An exploration of the experience of living with Body Dysmorphic Disorder (BDD) using multimodal hermeneutic phenomenological approaches and Interpretative Phenomenological Analysis

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Body Dysmorphic Disorder (Body Dysmorphia; BDD) is a debilitating mental health condition characterised by experiencing impairing preoccupations with one or more perceived defects in one's physical appearance. BDD affects approximately 2% of the general population but has a suicidal ideation rate of 80%. BDD is under-researched, and the majority of research published on the disorder focuses on risk factors, comorbidities and interventions, meaning there is very little understanding of the personal and idiographic experiences of those living with it. This research took a qualitative, phenomenological approach to explore the disorder using Interpretative Phenomenological Analysis (IPA; Smith, 1996) and multimodal hermeneutic phenomenological approaches in order to offer participants an array of modes in which they could make sense of their experiences of BDD. In a hermeneutic-autoethnographic piece, I explored my own BDD experience regarding difficulties with experiencing childhood appearance-related bullying, race-related bullying, rejection, and psychological abuse. In a study exploring people's self-identified origins of BDD, some of the key themes generated from participant data included experiencing a sense of entrapment with a distorted view of the world; being a prisoner in one's own skin; having an exposed and vulnerable relational self; experiencing loss and 'stolenness'. Additionally, I explored the psychological process of coping with BDD, through artwork and semi-structured interviews. Participants highlighted the fusion between BDD and their lifeworld; attempting to detach from their perceived selves; experiencing a fragmented self, and moving towards a reconciliation of the self and body. The research findings in this thesis demonstrate that using qualitative and creative methods can help to gain a deeper understanding of what it is like to live with BDD from the perspective of those who experience it. My research indicates that professionals should consider individuals' perceived BDD origins in treatment, implement peer-to-peer support and explore the embodied experience of the disorder.

Key words: Body Dysmorphia; Hermeneutic Phenomenology; Qualitative Research; Autoethnography; Visual Data

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Chapter 1: Introduction

1.1 Introduction to the thesis

The core aim of this PhD thesis is to make a contribution to the psychological and phenomenological understanding of what it means to live with Body Dysmorphic Disorder (Body Dysmorphia; BDD). BDD is a mental health condition that affects approximately 1.7-2.9% of the general population (Buhlmann et al., 2010) and is characterised by individuals experiencing debilitating preoccupations with one or more aspects of their appearance. BDD has a suicidal ideation rate of 80% (Phillips, 2007) and its symptoms are often unrecognised and misunderstood by professionals (Phillips, 2005), meaning people who live with it are left invalidated and ignored. Literature on BDD is limited, and this programme of work seeks to advance knowledge of the disorder qualitatively in order to gather authentic, first-hand experience from individuals with lived experience. In this thesis, I have used multimodal hermeneutic phenomenological approaches in combination with Interpretative Phenomenological Analysis (IPA; Smith, 1996) to explore how people living with BDD make sense of this devastating condition using innovative study designs to obtain a range of multimodal data and powerful insights. To the best of my knowledge, this is the first piece of research to explore the experience of living with BDD using IPA and multimodal phenomenological approaches.

My decision to research BDD and undertake this PhD journey developed from deeply personal events that have occurred in my life and my own lived experience of BDD. After struggling with BDD for many years and being unaware of what I was experiencing until I reached the age of 20, I wanted to explore the disorder further due to the lack of support and understanding I received in the hope of making the help seeking process more straightforward and positive for others in the future. Upon discovering IPA as a methodological approach, I became immediately interested in its application in the context of mental health research and found its focus on individual experiences and language usage highly applicable to the work I set out to complete.

My interest in how people use language to convey their experiences stemmed from my background in linguistics, which made me highly attuned to analysing the nuances in the numerous ways people communicate. Delving into interpretative phenomenological research meant I was able to transcend the linguistic domain and find and interpret meaning in phenomena that are central to people's lives. Being introduced to the work of key existential phenomenologists such as Heidegger, Merleau-Ponty and Sartre through my engagement with IPA has elucidated many previously elusive and abstract elements of BDD that were previously inexpressible. Phenomenology has acted as a protective vehicle in which I have traversed rocky and unstable terrains in the safety of knowing a sense of understanding can be gleaned from even the most consuming spaces of the mind.

1.2 Thesis structure

For ease of navigation of this thesis, I will outline what can be expected of each chapter and subsequently the thesis as a whole.

In the next chapter (Chapter 2), I provide a narrative review of the BDD literature, paying particular attention to what is presently known about BDD and to also introduce qualitative literature as a way of framing my own research and looking into how IPA can be used effectively to explore participants' experiences of living with the disorder. First, I provide some background and historical context about BDD, then I discuss its epidemiology, salient issues regarding diagnosis and treatment, a range of quantitative and qualitative literature on BDD, and applications of my chosen methodological approach (IPA) in psychology, health and mental health settings. I decided to conduct a narrative review rather than a systematic review as there is not currently a substantial amount of qualitative BDD literature, which I will discuss in more detail in Chapter 2.

Chapter 3 describes the overarching methodological approach that I have used for the empirical studies this thesis in a broader sense (IPA). I give an overview of IPA and consider the way it is situated in the wider context of phenomenology. I also delve into the epistemological underpinnings of the method and their importance in shaping it.

Chapter 4 presents the first empirical study, an autoethnography of my personal experience of living with BDD. This chapter details some of my own authentic lived experience in written form from my autoethnographic journal, along with accompanying excerpts of reflexivity and interpretative analysis of my own data. I then discuss the analysis and reflections in relation to phenomenological and psychological literature to conceptualise the experiences and provide insight into an element of BDD that has not been explored in research before.

Chapter 5 offers an empirical study (Study Two) focusing on the perceived *origins* of participants' BDD. It explores instances of key moments or memorable events which participants in the study attribute to the development or onset of the disorder for them. This study uses a combination of narrative and verbal data.

Chapter 6 presents Study Three and delves more deeply into learning about what BDD entails by exploring participants' current experiences of *living* with it. This study used data from the previous study (Study Two).

Chapter 7 presents Study Four, an empirical study that explores the ways participants convey their experiences of coping with BDD through artwork, which draws upon Boden and Eatough's (2014) Framework for the Analysis of Drawings.

Chapter 8 is a discussion of the thesis in psychological and phenomenological context to make sense of the findings, along with reflections and a critical appraisal of what has been presented earlier and offers recommendations for professional practice and future research in this area.

Chapter 2: Background and Literature on Body Dysmorphic Disorder

2.1 Historical background of Body Dysmorphic Disorder

Body Dysmorphic Disorder (Body Dysmorphia; BDD) is a mental health condition characterised by experiencing impairing preoccupations with one or more perceived defects in one's appearance (Ruffolo, Phillips, Menard, Fay, & Weisberg, 2006). Although BDD has only been officially documented in psychological literature and subsequently recognised as an established mental health condition in recent years, historical cases have been recorded as far back as the 1800s. The earliest documented case of BDD was referred to as *dismorfofobia*, 'dysmorphophobia' in English, in 1891 by Enrico Morselli, an Italian psychiatrist. The term came from the Greek word 'dysmorphia' meaning ugliness. In his 1891 work, Morselli compiled and summarised his observations of a number of patients (≈78; Phillips, 2005) he came across during his time spent in private practice and described them in the following way:

> 'The dysmorphophobic, indeed is a really miserable individual; in the middle of his [sic] daily affairs, while talking, while reading, during meals, in short everywhere and at any time, he is suddenly caught by the doubt of some deformity, that might have developed in his body without his knowing it: he is afraid he has, or he might develop a squashed and flattened forehead, a ridiculous nose, bandy legs, etc., so he looks at himself in the mirror repeatedly, feels his forehead, measures the length of his nose, scrutinizes the smallest specks in his skin, or inspects the proportions of his trunk and the straightness of his limbs, and only after a period of time, he can to be reassured and free himself from the painful state the attack put him in.' (Morselli, 1891; English translation Cuzzolaro & Nizzoli, 2018: 90-91).

Morselli's description conveys the extent to which BDD can affect an individual's everyday way of living, and the description could still be considered an accurate portrayal of the condition in modern times. Morselli brought the delusional and obsessive nature of *dysmorphophobia* to the attention of his contemporaries, illustrating the significance of '*vera pazzia del dubbio*' (true madness of doubts), coupled with '*idee fisse che moltissime volte danno origine ad azioni coatte*' (fixed ideas that very often give rise to compulsive actions), highlighting the complex and compulsive nature of the condition that is still recognisable in today's BDD literature. The next documentation of dysmorphophobia was recorded in 1903 by French psychologist and philosopher, Pierre Janet. Janet (1903) presented the case of a woman who became housebound for a number of years due to her concerns about having excessive facial hair. He described the phenomenon as "*l'obsession de la hontu du corps*", which translates into English as an obsession with shame of the body (Janet, 1903; Vashi & Maymone, 2017). In 1979, George Philippopoulos, a Greek psychiatrist, additionally presented an analysis of a case of dysmorphophobia, which he described as "fear of facial ugliness" (Philippopoulos, 1979: 397). At the time of writing his report, he had come across only five cases of dysmorphophobia in Greece during the span of his career. Dysmorphophobia was not written about very often or consistently in the psychiatric or medical literature throughout the 19th century and was not present in the first two editions of the Diagnostic Statistical Manual (DSM I, 1952; DSM II, 1968). It was first included in the DSM III in 1980. Some years later, dysmorphophobia was renamed Body Dysmorphic Disorder and was first referred to as such in the DSM-III-R in 1987. The revised name has subsequently been used in all DSM classifications and wider literature. The change of name was based on the fact that there was no substantive evidence to support that people were actually 'phobic' of their perceived defect in appearance. Aside from issues surrounding its documented name, the classification of BDD also posed a problem. The DSM III and DSM IV classified BDD as a somatoform disorder, before being reclassified under Obsessive-Compulsive and Related Disorders in the DSM V (2013). The DSM III and IV classifications were widely contested by researchers and clinicians (Castle & Rossell, 2006; Mayou, Levenson, & Sharpe, 2003) with many arguing that BDD symptoms were not similar to other disorders in the somatic category (Jana, Praharaj, & Mazumdar, 2012; Mayou et al., 2003). Recent empirically driven research conducted by Hartmann et al. (2020) suggests that BDD should not be classified under the Obsessive-Compulsive and Related Disorders category and should instead form a body image category of its own along with eating disorders (Hartmann et al., 2020). This was also supported by Phillipou, Mountjoy, and Rossell (2017) who argued for an amalgamation of BDD with eating disorders in a body image spectrum of disorders category (Phillipou, Mountjoy, & Rossell, 2017).

In the DSM-V, the present diagnostic criteria for BDD is as follows:

A. Preoccupation with one or more perceived defects or flaws in physical appearance that are not observable or appear slight to others.

B. At some point during the course of the disorder, the individual has performed repetitive behaviours (e.g. mirror checking, excessive grooming, skin picking, reassurance seeking) or mental acts (comparing his or her appearance with that of others) in response to the appearance concerns.

C. The preoccupation causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

D. The appearance preoccupation is not better explained by concerns with body fat or weight in an individual whose symptoms meet diagnostic criteria for an eating disorder.

Specify if: With muscle dysmorphia

Specify if: With good or fair insight

Box 2.1 Diagnostic criteria for Body Dysmorphic Disorder from the Diagnostic and Statistical Manual, fifth edition, 2013

2.2 Epidemiology of Body Dysmorphic Disorder

At present, it is thought that 0.7% to 2.4% of the general population have BDD (Faravelli et al., 1997; Kelly, Walters, & Phillips, 2010; Phillips, 2005). It can affect people of all ages, and the onset typically occurs during adolescence at around 16 years of age (Bjornsson et al., 2013), although symptoms can begin to manifest much earlier. BDD affects men and women (Phillips & Castle, 2001; Phillips & Diaz, 1997; Perugi et al., 1997), however, it is not yet known whether they are affected equally. BDD is thought to be under-diagnosed due to people living with the disorder being too ashamed to voice their concerns, fearing being invalidated or perceived as vain. This surrounding stigma is a major barrier between people seeking and receiving help for their BDD. Providing appropriate support for those with BDD is essential, and this is further supported by the fact that 80% of patients report lifetime suicidal ideation (Phillips, 2007). In addition, it has been reported that 24-

28% of patients have made at least one suicide attempt (Phillips, 2007; Phillips et al, 2005; Ruffolo et al., 2006; Veale et al., 1996; Weingarden, Curley, Renshaw, & Wilhelm, 2017). Phillips and Diaz (1997) and Phillips et al. (2006) found that patients with BDD often experience functional impairment in a variety of areas in their lives; social impairment being the most prevalent area that is disrupted. People living with BDD are also reported as having considerably high rates of unemployment (Birnbaum et al., 2010; Didie, Menard, Stern, & Phillips, 2008; Frare, Ruffolo, & Toni, 2004; Perugi et al., 1997; Veale et al., 1996), however, a different perspective on unemployment in those with BDD is expressed in Brohede, Wijma, Wijma, and Blomberg's (2016) study in which participants described themselves as high-performing people despite experiencing copious negative effects on their social domain as a result of BDD.

2.3 Current issues surrounding Body Dysmorphic Disorder diagnosis and subsequent treatment

In addition to issues regarding under-diagnosis and social impairment in people living with BDD, there are a number of other problems in the current climate that the BDD population face, making it extremely difficult to access appropriate treatment and support. One such problem is the diagnosis process. At present, it can take up to 15 years to receive a clinical diagnosis for BDD (Veale, Gledhill, Christodoulou, & Hodsoll, 2016; Veale et al., 1996; Phillips et al., 2005). This unacceptable length of time to wait for diagnosis could contribute to increased experiences of suicidality due to lack of support and understanding of what the condition entails, especially as the majority of treatments for BDD rely upon the receipt of a diagnosis before they commence. The services and interventions that are offered in support of those with BDD are not always tailored specifically to the individuals' needs and can make people more reluctant to continue with the support. Due to lack of awareness of or insight into the condition, people living with BDD are highly likely to present themselves in non-clinical environments in an attempt to treat the physical flaws in their appearance that they perceive to be real. For example, an individual with BDD may visit a dermatology clinic, seek cosmetic treatments in dental surgeries or visit a cosmetic surgeon before seeking help from a mental health professional (Veale et al., 2016) to discuss and address their perceived defects. The current weighted prevalence of people with BDD amongst dermatology patients is thought to be 11.3% and a slightly higher rate of 13.2% in plastic surgery settings (American Society for Aesthetic Plastic Surgery; ASAPS, 2014). Along with the present increase in people seeking cosmetic treatments and procedures made common in contemporary culture, it is highly likely that BDD will continue to go unnoticed and unrecognised across the population by the professionals providing these services in sometimes unregulated or poorly regulated settings unless more research is conducted to increase the awareness of the effects of the condition.

As mentioned in section 2.1, BDD's place within the DSM taxonomy has been contested. At present, the DSM V describes BDD as an Obsessive-Compulsive Related Disorder, however, it is often amalgamated with other bodily-focused mental health conditions such as anorexia nervosa and bulimia nervosa in the broader context of body image disturbances. Due to lack of knowledge about BDD in professional settings, people living with the disorder often go undiagnosed, untreated, or receive misdiagnoses of depression, social phobia, social anxiety (Phillips, 2005: 40) and eating disorders (Angelakis, Gooding, Tarrier, & Panagioti, 2016: 61) which are equally unhelpful. People with BDD also face stigma in wider society due to their preoccupations with their own appearance. One particularly damaging misconception of the condition is that it is often incorrectly associated with vanity in the individual. This misconception of being perceived as vain is one of the many reasons that people with the disorder may keep their appearance concerns to themselves and avoid seeking help due to feeling ashamed about their experiences (Buhlmann, Teachmann, Naumann, Fehlinger, & Rief, 2009; Phillips, 2005). Further contributions to the stigma and misconceptions surrounding BDD include the misrepresentation of the condition in the public arena, including the often dramatised depiction of people with BDD in the media and the use of incorrect terminology to describe it, for example, 'selfie dysmorphia' or 'Snapchat dysmorphia' (Tremblay, Tremblay, & Poirier, 2020), which trivialises the condition.

2.4 What does the current literature tell us about BDD?

In order to determine which areas of BDD experience need to be researched, it is important to establish what is already known about the disorder from the literature. According to Smith, Flowers, and Larkin (2009), when conducting research using IPA, literature should be used carefully to set the scene for the subsequent research to take place. They propose researchers:

> Use the literature concisely and critically to develop some picture of the current state of research in your particular area. Often this will give a flavour of work in the area, and if most of it is quantitative, an indication of what a qualitative study can contribute (Smith et al., 2009: 112).

One notable point to acknowledge is that, as Smith et al. (2009) put forward, engaging in Interpretative Phenomenological Analysis is likely to reveal to the researcher new and unexpected domains of exploration. This newly obtained information will require further discussion in relation to literature not previously discussed in this chapter in order to make sense of it more comprehensively and from different perspectives. Therefore, the literature discussed in this chapter is not an exhaustive or finite source or reflection of the analysis that follows in the thesis. I will now discuss the recent quantitative literature in the BDD research field regarding current experiences and interventions that are presently available. For this thesis, I consider a narrative review of the BDD literature most appropriate in response to the limited research that is available in the field.

2.4.1 Quantitative studies on BDD

Although still limited, the body of research investigating BDD is growing, and quantitative studies currently dominate the field. Due to there being a larger amount of quantitative literature on BDD available, I have been selective in terms of choosing studies to give a flavour of the kinds of work and the kinds of claim that typify the field. Where I will focus more systematically is in the qualitative BDD literature section of this review as this is the main focus of the thesis.

Studies have looked into identifying the potential ‘causes’ of BDD, available treatments to ease its symptoms, including assessing the effectiveness of selective serotonin reuptake inhibitors (SSRIs) and

Cognitive Behavioural Therapy (CBT) (Ipser, Sander, & Stein, 2009; Williams, Hadjistavropoulos, & Sharpe, 2006). Comorbidities with other mental health conditions have also been explored, for example Obsessive-Compulsive Disorder (Buhlmann, Etcoff, & Wilhelm, 2008; Phillips et al., 2012; Toh, Castle, & Rossell, 2015), anorexia nervosa (Castellini et al., 2013; Gaudio & Quattrocchi, 2012; Moody et al., 2017; Phillips et al., 2012), and social anxiety (Kelly, Walters, & Phillips, 2010; Pinto & Phillips, 2005). At present, there is still much more to learn about multiple aspects of BDD, and as BDD can have an extremely detrimental effect upon an individual's life, it is important to establish at-risk groups in order to potentially minimise or prevent its development.

2.4.1.1 Who is at risk of developing BDD and how does it develop?

BDD onset typically occurs during adolescence, usually at around 16 years of age (Bjornsson, 2017; Phillips, 1991; Phillips, 2005), and a recent study found that around 60% of adults with BDD developed the disorder before the age of 18 (Jassi, 2019). It has been suggested that the earlier the onset of BDD in an individual, the more likely they are to experience more severe symptoms later in their lives. Such symptoms include engaging in severe substance abuse, experiencing stronger delusionary beliefs and more frequent suicide attempts (Phillips, Gunderson, Mallya, McElroy, & Carter, 1998; Phillips, Pinto, & Jain, 2004).

With regards to the identification of potential contributing factors of BDD development, this is still an area that remains unclear and under-researched across the literature. It should be noted that, as yet, there is no definitive set of events that are 'proven' to contribute to the development of BDD. As is the case with numerous mental health conditions, researchers have suggested that there may be a number of predisposing factors that have influence over the development, or triggering, of the condition. Some of these proposed factors include genetic or hereditary implications, and physical differences in brain structure, such as differences in regional brain volumes (Buchanan et al., 2014), and reduced cortical thickness (Grace et al., 2017) in comparison to healthy control groups.

It has only been in recent years that external, social and environmental factors have been taken into consideration as potential contributing factors towards the emergence of BDD in individuals. In a mixed-methods study conducted by Weingarden, Curley, and Renshaw (2017), 165 adults with BDD were asked via online questionnaire if they had experienced a triggering event that may have been the origin of their BDD. If respondents replied ‘yes’, they were then asked to describe the event(s). The events that were disclosed most frequently related to bullying and teasing, and other reported events included being exposed to cultural beliefs regarding beauty, experiencing abuse, and family stress (Weingarden et al., 2017). Although this study identified a range of possible origins of BDD, it did not provide sufficient information about the significance in meaning of those events to each individual and an in-depth discussion around the identified events did not take place. For example, the event descriptor ‘family stress’ is vague, and it may have been more helpful to know exactly what the respondents’ experience of family stress involved, and how they believed it may have triggered their BDD in order to take into consideration the most effective intervention(s) for specific experiences.

Neziroglu, Khemlani-Patel, and Santos (2004; 2012) proposed a biopsychosocial model for the examination of the presence of environmental influences upon BDD development. Their biopsychosocial model takes into account external stimuli including cultural beliefs and values, life events and social influences (Neziroglu et al., 2004; 2012) as well as the neurobiological and evolutionary factors that may be associated with the development of BDD. According to Neziroglu et al.’s (2004; 2012) model, some of the key social and environmental influences or risk factors that may lead to or trigger BDD include pressures from society to be ‘perfect’ due to cultural beauty standards, perceived teasing, aesthetic sensitivity, and, from an evolutionary stand point, the pre-existence of some personality disorders or traits. With regards to possible identifiable personality traits of people with BDD, a study by Veale and Lambrou (2002) additionally determined that those with BDD are highly likely to have heightened ‘aesthetic perceptual skills’, hypothesizing that BDD patients “are superior at appreciating art and beauty than the rest of the population” (Veale & Lambrou, 2002: 430). ‘Aesthetic perception’ is defined as a subjective measure of considering how aesthetically pleasing something may be, however, an example of objectifying this measure could be achieved by obtaining "a composite rating by a group of artists for works of art or cosmetic surgeons for the human form" (Veale & Lambrou, 2002: 430). Veale and Lambrou also noted that people with BDD will often have an aptitude for the arts, including a proclivity for creating art and sensitivity to very slight visual differences and asymmetry, particularly in faces (Veale & Lambrou, 2002). The latter characteristic becomes more visible in cosmetic surgery settings. In this same study, 20% of BDD patients had an educational background in an art related subject or an occupation centred around art and design. This was a much higher percentage than the other groups included in the study; of the depression, OCD and posttraumatic stress disorder groups, less than 5% of patients had an art related background or occupation (Veale & Lambrou, 2002). These perfectionistic traits and potentially heightened focus on aesthetics have also been linked to people with BDD choosing to pursue careers in creative areas involving art and design (Veale & Riley, 2001). This finding is further strengthened by Krebs, Quinn, and Jassi (2019), Veale (2004), Weiffenbach and Kundu (2015), and Willhelm (2006) who agree that according to cognitive behavioural models, having perfectionistic personality traits is common in people with BDD and they are likely to display a particularly high standard of aesthetic appraisal (Schieber et al., 2013).

Possible social risk factors for developing BDD include being exposed to childhood abuse, neglect and teasing (Constantian, 2019: 273), and a pediatric BDD sample in Neziroglu, Borda, Khemlani-Patel, and Bonasera's (2018) study showed that the children with BDD were highly likely to have experienced bullying, equally as a victim and as a perpetrator. This finding is bolstered by Zimmer-Gembeck, Webb, Farrell, and Waters' (2018) longitudinal study, which found that adolescents who had been teased about their earlier-matured appearance experienced an increase in anxiety about their appearance. This anxiety worsened significantly when the teasing came from peers (Zimmer-Gembeck et al., 2018). The significance of peer criticism on adolescent concerns about appearance was also supported by findings from Lavell, Farrell, and Zimmer-Gembeck (2014) and Webb et al. (2015), who stated that adolescents and adults who reported more instances of peer victimisation reported more frequently occurring and severe BDD symptoms. There is also some research that suggests BDD development in an individual may be linked to a familial presence of BDD, particularly when first-degree relatives display symptoms of the disorder (Phillips, 2005; Fang, Matheny, & Wilhelm, 2014). Due to there being a range of factors that may contribute to the development of BDD in individuals, it is important to explore the ways in which it might present itself in order to aid the diagnosis process or find suitable treatments for individuals displaying symptoms.

2.4.1.2 How does BDD present itself?

With regards to the presentation of BDD, there are many ways it can manifest itself in an individual and this can vary considerably across the population. Excessively viewing oneself in the mirror to examine perceived defects is very common in people with BDD, and 90% of individuals with BDD have reported doing this (Phillips et al., 2005). By contrast, some people with BDD avoid mirrors and viewing themselves in other reflective surfaces altogether due to the distress this causes them. In a study conducted by Phillips, Menard, and Bjornsson (2013), approximately 10% of participants with BDD disclosed that they had experienced a panic attack after viewing themselves in a mirror (Phillips et al., 2013), triggered by seeing their perceived defect(s).

Some people with BDD may seek cosmetic procedures in an attempt to rectify their perceived defect(s), and this can reach excessive levels in some cases. People with BDD are more likely to present themselves in a cosmetic setting rather than to a mental health professional (Veale, 2016). It has been reported that around 90% of people with BDD who undergo cosmetic surgery see no change in their BDD symptoms or report that their symptoms actually worsened (Phillips, Grant, Siniscalchi, & Albertini, 2001; Crerand, Phillips, Menard, & Fay, 2005), showing that employing cosmetic procedures to ‘correct' the defect(s) often leads to unsatisfactory results for the individual. In cases where cosmetic intervention is refused, unaffordable, or inaccessible, some people with BDD will resort to engaging in self-surgery, or DIY surgery (Veale, 2000), in an attempt to ‘fix’ their defect(s) themselves. This often has grievous consequences for the individual and can ultimately result in severe infection or death.

A large number of people with BDD avoid social situations due to the shame they feel towards their physical appearance. For example, the avoidance of being in public places, group settings or being in a relationship are common as the disorder drastically affects the social functioning of the individual. This social avoidance can lead to an individual becoming housebound for an extensive period of time, and it is thought that 30% of people with BDD will become housebound at some point in their lives (Phillips et al., 2006). In addition, people with BDD with poorer insight are likely to miss periods of school and work due to the social impairment associated with the disorder, which can have a detrimental effect on their future prospects. Other physical manifestations of BDD include frequently checking one's reflection in other reflective surfaces, engaging in excessive grooming rituals and hiding or camouflaging aspects of one's appearance (Veale, Kinderman, Riley, & Lambrou, 2003; Veale & Riley, 2001), for example with cosmetics or by strategic use of items of clothing. These rituals are often very time consuming and distressing for individuals, severely impacting their daily lives and often worsening symptoms overall.

As BDD is a very complex and multifaceted disorder, people who live with it may also experience symptoms that overlap with other mental health conditions and it can be mistaken as such. In the following section, I will outline some of the mental health conditions that have been shown to be comorbid with BDD.

2.4.1.3 What are the comorbidities associated with BDD?

BDD is thought to be comorbid with a range of other mental health conditions, which, when appearing concurrently, can increase the severity of the symptoms experienced by an individual significantly. Research has found that BDD is likely to be comorbid with depression, social anxiety, and Obsessive-Compulsive Disorder (OCD), and it is often misdiagnosed as those disorders by people who are unfamiliar with its presentation and symptoms (Phillips, 2005). The co-occurrence of OCD with BDD is particularly high in young females, with a higher suicidal ideation and engagement with substance abuse (Constantian, 2019; Stewart, Stack, & Wilhelm, 2008; Phillips et al., 1998). Some potentially comorbid disorders such as anorexia nervosa and bulimia nervosa are more likely to develop once the onset of BDD has already occurred (Bjornsson et al., 2013; Volpe et al., 2016). It is possible that the development of an eating disorder alongside BDD is in response to the appearance concerns of the individual, and will often centre on the desire to lose weight from particular body parts or reduce the size of specific facial features, rather than general loss of weight overall, which would therefore constitute a diagnosis of BDD instead of an eating disorder. Identifying appropriate interventions and treatments for people living with BDD may pose problems for professionals due to the diverse range of symptoms that individuals can display. In the next section, I explore the literature surrounding the consideration of interventions for BDD treatment.

2.4.1.4 What interventions have been studied for BDD?

Establishing the efficacy of interventions for BDD is a growing area of interest in the BDD literature, however, there is currently no ‘one size fits all’ approach to treatment due to the complexity of the disorder. At present, the interventions that have shown to be most effective in managing BDD are Cognitive Behavioural Therapy (CBT) and Selective Serotonin Reuptake Inhibitors (SSRIs), sometimes used in combination in a multidisciplinary approach (Vashi, 2016). However, CBT for BDD has received some criticisms regarding its long-term efficacy for managing the disorder. In Harrison, Fernández de la Cruz, Enander, Radua, and Mataix-Cols’ (2016) systematic review of randomised controlled trials using CBT to treat BDD, they reported numerous studies showed therapeutic gains from engaging with CBT treatment lasted approximately 2-4 months in individuals. They emphasised the importance of sustained CBT treatment for BDD, but acknowledged that there are some barriers to receiving this. One barrier is that it can be extremely difficult to obtain a formal diagnosis in order to access mental health services and treatment, which is supported by Veale’s (2016) finding that it can take up to 15 years to receive a clinical diagnosis for the disorder. Another barrier is that many mental health professionals are not aware of the condition and subsequently may not be able to recognise and diagnose it as BDD. Without individuals receiving continued support for their BDD, it is possible that they will relapse (Harrison et al., 2016), therefore CBT may not be a suitable long-term solution for managing BDD.

Another treatment for BDD that is sometimes used in combination with CBT is mirror exposure therapy. Mirror exposure therapy is described as “the systematic, repetitive viewing of oneself in the mirror with specific guidance” (Griffen, Naumann, & Hildebrandt, 2018: 163). It seeks to highlight where people focus their attention and gaze when viewing themselves and using this insight to work towards developing a healthier relationship with one’s appearance. Neziroglu, McKay, Todaro, and Yaryura-Tobias (1996) explored the concept of mirror *retraining* (changing the way individuals gaze at their appearance in the mirror) in people with BDD using mirror exposure therapy. They found that the majority of participants in the study had benefitted from engaging in the task over a four-week period, demonstrated by reduced scores in the BDD-YBOCS (The Yale-Brown Obsessive-Compulsive Scale Modified for Body Dysmorphic Disorder) questionnaire (Neziroglu et al., 1996) upon completion of the intervention. Mirror exposure therapy was also shown to be an effective treatment for BDD in adults in Wilhelm et al.’s (2019) study.

More recently, the efficacy of compassion-focused therapies has been taken into consideration as possible interventions for people with BDD. Self-compassion therapy focuses on the components of self-kindness, common humanity, and mindfulness (Neff, 2003) and seeks to improve an individual’s attitude towards themselves. Foroughi, Khanjani, and Mousavasi Asl (2019) suggest that BDD is driven by two forms of shame: internal shame (relating to one viewing themselves as faulty or incompetent) and external shame (relating to bodily dissatisfaction in the public domain) (Foroughi et al., 2019). The study they conducted explored the role of self-compassion therapy for 210 individuals with BDD and found it effective in helping them reduce the perfectionism and negative affect they experienced. However, they found that self-compassion therapy did not significantly help individuals with reducing external shame and BDD concern (Foroughi et al., 2019). The use of Compassion-focused therapy has also been explored by Chou et al. (2020) for hoarding disorder, an obsessive-compulsive and related disorder that has been linked to BDD. In this study, they found that the retention rates after using Compassion-focused therapy to treat hoarding disorder were significantly higher than when CBT was used, suggesting that Compassion-focused therapy may be a strong alternative to treating BDD with CBT.

Specialist-delivered interventions such as Compassion-focused therapy and CBT can be costly to facilitate, and researchers have suggested alternative and simpler interventions that may support people with milder forms of Obsessive-compulsive and related disorders, including BDD. Fontenelle, Zeni-Graiff, Quintas, and Yücel (2018) reviewed the suggestion of considering lifestyle approaches for improving the lives of people with Obsessive-compulsive and related disorders, and looked at aspects of individuals' lifestyles that could be adapted to support this. In conducting this study, they found "meditation-based therapies and interventions focusing on eliminating sedentarism to be promising approaches" (Fontenelle et al., 2018: 5698). However, others state that treating BDD effectively requires the expertise of specialists due to the complexity of the disorder (Marques, Weingarden, LeBlanc, & Wilhelm, 2011).

It is also very important to note that cosmetic surgery is not a recommended treatment for BDD and has been shown to significantly worsen symptoms in a large proportion of people living with BDD who undergo it. Studies have shown that people with BDD who are given cosmetic surgery exhibit a dissatisfaction rate between 80% and 90% towards the outcome of their surgery (Phillips, 2005; Barone, Cogliandro, & Persichetti, 2013), and if their BDD symptoms were very slight before the procedure, cosmetic surgery patients began to show signs of severe BDD postoperatively (Crerand, Sarwer, & Ryan, 2017).

There are some inconsistencies in the effectiveness of current recommended treatments for BDD (for example, regarding CBT as detailed earlier in this section), and a notable lack of services available to treat people who live with the disorder. Therefore, it is imperative to take into consideration the support needs and experiences of individuals with BDD. These factors can only be explored fully using a qualitative approach towards data collection and analyses, and it is hoped that gaining an understanding of such factors idiographically may lead to the development of more robust services and clearer treatment pathways to address the unique symptoms and concerns of individuals with BDD.

2.4.3 Qualitative Research on BDD

As mentioned earlier in this chapter, despite the emerging interest in researching BDD, the majority of the research is quantitative and therefore there is still very little understanding of the personal, idiographic experiences of those living with the disorder. In order to find out what qualitative BDD research is currently available, I conducted literature searches from February 2017 to September 2020 using the following search terms on the electronic databases Web of Science Core Collection and Google:

Table 2.2 Table of Qualitative literature search terms

Type	**Database**	**Search terms**
Peer-reviewed journal articles (from 1970-2020)	Web of Science Core Collection	“body” AND “dysmorphic” AND “disorder” OR “body dysmorphia” AND “qualitative” “body” AND “dysmorphic” AND “disorder” OR “body dysmorphia” AND “interview$”
Peer-reviewed journal articles	Internet search engine (Google)	“body dysmorphic disorder” OR “body dysmorphia” AND “phenomenology” “phenomenology of body dysmorphic disorder” “qualitative body dysmorphic disorder studies”

These search terms brought up 16 articles. Of those 16 articles, only seven were qualitative BDD studies. The remaining nine articles were excluded after screening the titles and abstracts on the basis that they were either not related to BDD or not qualitative studies. To the best of my knowledge, there have not been any additional qualitative BDD studies published at present that have not been mentioned in this narrative review, highlighting again the lack of qualitative literature exploring BDD and individual accounts associated with it. Veale (2016) also points out that there is a noticeable lack of literature exploring the individual accounts of people living with BDD. In order to learn more about people's support needs and to help others better understand what it is like to have the disorder, it is essential to carry out qualitative research on it and foreground the lived experience of people living with BDD. With regards to the current literature published on BDD, there is a very notable gap in the empirical research concerning the ways that people living with BDD embody the disorder and describe their experiences of living with it. To the best of my knowledge and after conducting thorough searches of the available literature, there are currently only seven qualitative BDD studies that have been published. Of those seven, three are theoretical (which I will discuss in more depth later on), and four are empirical. Table 2.3 (page 31) provides details about the four qualitative empirical BDD studies published.

Table 2.3 Table of published empirical qualitative studies on BDD

Name of paper, author(s), and year of publication	**Method(s)**	**Participants**	**Analysis**	**Findings**
" 'I will be at death's door and realize that I've wasted maybe half of my life on one body part": the experience of living with body dysmorphic disorder' **Brohede, Wijma, Wijma, & Blomberg** (2016)	Interpretative description	15 participants with BDD (9 female, 6 male)	Interview transcripts were analysed using interpretative description (Thorne et al., 1997). First author completed initial analysis, last author validated the analysis. All interviews were coded for words/phrases that captured the essence of the content	Six main themes were identified: Being absorbed in time-consuming routines; Facing tension between one's own ideal and perceived reality; Becoming the disorder; Being restricted in life; Attempting to reduce one's problems; Striving to receive care.
'How do people with body dysmorphic disorder view themselves? A thematic analysis' **Silver, Reavey, & Fineberg** (2010)	Thematic Analysis	11 participants with BDD. Six recruited via national OCD clinic, four via BDD self-help group	Researchers discussed visual data with participants during interviews. Photographs and drawings were used to add context to accounts, rather than analysed separately. Researchers looked for patterns of repetition and meaning in data	Five main themes were identified: Increased threat perception resulting in disordered interpersonal relationships; Wish for regularity and symmetry in appearance versus beauty; Idealisation of childhood self; The duty to look good; Focus on specific defects rather than "ugliness".
'I once stared at myself in the mirror for eleven hours.' Exploring mirror gazing in participants with body dysmorphic disorder' **Silver & Farrants** (2015)	Photo elicitation and Interpretative Phenomenological Analysis	10 participants with BDD (7 female, 3 male). Age range: late teens to mid-30s	Photographs were discussed during participants' interviews. Verbal data were analysed using IPA. Initial notes were made in transcript margins and themes were developed from notes. Patterns across cases were identified	Four main themes were identified in the data: The self as an aesthetic object; Striving for the 'Good Enough' self; The confused self; The imprisoned self.
"He's a good-looking chap aint he?": Narrative and visualisations of self in body dysmorphic disorder' **Silver & Reavey** (2010)	Photo elicitation and Narrative Analysis	11 participants with BDD aged 20-39. Six via OCD clinic, four via BDD self-help group	Researchers identified themes and notable instances of narrative tone and imagery. Narratives were cross-analysed for similarities and differences and pieced together to create a story.	Participants struggled to come to terms with no longer having their childhood appearance, made direct comparisons between 'past self' and older, "uglier" self.

Of the small number of qualitative studies published, previous studies (Brohede et al., 2016; Silver & Reavey, 2010; Silver, Reavey, & Fineberg, 2010) have highlighted and supported the findings of Veale and Lambrou (2002) who stated that there are inconsistencies between the ideal and actual self of those living with the condition. Silver and Farrants (2015) conducted a study exploring BDD participants' experiences of mirror gazing and argue that the phenomenon is extremely complex, however, this study only focuses on one specific manifestation of the disorder, rather than living with the condition as a whole, embodied disorder. Weingarden et al. (2017) published a study regarding triggering events that patients believed contributed to their development of BDD. This study involved analysing the self-identified triggering factors of 165 adult BDD patients, and it was suggested that the most common event contributing to the emergence of BDD symptoms described in their narratives was the experience of bullying. Although this study collected data from a large sample size and gave a good idea of the scope of events people with BDD may attribute the disorder to, it was not analysed in depth and so the personal anecdotal data that is significant to helping people move towards better understanding BDD was not captured. The study did not look at the appraisal of meaning for the events mentioned by BDD patients, for example, how they made sense of the triggering events or what they thought of the outcome of their diagnosis.

The studies that have been discussed in this literature review are helpful in gauging information about current implications in the BDD research field and in giving us an overview of BDD, however, they do not further our understanding of *how* people navigate the world whilst living with BDD and what the experience is like for them as individuals. The literature has shown that people living with BDD experience an extremely distressing disparity between their perceived and actual selves and this raises questions regarding how they might embody the disorder, which have been left unanswered. It is therefore important to further explore individual experiences of BDD qualitatively to help us gain a better understanding of what their experiences are like. Grounded theory and Discourse Analysis are two qualitative methods that have been used previously in qualitative psychology research to analyse the narratives of individuals. Grounded theory was originally used in sociology research and was developed by Glaser and Strauss in 1967. Its application is not limited to psychology, and it has been used in many disciplines. Studies that employ grounded theory start off with open research questions and then hone-in on any ideas that are generated by the researcher once they are engaging with the investigation (Pidgeon & Henwood, 2004), and the method itself is highly structured (Smith et al., 2009). Grounded theorists are usually required to use a relatively large sample size with regards to recruitment. Morse (1994) recommends 30-50 participants are interviewed for ethnographic studies, however, for the purpose of working towards a greater understanding of a very under-researched and underrepresented group such as people living with BDD, a smaller sample size may be more useful. This would allow for the researcher to delve more deeply into individual participants' experiences. Discourse Analysis (DA) is particularly interested in the way people interact with one another. Within DA, there are two main approaches: Discursive Psychology and Foucauldian Discourse Analysis. Discursive Psychology has more of a focus on the individual level and constructive, contextual dimensions (Willig & Stainton Rogers, 2017), whereas Foucauldian Discourse Analysis seeks to look at the way things are understood on a societal level or in specific social settings. DA would be an appropriate method of analysis for researchers wanting to gain more of an understanding of "how language functions in specific contexts" (Smith et al., 2009) and how individuals make use of cultural resources in their interactions (Potter & Wetherell, 1987). However, in this body of work, I aim to move towards developing a greater understanding of BDD by focusing directly on the experiences of individuals and how they make sense of their relationship with it. After these considerations, it would be very useful to explore questions of embodiment and BDD through a phenomenological lens. Phenomenology is perfectly suited to exploring "human experience and the way in which things are perceived as they appear to consciousness" (Langdridge, 2007: 10). In order to explore such important insights in depth, the use of an approach that enables the application of phenomenology to first-person accounts of particular phenomena is needed. Phenomenology can therefore reveal those in-depth first-person accounts of subjective, embodied experiences of BDD. Interpretative Phenomenological Analysis (IPA; Smith, 1996) is a methodological approach that facilitates the exploration of phenomena very deeply at the idiographic level. I will now discuss a range of prior literature that has employed IPA as a methodological approach that focuses on the individual level and how it has been successfully applied to psychology, health, and mental health research to give a richer understanding of living with a variety of conditions.

2.5 Interpretative Phenomenological Analysis in psychology, health, and mental health research

Delving into the lifeworlds of participants calls for a qualitative approach to data collection and analysis. Qualitative research sets out to find out more about people's experiences in particular contexts. As Ashworth (2015) explains:

> those who wish to investigate the person's grasp of their world in detail will tend to turn to qualitative methods. A concentration on human *experience* as the central topic of psychology or a focus on *construction* or *interpretation* seems, for us, to lead, almost inevitably to qualitative research (Ashworth, 2015: 5)

With regards to investigating personal and individual phenomena such as experiences associated with living with a complex disorder like BDD, it is vital to look more closely into the meaning making processes of this under-researched population. IPA provides a robust foundation for enabling a thorough exploration of human experience and accessing nuanced and complex phenomena. IPA is a qualitative methodological approach which focuses on gaining deep insight into first-person accounts of individuals in order to gain access into their lifeworld, aiming to understand how they make sense of and interact with their social world (Smith, Flowers, & Osborn, 1997). I will discuss IPA as my chosen methodological approach in greater depth in Chapter 3, for now I focus on reviewing the relevant literature in this area.

Prior applications of IPA in research have demonstrated that it is a particularly effective approach for helping us grasp an understanding of participant experience and using this obtained knowledge to increase awareness of particular medical or mental health conditions from the perspective of the people experiencing them. IPA has not yet been used to research the experiences of living with BDD, however, there is a large body of phenomenological research on other mental health and physical health conditions in the field, making a compelling case for its application to BDD research. Murray and Rhodes (2005) used IPA to explore the experience of living with visible adult acne, and this generated some insightful findings about a condition that has been considered a possible precursor to the development or onset of BDD (Phillips et al., 2000). The experience of living with depression, a condition that is also thought to be comorbid with BDD, has also been explored using IPA in a case study by Rhodes and Smith (2010) who discussed the numerous benefits of using this methodological approach to access new insights. They found that using IPA allowed them to investigate how one person's experience of depression was interwoven with complicated issues of the self and other interconnected elements, going beyond the scope of the DSM criteria for depression and providing a much more insightful, personal representation of the condition.

