP to return to school before they feel ready, as this may have negative outcomes;
- Reducing any broader familial focus on appearance, as this may perpetuate the experience of BDD;
- Addressing any traumatic family experiences and being open about these to any professional supporting the YP;
- That YP should be prepared to understand that camouflage and safety behaviours (e.g., mirror-checking) may draw attention to themselves and ignite rumours amongst their peers;
- That YP may benefit from sharing their experiences with others (e.g., via the media) but are likely to require psychosocial support to manage potential responses;
- That BDD support groups may be helpful and may support the YP, and family members, to feel less alone and misunderstood; and
- That it can be very helpful for both YP and family members to hold in mind that they are not alone.

7.7 Dissemination

A core remit of this research was to facilitate the sharing of the voices of YP experiencing BDD. This was, in fact, the primary driving force behind the desire to meticulously and sensitively analyse and write up the YP's experiences within this thesis. The findings of this study have, thus far, been disseminated in the following ways:

- Presentation of the preliminary findings at the Eastern Regional Conference for EPs (December 2018, in Norwich), at which time the Leaflet for Educational Professionals (Appendix 13) was disseminated (see Appendix 16 for presentation slides);
- Presentation of the preliminary findings at the BDD Foundation Annual General Meeting in January 2019;
- Presentation of the preliminary findings at the Tavistock Doctoral Conference in May 2019; and
- Posting the Leaflet for Educational Professionals (Appendix 13) on the BDD Foundation website, the OCD Action website, and other relevant websites.

There is also the additional intention to disseminate the findings of this study in the following ways:

- Signposting educational provisions across the country to the leaflet in Appendix 13, through the 'Schools Project' recently funded by the Ardonagh Trust, to be delivered by the BDD Foundation and the Michael Rutter Centre at the Maudsley;

- Presenting the findings and handing out the leaflet to all delegates at the British Association of Chartered Psychologists Conference in September 2019 (at which I will be giving a presentation on BDD);
- Presenting my findings and handing out the leaflet to all delegates at the International BDD Conference in London in November 2019;
- Co-authoring *A Parent's Guide for BDD*, to be published by Jessica Kingsley in 2020, informed by the findings of this research;
- Providing all participants with a copy of this thesis and the leaflet (should they so wish) to share within their educational settings; and
- Publishing the findings in relevant journals and periodicals.

7.8 Conclusions

The lived experiences of YP who self-identify and/or have a diagnosis of BDD are complex and multifaceted. The current study suggests: *Appearance-based identity becomes the focus of adolescent identity formation in young people's experiences of BDD, informed by relational experiences of shame and low self-worth.* Consequently, addressing underlying experiences and feelings of shame and low self-worth with YP who self-identify with/have a diagnosis of BDD and supporting them in finding and developing their sense of self/identity is conjectured here to be important, even necessary. Challenging societal exertions of power and threat, epitomised through the equation of homogenous notions of beauty with success, happiness, and lovability, is also proposed to be of great importance.

YP's experiences of BDD in the home and education settings would appear to be pervaded by: (1) societal power structures centred around homogenous appearance ideals

and equability of human worth with appearance ; (2) experiences of shame; (3) low self-worth; (4) identify confusion; (5) a lack of societal and professional knowledge and understanding of BDD; (6) minimisation of distress; (7) punishment for BDD-related behaviours, particularly in the secondary school setting; (8) high appearance and academic expectations; and (9) teasing from family members, siblings, and peers. School attendance was disrupted for most participants in this study, which, in turn, had an impact on academic self-concept, number of exams taken; stress levels, teacher relationships, and peer relationships.

The YP who took part in this study found a range of approaches and practices both helpful and unhelpful in the educational setting (presented in leaflet form in Appendix 13). Overarching these aspects are: (1) the provision of key, attuned adults in educational settings; (2) empathy and understanding from educational staff; (3) sensitive curiosity in place of assumptions; and (4) offering adaptations (e.g., amended timetables). Receiving therapeutic input to learn coping strategies for attending school/college/university was also cited as important. Given the focus on the achievement of the ideal self in BDD, it is suggested that person-centred planning (Mount, 1992; Sanderson, Kennedy, Ritchie & Goodwin, 1997) and personal construct psychology (Kelly, 1955) tools may be beneficial for this population.

The findings of this study add to the small amount of qualitative literature (almost predominantly based on single-case studies, which failed to ask in-depth, exploratory questions) on YP's experiences of BDD. These previous studies arguably failed to either comprehensively recognise the core aspects of identity formation and shame in YP's experiences of BDD, or to consider the impact of BDD on YP's educational experiences and reasons for poor attendance.

7.9 Limitations

The findings of this study are a personal view of the data, informed by my theoretical viewpoint and experiences, including: (1) a historic diagnosis of BDD; (2) charitable work with the BDD Foundation; (3) career experiences as a teacher, school counsellor, and trainee EP; and (4) a strong view on the questionable validity of psychiatric diagnoses. I recognise that my experiences and opinions will have informed the way in which data were collected and analysed.

The ethical approval given for this study mandated all participants to be interviewed at the Tavistock and Portman Centre. Several participants who came forward for this study would have been willing to be audio-interviewed over the Internet (without video). This was unsurprising, given the nature of BDD. Therefore, it would appear those most affected/incapacitated by their experience of BDD were unable to participate.

