

# **I will be at deaths door and realize that Ive wasted maybe half of my life on one body part: the experience of living with body dysmorphic disorder**

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## **Journal Article**



N.B.: When citing this work, cite the original article.

Original Publication:

Sabina Brohede, Barbro Wijma, Klaas Wijma and Karin Blomberg, I will be at deaths door and realize that Ive wasted maybe half of my life on one body part: the experience of living with body dysmorphic disorder, *International journal of psychiatry in clinical practice* (Print), 2016. 20(3), pp.191-198.

<http://dx.doi.org/10.1080/13651501.2016.1197273>

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Postprint available at: Linköping University Electronic Press

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-131206>

*'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

Running title: The experience of living with BDD

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## **ABSTRACT**

**Objectives:** The purpose of this study was to explore the experiences of patients living with body dysmorphic disorder (BDD), including their experiences with the health care system. **Method:** Fifteen individuals with BDD were interviewed, and interpretive description was used to analyse the interviews. **Results:** The following six themes were identified: being absorbed in time-consuming procedures, facing tension between one's own ideal and the perceived reality, becoming the disorder, being restricted in life, attempting to reduce one's problems, and striving to receive care. The overarching concept derived from the themes was feeling imprisoned – struggling to become free and to no longer feel abnormal. **Conclusions:** Ideas of imprisonment and abnormality compose the entire experience of living with this disorder. Although the participants suffered greatly from their BDD, these patients encountered difficulties in accessing health care and had disappointing experiences during their encounters with the health care system. Therefore, it is important to increase awareness and knowledge of BDD among health care professionals to ensure that patients with BDD receive the appropriate care.

## **KEYWORDS**

body dysmorphic disorder, interview, qualitative research, body image

## INTRODUCTION

Body dysmorphic disorder (BDD) is a psychiatric disorder defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM)-5 as a distressing and impairing preoccupation with perceived defects or flaws in appearance that are not observable or appear only slight to others (American Psychiatric Association, 2013). Although concerns may focus on any part(s) of the body, the most common areas of concern are the skin, hair and nose (Phillips 2009; Phillips and Diaz 1997). In the literature, BDD has been described as a disorder characterized by a pattern of obsessive thoughts, feelings and compulsive behaviours. The preoccupations are generally quite time-consuming, occurring on average 3–8 hours a day and are difficult to resist or control (Phillips 2014; Phillips and Hollander 2008). The largest studies of the general population have identified BDD prevalence rates of 1.7%-2.4% in Germany, Sweden and the United States (Brohede et al. 2015; Buhlmann et al. 2010; Koran et al. 2008; Rief et al. 2006). Quantitative studies have demonstrated that the condition leads to impaired functioning in relationships, socializing, and intimacy as well as to a decreased ability to function at work, in school, or in other daily activities (Perugi et al. 1997; Phillips 2009). BDD is associated with significant distress, shame, disability, and suicidality (Crerand et al. 2005; Fang and Wilhelm 2015; Phillips 1991; 2007; Phillips and Menard 2006). BDD often goes unrecognized by dermatologists, plastic surgeons, and other physicians whom patients with BDD often approach first in their attempts to correct their perceived flaws (Phillips 2007). The age of onset of BDD is commonly during adolescence; however, patients are generally diagnosed 10-15 years later (Veale 2004). Treatments that have been shown to be effective for BDD are serotonin-reuptake inhibitors and cognitive behavioural therapy (Crerand et al. 2005; Enander et al. 2016; Phillips and Hollander 2008; Veale et al. 2014; Wilhelm et al. 2014).

Previous studies on BDD have primarily described the clinical features of BDD through quantitative methodologies. Only a few qualitative interview studies have explored BDD. Silver et al. have interviewed eleven individuals with BDD and have used a visual approach with photographs combined with narrative analysis to assess the manner in which people with BDD perceive their appearance (Silver and Reavey 2010; Silver et al. 2010). These authors identified an increased threat perception, resulting in disordered

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interpersonal relationships, a wish for regularity and symmetry in appearance, idealization of the childhood self, the duty to look good, and a focus on specific details rather than on 'ugliness' (Silver et al. 2010). In a recent study exploring mirror-gazing in ten individuals with BDD, the participants described mirrors as being controlling, imprisoning and disempowering forces with crippling and paralysing effects on life (Silver and Farrants 2015).

