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Body Dysmorphic Disorder

Capturing a prevalent but under-recognized disorder

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ABSTRACT

Background

Individuals with body dysmorphic disorder (BDD) are highly distressed due to defects they perceive in their physical appearance that are not noticeable to others. The condition often leads to impaired functioning in relationships, socialization, and intimacy and a decreased ability to function in work, school, or other daily activities. Although BDD seems to be relatively prevalent, it is under-recognized by people in general and by health care professionals. Individuals with BDD are secretive about their symptoms, and they usually do not recognize that they are suffering from a psychiatric disorder. Instead, in an attempt to relieve their symptoms by correcting their perceived defects, they commonly seek dermatological treatment or cosmetic surgery. However, such interventions usually do not result in any decrease in BDD symptom severity, but can rather aggravate the symptoms. Therefore, it is crucial that health care professionals recognize BDD in order to offer adequate care. Prior to the studies conducted for this thesis, there were no known data regarding the prevalence of BDD in Sweden.

Main aims

(i) To translate a screening questionnaire for BDD (the Body Dysmorphic Disorder Questionnaire, BDDQ) into Swedish and validate the questionnaire in a community sample. (ii) To estimate the prevalence of BDD in the general population of Swedish women and in female dermatology patients. (iii) To explore BDD patients' experiences of living with the disorder, including their experiences of the health care system.

Methods

The BDDQ was validated using the Structured Clinical Interview for DSM-IV (SCID) as the gold standard for diagnosing BDD (Study I). The validated BDDQ was used to estimate the prevalence of BDD in a randomly selected population-based sample of Swedish women ($n=2885$) (Study II) and in a consecutive sample of female dermatology patients ($n=425$) (Study III). In Studies II and III, the Hospital Anxiety and Depression Scale was used to assess symptoms of depression and anxiety. In Study III, quality of life was evaluated by the Dermatology Life Quality Index. BDD patients' lived experiences were explored using a qualitative research design (Study IV). Fifteen individuals with BDD were interviewed, and the interviews were analysed using Interpretive Description.

Results

The Swedish translation of the BDDQ displayed a sensitivity of 94%, a specificity of 90% and a (positive) likelihood ratio of 9.4. The prevalence of women screening positive for BDD was 2.1% (95% CI 1.7–2.7) in the population-based sample of women and 4.9% (95% CI 3.2–7.4) in the dermatology patients' sample. The positive predictive value of the BDDQ (71%) gave an estimated BDD prevalence of 1.5% (95% CI 1.1–2.0) in the female Swedish population. Women screening positive for BDD had significantly more symptoms of anxiety and

depression compared to those screening negative for BDD in both samples. In the dermatology patients, quality of life was severely impaired in patients with positive BDD screening. The overarching concept found in Study IV was that patients with BDD felt imprisoned and were struggling to become free and to no longer feel abnormal. The participants had encountered difficulties in accessing health care and had disappointing experiences of the health care system.

Conclusion

The findings of this thesis indicate that BDD is a relatively common disorder in the Swedish female population, and that it is more prevalent in dermatology patients. BDD patients struggle to be free from a feeling of imprisonment, and in this struggle they encounter difficulties in accessing health care. Therefore, it is important to increase awareness and recognition of BDD among health care professionals to ensure that patients with BDD receive the appropriate care.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Introduktion

BDD (body dysmorphic disorder) är en psykisk sjukdom som innebär en kraftig upptagenhet vid någon del av kroppen som upplevs deformerad, trots att dessa "utseendedefekter" inte är tydliga för andra. Personer med BDD är vanligtvis upptagna av sin hud (oftast i ansiktet), näsa, öron, behåring eller ansiktsdrag, men det kan röra sig om vilken del av kroppen som helst och ibland om flera områden. BDD är förknippad med tidskrävande tvångs- och säkerhetsbeteenden, som att dagligen spendera många timmar framför spegeln, sminka sig och försöka dölja sina defekter. Sjukdomen medför stort psykiskt lidande med ångest- och depressionssymtom, samt funktionsnedsättning såväl socialt som i arbets- och studiesituationer. Personer med BDD kan bli uttalat handikappade till den grad att de inte klarar att gå ut och det är inte ovanligt med självmordstankar och självmordsförsök.

Ett fåtal studier i andra länder har visat på en förekomst kring 1-2% i befolkningen, och BDD verkar därmed vara en relativt vanlig psykisk sjukdom. Det finns ingen tidigare forskning om hur vanlig sjukdomen är i Sverige.

BDD kan behandlas med psykoterapi och/eller psykofarmaka. Personer med BDD söker dock ofta istället plastikkirurgisk eller dermatologisk behandling för att "rätta till" sitt utseende. Forskning visar att sådan behandling sällan hjälper, utan snarare förvärrar symtomen. Därför är det viktigt att vårdpersonal känner till och kan identifiera sjukdomen, så att personer med BDD får effektiv hjälp.

Syfte

Det huvudsakliga syftet med avhandlingen är att uppskatta förekomsten av BDD bland svenska kvinnor, både i befolkningen generellt och bland patienter på hudkliniker. Dessutom syftar avhandlingen till att utforska vad det innebär att lida av BDD samt vilken erfarenhet personer med BDD har av sjukvården.

Metod

Förekomsten av BDD undersöktes i en tvärsnittsstudie av 2 885 svenska kvinnor i ett befolkningsbaserat urval (Studie II), samt i ett urval av 425 kvinnliga patienter på två hudkliniker (Studie III).

För att mäta förekomsten av BDD, användes ett frågeformulär som tidigare har visat sig kunna fånga symtom på BDD. Frågeformuläret (Body Dysmorphic Disorder Questionnaire, BDDQ) översattes till svenska och validerades i en mindre grupp studiedeltagare från det befolkningsbaserade urvalet. Dessa 88 studiedeltagares svar på BDDQ jämfördes med resultat från diagnostiska intervjuer (Studie I).

Utöver tecken på BDD, mättes också symtom på ångest och depression samt livskvalitet hos deltagarna med hjälp av frågeformulär.

I en kvalitativ delstudie deltog 15 personer med BDD (9 kvinnor och 6 män) i djupintervjuer som utforskade deras upplevelse av sjukdomen samt deras erfarenhet av sjukvården (Studie IV).

Resultat

Resultaten tyder på att frågeformuläret BDDQ fungerar relativt bra för att undersöka förekomst av BDD i ett befolkningsbaserat urval. 71% av dem som hade tecken på BDD enligt frågeformuläret hade sjukdomen också enligt den diagnostiska intervjun.

I det befolkningsbaserade urvalet hade 2,1% av kvinnorna tecken på BDD enligt BDDQ, vilket innebär att uppskattningsvis 1,5% av den kvinnliga befolkningen lider av BDD. 4,9% av de kvinnliga patienterna på hudklinikerna hade tecken på BDD enligt BDDQ, alltså mer än dubbelt så många som generellt i befolkningen. Det är dock vanskligt att överföra kvalitetsmått på frågeformulär från ett urval (generell befolkning) till ett annat (patienter på hudkliniker). Därför är den uppskattade förekomsten av BDD bland patienter på hudkliniker mer osäker.

Både i den befolkningsbaserade studien och i studien på hudkliniker hade personer med tecken på BDD höga nivåer av ångest- och depressionssymtom, och hudpatienter med tecken på BDD hade också en kraftigt försämrad livskvalitet enligt frågeformulären. Studierna visade också att sjukskrivning och arbetslöshet var vanligare hos personer med tecken på BDD.

Det övergripande temat i den kvalitativa intervjustudien var att personer med BDD "känner sig som i ett fångelse och kämpar för att bli fria, och för att inte längre känna sig onormala". Deltagarna beskrev hur de blev uppslukade av sin sjukdom, mådde psykiskt mycket dåligt och att livet blev tydligt begränsat. I sin kamp för att bli fria från sina symtom hade de upplevt svårigheter att få tillgång till rätt vård, delvis för att BDD är en okänd sjukdom. Många var besvikna på kontakter med sjukvården.

Slutsatser

Dessa första studier som har undersökt förekomst av BDD i Sverige tyder på att det är en relativt vanlig psykisk sjukdom bland kvinnor i befolkningen, och ännu vanligare bland kvinnor som söker hjälp på hudkliniker. Samtidigt verkar sjukdomen vara okänd inom sjukvården. Eftersom personer med BDD har ett kraftigt psykiskt lidande och en psykosocial funktionsnedsättning, är det av största vikt för vårdpersonal såväl inom som utanför psykiatri att lära sig känna igen tecken på BDD för att kunna erbjuda adekvat vård.

LIST OF ORIGINAL PAPERS

This thesis is based on the following four papers, which are referred to in the text with Roman numerals (Studies I-IV):

- I. **Brohede, S**, Wingren, G, Wijma, B and Wijma, K (2013). Validation of the Body Dysmorphic Disorder Questionnaire in a community sample of Swedish women. *Psychiatry Research*, 210(2), 647-652. doi:10.1016/j.psychres.2013.07.019.
- II. **Brohede, S**, Wingren, G, Wijma, B and Wijma, K (2015). Prevalence of body dysmorphic disorder among Swedish women: A population-based study. *Comprehensive Psychiatry*, 58, 108-115. doi:10.1016/j.comppsy.2014.12.014.
- III. **Brohede, S**, Wyon, Y, Wingren, G, Wijma, B and Wijma, K. Body dysmorphic disorder in female Swedish dermatology patients. Submitted (2016).
- IV. **Brohede, S**, Wijma, B, Wijma, K and Blomberg, K (2016). '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. *International Journal of Psychiatry in Clinical Practice*, 20(3), 191-198.

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PREFACE

In 2004, I attended a seminar while searching for a topic for a research project during my medical studies. In one of the presentations, Professor Klaas Wijma (who would later become my main supervisor) talked about the features of body dysmorphic disorder (BDD), a psychiatric disorder in which sufferers are highly distressed due to defects they perceive in their physical appearance that are not noticeable to others. I had never heard about this disorder before and because of my interest in psychology and psychosomatics, I started to look into existing knowledge of BDD. I found out that BDD seemed to be prevalent (affecting about 1 to 2% in the general population), although only a few studies existed that had assessed the occurrence of the disorder. The amount of research regarding BDD was limited and no studies had yet investigated BDD in Sweden. I went to a workshop at Karolinska Institutet and heard two American psychotherapists talking about BDD and I was quite affected by their stories of patients suffering from the disorder. That was when I decided that I wanted to investigate the occurrence of BDD in Sweden and I embarked upon my journey to become a researcher.

Parallel to my PhD studies, I chose a different course in my clinical career and became a resident in paediatrics. Therefore, in my clinical work, I meet mostly non-psychiatric health care professionals. Almost everyone I have ever told about my PhD project, privately or at work, has been unaware of the BDD diagnosis (with the exception of some mental health professionals and a few dermatologists). The few people who have recognized BDD believed it to be a rare phenomenon. Thus, in my personal experience, knowledge about BDD in Sweden is still limited, although the awareness seems to have increased in recent years, in part owing to increased attention in the media. Sometimes, when explaining my research to others, I have used an analogy with anorexia nervosa (AN) (one of the disorders that may be approximately as common as BDD). Most people would recognize that the problems might be due to a psychiatric condition in an individual with features of AN who seeks help to lose weight. In fact, it would be considered an oversight to help an individual with AN to lose weight. On the other hand, individuals with BDD seeking help to correct their perceived defects in appearance may not be recognized as suffering from a psychiatric disorder and therefore they may not receive appropriate care. The recognition of a disorder is a prerequisite for enabling help and effective treatment.

To me, the under-recognition of this highly distressing condition has added to the importance of my research. I hope that this thesis will contribute to an increased recognition of BDD in Sweden.

ABBREVIATIONS AND DEFINITIONS

Abbreviations

AN	Anorexia nervosa
BDD	Body dysmorphic disorder
BDDQ	Body Dysmorphic Disorder Questionnaire
BN	Bulimia nervosa
CBT	Cognitive behavioural therapy
DLQI	Dermatology Life Quality Index
DSM-III	Diagnostic and Statistical Manual of Mental Disorders, 3rd edition
DSM-III-R	Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, revised
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4th edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
EDNOS	Eating disorders not otherwise specified
HADS	Hospital Anxiety and Depression Scale
ICBT	Internet based CBT
ID	Interpretive Description
LR	Likelihood ratio
M.I.N.I.-Plus	Mini-International Neuropsychiatric Interview-Plus
NCS	National Comorbidity Survey
NCS R	National Comorbidity Survey Replication
OCD	Obsessive-compulsive disorder
OR	Odds ratio
PPV	Positive predictive value
SAD	Social anxiety disorder (previously social phobia)
SCID	Structured Clinical Interview for the DSM

Definitions

Definitions specific for this thesis

BDD respondents refers to respondents screening positive for BDD by the BDDQ in Studies I-III. Thus, 'BDD respondent' and 'individual with positive BDD screening' are used interchangeably.

SCID evaluation refers to the SCID interview including a standardized clinical assessment of the severity of the perceived appearance defect, as used in the validation of the BDDQ (Study I). For details, see section 3.4.1.

Definitions of prevalence and comorbidity rates

Point prevalence is the proportion of a population that has a disorder at a specific point in time. The prevalence rates referred to in this thesis are point prevalence figures if not otherwise specified.

Twelve-month prevalence is the proportion of a population that has had a disorder at some time during the past year, and therefore includes people who already had the disorder 12 months earlier.

Lifetime prevalence is the proportion of people that at some point in their life (up to the time of assessment) have had a disorder.

Self-reported prevalence refers to prevalence assessed by self-report questionnaires, in which respondents read (or listen to) the questions and select a response by themselves. (Self-reported prevalence can be point, 12-month, or lifetime prevalence.)

Current comorbidity refers to the presence of co-occurring disorder(s) at the time of assessment.

Lifetime comorbidity refers to the presence of co-occurring disorder(s) at some point during a person's life (up to the time of assessment).

1. BACKGROUND

1.1. INTRODUCTION

A woman, now in her thirties, started saving up for her first cosmetic surgery at the age of 16 and had her nose operated on a month after her 18th birthday. After that, she had seven more operations and spent years of her life moving from city to city to find the right surgeons. Because no one could find anything wrong with her physical appearance, she felt ashamed and kept the operations secret and started lying to family and friends about her worries. Looking back on her life, she described feeling disabled because her worries had affected everything in life. She could get stuck in front of mirrors, sometimes for eight hours a day, watching 'the monster' in the reflection, and formulating concrete suicide plans. There was a period when she did not leave her house for three months. She had a constant feeling that something was wrong, and that if she could not get this 'fixed' there was no point in living. She described her frustration,

I have been stationed in villages where there is no electricity or running water in one of the poorest countries in the world, and I was 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, a roof over my head – but it doesn't help, I can't get this sorted, I cannot get over how dissatisfied I am. And I will be at death's door and realize that I have wasted maybe half of my life worrying about one part of my body.

Interviewee in Study IV

Individuals with BDD are highly distressed due to defects they perceive in their physical appearance that are not noticeable to others (American Psychiatric Association [APA], 2013). They have a pervasive feeling of ugliness and are convinced that some part of their body is defective (Mufaddel et al., 2013). The most frequent areas of concern are the face and head, and the main worries are related to problems such as acne, wrinkles, scars, the size and shape of the nose or ears, asymmetric or disproportional face, thinning hair or excessive facial hair. However, there may be a concern regarding any part of the body or with more than one part of the body (Phillips, 1991; Phillips, 2009).

Individuals with BDD engage in excessive grooming, skin picking, mirror checking, and camouflaging of their appearance, with the aim of correcting, hiding, or distracting others from perceived defective parts of the body. Focusing on unattractive parts of the body, rumination, mental rituals or other mental acts are also often reported by individuals with BDD (Phillips et al., 2005; Kollei and Martin, 2014). These preoccupations are very time-consuming and occur, on average, 3-8 hours per day; they are typically difficult to resist

or control (Phillips and Hollander, 2008). BDD is associated with significant distress, disability, unnecessary cosmetic surgery, and suicidal behaviour (Phillips, 1991; Crerand et al., 2005; Phillips, 2007).

BDD seems to be a relatively common psychiatric disorder, affecting about 1-2% of the general population (Veale et al., 2016). However, BDD is still under-recognized as well as under-studied. Studies assessing BDD in community settings are scarce, and prior to the studies conducted for this thesis, there were no known data regarding the prevalence of BDD in Sweden.

Therefore, this thesis aimed to study the occurrence of BDD in Sweden and to understand more of the impact of the disorder on individuals suffering from it.

1.2. HISTORICAL AND CULTURAL PERSPECTIVES OF BDD

BDD has been described in the literature for over a century. The condition was initially identified by the Italian psychiatrist Enriquo Morselli in 1891 and termed dysmorphophobia to describe worries and complains about an imagined deformity. Dysmorfia is Greek and means 'bad shape' or 'bad body'. BDD has also been known as dermatologic non-disease, dermatologic hypochondriasis, beauty hypochondria, and dermatophobia (Castle et al., 2004).