Furthermore, I would have preferred to conduct interviews in a non-medicalised environment. Coming to the Tavistock ignited anxiety in some participants, particularly in those with previous mental health setting experiences. I feel the location may have possibly increased the power differential and unconsciously and erroneously communicated to participants that I was a medical person who presumed them to be ill. This may have impacted the experience, both for the participants and the data gathered.

Only one male participant initially came forward to take part in this study. Given the prevalence rate of BDD is almost equal between males and females³³ (Phillipou & Castle, 2015), the reason for such little male participation warrants further reflection and

³³ Although, muscle dysmorphia is more prevalent in males (Phillipou & Castle, 2015).

investigation. Adult BDD studies have indicated men typically experience more severe BDD and are less likely to be working (Phillips, Menard & Fay, 2006). Two additional male participants came forward for this study following theoretical sampling, yet only one was able to attend the interview, as the other felt too distressed to leave the house. As Edward explained, he felt it was more difficult for him to both deal with and talk about his BDD as a male, as he felt it to be less societally acceptable for him to be distressed by his appearance. The findings of this study may not be adequately reflective of experiences across the feminine and masculine genders. Future studies on male YP's experiences of BDD will be an important next step in this area of research.

Nine of the 10 participants in this study were white-British, and one participant was of Caribbean descent. Cultural differences across experiences of BDD were not explored and warrant further investigation.

This study comprised a small sample size wherein seven of the 10 participants were White-British females. The findings and suggestions for practice may not be generalisable or relevant for all YP of varying demographics experiencing BDD.

The 10 interviews conducted for this research were rich and replete with information. Therefore, I necessarily had to condense large amounts of information into limited word counts, and, as such, it is possible some of the intricacies and nuances of participants' individual experiences of BDD were lost/reduced in some areas.

7.10 Reflective statement

This research was an emotionally-charged and challenging journey for me. I was given an initial diagnosis of anorexia at the age of 13, and, later, a diagnosis of BDD. This involved

inpatient experiences from the age of 14 and missing almost a year of secondary school. Despite having received specialist treatment in my teens and working through and beyond my emotional pain during my 20s, some implicit, embodied memories and experiences of BDD remain. It was not possible to interview participants nor analyse the data outside my current embodied experience, nor would I have wished to.

Undoubtably, my experiences have shaped this research to some degree, and I believe they have enriched the emergent GT. I have the sense that the core aspects of shame and identity would have revealed themselves to a non-expert-by-lived-experience researcher as one possible GT within the data, as they so strongly and evidently underpinned each of the aspects of BDD shared by participants. Additionally, I feel my experiences afforded an inferential leap towards the notion that BDD is a bid for resolution; the perceived defect or defects become the means through which a YP tries to make sense of and emerge beyond their felt sense of shame, and the way they try to forge a self-perceived acceptable identity for themselves. Thus, one could say BDD is an act of hope, as opposed to a destructive act; that BDD is possible evidence of an attempt at order, as opposed to being a disorder.

I did not expect such clear correlations to be drawn between disordered eating and BDD by this study's participants, as the clinical position is that they are separate diagnoses and need to be conceptualised as such. There is a dearth of understanding in the scientific literature and clinical discourse of the overlap between BDD and disordered eating, which I would like to see changed. A clear yet unexpected message to arise from this research is that YP diagnosed with eating disorders would have ultimately appreciated being screened for BDD. I now understand I may have benefited significantly from such a screening earlier in my personal journey, also.

I have learned not only a great deal about BDD, shame, and identity through conducting this study, but also a tremendous amount about myself as a TEP, researcher, and human being. There has also been an element of personal emancipation and catharsis, mirroring what appears to have been the experience of the participants. I wonder if it is possible to conduct any sort of research without a level of restructuring the inner life of the self. I am both humbled by and grateful for the research process and all who participated in this study.

7.11 Directions for future research

The current study raises important questions about the role of parents, teachers, and peers of YP struggling with BDD. Future suggested lines of inquiry include: (1) parents' experiences of supporting a CYP with a diagnosis of/who self-identifies with BDD; (2) teachers' and other educational staff members' experiences of teaching/supporting CYP struggling with BDD; and (3) how peers can support friends experiencing BDD. Further research with those under the age of 16 is also recommended.

Additional research on the experiences of males who have a diagnosis of and/or self-identity as having BDD would appear to be highly important, particularly given the high suicide rate of males with this diagnosis (Pope et al., 2005).

Many of the participants in this study both sought and received cosmetic/dermatological/dentistry procedures and/or attempted do-it-yourself procedures at home. Important areas of further research are: (1) why and how CYP struggling with BDD seek and receive physical treatments; (2) what the emotional outcomes of these treatments

are in the short- and long-term; and (3) if and how screening is employed by cosmetic surgeons/dentists/dermatologists.

Of significant concern was an open code entitled, *being punished in school for BDD-related behaviours*, which emerged early in the research. I believe this holds a wider implication for EP practice, in terms of how CYP experiencing mental health struggles may be treated within educational institutions in general. It strikes me that an important aspect of the EP role is to notice and actively address aberrant power dynamics within educational settings, including between teachers and their pupils. Further research on both treatment of CYP struggling with BDD in educational settings, and the wider treatment of CYP with mental health difficulties in educational settings, appears to be indicated, perhaps particularly within the secondary-school environment.

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