To the best of our knowledge, no previous studies have explicitly solicited patient perspectives or addressed the experience of living with BDD. Because the disorder remains relatively unknown, it is important to study patient perspectives to provide data to increase understanding of BDD, particularly among health care professionals. Therefore, the purpose of this study was to complement existing quantitative research by exploring patients' experiences with the disorder, including their experiences with the health care system.

## METHOD

### Design

This study is a portion of a larger project exploring BDD in Sweden. In the present study, an explorative qualitative design was used. The study was approved by the regional Ethics Board, Linköping, Sweden (D-no 2013/491-32).

### Participants

Based on the assumption that people who have lived with certain experiences are the best source of knowledge (Kvale and Brinkmann 2009), a purposive sampling was used, and 15 participants were selected based on their experience with BDD. Three women were recruited from a previous study by our research team, which assessed BDD prevalence in female dermatology patients. Of the 21 dermatology patients who screened positive for BDD in that study, only seven women accepted an invitation to a diagnostic assessment (the remaining 14 women declined participation or could not be contacted by telephone or mail). Three of these seven women who were diagnosed with BDD were invited and agreed to participate in the present study. Because fewer participants than expected could be recruited from the dermatology patient study, twelve additional participants were recruited from a clinic specializing in treating BDD. Individuals diagnosed with BDD who had been placed on a waiting list for treatment received an invitation letter to participate in the present study. The first twelve who declared their willingness to participate were invited, and they agreed to participate in the study. Their experiences with the disorder would theoretically contribute to expanding the emerging data, according to the principle of maximum variation sampling (Patton 2002). For the same reason, both male and female patients were recruited into this group. Participants were included even if current comorbidities existed, which was recorded in three cases (one participant with social anxiety disorder, one with borderline personality disorder and attention deficiency hyperactivity disorder combined, and one with Asperger's syndrome and generalized anxiety disorder combined). However, during the interviews, the specific focus was on their experiences with BDD. The background characteristics of the 15 participants are shown in Table 1.

\*Table 1 approximately here

### Data collection

The 15 individuals with BDD were interviewed individually by the first author between April 2013 and May 2014, using an interview technique based on Price's ladder questions. This technique begins with less sensitive questions regarding actions/behaviours and is followed by questions regarding feelings and more intimate and potentially more sensitive topics, e.g., suicidality (Price 2002). A general interview guide approach was used that listed the areas to be studied (Kvale and Brinkmann 2009). The experience of living with BDD was explored in the following themes: well-being, occupation/school, social life/leisure, relationships, intimacy/sexuality, communication of problems, and experiences with the health care system. Each interview began with the question, 'How has BDD influenced your everyday life?' Subsequent questions were more probing to further explore the participants' experiences. Researchers kept a reflective journal to make some minor adjustments to the interview guide for subsequent interviews. The interviews lasted between 60 and 90 minutes. Ten participants were interviewed face-to-face in rooms of the participating hospital buildings. Five participants were interviewed by telephone because no suitable time or place for face-to-face interviews could be arranged. One interview was conducted in English because the participant was a native English speaker. The interviews were audio-recorded and transcribed verbatim by the first author (n=3) and by an external transcriber (n=12). Participants' names were removed, and identifiable details were changed to ensure confidentiality.

### Data analysis

Interpretive description, developed by Thorne et al., was used to analyse the interviews, because it is an inductive approach to understanding clinical phenomena with the purpose of capturing human experiences with health and illness (Thorne et al. 1997; Thorne 2008).

All interviews were analysed by the first author and validated by the last author. The first step of the analysis was reading through and listening to the interviews several times to obtain a sense of the whole (Step 1). In the next step, all interviews were coded

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by marking text units and/or entire phrases related to the purpose, and headings were formulated that described the essence of the content (Step 2). Related headings were grouped together by considering questions such as 'What is happening here?', 'What is this about?' and 'What differences and similarities exist?' (Step 3). In the fourth step, subthemes and themes were formulated in an iterative process (Step 4). A subtheme was formulated for each group of headings, and these subthemes were grouped together in themes reflecting similarities and differences. Common patterns as well as individual variations were sought out (Thorne et al. 2004). The analysing authors had on-going discussions, attempting to minimize overlap and inconsistency, and reached consensus on themes and subthemes. The analysis identified six themes, and subthemes were described within each theme. Finally, an overarching concept was developed from the underlying meanings of the themes.

## RESULTS

The overarching concept, themes and sub-themes identified by the analysis are illustrated in Table 2.