1.2.1. BDD in the Diagnostic and Statistical Manual for Mental Disorders

The Diagnostic and Statistical Manual for Mental Disorders (DSM), published by the American Psychiatric Association, is the most widely accepted nomenclature used by clinicians and researchers for the classification of mental disorders. The DSM is intended to be used in all clinical settings as well as a manual for research in clinical and community settings.

Dysmorphophobia was first described in the third edition of the DSM (DSM-III; APA 1980) as an example of an 'atypical somatoform disorder' without any diagnostic criteria. Body dysmorphic disorder appeared as a separate disorder in the DSM, 3rd edition, revised (DSM-III-R; APA 1987). The 'clinical significance criterion', i.e., that the physical appearance preoccupation must be associated with clinically significant distress and/or functional impairment in order to be regarded as a psychiatric disorder, was added in the DSM, 4th edition (DSM-IV; APA 1994) and the criteria for BDD remained unchanged in the DSM, 4th edition, text revision (DSM-IV-TR; APA 2000).

In the DSM-III-R and DSM-IV, BDD was classified as a somatoform disorder, because of the preoccupation with somatic complaints, while its delusional form was classified as a psychotic disorder. Since BDD has low comorbidity with other somatoform disorders, and instead has presented similarities in symptoms, assessment scores, and treatment approaches with obsessive-compulsive disorder (OCD), researchers have proposed that BDD should be conceptualized as an OCD spectrum disorder (Cororve and Gleaves, 2001). In addition, several studies have indicated that there are many more similarities than differences between individuals with delusional and non-delusional BDD, including response to treatment (Phillips

et al., 2010b). The latest edition of the DSM (5th ed.; DSM-5; APA 2013) has assigned the diagnosis of BDD, including its delusional form, to a new section of Obsessive-compulsive and related disorders. A new criterion was added in the DSM-5, which states that at some point during the course of BDD, the individual should have performed repetitive behaviours (e.g., mirror checking, excessive grooming, and skin picking) or mental acts (e.g., comparing her or his appearance with that of others) in response to the appearance concerns (APA, 2013).

DSM-IV (APA, 1994)

- A. Preoccupation with an imagined defect in appearance. If a slight physical anomaly is present, the person's concern is markedly excessive.
- B. The preoccupation causes clinically significant distress or impairment in social, occupational or other important areas of functioning.
- C. The preoccupation is not better accounted for by another mental disorder (e.g. dissatisfaction with body shape and size in Anorexia Nervosa).

DSM-5 (APA, 2013)

- A. Preoccupation with one or more perceived defects 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 (e.g., 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 preoccupation is not better explained by concerns with body fat or weight in an individual whose symptoms meet criteria for an eating disorder.

The studies of this thesis are based on the DSM-IV criteria for BDD, since the DSM-5 was published after all data had been collected.

1.2.2. Aetiology and Sociocultural context

The aetiology of BDD is largely unknown, but research suggests that it is multifactorial, including biological, psychological and sociocultural factors. Hypothesized risk factors include genetic factors, temperament, childhood adversity such as teasing or bullying, increased aesthetic sensitivity, and a history of dermatological or other physical stigmata (Veale, 2004; Veale et al., 1996b). Neurobiological factors in BDD are not well-established, but there may be abnormal processing of facial and bodily images, and some studies have indicated defects in

fronto-striatal and temporo-parietal regions of the brain (Stein et al., 2006). Physical symmetry has been associated with perceived attractiveness and also possibly with physical health across different species, including humans (Stein et al., 2006). Therefore, a preference for symmetry may even be a selective adaptation and, thus may have an evolutionary basis.

There has been little research comparing BDD features across cultures, and the extent to which cultural factors have an impact on the pathogenesis of BDD is not clear (Phillips et al., 2010b). Community studies of BDD occurrence have only been carried out in Europe and the US, but studies in cosmetic settings have found the highest prevalence rates in Iran and Brazil (Veale et al., 2016). Americans have been reported to place greater value on physical attractiveness than the Japanese and Germans (Crystal et al., 1998). In a study comparing American and German students, body image concerns and preoccupation with physical appearance were found to be significantly greater in Americans, although the prevalence of self-reported BDD was similar in the two groups (Bohne et al., 2002). Case reports and case series of BDD across cultures have shown mostly similarities, including regarding gender ratio, which body areas are disliked, types of compulsive behaviours, and levels of distress and impairment (Phillips et al., 2010b). Nevertheless, cultural differences may influence BDD symptoms to some degree, for example eyelid concerns are common in Japan but rare in Western countries (Phillips et al., 2010b). The anxiety disorder *taijin kyofusho* in Japan refers to people that are perfectionistic and extremely self-conscious, and are concerned about matters such as blushing, or body odour (Barlow, 2002). One subtype of the disorder is defined as 'the phobia of a deformed body'. This self-preoccupation seems to be similar to that in social anxiety disorder (SAD) or indeed BDD, but individuals with *taijin kyofusho* are concerned about offending others instead of experiencing anxiousness about being scrutinized by others, as typically seen in Western cultures (Phillips et al., 2010b).

1.2.3. Body image disturbance

Body image can be defined as the mental representation of the body and its organs, or to put it in other words, 'the picture we have in our minds of the size, shape and form of our bodies; and to our feelings concerning these characteristics and our constituent body parts' (Slade, 1994). Body image, thus, has two components, a perceptual component (how we view our bodies) and an attitudinal component (how we evaluate our bodies). Body image develops early in life as the caregivers touch, caress and hold the infant, and body image development is of basic importance for self-development (Gupta and Gupta, 1996). During normal development, the awareness of one's own body and the perception of others' responses to it are incorporated into one's self-awareness (Krueger, 1989). Although body image is a complex and multifaceted construct, including perceptual, affective, cognitive and possibly behavioural aspects of body experience, in Western society the major focus regarding body image has been on the body's appearance, in particular on body shape and weight (Tiggemann, 2004). Negative body image is common in both men and women and has adverse consequences for individual functioning, including greater psychological stress. Sociocultural factors, such as exposure to media images portraying thin ideals, have been found to contribute to negative perceptions of one's body (Allen and Walter, 2016).

BDD involves two components of body image disturbance: perceptual distortion and body dissatisfaction. Veale et al. (1996b) have hypothesized that BDD patients have an increased selective attention to their perceived defects. In a study including 100 BDD patients, one in five had an occupation or education in art or design, a finding that could reflect a high aesthetic sensitivity among BDD patients (Veale et al., 2002). Selective attention is an important factor in the maintenance of several emotional disorders, e.g. in patients with panic disorder, who have an increased perception of bodily sensations and have been found able to more accurately estimate their heart rate than controls (Ehlers and Breuer, 1992). Regarding the attitudinal component of body image, BDD patients may have a desire for perfection or symmetry in their physical appearance (Veale et al., 1996a). In one study evaluating physical attractiveness perception using facial photos, BDD patients (n=19) followed similar normative ratings of the attractiveness of others (i.e., rating photos of others as 'attractive', 'average', or 'unattractive') as healthy controls (Buhlmann et al., 2008). However, BDD patients rated their own attractiveness significantly lower than 'independent evaluators' did and they rated photos in the 'attractive' group higher than healthy controls did. The author's conclusions were in line with the self-discrepancy theory as proposed by Higgins (Higgins, 1987), that the discrepancy between the perception of one's own physical appearance and the physical appearance of others may lead to negative emotions and low self-esteem in BDD. In the study by Buhlmann et al. (2008), BDD patients also displayed higher levels of perfectionism than healthy controls. High levels of perfectionism have also been found in other disorders, such as depression, eating disorders, OCD and SAD, supporting an association between perfectionism and psychopathology (Buhlmann et al., 2008). In addition, individuals with BDD are believed to have an exaggerated sense of the importance of attractiveness to others that contributes to a self-esteem that is excessively dependent on physical appearance (Allen and Hollander, 2004). BDD patients tend to misinterpret imperfections they perceive in their appearance as major flaws in self-worth (Hartmann et al., 2015). In analogy with the patient suffering from panic disorder who has an increased awareness of her heart rate, but is likely to misinterpret the cause and the importance of the sensations (e.g., as evidence of heart disease), the BDD patient may have an increased aesthetic sensitivity, but misinterprets her own physical appearance, and the importance thereof.

1.3. EXISTING KNOWLEDGE OF BDD PREVALENCE AND THE IMPACT OF LIVING WITH BDD

1.3.1. Assessing BDD

A face-to-face diagnostic interview using the DSM is the gold standard for diagnosing BDD (Phillips, 2009). The Structured Clinical Interview for DSM (SCID) is a semi-structured diagnostic interview intended to be used by clinicians, and is considered a state-of-the-art clinical research interview (Kessler et al., 2004). BDD was first introduced in the SCID for DSM-IV in 2002 (First et al., 2002). The Body Dysmorphic Disorder Diagnostic Module (BDD Diagnostic Module) (Phillips et al., 1995) is a clinical interview based on the DSM-IV criteria

using the SCID format, which was used as the gold standard for diagnosing BDD in research settings before BDD was included in the SCID. In this thesis, 'semi-structured clinical interviews' refers to the diagnosis of BDD by a clinician using the DSM criteria (including use of the SCID and the BDD Diagnostic Module).

The Mini-International Neuropsychiatric Interview-Plus (M.I.N.I.-Plus) is a brief, fully structured diagnostic interview for DSM-IV, which can be used by non-specialized interviewers (Sheehan et al., 1998). The M.I.N.I. has shown good concordance with the SCID for several diagnoses, but the validity properties of the M.I.N.I.-Plus regarding the BDD diagnosis are not known (Sheehan et al., 1998).

Some screening instruments have been developed for BDD, and here I briefly describe the ones referred to in this thesis. The Body Dysmorphic Disorder Questionnaire (BDDQ) has been validated and exhibited high sensitivity and specificity in psychiatric and cosmetic surgery samples (for details, see section 3.3.1) (Phillips et al., 1995; Grant et al., 2001; Dey et al., 2015). The BDDQ is the most commonly used screening instrument for BDD across studies (Veale et al., 2016); however, prior to the present thesis, it had not been validated in a community setting. The BDDQ dermatology version (BDDQ-DV), a modification of the BDDQ for more continuous scoring, was validated with dermatology patients seeking cosmetic surgical consultation, and presented high sensitivity and specificity (100% and 92% respectively) (Dufresne et al., 2001). The Body Image Disturbance Questionnaire is also modified from the BDDQ for more continuous scoring (Cash et al., 2004) and the Body Dysmorphic Disorder Examination- Self-Report version (BDDE-SR) is a self-report version of the BDDE clinical interview (Rosen and Reiter, 1995). Neither of the latter two instruments has been validated against diagnostic interviews.

1.3.2. Prevalence of BDD in community settings

A few epidemiological studies have estimated the prevalence of BDD in the general population and suggest that it is a relatively common disorder. The diagnostic assessments used and results yielded by these studies are presented in Table 1. Studies examining smaller community samples using semi-structured clinical interviews have identified a BDD prevalence of 0.7 and 0.8% in Italy and in the US (the US study comprised a cohort including females between the ages of 36 and 44, with 33% screening positive for major depressive disorder) (Faravelli et al., 1997; Otto et al., 2001). Only three larger population-based studies using representative samples had been conducted prior to Study II in the present thesis and another study was published in 2015 (Rief et al., 2006; Koran et al., 2008; Buhlmann et al., 2010; Schieber et al., 2015). The BDD prevalence rates reported in those studies showed only a modest variation between 1.7 and 3.2%. Schieber et al. (2015) found a prevalence rate of 3.2% based on DSM-IV criteria and of 2.9% based on DSM-5 criteria, but the difference was non-significant. All of those studies used self-report questionnaires to estimate BDD prevalence, but these were not validated against diagnostic interviews.

Table 1. Prevalence of BDD in population-based samples

Study	Country	Number of participants	Mode of assessment	Diagnostic instrument	Prevalence (95% CI)		
					Total	Female	Male
Faravelli et al. (1997)	Italy	673	Interview by general practitioner	'Structured clinical interviews following the DSM-III decision tree'	0.7% (0.3-1.8) (12-month prevalence)	1.4% (0.5-3.2)	0% (0.0-1.2)
Otto et al. (2001)	US	976 (women aged 36-44)	Face-to-face interview	BDD Diagnostic Module (DSM-IV)	0.8% (0.4-1.6)		
Rief et al. (2006)	Germany	2 552	Self-report questionnaire	Four items assessing DSM-IV criteria (excluding individuals with primary weight concerns)	1.7% (1.2-2.1)	1.9% (1.3-2.7)	1.4% (0.9-2.2)
Koran et al. (2008)	US	2 048	Telephone interview	A series of questions slightly modified from the BDDQ (excluding individuals with primary weight concerns)	2.4% (1.8-3.1)	2.5% (1.8-3.5)	2.2% (1.3-3.5)
Buhlmann et al. (2010)	Germany	2 510	Self-report questionnaire	Four items assessing DSM-IV criteria, requiring thinking about the appearance concerns for at least one hour/day (excluding eating disorders by a four-item assessment)	1.8% (1.3-2.4)	2.0% (1.4-2.9)	1.5% (0.9-1.4)
Schieber et al. (2015)	Germany	2 129	Self-report questionnaire	Four items assessing DSM-IV-criteria, requiring presence of daily thoughts regarding appearance (excluding eating disorders by a 12-item assessment)	3.2% (2.5-3.9) DSM-IV	4.4% (3.2-5.6)	1.7% (0.9-2.5)
				In addition to the above, requiring presence of daily repetitive behaviours	2.9% (2.2-3.6) DSM-5	4.2% (3.0-5.4)	1.3% (0.6-2.0)

1.3.3. Prevalence of BDD in clinical settings

Studies that have used semi-structured clinical interviews to assess BDD prevalence have primarily been conducted in psychiatric settings, and have reported BDD prevalence rates of 1.9 to 16% in inpatient samples in Germany, UK and the US (Conroy et al., 2008; Kollei et al., 2011; Grant et al., 2001; Veale et al., 2015) and 3.2 to 11% in outpatient samples, all in the US (Wilhelm et al., 1997; Zimmerman and Mattia, 1998; Kelly et al., 2015).

In general dermatology settings, a few studies have systematically assessed the occurrence of BDD (Table 2). Two studies used the SCID to diagnose BDD and found prevalence rates of 6.7% and 8.8% indicating that BDD is common in dermatology settings (Uzun et al., 2003; Conrado et al., 2010). Studies using the screening instrument BDDQ-DV found a prevalence of 4.2% in a Turkish sample (Dogruk Kacar et al., 2014) and about 14% in two US samples (Phillips et al., 2000; Bowe et al., 2007).

Table 2. Prevalence of BDD in general dermatology samples

Study	Country	n	Diagnostic assessment	Prevalence		
				Total	Female	Male
Phillips et al. (2000)	US	118	BDDQ-DV	14.4% (9.1–22.0)	–	–
Uzun et al. (2003)	Turkey (acne patients)	159	SCID (Turkish version)	8.8% (5.3–14.2)	8.3% (3.9–17.0)	9.2% (4.7–17.1)
Bowe et al. (2007)	US (acne patients)	128	BDDQ-DV	14.1% (9.1–21.1)	–	–
Conrado et al. (2010)	Brazil	150	SCID (and BDDQ-DV)	6.7% (3.7–11.8)	6.1% (3.0–12.1)	8.3% (2.9–21.8)
Dogruk-Kacar et al. (2014)	Turkey	167	BDDQ-DV	4.2% (2.0–8.4)	–	–

Some studies suggest that BDD may be even more common in cosmetic settings. Studies using semi-structured clinical interviews to diagnose BDD, have found prevalence rates ranging between 2.9 and 15% in cosmetic dermatology clinics, and ranging very widely between 6.3 and 53% in cosmetic surgery settings, although the heterogeneity was high and the study quality varied in the latter setting (Veale et al., 2016).

1.3.4. Prevalence in men and women

BDD appears to be slightly more common among women, as indicated by a female:male ratio ranging from 1:1 to 3:2 in previous studies (Phillips and Hollander, 2008). All of the population-based studies cited above, found slightly higher prevalence rates in women than in men, although the differences were statistically non-significant in most studies (Table 1). In dermatology patients, the two studies that reported prevalence rates for men and women separately found slightly higher rates in men, although the differences were non-significant (Table 2). While BDD in its most serious manifestation seems to affect both sexes almost equally, it has been suggested that mild BDD predominantly affects women, and even that preoccupation and manipulation of the body surface is considered a 'normal' gendered activity for women (Parker, 2014).

1.3.5. Living with BDD

Quantitative studies have demonstrated that BDD is associated with significant distress and leads to impaired functioning in relationships, socializing, and intimacy as well as to a decreased ability to function at work or in school (Perugi et al. 1997; Phillips 2009). BDD patients have reported low health-related quality of life, including decreased general mental health, enjoyment, social adjustment, and social functioning (Ishak et al., 2012). In some studies, individuals with BDD have reported high rates of unemployment and social isolation, and also a high frequency of suicide attempts (Phillips 1991; Veale et al., 1996a; Crerand et al. 2005; Phillips and Menard 2006; Phillips 2007; Fang and Wilhelm 2015).