In relation to body image, previous IPA studies have explored the lived experience of people with anorexia nervosa, including their experiences of using online pro-anorexia forums (Mulveen & Hepworth, 2006), the experience of bodily changes in men living with HIV (Kelly, Langdon, & Serpell, 2009), and the experience of women's body image and sexuality after amputation (Khan, O'Keeffe, Nolan, Stow, & Davenport, 2019). In each of these studies, researchers were able to grasp insightful perspectives on a number of sensitive issues regarding the body in potentially vulnerable states using IPA to explore those experiences thoughtfully.

2.5.1 Phenomenological research on BDD

Literature searches have not found any other existing IPA studies on BDD, however, work from my doctoral programme of research has been published (see Craythorne, Shaw, & Larkin, 2020). With regards to other phenomenological research on BDD in a broader sense (not specifically IPA), there is still a limited amount of theoretical work that considers BDD through a phenomenological lens. Morris (2002) drew upon concepts from Sartre's philosophical work to examine BDD phenomenologically. In particular, she placed emphasis on the importance of his concept, the 'lived-body-for-others' (Sartre, 1943), and argued that BDD is "a disorder of *this* dimension" (Morris, 2002: 172) of the 'lived body' (Sartre, 1943). Although there is clear evidence that the way another may perceive one’s body and appearance is significant to individuals with BDD, this perception of the other is only one facet of the disorder. A more holistic approach to the exploration of BDD needs to take place in order to fully understand this complex disorder and what it is like to live with it with the addition of empirical data generated using a phenomenological approach.

In Fuchs’ (2003) study, he focused on two specific emotions associated with BDD and depression: shame and guilt. In this study, he used phenomenology to gain insight into the gaze and the voice of the other and explore how both of these elements are intertwined within those with mental health conditions. In his work, he acknowledged that across the literature, there is more focus on BDD behaviours rather than the reflective beliefs that people with BDD have. Although some of those beliefs were explored in Fuchs’ work, for example, via theoretical viewpoints on the distorted self, empirical data was not included and so valuable insight in the form of lived experience was missed. Mitchell (2017) broadened the scope of the exploration of BDD by drawing upon the work of Husserl and Sartre to analyse the embodiment of the anxiety one feels about one’s appearance when living with BDD. Through engaging with prior theoretical research phenomenologically, his work revealed the significance of this anxiety and the instability it creates within an individual’s life. He also delved into the importance of mirrors and the perceived self in relation to this instability, however, like Fuchs’ (2003) research, this was not explored using empirical data and instead used secondary narrative data to elucidate specific theoretical concepts.

The small amount of phenomenologically-informed BDD literature that is presently available illuminates the significance of exploring the body through a phenomenological lens. Drawing upon phenomenological insight in this way enabled researchers to consider aspects of BDD that may have previously been considered ambiguous and unknown to those without knowledge of its symptoms, such as the strong sense of instability BDD a person with BDD may experience. This conceptual phenomenological work adds to the knowledge base because it interprets the phenomenon of BDD in a different way. It shifts us from the DSM (the clinical, potentially biomedical way of making sense of it) towards a different order – a phenomenological order which puts the person at the centre and focuses on how phenomena appear to us in consciousness. In using empirical data in my idiographic phenomenological research on BDD, I hope the reader will agree that I have further illuminated aspects of the condition that are salient in the lives of individuals, honouring their authenticity and identifying what living with BDD means to them, bringing their voices to the fore.

2.6 Summary

Overall, in comparison to the vast amount of literature on other mental health conditions of a similar prevalence, the BDD literature is significantly lacking. The majority of BDD literature is quantitative and, as a result, little is known about the first-hand experiences and meaning making processes of people living with this debilitating condition. It is essential to establish how people living with BDD make sense of the disorder in order to grasp what the key elements of it are for them and the ways in which it may be best to address them in appropriate settings. By engaging in qualitative research to explore phenomena associated with BDD, I hope to be able to potentially help professionals develop an awareness of the disorder and its symptoms, whilst moving towards changing public attitudes towards this devastating condition.

2.7 Research Questions

I used the literature review to identify gaps in the current literature and to develop appropriate research questions to address those gaps. From conducting the review, I found there were notable gaps in the understanding of BDD using subjective experience and empirical first-hand data. The overarching research question was: ‘What are people’s subjective, embodied experiences of living with BDD?’, and the specific research questions asked in each study are presented below in Table 2.4 (page 38).

Table 2.4 Table of Research Questions

Overarching Research Question

What are people's subjective, embodied experiences of living with BDD?

Research Questions	**Location in thesis where addressed**
To what extent does autoethnographic work contribute to the exploration of Body Dysmorphic Disorder (BDD)?	Chapter 4: Study 1
How might my own experience of BDD provide useful ways of looking at my research and analyses?	Chapter 4: Study 1
What do people with BDD believe might have caused or contributed to the onset or development of their BDD?	Chapter 5: Study 2
How do people with BDD make sense of their self-identified origins of BDD?	Chapter 5: Study 2
How do people with BDD use language to communicate and make sense of the embodied qualities of BDD?	Chapter 6: Study 3
What do the narratives of people with BDD tell us about the support needs of people living with it?	Chapter 6: Study 3
What do the images of people with BDD tell us about their experience of coping with it?	Chapter 7: Study 4
How does the combination of image making and interviews help people with expressing ambiguous elements of their experience of living with BDD?	Chapter 7: Study 4

Chapter 3: Methodology

In this chapter, I describe the overarching methodological approach used across the four studies within this thesis: Interpretative Phenomenological Analysis (IPA; Smith, 1996). IPA is a qualitative methodological approach to data analysis with a theoretical foundation of both phenomenology and hermeneutics. Each study in the thesis combines IPA with additional distinctive qualitative methods, thereby taking an innovative multimodal approach to the research in order to deepen phenomenological and psychological insight. The additional methods used in those individual studies will be described in more depth in the respective study chapters, and I have used Yardley's (2000) quality criteria for qualitative research to assess the quality of my research, which will be discussed and evaluated further in Chapter 8. Firstly, I will discuss the development of phenomenology as one of the key theoretical foundations of the IPA method.

3.1 Phenomenology

From a social science perspective, phenomenology is "the study of human experience and the way in which things are perceived as they appear to consciousness" (Langdridge, 2007: 10). Philosophically, it is a movement that is centred on the study of subjectivity of which Husserl (1859-1938) is considered the founder. Husserl referred to subjectivity as the foundation for all experience and the means through which we interrelate with the world. One of Husserl's key epistemologies regarding our understanding of the world from a phenomenological perspective is the suspension of the 'natural attitude'. This refers to the objective, taken for granted view that we have of the world. It is interested in the natural sciences, facticity and the world in-itself. Although important, these areas do not further our knowledge and understanding of complex, subjective human experience, and so Husserl proposed that we put them aside or *bracket* them in order to explore more meaningful human experiences. This bracketing of the natural attitude is referred to as phenomenological reduction (epoché) and constituted Husserl's call to go back to the things themselves, "to the way in which the world shows itself in and through consciousness, in order to obtain knowledge about the subjective realm"

(Bullington, 2013: 19). Going back to the things themselves allows us to consider the subjective meaning of phenomena and think about the world in terms of its appearance to human consciousness and what we understand them to be, which could be useful for exploring ambiguous phenomena such as BDD. Another key Husserlian idea regarding the consideration of experiences is *intentionality*. Intentionality refers to directing consciousness towards an external entity, thinking about how this is done and its inherent meaning. Studying the intentionality of phenomena involves focusing on alternative modes of meaning in the world and putting aside any preconceived knowledge about them. Within the concept of intentionality, Husserl described a distinction between the subject and object of what we experience (Langdridge, 2007), and stated there are two distinct branches to consider: noema and noesis. Noema concerns the experience itself, and noesis refers to "the way it is experienced" (Langdridge, 2007: 15). Intentionality is therefore considered to be the relationship between what is experienced and how we as humans experience that particular phenomenon. Considering the intentionality of phenomena is a key element of phenomenological psychology, and foregrounds the importance of the consideration of that human experience in the world of the individual.

One of the significant moments in the development of hermeneutic phenomenology was the introduction of the 'existential turn'. The existential turn signalled a period in which phenomenologists became interested in ontological aspects of our human nature, for example, wanting to explore and gain an understanding of our *existence* in the world. This was of particular interest to Heidegger (1889-1976), who dedicated much of his life to exploring the meaning of 'Being'. In his renowned work, *Being and Time* (1927/1962), he considered the examination of this meaning in great depth and additionally suggested that we are unable to distance ourselves or separate ourselves entirely from the world we inhabit, arguing against Husserl's belief that we are able to bracket ourselves off from the phenomena we are investigating. Rather than bracketing, Heidegger proposes that this is not possible and that we should consider experiences along with the cultural and historical context in which they occur (Langdridge, 2007) and also seek to develop an understanding of those experiences and 'being' via the examination of the language used to express them. With regards to the consideration of language, Heidegger believes that it should always be interpreted, rather than described (Langdridge, 2007; Mulhall, 2005). He highlights the importance of observing the connection between understanding and interpretation, and this foregrounding of interpretation is a central aspect of the IPA method, which I will discuss in more depth later on. If we consider language as a means of communication, it could also be thought of as a way of *disclosing* the mode of the world in which we exist and therefore revealing intimate aspects of our ontological existence and experience that would otherwise exist only as inner thoughts and phenomena.

Phenomenological enquiry therefore lends itself very aptly to finding out more about a wide range of complex human experiences and phenomena, particularly with matters of the body and our perception, which are very subjective and nuanced areas of thought highly relevant to expanding the understanding of living with BDD. The work in this thesis is particularly interested in how people with BDD embody the disorder, and looking at this embodiment and other aspects of BDD through a phenomenological lens is a helpful way of exploring what is considered important by those who live with it.

3.1.2 Phenomenology in relation to the body

As mentioned previously, due to its intrinsic focus on embodiment and the way we as humans make sense of the world, phenomenology provides a useful and effective toolkit for exploring phenomena relating to the body in significant depth. A number of phenomenologists have taken into consideration the role of the body in our experience of the world and explored its involvement thoroughly in their work. In this section, I discuss the work of specific phenomenologists who have focused their ideas on the body and developed concepts that have been significant in shaping phenomenology and its application to corporeal experience. It is this holistic approach that is required to understand the embodied, socially-situated experience of BDD.

3.1.2.1 Merleau-Ponty

Maurice Merleau-Ponty (1908-1961) has produced an extensive amount of phenomenological work on embodiment in relation to the mind, body and world (which he termed “the lived world”). In his work, he argued that science and the objective study of the world makes it difficult for us to consider bodily experiences, highlighting the significance of phenomenology with regards to going beyond the objective, biological body. One of Merleau-Ponty’s core ideas is that the body could be thought of as a vehicle through which we experience the world, central to the way we understand it: “my body is the fabric into which all objects are woven, and it is, at least in relation to the perceived world, the general instrument of my ‘comprehension’” (Merleau-Ponty, 1945: 273). The richness and complexity of our bodies and the way they mesh with the world calls for a thorough exploration of such, taking into account the subtle and subjective appraisal that phenomenology offers. Merleau-Ponty challenged the notion of subject and object being two distinct and separate entities, stating, “Inside and outside are inseparable. The world is wholly inside and I am wholly outside of myself” (Merleau-Ponty, 1945: 407). In a similar way, he described the movement between objectivity and subjectivity as transient or interchangeable and vied against the mind-body dualism presented by earlier philosophers such as Descartes. According to Merleau-Ponty, the lived world and the elements that constitute it (mind, body, and world) are inseparable, and the elements will always permeate one another to form an infused bodily experience.

3.1.2.2 Heidegger

In a similar way to Merleau-Ponty, Heidegger acknowledged the complexity of the body and how it is embedded and intertwined with many other aspects of the world (Cerbone, 2009; Heidegger, 1927/1962). He asserts that our bodies are ‘being-there’ in the world, and part of our ‘being-in-the-world’ constitutes thinking about how our experience and interaction with the world may have influence upon the way we understand our bodies and vice versa. Heidegger described issues of the body (‘the bodily’) as being particularly difficult to understand (Heidegger, 1927/1962; Langdridge, 2007), and differentiates between the body, and what he describes as corporeal matters, in his work. His ideas regarding embodiment in relation to the body's corporality are especially interesting, and when applied to empirical data concerning bodily experience, will help to elucidate abstract phenomena in context. He suggests that the corporeal body is bound or enclosed within our skin and the extremities of our physical bodies, and beyond this boundary of the skin can exist the experience of an extended and embodied self (Heidegger, 2001).

3.1.2.3 Sartre

Sartre also wrote comprehensively about the body in his work, and attributed problems or disturbances with the body to instances where we consider it in relation to the other: "[problems] of the body and its relations with consciousness… stem from the fact that I try to unite my consciousness not with *my* body but with the body *of others*" (Sartre, 1943: 303). He makes the case for there being different facets (ontological dimensions) of one's body: the body *being-for-itself* and the body *being-for-others*. The body being-for-itself refers to the body as it is normally presented to the individual, and the body being-for-others takes into account the way our body appears to others, and how the body of the other appears to us. Sartre's ontological dimensions lend themselves well to the consideration of a distorted perception of one's own body (for example, in the case of living with BDD), as they encourage a more detailed examination of the body in relation to the world and from different perspectives.

3.2 Qualitative methods in Psychology

Historically, the discipline of psychology has been largely dominated by quantitative research, however, the extensive contributions qualitative research has proffered the field in recent years has established its undeniable significance in the research domain (Shaw, Bishop, Horwood, Chilcot, & Arden, 2019). Qualitative methods are used by researchers who wish to investigate a "person's grasp of their world in detail" (Ashworth, 2015: 5), and according to Smith (2015), qualitative research seeks to obtain rich and in depth accounts of participant experience in order to gain a deeper understanding of particular phenomena. The use of qualitative methods in psychological research "has emerged as part of a broad movement that Rainbow and Sullivan (1979) call an 'interpretative turn' in social science epistemology" (Kelley, 1999: 398). It was not until the 1980s that the potential of linguistic analysis in psychological research was acknowledged, and this 'turn' to both language and interpretation was made. More focus was placed on the meaning behind interactions, and many approaches to analysing spoken and written (linguistic) data were developed in order to investigate those meanings (Stainton Rogers & Willig, 2017). The interpretative 'turn' developed out of a growing interest in qualitative researchers wanting to learn more about the psychological meaning or processes within the themes that were generated by their analyses (Stainton Rogers & Willig, 2017). Interpretative researchers seek to engage with rich narrative data and explore it deeply by using and applying theory after the analysis to gain an understanding of the phenomena in question.

Human experience is naturally communicated via language and experienced by our bodies, therefore it makes sense to capture this experience in ways that are authentic and most closely related to our everyday interactions with the world around us. By taking a qualitative approach to research, the exploration of naturalistic language and experience is brought to the fore, and this provides us with an authentic portrayal and access to insights that would otherwise be lost within a quantitative paradigm. Such insights can be captured linguistically via media such as interviews, and we can also gain insight into the experiences we sense through our bodies, thinking about how we might come to understand what they mean for us. In qualitative psychology research, there has been growing interest in the concept of embodiment as an "extra discursive-phenomena" (Willig & Stainton Rogers, 2017: 8) and this provides a complimentary facet through which to consider human experience. Smith, Flowers, and Larkin (2009) describe embodiment as "a sense of bodiliness which may exceed physical limits" (Smith, Flowers, & Larkin, 2009: 199), and using qualitative approaches along with phenomenology in psychological research enables researchers to gain access to aspects of the body and bodily experience that are otherwise hidden. In order to capture the authentic and embodied experiences of individuals living with BDD, I chose to use Interpretative Phenomenological Analysis as my qualitative methodological approach. I will now introduce the method and describe its applicability to my research in the section below. In Chapter 5, I describe the approach in more depth and demonstrate how I applied it to data collected for one of the studies in this thesis as an example of its application to empirical data.

3.2.1 Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) was developed in the 1990s by Smith (1996) and is used to facilitate a deep understanding of individual lived experience. Initially applied within the context of health and clinical psychology, it is now used much more widely across disciplines to gain access to an individual's meaning-making of phenomena. This process involves interpretation from both researcher and participant (Eatough & Smith, 2017), making it double hermeneutic (the researcher makes sense of the participants' sense-making). Smith (1996) combined hermeneutic philosophy with phenomenology and delved into the personal experience of others using IPA, making it an ideal toolkit for exploring the complexities of multifaceted phenomena, such as the lived experiences of those living with BDD. IPA is concerned with understanding what is considered important to the individual, and what they attribute the fundamental underpinnings of a particular topic to be; "the relationship between person-and-world is operationalised at the individual level" (Larkin, Shaw, & Flowers, 2019).

Prior to the 1990s, health psychology research was largely dominated by quantitative methods and mostly focused on cognitions (Quinn, Chater, & Morrison, 2020). The efficacy of these methods in such a person-centred setting were drawn into question, and health psychologists wanted there to be more of a focus on "social, political, and cultural factors" (Quinn et al., 2020), giving rise to a critical approach to psychology. IPA facilitated the exploration of all of these factors and was initially applied in health psychology settings, becoming an increasingly useful methodological approach for gaining a richer and deeper understanding of what it is like to live with physical illnesses and what effects they may have upon an individual. Since then, it has also been used to gain understanding of experiences relating to mental illness, and an increasingly wide range of phenomena outside of the psychology field. In past psychological literature, IPA has been used to explore the meaning making process of people experiencing depression (Smith & Rhodes, 2015; Rhodes & Smith, 2010), post-natal depression (Khalid & Hirst-Winthrop, 2020), and anger (Eatough & Smith, 2006; Eatough & Smith, 2006b). It has also been used successfully to explore the experience of undergoing deep brain stimulation surgery for Parkinson's disease (Eatough & Shaw, 2017); the experience of returning to work after cancer (Brusletto, Ihlebaek, Mjosund, & Torp, 2020) and the analysis of pain metaphors used by women with endometriosis (Bullo & Hearn, 2020), demonstrating the versatility of IPA and the broadness of its scope.

The idiographic quality of IPA therefore makes it a robust methodological approach for the exploration of issues concerning the self. Smith, Flowers, and Larkin (2009) describe IPA as being "concerned with the detailed examination of human lived experience" (Smith, Flowers, & Larkin, 2009: 32). Its interest in the study of experience is drawn directly from phenomenology, and additionally it seeks to provide a way for researchers to find out how people navigate and understand the world they live in. What differentiates IPA from other phenomenological work is its idiography and its exploration of people's own sense-making processes. It is a phenomenologically informed mode of enquiry that affords users of this method access to a wide range of useful ideas and concepts which act as a lens through which we can view human experience more profoundly. In addition to phenomenology, IPA's other theoretical underpinnings are idiography and hermeneutics, which I will discuss in more depth in the sections below.

3.2.2 Idiography

As mentioned previously, IPA's dedication to the idiographic makes it ideal for taking into consideration issues of the self. IPA has a strong commitment to the individual level and is highly influenced by the 'particular' (Smith et al., 2009). It seeks to facilitate great depth in the analysis of an individual's experiences and gain insight into how they make sense of phenomena by exploring the phenomena in question very thoroughly with regard to specific worldly context. IPA researchers achieve this by focusing on the individual case level first to gain an in depth understanding of an individual's experience. Once the researcher has explored individual experience at case level, cross case analysis can take place in order to make more general observations and claims across the data.

3.2.3 Hermeneutics

Another key theoretical underpinning of IPA is hermeneutics. IPA draws upon aspects of hermeneutic phenomenology and facilitates analysing data interpretatively. It is described as 'double hermeneutic', meaning the researcher makes sense of the participant making sense of their experience of phenomena. Hermeneutic phenomenologists believe that it is not possible to give a pure description of phenomena, and engaging with the data on an interpretative level is essential in order to understand the inherent meaning encased within it, as suggested by Heidegger. Traditionally, the term hermeneutics was used in relation to the interpretation of the Bible and was then eventually applied to the interpretation of other texts more broadly (Smith et al., 2009). Gadamer's (1960/1989) work discussed the importance of context (including history and traditions) and how this may influence the way we engage in interpretation. He writes:

> It is necessary to keep one's gazes fixed on the things throughout all the constant distractions that originate in the interpreter himself [sic]. A person who is trying to understand a text is always projecting. He projects a meaning for the text as a whole as soon as some initial meaning emerges in the text (Gadamer, 1960/1989: 266-267).

Gadamer suggests that when we interpret language, we bring to it our presuppositions and experiences from throughout our lives prior to that moment. These prior experiences add unique insight, and approaching the research from different horizons of understanding can shape the way researchers interact with the data that are presented to them. In the case of my research, I believe it is necessary for me to consider the role my lived experience of BDD has in my interpretations, and a way that IPA allows for this is by incorporating hermeneutic reflection (Finlay, 2003) in the form of reflexivity.

3.2.4 Reflexivity

The third theoretical underpinning that IPA draws upon is reflexivity. Heidegger argues that engaging with the world phenomenologically means to also be interpretative in our considerations. IPA focuses on the importance of everyday lived experience and highlights the need to engage in reflective practice to think about how our lived experience fits in with the subject of our focus. This is a key element of IPA and phenomenological inquiry. It is also important to reflect upon both the act of research itself and "the mental experience which constructs the meaning about practice" (Mortari, 2015: 1) in order to acknowledge one's stance with regards to unique lived experience which may influence the way we engage and interact with our research.

> A person can live in an unauthentic way or in an authentic way: the unauthentic experience happens when the person adopts an unreflective stance that consists in staying passively enmeshed in one's thoughts and the authentic condition happens when the person develops a mindful stance on his or her mental life (Mortari, 2015: 1).

In keeping with the reflective nature of the IPA methodological approach, it is important for me to present and incorporate my authentic self and experience in this body of work. My lived experience of BDD has encouraged me to undertake this PhD research, and engaging in reflective practice to examine the things I have experienced in relation to data I have elicited is therefore an essential element of the analytical and interpretative process. As Finlay (2008) explains, "the challenge for the researcher is to remain focused on the phenomenon being studied while both reining in and reflexively interrogating their own understandings" (Finlay, 2008: 29). My experience of living with BDD provides some advantages with regards to interviewing and understanding some of the difficult and abstract phenomena that others with BDD in this thesis have discussed. However, due to the possibility of viewing these phenomena from a different order (or different horizon) to the reader, it will be necessary to bracket my own presuppositions and experiences from those of my participants in order to delve into their lifeworlds fully. To do this, I will be *bridling* (Dahlberg, Dahlberg, & Nystrom, 2008) my self as a researcher and self as a participant. Bridling is Dahlberg et al.'s (2008) take on the Husserl's concept of *bracketing* and is considered a more positive approach in comparison, providing the researcher the opportunity to allow phenomena to come forward and be acknowledged in the present moment rather than completely suspending one's preconceptions.

> Bridling is thus essentially a sort of self-reflection, a continuous investigation of one's own point of departure, one's presumptions and presuppositions… By means of reflecting on, and asking questions to our own understanding (e.g., What is it that I understand? Why is it that I understand in this way?), it is possible to understand differently… The goal of bridling is to reach that presence where we are open for the new; an improvisational openness where we don't know what will show up but are attentive and ready for it. (Dahlberg & Dahlberg, 2019: 3-4)

Bridling allows me the freedom to harness my lived experience and let it openly inform my analysis and interpretations whilst still honouring the idiosyncrasies of my participants and searching for a deeper understanding. According to Merleau-Ponty, it is important to 'slacken' the grip of the metaphorical bindings that keep us attached to the world (Merleau-Ponty, 1995/1962), for it is impossible to sever them entirely and put them to one side in isolation. He suggests that we relax the reins slightly, still allowing us control but additionally giving us the ability to take notice of what is going on around us, making observations, questioning and inspecting our own relationship with particular phenomena.

3.3 Ethnography and Autoethnography as method

In a similar way to phenomenology and IPA, ethnographic research seeks to find out more about a relatively small homogenous sample of individuals in order to gain an understanding and perspectives on a particular phenomenon that they all have in common. Ethnography is a qualitative method traditionally used in anthropological research and has a particular interest in social interaction and culture within a specific community of people (Reeves, Peller, Goldman, & Kitto, 2013) and how those people view the world (Hammersley, 1985). The ethnographic method is concerned with 'naturalism', and it highlights the importance of understanding meaning in everyday, natural contexts (Griffin & Bengry-Howell, 2017: 39). To get as close as possible to this naturalistic way of understanding meaning, ethnographers use a variety of ways of collecting data to mimic everyday interaction. For example, ethnographic researchers may gather data via conversation or by making observations during fieldwork so as to not interfere with or restrict the subject of interest being explored. Due to my personal connection with the phenomena of interest this programme of work sets out to explore, I decided to employ autoethnography as a method in order to present my position as both a researcher and participant in the work. Following on from ethnography in a broad sense, autoethnography is a type of ethnography that is primarily interested in the subjective experience of a single author (Chang, 2008) rather than a homogenous sample. It takes on a more autobiographical style of writing (Denzin, 2003) and offers substantial insight into the life of the narrator, transcending the idiographically significant aspects of IPA by focusing solely on the researcher and their own experience and sense-making within their world. Autoethnography as a method encourages researchers to write "stories of/about the self told through the lens of culture" (Adams, Holman Jones, & Ellis, 2014: 1) and can be used as a way of considering their positionality as an insider and outsider in the research, navigating the tensions that this can generate (Reed-Danahay, 2009). Autoethnography is one, perhaps more formalised, way of being reflexive and it was through this work that I channelled my reflexivity. This was then presented throughout the remainder of my encounters with participants and working with their data.

This chapter has described the overarching methodological approach used in this exploratory body of work, IPA. It began with a description of the origins and development of phenomenology; its applicability and suitability to considerations of the body; the theoretical underpinnings of IPA, and then went on to briefly describe ethnography and autoethnography as a way of acknowledging and reflecting upon my stance in the overall research. In the chapter that follows (Chapter 4), I begin the programme of empirical research with a piece of hermeneutic-autoethnographic writing regarding my own personal experience of BDD, analysed using IPA.

Chapter 4 of this thesis has been redacted at the author’s request.

Chapter 5: Study 2 – Exploring the self-identified origins of Body Dysmorphic Disorder

5.1 Introduction

In the previous chapter, I presented an autoethnography of my personal experience of living with BDD. In this, I reflected upon and interpreted a series of evocative vignettes from various moments in the past to illustrate the expansion and pervasive presence of BDD throughout my temporal world. It gave insight into one case and provided experiential evidence for aspects of BDD that are lacking in the BDD literature, such as race related bullying. This experiential evidence is very much needed, supported by Veale (2016) who pointed out that there is a notable absence of individual accounts from people living with BDD, as discussed in Chapter 2. As well as experiential evidence, there is also a need for empirical evidence in order to work through the phenomenological concepts that have been explored as a way of explaining BDD. This empirical evidence needs to be generated through new data in order to begin our understanding of the lived experience of BDD.

This chapter presents the second study of this thesis concerning the self-identified origins of BDD and broadens the scope of the exploration of this disorder by introducing new voices and new insights. Not a lot is presently known about the potential origins of BDD, further supporting the need to take an exploratory approach to research this subject, therefore it is essential to understand the condition better through people's individual experiences to help provide earlier diagnosis and design appropriate services. In order to do this, we must develop a greater understanding of the development of BDD and the idiosyncratic circumstances in which it can occur. It is important to note that I do not anticipate these circumstances to be the same for each person living with BDD, and the focus is on making sense of individuals' own sense-making processes. The aim of this study was therefore to elicit and analyse the accounts of people living with BDD in order to examine their beliefs about its origins. The multimodal design of the study invited participants to provide both written and verbal accounts. The data generated formed the basis of this chapter and the following chapter.

In Chapter 3, I briefly outlined the overarching methodology that I used for all studies in this thesis: Interpretative Phenomenological Analysis (IPA). Following on from this outline, I will now discuss in more depth how I applied the method to this second study.

The following research questions helped to steer the direction of the research for this study:

- What do people with BDD believe might have caused or contributed to the onset or development of their BDD?
- How do people with BDD make sense of their self-identified origins of BDD?

The overarching research question this thesis as a whole aims to address was presented in Chapter 2 in Table 2.4 (page 38), whereas the specific research questions in the same table illustrated the unique topics of interest for each subsequent study chapter.

This second empirical study is an in-depth multimodal study that explores what events or experiences people living with BDD attribute to the development or onset of their condition to be. It pays particular attention to the way participants make sense of these experiences and delves into how certain events may have influenced their own perceptions of self. The data that forms the basis of this study consists of biographical written pieces provided by each participant and subsequent follow-up semi-structured interviews based upon the content of participants' written pieces of narrative. Both elements were analysed using IPA.

5.2 Method

5.2.1 Sampling and recruitment strategy

As mentioned in Chapter 3, IPA has a strong focus on the idiographic and therefore requires a relatively small sample size to enable a thorough analysis and exploration of individual accounts of a specific phenomenon. For each empirical study in this thesis, I focused on recruiting people aged 18 and over who identified as living with BDD. In accordance with the IPA method, the main focus is on the individual's authentic experience, and so I deemed it inessential to only include people with a clinical diagnosis of BDD. As explained in Chapter 2, it can take an incredibly long time to obtain a diagnosis (Veale, 2016), and taking participant's experiences as immediately authentic also helped to reduce feelings of invalidation that people with BDD so often experience due to stigma surrounding the condition. Some participants across the studies did have a clinical diagnosis, but this was only revealed by the participant if they felt they wanted to discuss it with me. Some were in the process of being referred for diagnosis and treatment at the time of their interview.

5.2.2 Ethical procedure

The research received ethical approval from the Aston University School of Life and Health Sciences ethics committee (Appendix A). Once ethical approval had been granted, I circulated a study advertisement online via Twitter (Appendix B). The same study advertisement was also circulated by the Body Dysmorphic Disorder Foundation (BDDF) on Twitter and on their website. Participants were invited to contact me by email or telephone for additional information (in the form of a Participant Information Sheet (Appendix C) and once they were satisfied with the information received and had the opportunity to ask any questions, they were invited to complete an online questionnaire hosted by Qualtrics. The online questionnaire comprised of the Body Dysmorphic Disorder Questionnaire (BDDQ; Appendix D), which was used as a screening tool, and a consent form. All participants agreed to having their interviews audio recorded and were given a choice of interview locations and media including face-to-face at Aston University, their own home, online via Skype (audio only if preferable), telephone or via email. It was important to emphasise to prospective participants that face-to-face or video interviews were not requirements to participate in the study, as the nature of the condition means that some may feel extremely uncomfortable or distressed by viewing themselves on camera or being viewed in person. All participants were informed they could stop the interview at any time without providing a reason for doing so, and they could also withdraw their data from the study up to 14 days after the interview. Participants digitally signed the consent form on the Qualtrics questionnaire (Appendix E).

5.2.3 Participants

Sixteen prospective participants responded to the study advertisements. Of those 16 participants, eight subsequently took part in both components of the study.

Table 5.1 Participant demographics

Pseudonym	**Age at interview**	**Sex**	**Location**	**Interview medium**
Angelina	28	F	USA	Email
Bethany	53	F	UK	Telephone
Claire	32	F	UK	Telephone
Elliot	44	M	UK	Telephone
Jenny	34	F	UK	Skype (Video)
Kate	20	F	UK	Telephone
Rohit	28	M	India	Skype (Audio)
Victoria	18	F	UK	Email

Two participants identified as male and six as female. Six participants lived in the UK, one in the US, and one in India.

5.3 Data collection

Data collection for this study consisted of two parts. Participants were invited to first complete a biographical writing task about their BDD origin stories, and they were then invited to take part in a follow-up semi-structured interview where we discussed the content of the writing task more thoroughly. Having participants complete the biographical writing task first meant I was able to gain an understanding of the events or experiences that were significant to them and use the semi-structured interview to delve more deeply into those experiences in relation to their perceived development of BDD. A semi-structured interview follows an interview guide, "which structures the course of the interview more or less tightly" (Kvale & Brinkmann, 2009: 130). Semi-structured interviews are commonly used in IPA studies as a way of collecting data (Smith, 2016), and are developed to be flexible and led by participants. I was additionally granted permission by the School of Life and Health Sciences ethics committee to exchange a maximum of five emails with participants to clarify any specific points of interest that I wished to elucidate further before the interview. For the writing task, participants were emailed the question and prompts in Box 5.2 below.

Box 5.2 – Question and prompts for biographical writing task

Can you tell me about a time when you first became worried about your appearance?

Some other prompts to consider:

- *What was going on in your life at the time?*
- *Did you speak to anyone about it at the time? If you did, who did you speak to?*
- *How were you feeling?*
- *What were you thinking?*
- *What did you do about it?*

The prompts for the biographical writing task included after the questions were entirely optional and were added to help participants shape their written responses if they were unsure about what to include in their piece. The structure and specific content of the written piece was entirely at the discretion of each participant, but they were advised to not spend more than two hours on writing it. This suggested two-hour limit was a rough guide for participants to ensure that they did not spend too much time writing about potentially distressing topics but could still write freely without feeling time pressured. However, they were free to spend more or less time on the writing task if they wished to and were encouraged to take breaks when needed. Once I had received participants' written pieces, I read through them, anonymised them and noted down any immediate questions I had, highlighting and coding any information identifying possible origins of their BDD to explore further in the interview. Interviews were arranged with participants at a time and location that was convenient for them. Interviews typically lasted around one hour, and one interview lasted two hours. The semi-structured interview indicative topic guide is shown in Box 5.3 (page 81).

Box 5.3 – Indicative interview topic guide

Study title: Biographical writing task and interview regarding participants’ origin stories prior to Body Dysmorphic Disorder (BDD) onset.

1. In your written description, you told me about [x]. Please could you tell me more about this?
   Possible prompts: How were you feeling when you were going through this? What was that like? What support did you have at that time? How were you feeling when you wrote about this? How do you feel about this now?

2. (In a face-to-face interview/ Skype video interview) If I had not met you, and we only spoke on the phone, how would you describe your appearance?
   Possible prompts: How do you feel when you think about your appearance? What do you like about your appearance? What was it like to describe your appearance?

3. If I asked your friends, how would they describe your appearance?
   Possible prompts: What descriptors would you agree/disagree with and why? What support do your friends offer? How do you feel when they do/say this? What do you think your friends see when they look at you?

4. Could you describe how your feelings about your appearance have changed over time?
   Possible prompts: Have your thoughts changed? How? What have you learnt about yourself? What has been useful? How satisfied are you with your appearance now?

5. How do your feelings about your appearance change day to day?
   Possible prompts: What do you think about it? Do you do anything in your daily routine that changes the way you feel about your appearance? Would you change anything? What do you like the most about your appearance?

6. In terms of having a good day with your appearance, what is important to you?
   Possible prompts: Why is this important to you? How did you find out this was important to you? What would happen if it was not possible for you to do this/have this? How do you achieve this? How often do you have good days?

7. Are there certain people who make you feel differently about your appearance?
   Possible prompts: What do they do to make you feel this way? How does it make you feel? Do you view yourself differently because of this person/these people?

8. Does anyone know you have BDD?
   Possible prompts: Who knows about this? What kind of relationship do you have with them? How did they become aware? What support did they offer you? How do you feel about them knowing?

9. What do you do for a living?
   Possible prompts: What effect does BDD have on your job? Do you have to adapt your appearance for your job? How do you adapt your appearance for your job? How does this make you feel?

Version two: 23.05.18 Indicative Interview Topic Guide

The majority of questions asked in the interviews were in the style of the first question in the indicative interview topic guide. The topic guide was created in order to assist with the exploration of each participant's unique experience of BDD. I aimed to construct understandable questions that could show us how their narrative developed and unfolded at a comfortable and adjustable pace for the participant. I made sure to not begin with questions that could have been considered too direct or potentially distressing in order to put the participant at ease as much as possible, and reminded them that they did not have to answer any questions they did not want to. Additional tailored questions were asked in participant interviews based upon the content of their biographical writing tasks, which will be discussed later on in this chapter in section 5.4. Using the biographical writing task as a starting point meant participants had control over what we discussed in the interviews, and they could decide how much they were comfortable sharing with me as the researcher. Some participants shared very sensitive information in their written accounts, and knowing they were comfortable enough for me to read about those experiences aided my questioning in the interviews, making it easier and more comfortable for them to open up about potentially distressing experiences. If talking about particular experiences was distressing for participants, they were reminded that they did not have to answer all of the questions, and that they could stop the interview at any point without providing a reason, as specified in the Participant Information Sheet for this study (Appendix C).

The remaining questions in the interview schedule were included to help provide additional context to situate their accounts and help me better understand how participants' origin stories impacted their day to day lives with BDD. Discussions around participants' experiences of living with BDD formed the basis for the third empirical study (Chapter 6). So much rich data were generated that to do them justice in an idiosyncratic analysis, they were split into this chapter and the next. Prior to arranging the interviews with participants in this study, I disclosed my lived experience of BDD to them. I decided to do this upon carefully considering my role in the research as both the researcher and the researched. As discussed in Chapter 4, I chose to engage in 'bridling' (Dahlberg & Dahlberg, 2019) in order to harness my own experiences and reflect upon how they may shape my interaction with the phenomena under exploration. Disclosure of my experience of living with BDD provided some assistance with having a mutual understanding of what it is like to have BDD, and this may have been reassuring for some participants who previously struggled to talk about their experiences with others. My lived experience also presented some challenges in the research. For example, some experiences participants shared were so similar to my own that I found it difficult to separate them from my own, and this sometimes led to the resurgence of upsetting memories. In addition, before conducting the interviews, I was aware that too much mutual understanding may impact the way participants verbalise their experiences. For example, I took into consideration that some participants may not discuss their experiences in-depth because they could assume shared knowledge. To ensure this did not occur, I adapted my interviewing where applicable in order to elicit detailed and authentic descriptions that would clarify experiences to those without prior understanding of the condition. I will discuss further reflections on my lived experience and other areas of interest in more detail later on in this thesis in Chapter 8.

All audio interviews were recorded using an encrypted digital voice recorder and transcribed verbatim. All biographical written pieces and email interview answers were anonymised and any excerpts presented in the thesis are exactly as participants had written them in order to present their experiences as authentically as possible. The interview excerpts included in the study chapters use the transcription notation shown in Box 5.4 below. The notation represents instances of hesitancy, self-correction, natural pauses in speech, words that have been omitted and any additional supplementary information that is contextually relevant.

Box 5.4 – Transcription notation key

word- word	self-correction or hesitation
word – word	natural pause
…	words omitted
[word]	additional information

5.4 Analysis

I will now discuss the steps I took to analyse the data using IPA. Before beginning the analytical process, the first step I took was to read each of the participant biographical writing tasks thoroughly several times. Reading through participant data multiple times is recommended by Smith et al., (2009) as it helps the researcher become immersed in the data they will analyse, and it also means the researcher can increase their familiarity with the data, additionally aiding the analytical process. Whilst reading through the data thoroughly, I made a note of any initial observations throughout alongside the text. These initial observations included points of interest, questions, or instances of language usage that I considered significant in helping me understand how participants made sense of their perceived BDD origins. I recorded observations both on the original text and in my research journal. Any initial readthroughs and analyses of the biographical writing tasks that took place ahead of the interviews informed the individual development of the semi-structured interview schedules for each participant, demonstrated in Box 5.5 (page 85) and Table 5.6 (page 86). I made a note of any areas of interest that I wished to explore more deeply with the participants in their subsequent interviews, and recorded some relevant questions to facilitate this exploration.

Box 5.5 – Excerpt from Participant Biographical Writing Task

When I was at school, aged approximately seven, I was sitting at a table with another boy ([name redacted] I think), and two girls. Generally speaking, I was quite happy at that time as far as I can recall, if a bit insular maybe. Anyway, one of the girls said something like 'you have lots of beauty spots' in a pleasant way referring to facial moles I had/have. I think I was probably quite pleased at the affectionate attention(probably not getting any elsewhere and still not!). [Name redacted], who also had facial moles, said something like 'they're not beauty spots, they're moles' in a very harsh and disparaging way. Maybe he was upset at the attention being focused on me in that moment. I don't recall openly reacting in any specific way. But I think it was quite soon after that I tried to dig a mole on my right forearm out with a sharp stone in the playground. Funnily enough, it seems to have been quite effective as subsequently there has been little to see where it was apart from dark hairs. I also tried to dig a mole out of the rear of my thigh, but that was not successful. I do now wonder whether I was performing an act of self-surgery even at that age, or maybe just doing something on the spur of the moment. I certainly can't recall what I was thinking or feeling, but I certainly seemed to act as if there was some sort of problem. Later, in my early teens, when I started using spot cream, I tried putting a lump of cream on one of the moles on my cheek to see if it would do anything. Again, it did seem to work with the mole receding and becoming much less visible, only really palpable to this day. I tried on another mole but with no success. I'm not sure whether it was before or after this that I got my first passport, in which my mother wrote in the distinguishing marks section 'facial moles'. Probably out of inflated concern that there might some sort of trouble if such a thing were not declared! When, in hindsight of course, I think BDD really kicked in was when I went to university. I think the first real problem I had was looking at the left side of my face. However, although this is the side of my face that has the most moles, I can't say for sure that they were the reason.

Table 5.6 – Example interview questions based on participant biographical writing task in Box 5.5

Example questions	**Prompts**
How did you find writing about your experiences of BDD?	Did you complete your written piece in one sitting or take any breaks? Did you face any challenges whilst writing about your BDD experiences? What was that like?
How did you feel when [name redacted] said "they're not beauty spots, they're moles"?	What thoughts did you experience after this happened? Can you remember what you did in the classroom after he made that remark?
You talked about digging a mole out of your forearm using a stone. What was going through your mind before you did this?	Why do you think you decided to do this? Can you remember how you acted afterwards? What sort of behaviours did you show at that time?
You mentioned BDD kicking in when you went to university. Were there any specific events that happened to you at university that may have made it difficult to view the left side of your face?	What was going on around that time? How were you feeling?

Once the initial observations had been made and subsequent interviews had been conducted and transcribed, more thorough analysis of the data began. This involved detailed analysis of the written pieces and interview transcripts, focusing on making descriptive, linguistic, and conceptual comments throughout, as well as adding in any reflections from the researcher. Descriptive comments sought to describe what participants have said, and the subject matter of particular excerpts; linguistic comments are relevant to the specific language usage of participants; conceptual comments involved interacting with the transcript in a more critical or interrogative manner, considering relevant conceptual ideas (Smith et al., 2009). An example of the descriptive, linguistic, and conceptual comments made during the analytical process is presented in Table 5.7 below (page 87) and illustrated using an excerpt from a participant interview with the same participant that produced the written excerpt from Box 5.5 (page 85).