\* Table 2 approximately here

### Feeling imprisoned – struggling to become free and to no longer feel abnormal

Living with BDD was described as a constant struggle, comparable to constantly carrying a weight or being in a prison and never being free. Several of the participants suggested that the disease had taken over their lives and had become a part of them. One woman called BDD her worst enemy, comparing the disease to a *'cyclone or a black hole that has no mercy'*. Participants described feeling different, abnormal and not consistent with the norm. Some equated living with BDD with being disabled. They described striving to fit in and *'be normal'*, and they hoped for *'a normal life'*. For the majority of the participants, the problems had started before or during adolescence and had been present throughout their lives. Although the severity of symptoms typically varied over time, several described a progressive worsening.

### Being absorbed in time-consuming routines

#### **Being preoccupied by one's appearance**

Participants described their appearance concerns as consuming all of their focus to the point of becoming an obsession. The preoccupation commonly shifted, and different body parts were perceived as being defective during the course of the illness. The participants felt that they had no control over their appearance and also had difficulties coping with changes in appearance. Participants worried about appearing superficial but insisted that living with BDD is not about being superficial or vain. However, these patients could not accept their perceived appearance flaws and felt bad when reminded of their appearance. Attempting to put appearance concerns in perspective typically did not help, as illustrated by a 34-year-old woman who went to a developing country for work:

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*'I am stationed some of the time in villages where there is no electricity or running water, in one of the poorest countries in the world, and I'm like 'what about my nose' [scoffs], so that's, well, that is, like, completely insane; this thing is out of proportion [...]. I have all these perspectives [...] I have the nicest family in the world and friends who love me and would do anything for me. I have food on the table, roof over my head - it doesn't help. [...] I cannot get over how dissatisfied I am'.*

### **Being controlled by the mirror**

Nearly all of the participants expressed a need to constantly look in the mirror. Participants described losing track of time while scrutinizing their reflections and becoming stuck in front of mirrors and other reflecting surfaces for hours or even the majority of the day. Looking in the mirror was described as a terrible experience, causing anxiety, panic, fear, sadness and disgust. Seeing one's reflection was equated with a specific phobia, becoming '*paralysed by fear*'. Although most participants believed that the mirror was their worst enemy and felt an urge to avoid looking in the mirror for periods of time, some participants expressed varying feelings, describing a love-hate relationship with the mirror. One factor driving the respondents to look in the mirror was hoping that the reflection would not confirm their mental image of themselves. Participants expressed seeking a calming effect from looking in the mirror; however, these patients also reported that such a calming effect typically did not last long and that mirror-checking did not ultimately improve their self-image.

### **Being bound by obsessive thoughts and behaviours**

The participants described having time-consuming thoughts or obsessions and routines or behaviours. The most commonly reported behaviour was checking one's appearance. Scrutinizing other people, and comparing their own appearance with the appearance of others also occurred quite frequently. The participants had different types of routines, such as washing, putting on make-up, and changing clothes repeatedly. Sometimes these patients engaged in their routines for hours at a time and had to start over if the routine was disturbed. Several expressed being bound by their behaviours, calling them compulsions.

## Facing tension between one's own ideal and the perceived reality

### **Perceiving internal and external expectations**

Participants discussed having high standards for themselves and described themselves as high-performing people. These respondents were often able to perform quite well in work and studies but were never satisfied and never felt good enough. More specifically, some participants indicated that they had to look perfect but were unable to live up to their appearance ideals. Some participants had perceived high requirements from their families; however, the participants imposed requirements on their appearance themselves. Some respondents believed that life would be perfect if they looked ideal, as expressed by a 35-year-old woman:

*'I am always admiring beautiful people, like, it's as if I looked like them, my life would be, like, perfect, and I would be able to live a normal life'.*

### **Seeking confirmation regarding one's appearance**

Participants were frequently concerned about what others thought about them, particularly regarding their looks, and often sought confirmation from other people; however, such confirmation only temporarily alleviated their problems. These patients were sensitive to how other people treated them and described a discomforting feeling of being scrutinized by others. Family and friends tried to reassure the participants, for example, by paying compliments; however, the participants would typically not trust those comments, and sometimes compliments even augmented the participants' problems. Remarks of all types directed against participants, not only regarding appearance, were interpreted negatively, and comments regarding appearance were described as *'destroying you'*.