Only a few qualitative interview studies have analysed aspects of BDD. Silver et al. interviewed 11 individuals with BDD and used photographs combined with narrative analysis to assess the manner in which people with BDD perceive their own appearance (Silver and Reavey, 2010; Silver et al., 2010). The most common theme identified by these authors was an exaggerated perception of threat because the BDD patients feared other people's judgements and this resulted in disordered interpersonal relationships. Other themes found were a wish for regularity and symmetry in physical 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 and imprisoning, with crippling and paralysing effects on life (Silver and Farrants, 2015). To the best of my knowledge, no previous studies have used a qualitative approach to explore other aspects of living with BDD.

1.4. AN UNDER-RECOGNIZED DISORDER

Although the condition has been described for over a century, BDD is an under-studied disorder. Research has increased in the last few decades, but is still limited, as illustrated by searching the PubMed database (in September 2016) for 'body dysmorphic disorder' (or any of the previous names of BDD), which generated about 1 400 scientific articles, as compared to 'obsessive-compulsive disorder' (15 500 articles) and 'eating disorders' (almost 20 000 articles). There is a low level of awareness about BDD among healthcare professionals and few practitioners ask simple questions to detect the diagnosis (National Collaborating Centre for Mental Health [NCCMH], 2006). Symptoms of BDD are easily trivialised and stigmatised, and can be confused with mere body dissatisfaction, which does not cause major distress or interference with life. Patients with 'real disfigurements' may be viewed as more worthy of attention, but they are often less disabled than individuals with BDD (Veale and Bewley, 2015).

The lack of recognition is problematic for BDD sufferers, since the detection rate in primary care even for well-known mental health problems such as depression may not be more than 50% (Gilbody et al., 2003). A study on well-established anxiety disorders in primary care in the US concluded that less than one-third of patients had received either psychotherapy or pharmacotherapy that met the criteria for quality care (Stein et al., 2004). In a large survey assessing the occurrence of 14 DSM diagnoses (not including BDD) in over 8 000 US citizens, less than 40% of those with a lifetime disorder had ever received professional treatment, and less than 20% of those with a recent disorder had been in treatment during the past 12 months (Kessler et al., 1994). In light of this, the detection of BDD in primary care is probably also deficient, but there is no known empirical data to confirm this apprehension.

A few studies suggest that BDD is an under-recognized diagnosis even in psychiatric settings. Since BDD is not routinely included in psychiatric evaluations, the diagnosis is likely to be missed, as demonstrated by Zimmerman and Mattia (1998). These authors reported that none of the 500 referrals to a psychiatric outpatient clinic in the USA had been diagnosed as having BDD through routine clinical interviews, but 3.2% of a second group of 500 referrals were diagnosed as having BDD according to semi-structured diagnostic interviews. Similarly, when Grant and colleagues (2001) evaluated 122 consecutive psychiatric inpatients, 13% were diagnosed as having BDD by semi-structured diagnostic interviews, although none of the participants had been diagnosed as having BDD by their treating physician. Patients with BDD may be found among patients diagnosed with, e.g., OCD, eating disorders and SAD (some aspects of comorbidity are outlined in section 1.7). 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).

A contributing factor to the low level of awareness among healthcare professionals is that individuals with BDD are often secretive about their symptoms because they believe that they will be viewed as vain or narcissistic (Mufaddel et al., 2013). Moreover, most BDD sufferers have poor insight into their illness; several studies have reported that 30 to 60% are

delusional regarding their perceived appearance flaws (Phillips et al., 2001; Crerand et al., 2005; Phillips et al., 2010a). Therefore, presumably, they do not recognize a need for psychological or psychiatric treatment. Instead, in an attempt to relieve their symptoms by correcting their perceived defects, a majority of BDD patients (over 70%) have reported seeking non-psychiatric medical care, most commonly dermatological or surgical treatment (Phillips et al., 2001; Crerand et al., 2005). However, BDD seems to go unrecognized by dermatologists, plastic surgeons, and other physicians whom these patients approach first in their attempts to correct their perceived flaws (Phillips, 2007). For example, of 31 patients diagnosed with BDD using the SCID in Brazilian dermatology settings, none had previously received a BDD diagnosis (Conrado et al., 2010). Understandably, it can be difficult to determine if the concerns are 'markedly excessive' in a patient with a visible 'minor physical anomaly', but if physicians are not even aware of the BDD diagnosis, they may not enquire about the magnitude and the consequences of the concerns and may, thus, fail to detect this highly distressing disorder.

1.5. BDD IN DERMATOLOGY PATIENTS

Similar to body image, the construct cutaneous body image (CBI) refers to the individual's mental perception of his or her skin, hair and nails. CBI dissatisfaction can increase the overall morbidity in dermatologic disease and has been associated with intentional self-injury, such as self-induced dermatoses, and suicide (Gupta and Gupta, 2013; Gupta and Gupta, 2014). About one-third of dermatology patients are estimated to have underlying psychiatric comorbidity, and the psychiatric illness may either be the cause or the consequence of dermatologic disease (Yadav et al., 2013; Brown et al., 2015). In a recent review, three broad categories were used to classify psychodermatologic disorders (Yadav et al., 2013). First, some skin diseases can be precipitated or exacerbated by psychological factors such as stress or anxiety (for example, acne, psoriasis, atopic dermatitis, and rosacea); second, some chronic and disfiguring skin diseases can cause secondary depression, anxiety, social phobia, and suicidal ideation; and third, there are psychiatric disorders, in which skin complaints are secondary and self-induced (for example, BDD, trichotillomania, acne excoriee, and dermatitis artefacta). Psychodermatologic problems are more common in women than in men (Cotterill and Cunliffe, 1997).

In 1997, Cotterill and Cunliffe published a report on 16 cases of completed suicide among dermatology patients, most of whom had suffered from acne (n=7) or BDD (n=3). Since then, an increasing number of dermatology studies have investigated psychological symptoms and specifically suicidal behaviour (Picardi, 2013). In a recent multicentre study including 3600 general dermatology outpatients, comorbidity rates of 10% for depression and 17% for anxiety were found, and suicidal ideation was reported by 13% of the patients (Dalgard et al., 2015). Only a minority of suicidal individuals seek psychological or psychiatric care, and therefore dermatologists may play an important role in recognizing suicidal ideation and preventing suicidal behaviours in the risk population of dermatology patients (Picardi et al., 2013).

As the skin is one of the most commonly reported areas of concern in BDD, many BDD sufferers seek dermatologic or cosmetic treatment in an attempt to relieve their symptoms (Phillips and Diaz, 1997; Phillips et al., 2005). However, several studies indicate that what these specialists can offer by means of appearance-enhancing treatments, such as various dermatological treatments or cosmetic surgery, usually do not result in any decrease in BDD symptom severity. Following cosmetic treatments, some individuals instead develop new appearance concerns, and, unfortunately, even symptom exacerbations are not uncommon (Phillips et al., 2001; Crerand et al., 2005). In one study, 70% of BDD patients (n=200) had sought non-psychiatric treatment, most commonly by dermatologists (Crerand et al., 2005). Although in the subjects' view, a quarter of all treatments improved the appearance of the treated body part, their preoccupation and concern usually did not improve. Only 3.6% of all treatments led to overall improvement in BDD symptoms.

As outlined by Gupta and Gupta (2013), it is important to rule out body image pathologies, including BDD, before initiating dermatological therapies because these patients are often dissatisfied with treatment outcomes and because body image dissatisfaction is associated with increased morbidity, intentional self-injury, and suicide. Dermatologists are recommended to try to refer BDD patients to mental health professionals for appropriate assessment and treatment (Phillips and Dufresne, 2000; Veale and Bewley, 2015).

1.6. EFFECTIVE TREATMENT

As mentioned above, appearance-enhancing treatments, such as various dermatological treatments or cosmetic surgery, usually do not result in any decrease in BDD symptom severity. Treatment needs to target the underlying psychiatric pathology, and involves psychological and/or pharmacological interventions. Without effective treatment BDD is usually chronic with a low probability of remission (Phillips et al., 2013). Treatments that have been shown to be effective for BDD are selective serotonin-reuptake inhibitors (SSRIs) and cognitive behavioural therapy (CBT) (Phillips and Hollander, 2008; Veale et al., 2014; Wilhelm et al., 2014; Harrison et al., 2016; Phillipou et al., 2016). However, a Cochrane review from 2009 and an updated review from 2016 concluded that there is still a lack of experience and evidence regarding effective treatment of BDD and more research is required to supplement available data (Ipser et al., 2009; Phillipou et al., 2016). For example, there is no evidence on optimal dose or duration of treatment, and no studies have yet compared SSRI to CBT or combined the two (NCCMH, 2006). Nevertheless, the National Institute for Health and Clinical Excellence (NICE) guidelines recommend that BDD patients should be offered either a course of CBT or an SSRI, or a combination of these if symptoms are severe (NCCMH, 2006). A recent Swedish RCT including 94 outpatients found promising effects of Internet-based CBT (ICBT) in the treatment of BDD; 56% of those receiving treatment had markedly improved and 39% no longer met the diagnostic criteria for BDD three months after the end of treatment (Enander et al., 2016).

1.7. PSYCHIATRIC COMORBIDITY

BDD shares similarities with and also has high comorbidity rates with other psychiatric disorders including OCD, major depression, eating disorders, and anxiety disorders (most commonly SAD) (Gunstad and Phillips, 2003; Phillips et al., 2005; Phillips, 2007). It is important to be aware of conditions comorbid with BDD, as BDD patients are often secretive about their appearance preoccupation due to shame and fear of meeting judgemental attitudes. Therefore, they are more likely to complain of symptoms of depression or social anxiety unless they are specifically questioned about symptoms of BDD (Mufaddel et al., 2013).

Table 3 presents the rates of psychiatric disorders most commonly comorbid with BDD. The table includes only studies with at least 50 BDD-patients that used semi-structured clinical interviews to assess the diagnoses (one study used the M.I.N.I.-Plus).

1.7.1. Depression

Lifetime prevalence rates for major depression ranged from 41 to 76% in studies of comorbidity in BDD patients and depression may, thus, be the disorder most commonly comorbid with BDD (Table 3). In the largest samples the lifetime comorbidity rate for major depression was 75 to 76% and the current rate was 58% (Gunstad and Phillips, 2003; Phillips et al., 2005). Veale et al. (1996a) found a much lower rate of current major depression (8%) as assessed by the SCID. In the study by Veale et al., depressive symptoms were also assessed according to the Montgomery and Åsberg Depression Scale (MADRS), defined as a score of >20 to denote 'clinically significant depression'. Using this definition, 28% of the BDD patients had (current) depression. In the study by Van der Meer et al. (2012) 50% of the BDD patients had a MADRS score >20.

Studies that have assessed the rate of BDD in patients with depression are scarce. Nierenberg et al. (2002) evaluated 350 consecutive patients with major depression using the SCID and found a current BDD prevalence of 7% and a lifetime occurrence of 8%. The patients with comorbid lifetime BDD in this study had an earlier age of onset of depression and longer duration of the current episode, but not a greater severity of depression. In a sample of 86 patients with atypical depression the lifetime comorbidity rate of BDD as assessed by a semi-structured interview was as high as 42% (Perugi et al., 1998).

1.7.2. Obsessive-Compulsive Disorder

BDD and OCD are both classified as obsessive-compulsive spectrum disorders and are characterized by intrusive thoughts and/or repetitive behaviours (APA, 2013). An obsession is defined as an unwanted thought, image or urge, which repeatedly enters the person's mind. Compulsions are repetitive behaviours or mental acts that the person feels driven to perform. A compulsion can either be overt and observable by others, such as checking that a door is locked, or a covert mental act that cannot be observed as in repeating a certain phrase in the mind (Barlow, 2002). The symptoms of BDD are generally similar to symptoms of OCD, with

Table 3. Lifetime (L) and Current (C) comorbidity of other psychiatric disorders in patients with BDD.

Study	Setting	n	Assessment instruments	OCD	Eating disorders	Anxiety disorders (SAD)	Major depression
Hollander et al. (1993)	Psychiatric inpatients (US)	50	Clinical interview (DSM-III-R)	78% ^L	20% ^L	60% (12%) ^L	68% ^L
Veale et al. (1996a)	Mixed sample recruited via psychiatrists, dermatologists, and cosmetic surgeons, and via advertising (UK)	50	SCID (DSM-III-R) + BDDE	6% ^C		32% (16%) ^C	8% ^C
Perugi et al. (1997)	Psychiatric outpatients (Italy)	58	Semi-structured clinical interview (DSM-III-R)	41% ^L	22% ^L	38% (12%) ^L	41% ^L
Gunstad and Phillips (2003)	Patients in a research program, recruited via psychiatrists and via advertising (US)	293	SCID (DSM-III-R) + BDD Diagnostic Module	25% ^C 32% ^L	4% ^C 10% ^L	55% ^a (32%) ^C 64% ^a (37%) ^L	58% ^C 76% ^L
Phillips et al. (2005)	Patients in a research program, recruited via psychiatrists, non-psychiatric physicians, and via advertising (US)	200	SCID (DSM-IV)	33% ^L	21% ^L	70% (39%) ^L	75% ^L
Van der Meer et al. (2012)	Psychiatric outpatients (the Netherlands)	54	M.I.N.I.-Plus (DSM-IV)	17% ^C	2% ^C	52% (35%) ^C	46% ^C

^a Anxiety disorders also included OCD.

Note. The table includes only studies with at least 50 BDD-patients that used semi-structured clinical interviews to assess the diagnoses (one study used the M.I.N.I.-Plus).

intrusive thoughts and compulsive behaviours to relieve anxiety. BDD and OCD display similarities in demographics, clinical course, neurobiology and treatment response (Allen and Hollander, 2004). Body dysmorphic and obsessive-compulsive traits have also been found to share a common genetic basis and in first-degree relatives of patients with either BDD or OCD, both disorders are overrepresented (Monzani et al., 2012; Frias et al., 2015). In individuals with OCD, obsessions are usually regarded by themselves as unreasonable or excessive. In contrast, insight is poorer in BDD patients than in OCD patients with 27 to 60% of BDD patients currently having delusional beliefs versus only 2% of OCD patients (Phillips et al., 2010a). In addition, patients with BDD usually do not succeed in reducing anxiety by rituals in the same way as patients with OCD do, albeit only temporarily. BDD seems to be more impairing overall than OCD, including higher hospitalization and suicide rates (Allen and Hollander, 2004; Phillips et al., 2010a; Mufaddel et al., 2013).

A high proportion (32 to 78%) of BDD patients have reported lifetime comorbid OCD, and current prevalence of OCD has varied between 6 and 25% among BDD samples (Table 3). In large studies of patients with OCD (n=380-900), the lifetime prevalence of BDD as assessed by semi-structured clinical interviews ranged from 6 to 15% (Simeon et al., 1995; Lochner and Stein, 2010; Bienvenu et al., 2012; Conceição Costa et al., 2012).

1.7.3. Social anxiety disorder

SAD is one of the most common comorbid disorders in BDD, in part because SAD is common, with a lifetime prevalence of 12 to 13% (Barlow, 2002; Allen and Hollander, 2004; Kessler et al., 2005a). Patients with SAD fear that they will act in a way or show anxiety symptoms that will be negatively evaluated (APA, 2013). Patients with BDD and SAD both have high levels of social anxiety and suffer from social avoidance due to fear of negative evaluations (Kelly et al., 2013). Most often, individuals with SAD are concerned with public speaking, meeting strangers, or eating in public, and though it is not unusual for individuals with SAD to have some appearance concerns, these are not predominant (APA, 2013). If the social fears are caused only by negative beliefs about physical appearance, a BDD diagnosis should be considered and a separate diagnosis of SAD is not warranted (Allen and Hollander, 2004). Similar to OCD, adults with SAD are generally aware that their fears are not realistic, in contrast to BDD patients who seem to be delusional to a higher degree (Allen and Hollander, 2004).

SAD was the most commonly comorbid anxiety disorder in most studies in Table 3. In the largest clinical samples of BDD patients, SAD was the second most common comorbid diagnosis, with a lifetime prevalence of 37 to 39% and a current comorbidity rate of 32% (Gunstad and Phillips, 2003; Phillips et al., 2005). Likewise, in two small samples of SAD patients (n=25 and n=54), comorbid BDD was found in 11 to 12%, as assessed by semi-structured clinical interviews (Brawman-Mintzer et al., 1995; Wilhelm et al., 1997).

1.7.4. Eating disorders

Individuals with BDD and eating disorders share features such as severe body image disturbance, physical appearance preoccupation, body dissatisfaction, and distress from obsessional thinking and compulsive behaviours. However, BDD patients seem to have more negative self-worth and more avoidance behaviour, as well as poorer functioning and quality of life, due to appearance concerns (Rosen and Ramirez, 1998; Hrabosky et al., 2009). For separating the disorders it is important that the recommended pharmacotherapy and psychosocial treatments differ between the conditions (Phillips et al., 2010b). However, eating disorders and BDD can be comorbid conditions, in which case both disorders should be diagnosed (Hartmann et al., 2013).