Table 5.7 – Example of analysis including exploratory comments

Original Transcript	**Exploratory comments**
S: first of all I just wanted to ask how you found actually writing about your experiences of BDD	Recollection of negative feelings/emotions occurred when Elliot wrote about his experiences of BDD. Metaphor/phrasal verb – stir up
E: erm (pause) I found it quite – erm – difficult because it does sort of stir up feelings erm – and sometimes I don't feel like sort of thinking about the past too much or	Use of filler 'erm' indicates how challenging it is to verbalise writing about his experiences Use of adverb/filler 'sort of' – uses as a hedge
S: mm	Internal conflict – sometimes, there is little desire to think about past events, whereas other times, he ruminates about the past more than he wants to. He could be saying when he thinks about the past a little, he ends up thinking about it frequently
E: or I think about the past far too much	
S: yeah	
E: erm so yeah – and erm so I sometimes wonder whether- whether I'm- I'm kind of imposing- imposing on the past maybe – erm things that may be – you know – may or may not be being there – you know with hindsight from a BDD point of view – I don't know	Hesitant repetition – "whether, whether, I'm, I'm, to know, to know" Hedge – "kind of" A sense of doubt/lack of certainty – "imposing on the past maybe" Questioning the true origins of his BDD It is hard for Elliot to think about and describe what may have contributed towards his BDD onset Choice of wording – "from a BDD point of view" – seeing the world through the eyes of BDD – importance of perception. Personification of BDD?
S: mm	
E: quite hard to know – to know	
	Key: Descriptive comments; Linguistic comments; Conceptual comments

After the analysis, the next step of the IPA approach is to generate themes from the exploratory comments and reflections. An additional step I took was creating case level notes (Appendix F) for each participant to help with cross analysis and the clustering and generation of main themes. Creating the case level notes allowed me to determine what was important to each individual participant in the study and then identify any commonalities or contrasting experiences with all participants, bringing together the data from their biographical writing tasks and interviews to present in this study and the study in the next chapter. Potential themes (placeholder themes) were generated first of all by identifying any significant events or moments that participants attributed to what they believed may have contributed to the onset or development of BDD for them based upon the analysis. Table 5.8 below (page 89) demonstrates how potential themes were developed from the analysis shown in Table 5.7 (page 87).

Table 5.8 Example of analysis including possible themes

Original Transcript	**Possible themes**
S: first of all I just wanted to ask how you found actually writing about your experiences of BDD	
E: erm (pause) I found it quite – erm – difficult because it does sort of stir up feelings erm – and sometimes I don't feel like sort of thinking about the past too much or	Revisiting past memories is painful
S: mm	
E: or I think about the past far too much	Slipping into rumination
S: yeah	
E: erm so yeah – and erm so I sometimes wonder whether- whether I'm- I'm kind of imposing- imposing on the past maybe – erm things that may be – you know – may or may not be being there – you know with hindsight from a BDD point of view – I don't know	Distrust of the self Acknowledging different horizons within BDD
S: mm	
E: quite hard to know – to know	Perceptions can be misleading

Once potential themes had been identified in both the biographical writing tasks and interview transcripts, I collated them and compared cases across all participants in the study, then generated the main themes and subthemes presented in Box 5.9 (page 90) in the results section of this chapter.

5.5 Results

I now present the results of this second empirical study, beginning with a table of themes regarding participants' understanding of the origins or contributing factors towards the development of their BDD (Box 5.9, page 90).

Box 5.9 Table of themes for Study 2

Theme 1 – Exposure to bullying, abuse and critique of appearance

Experiencing childhood bullying

I was literally verbally “attacked” from head to toe (Angelina)
I would have people telling me I look weird (Kate)
[the boy]… said something like ‘they’re not beauty spots, they’re moles’ in a very harsh and disparaging way (Elliot)
I was teased about my accent, how I looked and had trouble fitting in (Bethany)

Experiencing abuse in relationships

He put me down, made fun of me, and embarrassed me in front of other kids at school (Angelina)
he got violent with me… held me up against the wall with my- with my throat (Jenny)

Theme 2 – Experiencing rejection, shame, and a sense of not being good enough

Being rejected romantically due to appearance

I remember feeling quite um crushed and almost erm taken aback (Claire)
I remember being rejected by a few boys and I do think that was a contributing factor (Jenny)

Having actions criticised by family members

I just have a sense of not feeling good enough in his eyes… I’m not a good enough person, therefore if I look more attractive, I might be more accepted (Jenny)
She would keep pointing out mistakes and negatives in me and everything I did (Rohit)

Theme 3 – Becoming aware of the solidifying of concerns

Realisation of a problem with the self being present

I started to feel as if my flaws were deformities (Victoria)
One day I couldn’t er I just couldn’t cope with looking in the mirror and seeing the left hand side of my face (Elliot)
I also became very critical of others and would make fun of their appearance… I had been hurt for so long that I wanted to hurt others so they would feel as bad as I did (Angelina)

Strengthening of distorted beliefs

I’m not pretty enough for it to just be my brain lying about a couple of things because it’s not that it’s my actual face being ugly and deformed (Victoria)
I don’t see a face as such – I just see faults (Claire)

Theme 4 – Learning about and reflecting on triggers

Ingrained triggers

> *It would be easier to let you know how often I don't think about it. It is quite often my waking thought and I dream about it regularly (Bethany)*

External and social triggers

> *It's still really easy to knock my confidence especially if it's coming from a boy and if I see a [sic] ugly photo of myself (Victoria)*

From the analysis of the data, four main themes were generated: *Exposure to bullying, abuse and critique of appearance; Experiencing rejection, shame, and a sense of not being good enough; Becoming aware of the solidifying of concerns; Learning about and reflecting on triggers*. The first theme of interest was *Being exposed to bullying and critique of appearance*, which caused a significant amount of distress to a number of participants in the study and was often something they thought about in relation to their own appraisal of their appearance.

5.5.1 Theme 1: Exposure to bullying and critique of appearance

Experiencing appearance-related bullying and criticisms of appearance from a young age was reported by participants as a potential origin of their BDD. The criticisms were often made by peers, friends, and family members, and in most cases, the aspect of the appearance that received the criticism went on to become an area of concern and distress for the participant. Criticisms were often extensive and were not limited to one aspect of the participants' appearance.

5.5.1.1 Experiencing childhood bullying

Such criticisms were experienced by Angelina, who shared her account of being bullied during her childhood and discussed how the same criticisms of her appearance continue to affect her in adulthood.

> *It was around the time of 3rd or 4th grade* [aged approximately 8-9 years] *that I started to experience bullying, which usually consisted of insults and ridicule directed towards my appearance. I was literally verbally "attacked" from head to toe; my hair, my nose, my moles, my body hair, my weight and size, my "lack of curves"... Even though I tried to hide it and act unbothered by them, these comments cut me to the core and I stored them deep within the corners of my brain, ruminating on them even to this day.* (Angelina, Written piece)

The criticisms she received from her peers targeted numerous aspects of her face and body. She lists the aspects of her body that she was bullied about, showing how extensive the bullying was and due to the amount of criticisms she received, this may have made her feel overwhelmed by the negative perceptions other people had about her body and possibly reinforced any negative feelings she previously had about her appearance. By using words such as "insults", "ridicule" and "attacked", Angelina helps us to realise how severe these incidents of bullying were for her. She talks about hiding her true feelings towards what her bullies said to her at the time by pretending that their comments did not bother her, however, she reveals through a powerful metaphor that they "cut [her] to the core". The word "cut" demonstrates just how damaging those criticisms were to Angelina, and how, in her view, the words were weaponised. Using the words "core" and "deep" may also reflect the way she tried to supress the criticisms that continue to affect her years later. Bullying was also considered a contributing factor towards BDD development by Kate.

> *Well I've- I've- I've been bullied since I was in year three up until year eleven* [aged approximately 7-16 years]*... I would have people telling me I look weird... I had people anonymously messaging me and saying that I look like a dog... saying that I'm ugly... I felt hurt that people would actually say it... but at the same time I was like 'yeah you're right'... 'yeah I know I'm that – I just wish I wasn't'* (Kate, Interview)

The comments Kate received from her peers occurred over an eight year period of bullying. She described some of the hurtful remarks people had said to her about her appearance that have stayed with her into adulthood. Being told that she looked “weird”, “like a dog” and “ugly” may have instilled the belief within her that something was truly wrong with her appearance, further illustrated by her coming to accept this and agreeing with the comments made. In a similar way to Angelina and Kate, Elliot experienced others commenting on his appearance at a young age and described a scenario that look place at his school.

> *When I was at school, aged approximately seven, I was sitting at a table with another boy… and two girls… one of the girls said something like ‘you have lots of beauty spots’ in a pleasant way referring to facial moles I had/have…* [the boy]*, who also had facial moles, said something like ‘they’re not beauty spots, they’re moles’ in a very harsh and disparaging way… I don’t recall openly reacting in any specific way. But I think it was quite soon after that I tried to dig a mole on my right forearm out with a sharp stone in the playground… I also tried to dig a mole out of the rear of my thigh, but that was not successful.* (Elliot, Written piece)

Here, Elliot describes being in a situation where an aspect of his appearance was brought to the attention of himself and others in a negative way. He draws focus to the tone of the boy as well as the comment he made, showing the significance of the experience not only at the time but also many years later. Like Angelina, he recalls internalising his reaction to a situation that, upon reflection, affected him significantly. He acted on the criticisms of his appearance by engaging in self-surgery in an attempt to remove the aspect of his appearance that made him seem different to others and vulnerable to criticism. Using a stone from the playground to perform this action shows how desperate he felt in the situation to find a solution to the humiliation he experienced. Most participants in this study recalled instances of being shamed or bullied. They described those experiences as being salient to them. Participants also felt they were inferior and unequal to the people making the bullying comments and reported that this may have contributed to their BDD. In addition to being exposed to bullying, some participants attributed the development or onset of their BDD to being subjected to abuse in romantic relationships.

5.5.1.2 Experiencing abuse in relationships

Several participants in the study described experiencing verbal, psychological and physical abuse in their romantic relationships, which they attributed to the development or worsening of their BDD symptoms over time. Angelina described an unhealthy historic relationship she was involved with during her teenage years that made her extremely self-conscious about the way she looked.

> *At the end of that school year, I began dating a guy who I had known for years. In the beginning, it was nothing serious. Over the summer we only talked on the phone once and when school started back, we were shy and awkward around each other. However, after a couple more months, he started to become controlling and cruel. He kept me from my friends and turned me against my family. He put me down, made fun of me, and embarrassed me in front of other kids at school. He would not "allow" me to talk to other boys at school and warned me that he had people "watching" me and would let him know if I messed up. He also criticized and made fun of nearly every aspect of my appearance. My hair was too curly and stiff, my nose was too big, I had so much body hair, I was like a man, my stomach was too pudgy, and he would pinch and poke my belly and laugh. He compared me to other girls and would allude to the fact that he could do better than me and would cheat on me if I did not "behave".* (Angelina, Written piece)

In completing the writing exercise, Angelina was able to reflect on this distressing part of her life and identified that a short period of time into her new relationship, her ex-boyfriend was "controlling and cruel" towards her. She stated that he would mock and humiliate her publicly, and this behaviour may have further depleted her self-worth, possibly making her believe he was superior to her. The scope of the criticisms she received from him was significant, and the fact that those criticisms targeted her appearance could have contributed heavily to the worsening of her emerging BDD symptoms. A particularly revealing aspect of Angelina's written narrative was the way she listed the criticisms she received: "My hair was too curly and stiff, my nose was too big, I had so much body hair, I was like a man…". In this sentence, the criticisms could be interpreted as being factual, as though she shared the same belief, and the words of her boyfriend of that time come through strongly in the way she spoke about her appearance. It feels as though his words are being spoken directly through her. Having her appearance compared to the appearance of others may have been especially harmful for Angelina, as she had previously described engaging in making direct and destructive comparisons between herself and peers growing up. The comparisons made by her partner may have further reinforced her belief that she is inadequate to others. Like Angelina, Jenny experienced being involved with an abusive partner and spoke about the ways he would inflict his abuse.

> *erm and then he got violent with me – erm he like- like held me up against the wall with my- with my throat – he would – you know – be verbally abusive and also erm with sex he was quite highly sexed- sexed- had a high sex drive – and so he would put pressure on me erm to have sex with him – and – you know – it's not rape – but I- you know – when you just do it because it's just easier… to keep him quiet basically – erm so I think those kinds of things it was just- it was just a really unhealthy relationship – and erm I split up with him – and then I would be on my own for maybe six months – and then not find anyone – and then end up going back to him because I felt like I couldn't find anyone better than him* (Jenny, Interview)

Jenny had previously discussed being unhappy with her appearance as a child in her written piece and interview, and with the combination of physical violence and verbal abuse she was exposed to, this could have significantly worsened her self-perception. The violent acts she was subjected to further cemented the idea that she was inadequate from her partner's perspective and that others would also share that same belief. The severity of the abuse Jenny experienced was reinforced by the phrase "it's not rape – but I- you know – when you just do it because it's easier". This could be interpreted as an example of bodily manipulation and adds to her experience of psychological abuse and sexual violence. This is also a challenging area where consent is concerned, and it is possible that she felt obliged to comply with her partner's demands due to the history of violence in her relationship and concerns for her own safety. Her perceived inadequacy was highlighted by the fact that she re-entered the relationship with her abusive ex-partner as she believed she was not good enough to find a more suitable partner. The psychological and physical abuse that participants in this theme disclosed heavily impacted their self-perception and may have contributed to a sense of inadequacy, which was a common feature participants reported in their narratives through experiences of rejection, shame, and an overall sense of not being good enough.

5.5.2 Theme 2: Experiencing rejection, shame, and a sense of not being good enough

In addition to bullying and abuse in relationships, experiencing social difficulties in relationships was also thought to be a potential contributing factor towards BDD development. Some participants recalled being exposed to rejection in romantic and familial relationships. The rejection and sense of not being deemed good enough led to an increased concern about appearance and may have contributed to the development of thoughts associated with BDD.

5.5.2.1 Being rejected romantically due to appearance

This is illustrated by Claire, who described a scenario in which she experienced rejection from a friend who she considered quite important to her at the time.

> *I do remember in detail how he teased me that he found my sister attractive and I tried (very poorly on reflection) to flirt with him by stating that 'I am always told that we both look alike so that must mean that I am attractive to* [sic]*?'… I distinctly remember the pause, the awkward laugh and the comment 'No, not really'… it is vivid in my mind during and after the phone call I was staring in the mirror…* (Claire, Written piece)
>
> *I remember feeling quite um crushed and almost erm taken aback really a bit in shock… it felt like the bottom of my stomach had fallen out* (Claire, Interview)

Claire suggests that she remembers this particular memory quite strongly, evidenced by her use of the words "detail", "distinctly", and "vivid in my mind", highlighting the significance of this particular memory for her. Being told by a friend that she was not attractive like her sister had a highly negative impact upon Claire, and she recalls looking at her reflection in a mirror whilst talking to her friend and after the conversation had ended. She describes the feeling of experiencing rejection as feeling 'crushed', which powerfully illustrates the strength of the impact the rejection had on her body. She also goes into more depth with regards to describing bodily sensations she felt upon the experience of rejection, and uses the metaphor "it felt like the bottom of my stomach had fallen out". The feeling she describes demonstrates how the experience of rejection manifested itself in her physical body and expresses the anguish she felt in that moment. Jenny also identified a link between experiencing rejection throughout her teenage years and BDD development.

> *During the period between the age of 12-16 I remember being rejected by a few boys and I do think that was a contributing factor. Overall, I was heavily comparing myself to others and idolising girls who were slim and pretty.* (Jenny, Written piece)

Jenny made the link between being rejected and comparing herself unfavourably to others. She shows here that multiple rejections, in combination with her preconceived notion of what is and is not considered “pretty”, may have reinforced the perception that she was defective and inadequate compared to her peers. During this time in her life, she describes making direct comparisons between her own appearance and the appearance of others she considered more desirable.

5.5.2.2 Receiving criticism from family members

Not all criticisms participants reported receiving were related to their appearance. Jenny also faced physical abuse as well as negative comments and observations from family members about the way she behaved.

> *My dad would get short tempered with me and tell me off, although I don't remember the details, I just have a sense of not feeling good enough in his eyes so whatever was said created that belief in me. He once hit me (slapped across my face leaving a hand print) because I did something wrong and I remember the moment clearly, although I have no idea what I did wrong. I also got told repeatedly when I was naughty or annoying that 'I was so much like my auntie* [name redacted]*' who was viewed very negatively by the family.* (Jenny, Written piece)

She described being physically abused by her father for reasons that remain unclear to her, and being directly compared to another family member who was not well liked. In a similar way to Jenny, Rohit experienced many criticisms from a family member during his childhood that focused on his behaviours rather than his physical appearance.

> *She* [Rohit’s mother] *had an abusive nature, was harshly critical and discouraging towards me. She would keep pointing out mistakes and negatives in me and everything I did. She used foul language and cursed regularly. I do not remember being appreciated or encouraged for anything by her. I remember getting shamed often, in comparison to other kids of my age, my cousins and friends. I received verbal abuse often for the mistakes I made, even simple things like buying the wrong vegetables from the shop. The words were ugly very often.* (Rohit, Written piece)

Being shamed and harshly criticised by his mother may have left Rohit vulnerable to developing a poor relationship with his own sense of self during his formative years, which would shape his self-identity as he grew older. Rohit describes his mother’s abusive nature and reflects on the comparisons with other children his age. We might speculate, by his detailed description, that Rohit's experience of his mother may have affected his self-concept. Experiencing a lack of appreciation and encouragement from a young age is likely to cultivate negative evaluations about one's sense of worth. These negative evaluations of the self could then manifest as a sense of not being good enough. As the negative manifestations of the sense of self built up, participants discussed becoming more aware of concerns about aspects of their physical appearance.

5.5.3 Theme 3: Becoming aware of the solidifying of concerns

Some participants reported having a poor relationship with their appearance from a young age prior to their BDD onset, but this relationship deteriorated further over time and they noticed concerns solidifying and becoming more 'real' to them. This shows one potential way the disorder may develop in some people.

5.5.3.1 Realisation of a problem with the self being present

It is possible that Victoria may have experienced concerns about her appearance from a young age due to her receiving critical comments about her appearance at school, but describing aspects of her appearance as "deformities" is symptomatic of BDD.

> *…when I started sixth form I became even more concerned with my appearance and I started to feel as if my flaws were deformities…* (Victoria, Written piece)
>
> *I think I found an article about it [BDD] once and it sounded like me or something like that happened I'm not sure. But it sounded like what was happening and I didn't really know wether [sic] I actually had it or wether [sic] I was being a hypochondriac but I must have it or I'm really hideous and I'm using it as an excuse for my horrible face. It made me feel kind of good that other people had it and I started to read about it more and it would always make me feel sad and I also felt like I didn't have it because everybody else with it was actually quite pretty and I'm not pretty enough for it to just be my brain lying about a couple of things because it's not that it's my actual face being ugly and deformed.* (Victoria, Interview)

Victoria appears to express doubt that she has BDD and convinced herself that her perceived flaws were actually real. She describes a tension in her belief of having BDD and not having BDD. When she initially heard about BDD and its symptoms, she felt it matched up with her own experiences, however, she seems to express doubt as to whether she has BDD due to the inseparability of her perceived self and objective self. In other words, her perceived distortions are so strong that she does not believe they are distortions. She alludes to this idea by using the phrase “my horrible face”. By using this phrase, she attaches her distorted perception to her objective appearance, and is unable to separate them. She also uses words such as “hideous”, “ugly”, and “deformed” to describe her appearance, conveying how real the distortions are to her. This is further evidenced by Victoria viewing images of others who have BDD. She is suspicious of her own claims to having BDD because she views the others as beautiful and only views *herself* as “hideous”. Rather than being unsure about the others having BDD (as she considers them attractive), she doubts herself. This is a symptom of her BDD and makes the vicious cycle even deeper for her.

5.5.3.2 Strengthening of distorted beliefs

Like Victoria, Claire talks about the foregrounding of her appearance concerns becoming more concrete and problematic during a specific time period.

> *The longer I looked* [in the mirror] *the less it made sense what I was looking at… the features seemed to be much more individual rather than looking at a face as a whole…* (Claire, Written piece)
>
> *I don’t see a face as such – I just see faults* (Claire, Interview)

Seeing her face as a series of characteristics, or “faults” illustrates the atomistic viewing that Claire, and many others living with BDD, experience. Breaking the face down into its constituent parts and not being able to see the whole picture any longer is characteristic of BDD.

Claire momentarily brings our attention to the temporal domain when viewing her appearance in the mirror. She makes a link between the prolonged duration of time she spent looking at her appearance and the sense of ambiguity she feels regarding the focus of her gaze as she looks at her reflection. She describes a scenario in which she began to focus on parts of her face in isolation rather than appraising her whole face. This could be interpreted as a gradual process in which she (over a period of time) experienced the separation and possible foregrounding of her perceived problematic features, and a lack of cohesion between them. This supports the idea of appearance concerns solidifying and becoming more apparent to the perceiver over a period of time.

By contrast, Elliot makes sense of his BDD onset as acute. Unlike other participants, Elliot described the onset of his BDD symptoms as occurring quite suddenly, rather than gradually solidifying and becoming more real over time. He did not attribute the onset to a particular event or series of events, but he did acknowledge having a problematic relationship with his appearance previously. Here, he talks about a time in his life when he recalls suddenly not being able to look at a particular aspect of his appearance.

> *I think BDD really kicked in when I went to university. I think the first real problem I had was looking at the left side of my face.* (Elliot, Written piece)
>
> *I probably already had- had quite erm an unhealthy relationship with my appearance in a way- but just- it just sort of- I just remember thinking- there was just one day I couldn't er I just couldn't cope with looking in the mirror and seeing the left hand side of my face* [and] *just… just- just- it just sort of – you know – just- just really happened… erm and then it was really- yeah I dunno it just seemed to happen – it wasn't sort of- I think it may have just been er the overall pressures of being in that situation – not really being… having the resources to deal with it – it wasn't like – you know – any- it wasn't- I don't recall it being anything specific* (Elliot, Interview)

Using the phrase "kicked in" suggests Elliot was able to identify the time in his life when he began to experience symptoms of BDD. Specifically, when he experienced a negative relationship with the left side of his face. Like Claire, Elliot displays the atomistic behaviour of somebody living with BDD as he identifies the specific area of his face he struggles to view. It is apparent in Elliot's communication that recalling this significant phenomenon was difficult to express with language. The amount of effort he puts into explaining the phenomenon is very apparent with lots of self-correction and hesitancy. He describes his sudden onset as "…one day I couldn't... cope with looking in the mirror and seeing the left hand side of my face… it just… happened". His reference to coping in this excerpt is particularly interesting. Elliot may have been able to pinpoint his onset by reflecting on his capacity to cope with appearance-related events leading up to and after that day. It is evident that this day was significant to him, as he is able to recall a time when a part of his life changed, but he cannot express what he believes may have caused it.

The experiences reported by participants regarding how they make sense of their appearance concerns solidifying demonstrate the wide range of ways BDD may have developed for them. There appears to be a 'tipping point' where participants are able to come to a realisation that their relationship with their appearance is not typical, and it may be this point that participants remember more clearly. Some participants were able to identify specific circumstances that made them think about their appearance concerns more, and this was an important step in their reflective process and self-awareness of BDD.

5.5.4 Theme 4: Learning about and reflecting on triggers

An important element of understanding the origins of people's BDD is understanding what people believe their BDD triggers to be. Whilst the triggers may not directly reveal specific origins of the disorder in participants, they help us to gain an understanding of what could worsen BDD in people who live with it, and potentially, how it could be managed. In completing the study, participants were able to reflect on the triggers that affect them presently as well as in the past, providing some insight into their struggles.

5.5.4.1 External and social triggers

Victoria was able to reflect on triggers that worsen her BDD symptoms. She identified particular incidents that amplified her negative perception of self. Examples of this included times when her confidence was knocked by a boy (this might include receiving criticisms of appearance or experiencing rejection) or when she, like Angelina, views a photograph of herself that she considers unattractive.

> *When a photo is taken of me I have to spend ages looking at it and it makes me feel disgusting and I feel disgusting now thinking about different photos I've looked at with me in. I look deformed and it makes me worry because I must look that vile in real life and I try to look at what individual features are the problem but it's all of them… it's something that can't be fixed easily or can't be fixed at all. I always notice new features I hate in photos.* (Victoria, Interview)

Here, Victoria describes how viewing a photograph of herself that she considers unattractive can cause elevated and prolonged feelings of worry and concern. Additionally, experiencing a sense of compulsion is conveyed when she states "… I have to spend ages looking at it [the photograph]". She experiences a feeling of disgust if she does inspect an image of herself, and this disgust is also evoked by her memories of her appearance in particular pictures, too. Whilst Victoria was describing her feelings of disgust when viewing photographs in her interview, she said she felt disgusting in that moment "*now* thinking about different photos I've looked at with me in" [emphasis added]. This could convey how ingrained the images of her perceived self are; she is able to imagine them vividly enough upon thinking about them to feel physically nauseous. Victoria finds viewing photographs of herself particularly disturbing as they reinforce her perceived view of her appearance: "it makes me worry because I must look that vile in real life". This may be due to her considering the photographs as concrete objects or evidence that truly represents the subject matter they show. This leads her to attempt to localise the features that cause her disgust, but instead she identifies new areas of concern in the process, and this torturous cycle continues. Angelina reflected on the thoughts she experiences currently with regards to her BDD triggers. She expresses very succinctly what Victoria describes – the photograph or visual stimulus itself is no longer required; the thoughts about the photograph or scenario are sufficient to act as a trigger in their own right.

> *I do have certain triggers that definitely bring them* [the thoughts] *on, such as if I run into a person I went to school with, if I see a picture of myself that I don't like or when I look at old pictures; but for the most part the thoughts ARE the triggers and they truly never stop.* (Angelina, Interview)

Angelina conveys here that the negative thoughts she experiences are nuanced – they are both the trigger and the symptoms. She identifies specific events that act as catalysts, leading her to think about the adverse experiences of bullying she went through which subsequently contributed to the development of her negative perception of her appearance. Associating the sighting of people with traumatic events shows how significant and harmful Angelina's memories are for her, however, as well as her thoughts being linked to past events, triggers were also identified as states of mind or emotions. She also acknowledges that her thoughts are continuous throughout her everyday life regardless of the possibility of those events occurring, suggesting that some of her triggers may be ingrained within her. This was similarly discussed by Bethany, who reported the worsening of BDD symptoms due to particular feelings or thoughts that are consistently present in her life.

5.5.4.2 Ingrained triggers

Like Victoria and Angelina, Bethany was able to pinpoint specific situations in which her BDD worsens but also highlighted its permanent omnipresence within her.

> *My BDD flares up considerably whenever I am stressed or anxious but even when I am not, it is there with me constantly every day… you asked how often I thought about my body image and I can honestly say that it would be impossible to say because it feels like the thoughts are there almost all the time. It would be easier to let you know how often I don't think about it. It is quite often my waking thought and I dream about it regularly.* (Bethany, Written piece)

Bethany identifies that her BDD symptoms worsen when she is feeling stressed or anxious. It is possible that experiencing heightened negative emotions may lead her to become more concerned about her perceived flaws in her appearance, however, she also recognises that a constant level of BDD is maintained during her everyday life regardless of any external stressors she may be affected by. The thoughts Bethany experiences are encompassing, and her concerns infiltrate her life when she is awake and asleep.

5.6 Discussion

This discussion section will help to conceptualise the self-identified origins of participants' BDD by drawing on phenomenological concepts and psychological literature. I will demonstrate how a phenomenological perspective can be valuable in helping us gain a richer understanding of possible origins or contributing factors towards the development of BDD. I hope to then show how this phenomenologically gained insight and understanding could potentially aid their care and treatment in professional settings. In the remainder of the discussion, I will draw on the work of Merleau-Ponty, known for his contributions to understanding bodily perception and consciousness. I will also draw on Sartre and Heidegger's work to reflect upon issues of interacting with the world and existentialism. The data presented in this study illustrate the varied ways that individuals living with BDD believe the disorder developed for them, ranging from experiencing appearance-related bullying, rejection, shame, sudden onset, and the solidifying over time of perceived defects. To make sense of the events contributing to the development and onset of their BDD, participants employed imagery, for example, of being attacked by words, feeling strong bodily sensations, and vivid descriptions of self-surgery.

Through a phenomenological perspective, I was able to access and pay attention to the subtle nuances of individual phenomena expressed by participants and better understand from where and how the onset of BDD may originate. Living with a disorder such as BDD can greatly affect an individual's 'being-in-the-world' (Heidegger, 1927/1962), as the relationship with one's body is disrupted and the interface with one's world is affected.

The disruption of a participant's being-in-the-world is exemplified by Angelina's account of experiencing appearance-related bullying. Bullying was identified as a potential contributing factor of BDD development by several participants in this study. In addition to this, Weingarden et al. (2017) found that bullying was the most prevalent experience reported by BDD patients, further suggesting that receiving criticisms of appearance may be linked to BDD onset. Having many parts of Angelina's appearance extensively criticised and mocked by her peers may have focused her concerns on those aspects and therefore changed the way she views her existence in the world. This situation is reminiscent of being *othered* (Wilkinson & Kitzinger, 1996), as she is made to feel inferior to her peers, reinforcing her perception that she is different to the larger social group. Similarly, Elliot has also experienced othering when his moles were pointed out by the children in his class. This interaction led him to make the decision to engage in self-surgery in an attempt to remove the moles from his body using "a sharp stone in the playground", thus removing the very object that caused him to be othered in that situation. Elliot taking the stone and using it as a tool to alter his body could be described as a fulfilment of Heidegger's (1927/1962) concept 'readiness-to-hand' which "captures the serviceability or usability connotations that belong to the very being of implements" (Stapleton, 2010, cited in Davis, 2010: 51). An object's readiness-to-hand takes into consideration the Being that the object possesses, and how it presents itself to the individual's world. When Elliot wielded the stone, he would have become aware of its usability only upon holding it, gauging its ability to pierce his flesh. Elliot's motivation to radical self-deforming action conveys his strong desire to change his body. He viewed the stone as a tool that could help him remedy the problem he had with this particular aspect of his appearance, and the use of such an unsuitable item highlights the sense of agonising desperation he felt in that exact moment. Elliot's altering of his appearance could also be likened to him viewing his body as a 'body project'. Placing emphasis on one's body and adapting our appearance for public display turns our body into a 'project' (Nettleton & Watson, 1998: 1). Shilling (1993) states that "the body might best be conceptualised as an unfinished biological and social phenomenon, which is transformed, within limits, as a result of its participation in society" (Shilling, 1993, cited in Nettleton & Watson, 1998: 7). When viewing Elliot's body as a project, we can consider the possibility of him altering the appearance of his body due to his want to be accepted as part of his social group and being objectified under their critical gaze. Consequently, we need to further consider the implications of appearance-related bullying amongst people living with BDD and address the tormenting feelings that may remain after the initial 'othering' event has happened.

Sartre noted that, as humans, we become aware of ourselves when we are viewed by others. It could be due to this sense of 'bodily vulnerability' (Dolezal, 2017: 423) that Elliot became more aware of his moles during the event he describes. The fact that he attempted to change a part of his physical appearance subjected to critical gaze suggests that, from this moment, he was no longer unconscious of his appearance (being-in-itself; Sartre, 1943), but now aware of his own appearance and others' perception of his appearance, and wanting to adjust it in response to the criticisms (being-for-itself; Sartre, 1943). In psychological literature, there is some evidence to suggest that a number of people with BDD 'dissociate' or feel betrayed by their bodies. For example, they may experience thoughts such as "'the way my face/body looks made this happen to me. My body betrayed me therefore I hate my body'" (Constantian, 2019: 119). It could be said that some people with BDD who receive criticisms about their appearance from others in the same way that Angelina and Elliot have may feel betrayed by their appearance and resort to self-surgery or self-harm as a reaction to their bodily awareness shifting to 'being-for-itself'. The behaviour that Elliot describes is in line with findings from Veale's (2000) study, in which he highlights the fact that people with BDD may engage in self-surgery, or 'DIY surgery', in order to alter their appearance without going to a surgeon. Professionals should be aware that this often has disastrous effects on the individual and can worsen BDD symptoms.

Rejection, shame, and a sense of not being good enough were fundamental experiences to participants living with BDD in this study. Previous literature has explored the relationship between shame and BDD (Weingarden et al., 2018), however, the personal lived experience of participants was not explored. Instead, participants' shame was measured using the Young Schema Questionnaire-Short Form. In Weingarden et al.'s (2018) study, shame was presented as an internal emotion experienced by people living with BDD as a result of their BDD and concerns about the way others may view their perceived flaws. However, it did not address other potential sources of external shame such as bullying and rejection, which played important roles in the lives of participants in this study. As a consequence, I argue that future studies of BDD should incorporate clear and robust methods for thinking about the dimension of shame. Sartre described shame "as central to the ontology of human existence…" (cited in Dolezal, 2017: 421). All participants reported several events that led them to feel a sense of shame. In most cases, the events were directly linked to the participants' physical appearance, but there were some exceptions.

Heidegger (1927/1962) put forward the idea that we often take our bodies for granted, and only become aware of our bodies when we become ill or experience a feeling of pain or discomfort. It is possible that being subjected to an external source of shame may lead a person to become aware of bodily concerns. However, a person with BDD may perceive this critiqued image of their self as being concrete and completely real to them, thus reinforcing their belief that their appearance is defective. This may have been the case for Claire, who stated that she only saw individual "faults" rather than her whole face when she viewed herself in the mirror after experiencing rejection and criticism of her appearance. Victoria also talked about elements of her appearance transcending concern and becoming "deformities" for her. It was noted by Veale and Riley (2001) that as individuals with BDD looked in the mirror, they became increasingly self-conscious and their negative perceptions of themselves were reinforced, which further elucidates Claire's and Victoria's experiences. Further to this, a clinical eye tracking study by Greenberg, Reuman, Hartmann, Kasarskis, and Wilhelm (2014) examined attention bias in people with BDD and a healthy control group. They found that the BDD group focused more frequently on specific features on their own faces that they considered unattractive when viewing photographs of themselves than the control group. This finding is in line with participants from my study who often reflected on being preoccupied by specific areas of concern in their appearance when viewing themselves in mirrors or photographs. These areas of concern were often linked to criticisms made by others, emphasising once more the need to elicit and address the personal meaning behind specific appearance concerns in people living with BDD in professional settings and future research.

As well as participants receiving criticisms of their appearance, non-appearance related criticisms were also of interest. The experience of being criticised for behavioural aspects of the self was talked about by Jenny and Rohit, who both recalled receiving physical or verbal abuse from family members at a young age. Recent findings from Constantian (2019) suggest that childhood abuse may be linked to the experience of feeling ashamed of one's body, as it "imparts a sense of vulnerability, fear, and helplessness" (Constantian, 2019: 139). In addition, it has been argued that all types of abuse are tied to the body "by inflicting fear or pain, denying needs, or negating the importance of the individual" (Herman, 1992, cited in Constantian, 2019: 140).

Participants also reflected on what their self-identified BDD triggers were at the time of interview and I felt this was an important step towards finding out what may contribute towards or worsen BDD symptoms. The triggers were varied, and all posed a substantial threat to the wellbeing of the individual. Angelina's triggers include crossing paths with people from school and viewing photographs of herself that she does not like. This example is reminiscent of embodied knowing (Merleau-Ponty, 1945/1962), in which the world foregrounds the body. In this instance, elements of the external world (people from Angelina's school or certain photographs) draw Angelina's attention to the parts of her body she is affected by. As a result of these visual reminders of the harsh criticisms she faced, she still strongly associates with them, in a similar way that knowledge and experience can be "imprinted" on one's body (Tanaka, 2011, cited in Stenner, Cromby, Motzkau, & Yen, 2011: 149). She alludes to a cyclical relationship between experiencing BDD thoughts and triggers, making it difficult for her to separate the two and establish what is worsening her BDD. Weingarden et al. (2017) found that participants in their study "actually recalled an early experience of a BDD ritual, rather than the trigger of their BDD onset itself" (Weingarden et al., 2017: 23), highlighting the difficulty in differentiating between rituals and triggers and similarly relating to Angelina's identification of distressing thoughts being both a trigger and a symptom. However, not all participants named specific triggers that worsened their symptoms. In addition, the rumination that Angelina describes may be further explained by Osman, Cooper, Hackmann, and Veale (2004), who stated that people living with BDD who were bullied often experience spontaneous memories of the bullying and teasing that took place.

It is clear from the participant data that BDD is all-consuming and affects the lifeworld of those who live with it. As Bethany states, *"...it* [BDD] *is there with me constantly every day."* She acknowledges that it is a part of her life, that is, she lives with it and, like many others, is forced to adapt her being-in-the-world in order to accommodate it.

5.7 Summary

This study explored the self-identified origins of Body Dysmorphic Disorder (BDD) in eight participants living with BDD and how it impacts their daily lives. The results of the study identified some potential contributing factors towards the development of BDD, such as experiencing childhood bullying and criticism, rejection, and abuse. It also explored the idea of differing rates of BDD onset ranging from gradual development to sudden onset.

There is still much more to learn about the origins of BDD, therefore more research in this area is needed in order to bring its potential beginnings, symptoms and manifestations to the attention of professionals and aid them in providing treatments and necessary support to those living with BDD. I believe that using qualitative approaches such as IPA can help to gain a deeper understanding of what it is like to experience BDD from the perspective of those with lived experience. Phenomenological research could also provide further insight into under-researched areas such as implications of rate of BDD onset, investigations into coping strategies and management of BDD symptoms, experiences of help seeking, and the effectiveness of treatments for BDD. In addition, this study highlights the need for professionals to take into account the role of problematic social-developmental events and individual experiences in the onset of BDD, and emphasise the importance of continuing to foreground the experiences of those living with BDD as they currently remain vastly unheard and underrepresented in the research domain.

As mentioned previously, due to the amount of rich data participants provided regarding their overall experiences of living with BDD in addition to their origin stories, I considered it appropriate to explore those experiences in more depth in a separate study. The additional data regarding the experiences of living with BDD formed the basis for my third study presented in Chapter 6.

Chapter 6: Study 3 – Exploring current experiences of living with Body Dysmorphic Disorder

6.1 Introduction

The previous study delved into finding out about the situations and events to which people attribute the origins of their BDD. Participants talked about previously experiencing bullying, having their appearance criticised, and noticing their appearance concerns solidifying over time. In the same data set (the same biographical writing tasks and interviews), participants also placed a focus on their current experiences of living with this disorder. After exploring the 'starting points', dialogue naturally flowed and, in all interviews, the topic of discussion shifted to present issues and experiences. Participants wanted to share how they were feeling in the current moment of their lives, and this also added another layer to their lifeworlds, helping me build a more expansive picture of their life with BDD and how it affects their day to day lives. One possible reason for this is that a number of participants mentioned that writing and talking about their experiences had a therapeutic quality and described feeling a sense of relief that they were able to discuss them, as in some cases it was the first time they had shared their thoughts on BDD with another person. This reflects how difficult it can be for people living with BDD to discuss their feelings in 'normal', organic situations, and reinforces the importance of listening to and exploring their stories. This chapter broadens our understanding of the participants' lifeworlds from Study 2 by exploring how they make sense of their everyday experiences of living with BDD and offers more insight into the condition.

This study addressed the following research questions:

- How do people with BDD use language to communicate and make sense of the embodied qualities of BDD?

- What do the narratives of people with BDD tell us about the support needs of people living with it?

6.2 Results

The same data from Study 2 are used in this study, however the analysis focuses on participants' current experiences of BDD. IPA was used again in a similar way to the previous chapter. From the analysis, four main themes were generated: *Trapped with a distorted view from somewhere else*; *Being a prisoner in one's own skin*; The *exposed and vulnerable relational self*; *Loss and Stolenness*. Box 6.1 (page 112) shows the table of themes and subordinate themes for the study.

Box 6.1 Table of themes for Study 3

Theme 1 – Trapped with a distorted view from somewhere else

Experiencing perceptual distortion

I just can’t make that leap (Elliot)

I would stand in the mirror and cry, utterly devastated (Angelina)

BDD as a prison

it’s a brick wall that’s round you all the time (Bethany)

I have to remind myself to breathe in all the time (Kate)

Feeling isolated

I’ve never been in a relationship – that in itself is quite difficult (Elliot)

I felt alone even when there were people around (Rohit)

Mirrors as windows to a world others cannot see

if I actually focus on the mirror everything that I hate about myself just changes and gets bigger (Bethany)

I have smashed mirrors because I have become so angry and upset while looking at my reflection (Angelina)

Theme 2 – Being a prisoner in one’s own skin

The experience of physical bodily sensations

I remember feeling uncomfortably aware of my appearance all day and it felt physically painful to look in the mirror (Angelina)

I sometimes feel as if my mind and my body are separate (Claire)

I can’t describe how I feel when I have to wear my hair up it just feels really wrong (Victoria)

when a thought would enter my mind I would feel the dropping sensation in my stomach (Angelina)

I have this weird feeling that comes over me every single time I see a female body (Kate)

BDD is all-encompassing

I would describe it as I have multiple children in my head (Kate)

I felt as if I were carrying a back pack full of concrete around at all times (Angelina)

BDD doesn’t just affect everything in my life – BDD kind of is my life (Elliot)

Theme 3 – Exposed and vulnerable: The relational self and BDD

Feeling misunderstood by others

> *there's always a fear inside us that er they're going to laugh at us (Rohit)*
> *Those who have not experienced or do not know about this disorder believe you are being vain or petty (Angelina)*

Feeling unsupported and experiencing invalidation

> *she laughed at me and tell me- and she did tell me I was an idiot – and that I'm stupid (Kate)*
> *I am constantly invalidated and this has worsened my mental health symptoms (Angelina)*

Theme 4 – Loss and 'Stolenness'

Compulsion and a loss of control

> *every mirror I go past – I will look at my legs – I will look at my tummy – I will look at my hair… it's now on autopilot (Kate)*
> *my eyes and my- my mind immediately scans all the proportions of the face and I- it's just- it just happens uncontrollably (Rohit)*

Conflict between the logical and illogical

> *I now find a lot of the time I've got two parts of my brain (Bethany)*
> *it's almost like a deep desperation that- why wouldn't they change? why won't the measurements change? (Rohit)*

BDD as a thief

> *I have just let time pass away, just sitting on great potential (Rohit)*
> *I hope that I can [recover] before any more of my life is stolen from me.* (Angelina)
> *I am at the stage where I can see what damage it is doing to me but don't know how to stop it happening (Bethany)*

6.3 Theme 1 – Trapped with a distorted view from somewhere else

A key characteristic of BDD for the participants in this study is the experience of perceiving a distorted view of one's appearance. This perceived distortion can be extremely distressing to those who live with the condition as it appears very real to them. Participants compared this aspect of living with BDD to being in a 'trap' with a distorted view or being partitioned off in another realm, looking out. This trap acts as a barrier between the person living with BDD and the world, and also distorts their perception of the world.

6.3.1 Perceptual distortion

A concept that appeared quite prominently in the accounts of participants was the varying levels of awareness of their perceptual distortion. Elliot acknowledged and described experiencing a discrepancy between his objective appearance and the way he perceives his appearance:

> *I can't make that leap from- from understanding that it's not my appearance that's the problem – it's my relationship with my appearance and my- my thinking – and my values – and everything else – I can't- I can't er- I can't seem to – you know – it sounds so obvious written down when it's read – it sounds so clear – but I cannot- I cannot make that leap – I don't think I'm stupid or that my brain just doesn't really- doesn't function very well – erm but I just can't- I just can't make that leap you know* (Elliot, Interview)

This excerpt from Elliot's interview shows how he tries to give language to the 'problem' he mentions. The language and syntax he uses demonstrates how much struggle is involved in trying to articulate the gap between his perceived appearance and objective, external appearance. He puts a lot of effort into trying to find the right words to describe the phenomenon he experiences. Elliot describes navigating the gap between his understanding of his objective appearance and distorted perception of his appearance as a 'leap'. Navigating the gap is difficult for Elliot, as his appearance concerns are very real to him, but he does also have a strong level of awareness of BDD being responsible for those concerns. Reducing the distance between the two phenomena can only be endeavoured by making 'that leap', which has connotations of needing strength and support to complete a big task. Describing navigating the gap as a ‘leap’ emphasises the gravity of Elliot’s situation.