### **Being uncertain about the reality of one's flaws**

Nearly all participants reported that other people did not acknowledge their perceived appearance defects. Participants expressed being uncertain about whether they were exaggerating their perceived flaws. Several respondents specifically expressed believing their appearance flaws to be real and were convinced that they had a correct or objective image of themselves. Some participants were unsure whether other people noticed their flaws, and other participants firmly believed that other people did notice

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their flaws but were humouring them to spare their feelings. Several participants did not truly believe that they had BDD because they believed their flaws to be quite obvious. Other respondents acknowledged that their preoccupation was out of proportion and irrational and that perhaps their flaws were imaginary, even to the point of thinking of themselves as unsound or crazy. Some participants could intellectually recognize that their appearance was not so bad but could not refrain from thinking irrationally about their flaws, as one woman expressed when discussing her reaction when looking in the mirror:

*'I lose, uh, my sense of rationale and I can't logically think [...] It's this wave that inhibits me from – from – thinking straight, so to speak, from thinking logically. It's a feeling of fear that's associated with – uh, with the whole experience as well.'*

### Becoming the disorder

#### **Feeling ugly**

All participants acknowledged feeling ugly, and this feeling became a component of their identity. Participants hated their appearance and used phrases such as *'being the ugliest person in the world'*, *'being indescribably ugly'*, *'feeling severely deformed'*, *'looking inhuman'* or *'like a monster'*. A 27-year-old woman said,

*'I never had an ambition to be the most beautiful - I would just like not to be grotesque.'*

Related to this feeling, some participants mentioned feeling that ugly people do not have the same rights or even may be perceived as being bad people. One of the participants did not feel ugly in general and said that he knew he was not ugly, but that certain defects made him feel ugly.

#### **Being emotionally distressed**

The participants described feeling obnoxious or even being disgusted by themselves. Several participants were ashamed of their appearance, although a more general sense of shame was more often described. These patients knew that something was wrong and blamed themselves. Participants expressed hating themselves, feeling inferior to other

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people or even worthless, thus resulting in a loss of self-esteem and self-confidence. Depression and anxiety caused by their appearance concerns were common. Participants described crying for hours, being sad every day, and feeling grief for having destroyed themselves. These sufferers were never able to relax, had difficulty sleeping, were extremely tired and lacked energy. General anxiety and panic attacks were most commonly caused by looking in the mirror but could also be caused by getting dressed or seeing a picture of themselves. In their attempts to reduce anxiety, several participants discussed abusing alcohol, drugs, and steroids. Some patients also had a history of eating disorders.

### **Losing the will to live**

Participants experienced feelings of hopelessness and futility, saying, *'There is no way to escape'*, *'Life is not worth living'* and that they *'cannot take it anymore'* or *'didn't want to live anymore'*. Almost all participants had experienced suicidal ideations. Many of these patients had formulated concrete suicide plans, and two participants had even tried to kill themselves. One young man, when considering suicide, remained quite concerned about his looks when dead:

*'I had a clear image of how I, well, like shoot myself in the temple - with a hand gun of some kind, I also think about how I would place the shot, eh, so that I wouldn't [laughing a bit] ruin my hair line, kind of morbidly ...no but I would like to be a nice corpse'.*

Suicidal ideation commonly varied over time, and some participants expressed feeling relieved that they had not killed themselves and that the thought of suicide now felt surreal.

### **Being restricted in life**

#### **Finding one's achievements and work/studies to be affected**

Participants experienced being unable to fully achieve their goals and felt that the disorder affecting everything in their lives; participants expressed feeling confined, being restrained and as if they were not fully living. Their quality of life was affected by

losing interest in '*all other things*', losing motivation and only being half-heartedly involved in things, as described by a 34-year-old woman:

*'And I will be at death's door and realize that I've wasted maybe half of my life - on one body part.'*

Work and studies were frequently described as being negatively affected. Descriptions ranged from difficulties in getting to work, absences from school and not going to school or work to being unable to work for extended periods of time and quitting school altogether. A majority were presently or had been unemployed or on sick leave, and a few indicated that the disease had caused burnout. Several respondents did, however, manage to go to school or work for periods of time and some participants expressed positive feelings regarding work, such as feeling safe at work and loving their jobs.

### **Staying at home and keeping away from people**

Participants described avoiding socializing with people, including cancelling meetings, making excuses, being late, and frequently missing out on activities. Some confessed not wanting to socialize, not letting people in, and being uncomfortable or even hating being around people. Some patients experienced anxiety induced by social situations, and several acknowledged suffering from social phobia. Other participants expressed feeling lonely and longing to get to know people, the desire to be part of social contexts, and attempting to socialize. Although some participants had no problems socializing and thought that other people would probably describe them as outwardly social and positive, the common pattern was that inside, participants felt socially restricted, as illustrated by feelings of not being socially involved or '*ending up outside society*'.