Rates of comorbid eating disorders in BDD patients have varied across studies; 10 to 22% of BDD patients had lifetime occurrence of either AN or bulimia nervosa (BN) (Table 3). In the sample of 200 BDD patients, 33% (42% in women) met the criteria for a lifetime comorbid eating disorder, including an eating disorder not otherwise specified (EDNOS) (Phillips et al., 2006). However, Gunstad and Phillips (2003) reported a much lower rate of current eating disorders (4%), which was confirmed by Van der Meer et al. (2012) (2%).

In patients with eating disorders, a few studies have reported high prevalence rates of comorbid BDD, unrelated to weight concerns. In patients with AN (n=41) 39% had current comorbid BDD as assessed by the BDD Diagnostic Module (Grant et al., 2002), whereas in a larger sample of 100 patients with eating disorders (AN, BN and EDNOS), 12% had current and 15% had lifetime comorbid BDD as assessed by the SCID (Kollei et al., 2013). It is noteworthy that in the study by Grant et al. (2002), the patients who had BDD in addition to AN had more functional impairment, psychiatric hospitalizations were twice as common, and the lifetime suicide attempt rate was three times higher (63% compared to 20%).

1.8. EPISTEMOLOGICAL ASPECTS OF CAPTURING BDD

Epistemology is the study of how we acquire knowledge: 'How do we know?' The epistemological paradigms that have dominated medical research are (logical) positivism and post-positivism (Polit and Beck, 2008). A fundamental assumption of positivists is that there is a reality out there that can be studied and known, and research objectivity is valued. Post-positivists still believe in reality, but recognize the impossibility of total objectivity, although they try to be as neutral as possible. Medical research is traditionally directed at understanding underlying causes of phenomena, and probabilistic evidence is sought by the means of quantitative research methods (Polit and Beck, 2008). Throughout my medical studies and as a physician, I have primarily become familiar with positivistic reasoning and quantitative methods.

In order to assess the occurrence of BDD in terms of prevalence rates, quantitative methods are necessary. However, positivist research is reductionist and inadequate to capture the complexity of human experience, as the concepts to be investigated are defined in advance by the researcher (Polit and Beck, 2008). On the contrary, the epistemological grounds of Naturalistic Inquiry are that 'reality' exists within a context that can only be studied holistically (Lincoln and Guba, 1985). Thus, reality is complex, contextual, constructed, and ultimately subjective, and therefore no a priori theory can comprehend the multiple realities that are likely to be encountered when studying human experience (Thorne et al., 2004).

In a psychiatric construct such as BDD, the reality of a diagnosis can be context-bound. The diagnostic criteria for BDD have been stipulated by the creators of the DSM, and are likely to be influenced by current norms, and cultural lines of thought. Moreover, in naturalistic inquiry, the voices and interpretations of those under study are crucial to understanding the phenomenon of interest. In light of this, it was appealing to complement the quantitative research with more constructivist methods. Most qualitative methods used in health research derive from other disciplines (sociology, philosophy, anthropology, and education), although 'applying methods outside the discipline for which they are intended tends to create problems: in application or in relevance of the results' (Thorne, 2008, p 24). Interpretive description (ID), as used in Study IV, shares ideas from naturalistic inquiry, but was developed to mimic clinical reasoning to find shared experiences, for example, among patients with a specific diagnosis (Thorne et al., 1997). ID can be used to increase general knowledge and to gain a more detailed clinical understanding of a condition. In ID, prior knowledge is not 'bracketed' as in many other qualitative methods, but embraced, which implies that sampling and data collection methods derive from specific research questions, informed by the framework of what is already known about the phenomenon (Thorne et al., 2004).

In this thesis, (post) positivistic and constructivist paradigms and research methods are used in a complementary manner to capture BDD.

2. AIMS AND RESEARCH QUESTIONS

2.1. AIMS OF THE THESIS

The overall aims were to estimate the prevalence of BDD in Swedish women, and to understand more of the impact of the disorder on BDD patients' lives and what experiences BDD patients have of the health care system.

The specific aims of each individual study were:

Study I

To translate the BDDQ into Swedish and to validate the translated version in a community sample of Swedish women.

Study II

To estimate the prevalence of BDD in a large randomly selected population-based sample of Swedish women and to assess symptoms of depression and anxiety in women with positive BDD screening.

Study III

To estimate the prevalence of BDD in a female dermatology patient sample and to evaluate the psychological condition of dermatology patients with positive screening of BDD, by assessing symptoms of depression and anxiety, and quality of life.

Study IV

To complement existing quantitative research by exploring BDD patients' experiences of living with the disorder, including their experiences of the health care system.

2.2. RESEARCH QUESTIONS

Study I

- What are the validity properties of the Swedish translation of the BDDQ when validated against the SCID in Swedish women?

Study II

- What is the prevalence of BDD in the general female Swedish population, as assessed by the BDDQ?
- Do women with positive BDD screening differ from those with negative BDD screening in regard to symptoms of depression and anxiety, as assessed by the Hospital Anxiety and Depression Scale (HADS)?

Study III

- What is the prevalence of BDD in female Swedish dermatology patients, as assessed by the BDDQ?
- Do patients with positive BDD screening differ from those with negative BDD screening in regard to symptoms of clinically significant depression and anxiety, as assessed by the HADS?
- Do patients with positive BDD screening differ from patients with negative BDD screening in regard to quality of life, as assessed by the Dermatology Life Quality Index (DLQI)?
- Which dermatologic problems do dermatology patients with positive BDD screening present with?

Study IV

- What experiences do individuals with BDD have of living with the disorder?
- What are BDD patients' experiences of the health care system?

3. MATERIAL AND METHODS

An overview of research designs, samples and methods used in the different studies is presented in Table 4.

Table 4. Overview of the different designs, samples and methods used in the studies in this thesis

Study	Design	Sample	n	Year of data collection	Method
Study I	Questionnaire validation	Population-based (sub-sample of Study II) ^a , women	88	2009–2010	Semi-structured diagnostic interviews (SCID)
Study II	Cross-sectional point prevalence estimation	Randomly selected, population-based, women	2 885	2009	Self-report questionnaires (BDDQ, HADS)
Study III	Cross-sectional point prevalence estimation	Consecutively selected, dermatology patients, women	425	2013	Self-report questionnaires (BDDQ, HADS, DLQI)
Study IV	Qualitative interviews	Purposive sampling, BDD patients, men and women	15	2013–2014	Qualitative analysis (ID)

^a The sample had been selected to increase the proportion of respondents with positive BDD screening, in order to evaluate the questionnaire’s properties at the cut-off point.

3.1. DESIGN

In Study I, the screening questionnaire BDDQ was validated in a community sample of women. The BDDQ was translated into Swedish, using verbatim translation with the aid of the wording from the Swedish translation of the DSM-IV where applicable. The Swedish translation of the BDDQ was validated with diagnostic interviews as the gold standard, using the SCID (First et al., 2002).

Studies II to IV were descriptive studies. Two prevalence studies were conducted using cross-sectional designs with randomly selected, population-based sample of Swedish women (Study II) and a consecutively selected sample of female Swedish dermatology patients (Study III). Validated self-report questionnaires were used to estimate prevalence rates of BDD, symptoms of depression and anxiety, and health-related quality of life. The questionnaires

also recorded self-reported sociodemographic data and, in Study III, information about the participants' dermatologic problems.

In Study IV, a qualitative research design was used to study the patients' experiences of living with BDD, including their experiences of the health care system. Interviews with 15 BDD patients were analysed using ID, which is an inductive approach to understanding clinical phenomena with the purpose of capturing human experiences of health and illness (Thorne et al., 1997; Thorne, 2008).

3.2. PARTICIPANTS

Studies I-II

The eligibility criteria included all women aged 18-60 years in the county of Östergötland, who were registered with an accessible address in the national population register. Sampling randomization was performed based on the social security numbers in the national register, and questionnaires were sent via mail to 7 000 women. A follow-up reminder with a second copy of the questionnaire was sent to the 4 700 women who had not responded after four weeks. A total of 2 885 women participated in the study, after excluding six responders because of non-response to items required for the BDD screening (response rate 42%). Participants in the validation study (Study I) comprised a sub-sample from Study II (n=88). See section 3.4.1 for the generation of the sub-sample.

Study III

From February to September 2013, 523 female outpatients were consecutively selected at two tertiary referral (hospital) dermatology clinics. The eligibility criteria included female non-cancer, general dermatology patients aged 18–60 years. These patients were asked to voluntarily fill in questionnaires. A follow-up reminder with a second copy of the questionnaire was sent to the patients who had not responded after four weeks. A total of 425 women participated in Study III, after excluding seven responders because of non-response to items required for the BDD screening (response rate 81%).

Study IV

Based on the assumption that people who have lived with certain experiences are the best source of knowledge, a purposive sampling was used for Study IV, and 15 participants with BDD were selected (Kvale and Brinkmann, 2009; Patton, 2002). Originally, we intended to recruit all interviewees from dermatology patients diagnosed with BDD by the SCID in Study III (see section 3.4.2). Since fewer participants than expected could be recruited from the dermatology patient study (n=3), additional participants (n=12) were recruited from a clinic specializing in treating BDD. To expand the emerging data, according to the principle of maximum variation sampling (Patton, 2002), both men and women were recruited into this group. Patients diagnosed with BDD (by a clinical interview), who had been placed on a

waiting list for treatment, received an invitation letter to participate in the present study. The first 12 who consented to participate were invited, and they agreed to participate in Study IV.

3.3. MEASUREMENTS

3.3.1. The Body Dysmorphic Disorder Questionnaire

The BDDQ is a brief, self-report measure that is derived from the DSM-IV diagnostic criteria for BDD (Phillips et al., 1995). Using close-ended questions it assesses whether the respondent's appearance concerns are sources of preoccupation and, if so, whether they cause distress or interfere with the individual's social or occupational functioning. The questionnaire was developed as a screening instrument for BDD in psychiatric settings and has exhibited high sensitivity (100%) and specificity (89 to 93%) when validated in psychiatric samples (Phillips et al., 1995; Grant et al., 2001). It has also been validated against the SCID in a sub-sample (n=127) of a facial cosmetic surgery sample, and displayed a sensitivity of 100% and a specificity of 91% (Dey et al., 2015).

The questions of the BDDQ are presented in Fig. 1. The numbers 0-4 denote the scoring created for the validation procedure (see section 3.4.1). To continue the questionnaire, positive answers to the first two questions are required. The third question is used to exclude respondents that are primarily concerned with not being thin enough to ensure that BDD is not over-diagnosed when an eating disorder may be a more accurate diagnosis. A positive answer to at least one section of the fourth question, which assesses distress and impairment caused by the preoccupation, is further required for a positive BDD screening. In the interpretation of the BDDQ, it is suggested that the time spent thinking about the perceived defect should be at least one hour per day to fulfil the BDD diagnostic criteria (Phillips, 1998). Thinking about the appearance flaw for at least an hour per day is also a time criterion (optional) in the diagnosis of BDD according to the SCID (First et al., 2002).

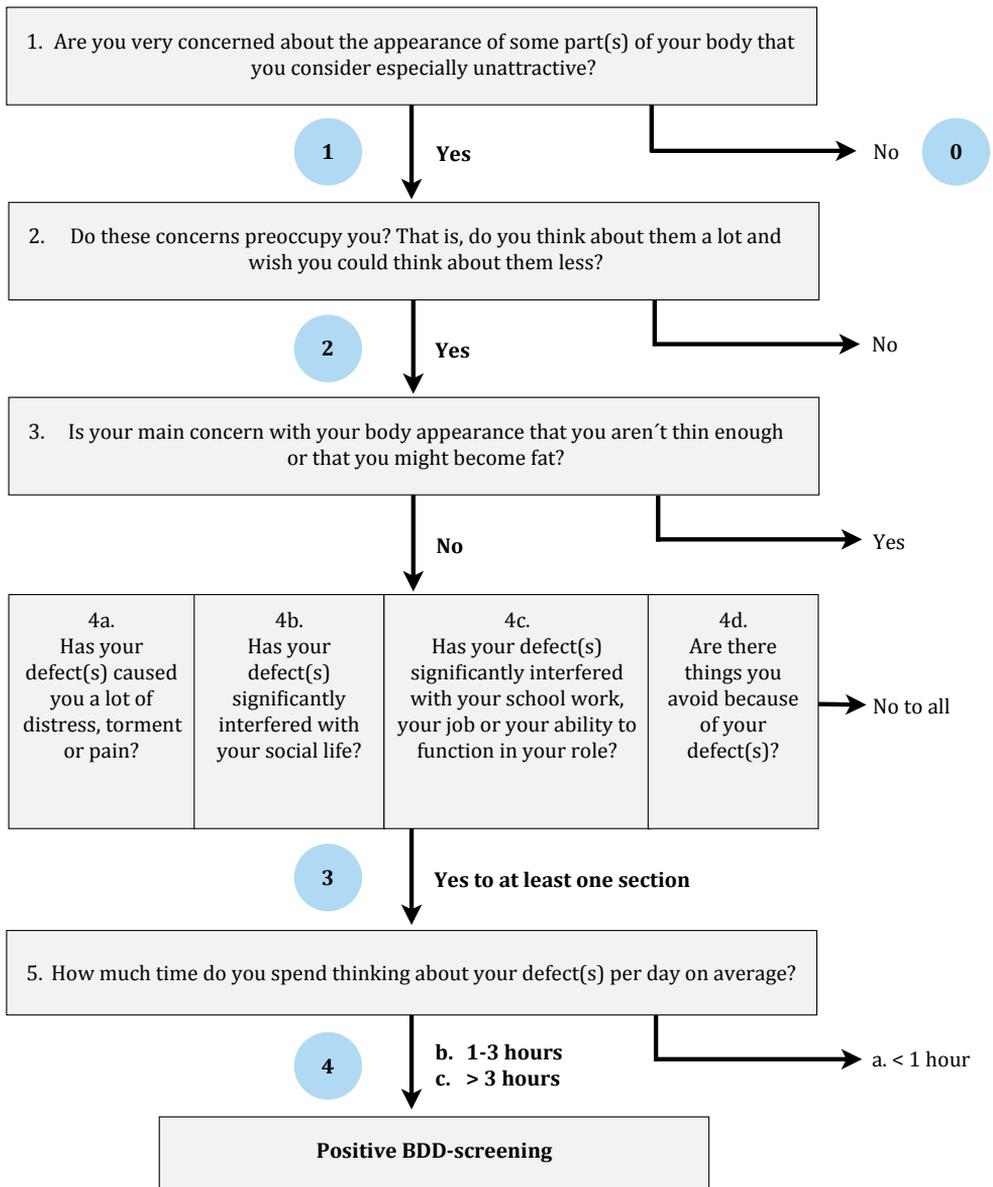


Figure 1. The questions of the BDDQ. The numbers 0-4 denote the scoring created for the validation procedure.

3.3.2. The Hospital Anxiety and Depression Scale

The HADS is a 14-item self-report screening scale that was originally developed to indicate the potential presence of anxiety and depression in medical, non-psychiatric patients (Zigmond and Snaith, 1983). A review from 2002 indicated that the HADS performs well in screening for anxiety disorders and depression in patients from non-psychiatric hospitals, general practice, and psychiatric clinics, as well as in individuals in the general population (Bjelland et al., 2002). The scale assesses the occurrence of symptoms of depression and anxiety during the previous week and consists of a seven-item anxiety subscale and a seven-item depression subscale; each item is scored from 0 to 3 (maximum score of 21 in each subscale). Receiver operating characteristic (ROC) curves have identified a score ≥ 8 as an optimal cut-off for both anxiety disorders and depression, yielding sensitivities and specificities of approximately 80% when compared to the DSM and the International Classification of Diseases (ICD)-9 (Bjelland et al., 2002). In Study II we used the cut-off at ≥ 8 to indicate depression/anxiety. Snaith proposed that a score of ≥ 11 indicates the probable presence of a mood disorder (and that a score of 8-10 is only suggestive of a disorder), and a HADS score ≥ 11 is often used as the cut-off value for clinically significant depression/anxiety (Snaith, 2003). Most studies that have used HADS ≥ 11 have exhibited specificities of over 90% (Bjelland et al., 2002). Since Study III involved a clinical sample, in that study we used the cut-off for clinically significant disorder (HADS ≥ 11) to increase the specificity in assessing anxiety and depression.

3.3.3. The Dermatology Life Quality Index

The DLQI is a widely used, validated self-report tool specific for dermatology (Basra et al., 2008; Finlay and Khan, 1994). The DLQI comprises ten questions assessing the quality of life in six subdomains: symptoms and feelings, daily activities, leisure, work and school, personal relationships, and (problems related to) treatment. Respondents indicate the extent to which they have experienced certain problems during the previous week. Response options are on a four-point Likert scale from 'not at all/not relevant' to 'very much.' Scores for each item range from 0 to 3, and are totalled to create an overall DLQI score up to a maximum of 30; the higher the score, the more the quality of life is impaired. The total DLQI score is interpreted in an ordinal scale as follows, 0-1 = no effect at all on the patient's life, 2-5 = small effect on the patient's life, 6-10 = moderate effect on the patient's life, 11-20 = very large effect on the patient's life, and 21-30 = extremely large effect on the patient's life. The subdomains have one or two questions and, thus, have a maximum score of 3 or 6. Individual subdomain scores can be expressed as a percentage (0-100%) of the maximum subdomain score.