It is interesting to see that Elliot seems to be reflecting upon his own perceptions of his appearance and tries to make sense of the disparity between his physical appearance and his relationship with his “thinking… values – and everything else”. He acknowledges that his brain functions well, and that he is able to realise the experience logically, however, for Elliot, understanding that his appearance is not physically problematic is inconceivable.

In a similar way to Elliot, Angelina recognises that the way she perceives her appearance when looking in the mirror is not a true representation of her ‘objective’ appearance, but it is true to her. She reflected on a time when she was younger and described what she perceived whilst viewing herself in a mirror at home.

> *I began to see that one of my front teeth was shorter than the other (which was not at all true) and I would stand in the mirror and cry, utterly devastated. My nose appeared bigger and more crooked than ever…* (Angelina, Written piece)

Angelina’s use of the word “began” suggests that what she saw in the mirror had changed in comparison to a previous time she remembers. She had not always viewed her front teeth through a distorted lens, and this was a new experience for her. Viewing her distorted image was extremely distressing, and despite this, she continued to look in the mirror. She alludes to a change in her perception once again. In this instance, she states that her nose “appeared bigger and more crooked than ever”. By using the word “appeared”, she identifies that her nose was not physically growing larger or crooked, therefore showing awareness of the perceived quality of the distortion. For some participants, being exposed to such distortions was a confining experience, and in some instances, BDD was compared to a prison.

6.3.2 BDD as a prison

BDD was described as restricting and limiting. In their narratives, some participants positioned themselves as prisoners, reporting that they feel unable to escape the constraints BDD has over them. In her interview, Bethany stated that BDD is a metaphorical brick wall, suggesting connotations of impenetrability and division.

> *S:* *if BDD was a physical object – how would you describe it? – what kind of features would you imagine it to have?*
>
> *B:* *erm it's a brick wall – erm that's round you all the time – erm and every time you try to get out of it there's big hands pushing you back in… it's impossible that's- you know to climb over a brick wall that's too high to climb over… it's talking back at me all the time – so yeah – there'd be mouths in it as well*
>
> *S:* *yeah – what would it say to you?*
>
> *B:* *erm "you're fat" – "you're a loser" – erm "you're a disgrace"* (Bethany, Interview)

Bethany explains that the brick wall (BDD) is "round you all the time", which portrays how overwhelming and restricting her experience of living with BDD is. She talks about 'trying to get out of it' but being forced back into the enclosure by big hands, personifying BDD and illustrating its forceful nature. This evokes imagery of a physical struggle between Bethany and BDD, in which the BDD overpowers her. She views the brick wall (BDD) as an obstacle that is bigger than herself, therefore 'impossible' to scale and escape over the top of, much like a prison. The personified BDD brick wall keeps her inside, taking away her freedom and denying her experience of living in and experiencing the outside world. The exchange of language between Bethany and the brick wall also appears to be representative of a struggle. She talks to it (this may be an ongoing internal dialogue Bethany has with BDD), and it answers her back with aggressive and threatening statements: "you're fat"… "you're a loser"… "you're a disgrace". The statements sound factual to Bethany, and due to the brick wall surrounding her, the voice of BDD feels omnipresent and overwhelming. Interestingly, Kate offers a different perspective and talks about policing herself, discussing the importance of monitoring her own appearance within her lifeworld:

> *I have to remind myself to breathe in all the time… I will never ever breathe out in front of people- rarely on my own to be honest – I never really breathe out* (Kate, Interview)

She talks about her concerns regarding the appearance of her stomach, and holds her stomach in at all times, monitoring the image she puts across to other people who may view her body. By saying "I have to remind myself", this suggests her concerns about the appearance of her stomach are on her mind constantly and she feels she must actively do something to improve the way it is perceived by others and also by herself. There is a sense of compulsion and certainty in her narrative: "I have to"; "I will never". Using the emphatic words "never ever" abolishes any possibility of Kate relaxing her level of vigilance with regards to controlling her appearance. Being trapped by BDD may also contribute to feeling isolated or separated from the rest of the world.

6.3.3 Feeling isolated

Numerous participants identified feelings of isolation as a result of living with BDD. Elliot describes experiencing isolation and exclusion, highlighting the impact BDD continues to have on the social aspects of his life:

> *I've never been in a relationship – that in itself is quite difficult 'cause I'm constantly around people and it's just constantly like- kind of stimulating that* (Elliot, Interview)

For Elliot, BDD appears to separate him from the rest of the world, restricting his membership that would enable him to feel a part of the social groups around him. In his day to day life as a nurse, he interacts with a lot of people and this is a recurring reminder of his single status. Despite working in a highly social and interactive setting, Elliot may view himself as an outsider looking into a world that he is not part of. The sense of isolation he feels may also be linked to his experience of a set of very individualised phenomena that he knows other people may not have access to, thus making him feel alone in what he perceives and experiences.

A similar experience was described by Rohit. He spoke about feeling a sense of loneliness despite being in the company of others at university and experiencing suicidal thoughts as a result of his BDD symptoms.

> *I was constantly feeling uncomfortable being at the university and I would rush back home as soon as my lectures got over. I even started absenting myself from lectures as much as I could while meeting the minimum attendance requirements. I felt alone even when there were people around. I compared myself with others and that was destructive. I saw happy young people, confident and expressive, having fun with friends, being in relationships, basically doing everything that young people do.*
>
> *I cried a lot when alone. I should mention thoughts about death and suicide. I have had thoughts about suicide for many years. They would just come and go. I guess that is very normal. But for the last 18 months, I have dealt with dark thoughts very regularly and on bad days, several times a day. It was here that I first learnt about the term body dysmorphic disorder. I did some reading on the symptoms and saw similar patterns in what was happening in my head. I felt very disturbed by the prospect of me having a mental disorder.* (Rohit, Written piece)

From Rohit's description, it seems that he associated feeling uncomfortable at his university with further isolating himself by missing lectures, and potentially even having an effect on his work. He talks about making destructive comparisons between himself and others, which is characteristic of a person living with BDD. He observes that the people around him were enjoying themselves with friends and were in relationships, noting the normality of these activities that young people engage in. Like Elliot, being around people in social situations may have made Rohit more aware of his loneliness and the restrictions that BDD has imposed upon him, preventing him from participating in platonic and romantic relationships, thereby feeling excluded. This exclusion was sometimes portrayed as a physical barrier, and one way participants became aware of this barrier was via mirrors and the distorted image only they were able to see in them.

6.3.4 Mirrors as windows to a world people cannot see

Participants described the significance of their relationships with mirrors. Mirrors were depicted as windows or portals to a distorted world, only accessible by the individual with BDD. Other people are not able to see what the viewer with BDD sees in the mirror, so it could be considered a very personal and isolating experience.

Bethany discussed her experience of viewing herself in mirrors and drew upon a particular encounter with mirrors at her gym.

> *if I actually focus on the mirror – everything that I hate about myself just changes and gets bigger – and fatter and- I've seen it happen 'cause when I go to the gym there's mirrors when I'm doing workouts and things and I can see myself doing it so I have to turn my back on them* (Bethany, Interview)

When Bethany views her reflection in the mirror, she is exposed to the perceived, distorted version of herself. Her preoccupations become more visible and more pronounced to her, which she experiences as disorientating and distressing. She engages in mirror avoidance ("*I have to turn my back on them*") in order to protect herself from the image that actively distorts as she views it.

Angelina's experience of viewing her reflection in the mirror, like Bethany's, impacts heavily on her wellbeing. In her interview, she described breaking mirrors due to the debilitating emotions she experienced whilst using them.

> *A:* *I have smashed mirrors because I have become so angry and upset while looking at my reflection*
>
> *S:* *How did it feel when you smashed mirrors after looking at your reflection?*
>
> *A:* *It feels powerful and defiant. It gives me a rush and I want to do it over and over. Especially when I get a cut that bleeds particularly heavily. It feels like I am punishing myself, almost destroying myself and the parts that I hate.* (Angelina, Interview)

Viewing her reflection is extremely difficult for Angelina, and in her written task, she previously mentioned her anguish regarding seeing it in mirrors in particular. Describing the act of smashing the mirror as "powerful and defiant" suggests that the destruction of the object may help her distance herself from the perceived version the mirrors give access to and may also signal escaping the realm that others do not see, cutting off her connection to the distorted world within the mirror. The self-harm she discusses seems to have a dual purpose. Not only does it fulfil the act of self-punishment, but there also seems to be a sense of relief as it is possible that she may experience a release seeing her perceived self being shattered and gain freedom from the very thing that imprisons her.

6.4 Theme 2 – Being a prisoner in one's own skin

As well as feeling trapped by BDD itself and being confined to a distorted world, participants also expressed feeling trapped within their own corporeal existence. Feeling imprisoned within the boundaries of one's own body was a recurring area of concern in participants' dialogue, and this theme explores the impact of BDD in this context.

6.4.1 Experiencing bodily sensations

The experience of feeling physical sensations within the body in relation to their experiences of living with BDD was something that several participants recalled. In Claire's written piece, she discussed sensations she experienced with regards to her perception of her physical body in her everyday life, including when she viewed herself in the mirror.

> *I remember feeling uncomfortably aware of my appearance all day and it felt physically painful to look in the mirror. I felt that life has ended and nothing could feel as bad as this, the panic of knowing that I would never be free of acne. The best way to describe that feeling is to describe it like being a prisoner in your own skin…* (Claire, Written piece)

The uncomfortable awareness Claire felt towards her appearance is a particularly intriguing phenomenon to consider. It is a very abstract manifestation of her corporeal discomfort and may be a feeling that she is not able to convey fully using language. She also discusses feeling physical pain when she viewed her reflection in the mirror. This very powerful, physical feeling she experienced was a result of the high level of panic she felt when she acknowledged the possibility of having acne for the rest of her life. It was this potent realisation that led to her feeling her life had actually "ended"-

perhaps in the sense of her life being heavily restricted, and not being able to live to what she felt could be her full potential. Describing this experience as “like being a prisoner in your own skin” not only emphasises how confining living with BDD can be, but also gives rise to the importance of exploring the duality of mind and body in conflict. When discussing the panic she feels about viewing her appearance and having acne, she elaborates on the prisoner analogy in her interview and further explains that she considers her mind and her body as separate entities:

> *erm I’d- I’d- I’d probably describe it as- I- it’s hard but the best way I can describe it is as – I sometimes feel as if I’m not- so my mind and my body are separate… so I’m my mind and how I feel – and my body is just this separate thing that I have to live in and look at… erm and I don’t- I don’t want it- you know… I don’t want to be in this body – this- this- this thing – and I- and it’s- it’s like it’s a com- completely separate thing sometimes yeah* (Claire, Interview)

She described her mind as the entity that contains her identity, feelings and her whole self (“I’m my mind and how I feel”), metaphorically disregarding and leaving her physical body almost an empty shell. She corrects herself and changes “body” to “thing”. By referring to her physical body as “this thing”, she further demonstrates that she views it as an inanimate object that is not part of her and she is very much detached from it, conveying the strong dislike she has for the way her body looks. Despite feeling as though her mind is separate to her body, they are fused and she is unable to escape from her body, which could explain why she perceives herself as a prisoner inside it as she is forced to reside within it.

Victoria presented an alternative view on experiencing bodily sensations relating to her BDD experience:

> *When I wear my hair up outside my house I feel as if everyone is looking at them [Victoria’s ears], I feel they stick out farther than they do. It just makes me feel a bit sick and I couldn’t do it. I can’t describe how I feel when I have to wear my hair up it just feels really wrong and I can’t concentrate on anything other than the fact everyone can see my ears…*
>
> *When a photo is taken of me I have to spend ages looking at it and it makes me feel disgusting and I feel disgusting now thinking about different photos I’ve looked at with me in* (Victoria, Written piece)

For Victoria, her ears are a feature that she is particularly preoccupied by and in her description, she talks about experiencing a feeling that occurs when she believes her ears are visible to others. She struggles to put language to the feeling, however, she is able to identify that it causes her to “feel a bit sick” and that it “feels really wrong”. It could be said that the feeling is intrinsically linked to the social aspect of her lifeworld, and how her interactions with the world have a physical and tangible effect on her body as she experiences it. In a similar way, interacting with external stimuli within the world such as photographs of herself invokes a sense of nausea for her. Reflecting upon moments when she viewed herself in photographs creates physical feelings of disgust for Victoria, and this suggests that her perception of her appearance is intricately entwined with both her internal and external worlds. Angelina also reported experiencing physical bodily sensations as a result of living with BDD.

> *To me, the world became a scary place in all aspects. This made it hard for me to ever have fun or enjoy anything. I would feel restless and fidgety, uncomfortable in my body as if something just wasn’t right; this is what would usually lead to the physical “tics” I mentioned. Sometimes, when a thought would enter my mind I would feel the dropping sensation in my stomach, such as when you are on a rollercoaster. I also suffered from stomach aches and I actually developed an ulcer that bothered me from 4th grade until 8th grade. Lots of times I had a painful lump in my throat from holding back tears* (Angelina, Interview)

Angelina believes she began to experience physical manifestations of BDD in her childhood. Feelings of fear and worry combined with physical discomfort and ailments are sensations she associates with BDD. She finds it difficult to explain the exact sensations within her body that she experiences but mentions feeling “restless” and “fidgety” and having tics due to her sensing there was something that did not feel “right” to her. Unwanted thoughts caused her to stomach to drop, and she also notes that she developed issues related to her stomach in childhood. Experiencing negative events and feelings in her childhood had a profound effect on Angelina, and the possibility of her feelings contributing to the development of physical ailments and conditions could reveal how intricately BDD is interwoven within the mesh of her body.

Kate talks about experiencing a particular recurring feeling when she sees a female body, leading her to make comparisons between her own body and the body she is viewing. The experience of this feeling differs slightly to what Angelina describes, in that Kate is able to pinpoint the origin of the feeling and the path it follows. For Kate, the comparisons manifest themselves physically as sensations, which she feels within different parts of her body.

> *I have this weird feeling that comes over me every single time I see a female body – and I don't know what- I really don't know what it is but it's- I can feel it… physically – it's like something goes through from my- from my brain through the rest of my body… and I feel like my body becomes more sensitive – like physically – so like- or if I see someone who I think 'I want to look like them' or 'they're skinnier than me' then all of a sudden I can feel everything that touches my legs – I can feel the wind – I can feel my jeans – I can feel (pause) I dunno – I can feel the vibrations when I walk – everything… erm so it goes like from my brain – as if I was working down – it's like all of a sudden I have a double chin – and like I can suddenly feel this double chin there all the time… and then it will go to my boobs – and I feel like oh it's not moving so therefore I have no boobs – so there's a complete contrast – and then it goes to my tummy being like 'am I poking out? am I poking in?'… and then it will go to my legs – and then sometimes my feet – I get weird about my feet depending on what shoes I'm wearing* (Kate, Interview)

Although Kate is able to trace or map the trajectory of the unique feeling that moves through her body, she finds it difficult to put into words what the feeling she experiences actually is, as it transcends language and is an individual, bodily sensation. She experiences heightened sensitivity in numerous parts of her body when making comparisons between her own appearance and the appearance of others, particularly women. This heightened sensitivity could be thought of as a physical awareness of aspects of her body triggered by external stimuli, demonstrating that BDD is also a socially complex phenomenon as well as an internal issue. This compounding of both the internal and external disturbances may create a sense of feeling overwhelmed, which participants raised as another element of living with BDD.

6.4.2 BDD is all-encompassing

It is clear from participant narratives that BDD has a huge impact on the lives of those who live with it. Participants reported the ongoing and lasting effects they experience due to the condition and explain how it is entwined in almost every aspect of their everyday lives.

Kate uses a metaphor to describe BDD to those who may not be familiar with the condition, expressing how challenging and exhausting it can be to maintain the pacifying of various concerns she has about her appearance due to BDD.

> *I would describe it as I have multiple children in my head… all crying for different reasons – for example one's crying 'cause they need a nappy changed – one's crying 'cause they need fun – one's crying 'cause they need a bottle – I think about the nappy as my legs – the bottle as my boobs – and the fun as- I don't know – my makeup… who do you think about first? it's that worry of- I don't know what to focus on- what child do I pick up? you know… can I- can I get all of it done? can I- can I sort- make everything better again?... 'cause when you're in the moment you don't feel like you're gonna get out of it* (Kate, Interview)

She likens BDD to having multiple children to take care of. This suggests that each aspect of her appearance needs her attention and her concerns can become overwhelming if she does not address them straight away. The reasons she suggests for each 'baby' crying are all of equal importance (needing to be clean and comfortable, needing interaction, and needing to be fed), and this illustrates how difficult it can be for her to decide which issue to tackle first with regards to the maintenance of her appearance. Each aspect of her appearance needs the same amount of attention but requires a different resolution to remedy the problem. This creates additional pressure for Kate, as she struggles to meet the needs of the 'children' and juggle the different responsibilities that BDD creates for her. This leads her to question whether she is able to deal with them all. She states "… when you're in the moment you don't feel like you're gonna get out of it." Her description demonstrates how overwhelming and encompassing her thoughts about her appearance are. Not knowing how to prioritise her concerns brings her great distress and she is uncertain as to whether she can find a sense of relief from what she is feeling.

Similarly, Angelina shares her thoughts on the extent that BDD has affected her life and expresses concern about the effects of it being in her life constantly and being unable to escape it. She recalls a difficult period in her life when she found her BDD was particularly hard to manage.

> *I was tired and my body ached. I felt as if I were carrying a back pack full of concrete around at all times. The world around me seemed to be physically grey. I did not go out with friends and would often cancel plans. I worried about my skin at all times…*
> *I think about my appearance from the time I wake up until I fall asleep. I feel that everyone around me thinks I am ugly and that they are constantly comparing me to others. If someone says another girl is pretty, all I hear is that I am ugly.* (Angelina, Written piece)

Describing her body as tired and aching emphasises the exhaustion and strain Angelina was put under due to living with BDD. She reinforces the strain she felt by representing the burden constantly forced upon her as a "back pack full of concrete", the weight of which caused her to struggle both emotionally and physically. This appeared to have a cumulative effect and began to infiltrate wider aspects of her life, including the way she perceived the physical environment she lived in: "the world around me seemed to be physically grey". It could be suggested that her BDD is a 'bubble' that surrounds her and continues to expand and spread into her lifeworld. The greyness she describes could be a result of BDD overshadowing and dulling or drawing the colour out of her surroundings, and may reflect a lack of interest in life. These concerns affected her ability to socialise with her friends and demonstrate how BDD made it impossible to put relationships before her appearance concerns.

Angelina's thoughts about her appearance are present and consistent throughout her daily life. Due to BDD being intertwined in many aspects of her life and her perceived defects being very real to her, she has additional concerns about other people sharing the same beliefs she has about her appearance: "I feel that everyone around me thinks I am ugly…". Her use of the word 'feel' in this quotation may indicate that there is a rational knowing that everyone believes she is ugly, and this may also be an illustration of the significance and continual effect of her own perceived ugliness.

Like Angelina, Elliot also experiences persistent and continuous thoughts regarding his appearance. He talks about the many ways that BDD has had an impact on his life and impeded the way he goes about his everyday routine.

> *the BDD just affects everything – erm you know – BDD doesn't just affect everything in my life – BDD kind of is my life… trying to keep my skin under control so then I don't have that moment when I have to look in the mirror and my skin's either really red or really come up or really dried out… trying not to look too much – trying to do this – trying to do that – trying to be very careful about what I eat – and when I shower – when I shave* (Elliot, Interview)

By saying "BDD kind of is my life", Elliot reinforces the idea that BDD has become inseparable from his lifeworld. It is ingrained in everything that he does and has become synonymous with his identity. He gives examples of ways that BDD has affected many aspects of his life, including his interactions with the world, his diet choices, washing, and grooming routines, showing how deeply BDD is embedded into his life. His repetition of the word "trying" is telling, as it suggests that in his view, he is not succeeding in managing the aspects of his life and appearance that cause him concern.

Participants have shown that BDD can affect numerous areas of a person's life, causing a great deal of distress due to the way it can envelop the individual in harmful thoughts and perceptions, leading to feelings of restriction. Participants identified that another important area to talk about was the link between BDD and the problems that have arisen with their relational selves and social interactions.

6.5 Theme 3 – Exposed and vulnerable: The relational self and BDD

6.5.1 Feeling misunderstood

Participants reported that other people in their lives did not understand the implications of living with BDD and as a result of this, opening up to other people about their struggles became very difficult. Rohit discussed some of the unhelpful advice he has been given and how it since prevented him from talking about his concerns.

> *… sometimes the most annoying thing is that 'just get over it' – 'just stop thinking about it' – this is exactly what we cannot do… if they cannot [understand] then (pause) I will be very disappointed in the end… I don't want to take that chance so I keep holding it back… I don't share… there's always a fear inside us that er they're going to laugh at us* (Rohit, Interview)

Rohit conveys the frustration he feels when people tell him to "just get over it" or "just stop thinking about it" when he talks about the BDD symptoms he experiences. He describes it as "annoying" when people suggest that a person with BDD can simply ignore the adverse symptoms they are experiencing. Rohit explained that the way individuals had previously disregarded his concerns when he opened up to them about his feelings towards his appearance has prevented him from talking to others and seeking support for his BDD, out of fear the same would happen again. Box 6.2 below contains an excerpt from my reflexive journal regarding the interaction between Rohit and I during his interview.

This [excerpt from Rohit's interview] was more of a conversation between ourselves about the lack of awareness and understanding surrounding BDD and its symptomology. Where he says "we" and "us" he is referring to he and I during the interview. This created a sense of solidarity between us as we both had a shared understanding of the experiences he was describing. When he said "there's always a fear inside us that er they're going to laugh at us", this resonated with me, as I could immediately relive the times when I had been laughed at and not taken seriously when sharing some very sensitive thoughts about my own appearance concerns.

Box 6.2 Excerpt from reflexive journal regarding Rohit's interview

In a similar way to Rohit, Angelina highlighted some of the misconceptions people have regarding BDD that she has witnessed in her life.

> *Those who have not experienced or do not know about this disorder believe you are being vain or petty. They say things like "oh everyone hates how they look" or "you're just looking for attention, you know you're pretty." Comments like these only increase the pain and cause the stigma against this disorder to spread* (Angelina, Written piece)

The comments Angelina received show a distinct lack of knowledge about BDD, and she identifies that, from her experience, the severity of BDD is often played down by those who are unfamiliar with its symptoms. She described facing this ignorance as painful and stigmatising, adding to the feeling of being misunderstood and ostracised.

Due to there being a lack of understanding of BDD, participants reported experiencing a lack of support for their condition and ultimately, a lack of resources available to help those living with it. In the next subordinate theme, participants outlined some of the experiences they have had regarding help seeking from professionals for their BDD.

6.5.2 Feeling unsupported and experiencing invalidation

Kate disclosed to her secondary school nurse that she had concerns about her appearance, specifically her legs.

> *I got forced into seeing the- my secondary school's- she was a nurse but she saw me for like mental health reasons… and this was the- the first time I'd even mentioned any slight problem I- I had with my body and she laughed at me and tell me- and she did tell me I was an idiot – and that I'm stupid – and- because I felt this way… that's why I never- never told anyone until about four years later… I felt so embarrassed… and then angry* (Kate, Interview)

She describes opening up about her concerns about the appearance of her legs to a professional and receiving unsupportive responses when she was feeling vulnerable, such as being called "an idiot" and "stupid". She mentions that this interaction with her school nurse was the first time she had discussed the way she felt about her appearance with anyone, and as a result of this experience she did not speak to anyone about those concerns for another four years. This may have been due to feeling concerned about experiencing similar responses from other people, and as Rohit explained in the previous section, "There's always a fear inside us that er they're going to laugh at us". By referencing feelings of embarrassment and anger, she demonstrates how this interaction negatively impacted and exasperated her condition further. In addition, this scenario highlights the importance of initial encounters when seeking help for such a personal and sensitive issue.

Angelina also had a negative experience when seeking help from a professional. She describes visiting her doctor to seek help for the way she was feeling about her appearance.

> *I was exhausted and was even suicidal. This is also the year when I began to self-harm. I would cut and burn the skin on my left arm because I was so angry and I wanted to punish myself for being so hideously ugly. I went to my family doctor at the age of 17 and tried to express to him that I was depressed and he played it off as teenage stress, prescribed me an anti-depressant and sent me on my way. I took this medication for a year with no success.* (Angelina, Written piece)
>
> *I was disappointed and I felt very invalidated. My family had always told me that I "worried too much", that I was "ungrateful" had a bad attitude, that I needed to "cheer up" and "get over it" and those types of things… So to reach out to a medical professional and have him basically say the same things was very disheartening. And I have felt this way over and over all my life. From family, to friends, to partners, to counselors, doctors; none really seem to take me seriously when I try to reach out for help… I am constantly invalidated and this has worsened my mental health symptoms, made me bitter, and made me isolated from people.* (Angelina, Interview)

The words "exhausted" and "suicidal" reflect how desperate Angelina felt at this difficult point in her life. She details her experience of self-harming and uses words with connotations of destruction such as "cut", "burn", and "punish". In her view, the deliberate burning of her skin was justifiable due to her perception of herself as "hideously ugly". The behaviours she displayed prior to visiting her doctor were very serious and should merit some specialised support, however, the lack of care he displayed amongst other factors affected Angelina's condition more. She elaborated on this situation and evaluated it with descriptors such as "disappointed", "invalidated", and "disheartening", and it is possible that the additional misunderstandings from her family members contributed to making it feel even worse for her.

6.6 Theme 4: Loss and 'Stolenness'

Another key characteristic of BDD is engaging in repetitive and compulsive behaviours, especially in relation to disguising or checking one's appearance. Participants talked about how engaging in these behaviours made them feel they had lost control and wasted time.

6.6.1 "It's now on autopilot": Compulsion and loss of control

Some participants talked about the way BDD had an effect on their ability to feel as though they are in control of aspects of their lives. They reported being unable to control their compulsions with regards to monitoring their appearance in mirrors and other reflective objects as an example of this.

> *so every day in the morning as soon as I- as soon as I get up- like leave my bed – I look in the mirror… and the first thing I'll look at is my legs – every mirror I go past – I will look at my legs – I will look at my tummy – I will look at my hair – I have to make sure my hair is over my face and not behind my ears… I have to make sure that I'm wearing correct clothing to flatter my body – it's every mirror – every window – every- anything that provides a reflection like a car… or even a puddle or like a- a sign that has like plastic over it that's r- or like clear plastic that's reflective – anything (pause) I have to look in it- look in it… it's now on autopilot* (Kate, Interview)

Kate discussed the routine she engages in every morning. The language she uses when describing her routine is particularly revealing. Her repetition of "I will" and "I have to" suggests a modality of certainty and also demonstrates how she feels she does not have a choice but to engage in each element of her routine. Another example of repetition is "every" ("every mirror", "every window"), which highlights how extensive her preoccupation with monitoring her appearance in reflective surfaces is, and also gives a glimpse into how these preoccupations affect the temporal domain in her life. Her use of the phrase "it's now on autopilot" shows how checking her appearance in reflective surfaces daily has become a compulsion and monitoring it is a habitual aspect of her routine that she no longer has to actively think about. Similarly, Rohit described how he often feels compelled to look for differences between his own appearance and that of others.

> *I cannot stop myself from comparing and feeling that although I- 'he's got much better hair than have'… you know – things like that … erm I couldn't stop myself from observing er- you know – the angle of the jaw – and the chin – and the- and the lower portion of the face- I- it- it is almost like I'm- I'm- there's a computer program running in my head- you know – if I see a face my- my eyes and my- my mind immediately scans all the proportions of the face and I- it's just- it just happens uncontrollably* (Rohit, Interview)

Rohit's appearance concerns are highlighted by the comparisons he draws when he observes another person. He is immediately drawn to look at their hair and lower section of their face, specifically the "angle of the jaw and the chin", which are the areas of his own face that he is most preoccupied by. He compares this experience to there being "a computer program running" in his head. This is a particularly interesting comparison to make and suggests there is a degree of rigidity to the machine-like process he describes. It also suggests that there may be an element of perceived separation between Rohit's body and mind, indicating that Rohit may believe that his mind is controlled by something other than himself and that its actions are beyond his control. Separation of parts of the mind as well as the mind and body was also a recurrent idea in participant narratives in this study.

6.6.2 "My brain's split": Conflict between logical and illogical

A number of participants reported a tension between the logical and illogical thoughts they experienced as a result of living with BDD. For Bethany, this was particularly difficult to deal with, and she explained her experience of having contradictory beliefs about her appearance.

> *I now find a lot of the time I've got two parts of my brain – I've got the logical part – erm I can sort of talk to myself and say "no you're being silly" and change somehow other things I'm thinking – but quite often the illogical part still takes over so it's quite a challenge… my brain's split* (Bethany, Interview)

By metaphorically representing her brain as being divided into two parts, Bethany illustrates how problematic it is to manage the polarising thoughts that she lives with daily. She refers to each of the parts as the "logical" and "illogical" suggesting that they are not equal, as the illogical part is portrayed as being the more prominent aspect. There seems to be an inner conflict for Bethany between both elements she refers to, and this is exemplified by her use of language such as "takes over" and "my brain's split". The illogical aspect of her brain that "takes over" could represent BDD itself, skewing her perception of her appearance and making her question the authenticity of her reality. For Rohit, the illogical thoughts he experiences compel him to measure parts of his face using a ruler and, like Bethany, he struggles to override them.

> *S:* *...you mentioned that it [face measuring] was happening regularly and causing you a lot of anguish er but I wondered – why did you keep doing it even though it was upsetting you? what was making you carry on measuring?*
>
> *R:* *it was almost like- you know – it's- it's- it's weird – I- I'll try to describe – it's almost like- you know – I measure er now- er it's almost like a deep desperation that- why wouldn't they change? why won't the measurements change? – you know*
>
> *S:* *yeah*
>
> *R:* *something like that – it's- it's- it's a deep longing for it to change*
>
> *S:* *okay*
>
> *R:* *it- it just forces me to take er- do the measurements – and- and you know- it's- it's- maybe I measured it wrongly – maybe I- I- I did not er measure properly or something like that – it's- it's just like er why wouldn't it be right? why wouldn't I get it right? I know that it is what it is – but er I don't know how to describe that* (Rohit, Interview)

Here, Rohit reflected upon a time in his life when he measured his face frequently. He acknowledged experiencing illogical thoughts about the possibility of his facial features changing in size and described feeling a "deep desperation" that this would happen. This strong sense of desperation he felt led him to engage in the repetitive measuring behaviours and he shared that he felt forced to carry out the measurements. In a similar way to Bethany, he seemed to question his reality: "maybe I measured it wrongly… I did not er measure properly" however stating that he knew "that it is what it is", implying some acceptance of the situation and the true reality of it. The contradictory thoughts that participants experienced and described show how complex and uncertain living with BDD can be.

6.6.3 BDD as a thief

Contributing to the complexity of the disorder is experiencing a sense of stolen time and loss of living as a result of BDD, which was very apparent in discussions with participants. Rohit reflected upon his life thus far leading up to his thirtieth birthday, and expressed regret for the choices he had made in order to accommodate the disorder:

> *… as I approach my 30th birthday, I experience a lot of regretful thoughts, the "What ifs". I criticize myself for not fighting it out earlier in life, not working on my body much earlier, not opening up to people and discovering my strengths and weaknesses, earlier. And, how that could have made my 20s a whole lot better. A particularly gripping feeling which I have most of the time, "The best part of my life is behind me and I have not been courageous enough to try and do things. I have just let time pass away, just sitting on great potential."* (Rohit, Written piece)

The self-criticism Rohit engages in centres around him not addressing his BDD symptoms sooner. It seems that Rohit puts blame on himself for not being able to confront the difficulties he faced in his younger years and at present, particularly relating to his physical appearance and relational interactions. He frames this period of his life as stagnant and ruminates over lost time and unfulfilled experiences: what he describes as "What ifs". Using language such as "I have not been courageous enough" and "I have just let time pass away" suggests that Rohit feels he is responsible for holding himself back. He draws upon imagery of a battle or struggle between himself and BDD: "not fighting it out"; "strengths and weaknesses"; "gripping"; "I have not been courageous enough", which illustrates how despairing this particular aspect of living with BDD is for him.

In a similar way to Rohit, Angelina reflected upon either missing out on or being unable to participate in the seemingly mundane and everyday activities and aspects of life that most would take for granted:

> *I would love to be able to look in a mirror and not hate the image I see staring back at me. I would like to take pictures with my family and friends without obsessing about how I look and later deleting or destroying them. I want to have fun and be happy without always thinking I look hideous and that those around me are talking about me or thinking how ugly I look. I fear having children because I think they will be as hideous as I am and I could not bear that. I don't know if people with BDD recover, I have heard that some do, or that many are able to at least find some relief, but if it is possible, I hope that I can before any more of my life is stolen from me.* (Angelina, Written piece)

Looking in a mirror and taking photographs with loved ones are actions that could be considered harmless and enjoyable respectively, but for Angelina, they bring torment and anguish. Through her account, there is a strong sense of Angelina longing to live a fulfilling and comfortable life with the pleasure that BDD has taken away from her: "I want to have fun and be happy without always thinking I look hideous…". Like Rohit, she also conveys a large sense of responsibility for aspects of her life that have been broadly affected by BDD and that are out of her control. BDD and her hatred of her perceived appearance may have taken away her choices and influenced her decision regarding having children: "I fear having children because I think they will be as hideous as I am". The sense of guilt of potentially passing on elements of her appearance to another human form could also be interpreted as an aspect of protection; wanting to protect the unborn children from having an appearance like her perceived own.

6.7 Discussion

This study explored eight participants' everyday experiences of living with BDD by eliciting biographical written accounts, conducting follow-up semi-structured interviews and analysing both components using IPA. The accounts participants shared and the subsequent analysis revealed the significant impact BDD has on the lives of each individual, and facilitated a broader understanding of how they make sense of their situation. I developed four main themes from participants' accounts: *Trapped with a distorted view from somewhere else*; *Being a prisoner in one's own skin*; *Exposed and vulnerable: The relational self and BDD*; Loss and *'Stolenness'.* Participants reflected upon a wide range of phenomena relating to their lives with BDD and in this discussion section, I will explore participant narratives and my analysis in more depth, using phenomenological and psychological concepts and ideas to further elucidate and make sense of the unique experiences they revealed.

In the first theme, *Trapped with a distorted view from somewhere else*, participants placed emphasis on their appearance-related distortions and how they made them feel segregated from others and the rest of the world. A key idea participants made sense of through their narratives was that mirrors were windows to a world that others could not see. To delve into this further, I find it useful to think about reflections in mirrors as an extension of the perceived body. Considering objects as extensions of the body is a Heideggerian concept, in which we can view the body extending over the tools it uses. For some participants in this study, using mirrors is an important part of their experience of BDD. We could say that the corporeal body extends itself over the mirror to reveal their perceived selves to them, and the reflection offers a fragment of a distorted world. Building upon this idea further, we could take into consideration the overall significance and function of the other. Drawing upon Sartre's philosophy, Moran describes the ability of the other in revealing one's true, authentic self: "The other reveals to me something I cannot learn on my own: how I really am" (Moran, 2010: 44). However, in the case of BDD and viewing oneself in the mirror, the true self is instead replaced by the perceived and distorted self. Being unable to escape the distorted quality of the self may be what leads people with BDD to feel trapped.

One of the core aspects of living with BDD from participants' accounts was having a seemingly constant awareness of one's own body. Some participants reported experiencing a level of awareness but found it difficult to explain specifically and verbally what they were aware of, or how tangible it felt to them. Heidegger (1927/1962) suggested a concept called 'existential homelessness', which focuses on the idea that we, as humans, often take the existence of our bodies for granted and only become aware of them when we realise they are not functioning normally; for example, when we experience illness or feel pain and discomfort. This concept is particularly useful for thinking about the intangible feelings of awareness that some participants reported feeling in their bodies. The bodily awareness that participants refer to may have occurred as a result of them feeling that there is something wrong with their bodies, but the uniqueness of the experience makes it very difficult to verbalise. Merleau-Ponty (1945/1962) also puts forward the idea that the intuitively felt body is foregrounded during periods of illness or discomfort and that the body is too complex and great of an object to be expressed linguistically. In further support of this, a recent study by Summers, Matheny, and Cougle (2017) suggested that people with BDD sense 'Not just right experiences' and feelings of incompleteness more strongly than those without BDD. 'Not just right experiences' are regarded as "uncomfortable sensations of imperfection, or perceptions that the environment (internal or external) is not as it *should* be" (Summers, et al., 2017; Coles, Frost, Heimberg, and Rhéaume, 2003; Rasmussen and Eisen, 1992; Summerfeldt, 2004). Although the tasks in their 2017 study were not directly linked to appearance related reports of 'not just right experiences' (e.g. one task involved participants putting on an over-sized lab coat asymmetrically), it does suggest that people with BDD may be more susceptive to phenomena that are subtly different or unusual more so than those without BDD. For some participants in my study, the feelings they experienced surpassed bodily awareness and became feelings of physical sickness. This is illustrated particularly clearly by Victoria, who discussed feeling physically sick at the thought of displaying her ears and viewing photographs of herself: "*It just makes me feel a bit sick and I couldn't do it… it makes me feel disgusting and I feel disgusting now thinking about different photos I've looked at."* According to Sartre, the feeling of 'nausea' precedes all feelings of disgust within the body (Sartre, 1943/1956), and it is "a kind of ontological unease with the body, with being limited to a point of view" (Moran, 2010: 53). If we consider this with regard to the sickness participants reported, it could be suggested that there is a habitual sense of underlying disgust in people living with BDD. In some instances, for example, Victoria's repulsion of her own depiction in photographs, the disgust may surface more intensely when she is presented with a particular version of herself via the other, whether that other is in the form of an object (such as in a photograph, as mentioned) or another human. The other played an important role in the way participants in this study navigated themselves in the world, and at times, this was particularly problematic for them.

For participants in this study, social interactions regarding help seeking were considered difficult to navigate and, in some cases, damaging to the individual. If we think of the body as an intersubjective, social entity, we must consider the role and effect of the other on our bodies in more depth. When the body is present in the interactive dimension, according to Moran (2010), it is not experienced in isolation "but as reflected in the experience of it by others" (Moran, 2010: 44). The way participants reported interacting with other people in their accounts suggests that the other had a substantial influence on their experience of the world and their own bodies, and it is this reflection of the self, perpetuated by the other, that is residual in the individual. Participants described feeling shamed and demeaned as a result of sharing their appearance concerns with friends and professionals, and this could have been a significant barrier to them seeking further help for what they were experiencing. As Sartre writes, "I cannot be embarrassed by my own body as I exist it. It is my body as it may exist for the other which may embarrass me" (Sartre, 1943/1956: 421). In this instance, the interaction with the other led to a cumulative embarrassment or shame; the combined pre-existing shame of the individual fused with the new, additional shame from the other. It might be useful to consider this development of other-induced shame as a part of the authentic self being taken away. The version of oneself that the other perceives almost replaces an aspect of the original self. Sartre emphasised the significance of the role the other plays in our own perception via his concept of 'the look' (Sartre, 1943/1956). When one is the recipient of 'the look' (being viewed by the gaze of the other), the body becomes objectified and made aware of its presence in the world and view of the other; an object for others rather than for itself. This objectification of the self was also explored by Laing (1959) who refers to it by a different term, 'petrification' (Laing, 1959). According to Laing, the process of petrification involves, like 'the look', being objectified by the other and also incorporates a sense of depersonalisation. When this depersonalisation is experienced, feelings of loss of the self may occur within the body as a new version of the self is whittled and shaped by both the other and a sense of self-consciousness that is characteristic of BDD. For participants in this study, loss was also experienced in alternative ways, including loss within the domain of temporality.

The loss and stolenness participants alluded to was a significant aspect of living with BDD in their view. Some participants reported that monitoring and managing their appearance was incredibly time consuming, resulting in a sense of lost time. Others reported feeling they had a loss of control over themselves, using a thief as a metaphor for BDD due to what it has taken away from them: "*I hope that I can [recover] before any more of my life is stolen from me" (Angelina)*. We could also view BDD as a metaphorical 'other'; an internal but separate critic that engenders a loss of the true, authentic self.

The loss of time trope which participants reported is phenomenologically significant to the understanding of BDD, and thinking about time loss in a phenomenological way may help others to understand the anguish and uncertainty it can create for people living with BDD. Humans use time as a way of measuring or acknowledging our very existence, treating it as "a general ontological guideline, a way of understanding *all* entities" (Polt, 2010: 70). Heidegger (1927/1962) previously developed this idea and suggested that time could be thought of as a 'horizon' against which we comprehend our very being. We could therefore think about BDD as being a temporal disruption in one's world. When Rohit described reflecting upon the "*What ifs*" in his life and other "*regretful thoughts*" he had experienced as a result of BDD impacting the way he lives his life, these may have been instances of the disorder warping his horizon and consciousness of time. In Rohit's reflections on his life thus far, it is possible that he presents an unspoken awareness of his own mortality and facing his own death. In engaging with the time-consuming acts and limiting his interactions with the world in an attempt to reduce his BDD symptoms, he is thrown into the distorted world that is tacit to BDD experience, losing an awareness of time (in the present sense) and unwittingly moving towards his non-existence. The regret that Rohit feels may be a realisation that his 'primordial temporality' (Heidegger, 1927/1962) has been disarticulated by this condition, and he is tormented by what he could have been and what he could be (the past and future versions of himself) if it were not for his BDD. Those versions of Rohit could be thought of as limited by BDD, and it may be as if Rohit feels his present self is restrained, paralysed by what he experiences and in a form of temporal suspended animation by a fear of his own futurity. The fear and uncertainty that the future paradoxically gatekeeps was also reflected upon by Angelina, who expressed her apprehension regarding having children: "*I fear having children because I think they will be as hideous as I am".* Angelina's concerns about her appearance have impacted her perception of her own futurity. In a similar way to Rohit, she may feel tormented by her past and future selves and their uncertain potential. She may also feel a sense of future-embedded guilt and a sense of grief for the potential of 'passing on' her perceived "hideous" appearance to offspring that are not presently in existence. It is this potential that may contribute significantly to her anguish; the "*being out toward* what it is not yet, but can be" (Heidegger, 1935: 46).