Nearly all participants described some degree of difficulty leaving their houses and being worried when going out or being unwilling to go out alone. Indeed, almost half had experienced being unable to go out at all, some to the point of being homebound. For instance, one man said that he would '*hibernate and become bedridden from time to time*'. One woman said she was '*safe at home where no one could see her*' and further described,

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*'OK, I admit that I have to live, but I refuse to go out into life, I don't want to participate in it because people will just say that I am ugly and disgusting'.*

Only a few participants experienced few or no difficulties going out and said that they would *'pull myself together and go out'* or *'go out despite the risk of anxiety'*.

### **Having concerns with regard to friends and family**

Close friendships were limited for the participants. Several respondents had only a few friends, whereas others described being unable to socialize with friends at all or excluding friends. These participants expressed being uncomfortable around friends or how terrible it was when a person came knocking at the door unannounced.

Participants were concerned about negative effects on family members. Specifically, some participants mentioned that their problems were burdensome for their mothers and that their mothers were getting desperate. Some respondents also had concerns regarding becoming parents themselves. One woman expressed that *'you are not allowed to have these kinds of thoughts when you are a parent'*.

Participants found it difficult to explain their appearance problems to others; these patients were ashamed to talk about their problems and even afraid of abandonment if other people learned of their difficulties. Most participants had told only a few people or no one at all. In general, participants did obtain support from family and some close friends; however, nearly all participants also had experiences in which friends and family were not as understanding. Some friends were even condemnatory when participants attempted to explain their problems. Other friends would consider the participants to be superficial, ridiculous, or even crazy and had said *'Get over yourself'*. A few respondents expressed having no support at all, not even from close friends and partners and felt hurt or even betrayed by friends.

### **Experiencing difficulties in relationships with intimate partners**

The participants' relationships with intimate partners were commonly affected. Some patients described their relationships as restricted, reporting not having time for their partners because of their rituals or feeling that there was no room for a partner at all

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when living with this disease. Several participants had experienced their partners' being insufficiently understanding and losing patience. Participants were concerned about the negative effects of their problems on the partner's life and expressed that it would be better for the partner to live without them. Several respondents did, however, manage to maintain intimate relationships, and a few participants felt that their relationships had not been affected and felt safe with their partners.

Intimacy was described as a particularly difficult aspect of relationships. Because of constantly focusing on their looks, their '*hideousness*', feeling unattractive, or feeling that their looks had to be perfect, participants ended up avoiding intimacy or feeling anxious and unsafe in intimate situations. Avoiding being naked was common, as was not wanting to be touched and feeling suffocated by physical contact. These participants indicated not being interested in sex, having no sex drive, or not liking sex.

### Attempting to reduce one's problems

#### **Attempting to conceal defects**

Participants adopted various strategies to avoid facing their own flaws and to conceal these flaws from other people. Participants avoided looking at photographs of themselves or having their picture taken. One woman even refused to take her wedding photo. Trying to conceal their defects was a large component of the participants' everyday lives. These patients camouflaged their flaws using make-up (sometimes even when sleeping), clothes, sunglasses, hairdos, and wigs. Avoiding certain lighting or showing themselves from certain angles was also described. One woman said, '*I sometimes wish I could wear a burka*'. Participants also tried to conceal their behaviours and lied to others regarding their problems.

#### **Attempting to improve one's appearance**

In an effort to alleviate their problems, participants had frequently tried various products and methods to improve their appearance. These patients had consulted dermatologists and other physicians, who had sometimes prescribed medical treatments to alleviate their appearance problems. Most sufferers had considered plastic surgery to correct their flaws, and some participants even felt that they could not live

unless their defects were corrected and did not care about the risks associated with surgery. Several patients had in fact undergone surgical procedures. One woman had had seven or eight operations on her nose, spending years of her life saving for operations and moving from place to place to find accommodating surgeons. Several participants had encountered clinics that refused to conduct surgical procedures and had had to persuade both doctors and family members that the operations were necessary. Few sufferers had had any positive effects from appearance-enhancing methods or dermatologic treatments, and all participants who had undergone surgery were disappointed with the results and regretted having undergone the surgery.