3.4. PROCEDURES

3.4.1. Validation

For the validation, the BDDQ was scored from 0 to 4 points (Fig. 1, p 28). Although the BDDQ was not developed as a scale, but rather as a screening questionnaire following the diagnostic decision tree according to the DSM-IV criteria for BDD, the scoring of the BDDQ was created to ensure a validation of the questionnaire's properties at 'increasing levels' of appearance concern. A BDDQ score of 4 is equal to a positive BDD screening, as intended in the development of the BDDQ (Phillips et al., 1995). The BDDQ respondents from Study II (n=2885) were grouped into the five BDDQ score levels 0,1,2,3 and 4, and an interview sample was created that included respondents from all these BDDQ score levels. Twenty women were selected at random from within each group with BDD scores of 0, 1, 2 and 3. From the group with a BDDQ score of 4, more women were selected (n=25) in order to assess the questionnaire's validity more thoroughly at the cut-off at four points (i.e., positive BDD screening). Eighty-eight of these women agreed to participate in diagnostic interviews.

Diagnostic interviews were carried out by the author following a semi-structured diagnostic method, i.e., the Structured Clinical Interview for DSM-IV-TR Axis I Disorders, Research Version, Non-patient Edition (SCID-I/NP) (First et al., 2002). According to the DSM-IV, the perceived physical defect must be non-existent or slight to meet the diagnostic criteria for BDD (APA, 1994). It is therefore already implied in the SCID that the appearance flaw must be non-existent, or slight with a markedly excessive concerns (First et al., 2002). In several previous studies (in dermatology and cosmetic surgery settings) defect severity ratings have been used to standardize the assessment of the perceived flaws (Dufresne et al., 2001; Conrado et al., 2010). In the 'SCID evaluation' in Study I, a similar standardization of the clinical assessment of the perceived flaws was adopted. A Likert scale was used, that ranged from 1 to 3; 1 = no flaw present, 2 = minimal/slight flaw present, 3 = flaw present and clearly noticeable within conversational distance. A rating of 1 or 2 was considered the standardized evaluation that corresponded to the 'non-existent' or 'slight' as referred to in the DSM-IV criterion A. The SCID evaluation, i.e., the SCID interview including the standardized clinical assessment of the perceived appearance flaw, was considered the gold standard for diagnosing BDD. Before the interview, the interviewer was blinded to the interviewees' scoring on the BDDQ. After the interview, the results from the BDDQ were compared to the SCID evaluation.

3.4.2. Prevalence assessment

In Study II, the prevalence rate was based on positive screening on the BDDQ, since the validity properties of the BDDQ were satisfactory. In Study III, the original intention was to complement a positive BDD screening with a diagnostic interview using the SCID and a dermatological evaluation of the perceived appearance flaws. All patients with positive screening on the BDDQ, who had declared their willingness to participate, were contacted via telephone and invited to a diagnostic interview. Of the 21 patients who screened positive for

BDD, only seven accepted the invitation. Three of these seven women fulfilled BDD criteria in the diagnostic interview. Since only about one-third of those screening positive for BDD on the BDDQ participated in the diagnostic interview, the usefulness of the intended method for BDD assessment was considerably limited. Therefore, the BDD prevalence rate in dermatology patients (Study III) was reported based solely on positive BDD screening, in conformity with Study II.

3.4.3. Qualitative interviews

The author interviewed the 15 individuals with BDD using an interview technique based on Price's ladder questions (Price 2002). 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. 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 of 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. The researcher kept a reflective journal to make some minor adjustments to the interview guide for subsequent interviews. Ten participants were interviewed face-to-face in offices in 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 lasted 60 to 90 minutes, were audio-recorded, and then transcribed verbatim by the author (n=3) and by an external transcriber (n=12).

3.5. DATA ANALYSES

3.5.1. Statistical analyses (Studies I-III)

The point prevalence of BDD respondents (i.e., positive BDD screening) was reported as a percentage of the total sample with the 95% confidence interval (CI). The reliability of the HADS was estimated by calculating Cronbach's alpha. All analyses were performed using IBM SPSS Statistics software. The level of statistical significance was set at $p < 0.05$. Abbreviated descriptions of the study-specific analyses are provided here and more extensive descriptions are provided in each paper.

Study I

The sociodemographic characteristics of the interview sample were compared with the total sample in Study II using Pearson's chi-square analysis (employing Fisher's exact test when indicated) for categorical variables, and the Mann-Whitney U test for ordinal variables. The

validity was assessed using sensitivity, specificity, positive and negative predictive values and positive likelihood ratio (LR) (Fletcher et al., 1996).

Studies II-III

Between-group differences were assessed using the independent samples t-test for the continuous variables (age and mean HADS scores). Binary logistic regression was used for categorical sociodemographic variables (education, marital status, employment status, and income), with BDD respondent/non-BDD respondent as the dependent variable.

Between-group differences in anxiety and depression as dichotomous variables were assessed using binary logistic regression, with anxiety/depression as the dependent variable.

The Mann-Whitney U test was used to compare the total DLQI scores and the individual DLQI subdomain scores (because distributions were skewed). From the logistic regression models, ORs were used as effect sizes. The adjusted ORs were assessed after controlling for age. Effect sizes for difference in mean HADS score were reported using Cohen's d: 0.2=small effect, 0.5=medium effect, and 0.8=large effect (Cohen, 1992).

3.5.2. Qualitative analysis (Study IV)

Each separate interview was analysed by the author and validated by the co-author K Blomberg. The first step of the analysis was to read through and listen to the interviews several times to obtain a sense of the whole (Step 1). In the next step, all interviews were coded 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, sub-themes and themes were formulated in an iterative process (Step 4). A sub-theme was formulated for each group of headings, and these sub-themes 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 sub-themes. The analysis identified six themes, and sub-themes were described within each theme. Finally, an overarching concept was developed from the underlying meanings of the themes.

3.6. ETHICAL CONSIDERATIONS

All studies in this thesis were approved by the Regional Ethical Review Board in Linköping (registration numbers M103-09 and 2013/491-32). In Studies I-III, participants were invited to fill in questionnaires, and an enclosed letter explained that by returning a completed questionnaire, consent to participation would be assumed. Participants in the qualitative interview study (IV) volunteered to share their life stories, and informed consent was given by all the participants. Measures were taken to ensure confidentiality, and privacy. Interviews in Studies I, III and IV were held in offices in university or hospital buildings. Questionnaires contained only identification numbers; lists of names were kept separately, and were only accessible by the author. In Study IV, participants' names were removed from transcripts and identifiable details were changed. The participants in all four studies were informed about confidentiality and that they could withdraw their participation at any time.

For individuals that are concerned with their appearance, answering questions about those concerns may be associated with psychological distress. For all participants, questions aimed at assessing symptoms of depression and anxiety may similarly evoke negative feelings. All sent out questionnaires therefore included an information letter that encouraged the participants to contact the researcher if they had any questions.

As a large part of this thesis involved assessing BDD prevalence rates by means of screening for BDD, participants could potentially become aware that they suffered from a psychiatric disorder. When BDD was diagnosed in the diagnostic interviews in Study I a 'psycho-education' process was initiated, as recommended by Wilson & Arpey (Wilson and Arpey, 2004), which included providing verbal and written information about BDD. Contact details of independent therapists and of BDD information and patient organizations on the Internet were also given.

The qualitative interviews naturally included more in-depth questions and could potentially generate even more feelings of distress. The patients from the dermatology clinics were offered psychological support if needed after the interview. They were provided with written information regarding BDD, and contact details of an independent psychotherapist and of patient organizations on the Internet. The participants from the clinic specializing in BDD all had on-going contact with psychotherapists and were already on a waiting list for receiving specialized treatment.

Some of the participants in Study IV acknowledged a positive experience of sharing their life stories. On the other hand, it is not known whether any of the participants (in either study) felt the need to contact a psychotherapist due to increased psychological distress.

Since no intervention studies were included in the thesis, neither any great risks, nor any obvious benefits for the participants were anticipated. From a wider perspective, the desired consequences of this thesis include an increased recognition of BDD that would be favourable for individuals suffering from the disorder since an increased awareness among health care professionals may contribute to better access to treatment for individuals with BDD.

4. RESULTS

In this section, abbreviated descriptions of the results of studies I-IV are provided. More extensive descriptions are provided in each paper.

4.1. VALIDITY AND RELIABILITY

4.1.1. Validity of the BDDQ (Study I)

The interviewed women's BDDQ scores and BDD diagnoses according to the SCID evaluation are presented in Table 5. A BDDQ score of 4 was considered a positive BDD screening (n=24). Of the 24 women with a positive BDD screening, 17 were diagnosed with BDD according to the SCID evaluation.

Table 5. Distribution of the respondents' scores on the BDDQ and their diagnoses according to the SCID evaluation in the validation sample (n=88)

Supplement to Table 5, for comparison.

BDDQ score	BDD ^a	No BDD ^a	BDDQ score distribution in Study I (n=88)	BDDQ score	BDDQ score distribution in Study II (n=2 885)
0	0 (0%)	20 (100%)	20	0	1666
1	0 (0%)	18 (100%)	18	1	391
2	0 (0%)	11 (100%)	11	2	625
3	1 (7%)	14 (93%)	15	3	142
4	17 (71%)	7 (29%)	24	4	61

^aBDD diagnosis according to the SCID evaluation, i.e., the SCID interview, including standardized clinical assessment of the severity of the perceived appearance defects.

Table 6 summarizes the validation results. In this study, sensitivity is defined as the proportion of women with BDD, as determined by the SCID evaluation, who screened positive for BDD using the BDDQ. Specificity is defined as the proportion of women without BDD according to the SCID evaluation, who screened negative for BDD using the BDDQ. The LR summarizes sensitivity and specificity and is expressed as odds. The (positive) LR expresses how many times more likely it is that BDDQ screening will be positive in women with BDD compared to in women without BDD. The Swedish translation of the BDDQ displayed high rates of sensitivity (94%) and specificity (90%) in the community sample of women. The (positive) LR was 9.4, which means that it is almost ten times more likely that the BDDQ screening will be positive in women with BDD compared to in women without BDD.

Table 6. Validation of the BDDQ, by comparing the results of the BDDQ screening with the results of the SCID evaluation in Study I (n=88)

	SCID evaluation (gold standard) ^a	
	BDD	No BDD
BDDQ positive	17 (a)	7 (b)
BDDQ negative	1 (c)	63 (d)

Validation concept	Value (95% confidence interval)
Sensitivity (a/(a+c))	94% (71-100)
Specificity (d/(b+d))	90% (80-96)
Positive predictive value (a/(a+b))	71% (49-87)
Negative predictive value (d/(c+d))	98% (90-100)
Likelihood ratio (a/(a+c))/(b/(b+d))	9.4 (4.6-19.2)

^a BDD diagnosis (BDD/no BDD) according to the SCID evaluation, i.e., the SCID interview, including standardized clinical assessment of the severity of the perceived appearance flaws.

4.1.2. False positive BDD screening

Of those screening positive for BDD by the BDDQ in Study I, seven women did not fulfil BDD criteria according to the SCID evaluation, which means that 29% of those screening positive for BDD were not diagnosed with BDD by the SCID evaluation (false positive BDD screening). The positive predictive value (PPV) was thus 71% in the validation sample. Six of these seven respondents with false positive BDD screening did not meet the clinical significance criterion (i.e., the appearance concerns caused neither significant distress nor impairment). In one respondent, the reason for not meeting DSM criteria for BDD was that her perceived flaw was clearly noticeable from conversational distance.

In Study III, the validity of the BDDQ could not be properly assessed, because only one-third of the patients screening positive for BDD agreed to a diagnostic interview. Four of the seven women with positive BDD screening, who did agree to a diagnostic interview, did not fulfil the BDD diagnostic criteria. One respondent had misinterpreted the questionnaire because of difficulty with the Swedish language. In the remaining three respondents, the reason for not meeting the DSM criteria for BDD was that their perceived flaws were clearly noticeable. These respondents (including the one BDD respondent with noticeable ‘flaw’ in Study I) did, however, suffer significant distress and/or impairment due to their appearance ‘flaws’.

4.1.3. Reliability of the HADS

Cronbach’s alpha was 0.85 in the population sample and 0.84 in the clinical sample for HADS anxiety and 0.82 in the population sample and 0.83 in the clinical sample for HADS depression, indicating a good internal consistency for the HADS in both samples.

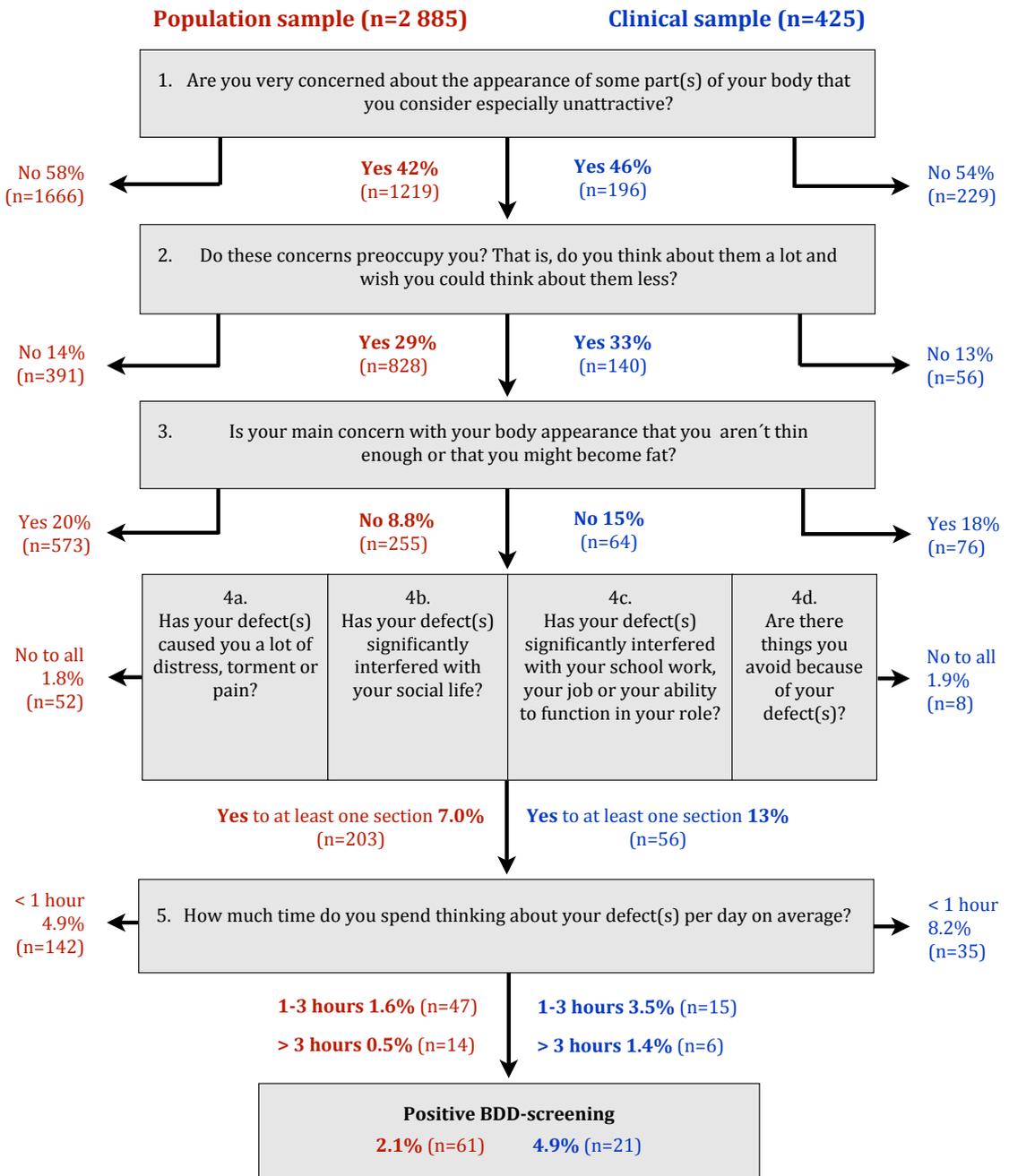


Figure 2. Proportions of the respondents screening positive for BDD in Studies II and III. Percentages are reported as the proportion of the total number of respondents in the different samples.

4.2. SAMPLE REPRESENTATIVENESS (STUDY II)

In Study II, the response rate was lower than expected (42%), and therefore an analysis of the representativeness of the sample was performed. The total study sample (n=2 891, including the six respondents with non-response on items required for BDD diagnosis) was compared with the general female population (women aged 18-60 years in the county of Östergötland at the time of the study, n=115 101) using the demographic data available from the respondents and the corresponding data on age, degree of education completed, employment status, and profession, available from existing Swedish population statistics (see Paper II, Table 1). Although some differences were identified, the distribution of the demographic parameters was reasonably similar between the study sample and the general female population.