6.8 Summary

To sum up, this study explored the experiences of living with BDD from the perspectives of eight people with lived experience, broadening the scope of our understanding of what it means to live with the disorder. Participants described feeling trapped and considered themselves prisoners in their own skin, exposed and vulnerable, and reflected upon experiencing a sense of loss or ‘stolenness’ as a result of their lives being intertwined with BDD. They made use of vivid descriptions of salient yet everyday moments and evocative metaphorical portrayals to convey the painful embodiment of BDD for them. Some travelled back and forth through the temporal domain via memories and thoughts about potentiality and employed poignant language to reflect upon experiences that are incredibly distressing to them. In exploring participants’ experiences deeply, we can consider some of the ways in which they might be better supported. For example, due to some of the experiences that participants found particularly difficult to describe using words, it could be beneficial to consider methods that encourage moving beyond language and accessing pre-reflective phenomena as they exist within the body in order to help them express their BDD experience more fully. One potential way of moving beyond language and accessing embodiment in a more naturalistic manner includes using artwork as a way of eliciting and communicating experience. Reprising Veale and Lambrou’s (2002) hypothesis regarding BDD patients’ natural proclivity towards creating and appreciating art, it may be possible that participants feel more able to express their evocative experiences in art form rather than through words alone. In the next chapter, I present the fourth study which uses a multimodal phenomenological methodology, combining the creation and analysis of artwork with IPA.

Chapter 7: Study 4 – An arts-based multimodal hermeneutic-phenomenological approach to explore the experience of coping with Body Dysmorphic Disorder

7.1 Introduction

This study explored participants' experiences of coping with BDD using a multimodal hermeneutic-phenomenological approach, which combined IPA with Boden and Eatough's (2014) Framework for the Analysis of Drawings, to explore visual data. Findings from the previous studies in this thesis provided a lot of insight into what it is like to live with BDD, and what its possible origins may be, however, the studies also raised questions about the ways in which people with BDD manage to live a 'normal' life and cope with some of the distressing experiences that were discussed. Although illuminating, the exploratory, open-ended written and interview data were not fully able to capture the quality of people's experiences of living with BDD. They provided a strong basis and starting point, however, I wanted to go further using a multimodal approach to see if using creative methods would enable more clarity of expression of the quality of the experience of living with BDD. The psychological process of coping with BDD is a highly personal and varied experience that has not yet been explored in qualitative research, however, researchers have previously employed qualitative visual methodologies in the form of photo elicitation to explore the experience of mirror gazing in BDD (Silver & Farrants, 2015) and living with BDD more generally (Silver & Reavey, 2010). My previous studies have shown that it can be extremely difficult 'to language' (Gendlin, 1997) the subtle and ambiguous phenomena that one feels when attempting to convey what it is like to cope with symptoms of BDD. For this reason, I decided to use a multimodal approach to data collection (Boden & Eatough, 2014) by inviting participants to create artwork to represent their lived experience of coping with BDD, following up with an interview to explore their visual representations in greater depth.

The majority of qualitative studies in psychology focus on the analysis and interpretation of 'spoken-word data', often elicited by "naturalistic conversation, semi-structured and unstructured interviews, diaries, case studies, focus groups and computer-based text analysis" (Reavey & Johnson, 2017). It should be noted that using visual approaches in qualitative psychology research is becoming an area of burgeoning interest (Reavey, 2011), and a number of studies have embraced visual methodologies to get closer to participant experience (Gabb & Fink, 2015; Holliday, 2004). However, it has been suggested that one of the key reasons visual data is not yet widely used in qualitative psychology research is due to it being considered polysemic or vague (Reavey & Johnson, 2017; Penn, 2000; Frith & Harcourt, 2005), lending to the arguably outdated narrative that the analysis of linguistic data provides a more robust basis for enquiry. Linguistic data can indeed provide great insight into the lived experience of individuals, however, in this chapter I illustrate the richness of experiential data that can be conveyed through images. Furthermore, what I demonstrate in this study is a multimodal approach to both data generation and analysis; the data generated in artwork is not simply used as a stimulus to the interview, it is analysed in its own right, and used in the interview to explore the meanings of lived experience of BDD together with the participants. When discussing the nature of BDD with participants in my second and third studies, some found it challenging to put into words what it is like to live with the disorder and how they would describe it to somebody who may not have experience of it themselves. Hearing participants struggle with forming their explanations and verbal descriptions of BDD during interviews led me to consider a different approach to data collection that may facilitate the exploration of hidden, pre-reflective (and pre-linguistic) phenomena. Some participants used metaphor in their explanations, which served the function of getting across their experiences in a way that could be considered relatable to those who do not live with BDD. Lakoff and Johnson (1980) describe metaphor as "one of our most important tools for trying to comprehend partially what cannot be comprehended totally: our feelings, aesthetic experiences, moral practices and spiritual awareness" (Lakoff & Johnson, 1980: 134). Building on Lakoff and Johnson's (1980) consideration of metaphor, one could argue that the creation of art is also a tool for helping others to comprehend, and have access to, a world that is unfamiliar to them.

This study set out to answer the following research questions:

- What do the images of people with BDD tell us about coping with it?
- How does the combination of image making and interviews help people with expressing ambiguous elements of their experience of living with BDD?

7.2 Method

7.2.1 Approach and design

In this study, I used Boden and Eatough's (2014) Framework for the Analysis of Drawings (Table 7.4, page 147) to enable a thorough appraisal of participants' artwork, and IPA (Smith, 1996) to analyse their accounts of the meanings conveyed in their artwork. Specific details regarding the process of IPA as the overarching methodological approach were described in Chapter 5. Boden and Eatough's (2014) framework facilitates the researcher in "exploring lived experience as fully as possible" (Boden & Eatough, 2014: 160). There are two components to the Boden and Eatough (2014) Framework: The Framework for the analysis of drawings (which I have used for this study), and the Framework for the analysis of the production of the image (see Boden & Eatough, 2014; 167). The Framework for the analysis of the production of the image was designed to be used face-to-face in a 'draw-talk' style interview and focuses on gaining insight into the participants' real time image making. It encourages the researcher to make observations during the artwork creation process and consider aspects such as the length of time participants spent on particular areas of the artwork, the amount of pressure they applied to the page, and any gestures or facial expressions they made. I decided not to use this second component of the Framework, as I wanted participants to complete their pieces privately due to the sensitivity of the phenomenon under exploration. I also wanted to give participants space to reflect upon their experiences and not feel pressured by time constraints or by being observed. Combining both the Framework for the Analysis of Drawings and IPA approaches helped me to gain access to an authentic expression of participants' experiences and enabled fruitful discussion and reflection to take place.

7.2.2 Ethical procedure

Participants were each informed in the Participant Information Sheet (Appendix G) that the study involved producing artwork which would be subsequently included in this thesis, publications and for dissemination purposes (for example, at conferences). Participants consented to their artwork being used in this way via a consent form hosted by Qualtrics (Appendix H).

7.2.3 Sampling strategy and recruitment

Participants were aged 18 or over and self-identified as living with BDD. The recruitment of participants began once ethical approval was granted by the Aston University Life and Health Sciences Research Ethics Committee (Appendix I). The Body Dysmorphic Disorder Foundation agreed to circulate a study advertisement (Appendix J) on Twitter and also included the study advertisement image in their October 2019 email newsletter. The Body Dysmorphic Disorder Questionnaire (BDDQ; Appendix D) was used as a tool to screen participants into the study, and this questionnaire was made available to them online via a link to Qualtrics. The BDDQ asks participants structured questions about how they feel about their appearance at the time of completion.

7.2.4 Participants

Sixteen prospective participants responded to the study advertisement. Of the 16 participants who expressed interest, six subsequently completed both parts of the study. Table 7.1 (page 144) presents the demographics of the participants in this study.

Table 7.1 Participant demographics

Pseudonym	**Age at interview**	**Sex**	**Location**	**Interview medium**
Aurora	41	F	USA	Email
Denise	39	F	UK	Telephone
Michelle	38	F	USA	Skype (Audio)
Petra	27	F	Norway	FaceTime (Audio)
Thea	32	F	UK	Face to face
Umbra	54	F	Canada	Email

All participants in this study identified as female. Two participants lived in the USA, two in the UK, one in Norway, and one in Canada.

7.2.5 Data collection procedure

This multimodal study comprised of two parts. This included an arts-based element and follow-up interview to discuss the content of the art piece in more depth. The two-part design of the previous work in the second and third studies enabled a deeper probing of meaning with participants with the use of the written description as a guide. As this worked well, I wanted to explore the use of art in a similar way to facilitate the discussion and exploration of meaning of BDD with participants using their images as the stimulus.

7.2.5.1 Arts-based activity

Participants were invited to create a piece of artwork to represent their experiences of coping with BDD. They were each sent the following questions and prompts (Box 7.2 below) via email to help them create their piece:

Box 7.2 Questions and prompts for image creation

Make an image to help me understand the following:

What does Body Dysmorphic Disorder look like to you on a bad day and on a more manageable day?

Some prompts to consider:

- *In what way(s) does BDD impact your everyday life?*
- *What coping strategies do you have to help you experience more manageable days?*

You can use any art material(s) you wish, including (but not limited to) pencils, paint, 3D materials etc. in any way you choose.

Please do not worry if you think the meaning behind your piece is not immediately obvious. You will have time to discuss your piece in more depth during a follow-up interview.

Participants were free to be creative with the form of their artwork. Some chose to represent their experiences of a more manageable day and a bad day together in one piece, whereas others decided to produce separate pieces for those experiences. Participants were advised to not spend any longer than two hours on creating their art piece, and they did not have to complete it in one sitting. If they felt concerned about how much time they were spending on their piece, they were advised to contact me to discuss this and send their piece in an incomplete form.

7.2.5.2 Follow-up interview

Once participants had completed their artwork and sent a scan or clear photograph of it to me via email, a follow-up interview was arranged to discuss their piece in more detail. Interviews lasted, on average, 50 minutes and were audio recorded, then transcribed verbatim. Participants were offered a choice of interview media including face-to-face, Skype (video or audio), telephone (including FaceTime audio), or email. An interview schedule was created to provide some structure to the interview (see Table 7.3 below), and semi-structured interviews were used for their flexibility in working around the interests of each participant (Kvale & Brinkmann, 2009).

Table 7.3 Indicative interview schedule for semi-structured interviews

Example questions	**Prompts**
How did you feel when you were creating your art piece?	What was that like? Did you face any challenges? What challenges did you face? How long did it take you to make? Did it turn out as you had planned? What did you enjoy most/least about this task?
In your piece, you included an image of [x]. What does this represent to you?	Is there anything important about its placement/size? Why did you choose to put it there?
How did you draw/paint the [x] section of the piece?	What did you use and why? What were you thinking about as you added this to your piece?
You used some vibrant colours in this part. Why did you choose to use them?	Do the colours mean anything to you? What do the colours represent?

7.2.6 Analysis

Initial observations of participants' images were noted, then they were analysed by the first author using Boden and Eatough's (2014) Framework for the Analysis of Drawings (Table 7.4 below). An example of the analytical process is presented in Appendix K.

Table 7.4 Framework for the Analysis of Drawings from Boden and Eatough (2014)

Framework for the Analysis of Drawings

1. Contents: Describe each of the distinct elements of the image.
2. Composition: How are the elements spatially laid out on the page? Are they sparse or dense, are there areas of blank page, do the elements overlap? Is there a sense of repetition, 'rhyme', or pattern?
3. Balance: How do elements interplay? Is there a sense of equilibrium or disequilibrium? Is there symmetry or pattern?
4. Geometry: What shapes are used? How do these interplay together?
5. Materials: Which material has been used for each element?
6. Texture: What are the textural characteristics of each element?
7. Colour: How have hue (colour), saturation (vividness), and value (lightness/darkness) been used?
8. Depth/Perspective: What spatial depth and perspective have been created through space and colour?
9. Temporality/Dynamism: Is there a sense of rhythm or movement? Does the image suggest a snapshot, continuity or duration?
10. Focus: What is the visual focus of the image? What is your eye drawn to?
11. Expressive content/Empathic reaction: What is the emotional tone of the image? What feelings does the viewer have in response (bodily, emotional, memories, images)?
12. Signs/Symbolism: Are there any overt symbols or cultural references included?
13. Style: Does the image 'shout' or is it 'quiet', or something in between? Does the drawing seem to imitate or reflect a particular trend or style, e.g., cartoonish, child-like, modern, romantic, pop-art, etc.?
14. Text: Has any text been included, for example a title? Where has this been placed? In what way has it been included? What style, font, capitalisation, etc., is used?
15. Distraction/Noise: Do any elements draw your attention away from the main focus? Is there a sense of confusion or clarity in the image?

Any areas of interest or aspects of the image that required clarification generated questions that were asked in the follow-up semi-structured interview with the participant, providing additional insight into their coping experience. Once interviews had been transcribed verbatim and any identifiable data had been anonymised, they were analysed using IPA individually at case level. I coded the linguistic data, and codes were discussed in supervision. The two forms of analysis were then revisited in parallel at case level in order to check for commonalities before themes were generated in cross-case analysis. The findings of those analyses are integrated into my commentary in my presentation of themes.

I will now present the art pieces participants created for this study and the results.

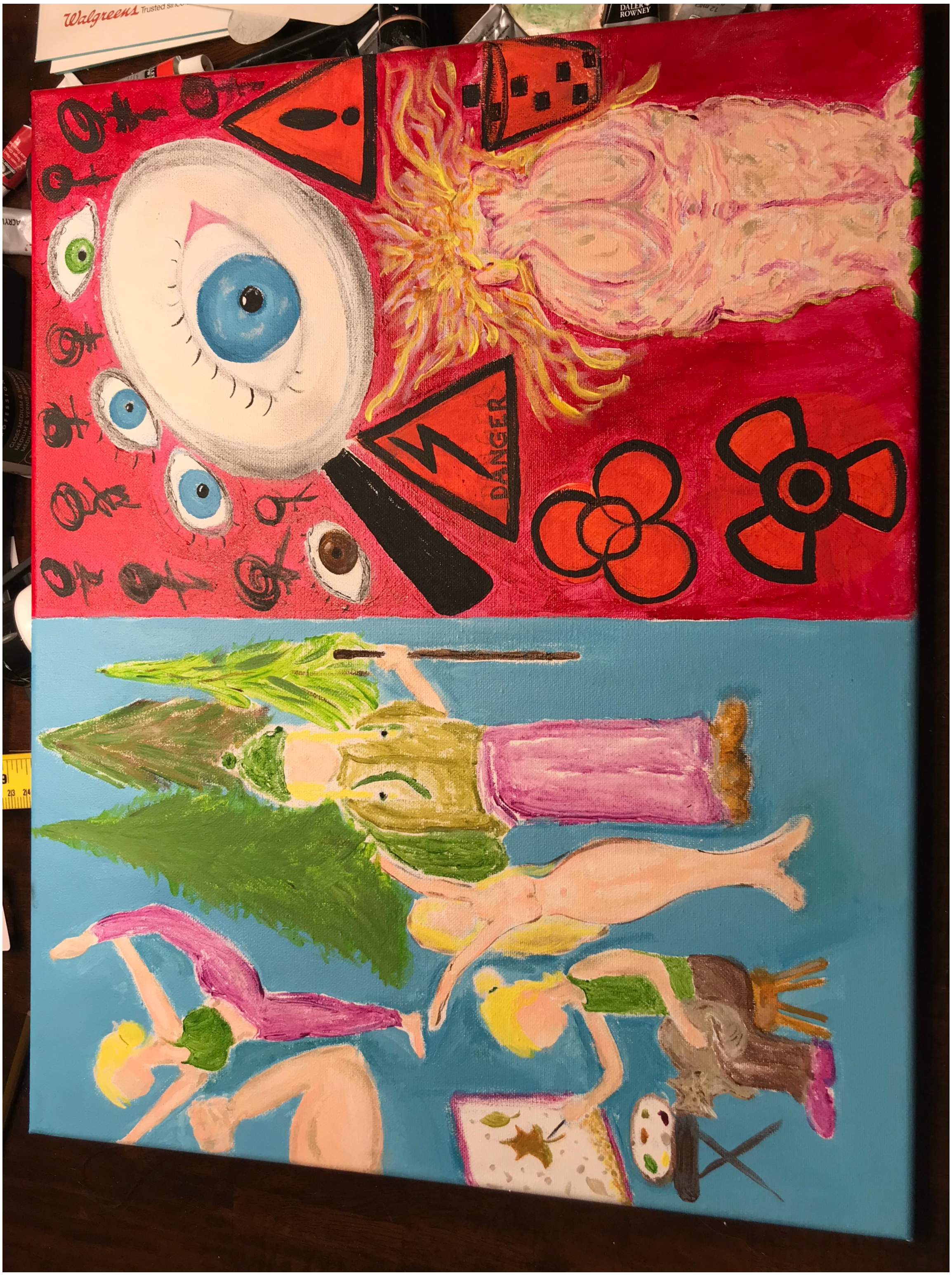


Figure 7.1 Aurora's painting

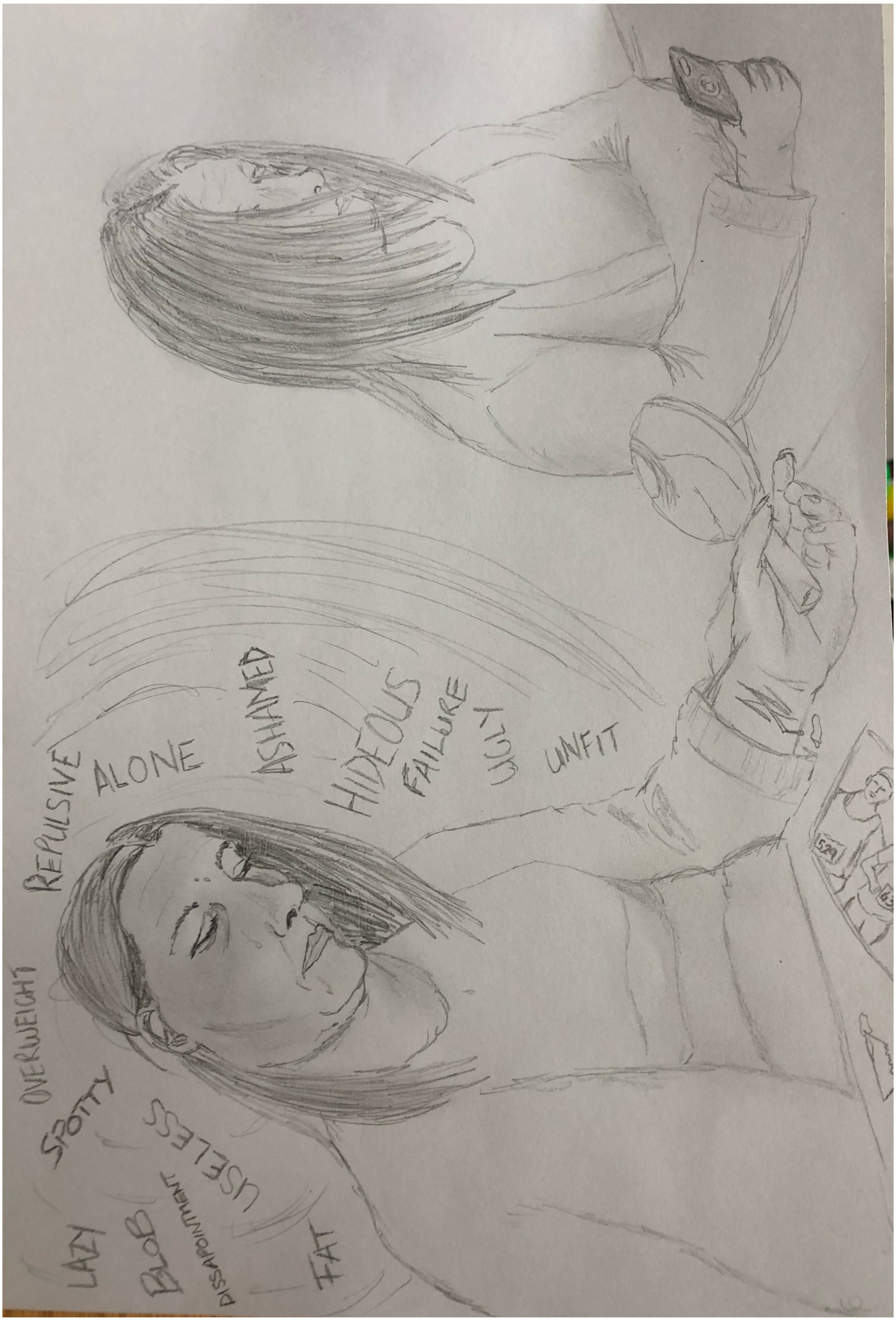


Figure 7.2 Denise's drawing

Figure 7.3 Michelle's drawing

Figure 7.4 Petra's drawing (BDD on a more manageable day)

Figure 7.4.1 Petra's drawing (BDD on a bad day)

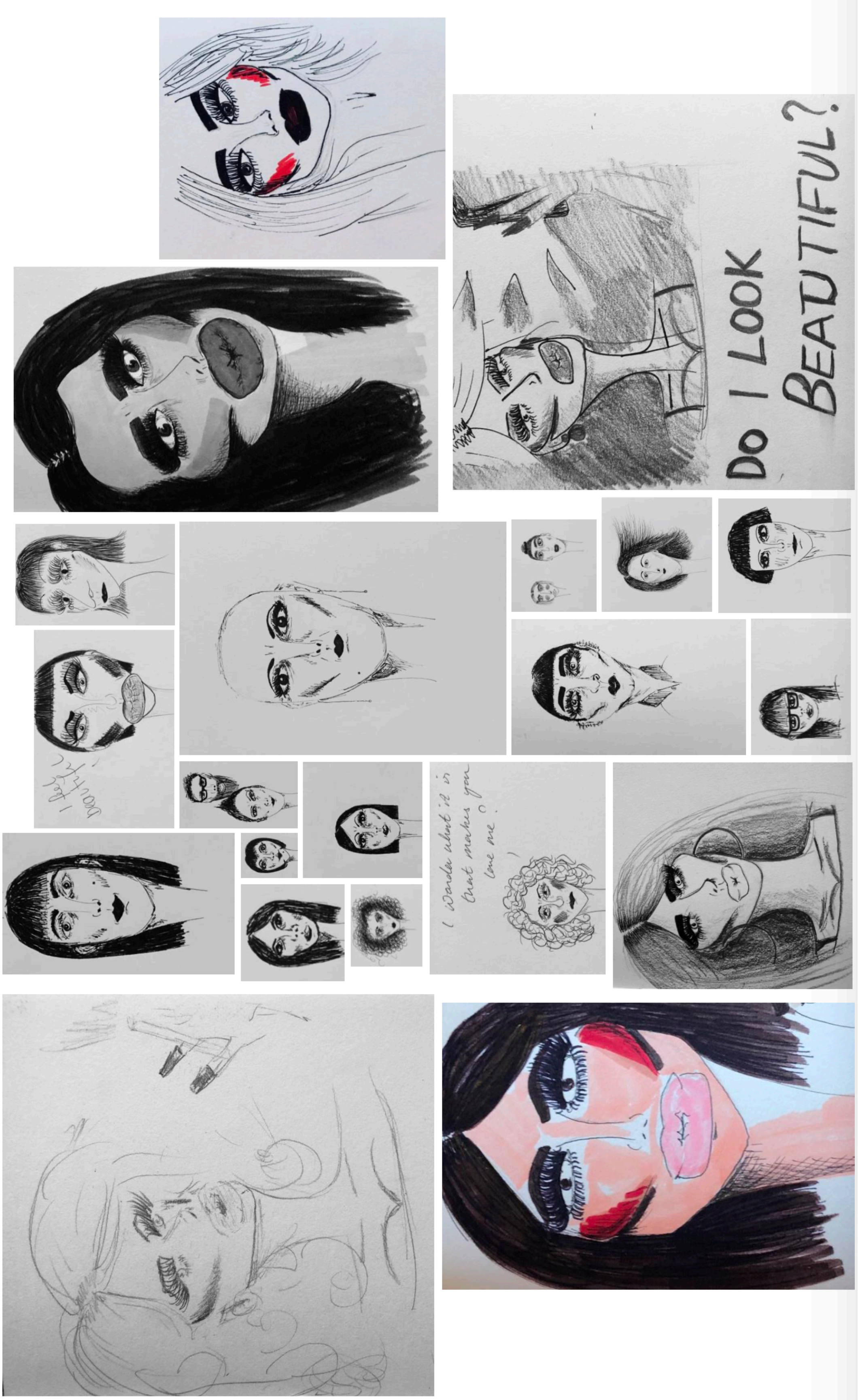


Figure 7.5 Thea's collage of drawings

Figure 7.6 Umbra's mixed media piece entitled 'Agony' (BDD on a bad day)

Figure 7.6.1 Umbra's mixed media piece entitled 'Hope' (BDD on a more manageable day)

7.3 Results

Table 7.7 Table of themes for Study 4

Theme 1 – "I don't really know any other kind of reality": Integration of BDD with lifeworld

- Omnipresence of BDD
  - *Dark undertones (Petra)*
  - *I feel smaller - Fluctuating proximity of the self (Petra)*
  - *Really deeply ingrained in how you feel about yourself (Petra)*
  - *People think it's just vanity but it goes into everything (Denise)*
  - *They see and already know (Aurora)*
  - *My BDD is at its worst when ALL of the distortions present all at once (Aurora)*
  - *I had an excruciatingly painful explosion of emotions… I could feel it in my chest (Umbra)*
- Imprisoned by BDD
  - *Trapped in skin, flesh and human form (Aurora)*
  - *She has no way out of human form and flesh (Aurora)*
  - *Living with BDD is like being awake during a nightmare (Umbra)*

Theme 2 – "She is a monster": Detachment and distancing of perceived self

- Hidden away from the other
  - *I became a bit of a hermit really (Thea)*
  - *She doesn't want to go out for anyone to have to be subjected to her (Aurora)*
  - *I tend to sort of hide away a bit… sit at the edge in a corner (Denise)*
  - *I am ashamed to show my face to almost everyone so I stay inside (Umbra)*
  - *I am a recluse (Umbra)*
- Disgust and rejection of the self
  - *Repulsed by my nature, by my being, by me (Aurora)*
  - *I hate what I see – I don't feel like it's me (Denise)*
  - *I did feel that the character had a degree of distress (Michelle)*
- Harm of the self
  - *I'll do that [cut myself] as a way of coping (Denise)*
  - *Having cancer is more acceptable than getting undressed (Denise)*

Theme 3 – Fragmented self

Viewing alternative versions of the self

you never know which mirrors are the funhouse mirrors and which are not set up to "trick" you (Aurora)
[Layered vectors in drawing] (Petra)
The person I used to be (Thea)
A sense of losing myself (Umbra)

Unable to view body as whole

I feel like I see them on their own (Petra)
I just see the surface – erm and I don't even think about it being me really (Michelle)
It's a bit odd to have a left side that I dislike (Petra)

Theme 4 – 'Being-at-ease': Towards a reconciliation of the self and body

The presence of hope and freedom

Less attention to detail, less attention to subtle nuances are my better days (Aurora)
Semblance of Hope… one can rise above and away from the clutches of BDD (Umbra)
I mirror check frequently throughout the day hoping something, anything has changed (Umbra)

Taking back control

I wanted to do something with my body [getting tattoos] that I had control over (Petra)

Sense of community and belonging

It doesn't mean that's true or that that's what other people see (Petra)
See how other people are managing with it (Denise)

Through my analysis of the artwork and interview data, I developed the following four themes within the study: *"I don't really know any other kind of reality": The integration of BDD with one's lifeworld; "She is a monster": Detachment and distancing of perceived self; Fragmented self; 'Being-at-ease': Towards a reconciliation of the self and body.* The generated themes explored the salience of BDD in one's life and how participants cope with experiencing such complex and volatile aspects of the disorder. In this results section, I present the visual interpretations facilitated by Boden and Eatough's image analysis method along with an Interpretative Phenomenological Analysis of participant interview data. I will begin this analysis by introducing the first theme, *the integration of BDD with one's lifeworld*.

7.4 Theme 1: "I don't really know any other kind of reality": The integration of BDD with one's lifeworld

Participants portrayed through their images, verbal and written accounts a sense of BDD being an inseparable part of their lives, making it extremely difficult to manage. The first theme generated from the data is 'the integration of BDD with one's lifeworld', which was considered a salient element of the numerous challenges in coping with BDD across participants.

7.4.1 Omnipresence of BDD

All participants reported that the effects of their BDD were widespread and deeply rooted within their lives and everyday experiences. This was exemplified in both artwork and commentary. In Petra's drawing (Figure 4.2), we can see a lone figure on an abstract background. The background appears to be quite chaotic, made up of dynamic lines moving in different directions.

Figure 7.4.1.1 Close up of background in Petra's 'bad day' image

The irregularity and harshness of this particular background and the way it seems to surround the figure may visually reflect the overwhelming and enclosing characteristic of BDD that Petra experiences. The colours used are also muted and contribute to the gloomy atmosphere portrayed. The grey aura surrounding the actual figure has a dense quality to it, as though it is mimicking heavy clouds clinging to her. In her interview, Petra expressed that she wanted to convey "dark undertones" in this image and described the way her preoccupations with her appearance can "change the feeling of that day and just be there as kind of an annoying- like erm- like- noise or something in the background". The presence of those fluctuating thoughts she experiences appear to be interwoven throughout the background and underpin the omnipresent nature of her BDD. The thoughts are constant and comparing them to "an annoying noise" suggests that they are inescapable and always present in some form. In some areas of the image, it appears that the background may be permeating or leaking into the central figure.

Figure 7.4.1.2 Close up of lower body in Petra's 'bad day' image

The same linear strokes that make up the background are faintly continuing into the boundaries of the body, suggesting that some aspects of the encapsulating background and body are interchangeable, and that they may have become inseparable. Petra elaborates on her experience of BDD being entrenched within her lifeworld:

> *I would say it's something I think about on a daily basis – and I don't really- that's- yeah – I don't really know anything – I don't really know any other kind of reality in a way… sort of been this way for as long as I can remember* (Petra)

In this excerpt from her interview, Petra reinforces the longevity of her experience of BDD. The preoccupying thoughts regarding her appearance occur every day and have become integrated within her lifeworld. It is hard for her to imagine a life without BDD being present as its symptoms could be considered habitual to her and therefore contribute towards her embodiment of the disorder. It is also interesting to note that Petra puts focus on historical concerns in her image in order to tell a story. She uses the same erratic pencil strokes in the area where her genitalia would be in order to represent the distortion and negativity she previously experienced when viewing it in the past.

> *one thing I thought about when I was drawing it was that in a way it's kind of a- it's not just my – like body issues here and now – but it's also – like – the whole history of it…*
>
> *that's* [concerns about the appearance of her genitalia] *like something that I bring with me today – and I wanted that history to be a part of it… even though I don't struggle as much with it now as I used to – it's still something that I carry – it's kind of a- I guess like a sort of wound* (Petra)

The image she created is a representation of her past and current experiences of living with BDD. By choosing to include past concerns, she illustrates that the site of her BDD related preoccupations may change, but they are always present. She uses the phrases "bring with me today" and "something that I carry", suggesting that the concerns could bear weight upon her and place emphasis on the permanency of her appearance related thoughts. Comparing those concerns to a "wound" conveys the pain she associates with them and illustrates how deeply they penetrate along with their inability to heal.

Denise also represents the omnipresence of BDD through the background of her image (Figure 2). Surrounding the figure on the left are numerous words that she attributes to her appearance and self. Despite the words being strongly meaning laden in their own right, the way she has positioned them around her head and upper body is also significant. As Denise explains:

> *they're just all the words I think to myself when I look in the mirror… or I tell myself all the time throughout the day* (Denise)

She provides a snapshot of some of the intrusive thoughts that she experiences regularly on days that are difficult for her to manage.

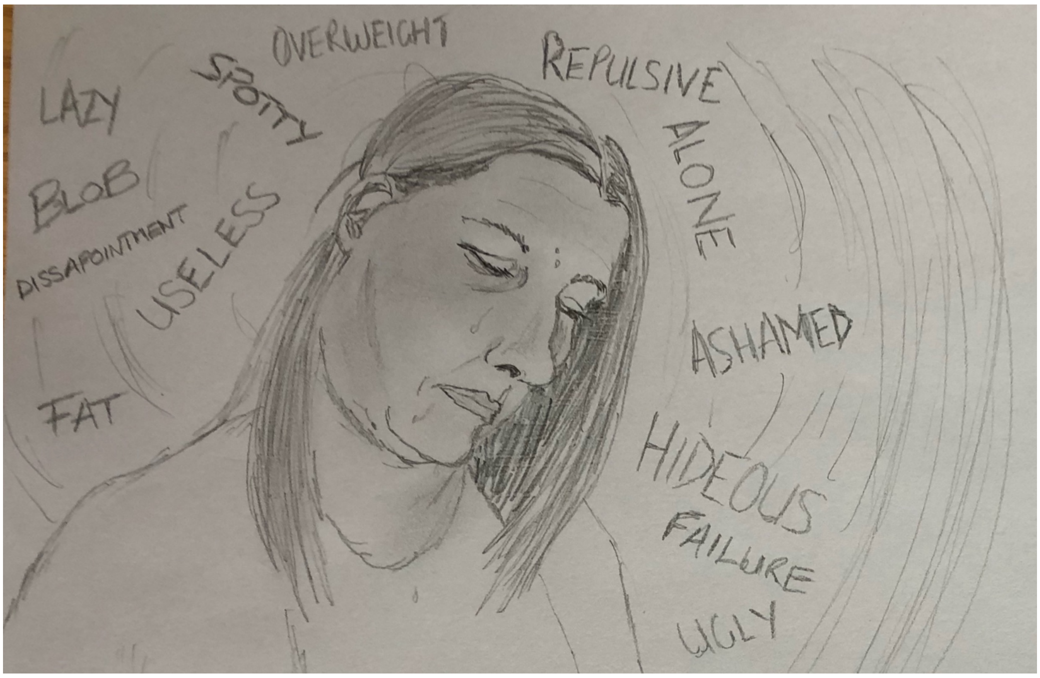


Figure 7.2.1 Close up of words surrounding Denise

The grey aura around the figure is reminiscent of the harsh lines Petra used to construct the background in her image. Combined with the grey colour palette used throughout the drawing, this section of the image feels suffocating. The lines seem to signify movement, as if they were a spiral, facilitating a sense of rotation around otherwise static, suspended words. Due to the cyclical form of the lines and words, they seem to close in around Denise and her posture looks like it could be weighed down by the words. They have a scratchy and jagged quality, possibly conveying how menacing and tormenting they are to her. She states that she tells herself the thoughts “all the time throughout the day”, which signifies that their repetition has become routine and an integral part of her life.

> *it just takes over everything… everything that you do... people just think it’s vanity and (pause) like it’s just the way you look – what difference does it make? – but it- it just goes into everything* (Denise)

Her use of the phrase “takes over everything” provides us insight into how dominant the effects of BDD are throughout multiple aspects of her life and how overpowering it is for her. She contrasts this discussion of its severity with her view that others see the disorder as a trivial matter, which may make it more difficult for her to cope with its symptoms as they are often normalised or invalidated by those who do not have knowledge of what the experience feels like. Explaining that "it [BDD] just goes into everything" suggests that her life could be viewed as a permeable container being filled with BDD and the deprecating words she associates with herself as a result of it. Experiencing a feeling of containment demonstrates how far BDD tethers itself into the lives of those who live with it and can make it extremely difficult to cope with. A number of participants reported feeling imprisoned by the condition, further emphasising its fusion with and impingement upon the lifeworld.

7.4.2 Imprisoned by BDD

Imprisonment was a recurrent theme in participant artwork and narratives. In Umbra's interview, she emphasised the feeling of restriction BDD brings and what this means for her experience of coping.

> *Living with BDD is like being awake during a nightmare. I am ashamed to show my face to almost everyone so I stay inside. I feel hopeless!! I am afraid. I feel trapped. I feel I have no control over my life. I mirror check frequently throughout the day hoping something, anything has changed. I have pushed most of my friends away and spend minimal time with my siblings. I am a recluse but I keep thinking this might be over one day.* (Umbra)

Comparing living with BDD to "being awake during a nightmare" may suggest that the experience is similar to that of sleep paralysis. Umbra evokes images of feeling locked in and unable to break free from the fear she feels. The shame she exhibits towards her appearance contributes heavily to this fear and results in her staying inside, confining herself indoors away from others. Using the words "hopeless", "afraid", and "trapped" highlight a heightened sense of fear and restraint that BDD creates in Umbra's life. It is possible that she may also experience a feeling of imprisonment with regards to mirrors. She describes checking her appearance in them frequently out of desperation to see it change. Her strong desire to notice a change in the way she looks could therefore suggest she hopes to break out of a distorted realm inside the mirror as a result of her BDD. Due to BDD, Umbra lives mostly in isolation, limiting contact with members of her family and friends, and this method of distancing oneself was identified as another way of coping with the disorder.

7.5 Theme 2: “She is a monster”: Detachment and distancing of perceived self

In the previous theme, concerns about being surrounded by BDD and having lifeworlds being taken over by BDD emphasise how the disorder became all-consuming within a person’s life. As a result of this, a number of participants reported feeling detached (or wanting to detach themselves) from their surroundings, from other people and from their perceived selves. The second superordinate theme was generated to represent this sense of disconnection between ‘real’ and perceived self that was apparent across artwork and interviews. This had a profound effect on participants’ wellbeing and amplified the challenges people living with BDD face when trying to manage the disorder.

7.5.1 Hidden away from the other

Some participants reported that isolation was a method they used in order to help them cope with living with BDD.

Through Aurora’s vivid imagery, she portrayed her sense of shame and disgust and how it manifests, forcing her to hide away. She uses isolation as a precautionary measure to both protect herself and to protect other people from being exposed to her. This is clear in her presentation of her perceived self in relation to the eyes above her, which she refers to as “society at large”.

Figure 7.1.1 Close up of the 'monster' and magnified eye in Aurora's 'bad day' side

The signs and symbols that are positioned around the "monster" or "the gross being" she perceives herself to be are commonplace in extremely hazardous settings and are reminiscent of radioactivity. They are arranged in such a way that it appears the monster is being confined and separated off from the world, with the warnings operating as a protective barrier between herself and the general viewing public – the other. The monster is shielding her face with her hands, which could be to obscure it from view or to stop herself from witnessing being subjected to the gaze of the other. As Aurora explains in her interview:

> *She is a monster. She is repulsive. Bloated and flabby. Exposed. Vulnerable. No one wants to be near her because of her disgusting nature. She is flab and flaw and odor and imperfection and dirty and trash. She is ashamed of being. She is ashamed of being seen. She is ashamed of having to subject anyone or anything to her presence. She, too, is disgusted. But she has no way out of human form and flesh. She is uncomfortable (understatement). She is hiding. She wants to disappear. She wants to isolate completely. She wants to disengage. She doesn't want to go out for anyone to have to be subjected to her. She knows everyone sees how disgusting and ugly she is.* (Aurora)

Aurora refers to herself using the third person pronoun 'she' and metaphorically as a 'monster'. By referring to herself as a separate entity that embodies her experience of BDD, she creates a distance between her actual and perceived selves, which may aid her in her coping. In conjunction with the inclusion and posture of the monster in the painting, the evocative words Aurora uses to describe herself ("repulsive", "bloated", "flabby", "disgusting") emphasise the great sense of shame and self-loathing she feels when she thinks about her appearance. The distortions she experiences are so strong that she feels other people would view her in the same way and be equally disgusted by the way she looks. Feeling responsible for another person's disgust would likely contribute to her build-up of shame and feeling the need to remove herself from sight: "She is ashamed of being seen… She doesn't want to go out for anyone to have to be subjected to her". By using the phrase "have to be subjected to her", she further emphasises her view of herself as a hazard or a danger to others around her and her need to protect them from the horror of herself.

The sense of wanting to be away from view was also described by Thea. In her interview, she discussed staying indoors during the summer due to concerns about her appearance:

> *erm I didn't like going outside – I just sort of became a bit of a hermit really – just erm facing people and- I dunno – worrying about getting hot and sweaty – and my makeup going down my face – and just generally being a bit- I dunno – unpresentable… just not really wanting to face people* (Thea)

Thea described feeling worried about being considered "unpresentable" to other people if she were to go out in public. To minimise experiencing those concerns, she would stay in for long periods: "I just sort of became a bit of a hermit really". The situation she described "worrying about getting hot and sweaty… makeup going down my face" could be especially intimidating to her due to the possibility of being judged by the critical gaze of the other. In her artwork, Thea represented her BDD experience through a series of drawings of other people.

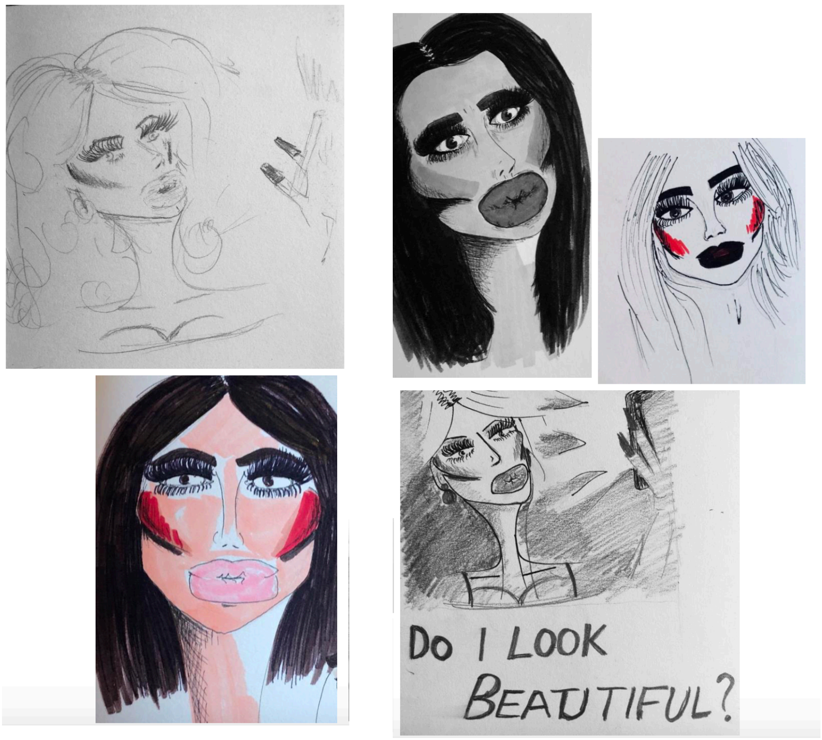


Figure 7.5.1 Close up of Thea's collage

Although Thea actively chose to not include herself in her artwork ("*I think that was my first thought actually overall – like should I do a self portrait? – and I decided against it*"), she conveys a powerful message about modern society and standards of beauty. The outer columns of the triptych are made up of characters with similarly enhanced facial features and they all appear to be wearing the same style of makeup. It is possible that her concerns about not being able to manage the appearance of her makeup in the hot weather may be part of a wider issue surrounding current perceptions of beauty and acceptance of a particular standard of appearance. This may be further supported by recent ethical explorations into the role of beauty standards within society, particularly the "contemporary ideal of beauty" (Widdows, 2020: 19) and how people can be judged against it as a way of measuring "successes or failures according to the extent they conform to it" (Widdows, 2020: 19). This judgement may be cast towards the self as well as others and may reaffirm the insights Thea conveyed through her artwork. In her interview, Thea shared her thoughts behind some of the characters she created for her piece:

> *I wanted someone looking- taking a selfie… and just being this really erm exaggerated version of- of what beauty is? – erm so she's got quite grotesque lips – erm er the cheekbones are like jutting out and- the kind of- (pause) the typical er version of what people might think of beauty is* (Thea)

By describing the appearance of the heavily made-up characters as a "typical version of what people might think of beauty is" contrasted with the unfavourable descriptor "grotesque", it becomes apparent that although the images could be considered caricatures, she raises an interesting point about the influence of societal beauty standards that may have shaped her perception of the world and her own self. Her inclusion of bold cosmetics on her characters' faces is also revealing, as it may indicate her sense making of presenting a carefully managed version of the self to the world.