### Striving to receive care

#### **Encountering difficulties in accessing health care**

Nearly all participants had experienced difficulties in obtaining help from the health care system. A majority described having to wait for a long time before obtaining help or not obtaining help in time; this delay occasionally led to increased suicidal ideation or even suicide attempts. The patients had sought help repeatedly. Some participants stated that they had desperately sought help and that they had to take matters into their own hands because health care professionals did not know where to refer BDD patients.

#### **Being disappointed in the health care system**

Participants had diverse experiences with their encounters with the health care system, experiencing not being taken seriously or being misunderstood. Several patients had had to educate health care professionals about their condition because knowledge regarding BDD was scarce or non-existent. Participants felt rejected, felt that the health care system lacked resources or felt disappointed that help was not available. One woman said that *'you lose faith in health care'*. A 37-year-old man whose problems had begun when he was as a six-year-old child described his experience with the health care system:

*'The help was non-existent; on the contrary, I came out of there feeling more downcast than before, so I just got it confirmed that I can't get any help with this. [...] I think I have met like at least seven, eh, psychologists eh up until today [...] but I have never received any*

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*help to get any further with the problems with my hair. [...] I guess they did not have any good idea concerning what could be done about this'*

However, many sufferers had ultimately found health care professionals, most commonly psychologists or psychology students, who were familiar with the disorder and could offer help. Several patients felt that they had been taken seriously within the psychiatric care system. Several participants noted that the diagnosis felt right; for some patients being diagnosed was a relief and reduced their shameful feelings. A few participants were soothed by receiving a diagnosis that indicated problems that could be treated.

## DISCUSSION

In this first qualitative study exploring the general experience of living with BDD, we observed that participants felt imprisoned and that life was a struggle to become free and to no longer feel abnormal. Their descriptions clearly indicate that the entire lives of the individuals in our study were affected by the disorder. Our results indicate that a feeling of imprisonment is a general theme in BDD, defining the entire experience of living with the disorder. Notably, the term 'imprison' was also reported in a recent qualitative study of people with BDD; that study has referred to mirrors as being controlling, imprisoning, and disempowering forces (Silver and Farrants 2015). The feeling of abnormality described by our participants referenced their psychological existence in relation to social life, work/studies, and close relationships. 'Normal' was the participants' own word choice; although it could be argued that it is an arbitrary term, it is nonetheless important to acknowledge these feelings of being abnormal. The longing for normality is consistent with reports in the existing literature on BDD, that have indicated that concerns of appearance are driven by a desire for 'normality' and not for beauty; BDD patients often emphasize that they do not seek an ideal body but simply want to change their imperfections so that they look 'normal' (Lemma 2009; Parker 2014). However, our participants generally had high expectations of themselves, and some participants specifically expressed high standards regarding their appearance. These expectations indicate that some participants were pursuing an unrealistic 'perfect' rather than 'normal' appearance. There is a discrepancy between how BDD patients see themselves and their ideal self, as demonstrated by Veale et al. (2003), and the resulting failure to achieve an internal aesthetic standard presumably contributes to the sense of abnormality, whether or not the ideal is realistic. Veale et al. (1996) have hypothesized that BDD patients have a magnified selective attention to their perceived defect because of their greater preoccupation with body image in terms of perfectionism or symmetry. In our study, however, only some of the participants admitted having high requirements for their looks.

The time-consuming patterns of obsessive thoughts, feelings, and compulsive behaviours described by the participants have been identified in previous quantitative studies (Phillips 2014; Phillips and Hollander 2008; Veale 2004). Our findings are also

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consistent with descriptions in the most recent version of the DSM (DSM-5), in which BDD is now classified in the section “Obsessive-Compulsive and Related Disorders” and a BDD diagnosis requires that the person engage in repetitive behaviours in response to appearance concerns (American Psychiatric Association 2013). The participants felt controlled by the mirror and described being stuck in front of the mirror, although mirror-gazing was associated with terrible experiences causing anxiety, panic and disgust. These findings confirm earlier results observed in quantitative and qualitative research. In a questionnaire-based study of BDD patients’ beliefs and behaviours in front of the mirror, Veale and Riley observed that individuals with BDD were driven by the need to know exactly how they looked. Similarly to the participants in our study, those subjects hoped to look better than their internal body image; however, the subjects were always more distressed after mirror-gazing than before (Veale and Riley 2001). In their qualitative study, Silver and Farrants have also observed mirror-gazing to be perceived as uncontrollable, addictive and entrapping, and their subjects described their reflections as monstrous and offensive (Silver and Farrants 2015).