4.3. PREVALENCE OF BDD (STUDIES II-III)

In the general female population (Study II) and in female dermatology patients (Study III), appearance concerns were common (Fig. 2). Almost half of the respondents (42% and 46% respectively) reported being very concerned about some part of their body that they considered especially unattractive and one-third (29% and 33% respectively) acknowledged being preoccupied with these concerns. Most of these women were primarily preoccupied by not being thin enough, but 8.8% of the community women and 15% of the dermatology patients were preoccupied by other aspects of their appearance. In total, 2.1% (95% CI 1.7-2.7) of the community sample and 4.9% (95% CI 3.2-7.4) of the dermatology patient sample screened positive for BDD (i.e., BDD respondents).

Distress and/or impairment due to the appearance concerns (the clinical significance criterion) are assessed by question 4 in the BDDQ. To fulfil BDD diagnostic criteria, at least one area needs to be affected. The proportional Venn diagrams in Fig. 3 illustrate that for most BDD respondents, the appearance concerns caused impairment in several areas. All areas were affected in 30% (n=18) of women with positive BDD screening in the community sample and in 43% (n=9) of those in the clinical sample.

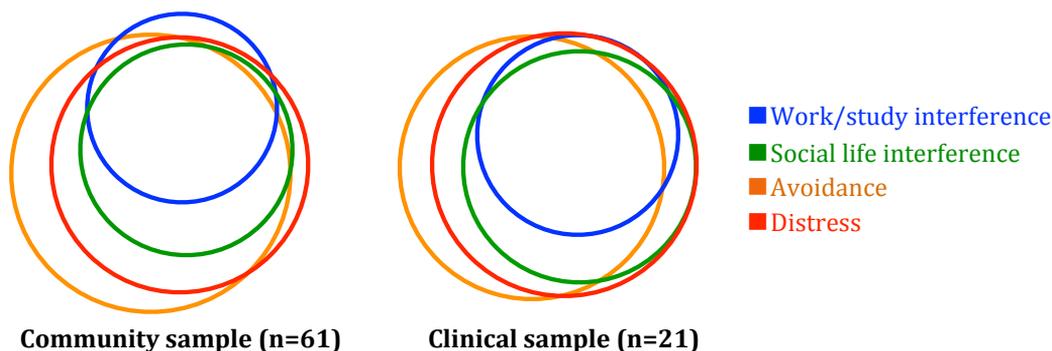


Figure 3. Proportional Venn diagrams illustrating distress and impairment caused by the appearance concerns (question 4 in the BDDQ) in the BDD respondents in Studies II and III.

4.4. BDD AND SYMPTOMS OF PSYCHOLOGICAL ILL HEALTH (STUDIES II–III)

In the quantitative studies (Studies II and III) the BDD respondents differed substantially from non-BDD respondents with respect to symptoms of depression and anxiety. In Table 7, BDD and non-BDD respondents are compared with regard to mean HADS scores, and depression and anxiety as dichotomous variables with the different cut-off values (HADS score ≥ 8 and HADS score ≥ 11). All differences were statistically significant ($p < 0.05$) and demonstrated large effect sizes.

The rates were very similar in the community and clinical samples, and in both samples the BDD respondents had considerably more symptoms of anxiety and depression. In the community sample (Study II) anxiety (HADS A ≥ 8) was more than twice as common (72% vs. 32%), and depression (HADS D ≥ 8) was more than four times as common (42% vs. 9.5%) in BDD respondents than in non-BDD respondents. In Study III, using the cut-off score for clinically significant disorders, anxiety (HADS A ≥ 11) was four times as common (48% vs. 11%), and depression (HADS D ≥ 11) was over ten times as common (19% vs. 1.8%) in BDD respondents than in non-BDD respondents.

In the dermatology sample (Study III), quality of life was severely affected in the BDD respondents, with significantly higher DLQI scores than in non-BDD respondents (Table 8). The median total DLQI score was 18 in the BDD respondents, compared with a score of 4 in the non-BDD respondents ($p < 0.001$), which is compatible with very large effects on the patients' lives in the BDD respondents. The BDD respondents exhibited the most impaired quality of life in the subdomain of symptoms and feelings, with a mean score twice as high (72%) as non-BDD respondents (36%) ($p < 0.001$). Daily activities and personal relationships were also highly affected in the BDD respondents, with mean scores of 55 to 60% compared to 14 to 18% in non-BDD respondents ($p < 0.001$).

Table 7. Symptoms of anxiety and depression in BDD respondents compared to non-BDD respondents in Studies II and III, as assessed by the HADS

Variable	Community sample			Clinical sample			p-value	
	BDD respondents (n=61)	Non-BDD respondents (n=2824)	Effect size ^a	p value	BDD respondents (n=21)	Non-BDD respondents (n=404)		Effect size ^a
HADS A (mean ± SD)	10.1 ± 3.9	6.4 ± 4.1	d=0.92	<0.001	10.3 ± 4.5	6.1 ± 3.8	d=1.13	<0.001
HADS D (mean ± SD)	6.7 ± 3.8	3.3 ± 3.0	d=0.99	<0.001	6.5 ± 4.0	2.9 ± 2.8	d=1.23	<0.001
Anxiety (HADS A ≥8)	72.1%	31.8%	OR=5.1 (2.8–9.1)	<0.001	66.7%	31.4%	OR=3.3 (1.3–8.6)	0.014
Depression (HADS D ≥8)	41.7%	9.5%	OR=6.6 (3.8–11.4)	<0.001	42.9%	8.8%	OR=6.4 (2.5–16.7)	<0.001
Clinical anxiety (HADS A ≥11)	42.6%	15.7%	OR=3.4 (2.0–5.8)	<0.001	47.6%	11.4%	OR=5.4 (2.1–13.8)	<0.001
Clinical depression (HADS D ≥11)	16.7%	3.2%	OR=6.4 (3.1–13.2)	<0.001	19.0%	1.8%	OR=11.8 (2.9–47.6)	<0.001

^a Cohen's d: 0.2=small effect, 0.5=medium effect, and 0.8=large effect. OR=Odds ratio (95% confidence interval), adjusted for age.

Table 8. Quality of life in BDD respondents compared to non-BDD respondents in Study III, as assessed by the DLQI

Variable	BDD respondents (n=21)	Non-BDD respondents (n=404)	p value
DLQI total score (median) ^a	18	4	<0.001
DLQI subdomain score ^b			
Symptoms and feelings	72.2	35.7	<0.001
Daily activities	60.3	18.5	<0.001
Leisure	51.6	16.1	<0.001
Work and school	41.3	17.1	<0.001
Personal relationships	54.8	14.5	<0.001
Treatment	41.3	14.7	<0.001

^a Total DLQI scores range from 0-30; higher scores indicate more impaired quality of life.

^b Mean scores for each of the six subdomains composing the DLQI, expressed as a percentage of the maximum subdomain score (3 or 6).

Among some of the BDD respondents in Study III, their reasons for attending the clinic were presumably to seek treatment for their perceived appearance flaw (e.g., seeking treatment for acne when preoccupied with the facial skin). However, not all patients sought dermatologic care because of their reported appearance preoccupations, and, for some patients, it was not obvious whether their preoccupation was the reason for attending the clinic (see Paper III, Table 2).

4.5. THE EXPERIENCE OF LIVING WITH BDD (STUDY IV)

The overarching concept, themes and sub-themes identified in Study IV are displayed in Table 9. Ideas of imprisonment and abnormality composed the experience of living with BDD. Living with this disorder was described as a constant struggle, comparable to constantly carrying a weight or being in a prison and never being free. The participants described time-consuming patterns of obsessive thoughts, feelings, and compulsive behaviours. Several of the participants suggested that the disease had taken over their lives and had become a part of them. The participants felt 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 they suffered greatly from their BDD, nearly all participants had experienced difficulties in accessing health care. A majority described having to wait for a long time before obtaining help; this delay occasionally led to increased suicidal ideation or even suicide attempts. Several patients had had to educate health care professionals about their condition because knowledge regarding BDD was limited or non-existent. Participants felt rejected, felt that the health care system lacked resources, or felt disappointed that help was not available.

Table 9. Overarching concept, themes and sub-themes identified by the analysis of the interviews in Study IV

Overarching concept	Theme	Sub-theme
	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
Feeling imprisoned – struggling to become free and to no longer feel abnormal	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
Attempting to reduce one's problems		Experiencing difficulties in relationships with intimate partners
		Attempting to conceal defects
Striving to receive care		Attempting to improve one's appearance
		Encountering difficulties in accessing health care
		Being disappointed in the health care system

5. DISCUSSION

5.1. MAIN FINDINGS

5.1.1. Validity of the Swedish translation of the BDDQ (Study I)

Study I is the first study to validate a BDD assessment instrument in a community sample. The Swedish BDDQ was validated against a face-to-face diagnostic interview using the SCID, including a standardized clinical evaluation of the appearance flaw, as the gold standard. With a sensitivity of 94%, a specificity of 90% and an LR of 9.4, the BDDQ proved to have a good validity in the sub-sample of Swedish women (n=88).

The BDDQ has previously been validated in a few studies. In two different psychiatric samples, (n = 66 (Phillips et al., 1995) and n=122 (Grant et al., 2001)), the instrument displayed a sensitivity of 100% and a specificity of 89% and 93% respectively when validated against the BDD Diagnostic Module. In a dermatology patient sample (n=46), the BDDQ-DV had a sensitivity of 100% and specificity of 92% when validated against the BDD Diagnostic Module (Dufresne et al., 2001). The BDDQ presented a similar sensitivity (100%) and specificity (91%) and a positive LR of 10.3 when validated against the SCID in a sub-sample (n=127) of a facial cosmetic surgery sample (Dey et al., 2015). The validity studies in dermatology and cosmetic surgery settings used a similar defect severity rating as used in Study I to standardize the evaluation of the perceived appearance flaws, and the prevalence of positive BDDQ screening was about 20% in these samples. The specificity of 90% in Study I was, thus similar to earlier validation results and confirms the level of specificity of the instrument, also when used in a community sample. The sensitivity was lower than in previous validation studies, which can be explained by our different setting with a sample from the general population rather than psychiatric/dermatologic settings. The desired validity properties depend on the reason for using the instrument. When using the questionnaire to screen for the diagnosis to detect possible BDD, a high sensitivity is more important than a high specificity. However, when using the screening instrument to assess the prevalence, both a high sensitivity (not to underestimate the prevalence) and a high specificity (not to overestimate the prevalence) are desired.

5.1.2. Prevalence of BDD in Swedish women (Study II)

Studies II and III are the first to estimate prevalence rates of BDD in Sweden. Study II is one of five studies worldwide to report BDD prevalence rates in representative population-based samples and the largest of these studies (n=2 885). The point prevalence of self-reported BDD among Swedish women was 2.1% (95% CI 1.7-2.6%), as assessed by the BDDQ. Similar results were obtained in the population-based studies in Germany and the US, with self-reported prevalence rates in women of 1.9% (Rief et al., 2006), 2.0% (Buhlmann et al., 2010), and 2.5% (Koran et al., 2008). Schieber et al. (2015) reported a slightly higher rate of

4.4% in German women, using self-report questionnaires with the DSM-IV criteria for BDD. A strength of Study II was that the BDD prevalence was estimated using a questionnaire with good validity properties in the population examined. None of the other large population-based studies used validated measurements to assess BDD prevalence. Assuming that the PPV of the BDDQ as identified in the sub-sample in Study I (71%) is transferable to the total sample in Study II, the prevalence of BDD (according to diagnostic interviews) is estimated at 1.5% in Swedish women. This rate is lower than the self-reported rates in the studies cited above. It is possible that the other self-reported prevalence rates of BDD are also over estimations of the BDD prevalence, since the prevalence rate obtained via semi-structured clinical interviews in smaller community settings was 0.7 and 0.8% (Faravelli et al., 1997; Otto et al., 2001). However, the BDDQ was validated in a sub-sample with different prevalence of positive BDD screening, and therefore the validity properties may be different in the total sample of Study II (as further discussed in section 5.2.3). Screening for BDD using the BDDQ involves a risk of under-diagnosing BDD, as individuals with primary weight concerns are excluded (also discussed below, in section 5.2.2). The other large population-based studies used different strategies to exclude eating disorders as the cause of appearance concerns, in which case BDD should not be diagnosed according to the DSM-IV criterion C (APA, 1994). The exclusion of eating disorders in these studies was based on self-reported symptoms using different questions (up to 12 items) (see Table 1, p 11).

Interestingly, although the self-report measurements used differed, similar prevalence rates of BDD were found in all five large population-based samples. These findings indicate a comparable occurrence of BDD across these Western countries (Sweden, Germany and the US), if the assessment methods have comparable accuracy. The procedure of excluding eating disorders may also present a comparable accuracy in the different population-based samples, although the measurements used in the different studies differed regarding assessment details.

In conclusion, although the BDD prevalence in Swedish women may deviate from that identified by the BDDQ, the findings in Study I-II indicate that BDD is prevalent in the general population of women. The prevalence of BDD is comparable to rates of other psychiatric disorders such as OCD and AN (as assessed by lay-administered structured interviews). In one of the largest population-based surveys the 12-month prevalence was 1.0% for OCD, among US citizens (Kessler et al., 2005b), whereas the reported 12-month prevalence rate of OCD internationally was 1.1-1.8% (Weissman et al., 1994). The reported lifetime prevalence of AN was 0.9% among adult females in the US and six European countries (Smink et al., 2012). In Sweden, the lifetime prevalence of AN was 1.2% in the world's largest population-based twin study of women (Bulik et al., 2006). Thus, BDD may be as common as more widely known psychiatric disorders, for which there are established routes of referral and treatments available, while BDD is still under-recognized and under-studied.

5.1.3. Features of BDD in dermatology patients (Study III)

In Study III, the point prevalence of self-reported BDD among female Swedish dermatology patients was 4.9% (95% CI 3.2–7.4), as assessed by the BDDQ. If the PPV of the BDDQ as identified in Study I (71%) were transferable to the dermatology sample, the prevalence of BDD (according to diagnostic interviews) would be about 3.5% in Study III. This assumption must be treated with the greatest caution, since the BDDQ was not validated in this setting (as further discussed in section 5.2.4). Nevertheless, the results indicate that BDD is more common in dermatology patients than in the general population of Swedish women.

The self-reported BDD prevalence in Study III was lower than those found in four of the previous studies of general dermatology samples in other countries (Table 2, p 12). About 14% of US dermatology patients screened positive for BDD by the BDDQ-DV (Phillips et al., 2000; Bowe et al., 2007). Using the SCID to assess BDD, prevalence rates of 6.7% and 8.8% have been found in Brazilian and Turkish settings (Uzun et al., 2003; Conrado et al., 2010). In another Turkish study, 4.2% of the subjects screened positive for BDD using the BDDQ-DV, a similar rate to that in our study (Dogruk Kacar et al., 2014). However, the majority of the patients with self-reported BDD in the latter study had weight concerns, and it is unclear if any measures were taken to exclude eating disorders as the cause of the body image concern, and therefore the BDD prevalence may be even lower in that setting. Thus, the varying rates of BDD obtained may be due to differences in methods of assessment and sample sizes and are not necessarily evidence of variations in prevalence of BDD in the source populations. Nevertheless, it is likely that the BDD prevalence truly varies between different dermatology populations, because of cultural differences and different health care systems. BDD patients may attend dermatology clinics to a lesser degree in Sweden because some appearance-enhancing treatments (e.g., fillers, minor surgery, threads, Botox etc.) are not performed in Swedish tertiary (hospital) dermatology clinics. A higher BDD prevalence may therefore have been found in private dermatology clinics. In addition, Sweden has a referral system, which requires that patients with dermatology concerns first seek advice in primary care for certain dermatologic problems. If the skin problems the patient presents with are judged as minor, the patient may not be referred to a hospital dermatology clinic. This may well be the case for BDD patients, as their perceived flaws are not evident to others. Therefore, the prevalence of BDD may also be higher in patients seeking primary care for dermatologic problems.

Among the BDD respondents in Study III, the reason for seeking dermatologic treatment was not always associated with their main body area of concern (or 'perceived appearance defect'). This result is consistent with findings in an earlier study in which, for more than half of the BDD patients, their dermatologic symptom was not the same as their major BDD concern (Conrado et al., 2010). These authors hypothesized that patients with BDD seeking dermatologic care may not be able to precisely report their symptom or 'real' complaint and that the shame associated with the disorder may prevent BDD patients from revealing their 'real' BDD preoccupations to health care professionals (Conrado et al., 2010). In addition, it is possible that, as many BDD patients scrutinize their skin and facial features, and spend a

significant amount of time in front of the mirror, in addition to their perceived defects, they may become aware of other skin changes and seek dermatologic care because of these symptoms.