7.5.2 Harm of the self

Some participants reported engaging in self-harm as a way of coping with the effects of BDD. Denise visually represented her experience of self-harm through her drawing.

Figure 7.2.2 Close up of Denise holding mirror

In this section of her sketch, Denise depicted a jagged and deep looking cut on her wrist with a razor blade positioned nearby. It is clear that her injury is fresh from the pooling blood on the table. She showed herself holding a mirror and viewing a historic photograph of herself from a time when she considered herself to be fit and healthy, running a marathon. The inclusion of the photograph and hand-held mirror suggests that she may be drawing comparisons between her past self and current self. When asked to elaborate on this aspect of her image, Denise shared:

> *erm that's when I have really low bad days… I'll do that [cut herself] as just a way of (pause) sort of coping with things and punishing myself I suppose – and then once I've done it it's like a- a visual reminder and the- 'cause I can feel it as well – the pain* (Denise)

The hatred Denise feels towards her appearance comes through particularly strongly here, as she describes physically punishing herself for the way she believes she looks. The method of coping she describes provides her temporary catharsis and a lasting visual memory of the pain. It is interesting that she uses the conflicting words "coping" and "punishing" to describe her experience of self-harm and how she uses it to manage her feelings. Michelle also discussed self-harm as a way of coping with her BDD and, like Denise, did not perceive it as a maladaptive experience for her, describing it as soothing.

> *M:* *you know – i-it's like- it's not- it's- I guess- some people see it as similar to self harm but it's not – you know – it's not meant to be self harm because the purpose behind it er ironically is trying to better yourself – it's just going about it in such the wrong way*
>
> *S:* *mm*
>
> *M:* *you know – I think maybe it is a feeling of helplessness – you know – not- not knowing- what else can I do to like soothe this feeling? – erm you know – to make it like okay or tolerate erm having this thing that is- that feels imperfect – just having it there* (Michelle)

Here, Michelle highlights an important point about the perception of violence towards the self, regarding living with BDD. She frames self-harm as an outlet, or a channel, for making sense of feelings that are very complex and difficult to manage despite it being destructive. She explains that some actions, for example picking her skin, are implemented in order to improve her appearance and the resulting damage is a secondary factor. The words “helplessness” and “imperfect” illustrate the absolute desperation that drives her to engage in behaviours that are maladaptive. This sense of indirect or unintentional harm was present in several participants’ accounts, and was powerfully illuminated by Denise:

> *it’s just- like the impact on like- I don’t go to the doctors and stuff like if- if I needed a- like smear tests and things I don’t- I won’t go for those ‘cause it means getting undressed… I think what my parents worry about – they know that I don’t go for these things and they worry that I would cover it up and hide it… and that’s when it- it gets- something that people think is just like a little vanity thing ends up life threatening… and they- they don’t understand how- how I could be so concerned about taking some clothes off if I might have cancer – but to me having cancer is more acceptable than getting undressed – and nobody understands that – they think I’m mad* (Denise)

In her interview, Denise wanted to highlight how debilitating BDD is to her physical health in order to help others who may not have experience of the condition understand its effects more fully. She discussed avoiding potentially lifesaving health checks such as cervical screenings due to the requirement of exposing her body and feeling uncomfortable in doing so. Additionally, she may feel responsible for the concern her parents feel about her avoidance of health checks, which could contribute to a sense of guilt or added pressure. She drew on her own experience of people’s misconceptions of BDD – “something that people think is just like a little vanity thing ends up life threatening” – to stress that people with little knowledge of BDD may underestimate the gravity of the condition. By saying this, she also reveals that she is aware of the potential (yet unintentional) harm BDD may have on her physical health. The phrase “having cancer is more acceptable than getting undressed” reveals the potency of BDD and puts into perspective how detrimental its symptoms are for her. In other words, possible death is more favourable than having aspects of her body viewed by another person for Denise. This demonstrates how Denise’s damaged relationship with her self could be life threatening if left unaddressed, and how it has a severe impact on her ability to cope with everyday experiences. The extent of the damaged self is explored in greater depth in the next theme.

7.6 Theme 3: Fragmented self

Central to BDD in these participants' experience is having a broken or fragmented perception of the self. This trope was highly visible in participants' artwork and was referenced in the majority of verbal accounts. One salient phenomenon portrayed in the work was viewing alternative versions of the self, which participants considered a disorientating and disturbing aspect of living with BDD.

7.6.1 Viewing alternative versions of the self

In Aurora's painting, she depicted two distinct versions of her physical self.

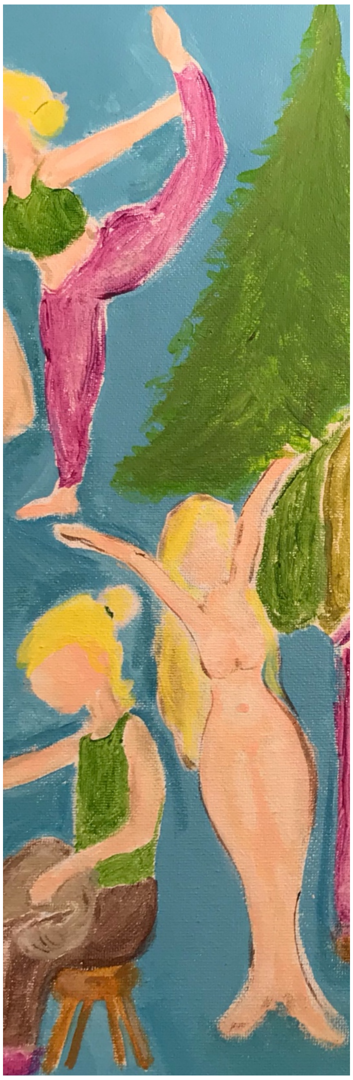


Figure 7.1.2 Close up of figures in Aurora's 'manageable day' side

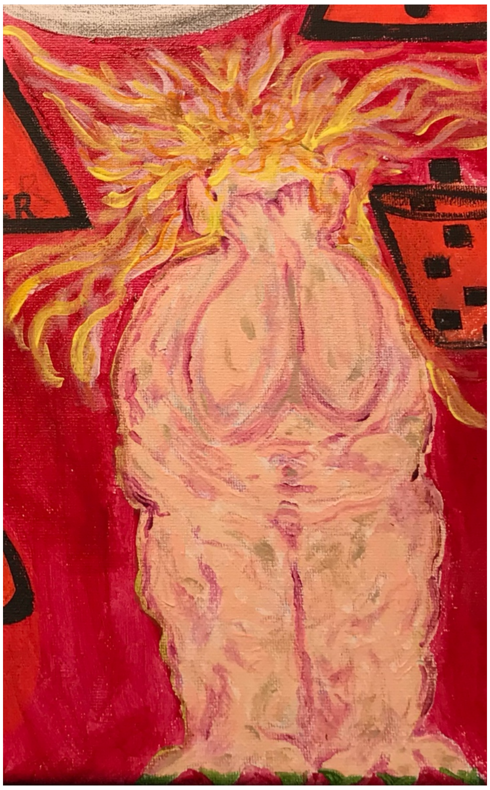


Figure 7.1.3 Close up of 'monster' figure in Aurora's 'bad day' side

In Figure 7.1.2, she portrays herself as carefree, with a standard, human form. The posture of the figures is open, for example with outstretched arms leaving the body exposed, and she is engaging in nourishing activities such as painting, dance and yoga: activities which help her BDD experience feel more manageable. Contrastingly, the version in Figure 7.1.3 is what she refers to as a 'monster'. Its posture is closed, with distinctive skin texture and clawed feet. This stark disparity between the two depictions of the same person emphasises the extreme and fluctuating nature of the fragmented self in BDD. Aurora explains the experience of being exposed, unpredictably, to multiple versions of her own body:

> *For me it's like constant gas-lighting. It's like being stuck in a fun-house but you never know which mirrors are the funhouse mirrors and which are not set up to "trick" you or distort the image. Everything can be distorted all at once without warning. One morning I can "look" a certain way and within an hour, everything is disproportionate, distorted, and amplified again. It's scary to not know what is real and it is scary to begin believing that what is real is that YOU are WRONG. The flaws that seem so amplified and apparent are what the "reality" is….* (Aurora)

Comparing this phenomenon to "constant gas-lighting" and "being stuck in a fun-house" places emphasis on the consistent level of uncertainty Aurora feels towards her appearance and the permanency of her distressing situation. She treats her own perception with suspicion, and the lack of trust in what she sees may contribute to the sense of fear she experiences. This leads her to doubt the authenticity of her own reality: "It's scary to not know what is real". Another factor that worsens this experience for her is the unpredictability and volume of the distortions presenting themselves to her: "Everything can be distorted all at once without warning". Interestingly, Aurora also presents an alternative view on coping with BDD. She appears to frame BDD as something familiar, almost protective, and explains that part of the fear she feels is due to the realisation that her perceived reality is not real: "it is scary to begin believing that what is real is that YOU are WRONG".

Petra illustrated a similar perspective in her drawing and depicted the uncertainty of her perceived reality using artistic technique.

Figure 7.4.1 Close up of layered vectors on Petra's face in 'more manageable day' drawing

This section from Petra's representation of BDD on a more manageable day shows that despite finding ways to cope with her BDD symptoms, the distortions are still very much present and a permanent element of her lifeworld. The slightly darker and more prominent lines and dots superimposed over her face show the extent of her distortions and also help the viewer to comprehend a concept that may be otherwise considered ambiguous to those without lived experience of BDD.

Like Aurora, she has a high level of insight into the condition and is able to acknowledge that the distortions she experiences are not real, however, it can still be extremely difficult for her to separate distortion from reality and she often focuses on individual elements of her appearance as a result of this.

7.6.2 Being unable to view the body as a whole

Petra talked me through the process of planning her artistic piece and incorporating the atomistic appraisals of her appearance in her artwork, drawing upon aspects of her BDD that make it difficult to cope with:

> *my first image that I had in my head of how I could describe it was kind of- or not describe it maybe – but erm illustrate it – erm was to kind of- I don't know – to- to pick apart these kind*

> *of details in my appearance that I get stuck on – because I feel like I see them on their own – I'm not really able to- kind of – er look at my body in a – kind of – integrated way or something* (Petra)

She discussed having an original starting point for her piece which involved showing the viewer how she sees herself as individual components. Getting "stuck" on those components further emphasises the control BDD has over her and how difficult it can be for her to override the fixations. Her preoccupations with the individual aspects of her appearance lead her to view her body as a collection of individual parts rather than as a whole: "I'm not really able to… look at my body in a – kind of – integrated way or something". This experience was similarly reported by Michelle, who explained what she sees as she focuses on specific details of her face in an attempt to make sense of the whole.

> *if I am focused on my pores and any imperfection I can find – even if it's not even there – then I don't even really see my face – I just see the surface – erm and I don't even think about it being me really – erm however if I back away and I take a minute to look at my face I think I have a fine face – you know – I'm not- I'm not- I don't look at myself and think that I'm not a good looking person – it's a very strange thing – you know – it's like I just wanna get in close and find out what's wrong – erm even if it's not even there* (Michelle)

Michelle experiences times when she is heavily preoccupied with perceived flaws on her skin. The preoccupations make it extremely difficult for her to view herself in a unified way. When she is drawn into assessing those preoccupations, evaluating her skin as being part of her body becomes problematic: "I don't even think about it being me really". The dissociation between her skin and body suggests that BDD can profoundly damage the cohesive relationship between the corporeal body and one's association with it.

7.7 Theme 4: 'Being-at-ease': Towards a reconciliation of the self and body

Despite the majority of participants reporting feeling a strong disparity between different aspects of the self and this causing much distress, they were able to identify some strategies that helped them cope with their experiences and move towards a reconciliation of their selves and bodies. One key element participants used to aid this process was the presence of hope and freedom.

7.7.1 The presence of hope and freedom

The presence and role of hope and freedom shone some light onto another aspect of coping with BDD. The images below are sections from Umbra's artwork. Figure 7.6 represents the physical pain and anguish Umbra feels when she is struggling with her BDD. Her fist is closed and clenched tightly to her chest, and we can sense the level of distress portrayed through her work among other powerful emotions:

> *hurt, fear, pain, a sense of losing myself and how, when I had an excruciatingly painful explosion of emotions come over me I could feel it in my chest. That is why my hand is pressed hard against my chest. It was to contain it but also, in hope of making it go away.* (Umbra)

Her description of her inclusion of the clenched fist in the image also suggests that it may be a way to soothe the "explosion of emotions" she experienced relating to her BDD, and an attempt to diminish the pain of the emotions that reverberated through her chest. Contrastingly, in her piece representing a more manageable day with BDD (Figure 7.6.1), the position of her hand is far more relaxed and open as she looks into the distance. This is the piece that represents hope for Umbra, and she explains why hope is such an important aspect of coping with BDD for her.

Figure 7.6.1.1 Close up of clenched fist in Aurora's 'bad day' image

Figure 7.6.1.2 Close up of open palm in Aurora's 'more manageable day' image

> *After creating 23 emotional portraits I decided, even though there is no cure for BDD, that there should be some semblance of Hope at the end of this creative journey to show people that one can rise above and away from the clutches of BDD. Even if you have periods where the illness controls your life, there may also be periods where you feel less weighted down and one can always Hope for times of remission.* (Umbra)

It is significant that despite suggesting BDD is incurable, Umbra is still able to convey a strong sense of positivity for others who may be finding it difficult to manage their BDD, which suggests having continued hope is an important factor in coping with BDD. The "semblance of Hope" she presents shows there are times when she feels more optimistic about her future. She uses powerful imagery to symbolise the freedom that can be opened up when looking forward to periods of solace from the disorder, and this may bring respite for others living through the ordeal of BDD. This imagery includes figurative language such as rising "above and away from the clutches of BDD", and this could be further illustrated by the sections of artwork mentioned above. A possible interpretation of the piece could be that the forceful hold BDD has over her is represented by her clenched fist in Figure 7.6.1.1. A clenched fist can be symbolic of violence, anguish, and frustration and may offer insight into the embodiment of the disorder – BDD is clutching at her body and she is using hope to free herself.

The importance of freedom as a way of coping with BDD is additionally represented in Aurora's artwork.

Figure 7.1.4 Blue sky, trees and hiking depicted in Aurora's painting

Figure 7.1.5 Magnifying glass and eyes depicted in Aurora's painting

In Figures 7.1.4 and 7.1.5, Aurora uses colour to illustrate the stark contrast in her sense of freedom on more manageable days and on difficult days. She depicts feeling free on more manageable days, using the colour blue to represent clear skies and peaceful, open space. Days on which she struggles are symbolised by the bright red background, connoting danger and fear. When asked whether the colours she used held any significance to her, Aurora responded:

> *On a FEELING and emotional experience level, yes. Blue like the wide open sky… that's why I chose it as the ENTIRE background for the better-days-side. Wide open, clear, smog-free sky -- not suffocating on expectations, not choking on demands of society, not hindered by walls or concrete or cages I've been kept in (by me or by society-at-large, metaphorically) -- breath, freedom, space, freedom to TAKE UP and encounter space, freedom to FEEL, freedom to BE, existing as just another beautiful and intricately designed piece of nature, just another leaf or drop of water or cloud or seagull…. open and free. Belonging. Connected…*
>
> *RED - the pain, the shame, the WARNING SIGN that surrounds my being, the danger, the feeling of not being safe in my skin, the color of what happens when BDD gets out of control and self-injury occurs* (Aurora)

Aurora draws on more powerful and vivid imagery in her narrative and further highlights the contrast between different ways of being with BDD. She describes the significance of her being-at-ease in the world with helping her cope with BDD's symptoms and achieves this by fusing her own horizon with the horizon of nature to feel part of a unified whole. In Figure 7.1.5, where there is no presence of hope or freedom, we can see the overpowering omnipresence of the other (pressure and fear instilled by "society-at-large"), and devastating sense of danger and loss of control; the latter being another important factor in the experience of coping with BDD.

7.7.2 Taking back control

Due to participants feeling a loss of control as a result of living with BDD, they had a strong desire to overcome the disorder and take back ownership and control over their bodies after experiencing its symptoms for so long. Petra previously represented feeling overwhelmed and suffocated by her BDD in her artwork and interview, and later revealed that creatively modifying aspects of her corporeal appearance helped her to regain control over her body. She described the process behind her decision to modify her body with a tattoo.

Figure 7.4.2 Close up of heart tattoo in Petra's drawing

> *it's- it's become kind of a thing- I guess I wanted to have some- do something with my body that I had control over and that I liked and chose myself – erm so I really love that tattoo* (Petra)

For Petra, living with BDD means that she often feels she has no control over the appearance of her physical body in its natural state. She wanted to have an influence or an input over what her own body should look like to help her feel more positive about it and invoke a sense of ownership. Designing and having a tattoo of her choice on her body helped her to achieve this. In her artwork, she connected her tattoo (Figure 7.4.2), an anatomical heart, to images representing hobbies and interests that help her cope with BDD (Figure 7.4). The yellow lines flowing from the heart tattoo and around her body may symbolise veins supplying life and hope throughout her body, providing the energy to take part in the activities that are important to her.

7.7.3 Sense of community and belonging

Other aspects of some participants' lives that were considered important with regards to the experience of coping with BDD were having a sense of community and belonging. Denise discussed the importance of feeling understood and being accepted by other people, and how this can have a detrimental effect when this experience is not fulfilled.

> *it's hard 'cause I don't think there's- there's not much awareness of it – you know like when people say about having anorexia or bulimia or OCD – people have heard of those things – they know what it is – and they're more understanding of it – but I don't think- well until somebody had mentioned it to me I'd never heard of it… erm but then I read online that only like two percent of the population or something have it – so it's hard to come across somebody else that- that suffers the same* (Denise)

She raised the point that there is a lack of awareness of BDD amongst the general population in comparison to other mental health conditions, which may make it difficult to feel comfortable opening up about its symptoms. Due to the fact a small number of the general population live with BDD, as Denise explained, it is rare to find others who share the same level of understanding through lived experience. This could further contribute towards a sense of loneliness and make it more challenging to cope with individually. Petra shared a differing experience to Denise and explained how having a support network helped her ability to cope with symptoms.

> *at one point in time I was kind of thinking – well now I've got rid of it entirely – and turns out I didn't – erm but it's- it's much better – and I think it has a lot to do with – yeah – being able to talk to people and not being as afraid to be myself with other people… erm that has helped me be able to think that although this is how I perceive myself – erm it doesn't mean that's true – or that that's what other people see* (Petra)

Petra recalled that her BDD symptoms began to ease significantly during a specific period in her life. Upon reflecting on this time, she identified that her symptoms improved when she felt comfortable enough to talk about her experiences with others and she could be her authentic self. Petra seemed to display a degree of acceptance of her distorted view of herself: "that has helped me be able to think that although this is how I perceive myself – erm it doesn't mean that's true". She differentiates between her perceived and authentic selves with the help and support of her social group.

7.8 Discussion

This study presented a wide range of experiences representing different levels of coping with BDD. As qualitative research on the psychological process of coping with BDD has not yet been published, it is important to review relevant coping theories that are available and consider how they may be helpful in informing our understanding of the experience or highlight gaps in their suitability in furthering our understanding the experience. An important step towards making sense of these experiences would be to first of all consider what coping means. Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984: 141). A psychological coping theory I will consider in relation to the data and my analyses is the transactional model of stress and coping (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) proposed that there are two types of coping responses: emotion-focused and problem-focused. They also note that as a person is coping, they are experiencing a 'shifting process' where they might alternate between relying on defensive strategies or problem-solving strategies (Lazarus & Folkman, 1984) depending on the environment they are in. In this theory, they suggest that the coping strategies people employ *directly* address the stressor (problem-focused coping) or "regulate emotions arising as a consequence of the stressful encounter (emotion-focused coping)" (Biggs, Brough, & Drummond, 2017: 353). Lazarus and Folkman's (1984) theory suggests that the problems an individual may face could be considered as a separate entity to them, whereas in the case of BDD and from the data presented in this study, the problem (BDD) seems to be internally intertwined or fused within the individual, severely affecting their self-perception and overall relationship with the self and world. The integration of BDD with an individual's world and the strategies people employ to manage this ongoing experience could therefore be thought of as coping with a *way of being* rather than coping with distinctly internal or external stressors or stimuli. As evidenced by themes developed from empirical data in this thesis such as 'Ingrained triggers' (page 103), 'Omnipresence of BDD' (page 159), and 'Imprisoned by BDD' (page 164), it is clear that some people with BDD may view the disorder as inseparable from their very being and find it difficult to locate specific stressors. As Angelina explained in Chapter 5, "*…for the most part the thoughts ARE the triggers and they truly never stop"* (page 102). Therefore, it is important to acknowledge the complexity of coping with and managing BDD, and alternative theories relating to coping may be more applicable. For example, theories that take threatened identities into account may help to better contextualise some participants' experiences. Breakwell (2015) suggests there are several ways in which people may cope with the experience of threatened identities. One example of a person experiencing a threat to their identity could involve sensing a conflict between 'real selves and unreal selves' (Breakwell, 2015: 87), which is highly applicable to BDD. Breakwell drew upon the work of Turner (1978) and Turner and Schutte (1981) who suggest that an individual's self-image may change when under threat depending on the social situation they are in, and that a coping strategy they might employ to manage this could be to reject the 'real self'. The visual data presented in this study highlighted a discrepancy between participants' objective ('real') and perceived selves. For example, Aurora depicted herself as a 'monster' in her painting (Figure 7.1, page 149) and this was juxtaposed with a series of images of Aurora represented in human form. Aurora referred to the monster in third person (e.g. "She is flab and flaw…"; page 167), thus distancing herself from her 'real' self to make sense of her experiences, and other participants also chose to represent themselves visually in ways that did not match their 'real' selves despite having a high level of insight regarding their BDD. While it is useful to consider the experience of coping with BDD alongside coping theories, such theories do not necessarily accommodate thorough consideration of the multifaceted and ambiguous nature of BDD. Therefore, it is necessary to further explore participants' experiences phenomenologically in order to understand what coping with BDD means for them.

Although my initial aim was to understand what people's images told us about their experience of coping with BDD and how combining image making with interviews helped people to express their experience, these images and accounts garnered more of an in-depth ontological exploration of BDD; what it means to live with, and to *be* with BDD. The richness of the artwork and accompanying commentaries participants provided showed how the experience of living with BDD can oscillate from one extreme to the other. The inclusion of the creative elements as part of the data brought amazing creativity and offered insights far in excess of expectations. It brought to life, exposed, and made clear people's experiences of being with BDD, opened up discussions and enabled participants to reflect upon the decisions they made in their work which illustrated their meaning making process. Through using Boden and Eatough's Framework for the Analysis of Drawings and IPA in combination, I was able to draw upon salient aspects of participants' lifeworlds and showcase the intricate layers that make up the many different facets of accommodating this disorientating condition, shining light on areas of meaningful experience that language alone may not have granted access to. Participants produced vivid imagery in the form of sketches, paintings and mixed-media pieces to creatively explore their own coping processes. The artwork and subsequent interviews generated the themes *Integration of BDD with Lifeworld; Detachment and distancing of perceived self; Fragmented self; Towards a reconciliation of the self and body.* I will discuss each of the main themes both in relation to pre-existing literature and through a phenomenological lens.

The majority of participants in this study framed BDD as an omnipresent entity that has shaped their lives, surrounding them and impeding their everyday actions. A study by Brohede et al. (2016) identified that a salient aspect of living with BDD was 'becoming the disorder', as informed by the verbal accounts of participants. This theme incorporated widespread issues in the daily functioning of participants such as experiencing frequent emotional distress, self-hate, "crying for hours, being sad every day, and feeling grief for having destroyed themselves" (Brohede et al., 2016: 194). These highly emotional experiences further demonstrate how people living with BDD often embody the disorder and observe the process of it becoming fused with their everyday life experiences. Looking at this idea of omnipotence through a phenomenological lens, it becomes apparent that, for some, BDD could be considered a constant background phenomenon that those living with it are continually aware of. There is an ongoing tension between the 'actual' self and perceived self distorted by BDD, creating a very complex and disquieting atmosphere and discord between self-other awareness. For some participants, this tension can be felt between multiple versions of the self and the world as demonstrated in their artwork and accounts. Trigg (2020) argues that atmosphere is important to consider when taking into account shared emotion, and it is possible that the shared emotion he describes could be used to understand the fusion of BDD with the lifeworld. He states:

> atmosphere can play a critical role in generating shared emotion thanks to its structure as a phenomenon that is both diffused in the air and grasped under the skin. (Trigg, 2020: 4)

With regards to the way BDD immerses the individual, it could be viewed as a phenomenon that infiltrates the lifeworld and permeates the skin, the barrier between the self and the world.

For other participants, their ability to cope with BDD was framed as a social issue as well as an individual issue. The physical and psychological detachment and distancing of the perceived self was a concept that participants represented visually and discussed frequently in their accounts and was often linked to their experience of other people. An example of this concept came through particularly strongly in Aurora's painting and interview data. The hazardous signs and symbols she included in her painting, along with the positioning of herself as a monster, illustrate her desire to both protect the other and also protect *herself* from the other. In previous research on the relationship between BDD and mirror gazing (Silver & Farrants, 2015), participants described themselves as inanimate creatures and monsters ("I look like a monster I just don't feel sort of human") and, like Aurora, felt that showing themselves to other people would cause them to feel offended and create other negative emotions within them. This might suggest that people with BDD hold themselves accountable for their image and how it may negatively impact the public, further contributing to a sense of guilt and shame.

On a physical level, Aurora described hiding away and corporeally removing herself from the other. In doing this, she shields herself from the gaze of the other *and* simultaneously prevents them from being exposed to the monstrous version of the self she perceives. This protective mechanism that serves two purposes could be interpreted as an example of ‘double bookkeeping’, in which one “may endorse attitudes that conflict with their delusions” (see Bortolotti, 2011).

Wrestling with the idea of viewing the true self over the perceived self was a key aspect of coping with BDD. To make sense of this phenomenon, I find it helpful to draw upon the work of Heidegger (1927; 1962) and his concepts of concealment and unconcealment. The data show that there is a ‘BDD self’ – a distorted self that others do not see. This version of the self is only disclosed or unconcealed to the individual with BDD; no one else has access to it. Conversely, we could also say that the physical (arguably, ‘real’) appearance of the individual is not appearing in the same way as others view it. This relationship an individual has with their BDD self is complex, and participants in previous studies reported finding it difficult to convey their experiences (particularly of viewing a distorted version of themselves) to other people who may not be familiar with BDD (Craythorne, 2019). The artwork participants created for this study could be thought of as a bridge between concealment and unconcealment, thus enabling those without lived experience to develop a visual understanding of what it is like to cope with the disorder and opening up a ‘discursive space’ (Hodgetts, Chamberlain, & Radley, 2007) for exploration via dialogue. A participant who illustrated the idea of concealment and unconcealment particularly clearly was Petra (Figure 8.4), with her use of layered vectors to show how the ‘real’ and perceived versions of herself differ.

Conflicting ideas that serve a protective purpose are also presented through her statement “It’s scary to not know what is real and it is scary to begin believing that what is real is that YOU are WRONG”. To elaborate on this idea further, I find it helpful to draw upon the psychological concept of the ‘doxastic shear pin’ (McKay & Dennett, 2009; Fineberg & Corlett, 2016) with regards to considering delusional beliefs. The doxastic shear pin is a metaphor that represents a misbelief that is designed to protect an individual (McKay & Dennett, 2009). It is based upon a shear pin mechanism, which is intended to protect and prevent the breakdown of machinery by destructing itself instead. Aurora points out that she fears acknowledging that her perceived reality may be wrong, and it is this uncertainty that causes her significant distress, therefore she destroys herself rather than destroying the other people around her.

Being unable to view the body as a whole, integrated system was another difficulty raised by participants with regards to their experience of coping with BDD. Thinking about this phenomenologically, Merleau-Ponty put forward the idea that we experience the world through the vehicle that is the body. Participant data suggests that people with BDD acknowledge all elements of the vehicle (the body) are there, but they are not working together harmoniously as they should from the perspective of the individual. This was demonstrated by Michelle, who described only focusing on the surface of her skin during the examination of her reflection, rather than her whole face. Studies have found that people with BDD often view themselves as an aesthetic object, or an object of examination or appraisal (Silver & Farrants, 2015; Veale & Riley, 2001). Taking into account participant data from this study, it is possible that this close and individualistic viewing of particular bodily features could be viewed as an introspection or reduction of the existence of one's body – reducing the body to its constituent components. The way Petra described changing an element of her appearance to assert a sense of control over the way her body appears is reminiscent of viewing the body as a 'project' (Nettleton & Watson, 1998). Shilling (1993) states that it could be possible to view the body as an "unfinished biological and social phenomenon, which is transformed, within limits, as a result of its participation in society" (Shilling, 1993, cited in Nettleton & Watson, 1998: 7). In Petra's drawing, she places emphasis on the connection between her tattoo and her lifeworld, suggesting that the adaptation of her appearance is strongly linked to her experiences and 'being-at-ease' with BDD. She acknowledges that being-at-ease is subjective and, interestingly, for some participants in this study, this state of comfort and happiness was felt when they were in nature and this made them feel more able to view themselves in a more cohesive and naturalistic way, aiding them in their coping.

As coping with BDD is a highly personal and individual experience (making it difficult for some to express and open up about their concerns), encouraging the creation of artwork meant the participants were about to have control over what aspects of their coping experience I was able to explore. This also meant the subsequent interview was shaped by what they chose to visually disclose, also adding to the sense of control and enabling them to feel more at ease during the discussion. Visual methods have been utilised in a range of studies to aid participant-led data collection in exploring highly personal and sensitive experiences such as altered appearance during chemotherapy (Harcourt & Frith, 2008) and hospital recovery (Radley & Taylor, 2003). Personal and complex bodily experiences such as those experienced by people living with BDD can be too abstract to put language to, and in this instance, the body is likely to have experienced phenomena that are ‘more than words can say’ (Levin, 1997; Todres, 2007). Attempting to put language to a bodily experience may change the meaning of that bodily experience (Todres, 2007), and in the case of exploring a multifaceted phenomenon like BDD, it is essential to capture the authentic meaning of that experience to understand what it is like to live with it.

7.9 Summary

This study explored the individual experiences of coping with six participants living with BDD using a multimodal hermeneutic-phenomenological approach. I identified ways that artwork can be used to transcend language and convey meaning that might not otherwise be captured by traditional methodologies for qualitative data collection. I believe that using creative approaches to data collection can facilitate gaining a deeper and more vivid understanding of the complex and subtle phenomena that living with and coping with BDD entails. The images participants created demonstrated how harrowing BDD can be, and suggest that there are many layers of exploration to consider when addressing an individual’s concerns regarding BDD.

Images can be interpreted differently by each individual that views them, and incorporating an interview element into the study meant participants had the opportunity to talk through their meaning-making process and offer even more individualistic insight into their lifeworlds by delving into the image more deeply together with me as a researcher.

Chapter 8: Discussion

8.1 Introduction

One of the primary research aims of this thesis was to explore and make sense of the subjective, embodied experiences of people living with Body Dysmorphic Disorder. As mentioned in the introductory chapter, this aim developed from my own lived experience and previous lack of understanding of the disorder. An intended outcome is to increase both professional and public knowledge of BDD to help others' experiences of discussing their concerns and seeking appropriate help. In addition, there is currently a notable gap in the documentation of individual experiences of the disorder, leading to misunderstandings, misdiagnoses and stigma towards people living with BDD. Not only has this thesis provided novel empirical research, but it has done so in a pluralist way using multimodal creative methods which have enabled participants to more deeply express the meanings of their experiences of living with BDD and fill that gap with their much needed voices.

In this discussion chapter, I will reflect upon the research presented in this thesis, taking into consideration successes and limitations, and whether it helped to answer the research questions initially stated in Chapter two. I will also reflect on the quality and validity of the research and make recommendations for future research based upon further questions raised by this programme of work.

8.2 Study 1 Summary – An autoethnography of the experience of living with Body Dysmorphic Disorder

The first study presented in this thesis explored my personal experience of living with BDD in the form of an autoethnographic piece combined with IPA and reflexive elements. It addressed the following research questions:

- To what extent does autoethnographic work contribute to the exploration of Body Dysmorphic Disorder (BDD)?

- How might my own experience of BDD provide useful ways of looking at my research and analyses?

In this study, I focused on evocative past memories and events that I consider important to my present-day life and how they contribute and continue to weave through its rich tapestry. The study demonstrated how BDD can transcend and traverse time, from its early germination in adolescence through to its gripping and tormenting existence in the present day, years later. Through engaging in autoethnographic work and exposing my vulnerability in this way, I hoped that my account would not only make my position in the research clear as someone living authentically with BDD, but also bring to light the issue of experiencing racial discrimination and prejudice with regards to BDD development, which has barely been addressed in the BDD literature. Reflecting upon my own perceived origins of BDD with this in mind has opened up a new avenue for exploration and, from a personal perspective, was also an extremely helpful outlet for making peace with the past events I experienced by turning those tormenting experiences into something useful to others. In the Heideggerian sense of authenticity, I have questioned myself, I have been displaced by BDD, felt unhomelikeness, and grown through the torment and distress through doing this work. In doing this, I now understand myself better and continue to move towards being with my experiences. Writing autoethnographically about a subject that does not receive enough focus from professionals and the wider public will increase knowledge about what the disorder involves and further general awareness amongst those who are introduced to it. It may also encourage others to share their own narratives around BDD and this could generate a dialogue of story sharing and exchanging of insights, enriching the understanding of the condition and changing people’s attitudes towards it.

Aside from driving my autoethnographic writing, my own experiences of BDD have also provided useful ways of looking at my research and analyses throughout the empirical studies and thesis as a whole. My personal experiences have aided me in building good relationships with participants during the recruitment and interview process by being particularly understanding of sensitive information that people disclosed, and having shared knowledge and a mutual involvement in a lot of concerns they expressed. A particularly notable example of the importance of positive researcher-participant interaction occurred in studies two and three, which I will discuss later on in this chapter.

With regards to the analytical process within the empirical studies, my personal experience has afforded me insight into making sense of some of the extremely complex and often multi-faceted views to which participants have given me access to. By engaging in autoethnographic and reflexive writing throughout all stages of my doctoral research, I was able to strengthen my ability to explore difficult and uncomfortable insights into my own life to then deepen the analyses of participant data, interacting with the analyses in ways that I feel I would not have been equipped with prior to beginning my doctoral research and coming to terms with my connection with BDD. My close affiliation and shared experiences with my participants were made openly available to the reader. This is novel and a strength of my research, and one contribution of my thesis as it demonstrates the benefit and impact of doing autoethnographic work when there is a close connection to the subject of study.

8.3 Study 2 Summary – Exploring the self-identified origins of Body Dysmorphic Disorder

The second study opened up the breadth of the research empirically by gaining the perspectives of 8 participants identifying as living with BDD on the perceived origins of the development or onset of their disorder. The research questions for this study were as follows:

- What do people with BDD believe might have caused or contributed to the onset or development of their BDD?

- How do people with BDD make sense of their self-identified origins of BDD?

Taking a multiperspectival yet idiographic approach to the study demonstrated how each person’s experience of living with BDD was unique to them, but it was also possible to move towards developing a more general consensus with regards to some of the experiences reported. Using the combination of eliciting written narratives prior to conducting semi-structured interviews allowed participants to lead the direction of the discussion and have control over the topics that would be explored in the follow-up interview. Being able to gain deep insight into a small yet diverse sample, as facilitated by IPA and its commitment to the idiographic, meant it was possible to delve into the richness of each participant's lifeworld and better understand what the origins of their BDD meant for them. Participants in this study each detailed distressing memories and events they considered salient to their present life with BDD. This included experiencing bullying and abuse from their peers in their childhood and earlier lives, receiving vast amounts of criticism regarding their appearance, being rejected by others, and the process of becoming aware of their handling of visual concerns worsening and solidifying. There was also an instance of sudden onset, in which a participant (Elliot) was not able to directly attribute his BDD onset to any one or particular set of events. Even though in most cases those events occurred many years prior to their participation in the study, their level of distress was palpable and was communicated via evocative language including the use of powerful metaphors. The suffering participants endured as a result of the events they often think about in present times provided the foundations for the disorder to take hold. This is a common occurrence in people living with BDD, as observed by Osman et al. (2004) who found that 88% of the BDD patients in their study experienced spontaneous images or visual memories associated with stressful events. In nearly all instances, the stressful events were linked to appearance related bullying and teasing, or difficulties with adapting to a change in appearance during adolescence.

Although participants in my study described experiencing difficult and vivid memories, they were able to reflect upon triggers that worsened their BDD symptoms, which could be viewed as a positive display of self-awareness and moving towards a greater understanding of their experience of the disorder.

Considering the potential origins of BDD directly from the perspective of those who live with it meant I was able to obtain an authentic picture of a significant and delicate time in each participant's life and see how such experiences are interconnected. For some, the biographical writing task and semi-structured interview were the first instances they had communicated concerns about their appearance to another person, and sharing this information revealed how difficult it may have been to previously convey the complexities of their experience to others. Something that I found particularly interesting was that discussions with participants about previous experiences often led to discussions around the present. The past was almost experienced as present, which could be explained by a distortion of temporality. As participants discussed their origin stories and past memories of their relationships with their appearance, they described their present-day experiences in more depth and how they interrelate and intertwine with one another, which formed the basis for Study Three.

8.4 Study 3 Summary – Exploring current experiences of living with Body Dysmorphic Disorder

The third empirical study focused on investigating the broader experiences of living with BDD from the perspective of the same participants who took part in Study Two, answering these research questions:

- How do people with BDD use language to communicate and make sense of the embodied qualities of BDD?
- What do the narratives of people with BDD tell us about the support needs of people living with it?

Participants placed emphasis on the embodied qualities of BDD by detailing distressing thoughts of being trapped in a distorted world and feeling they are unable to escape, being imprisoned by the disorder, experiencing immense isolation, and being held captive by the constraints of one's own body. The experiences participants described revealed how tormenting living with the disorder can be and several found it challenging to convey linguistically the true potency of what constitutes living with BDD for them. Some employed the use of metaphor in an attempt to convey abstract thoughts and ideas relating to their BDD experience, for example, comparing living with the disorder to being surrounded by a brick wall with mouths, or being overwhelmed by the pressures of tending to many infants all at once. This imagery was extremely potent and alluded to the enveloping and overwhelming nature of living with such a debilitating condition. The inclusion of such powerful imagery in participant accounts demonstrated the importance of the visual domain in conveying an authentic reflection of symptoms associated with BDD and in cultivating the relatedness of the experience for those who may not otherwise understand their significance. The use of metaphor has been examined in mental health literature previously and it has been suggested that people often use metaphorical language to express abstract phenomena in a more concrete way. Metaphor usage has been explored in the discourse of people living with depression (Charteris-Black, 2012; Levitt, Korman, & Angus, 2000; McMullen, 1999; McMullen & Conway, 2002; Pritzker, 2007), and OCD (Knapton, 2016). Due to the imagery participants conveyed using language as their vehicle, and given the difficulties some participants had with finding suitable words to convey their experiences, it became clear that there was a need for the inclusion of visual approaches to enable participants to represent BDD in a more authentic and pre-reflective way.

This study also highlighted some of the key support needs that participants suggested were missing or insubstantial after seeking help for their BDD. These support needs were revealed through discussions regarding personal experiences with professionals and other important people in their lives. A recurring area of discussion in participant interviews involved disclosures that they often felt misunderstood, invalidated, or perceived as vain if they eventually did open up to people about the BDD symptoms they had been experiencing. In response to participants finding it difficult to express their experiences fully when using only linguistic means, and sharing their anguish in being misunderstood by others, I wanted to harness a creative methodology, making it possible for participants to express themselves more freely and also be provided with the opportunity to talk without facing judgement. To do this, I designed the fourth empirical study with a focus on finding out more about people’s pre-existing coping strategies through artwork and by inviting them to take part in a follow-up interview about their artwork.

8.5 Study 4 Summary – An arts-based multimodal hermeneutic-phenomenological approach to explore the experience of coping with Body Dysmorphic Disorder

The fourth empirical study employed a multimodal creative approach to elicit visual data from participants in the form of artwork that represented bad days and more manageable days with BDD. The artwork was then explored further in a follow-up semi-structured interview, using Boden and Eatough's (2014) Framework for the Analysis of Drawings. The Framework for the Analysis of Drawings (2014) was developed to deeply explore phenomena that people felt were difficult to express fully through language alone (Boden & Eatough, 2014). In Boden, Larkin, and Iyer's (2018) study, the Framework was used to consider how drawings can add to IPA studies, and was applied to the images created by young people representing their first episode of psychosis. They found that combining IPA with the analysis of young people's drawings enabled the researchers to gain a richer understanding of their relational experiences and supported "participants to find ways to communicate the meaning of their relationship to the world that extend beyond traditional verbalisation" (Boden et al., 2018: 233). In my fourth study, I used the Framework to facilitate the analysis of my participants' images and thus shape the areas of interest in their interviews. This study addressed the following research questions:

- What do the images of people with BDD tell us about coping with it?
- How does the combination of image making and interviews help people with expressing ambiguous elements of their experience of living with BDD?

This study focused specifically on the process of coping with BDD and sought insight from a different group of participants to studies two and three. The psychological process of coping with BDD had not yet been explored within the remit of qualitative BDD research, and in doing so, it became clear that coping with the disorder is an extremely complex and nuanced experience.

Participants’ artwork portrayed coping with BDD as an immensely agonising and harrowing phenomenon which only offered mere glimpses of hope or reprieve to those left anguished by it. They described being subjected to the integration of BDD with their lifeworld and being overwhelmed by its very nature; detaching themselves from their perceived selves as a way of coping; experiencing a fragmented sense of self; moving towards reconciling the relationship between their selves and bodies. There was some overlap in the themes generated from the data in the third and fourth studies, such as the omnipresence of BDD in the lives of participants. However, in the fourth study, there appeared to be more of a focus on the future and hope of possible recovery, demonstrating a positive approach to dealing with very difficult emotions and painful experiences. There were aspirations and a sense of anticipation for the future to come, reminiscent of Heidegger’s (1927/1962) notion of living an authentic life; a life that has been ontologically challenged but is still progressing forward. Having hope for a better future was one of the coping strategies participants employed to help manage their BDD, although maintaining the hope consistently was extremely challenging in light of the difficult symptoms that participants live with. Some participants shared that when they felt they had control over the appearance of their bodies, for example through body modifications such as tattoos, their symptoms eased. Using imagery in combination with the verbal and narrative data participants provided in this thesis has presented unique insight into the lives of those living with BDD. This mode of data collection also proved effective for helping people convey their experiences more easily, more richly, and made them greatly accessible to the wider public (Craythorne et al., 2020). This demonstrates how one might access and present to naïve others the quality of a person’s experience in a way that resonates with the reader. It should also be noted that using Boden and Eatough’s (2014) Framework was novel, as it has not been applied in many ways yet.