The participants experienced tension between their own ideal and their perceived reality. The uncertainty regarding the reality of the flaws expressed by our participants indicates a heterogeneous sample with different levels of insight. Insight appears to occur on a continuum in BDD; where individuals on the most impaired end of the spectrum are delusional and are convinced that their appearance flaws are real (Fang and Wilhelm 2015). Our participants frequently sought confirmation from others regarding their looks while being quite sensitive to scrutiny by others. Notably, participants were concerned about appearing superficial to other people, although that knowledge did not help them to put their appearance problems in perspective. In line with existing descriptions of people with BDD, reassurance was received as patronizing, trivializing, or dishonest (Parker 2014). An important finding of our study is that reassurance and compliments from other people can in fact exacerbate symptoms. The findings of Silver et al. (2010) are consistent with our findings in areas such as sensitivity to other people’s comments, fear of being negatively perceived by others and that looking good is perceived as a necessity for succeeding in life.

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All participants expressed feeling ugly; this feeling was associated with emotional distress, shame and disgust, emotions that have also been reported in earlier research (Phillips 2014). For our participants, a general sense of shame was even more commonly described than shame regarding their appearance. Our participants also expressed hating themselves, feeling inferior to others, or even worthless, thus resulting in decreased self-esteem and self-confidence. The feeling of ugliness was profound and became a component of the individuals' identities. Previous studies have indicated that patients with BDD suffer social handicaps, experience disrupted studies or employment, and can even become housebound (Fang and Wilhelm 2015; Veale 2004). This is the first qualitative study to add detailed descriptions of how the disorder restricts patients' lives. Furthermore, symptoms of depression and anxiety were described, as was suicidal behaviour. According to earlier research, co-morbid depression and anxiety are indeed common in BDD patients (Brohede et al. 2015; Gunstad and Phillips 2003), and suicidality is a major clinical concern (Phillips 2007; Phillips and Menard 2006).

Although the participants suffered greatly from their BDD, they described difficulties in accessing health care and disappointing encounters with the health care system. As discussed above, BDD shares similarities with obsessive-compulsive disorder (OCD), and the disorders are probably related to each other (Phillips 2014). In a review from 2014, Garcia et al. have analysed factors associated with treatment barriers in OCD and have observed that shame regarding symptoms and not knowing where to obtain appropriate help are important factors in non-treatment or delayed treatment (Garcia-Soriano et al. 2014). Treatment barriers reported for individuals with BDD similarly include shame associated with talking openly about one's appearance concerns and lack of a specialized healthcare provider nearby (Buhlmann 2011; Marques et al. 2011). Although BDD is similar to OCD in some aspects, there are also some important differences between the disorders, including greater suicidality and poorer insight in patients with BDD (Phillips et al. 2007). Greater insight has been found to predict seeking health care in OCD patients (Garcia-Soriano et al. 2014), thus indicating that BDD patients, with poorer insight in general, may be subjected to even more delayed treatment. An online survey of 176 people with self-reported BDD found that only 23% had been diagnosed with BDD by a mental health professional (Buhlmann 2011). In the present study, participants' experiences indicated that knowledge of BDD was scarce

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both in the general population and within the health care system, even among mental health professionals. Instead of seeking mental health care, participants had attempted to improve their perceived flaws by dermatological or surgical procedures. Some participants vividly described having numerous surgical procedures performed, not caring about the risks associated with operations or the amount of money involved. For most participants, these appearance-enhancing treatments only aggravated their symptoms. In addition to the personal suffering of people with BDD when the disorder remains untreated, there are increased costs for society associated with related issues, including decreased school attendance, a decreased capacity to work, and comorbid conditions, such as substance use disorders, as observed in previous research (Grant et al. 2005) and confirmed by descriptions in the present study.

Our study contributes to the literature by indicating some implications for health care professionals. Difficulty in receiving care was quite common, although the participants sought help repeatedly and desperately. In addition, our results indicate that to only reassure or compliment their looks can make suffering worse for BDD patients. General practitioners and professionals in dermatology or plastic surgery clinics must take these concerns seriously, recognize the disorder, and refer BDD patients to mental health professionals. Our findings, however, indicate that even in the mental health care field, knowledge of BDD appears to be scarce, to the point of BDD patients having to enlighten health care professionals. Thus, educational programs to increase awareness of BDD must be directed to all clinicians who may encounter these patients, and routes of referral must be established. Phillips et al. have outlined some recommendations for approaching and treating BDD, beginning with taking the patients' appearance concerns seriously by empathizing with their suffering and not dismissing their concerns as trivial (Phillips et al. 2008). The participants in our study described a sense of relief when encountering compassion and endorsement within the health care community.