In Study III, features of BDD were common in dermatology patients. This suggests some clinical implications (see section 6.2) as well as some implications for research, specifically the interpretation of self-reported dermatology problems. BDD might cause a falsely high frequency of self-reported dermatologic disease, e.g. acne, which was one of the most commonly reported concerns in the BDD respondents in Study III. In several large surveys, self-reported acne has been found to be associated with increased psychological ill health, including suicidality (Picardi et al., 2013). A Norwegian study including almost 4 000 students found that suicidal ideation and social impairment were significantly increased in those who reported having major acne problems (14% of the sample) (Halvorsen et al., 2011). Similarly, a population-based study including over 9 000 adolescents in New Zealand found that those who reported having major acne problems (14% of the sample) had more severe symptoms of depression and anxiety, and an increased risk of suicide attempts; 13% had made a suicide attempt in the last year (Purvis et al., 2006). However, as acknowledged by Purvis et al. (Purvis et al., 2006), depression and anxiety could cause an increase in self-reported acne. BDD may also cause an increase in self-reported dermatologic problems, including acne. BDD seems to be especially prevalent in student populations; 5% as assessed by the SCID (Cansever et al., 2003), and 1.2 to 13% as assessed by screening questionnaires (about 5% in most of these studies) (Biby, 1998; Bohne et al., 2002; Sarwer et al., 2005; Bartsch, 2007; Liao et al., 2010; Boroughs et al., 2010). Therefore, in the dermatology surveys cited above, some respondents with self-reported major acne problems may instead have been individuals with BDD whose perceived acne problems would only have been judged as minor if objectively assessed. Although it is likely that acne does have an impact on body image and mental health as the authors of those studies concluded, the results of surveys with self-reported dermatologic problems must be interpreted with caution.

In summary, it is important for dermatologists to be aware that features of BDD seem to be prevalent among dermatology patients. Suggestions for detection and initial management of BDD are outlined in the Clinical implications section.

5.1.4. Emotional suffering and psychosocial handicap associated with BDD (Studies II–IV)

All BDD patients interviewed in Study IV expressed a profound feeling of ugliness; this feeling was associated with emotional distress, shame and disgust; emotions that have been reported also in quantitative research (Phillips, 2014). The participants also expressed hating themselves, feeling inferior to others, or even worthless, which resulted in decreased self-esteem and self-confidence. Symptoms of depression and anxiety caused by their appearance concerns were commonly described.

Symptoms of depression and anxiety were quantified in Studies II and III, whereas the descriptions by the BDD patients in Study IV illustrate the impact of high levels of depression and anxiety. In the community sample, anxiety (HADS A ≥ 8) was more than twice as common (72 vs. 32%) and depression (HADS D ≥ 8) greater than four times as common (42 vs. 9.5%) among BDD respondents than in non-BDD respondents. The high rates of (current) depression and anxiety in Study II confirm the results of some previous studies of comorbidity in BDD patients (Table 3, p 18). In the largest samples of BDD patients, the lifetime prevalence of major depression, as assessed by the SCID, was 75 to 76% and the current prevalence was 58% (Gunstad and Phillips, 2003; Phillips et al., 2005). In those studies, the lifetime prevalence of anxiety disorders (most commonly SAD) was 64 to 73% and the current prevalence was 55%. The rates of anxiety and depression in Study II fall within the range of earlier studies; however, the rates are difficult to compare because of differences in assessment methods. Studies using screening questionnaires to assess depression and anxiety in BDD patients are scarce and no previous study has used the HADS.

Study III is the first to report data on the psychological condition of patients with self-reported BDD in dermatology settings. In the dermatology sample, a HADS cut-off score of 11 was chosen to assess clinically significant disorder and obtain rates comparable with other clinical samples. Not surprisingly, levels of depression and anxiety were significantly higher in BDD respondents than in non-BDD respondents. Anxiety (HADS A ≥ 11) was four times as common (48% vs. 11%) and depression (HADS D ≥ 11) more than ten times as common (19% vs. 1.8%) in BDD respondents than in non-BDD respondents. These rates were lower than in the studies discussed above, although the rates are difficult to compare because of differences in assessment methods. Current depression was also lower compared to studies using the screening questionnaire MADRS, that have reported depression in 28 to 50% of BDD patients (defined as MADRS > 20 , 'clinically significant depression') (Veale et al., 1996a; Van der Meer et al., 2012). The rates of anxiety and depression can be compared to findings from other dermatology samples. A large study of dermatology out-patients from 13 European countries (n=3 600) reported depression in 10% and anxiety in 17% of the patients based on a HADS cut-off value of 11 (Dalgard et al., 2015). In a Swedish sample of women with hirsutism (n=132) (Ekbäck et al., 2013), anxiety was found in 37% and depression in 16% of the patients (HADS ≥ 11), rates that are similar to the rates in BDD respondents in Study III (those findings are discussed in section 5.2.4).

As discussed above, the rates of depression and anxiety are difficult to compare with those of other studies, due to differences in assessment methods. In Studies II and III symptoms of depression and anxiety were assessed with self-report questionnaires and different cut-off values were used to define depression and anxiety. Moreover, the groups of BDD respondents in the studies were small (n=61 and n=21). However, assessing the exact rates of depression and anxiety disorders was not the aim of the studies. The importance of the findings is that the BDD respondents had more symptoms of depression and anxiety than non-BDD respondents, as demonstrated by significantly higher mean HADS scores (Table 7, p 40).

Quality of life was severely impaired in the dermatology patients with positive BDD screening, with a median DLQI score of 18, which indicates very large effects on the patients' lives (Table 8, p 41). In the BDD respondents all of the subdomains were affected, with significantly higher scores than in non-BDD respondents. In previous studies, BDD patients have reported low health-related quality of life, including decreased general mental health, enjoyment, social adjustment, and social functioning (Ishak et al., 2012). As a comparison with scores for some of the dermatology disorders associated with considerably impaired quality of life, recent reviews have reported mean DLQI scores ranging from 2.0 to 17.7 for acne, 1.7 to 18.2 for psoriasis, 4.3 to 17.3 for rosacea, and 1.8 to 15 for vitiligo (Cresce et al., 2014; Amer and Gao, 2016). In a recent study of 694 psoriasis patients, patients with severe psoriasis exhibited a mean DLQI score of 11.2 (Korman et al., 2016).

The BDD respondents in the community sample (Study II) were more likely to be single at the age of 46-60 years, which is consistent with the impaired functioning in relationships and social isolation that are associated with the disorder (Phillips, 2009). In both Studies II and III, the BDD respondents were unemployed and on sick leave to a higher degree than non-BDD respondents, findings that may also reflect the distress and impairment associated with BDD. Previous studies have similarly demonstrated that patients with BDD suffer social handicaps, experience disrupted studies or employment, and can even become housebound (Veale 2004; Fang and Wilhelm 2015). Study IV is the first qualitative study to add detailed descriptions of how the disorder restricts BDD patients' lives, and, furthermore, descriptions of suicidal behaviour. According to previous research, approximately 80% of individuals with BDD experience suicidal ideation during their lifetime, and 24 to 28% have attempted suicide (Veale et al., 1996a; Phillips and Menard, 2006; Phillips, 2007). Suicide attempts increase mortality and health care costs, and unemployment (which was overrepresented in the BDD respondents in Study II and III) is considered a factor associated with suicidal behaviour (Picardi et al., 2013).

In summary, the BDD patients in Study IV and the BDD respondents in Studies II and III suffered considerable emotional distress and psychosocial handicap.

5.1.5. Struggling to be free from imprisonment (Study IV)

The overarching concept derived from the analysis in Study IV was that the BDD patients felt imprisoned and that life was a struggle to be free and to no longer feel abnormal. The results suggest that a feeling of imprisonment defined the entire experience of living with the disorder. The term 'imprison' was also reported in a recent qualitative study of individuals with BDD, where mirrors were perceived as imprisoning by the participants (Silver and Farrants, 2015). All participants in Study IV expressed feeling ugly, which was not surprising considering that the diagnostic criteria for BDD require preoccupation with perceived defects in physical appearance (APA, 2013). However, the feelings of abnormality referenced their entire lives, and not specifically their physical appearance. They were bound by obsessive thoughts and behaviours that affected social life, work, studies, and close relationships to a great extent. They struggled to be free from this imprisonment in order to live a normal life. Although it could be argued that 'normal' (the participants' own choice of word) is an arbitrary term, it is nonetheless important to acknowledge these ideas of being abnormal. In line with these findings, previous research has indicated that concerns with 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). Notably, participants were concerned about appearing superficial to other people, although that knowledge did not help them to put their appearance problems in perspective.

Although they suffered greatly, the participants had experienced difficulties in accessing health care and described disappointing encounters with the health care system. Their experiences indicate that knowledge of BDD is limited both in the general population and within the health care system in Sweden, even among mental health professionals. The BDD patients had apprehended a lack of resources and had felt rejected by the health care system. They even described increased suicidal ideation and suicide attempts due to the delay in obtaining help.

5.1.6. The importance of a BDD diagnosis

BDD sufferers are not merely dissatisfied with their appearance

One of the main findings of this thesis is that BDD is prevalent among Swedish women. As many are unaware of this disorder, the findings may raise questions from people in general and from health care professionals: 'Is BDD really that common?' 'Is BDD really a disease, and not just vanity?' 'Isn't everyone dissatisfied with their appearance?' or 'Do these people really suffer - can they not just shape up'? Although answering all of these questions is beyond the scope of this thesis, here, the importance of the BDD diagnosis will be discussed.

In Western contexts, negative body image appears to have reached normative levels, particularly among girls and young women (Swami et al., 2012). Several studies suggest that dissatisfaction and preoccupation with appearance are very common; 43 to 87% have reported being dissatisfied and about 30% have acknowledged being preoccupied with their

appearance, women more frequently than men (Phillips et al., 2010b). The studies in this thesis confirmed that concern regarding appearance is also a general phenomenon among Swedish women in general (Study II) and in female dermatology patients (Study III), as almost half of the respondents (42% and 46% respectively) reported being very concerned about some part of their body that they considered especially unattractive, and one-third (29% and 33% respectively) were preoccupied with these concerns.

However, individuals with BDD are not merely dissatisfied with their appearance. As confirmed by the findings in Study IV, BDD is a highly distressing condition accompanied by obsessions and compulsions that impair the lives of sufferers. The emphasis in diagnosing BDD therefore is on the suffering and the handicap as consequences of appearance concerns.

The clinical significance criterion is important

The DSM has been criticized for unclear distinctions between psychopathology and normal psychological phenomena, e.g. how to distinguish shyness in social situations from SAD, or sadness after a stressful event from depression (Spitzer and Wakefield, 1999; Van Praag, 2000; Stein et al., 2010). Regarding the BDD diagnosis, a corresponding problem would be how to distinguish BDD from 'normal' dissatisfaction with appearance. The DSM acknowledges that no definition can cover all aspects of a psychiatric disorder (APA, 2013, p 20). Since we do not have knowledge of objective biomarkers that adequately define most psychiatric disorders, the clinical significance criterion is useful in differentiating a disorder from 'normality'. In response to the criticism that the DSM criteria do not necessarily indicate pathology, the clinical significance criterion was introduced in the DSM-IV to minimize 'false positive diagnoses', i.e., non-disordered conditions being classified as disorders (Spitzer and Wakefield, 1999). Specifically, the clinical significance criterion is intended to differentiate between mild forms of disorders and conditions where symptoms of psychological ill health are not clearly pathological (Spitzer and Wakefield, 1999). The clinical significance criterion in BDD states that the appearance concern 'causes clinically significant distress or impairment in social, occupational or other important areas of functioning' (APA, 2013, p 242), and the criterion is similarly phrased across a number of DSM diagnoses. However, evaluating this criterion can be difficult and judgements may vary between clinicians.

What is clinically significant distress or impairment? According to the DSM, the diagnosis of a psychiatric disorder should have clinical utility; it should help clinicians to determine prognosis and treatment plans for their patients. More specifically, the DSM-5 states that 'until aetiological or pathophysiological mechanisms are identified to fully validate specific disorders, the most important standard for the DSM-5 disorder criteria will be their clinical utility for the assessment of clinical course and treatment response of individuals grouped by a given set of diagnostic criteria' (APA, 2013, p 20). Therefore, the DSM's emphasis on clinical utility can aid in judging what is clinically significant distress or impairment; who needs help and who could benefit from psychological or psychiatric treatment.

The BDDQ seems to capture ‘clinically significant distress or impairment’

Thus, in the assessment of BDD prevalence, needing and benefitting from treatment is an important component of what constitutes BDD and is why a diagnosis is important (Stein et al., 2010). Therefore, evaluating the clinical significance criterion is crucial in any instrument assessing BDD. The BDDQ assesses the clinical significance of the appearance concerns in question 4. It is required that at least one area of distress/impairment should be affected for the respondent to screen positive for BDD (see Fig. 1, p 28). As illustrated by the Venn diagrams (see Fig. 3, p 38), the vast majority of the BDD respondents in Studies II and III reported that more than one area of distress/impairment was affected by their appearance concerns. In 30% and 43% of the BDD respondents respectively, all four areas were affected. These consequences of the preoccupation, in combination with the requirement of fulfilling the time criterion (thinking about the defect for at least one hour/day) to qualify for a positive BDD screening, indicate that the BDDQ has captured individuals who suffer significantly from their appearance concerns.

In summary, the diagnosis of BDD emphasizes the degree of preoccupation, the distress and psychosocial impairment caused by appearance concerns. BDD sufferers are in need of treatment directed at the underlying psychopathology. That BDD seems to be prevalent in Swedish women is especially problematic since the disorder is under-recognized, because unless the condition is recognized, appropriate care cannot be provided.

5.2. METHODOLOGICAL STRENGTHS AND LIMITATIONS

5.2.1. Choosing female samples

It is an obvious limitation that Studies I-III only included women, since there is also a need to assess the occurrence of BDD in Swedish men. By including only half of the population, a better precision could be obtained in the prevalence estimation in Study II. Because BDD seems to be slightly more common in women, with a gender ratio of females to males of 1:1 to 3:2 (Phillips et al., 2008), women were chosen. There is also evidence that women are more likely than men to participate in scientific studies, and by including only women we anticipated a satisfactory participation rate (Galea and Tracy, 2007). In the dermatology prevalence study (Study III), only women were included because the Swedish translation of the BDDQ had been validated in a female sample. For practical and economic reasons, Studies I-III were not extended to include men. In Study IV, the opportunity was seized to include men from the clinic specializing in BDD. These patients had already been diagnosed with BDD and therefore no validated assessment instrument was needed to include them.

5.2.2. Limitations in evaluating the BDDQ

The SCID interviews were carried out by the author, a clinician who was not an experienced psychiatrist or clinical psychologist. To compensate for this limitation and improve the accuracy of the diagnostic interview, uncertain cases were discussed with the main supervisor (K Wijma), a clinical psychologist who has long clinical and scientific experience. For a second opinion, a psychiatrist, who was experienced in diagnosing BDD, could be consulted via telephone. Ideally, two experienced clinical psychologists or psychiatrists should have performed the SCID interviews to assess inter-rater reliability.

The reliability of the BDDQ was not evaluated. We considered determining the reliability of the BDDQ using a test-retest procedure to assess the stability of the questionnaire. If the same respondent had filled out the BDDQ on two different occasions, the results could have been compared, and correlations estimated. One approach would have been to ask the participants in Study I to fill out the BDDQ again before the diagnostic interview. However, the BDDQ and the SCID instruments are both derived from the DSM-IV criteria, and they use very similar wording. The risk that the answers to the BDDQ could influence the participants' answers in the SCID interview (or vice versa, depending on which was conducted first) was assumed to be considerable and not worth taking if it would impair the validation accuracy. An alternative approach would have been to select different respondents to invite for a test-retest procedure than those selected for the diagnostic interview. However, the respondents with a BDDQ score of 4 were difficult to recruit for the SCID interview. Therefore, a satisfactory number of additional respondents for a proper reliability assessment probably could not have been recruited.

The ability of the BDDQ to differentiate between BDD and eating disorders was not explored, which is a weakness of the studies. In the development of the BDDQ, Phillips stated that when

screening for BDD, a positive answer to question 3 (see Fig. 1, p 28) indicates the presence of an eating disorder rather than BDD (Phillips, 1998). This is the reason for the exclusion of all respondents who provided positive answers to question 3 from the BDD diagnosis. Thus, over-diagnosing BDD when an eating disorder may have been a more accurate diagnosis was avoided. However, eating disorders and BDD can be comorbid conditions, in which case both disorders should be diagnosed (Hartmann et al., 2013). In patients with eating disorders, a few studies have reported high rates of current comorbid BDD (unrelated to weight concerns), although the rates have varied between the studies (see Table 3, p 18). In a small sample of patients with AN, 39% had comorbid BDD as assessed by the BDD Diagnostic Module (Grant et al., 2002) and in a larger sample of eating disorders (AN, BN and EDNOS) 12% had comorbid BDD as assessed by the SCID (Kollei et al., 2013). The exclusion of all respondents who were primarily concerned with not being thin enough or who were afraid of becoming fat from the BDD diagnosis therefore creates a risk of under-diagnosing BDD. BDD concerns regarding other parts of the body may be a comorbid condition in women with eating disorders who are primarily concerned with their weight problems. There may also be respondents with primarily weight concerns who do not meet the criteria for an eating disorder, but may suffer from BDD. The comorbidity issue poses a dilemma when using screening questionnaires to assess the prevalence of psychiatric disorders.