The decision to ask participants to create their artwork *before* the interview rather than during the interview (as per Boden & Eatough, 2014) arose after considering a number of factors. Some participants in my previous studies (Study Two: Understanding the origins of BDD; Study Three: The experiences of living with BDD) lived outside of the UK and had expressed interest in participating in my future research. I wanted to ensure that, should they wish to take part, they would be able to without being hindered by travel constraints (affecting myself or participants). I did take into account that the interviews could take place via Skype and the 'draw-talk' methodology could still be fulfilled in that context, however, I felt this would not be accommodating of their experiences with the disorder and may have restricted a number of people who would not feel comfortable being viewed on Skype. One of the strengths of the draw-talk method was the closeness in physical proximity between researcher and participant. Being able to observe and talk about the actual production of the piece in real-time would indeed have added an additional layer of spontaneity and naturalness to the study. However, I had doubts about asking participants to invite me into such a personal process. Some participants later mentioned being perfectionistic in their approach to creating their artwork, and this reassured me that I had made the right decision for them as I wanted them to be happy with their pieces before showing them to me and including them in the study. The end result of each piece transcended what I would consider substantial, and it is unlikely that the artwork could have been produced in a 60-minute interview setting. Even though I was unable to view the production of images, pick up on visual cues, paralinguistic behaviours and choices actively being made (e.g. which colour should I use here? What should go in this space?), in place of this, I was lucky enough to receive incredibly rich pieces of art that challenged my presuppositions and granted me access into the complex lifeworlds of individuals from around the world.

8.6 Towards an integrative account of the experience of BDD

In this section, I will discuss the findings from across my research studies in an integrative and synthesised way, working towards a phenomenologically informed description of what it means to live with BDD. To structure this description, I will revisit the constructs I have used throughout the empirical studies to help explain the experience of BDD phenomenologically. From the research I have conducted, living with BDD seems to be represented by a number of tropes: distortion, embodiment and disembodiment, vividness and intensity of experience, and a disparity between self and other.

Distortion is one of the central tropes across all of the studies in this thesis. For participants in the studies, this sense of distortion was experienced in multiple ways. Most notably, in the form of a distorted perception of the self and the world, and in the form of temporal distortion. For many participants, distorted perception was expressed as viewing the self from a different horizon, and experiencing a disagreement between the subjective self and the objective self. For people living with BDD, there is an overwhelming sense of uncertainty present in their lives with regards to navigating an oscillating and unstable physical appearance. This is an exclusively private phenomenon, only experienced by the individual's body and, to others, it is therefore a concealed aspect of one's perception. With this in mind, BDD could be considered as a lens through which people who live with it view a warped version of themselves, leading them to question their perception of the world as a body. As Husserl states, "the same Body which serves me as means for all my perception obstructs me in the perception of itself and is a remarkably imperfectly construed thing" (Husserl, 1989: 167). The distortions not only affect the viewer with BDD, but also infiltrate their lifeworlds and often prevent them from viewing themselves as an integrated whole, instead as objectified, disconnected and fragmented bodily features. As van Deurzen puts forward, "the sort of body we have is instrumental in determining how we are in contact with the world. Each of our bodies has a limited range and potential" (van Deurzen, 2010: 148). For a person with BDD, the perceived distorted body is detrimental to one's interaction with the world. Some distortions experienced were so highly concentrated that individuals did not consider themselves as having a human form, describing themselves as monsters and grotesque creatures. These horrific self-perceptions evoked a deep sense of shame and disgust within individuals, causing them to remove themselves from view by camouflaging their appearance or physically hiding away from other people to avoid their gaze.

Another form of distortion was experienced in the temporal domain for many participants across the studies. One of the most salient examples of this was experiencing past events in the present, due to the all-consuming futurity of BDD and the distressing memories it impels individuals to harbour. Due to the bodies of individuals being present during those significant and disturbing moments, the body plays a central role in their experience and recollection of them. As Gendlin (1991) suggests, the body is implicated in what things mean and, to reinvoke Merleau-Ponty (1945/1962), we live our world *through* our bodies. In the case of BDD, it seems that time is a fabric on which it hangs painful thoughts and memories from the past that weaves through the embodied and subjective domains of one's lifetime. There were strong allusions to experiencing grief and a loss of the past, grieving for the loss of the future and for what has not yet become. Participants discussed the many regrets they have experienced and perceived as 'wasted', unfulfilled lives they lead as a result of their condition. Heidegger (1927/1962) asserts that humans are temporal beings and that we never reach a state of completeness in our lives; we are constantly 'becoming' and being-towards-death. With this in mind, Heidegger suggests that human existence is understood in terms of time:

> *The horizon from which something like Being in general becomes understandable is time. We interpret Being from time (tempus). The interpretation is a temporal one. The fundamental problematic of ontology, as the determination of the sense of Being from time, is that of temporality (Heidegger, 1927/1962: 2).*

It may be possible that the effects of living with BDD are even more raw and painful when considered from a temporal horizon due to the realisation that, as humans, our being-in-the-world is finite and the condition imposes greatly on the experience of the past, present, and future.

Another key trope across all four studies was the subject of embodiment and disembodiment with regards to living with BDD. In human experience, the body is first and foremost. It is the vehicle through which we experience our world (Merleau-Ponty, 1945/1962), and for a person with BDD, this can be a problematic and distressing realisation to navigate. Being trapped inside one's body and experiencing the body as a prison was a common image that participants in this programme of work conveyed and this led to a strong sense of anguish. Some reported feeling physical nausea and sickness from the experience of being in their bodies and from viewing them. In most cases, participants did not have to directly view themselves (either in photographs or in the mirror) to experience this feeling of disgust, as it may be an integral part of them, embedded and embodied within their very being. This suggests that BDD may become fused within one's lifeworld, and this fusion of horizons may create a sense that the distorted BDD self is inseparable from the objective self. Participants spoke of wanting to escape from their bodies, mutilating and harming them to invoke a sense of disembodiment; attempting to distance themselves and break free from the restrictive flesh of their corporeal form. Engaging in disembodiment was not only an attempt to remove the self from the body, but also remove the body from the world by hiding away or camouflaging it in various forms. Often, participants would place blame upon their bodies for the deeply upsetting experiences they have endured in their lives, and this would fuel the cycle of self-loathing and bodily shame.

The vividness and intensity of experiences described by participants conveyed the palpability of what it means to live with BDD. In a similar way to experiencing temporal distortions, there was a very strong sensory dimension expressed via descriptions of past memories. In instances where participants had experienced extensive criticisms of their appearance from other people for example, it was common for them to take on the voice of their tormentors as though they were reliving the experience in the original circumstance. The felt sense of those experiences was also revealed throughout the studies, suggesting that painful events and experiences felt by people with BDD were imprinted on their bodies, crystallised and suspended within them. Gendlin describes the process of creating meaning out of experiences as “a body-sense of meaning” (Gendlin, 1981: 11), highlighting the notion of the body being central to the way people understand experience.

Intensity was further conveyed via the responses to some of the experiences that participants remembered, and how encompassing and enveloping the memory was for them. This included detailed descriptions and depictions of engaging in self-harm, self-mutilation and self-surgery. In some instances, the pain invoked through these destructive activities provided a mixture of solace, relief, desperation and a sense of ‘deserved’ punishment for the individual. These extremely intense feelings reflect the complexity of the experience of living with BDD, and how torturous and pervasive it can be.

The self as perceived by the other and the tension that manifested from this relationship was also significant to a range of participants across studies and a common trope within the experience of living with BDD. For many, interactions with the other were harmful and often resulted in participants feeling ostracised, culminating in a feeling of being ‘othered’. As Sartre suggests, the other can be likened to ‘an internal haemorrhage’ in one’s world, taking away the control that one has over it (Sartre, 1943/1956). This signifies a drastic disruption in one’s lifeworld which affects one’s being-in-the-world (Heidegger, 1927/1962) and interface with it. Also present across the studies were examples of the process of depersonalisation due to experiencing ‘the look’ – the critical gaze from the other, resulting in the transition from the body ‘being-in-itself’ to ‘being-for-itself’ (Sartre, 1943/1956). The body being-in-itself is the state in which a person is unaware of their body as they navigate the world, whereas the body being-*for*-itself is aware of the way it is perceived by the world and is objectified as a result of this disclosed perception from the other. Across all empirical studies in this thesis, participants reported that they often felt misunderstood and reluctant to speak about their appearance concerns and BDD symptoms due to a fear of being invalidated or mocked. Some described scenarios in which others had suggested that BDD is a trivial matter or something that everybody experiences, forcing them to keep their BDD symptoms to themselves.

The misunderstandings and stigma attached to BDD are damaging to those who live with it and, in facilitating a more accessible way of displaying the severity of the disorder, it is hoped that this body of work can help to raise the profile of BDD, help people become aware of its symptoms and reduce the surrounding stigma and ambiguity presently associated with it. Although there were lots of similarities in the experiences participants shared across cases and across each study, the way each participant made sense of those experiences was entirely unique and thus provided a variety of perspectives on multiple facets of the disorder, made possible by IPA’s focus on the idiographic.

8.7 Engaging reflexively with my research

I strongly believe this body of research has contributed significant and novel insight to both the BDD literature and phenomenological literature. I am grateful for the enthusiasm and courage my participants have shown in coming forward and allowing me access to their lifeworlds by sharing such profound and painful experiences. They have helped me become a better researcher and given me purpose for pursuing a greater knowledge of BDD and continue working towards getting the disorder the recognition it deserves. Engaging in this phenomenological work has challenged my preconception of what it means to be a researcher in psychology and equipped me with new ways of ‘languaging’ BDD experiences as well as managing the processes of my own experiences. By far, the most rewarding aspect of facilitating this research was meeting and speaking to each participant and learning about their unique sense making processes of living with BDD. In interviews, I built good rapport with participants, allowing me to be with them in their experience and I believe this closeness was largely due to the shared first-hand knowledge of BDD and mutual understanding of the pain it can cause.

One particular instance of this that really stands out to me occurred during Rohit’s interview, which contributed to studies one and two in this thesis. Rohit disclosed in his written piece and interview that he had never spoken to anyone about his appearance concerns in great depth prior to taking part in the research. He discussed his experiences at length and commented on how relieving it was to speak to somebody who understood BDD and what he regularly experienced (*after I finished writing it you know – this – it was a bit of relief actually*). As he had never spoken to another person about his BDD before, or another person with BDD, he wanted to know more about my personal experiences of the disorder within the context of our discussion. He asked me many of the questions I had asked him during his interview with my permission, and this was an unexpected turn that I was more than happy to partake in due to the rapport we had formed throughout the course of the interview. At this point, my initial role in the interview as the researcher had switched and I became the researched. This dual researcher-researched role was described by Råheim et al. (2016) in the context of insider and outsider research and power relations. They discussed a series of qualitative interviews in which researchers shifted their position when interviewing participants who had more expert knowledge of a particular illness, leading to a phenomena termed ‘researcher vulnerability’. By contrast, in the interviews I conducted with my participants, we each had expert knowledge of BDD due to our personal experience of living with it, and so the power balance could be described as more equal. However, the transition from researcher to researched made me much more aware of my own interviewing style and how it may have felt for my participants to be interviewed by myself about such a sensitive and difficult topic. As a result of this unanticipated event within the interview, I felt a surge of admiration for my participants and their ability to share extremely painful experiences with a person they did not know in order to help raise awareness of the disorder and benefit others with similar experiences. Another possible reason that good rapport with participants was maintained during the studies may have been because I disclosed my experience of BDD to them in initial email communication prior to the interviews being scheduled. Several participants reported feeling comfortable discussing some of the more complex phenomena associated with their BDD as there was a pre-existing mutual understanding of what it entails. This sense of comfort could have been a response to previous feelings of shame and being misunderstood that arose when discussing BDD with people who were not familiar with, or sympathetic towards, the disorder and its associated symptoms. I believe my previous dealings with racial and appearance-related bullying and prejudice enabled me to empathise very deeply with my participants and the stories they shared with me and I was able to approach their interviews with particular sensitivity.

8.8 Quality and validity of the research

Throughout the duration of my research, I took into account quality criteria at various stages of the process to ensure that my work met the high standards of what constitutes good qualitative research in practice. There are a range of quality criteria available for assessing the suitability of research. One that I found particularly applicable to my work was Yardley’s (2000) criteria of characteristics of good qualitative research, presented in Table 8.1 (page 204).

Table 8.1 Yardley's (2000) characteristics of good qualitative research

Essential qualities	Examples of the form each quality can take
Sensitivity to context	Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues.
Commitment and rigour	In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.
Transparency and coherence	Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.
Impact and importance	Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers).

Yardley states that the suggested criteria are not prescriptive, but are flexible and open to interpretation in order to accommodate a wide range of qualitative methodologies and approaches to qualitative research. There are some domains within those criteria that are more attuned to phenomenological work than others, which I will discuss in this section. For example, within the criteria, the importance of 'sensitivity to context' is highlighted (Yardley, 2000: 219), as shown in Table 8.1 (page 204). In my research, I have engaged fully with phenomenological and psychological theory to make sense of both mine and my participants' empirical data collected for each study regarding experiences of living with BDD. Using IPA enabled me to take an idiographic approach to the research and carefully consider each participant as an individual, honouring their unique and complex perspectives on a very important subject matter.

Another criterion suggested by Yardley is the consideration of 'commitment and rigour' (Yardley, 2000: 219). In order to engage with the topic in an in-depth manner, I immersed myself in each participant's lifeworld via appropriate questioning and interview technique, deep analysis and engaging with their data through multiple analytical lenses (for example, descriptive, linguistic, and conceptual as per the IPA method). I analysed each set of data thoroughly at case level, making sure to focus on gaining a strong understanding of what was important to each participant with regards to their experiences involving BDD. In addition, alongside the data collection and analysis processes, I engaged in reflective writing to help with making sense of my own experiences. As well as the autoethnographic and reflexive writing presented in chapter four, another way I did this was by reflective journaling. This involved keeping a record of my reflections about the interviews and analyses I conducted, paying particular attention to my positioning in the research and additional thoughts or observations about relevant elements of the research. Reflective journaling as a way of contributing towards quality and validity in IPA research has been explored by Vicary, Young, and Hicks (2017) who found that journaling alongside the analysis within a computer software package prompted "the process of learning, interpretation and bracketing, thus evidencing transparency" (Vicary, Young, & Hicks, 2017: 550), enhancing the quality and rigour of the analysis and allowing researchers to engage more deeply with each stage of the analytical process of IPA.

Creating and implementing complex multimodal study designs used in concordance with IPA not only demonstrated methodological competence, but also made it possible for participants to have a choice regarding their mode of participation, enabling them to feel at ease during the recruitment and study processes and express their views and experiences in multiple ways. Using additional layers of data collection in the studies (written, verbal, and visual) made space for new and intriguing findings that previous BDD studies did not manage to access.

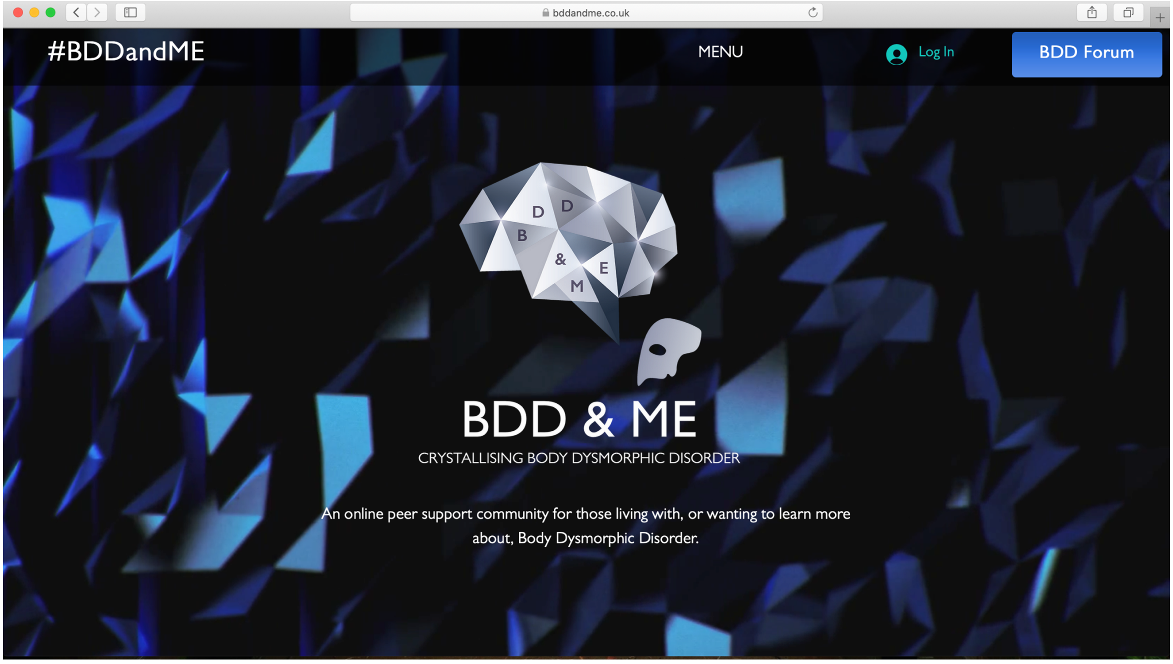
8.9 Considerations for therapeutic interventions and implications for practice

The research presented in this thesis has explored numerous accounts of people's experiences of living with and coping with BDD. From the detailed analyses of those written, verbal, and visual accounts, it is clear that present therapeutic interventions recommended for BDD may not be entirely effective or accessible to those who need support. As a qualitative methodological approach, IPA seeks to consider “theoretical transferability rather than empirical generalizability” (Smith, Flowers, & Larkin, 2009: 51). In this instance, in using IPA, my aim is not to generalise the support needs of people living with BDD, but to firstly make people aware of the condition, its severity, and to encourage clinicians and people implementing therapeutic interventions to take into consideration idiographic experiences that transcend the DSM criteria for BDD; for example bodily feelings and phenomena that cannot be expressed linguistically. However, it should be noted that there are some commonalities and aspects of participant experiences that are shared. For example, the critical life events, embodied felt senses, and the longevity of those life events being palpable even many years on. My research demonstrates that the experience of living with BDD is an extremely complex, multifaceted and embodied phenomenon, and in response to this, it is possible that a multi-layered approach that focuses on the phenomenological embodiment of the disorder may provide some respite and clarity for those who live with it. Some forms of psychotherapy include elements of embodiment that, when taken into consideration with other aspects of BDD, might help to plan suitable interventions for people living with it. For example, existential psychotherapy draws upon aspects of phenomenology, meaning it allows for the construction of a discursive space in which people can think about and discuss some of the embodied and complex experiences such as those described by the participants in each study in this thesis. As van Deurzen (2010) explains:

> existential psychotherapy does not seek to cure or explain, it merely seeks to explore, describe and clarify in order to try to understand the human predicament… The objective is to enable people to stand courageously in the tensions of life… while taking account of the context and horizons of the world in which they live. (van Deurzen, 2010: 4).

For a phenomenon such as BDD, an existential psychotherapeutic intervention may help people make sense of some of the difficult and intangible experiences they face that can unfold as part of the disorder’s manifestation and enable them to find suitable language or concepts for expressing and working towards developing an understanding of those experiences. Although existential psychotherapy may hold some potential for alleviating distress relating to issues regarding embodiment, it should be noted that an existential psychotherapeutic approach may not be entirely suitable for those who experience BDD symptoms akin to complex trauma, perhaps as a result of adverse earlier life events that may have occurred. For individuals whose BDD experience may have some overlap with PTSD symptoms, for example, people who experience vivid memories and flashbacks of traumatic events prior to their BDD onset, trauma-based interventions may be more appropriate. Although the efficacy of trauma-based interventions for BDD is not very well documented at present, there is some empirical evidence reported in my findings that highlight the need to explore this possibility further, for example regarding the intensity of past memories and distressing events. In support of this, Constantian (2019) emphasises the importance of taking the significance of traumatic events (particularly from childhood) into consideration when treating people with BDD. He found that many BDD patients he had observed who had undergone rhinoplasty surgery "screened positive for PTSD, particularly those with childhood trauma histories" (Constantian, 2019: 46). However, it has been suggested that there are not enough clinicians available with expertise in BDD to meet the therapeutic needs of the high volume of patients who require psychotherapeutic treatments (Lin, Stamm, & Cristidis, 2016), which could be considered another barrier to accessing appropriate treatment.

As well as addressing the trauma element that some people with BDD experience, it is also important to acknowledge that many participants in the studies in this thesis reported feeling invalidated, ignored, a sense of isolation and feeling misunderstood. Several suggested that they felt taking part in the respective studies and being interviewed was therapeutic in itself, which may have been due to there being a level of comfort present in speaking to another person with BDD about what they understood their experiences to be. This points towards the need for peer support, and for the establishment of a community to create a sense of belonging. In order to achieve this, I created a free to access, online peer-to-peer support forum entitled 'BDD & ME' (www.bddandme.co.uk; Craythorne, 2020), which has been endorsed by the Body Dysmorphic Disorder Foundation (https://bddfoundation.org/forums/). The forum is aimed towards people living with BDD, their families, friends, and anyone who wishes to learn more about the disorder. I created the BDD & ME forum to connect people with BDD and provide a protected and therapeutic space for people to share their experiences, seek support and share advice with over 100 members. This is a particularly important resource because it is something that has been created without relying on NHS services, which are currently overstretched and underfunded. I now present some images of the forum site:

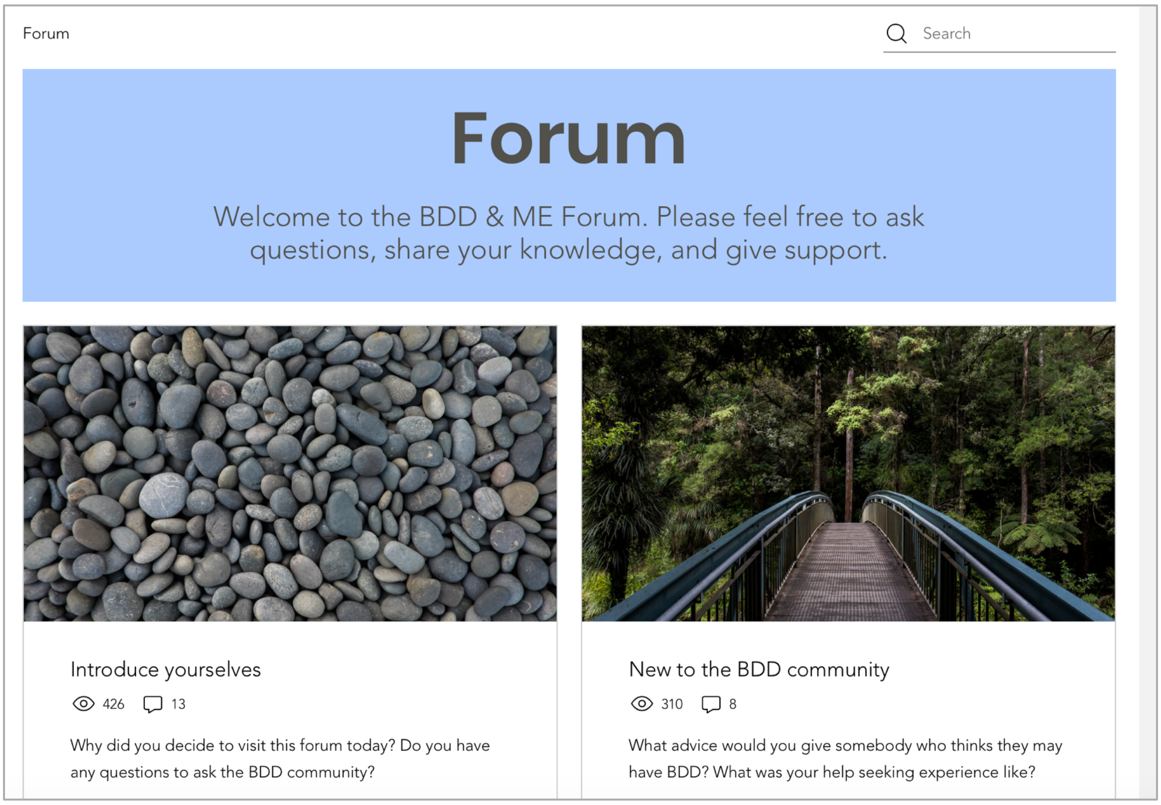


BDD & ME

CRYSTALLISING BODY DYSMORPHIC DISORDER

An online peer support community for those living with, or wanting to learn more about, Body Dysmorphic Disorder.

Figure 8.2 BDD & ME Homepage



Forum

Welcome to the BDD & ME Forum. Please feel free to ask questions, share your knowledge, and give support.

Introduce yourselves

426 13

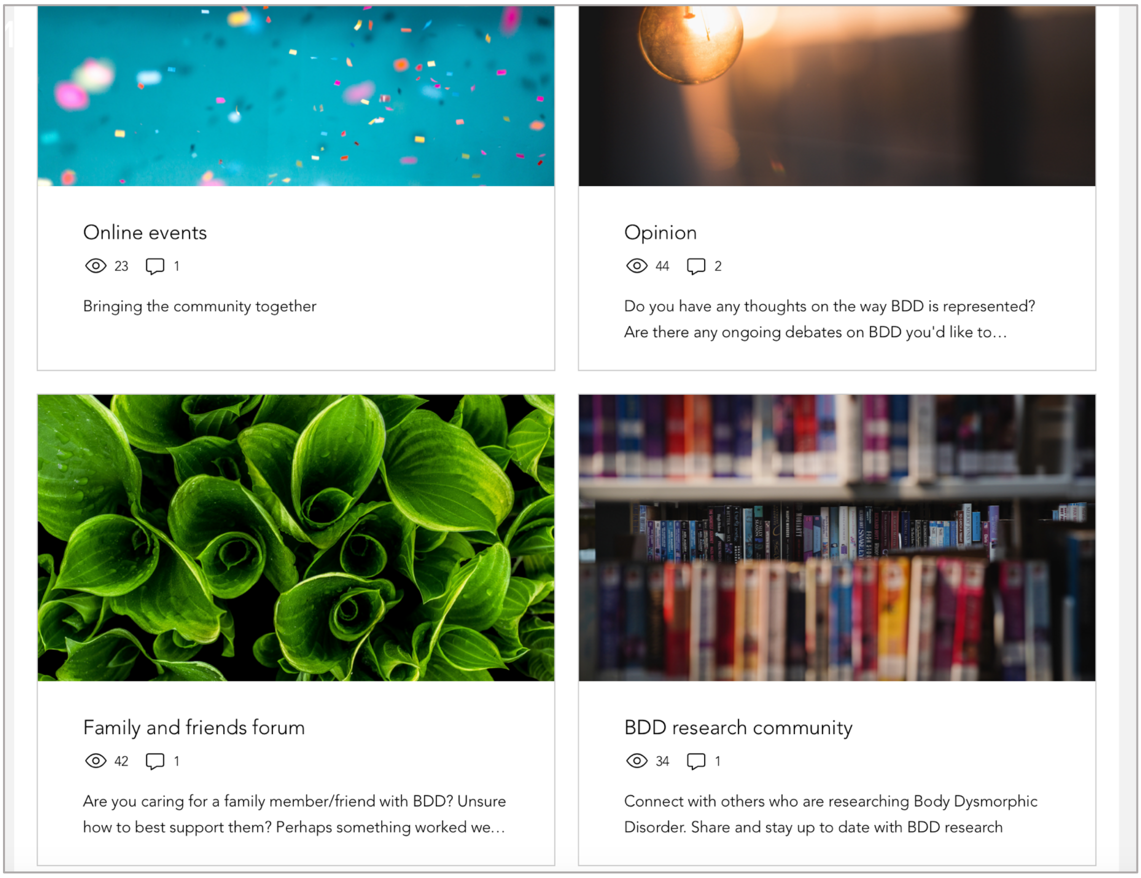
Why did you decide to visit this forum today? Do you have any questions to ask the BDD community?

New to the BDD community

310 8

What advice would you give somebody who thinks they may have BDD? What was your help seeking experience like?

Figure 8.3 Example BDD & ME Forum Categories



Online events

23 1

Bringing the community together

Opinion

44 2

Do you have any thoughts on the way BDD is represented? Are there any ongoing debates on BDD you'd like to…

Family and friends forum

42 1

Are you caring for a family member/friend with BDD? Unsure how to best support them? Perhaps something worked we…

BDD research community

34 1

Connect with others who are researching Body Dysmorphic Disorder. Share and stay up to date with BDD research

Figure 8.4 Example BDD & ME Forum Categories continued

There is evidence to suggest that peer support communities can have a positive effect on individuals living with mental health and health conditions (Chung, 2014; De Choudhury & De, 2014; Kirk & Milnes, 2016; Naslund, Aschbrenner, Marsch, & Bartels, 2016) and also for parents and family members of people with mental health needs (Croucher, Mertan, Shafran, & Bennett, 2020).

Due to the positive participant feedback on studies in this thesis involving eliciting biographical narrative pieces and the production of artwork, it might also be beneficial to others living with BDD to engage in interventions that incorporate elements of narrative therapy, storytelling or art therapy. Through a combination of the written word and artwork, it may be possible for people with BDD to find ways to express their thoughts more clearly and tangibly, exemplified in the studies in this programme of work, thus reducing the likelihood of being misunderstood by others.

8.9.1 Limitations and recommendations for future research

This programme of work has provided a great level of insight into a range of aspects concerning what it means to live with BDD from the perspective of a range of people with lived experience. I have created and implemented innovative research designs to facilitate the development of this insight and have demonstrated the novel contribution of my research to the psychological and phenomenological literature. However, there are some limitations within the research I wish to acknowledge in order to support further research in this area. In accordance with IPA’s focus on the idiographic, the sample sizes used for each study were relatively small, homogenous groups. Some readers may perceive the small sample size as a limitation, but this permitted very detailed analyses and deep exploration of a variety of phenomena to take place, but this also meant more general claims could not be made regarding participants’ experiences of living with BDD and, subsequently, generalised recommendations for suggested implications for practice could not be made. Taking into consideration the homogeneity of the samples, one limitation could be my decision to not request information regarding participants’ ethnic backgrounds during the data collection stage. Upon reflection, I also question whether this information was relevant to the study. It may have been through my own autoethnographic work that ethnicity became apparent as a possible area of interest in BDD development and it was also raised by others in the sample. This decision may have also been based on my own desire to be accepted as a human, rather than being identified by my ethnic background, and I wanted to afford my participants the same option; to have the choice to disclose their ethnic background or not. However, this additional knowledge may have provided some very useful and revealing context to situate their experiences in. Black, Asian, and Minority Ethnic (BAME) voices in the BDD community remain unrepresented and extremely limited, and future research that focuses on gaining an understanding of how BAME individuals living with BDD make sense of their experiences may provide additional insight into how those experiences might vary in comparison to groups that are more visible.

Another possible limitation relates to the need to explore people's experiences of treatment. This empirical research in this thesis focused purely on the origins and experiences of people living with BDD, rather than the experiences of treatment for BDD. There is a need to explore people's experiences of BDD treatment in order to make clearer recommendations in terms of what works for people with BDD and to inform the development of future, perhaps more tailored, interventions based on the lived experience of those with BDD. In researching this topic in depth, it might then be possible to determine which treatments are most effective in managing BDD and obtain valuable feedback on services from the service users themselves, aiding providers in improving aspects of the programme(s) on offer. Building on this idea further, a longitudinal study may provide a more in depth understanding of the efficacy of such programmes in relation to the reporting of severity of BDD symptoms over a specified period of time. Evaluating the efficacy of my online peer-to-peer forum (BDD & ME) could be a way of piloting an evaluative study on a smaller scale. The study could consider the forum's ability in providing therapeutic qualities and facilitating support amongst its users. The information gathered could then be used to enhance the experience of the BDD community in the forum and further raise the profile of BDD via its online presence.

Another area of research that I would very much like to explore in greater depth in the future is the use of visual methods in therapeutic settings, such as art therapy with a specific focus on BDD. My research has demonstrated that visual representations of BDD are an effective and powerful way of conveying previously inaccessible and intangible phenomena associated with living with BDD particularly regarding its embodiment, making them highly accessible modes of communication with those who are unfamiliar with some or all of its symptoms. Incorporating artwork into future studies about BDD may further increase understanding of the disorder and provide a suitable outlet for people with BDD to express the inexpressible.

There are still many avenues that I would like to continue to explore in the realm of phenomenological research and BDD, and I hope the reader agrees that I have offered new perspectives and novel insights into a previously unfamiliar domain for others to explore too. I strongly believe that using IPA can aid in granting access into the lifeworlds of forgotten individuals and can open up a range of opportunities for delving into hidden and highly valuable phenomena further. Additionally, I believe that combining IPA with other phenomenologically informed creative methodologies can help to broaden the scope of inquiry and significantly enhance our ability as researchers in not just ‘giving voice’, but helping people living with BDD in reclaiming voice and giving knowledge to the other so they can, too, have access to previously inaccessible other worlds.

> I am strong because I am enduring a bully
> Who isn’t anyone else but me.
>
> I am an adventurer because I am always trying to do
> Despite every situation making me insecure and afraid.
>
> I am untiring because I rebuild myself every time I get broken
> Not by others but by myself.
>
> I am a giver because I listen and try to lift people
> Even when I am down, dejected and regretful.
>
> I am a seeker because I am always curious to learn
> Even when I am tormented by pointlessness.
>
> I am a fighter because I will live on
> Even when all I want is to be gone.
>
> \- ‘Rohit’

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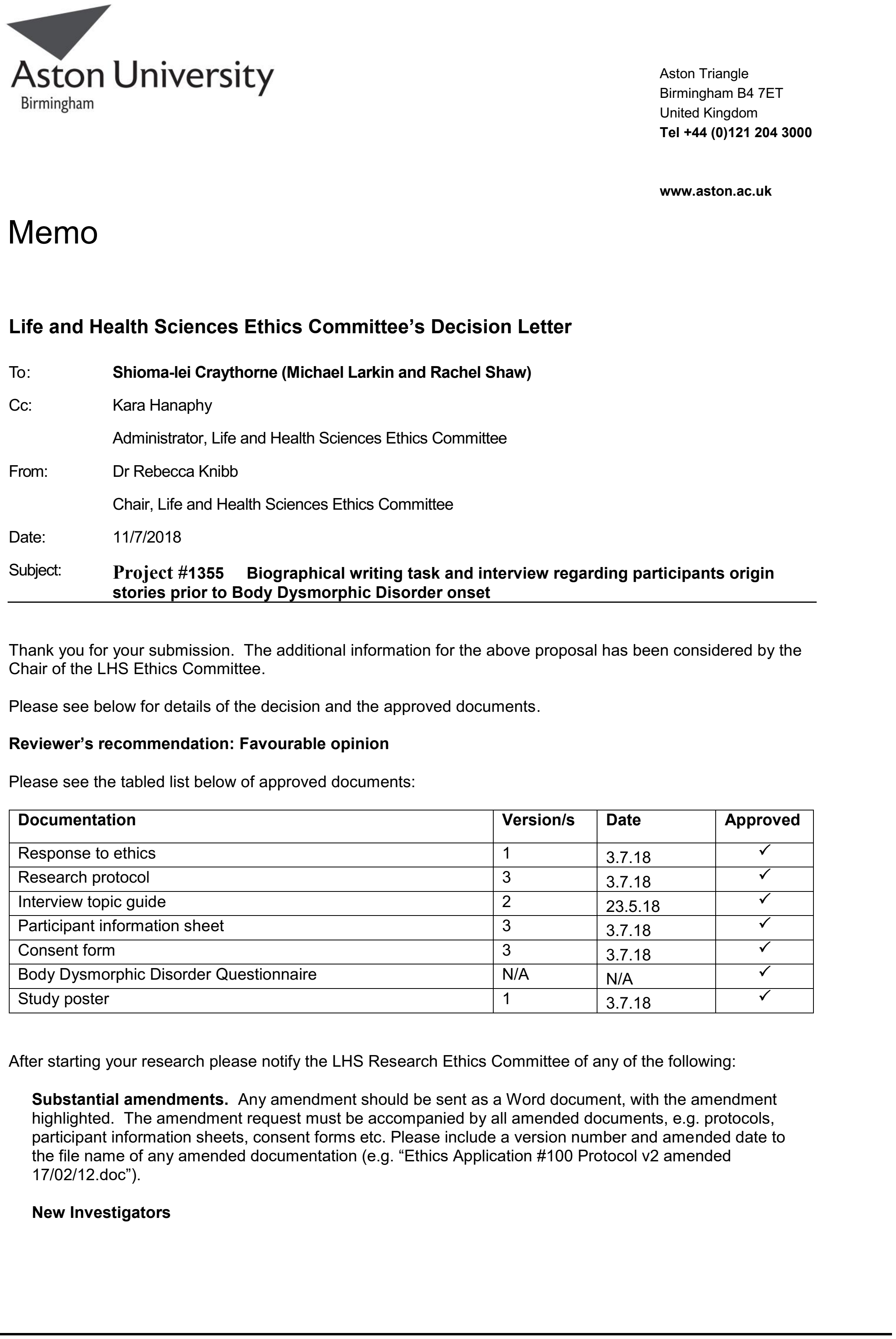
Appendices

Appendix A: Letter of Ethical Approval for Origins Study (Project #1355)



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Memo

Life and Health Sciences Ethics Committee's Decision Letter

To: **Shioma-lei Craythorne (Michael Larkin and Rachel Shaw)**

Cc: Kara Hanaphy

Administrator, Life and Health Sciences Ethics Committee

From: Dr Rebecca Knibb

Chair, Life and Health Sciences Ethics Committee

Date: 11/7/2018

Subject: **Project #1355 Biographical writing task and interview regarding participants origin stories prior to Body Dysmorphic Disorder onset**

Thank you for your submission. The additional information for the above proposal has been considered by the Chair of the LHS Ethics Committee.

Please see below for details of the decision and the approved documents.

Reviewer's recommendation: Favourable opinion

Please see the tabled list below of approved documents:

Documentation	**Version/s**	**Date**	**Approved**
Response to ethics	1	3.7.18	✓
Research protocol	3	3.7.18	✓
Interview topic guide	2	23.5.18	✓
Participant information sheet	3	3.7.18	✓
Consent form	3	3.7.18	✓
Body Dysmorphic Disorder Questionnaire	N/A	N/A	✓
Study poster	1	3.7.18	✓

After starting your research please notify the LHS Research Ethics Committee of any of the following:

Substantial amendments. Any amendment should be sent as a Word document, with the amendment highlighted. The amendment request must be accompanied by all amended documents, e.g. protocols, participant information sheets, consent forms etc. Please include a version number and amended date to the file name of any amended documentation (e.g. "Ethics Application #100 Protocol v2 amended 17/02/12.doc").

New Investigators

Appendix B: Study Advertisement for Origins Study

Aston University

Research on people's stories of the origins of their Body Dysmorphia

We are seeking participants. Would you like to take part in this research project?

Participation involves completing:

- A short online questionnaire
- A written piece about living with Body Dysmorphia
- A follow-up interview based on the content of the written piece (approx. 60 minutes)

You can participate in this study if you are aged 18 or over and identify as living with Body Dysmorphia (BDD)

Please contact **Shioma-lei Craythorne** for more information:

craythos@aston.ac.uk

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Appendix C: Participant Information Sheet for Origins Study

[Version three: 03.07.18. PIS]

Participant Information Sheet

Title of study: Biographical writing task and interview regarding participants' origin stories prior to Body Dysmorphic Disorder (BDD) onset.

You are invited to take part in a research study. Before you decide whether you would like to take part in this research, it is important for you to understand why this research is being conducted, what it will involve, and what you will need to do in order to participate. Please read all of the information provided and feel free to discuss it with friends, family or advisors. If you have any questions or wish to discuss the study further, please feel free to contact the researcher, Shioma-lei Craythorne, via email (craythos@aston.ac.uk) or telephone [omitted] before you decide whether to participate or not.

Thank you for your time.

Technical terms:

Body Dysmorphic Disorder: Body Dysmorphic Disorder (also called Body Dysmorphia or BDD) is an anxiety disorder relating to body image. People with Body Dysmorphic Disorder experience obsessive concerns about one or more perceived flaws in their appearance. The flaw may be very slight or may not be visible to other people at all.

Biographical writing task: This is a written piece about the stories and events leading up to the development of your BDD.

Origin stories: This refers to any stories or events that may have happened to you at any point in your life that you believe may have contributed to or caused your BDD (where you believe your BDD originated from).

Introduction to the research and invitation to take part

This research is being undertaken as part of a Psychology PhD qualification. The study aims to explore people's stories of the origins and experiences of their Body Dysmorphia (Body Dysmorphic Disorder; BDD) and consists of two parts: a biographical writing task and an interview. You have been identified as a potential participant in this research project. Individuals involved in this research project are Shioma-lei Craythorne (Researcher, PhD student) and her supervisors, Dr Michael Larkin and Dr Rachel Shaw.

What is the purpose of this study?

We are interested in exploring the origin stories and learning of any events that you believe may have contributed to the development of your Body Dysmorphic Disorder. In particular, we are interested in understanding how these stories and events may have affected you, and your personal experiences of living with BDD. Possible causes of BDD have been researched previously, however, there is a very limited amount of research focusing on the personal experiences and accounts of those living with the disorder. The findings from this research may help to raise awareness of BDD, may increase the knowledge of healthcare professionals and potentially help them to better support and advise those living with BDD or caring for someone with BDD.

Do I have to take part?

No, you do not have to take part in this study. It is your choice whether or not you decide to take part. The decision to participate in this study is completely voluntary. This research will be conducted in either a private room at Aston University in Birmingham, your own home or via telephone/Skype. You will not be coerced or forced to complete any part of the research in a public area unless you request to do so. In order to help you make an informed decision of whether you would like to participate, the researcher (Shioma-lei Craythorne) will describe the study to you in this information sheet. After reading this information sheet, you will have the opportunity to ask any questions about the research and if you would still like to participate in the study, you will be asked to read and sign the consent form, initialling the boxes. You are free to withdraw from this study at any time, without giving a reason. After signing the consent form, you will be asked to complete a short questionnaire about Body Dysmorphic Disorder (The Body Dysmorphic Disorder Questionnaire; BDDQ). The questionnaire will ask you how you currently feel about your appearance.

Why have I been asked to participate?

You have been asked to consider participating in this study because you have identified as living with Body Dysmorphic Disorder (Body Dysmorphia; BDD).

What will I have to do if I decide to participate?

If you decide to participate in this study, you will be asked to complete the Body Dysmorphic Disorder Questionnaire (BDDQ) in an online questionnaire sent to you via email by the researcher (Shioma-lei Craythorne). The questionnaire will ask you how you currently feel about your appearance. The researcher will contact you via email within 3 days of completing the online questionnaire with a question about your experiences of Body Dysmorphic Disorder and some prompts to help you answer the question. This question should take no more than 2 hours to answer, and we would not expect this to take more than 4 weeks to complete the process. If you are concerned that it may take you longer to complete this, please contact the researcher (Shioma-lei Craythorne) to discuss this. If you are concerned about email privacy, please feel free to password protect your written task file, and then send the password for the file to the researcher in a separate email. You will be sent instructions on how to do this when the researcher emails you with your question and prompts. This is optional, and the file you send does not need to be password protected if you do not wish it to be. Once you have sent your written piece to the researcher, she may email you asking you to clarify or go into more detail on specific points mentioned in your writing. A maximum of 5 emails about your writing will be exchanged between you and the researcher, and the researcher will only seek clarification within 14 days of her receiving your written piece.