A strength of the present study is that the analysis of each interview transcript was validated by a second author, thus increasing the credibility of the results. The study also has some limitations. Although method triangulation is recommended in interpretive description (Thorne 2008), in our study, individual interviews were considered to be the best method through which to address the study's aims. However,

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more than half of the informants from dermatological clinics initially approached for participation in the study declined or could not be contacted, a phenomenon that may be a reflection of the nature of the disorder. People who were too severely ill to participate in the study may have had different experiences with BDD. The use of telephone interviews as a supplement to face-to-face interviews may aid in partially overcoming this predicament because more severely ill patients may agree to a telephone interview. The participants may also have revealed more about themselves when interviewed by telephone because they may have felt more anonymous. Including patients who had been referred to a specialist clinic for treating BDD, and were assumed to have more severe symptoms, probably contributed to enriching the data. It is important to consider that the majority of the participants were selected from a clinical sample, who were on a waiting list for receiving treatment for BDD. These patients may have had experiences different from other individuals with BDD, particularly regarding experiences with the health care system. Because comorbidity was not an exclusion criterion for participation, it is possible that attributes of comorbid conditions influenced our results. However, comorbidities are common in patients with BDD, particularly mood disorders, anxiety disorders, substance use disorders and eating disorders (Dingemans et al. 2012; Gunstad and Phillips 2003; Hartmann et al. 2015; Phillips et al. 2005; Phillips et al. 2010). Therefore, including patients with comorbidities probably makes our results more characteristic of people with BDD.

In conclusion, detailed descriptions from participants suggest that BDD causes great suffering and ideas of imprisonment and abnormality. In their struggle to become free, participants described disappointing experiences with the health care system. It is therefore vital to increase the awareness and knowledge of BDD among health care professionals to ensure that patients with BDD receive the appropriate care.

### KEY POINTS

- # The experience of living with BDD was explored in interviews with fifteen patients, and analysed using interpretive description.
- # A feeling of imprisonment defined the experience of living with the disorder, and life was a struggle to become free and no longer feel abnormal.

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- # Although participants suffered greatly from their BDD, they found it difficult to access health care and had disappointing experiences with the health care system.
- # It is important to increase awareness and knowledge of BDD among health care professionals to ensure that patients with BDD receive appropriate care.

## **ACKNOWLEDGEMENTS**

We would like to thank all the participants for their contributions to our study.

## **DISCLOSURE OF INTEREST**

The authors report no declarations of interest.

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**Table 1.** Background characteristics of the participants

**Table 2.** Overarching concept, themes and sub-themes identified by the analysis

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**Participants (n=15)**

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**Age (years)**

Mean (range) 30.1 (19-48)

**Sex**

Male 6 (40%)

Female 9 (60%)

**Marital status**

Single 5 (33%)

In a relationship 10 (67%)

**Employment status**

Employed 8 (53%)

Sick leave 3 (20%)

Unemployed 1 (7%)

Students 3 (20%)

**Body part of concern<sup>a</sup>**

Hair 6 (40%)

Skin 4 (27%)

Facial features/facial asymmetry 5 (33%)

Nose 3 (20%)

Eyes 2 (13%)

Teeth 1 (7%)

General body features 3 (20%)

Muscle build 1 (7%)

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<sup>a</sup> Some participants reported more than one body part.

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## Feeling imprisoned – struggling to become free and to no longer feel abnormal

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<b>Theme</b>	<b>Sub-theme</b>
Being absorbed in time-consuming routines	Being preoccupied by one's appearance
	Being controlled by the mirror
	Being bound by obsessive thoughts and behaviours
Facing tension between one's own ideal and the perceived reality	Perceiving internal and external expectations
	Seeking confirmation regarding one's appearance
	Being uncertain about the reality of one's flaws
Becoming the disorder	Feeling ugly
	Being emotionally distressed
	Losing the will to live
Being restricted in life	Finding one's achievements and work/studies to be affected
	Staying at home and keeping away from people
	Having concerns with regard to friends and family
	Experiencing difficulties in relationships with intimate partners
Attempting to reduce one's problems	Attempting to conceal defects
	Attempting to improve one's appearance
Striving to receive care	Encountering difficulties in accessing health care
	Being disappointed in the health care system

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