When you have sent your written piece, the researcher will agree a date, time and location for your interview at your convenience. Your interview can be conducted in a private room at Aston University in Birmingham, your own home, via telephone, or Skype (audio only, if you would prefer). The interview should take no longer than 60 minutes and will involve the researcher discussing and asking you questions about your written piece and experiences of BDD. You can stop the interview at any time without giving a reason. The interview will be audio recorded using a digital voice recorder, allowing the researcher to listen to the interview later on and analyse it. The recording from the interview will not be listened to by anyone else apart from the researcher (Shioma-lei Craythorne) and her supervisors (Dr Michael Larkin and Dr Rachel Shaw). Any names of people or places you may mention in your writing or in your interview will be changed. None of the personal information collected from you during this study will be seen by anyone else outside of the research team (Shioma-lei Craythorne, Dr Michael Larkin and Dr Rachel Shaw). Your data will be anonymised and you will be assigned a pseudonym to protect your identity. Your data will normally take 2 weeks to be anonymised, and you can withdraw your data at any point within this 2 week period.

This study will NOT involve drugs or any other medical procedures.

What are the possible risks of participating?

There are no identified risks from participating in this research, and any information you provide will remain strictly confidential. If you do become distressed as a result of your participation, please let the researcher know either at the time or by contacting her using the contact details provided in this information sheet. In the first instance, we can discuss any difficulties that arose. If you need professional help, she will speak to you about this and you may then wish to contact your GP or another healthcare professional. If the answers you provide in the study cause the researcher concern about your own well-being, she will contact you and may suggest that you contact your GP for further advice.

Are there any possible benefits?

While there are no monetary benefits from taking part in this study, it is hoped that information provided by you will increase the knowledge of healthcare professionals, potentially enabling them to provide better support and advice for those living with Body Dysmorphic Disorder or caring for someone with Body Dysmorphic Disorder.

How often will I be contacted?

If you decide to take part in the study, you will be contacted via email once with the question and prompts to help you write your written piece. After sending this to the researcher, she may contact you asking you to clarify specific points. No more than 5 emails will be exchanged between you and the researcher at this point. After this stage, the researcher will contact you via email or telephone (whichever you prefer) to arrange a meeting for your interview at your convenience. The researcher will send you a reminder by email and/or text the day before your interview.

What if I need assistance in order to take part?

If you normally work with additional communication aids, the researcher will do what she can to incorporate this. However, as this project is self-funded, there will be no funding available to provide that resource. If you have communication problems due to a disability, please inform the researcher by contacting her via email (craythos@aston.ac.uk) or telephone [omitted]. If you have difficulties with reading, please contact the researcher. She may be able to offer you more time to complete the study and will assist you in reading the questionnaires. If you envisage any other problems, please contact the researcher, and every effort will be made to make things easier for you.

What do I do now?

Once you have read this information sheet and asked any questions you may have, the researcher will ask if you would still like to participate in the study. If you would still like to participate in this study, we will ask you to sign and initial a consent form. You will receive an email within 3 days of signing the consent form containing the question and prompts for your written piece. If you do not receive an email within 3 days, please check your junk inbox or contact the researcher.

What if I have a complaint?

If you have any concerns about the way in which this study has been conducted, you should contact the Director of Governance, Professor John Walter via email (j.g.walter@aston.ac.uk) or telephone (0121 204 4869).

Will anybody know I took part in the study?

Only the researcher (Shioma-lei Craythorne) and her supervisors (Dr Michael Larkin and Dr Rachel Shaw) will know who took part in the study. Your data will be anonymised. You will be assigned a pseudonym, as will any other people or places you mention in your written task and interview. Computer based data will be kept on file at Aston University and will be password protected. All of your paper data will be kept in a locked cabinet at Aston University. Only Shioma-lei Craythorne, Dr Michael Larkin and Dr Rachel Shaw will have full access to the anonymised data. Selected extracts will be used for teaching, training and dissemination purposes. Consent will be sought for audio recording and for anonymised quotations to be used. No outside party will be made aware of your participation and subsequent personal information provided for the study. If harm to yourself or others is indicated through information you have disclosed, the researcher may have to report this information to a suitable authority.

What happens at the end of the study?

On completion, the results of this study may be sent for publication in a scientific journal. However, you will not be personally identifiable in this report/publication. Each participant will be informed about the results of the study. If you are interested in the outcome of the research, a summary of the findings can be sent to you via email.

What happens if I have more questions?

If you are unsure of anything on this information sheet or have any further questions, please contact the researcher via email (craythos@aston.ac.uk) or telephone [omitted].

What happens now if I decide to participate?

If you decide to participate, you will be asked to read, electronically sign and initial the consent form online. By signing the consent form, you acknowledge that you understand the aims of the research and what you will do if you decide to take part.

What happens if I change my mind during the study?

You can withdraw from the study at any time during data collection. In the two weeks following the end of data collection, you can withdraw some or all of your data from the study. At the end of this period, anonymisation of the data of the data will be complete, analysis will begin, and it will not be possible to withdraw your data.

Who is organising and funding the research?

This research is being undertaken as part of a Psychology PhD qualification and is organised by the School of Life and Health Sciences at Aston University. It is funded by the researcher (Shioma-lei Craythorne).

Who has reviewed the study?

This study has been reviewed and received a favourable opinion from the School of Life and Health Sciences Ethics Committee at Aston University.

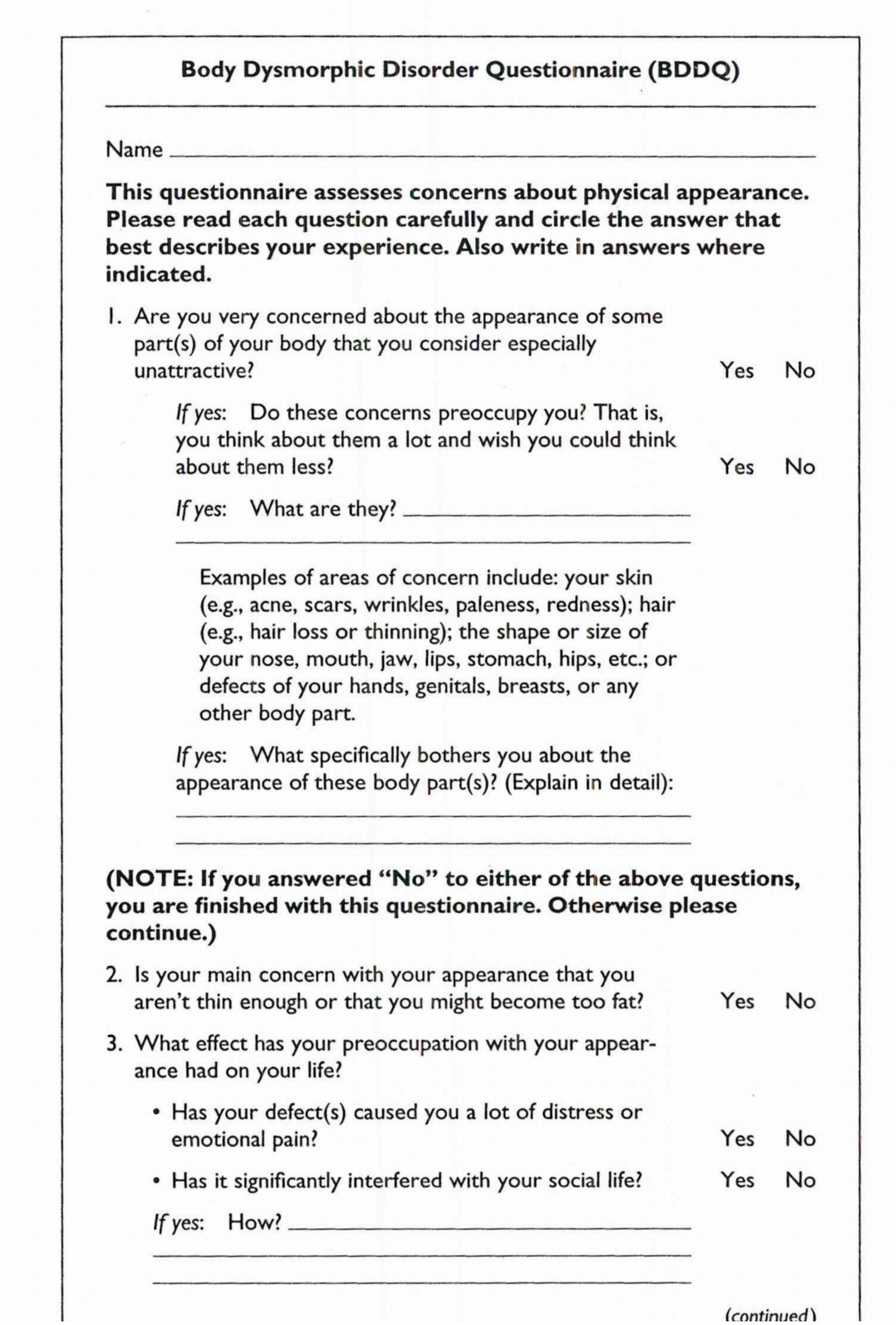
Who can I contact about this study?

If you have any questions or concerns, please contact Shioma-lei Craythorne (craythos@aston.ac.uk/ [omitted]), Dr Michael Larkin (m.larkin@aston.ac.uk / 0121 204 3112) or Dr Rachel Shaw (r.l.shaw@aston.ac.uk / 0121 204 4050).

If you have any concerns about the way in which this study has been conducted, you should contact the Director of Governance, John Walter via email (j.g.walter@aston.ac.uk) or telephone (0121 204 4869).

Thank you for taking the time to read this information sheet.

Appendix D: Body Dysmorphic Disorder Questionnaire (BDDQ)



Body Dysmorphic Disorder Questionnaire (BDDQ)

Name ______________________________

This questionnaire assesses concerns about physical appearance. Please read each question carefully and circle the answer that best describes your experience. Also write in answers where indicated.

1. Are you very concerned about the appearance of some part(s) of your body that you consider especially unattractive? Yes No

   If yes: Do these concerns preoccupy you? That is, you think about them a lot and wish you could think about them less? Yes No

   If yes: What are they? ______________________

   ____

   Examples of areas of concern include: your skin (e.g., acne, scars, wrinkles, paleness, redness); hair (e.g., hair loss or thinning); the shape or size of your nose, mouth, jaw, lips, stomach, hips, etc.; or defects of your hands, genitals, breasts, or any other body part.

   If yes: What specifically bothers you about the appearance of these body part(s)? (Explain in detail):

   ____

   ____

(NOTE: If you answered "No" to either of the above questions, you are finished with this questionnaire. Otherwise please continue.)

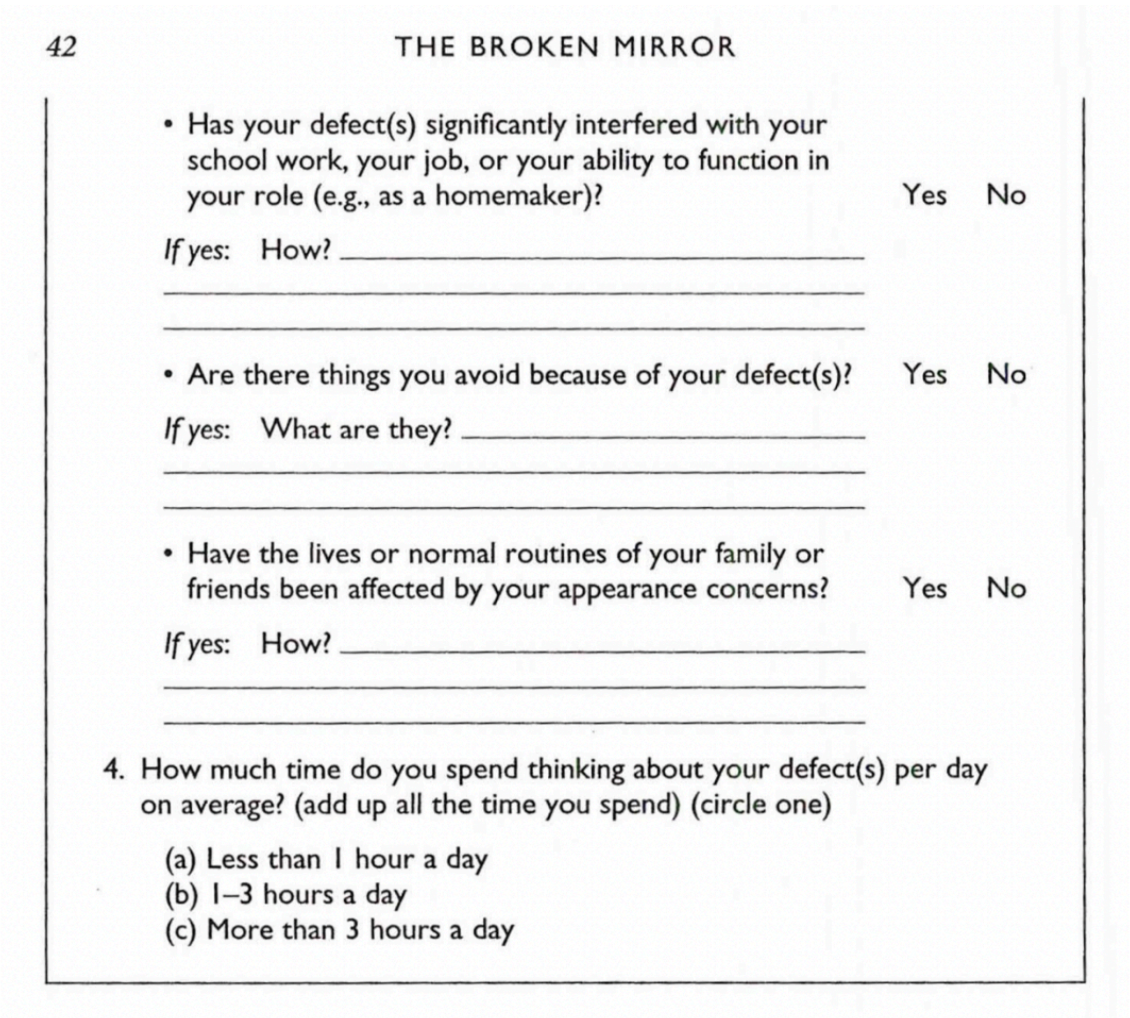
2. Is your main concern with your appearance that you aren't thin enough or that you might become too fat? Yes No
3. What effect has your preoccupation with your appearance had on your life?
   - Has your defect(s) caused you a lot of distress or emotional pain? Yes No
   - Has it significantly interfered with your social life? Yes No

   If yes: How? ______________________________

   ____

   ____

(continued)



- Has your defect(s) significantly interfered with your school work, your job, or your ability to function in your role (e.g., as a homemaker)? Yes No

If yes: How? ____________________________________

____

____

- Are there things you avoid because of your defect(s)? Yes No

If yes: What are they? ______________________________

____

____

- Have the lives or normal routines of your family or friends been affected by your appearance concerns? Yes No

If yes: How? ____________________________________

____

____

4. How much time do you spend thinking about your defect(s) per day on average? (add up all the time you spend) (circle one)

(a) Less than 1 hour a day
(b) 1–3 hours a day
(c) More than 3 hours a day

Appendix E: Consent Form for Project #1355

[Version three: 03.07.18. Consent Form]

Aston University
Birmingham

Consent Form

Title of study: Biographical writing task and interview regarding participants' origin stories prior to Body Dysmorphic Disorder (BDD) onset.

Please initial, rather than ticking the boxes.

1. I have read ALL of the information provided in the information sheet (Version three: 03.07.18 PIS) and have had any questions answered to a satisfactory standard.

2. I understand my participation is completely voluntary, and that I will not be paid for any aspect of my participation.

3. I understand that I am free to withdraw at any time during data collection, without providing any reason.

4. I understand that any personal data I provide will be stored confidentially and used ONLY for contact purposes.

5. I understand I will be audio recorded during the interview, however, this will only be listened to by members of the research team and will remain strictly confidential.

6. I understand that anonymised quotes from my written piece and/or interview may be quoted in project reports and publications.

7. I understand that I am free to withdraw some or all data for a period of two weeks after completing the written piece or interview.

8. I would like to receive a summary of the results from this study, and consent to my email address being stored until this is completed (Please circle one). **YES/NO**

I hereby give my consent to take part in this study.

Name (printed) ……………………………………………… Initials ………………

Signature ………………………………………………….. Date ………………….

Signature of researcher ……………………………………………….

Appendix F: Example of Participant Case Level Notes

Case Level Notes for Elliot

Age: 44

Objects are not trustworthy/ perceptions are misleading

"…I just can't seem to process the image I think in an acceptable way – it just has this kind of- just kind of almost- kind of visceral kind of erm- it's not like- sort of cerebral it's almost like er- I just react – like a real strong reaction of kind of disgust I suppose and **just trying to- just trying to er- I dunno just trying to process the image and just try and understand how it can be so extreme – er so kind of er- I dunno- it's erm very difficult to accept or process"** (EJ 4. 149-154)

- "can't seem to process the image I think in an acceptable way" – the image that he sees is not his ideal self (acceptable), therefore it is unacceptable.

- "process" – sounds quite mechanical.

- "try and understand how it can be so extreme" – element of insight. He is aware that there is a reason for the 'extreme' image he is seeing/perceiving.

"erm (pause) I suppose it's – again it's really hard because- because I think one of main- one of my main problems is that- is that sort of **feeling break down that's been that kind of three dimensional reality – and something that lacks that – it's like stepping into a- into a world where- where objects don't have- don't have that – what's it called – objective reality or- it's like – I don't know it's really hard because- because it doesn't have objectivity – it's that kind of loss of objectivity"** (EJ 15. 670-675)

- Break down of three dimensional reality - "reality" does not necessarily mean tangible reality.

- "it's like stepping into a world where objects don't have that objective reality" – this is a metaphor. He is expressing that having BDD is like stepping into a world where objects don't appear as they should. But in BDD's case, the world is your body, and the different parts of it don't appear as they should.

- BDD is subjective. Each person with BDD sees different things to another person with BDD, and sees different things to someone else viewing them.

EJ: it's really hard to- to say – it's not like seeing something that's just really- just like someone maybe who might be considered really ugly or really disfigured – because they still seem to have that sense of reality and objectivity – erm and they are- are on maybe a continuum – it's not- it's about sort of not being on a continuum as such – erm it's like – you know – I'm a nurse – and I see all sorts of things – and I've been seeing this lady and she's got this really large fungating tumour – it's like – sort of all coming out of her jawline and mouth and it's [like]

SC: [mm]

EJ: I mean it's something that I'm – you know – not- not- not that I'm not used to seeing and I – you know – and it isn't very pleasant but even seeing that – it has a reality – I mean someone who is maybe not used to seeing those things might think 'oh my god' – you know – and it is really extreme – but when I'm looking at it I- you know – I'm – you know – when I'm thinking about it I think – you know – it still seems to have a reality that I don't (EJ 15. 684-699)

Could be interpreted in different ways:

1. He could be making a comparison here. He might be highlighting the differences in perception between himself and the lady with the fungating tumour (the way that Elliot perceives himself, and the way that the lady perceives herself). For example, 'someone has a tumour, and I can't stand my hair' – could be comparing their capacity to cope. He might be referring to their different senses of perspective on reality, rather than reality itself.
2. He also discusses his desire to be on a 'continuum' – he says that he doesn't mind where he goes on there (the positive end or the negative end), he just wants to be on there. Here, he could be suggesting that someone with worse facial disfigurements (lady with the fungating tumour) would be on the continuum (presumably at the negative end of the continuum). Is he saying he would rather have a fungating tumour than look the way he perceives himself to be?
3. He discusses manipulating his appearance to make it more 'three dimensional' (three dimensional reality) – this could refer to his physical appearance, and viewing himself in a particular way (involving lighting?) to make it look like shadows are on his face, giving more depth and a more three dimensional appearance.

I can't make that leap from- from understanding that it's not my appearance that's the problem – it's my relationship with my appearance and my- my thinking – and my values – and everything else – I can't- I can't er- I can't seem to – you know – it sounds so obvious written down when it's read – it sounds so clear – but I cannot- I cannot make that leap – I don't think I'm stupid or that my brain just doesn't really- doesn't function very well – erm but I just can't- I just can't make that leap you know (EJ 24. 1111-1116)

- He is aware that his appearance is not problematic, but his relationship with his appearance *is* problematic.
- "leap" – requires a huge effort

“a lot of the hairs are very dark almost jet black – and quite thick like my eyebrows… erm but to me they’re just- it’s like they’re very- it’s like er **I can’t really see beyond them** it’s like… not having- it’s almost like- **it’s not that I have sort of hair on my ears – it’s like I can’t see my ears ‘cause of- or can’t process my ears ‘cause of the hair in a way**” (EJ 6. 243-254)

- A difference stance in terms of perception. Made me think of layers. Peeling back layers of the body. E.g. not being able to see scalp because of head hair, not being able to see tops of fingers because of nails. The density of his hair prevents him from viewing parts of his body.

BDD is encompassing

“the BDD just affects everything – erm you know – BDD doesn’t just affect everything in my life – BDD kind of is my life” (EJ 25. 1159-1160)

- BDD is inseparable from Elliot’s life. It is ingrained in everything that he does. It has become synonymous with his identity.

“trying not to look too much – trying to do this – trying to do that – trying to be very careful about what I eat – and when I shower” – when I shave’ (EJ 8. 350-352)

- BDD affects many aspects of Elliot’s life; his interactions with the world, his diet choices, washing, grooming etc.

- Repetition of ‘trying’ – syntactic parallelism. Shows how deeply BDD is embedded into his life

- ‘trying’ – but not succeeding

BDD is isolating

“I’ve never been in a relationship – that in itself is quite difficult ‘cause I’m constantly around people and it’s just constantly like- kind of stimulating that’ (EJ 25. 1154)

- Having BDD has affected Elliot’s ability to form personal relationships
- Being around people highlights his loneliness

“…the yoga’s quite a nice environment to be in – and sometimes it’s quite- quite nice – other times it’s really hard ‘cause like if my BDD’s sort of really kicking off there’s sort of (pause) – you know – people around that scrutinise – and quite often it’s women and it’s that constant reminder of maybe that – you know – again it’s kind of this constant reminder sort of bringing yourself in around people that you can’t really connect with people and – you know – I don’t know – it’s very difficult” (EJ 13. 585-591)

- Concerned about other people scrutinising him in a group setting. Being in a group setting can worsen Elliot's BDD
- Fear of consequence?
- Inability to form connections with people, and having to bring himself 'in' – keep himself to himself?

Appearance is something to be managed

"and my skin – so with the hairs it's like- it's like trying to keep them under control – and if I don't keep them under control – just like- and it- you know- like if I think "well just don't worry about them – just don't" – you know- you know sometimes it's nice just not to worry about them and just like try and forget about it but then- then I- then- you know – after a few days – you know – when I have to look in the mirror in the morning or whatever – and then- and then I'll notice them and it will be a **worse** **(18:52)** experience than if I hadn't kept them- tried to keep them under control – not that I really can keep them under control" (EJ 7. 307-314)

"and you try and let it go a little bit but then you- you know it's just- then suddenly you look and then suddenly it's really bad and then you have to invest more – all these resources and stress and trying to get it under control – and then have days where you feel 'I **can't** **(20:03)** control it'" (EJ 15. 330-333)

- "hair(s)" – Overlap with perception. Referring to individual hairs rather than a whole area of hair emphasises the very detailed/precise nature of BDD.
- "not that I really can keep them under control" – an infinite task. Keeping control is impossible
- 'Suddenly' – the cost of not maintaining vigilance/ his own standards. Taking a break from maintaining appearance means having to put in more work another time. (Fear of consequence)
- Tone – "I can't" – exasperation. Feeling that nothing you're doing is improving your appearance.
- BDD is a time commitment

"to be clear it's kind of stressful sometimes in trying to feel like you have to keep things under control" (EJ 7. 325-326)

- "have to keep things under control" – a compulsion?
- "trying" – but not succeeding

Fear of viewing oneself in an unacceptable way/ protecting oneself/ desire to achieve unattainable self/ mirror avoidance

it's not just like I'm having a- an exaggerated fight or flight response to a spider – it's like all of my- all of my identity – and my mood – and my confidence is all wrapped up in this – so like – you know – everything – I mean everything is- everything is- I suppose just everything is not seeing these things – erm and – you know – I- I – you know – **to survive I have to avoid seeing these things** – so – you know – it's quite- quite a big art – **and then to sort of start-start exposing myself – it's a bit like – you know – if I was contemp- contemplating suicide – I'd have to really- probably have to try and override my survival instincts to do that** (EJ 24. 1090-1097)

- Hesitant repetition – "everything – I mean everything is- everything is…" – demonstrates how difficult it is for Elliot to talk about this
- Overlap with encompassing metaphor – "it's like all of my- all of my identity – and my mood – and my confidence is all wrapped up in this"
- Use of verb 'exposing' suggests something is hidden
- Compares viewing himself in the mirror to suicide. He protects himself by shielding himself from his reflection and viewing the aspects of his body/face that distress him. His avoidance strategies are his survival instincts.

I mean I use like- just one mirror really at home – erm I don't use any others anywhere else or at home – and really limit the time I try and spend er and I'm quite routine about when I do certain sort of grooming activities – things like that (EJ 10. 444-446)

- Restrictive use of mirrors

I'm finding work more stressful – but I think it's because erm – partly as in already – low level stress – and I'm going around – there's mirrors everywhere wherever I go – I've always got to be scanning for mirrors and reflective surfaces when I'm out (EJ 13. 607-610)

would normally just try and use the tweezers like when I'm not looking in the mirror 'cause it's much easier er just to try and get as many as- away so when I do look it- it's not so difficult – 'cause there's less likely to- to be too much to catch my eye – erm and draw my attention (EJ 7. 322-325)

- Restrictive use of mirrors - mirror avoidance as a preventative measure
- Avoiding mirrors whilst grooming reduces the risk of focusing on other areas considered dissatisfying

Appendix G: Participant Information Sheet for Art-based Study

[REC ID: #1537, Version 2, 20190823]

Title of study: An arts-based study to explore the experience of living with Body Dysmorphic Disorder (BDD)

Participant Information Sheet

Invitation

We would like to invite you to take part in a research study.

Before you decide if you would like to participate, take time to read the following information carefully and, if you wish, discuss it with others such as your family, friends or colleagues.

Please ask a member of the research team, whose contact details can be found at the end of this information sheet, if there is anything that is not clear or if you would like more information before you make your decision.

Technical terms:
Body Dysmorphic Disorder: Body Dysmorphic Disorder (also called Body Dysmorphia or BDD) is an anxiety disorder relating to body image. People with Body Dysmorphic Disorder experience obsessive concerns about one or more perceived flaws in their appearance. The flaw may be very slight or may not be visible to other people at all.
Arts-based task: This involves creating a piece of art to represent your experiences of living with Body Dysmorphic Disorder.

What is the purpose of the study?

This research is being undertaken as part of a Psychology PhD qualification. The study aims to explore people's experiences of living with Body Dysmorphic Disorder (Body Dysmorphia; BDD) and consists of two parts: an arts-based task and a follow-up interview. Individuals involved in this research project are Shioma-lei Craythorne (Researcher, PhD student) and her supervisors, Dr Michael Larkin and Dr Rachel Shaw.
We are interested in exploring the experiences of people living with Body Dysmorphic Disorder. In particular, we are interested in gaining a deeper understanding of what it is like to live with BDD from the perspective of someone living with the condition. It is believed that using visual representations of living with BDD may help people better understand the disorder. The findings from this research may help to raise awareness of BDD, may increase the knowledge of healthcare professionals and potentially help them to better support and advise those living with BDD or caring for someone with BDD.

Why have I been chosen?

You have been asked to consider participating in this study because you have identified as living with Body Dysmorphic Disorder (Body Dysmorphia; BDD).

What will happen to me if I take part?

If you decide to participate in this study, you will be asked to complete the Body Dysmorphic Disorder Questionnaire (BDDQ) in an online questionnaire sent to you via email by the researcher (Shioma-lei Craythorne). The questionnaire will ask you how you currently feel about your appearance. After completing the questionnaire, the researcher will send you an email within 3 days containing a question and some prompts to help you create your piece of art. You can use any material(s) you wish, such as (but not limited to) pencils, paint, 3D materials etc. You will be asked to complete your piece of art at home and then send the researcher photographs of it once you have completed it. You will not be judged on your artistic skill. The focus will be on how you have chosen to represent your experiences of living with Body Dysmorphic Disorder.
Your art piece should take no more than 2 hours to create, and we would not expect this process to take more than a total of 4 weeks to complete. If you are concerned that it may take you longer to complete this, please contact the researcher (Shioma-lei Craythorne) to discuss this. If you are concerned about email privacy, please feel free to put your picture(s) in a Word document, password protect your file, and then send the password for the file to the researcher in a separate email. You will be sent instructions on how to do this when the researcher emails you with your question and prompts. This is optional, and the file you send does not need to be password protected if you do not wish it to be.
Once you have sent photographs of your piece to the researcher, she may email you asking you to send some additional photographs of specific areas of your piece for clarification purposes. A maximum of 5 emails about your piece will be exchanged between you and the researcher, and the researcher will only seek clarification photographs within 14 days of her receiving your art piece.
You will then be asked to take part in an interview to discuss your piece and experiences in more depth. The researcher will agree a date, time and location for your interview at your convenience. Your interview can be conducted in a private room at Aston University in Birmingham, your own home, via telephone, Skype (audio only, if you would prefer), or Zoom. The interview should take no longer than 60 minutes and will involve the researcher discussing and asking you questions about your art piece and experiences of BDD. You can stop the interview at any time without giving a reason.
With your permission, we will audio record the interview and take notes.

The recording will be typed into a document (transcribed) by the researcher. This process will involve removing any information which could be used to identify individuals e.g. names, locations etc.

Audio recordings will be destroyed as soon as the transcripts have been checked for accuracy.

We will ensure that anything you have told us that is included in the reporting of the study will be anonymous.

You of course are free not to answer any questions that are asked without giving a reason.

Do I have to take part?

No. It is up to you to decide whether or not you wish to take part.

If you do decide to participate, you will be asked to sign and date a consent form. You would still be free to withdraw from the study at any time without giving a reason. If you wish to withdraw from the study, please inform the researcher (Shioma-lei Craythorne) using the contact details at the end of this sheet.

Will my taking part in this study be kept confidential?

Yes. A code will be attached to all the data you provide to maintain confidentiality.

Your personal data (name and contact details) will only be used if the researchers need to contact you to arrange study visits or collect data by phone. Analysis of your data will be undertaken using coded data.

The data we collect will be stored in a secure document store (paper records) or electronically on a secure encrypted mobile device, password protected computer server or secure cloud storage device.

To ensure the quality of the research, Aston University may need to access your data to check that the data has been recorded accurately. If this is required, your personal data will be treated as confidential by the individuals accessing your data.

What are the possible benefits of taking part?

While there are no monetary benefits from taking part in this study, it is hoped that information provided by you will increase the knowledge of healthcare professionals, potentially enabling them to provide better support and advice for those living with Body Dysmorphic Disorder or caring for someone with Body Dysmorphic Disorder.

What are the possible risks and burdens of taking part?
If you become distressed as a result of your participation, please let the researcher know either at the time or by contacting her using the contact details provided in this information sheet. In the first instance, we can discuss any difficulties that arose. If you need professional help, she will speak to you about this and you may then wish to contact your GP or another healthcare professional. She will also provide you with the contact details of additional sources of assistance in your local area (such as Samaritans) if you are in distress. If the answers you provide in the study cause the researcher concern about your own well-being, she will contact you and may suggest that you contact your GP for further advice.

What will happen to the results of the study?

The results of this study may be published in scientific journals and/or presented at conferences. If the results of the study are published, your identity will remain confidential.

A lay summary of the results of the study will be available for participants when the study has been completed and the researchers will ask if you would like to receive a copy.
The results of the study will also be used in Shioma-lei Craythorne's PhD thesis.

Expenses and payments

Because the researcher is self-funded, there are no expenses or payments available.

Who is funding the research?

The study is being funded by the researcher (Shioma-lei Craythorne).

Who is organising this study and acting as data controller for the study?

Aston University is organising this study and acting as data controller for the study. You can find out more about how we use your information in Appendix A.
Who has reviewed the study?

This study was given a favorable ethical opinion by the School of Life and Health Sciences Research Ethics Committee.

What if I have a concern about my participation in the study?

If you have any concerns about your participation in this study, please speak to the research team and they will do their best to answer your questions. Contact details can be found at the end of this information sheet.

If the research team are unable to address your concerns or you wish to make a complaint about how the study is being conducted you should contact the Aston University Director of Governance, Mr. John Walter, j.g.walter@aston.ac.uk or telephone 0121 204 4869.

Research Team

Shioma-lei Craythorne (craythos@aston.ac.uk / [omitted])
Dr Michael Larkin (m.larkin@aston.ac.uk / 0121 204 3112)
Dr Rachel Shaw (r.l.shaw@aston.ac.uk / 0121 204 4050)

Thank you for taking time to read this information sheet. If you have any questions regarding the study please don't hesitate to ask one of the research team.

If you are experiencing a mental health crisis, you may find it helpful to speak to Samaritans on 116 123 or your local healthcare provide

Aston University takes its obligations under data and privacy law seriously and complies with the General Data Protection Regulation (“GDPR”) and the Data Protection Act 2018 (“DPA”).

Aston University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study. Aston University will process your personal data in order to register you as a participant and to manage your participation in the study. It will process your personal data on the grounds that it is necessary for the performance of a task carried out in the public interest (GDPR Article 6(1)€. Aston University may process special categories of data about you which includes details about your health. Aston University will process this data on the grounds that it is necessary for statistical or research purposes (GDPR Article 9(2)(j)). Aston University will keep identifiable information about you for 6 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information at www.aston.ac.uk/dataprotection or by contacting our Data Protection Officer at dp_officer@aston.ac.uk.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

When you agree to take part in a research study, the information about you may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of research, and cannot be used to contact you.

Appendix H: Consent Form for Arts-based Study

[REC ID: #1537, Version 2, 20190823]

Aston University

An arts-based study to explore the experiences of living with Body Dysmorphic Disorder (BDD)

Consent Form

Name of Chief Investigator: Shioma-lei Craythorne

Please initial boxes

1.	I confirm that I have read and understand the Participant Information Sheet (Version 2, 20190823) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	
3.	I agree to my personal data and data relating to me collected during the study being processed as described in the Participant Information Sheet.	
4.	I understand that if during the study I tell the research team something that causes them to have concerns in relation to my health and/or welfare they may need to breach my confidentiality.	
5.	I agree to my interview being audio recorded and to anonymised direct quotes and artwork from me being used in publications resulting from the study.	
6.	I agree to my anonymised data being used by research teams for future research.	
7.	I agree to my personal data being processed for the purposes of inviting me to participate in future research projects. I understand that I may opt out of receiving these invitations at any time.	
8.	I agree to take part in this study.	

______________________________ ______________ __________________
Name of participant Date Signature

______________________________ ______________ __________________
Name of person receiving consent Date Signature

Appendix I: Letter of Ethical Approval for Arts-based Study (Project #1537)

Aston University
Birmingham

Aston Triangle
Birmingham B4 7ET
United Kingdom
Tel +44 (0)121 204 3000

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Memo

Life and Health Sciences Ethics Committee's Decision Letter

To:	**Shioma-lei Craythorne** **Michael Larkin**
Cc:	Charanjit Bhatti Administrator, Life and Health Sciences Ethics Committee
From:	Dr Rebecca Knibb Chair, Life and Health Sciences Ethics Committee
Date	2/10/19
Subject:	**Project #1537 An arts-based study to explore the experience of living with Body Dysmorphic Disorder (BDD)**

Thank you for your submission. The additional information for the above proposal has been considered by the Chair of the LHS Ethics Committee.

Please see below for details of the decision and the approved documents.

Reviewer's recommendation: Favourable opinion

Please see the tabled list below of approved documents:

Documentation	Version/s	Date	Approved
Response to reviewer's comments	1	23/8/19	✓
Participant information sheet	2	23/6/19	✓
Consent form	2	23/8/19	✓
Research Protocol	1	27/5/19	✓
Risk assessment	1	23/8/19	✓
Recruitment poster	2	23/8/19	✓
Interview topic guide	1	8/7/19	✓

After starting your research please notify the LHS Research Ethics Committee of any of the following:

> **Substantial amendments.** Any amendment should be sent as a Word document, with the amendment highlighted. The amendment request must be accompanied by all amended documents, e.g. protocols, participant information sheets, consent forms etc. Please include a version number and amended date to the file name of any amended documentation (e.g. "Ethics Application #100 Protocol v2 amended 17/02/12.doc").

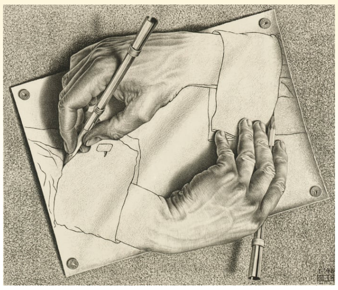
Appendix J: Study Advertisement for Arts-based Study

Aston University

Arts-based research on people's experiences of living with Body Dysmorphic Disorder (BDD)

We are seeking participants. Would you like to take part in this research project?

Participation involves completing:



- A short online questionnaire
- Creating a piece of artwork to represent your experiences of living with Body Dysmorphic Disorder
- A follow-up interview based on your art piece

You can participate in this study if you are aged 18 or over and identify as living with Body Dysmorphic Disorder (BDD)

Please contact **Shioma-lei Craythorne** for more information:

craythos@aston.ac.uk
craythos@aston.ac.uk
craythos@aston.ac.uk
craythos@aston.ac.uk
craythos@aston.ac.uk
craythos@aston.ac.uk
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craythos@aston.ac.uk
craythos@aston.ac.uk

Appendix K: Example analysis using Boden and Eatough's (2014) Framework for the Analysis of Drawings

[This analysis was conducted upon Aurora's painting shown in Figure 7.1 on page 149 of this thesis.]

Element of framework	Analysis
1. Contents: Describe each of the distinct elements of the image	The image is split into two equal parts – a 50/50 split – could this visually represent how often Aurora experiences bad vs manageable days? Cluster of faceless people each doing different activities in an outdoor environment Large eye and magnifying glass above nude figure covering her face
2. Composition: How are the elements spatially laid out on the page? Are they sparse or dense, are there areas of blank page, do the elements overlap? Is there a sense of repetition, 'rhyme', or pattern?	There is a clear boundary between the left and right sides – equally sized Images are close together, with some background visible In the eye section, the stick figures seem to represent a crowd (but they are relatively sparse) – Could this be an example of metonymy? Repetition of stick figures. Repetition of eyes each with a different colour iris – suggests they may belong to different viewers Given and new (left and right)? The BDD side is 'new' to most viewers of the painting, in that it is illustrating what BDD looks/feels like to people who may not be familiar with it – information she wishes to impart Images of eyes above the figure – could be representative of a panopticon - Foucault

3. Balance: How do elements interplay? Is there a sense of equilibrium or disequilibrium? Is there symmetry or pattern?	Juxtaposition of the images on the left and right Contrast between human eyes looking down upon a figure, a ‘monster’, or non-human
4. Geometry: What shapes are used? How do these interplay together?	Curved, human forms Nature, natural forms (for example, trees, leaves in painting) Triangular signs representative of a hazard, biohazard, radioactivity, danger Very clear contrast, definitely representative of a disruption (BDD), destroying the equilibrium An ‘irregular’ human form contrasting with ‘typical’ human forms.
5. Materials: Which material has been used for each element?	Used acrylic paint on canvas for the whole painting

6. Texture: What are the textural characteristics for each element?	There are some particularly interesting textures on the monster figure. Bumpy looking skin/flesh Slug-like composition of the body Three-dimensional, contrasted with the two-dimensional hazard signs (2D and 3D in the same 'world' – this could be viewed as surreal, and could be characteristic of the distorted BDD experience). Smooth texture for the people on the left, depicted on the 'more manageable' side of the painting. The eyes included could be seen as a 'normal' representation of human eyes above the monster figure. Smooth and reflective in appearance.
7. Colour: How have hue (colour), saturation (vividness), and value (lightness/darkness) been used?	There is a stark contrast between the blue and red sides of the painting, achieved predominantly via the choice of background colour. Blue skies on the left side depicting the natural world, freedom, escapism, freedom from BDD. Strong connection to nature, peaceful, tranquil. Harmonious relationship with nature and the body. The blue sky forms/connects to the horizon. Red background – traditionally associated with passion and anger. The red may also represent pain, pain associated with BDD and painful bodily experiences. Danger – red danger sign There are different shades of red included, and different intensities, whereas the blue background on the left is one, uniform block colour. Could represent the varying intensities of BDD. Connotations of Hell.

8. Depth/Perspective: What spatial depth and perspective have been created through space and colour?	Depth conveyed through different shades of red. Greater in depth than the blue colour used. Varying levels of depth may represent uncertainty, pitfalls, irregularities in experience Mixture of 2D/3D elements (hazard signs and high level of texture in the flesh of the monster figure) The eye looking through the magnifying glass seems more prominent an seems to almost come out of the page
9. Temporality/Dynamism: Is there a sense of rhythm or movement? Does the image suggest a snapshot, continuity or duration?	The activities depicted on the left possess a sense of movement e.g. yoga, hiking, painting. Being joyful and jumping for joy. They appear to be different snapshots that represent how Aurora copes with her BDD.
10. Focus: What is the visual focus of the image? What is your eye drawn to?	My eye is drawn to the large eye looking through the magnifying glass. Its size in comparison to the other aspects of the painting stands out. Contrasting colours white and blue with red. It is located in a high position on the canvas. Overall, I think lots of the aspects of the painting seem to be competing with one another for the viewer's focus – could represent how hectic and irrational the experiencing of coping with and living with BDD may be for Aurora.

11. Expressive content/Empathic reaction: What is the emotional tone of the image? What feelings does the viewer have in response (bodily, emotional, memories, images)?	On the right – torment, panic, torture. A vulnerability of the monster figure is conveyed when I view it. There is a palpable sense of sadness and fear On the left – relief, tranquillity. It is difficult to connect with the figures as they do not have faces or any specific features, but I can still identify that they are at peace. Being faceless may represent blending into the world as 'normal' humans, not being affected by BDD.
12. Signs/Symbolism: Are there any overt symbols or cultural references included?	The inclusion of the danger sign, hazard sign, symbolic of radioactivity, biohazards, disposal.

13. Style: Does the image 'shout' or is it 'quiet', or something in between? Does the drawing seem to imitate or reflect a particular trend or style, e.g. cartoonish, child-like, modern, romantic, pop-art, etc.?	The left side of the painting is serene and seems quite still when I view it. The right side 'shouts' and imposes upon the viewer. The stick figures could be viewed as child-like.
14. Text: Has any text been included, for example a title? Where has this been placed? In what way has it been included? What style, font, capitalisation, etc., is used?	The only text included in the painting is the word 'DANGER' as part of the danger sign. It is written in block capital letters in black, following the theme of the other signs.

15. Distraction/Noise: Do any elements draw your attention away from the main focus? Is there a sense of confusion or clarity in the image?	Lots of the images compete for the viewer's focus – there is a lot going on and I found my eyes flitting from one aspect to another, intrigued by what I might notice next in the painting. The image is clear to understand on both sides, but raises a lot of questions due to the intensity and 'busy-ness' of the piece.