The recently added criterion in the DSM-5 states that at some point during the course of BDD, the individual should have performed repetitive behaviours or mental acts in response to the appearance concerns (APA, 2013, p 242). Because the BDDQ is derived from the DSM-IV criteria for BDD, these symptoms are not specifically assessed by the questionnaire; however, question five assesses how much time is spent thinking about the perceived defect, which could represent mental acts. In light of the new criterion, one hour per day may not be a sufficient amount of time to fulfil the BDD diagnostic criteria. According to previous research, BDD preoccupations occur, on average, for 3-8 hours per day (Phillips and Hollander, 2008). If it had been required that respondents spend at least three hours per day thinking about the defect to screen positive for BDD, Studies II and III would have indicated lower self-reported BDD prevalence, i.e., 0.5% in the community sample and 1.4% in the clinical sample (instead of 2.1% and 4.9% respectively) (see Fig. 2, p 37). To date, only one study has estimated BDD prevalence using DSM-5 criteria (Schieber et al., 2015). In that study, the revised criteria of BDD in DSM-5 did not seem to have an impact on prevalence rates, as assessed by self-report measures (2.9% vs. 3.2%, non-significant difference), which implies that the BDD prevalence as identified in Studies II and III probably would not have been significantly different if the DSM-5 criteria had been used. However, more research is needed to determine whether the revisions in the DSM-5 criteria for BDD have an impact on the prevalence of BDD.

5.2.3. The ability of the BDDQ to capture BDD

The validation sample in Study I was selected in order to better evaluate the questionnaire's properties at the cut-off between scores 3 and 4 on the BDDQ (a score of 4 was equal to a positive BDD screening as intended in the development of the BDDQ (Phillips, 1998)). The increased proportions of respondents with scores 3 and 4 in the validation sample (Study I) compared to those in the total sample of Study II (see Supplement to Table 5, p 35) made the assessment of the questionnaire's properties at the cut-off (between 3 and 4) more thorough. If 100 women from the total sample of Study II had been randomly selected for an interview, it is likely that only a small percentage would have screened positive for BDD. If so, no proper assessment of the cut-off at four points could have been made, and the validation study would have had much less impact. Dey et al. (2015) chose another way of dealing with the problem when it was not possible to include all questionnaire respondents in a validation procedure. These authors chose to include all respondents screening positive for BDD and half of the respondents screening negative for BDD, thereby similarly increasing the prevalence of positive BDDQ screening. An advantage of increasing the prevalence of positive BDD screening in the validation sample was that a larger proportion of BDD respondents from Study II were diagnosed by the SCID evaluation. In 24 of 61 respondents who screened positive for BDD in Study II, the diagnosis according to the SCID evaluation was therefore known (17 respondents had BDD).

However, the procedure for increasing the prevalence of positive BDD screening in the validation sample probably affects the validation properties of the test (Altman and Bland, 1994; Fletcher et al., 1996). The BDDQ exhibited a high sensitivity (94%) and specificity (90%) in Study I, which indicates that the questionnaire has a good ability to correctly capture individuals with BDD and to correctly exclude individuals without BDD. The PPV of the BDDQ was 71%, which means that 29% screened falsely positive on the BDDQ. Thus, the probability that an individual with positive BDD screening would be diagnosed with BDD according to the SCID evaluation is 71%. Though the validation figures in Study I were indeed assessed in a population-based sample, they may vary in populations with different prevalence of BDD. The proportion of women with a positive BDD screening was higher in the validation sample (Study I), reaching a prevalence of 27% compared to 2.1% in the total sample in Study II. The PPV of the questionnaire would presumably decrease and the negative predictive value would increase in a different population with a lower prevalence of BDD (Fletcher et al., 1996). A disadvantage of choosing to create a sample with a different prevalence of positive BDD screening for the validation is, thus, that the validation properties for the BDDQ are uncertain in Studies II and III. On the other hand, the LR is less dependent on prevalence rates (Fletcher et al., 1996). A high LR of 9.4 means that it is almost ten times more likely that a positive BDDQ screening will be found in women with BDD than in women without BDD.

To conclude, the BDDQ can be a valuable instrument when screening for BDD. Although the exact rates of BDD are uncertain due to limitations in the assessment methods, the findings in Studies I and II indicate that BDD is relatively prevalent in Swedish women.

5.2.4. Capturing BDD in dermatology patients

Are the validity properties of the BDDQ transferable to a dermatology sample?

The validity properties of the BDDQ may also vary between settings and may therefore be different in the dermatology sample in Study III. In the previous discussion of self-reported acne, the validity of self-reported dermatologic problems was questioned and it was suggested that BDD might cause a falsely high frequency of self-reported dermatologic disease. On the other hand, one could argue that because of psychiatric symptoms secondary to dermatologic disease (Yadav et al., 2013), dermatology patients may screen falsely positive for BDD on the BDDQ. The dermatology patients screening positive for BDD on the BDDQ may be patients with noticeable skin defects due to dermatologic diseases who suffer distress or impairment due to these defects.

Yet, individuals who suffer significant distress or impairment due to noticeable appearance defects do not fulfil the BDD criteria. In fact, of the few BDD respondents in Study III who agreed to a diagnostic interview, three of seven screened falsely positive on the BDDQ for this very reason (they had noticeable appearance 'flaws' caused by their dermatologic disease). In Swedish women with hirsutism, levels of depression (16%) and anxiety (37%) as defined by HADS ≥ 11 were closer to the levels reported by the BDD respondents than by the non-BDD respondents in Study III (Ekbäck et al., 2013). Both hirsutism and acne patients may theoretically screen falsely positive for BDD, and thus may, in part, be included in the BDD respondents. On the other hand, perceived acne and perceived hairiness are common in individuals with BDD (Phillips, 1991; Phillips, 2009). Without a clinical evaluation, it is very difficult to know whether the appearance concerns, and the consequential distress and impairment, are excessive comparative to the perceived flaws, and, thus, whether BDD should be diagnosed or not. Therefore, the intention was to complement a positive BDD screening with a diagnostic interview using the SCID and a clinical evaluation of the perceived appearance flaw, in the dermatology sample (Study III). Regrettably, only about one-third of those screening positive for BDD in Study III agreed to participate in a clinical interview and therefore no conclusions could be drawn regarding the validity properties of the BDDQ in this setting.

Nevertheless, some studies have validated the BDDQ and similar screening instruments against semi-structured diagnostic interviews (including clinical evaluation of the perceived defects) in dermatology settings and demonstrated validity properties comparable to those in Study I. The BDDQ-DV was validated using the BDD Diagnostic Module as the gold standard in a cosmetic dermatology patient sample ($n=46$) (Dufresne et al., 2001). The perceived appearance defects were also rated and it was required that the defect was non-existent or only slight (comparable to 1 or 2 on the Likert scale as used in Study I) to diagnose BDD. The PPV of the BDDQ-DV was 67%, which indicates that the rate of false positives may not be higher in cosmetic dermatology patients than in Study I. However, the sample was small and included only patients seeking a cosmetic surgical consultation, and the results may not be generalizable to other dermatology patients. Conrado and colleagues (Conrado et al., 2010) also assessed the BDD prevalence in dermatology patients ($n=150$), using a procedure which

included both the BDDQ and the SCID. Although no validity figures were presented, these authors reported that 32 of 36 patients who screened positive for BDD by the BDDQ were also diagnosed with BDD in the SCID interview (thus, the BDDQ had a PPV of 89%), suggesting that the BDDQ performed well as a diagnostic instrument in that setting. The findings of those studies do not guarantee that the BDDQ will perform equally well with all dermatology patients. The validity properties depend on the specific setting of respondents. Naturally (and regrettably), the validity properties of any diagnostic questionnaire will be affected not only by the prevalence of disease and type of patients evaluated, but also by language and culture.

Because of limitations in the studies, including a limit to the number of respondents that could be diagnosed by the SCID evaluation in Study I and a resistance among BDD respondents in Study III to participating in diagnostic interviews, the validity properties of the BDDQ are uncertain both in Study II and Study III. However, the validity of the BDDQ was acceptable and the methods used for BDD prevalence estimation were comparable to those in other studies.

What about patients suffering from noticeable appearance 'flaws'?

Although a discussion regarding 'normal' or 'beautiful' when it comes to physical appearance is beyond the scope of this thesis, an important notion in this discussion is that what constitutes 'slight' appearance defects or flaws is subjective. What are considered 'objective flaws' in physical appearance undoubtedly vary between evaluators, between cultures and over time. It is likely that dermatologists and plastic surgeons may notice even minor anomalies because they are trained to be observant regarding details of physical appearance. Because it is difficult to evaluate whether the concerns are 'markedly excessive' in a patient with a 'slight' physical anomaly, once again, it is important to emphasize the 'needing and benefitting from treatment' aspect of a psychiatric diagnosis. The BDD diagnosis emphasizes the degree of preoccupation, the distress and psychosocial impairment caused by the appearance concerns. It is therefore important to assess the magnitude and the consequences of the appearance concerns for the individual patient.

The DSM excludes from the BDD diagnosis all individuals with larger anomalies in physical appearance. As the BDDQ does not exclude these individuals, some respondents with visible appearance 'flaws' screened positive for BDD and were included in the SCID evaluation. These individuals did suffer significant distress and/or impairment due to their appearance concerns. Preoccupation, distress and suicidal thoughts may, thus, exist and may also be substantial in patients with clearly noticeable skin disease (or other noticeable appearance 'flaws').

Although for dermatologists, treatment of the skin disease is of priority, treatments directed at the psychological suffering may also be required. This is especially important if the possibilities for treating the skin disease are limited or maybe non-existent. When it comes to the suffering of an individual who may benefit from psychological or psychiatric treatment, is it not reasonable to provide such a treatment, regardless of the aetiology of the appearance concerns and whether or not the 'flaws' are noticeable? An open discussion with all patients on these symptoms is necessary to find the best line of treatment. However, in patients with

BDD, psychological or psychiatric treatment is to be recommended because dermatological and appearance-enhancing treatments may exacerbate their symptoms (Phillips et al., 2001; Crerand et al., 2005).

5.2.5. Challenges in prevalence assessment of psychiatric disorders

The results from several large surveys reporting very high prevalence rates of psychiatric disorders have led to critical voices being raised regarding validity issues when diagnosing psychiatric disorders. As a relatively high prevalence of BDD was found in this thesis, some of these issues will be discussed here.

A challenge in the epidemiological research of psychiatric disorders is the difficulty of standardizing the diagnostic process, which has been suggested to have 'the qualities of an art and not a technique' (Brugha et al., 1999). An approach for a standardized diagnosing procedure is the use of a semi-structured clinical interview, e.g. the SCID, which is intended to be used by clinicians. Although the validity of the SCID interview can also be questioned, for this discussion the SCID is considered equal to diagnosing using the DSM, because it is necessary for research and evidence-based health care to have a standardized diagnostic procedure. SCID is considered a state-of-the-art clinical research interview (Kessler et al., 2004), and therefore the SCID is referred to as the gold standard: 'the best tool available at that time to compare different measures' (Claassen, 2005).

Another approach that enables large surveys is the development of lay-administered structured questionnaires, which are completely structured measures that can be used by interviewers without any clinical background or experience. Examples of the latter are the Diagnostic Interview Schedule (DIS) for DSM-III (Robins et al., 1981), the World Health Organization Composite International Diagnostic Interview (CIDI) for DSM-III-R (Robins et al., 1988), and the World Mental Health Survey Initiative expansion of the Composite International Diagnostic Interview (WMH CIDI) for DSM-IV diagnoses (Kessler and Ustun, 2004). These instruments were used in the Epidemiologic Catchment Area (ECA) and National Comorbidity Surveys (NCS) as discussed below.

The use of self-report questionnaires similarly makes epidemiological research cost-effective and large surveys possible. The use of the BDDQ enabled the assessments of large samples in Studies II and III. The Swedish translation of the BDDQ was validated using the SCID interview including a clinical assessment of the perceived flaws as the gold standard, with the intention to achieve the standardized diagnosing that is desired in research. The BDDQ presented good validity properties in the population-based sub-sample in Study I, albeit with some limitations, as previously discussed.

As mentioned above, several large surveys have reported high prevalence rates of psychiatric disorders in the US, as assessed by lay-administered diagnostic interviews. In the ECA survey, almost 30% of over 15 000 respondents had a 12-month prevalence of any DSM-III disorder according to the DIS (Regier et al., 1993). The national cross-sectional NCS assessed 14 DSM-III-R diagnoses in over 8 000 US citizens using the CIDI (Kessler et al., 1994). Nearly 50%

of the respondents reported at least one lifetime disorder and the 12-month prevalence of any disorder was 30%. The similar prevalence rates found in the ECA and NCS suggested that psychiatric disorders are very common in the general population. The claim that as much as half of the population could suffer from a lifetime psychiatric disorder led to reactions of disbelief, not least among health policy analysts, and the validity of the diagnostic interviews was questioned (Kessler et al., 2004).

Nevertheless, the validity studies carried out in conjunction with both surveys showed that the DIS and CIDI prevalence estimates were no higher than those found in blind semi-structured clinical interviews (Eaton et al., 2000, Kessler et al., 1998). Other studies have also found a satisfactory correspondence between lay-administered structured interviews and blinded clinical diagnostic interviews (Kessler, 2007). These studies (like the studies in this thesis) used the clinical application of the DSM criteria as the gold standard. Some critics therefore concluded that the DSM system itself may be 'overly inclusive' and that correct application of DSM criteria yields false positive diagnoses, i.e., non-disordered, 'normal' conditions being classified as disorders (Spitzer and Wakefield, 1999, Kessler et al., 2004; Regier et al., 1998). Such criticism contributed to the addition of the clinical significance criterion to many disorders in the DSM-IV to reduce false positive diagnoses. In the follow-up NCS R, DSM-IV diagnoses (anxiety, mood, impulse-control and substance use disorders) were assessed in over 9 000 US citizens, using the WMH CIDI. The lifetime prevalence was 47% and the 12-month prevalence 26% of any disorder; thus, the rates were similar to those 11 years earlier (Kessler et al., 2005a; Kessler et al., 2005b.). These findings confirmed that psychiatric disorders are very common in the general population and much like the findings in the validity studies for DIS and CIDI, the WMH CIDI diagnoses showed satisfactory concordance with blind semi-structured clinical interviews (Kessler et al., 2005a). Thus, the results from the NCS R indicate that the DSM-IV may not be more restrictive than previous versions of the DSM in determining what constitutes a psychiatric disorder, even though the clinical significance criterion had been added to many diagnoses. Therefore, the criticism of the DSM criteria of being overly inclusive may still be valid (Wakefield, 1997).

But what is the 'over inclusiveness' in reference to? The criticism evolved when an unreasonably high (according to the critics) prevalence of psychiatric disorders was reported. It may be considered unreasonable that 30% of individuals in the general population have been classified as having a psychiatric disorder (in the last 12 months). Therefore, one may argue that the concept of psychiatric disease according to the DSM is too broadly defined. When it comes to medical diseases it may also be considered unreasonable that the prevalence of hypertension is close to 30% in Swedish adults (SBU, 2007). However, whether or not the prevalence is unreasonable, many agree that hypertension ought to be diagnosed and treated, if the treatment could prevent morbidity and mortality caused by high blood pressure. Regarding psychiatric disorders, one could similarly argue that if a condition is associated with morbidity in terms of significant suffering and social handicap or even mortality due to increased risk of suicide, it ought to be recognized, diagnosed and treated.

5.2.6. Impact of a low response rate on sample representativeness

In Study II, the response rate of 42% was lower than expected. Although there is no scientifically proven minimally acceptable response rate, a rate of 60% has been used as the threshold of acceptability and a measure of survey quality (Johnson and Wislar, 2012). In the other four large population-based studies of BDD, rates of such size were obtained: 56% (Koran et al., 2008; Schieber et al., 2015), 61% (Rief et al., 2006), and 60% (Buhlmann et al., 2010). The higher participation rates compared to that in Study II may be explained, in part, by the choice of survey modes used in those studies, namely, contacting the participants via telephone or using face-to-face, methods that have been shown to correlate with increased response rates in self-report surveys (Edwards et al., 2002).

The low response rate in Study II is regrettably consistent with the trend of declining response rates in surveys in general (Galea and Tracy, 2007; Manfreda et al., 2008). In a meta-analysis of 308 mail surveys published in clinical psychology journals between 1985 and 2005, the mean response rate was 50%, and the results indicated a decline in survey participation over the 20-year period (Van Horn et al., 2009). One stipulated reason for the decreasing participation in epidemiological surveys over the last few decades is an increased number of research and marketing surveys that have created an 'over surveyed' society (Galea and Tracy, 2007). People facing an increasing number of requests to participate in surveys are therefore less inclined to take time to participate in each study. Other reasons are a general decrease in volunteerism in Western countries, which affects the willingness to participate in scientific studies (as well as to engage in organizational and social activities), and the fact that scientific studies have become increasingly demanding of participants, with survey assessments, biological sampling, and frequent requests for on-going follow-up that is burdensome for participants (Galea and Tracy, 2007).

Nevertheless, empirical evidence suggests that response rates may not be as strongly associated with the representativeness of surveys as has been generally believed, and low participation rates therefore do not necessarily indicate a high level of bias (Galea and Tracy, 2007; Johnson and Wislar, 2012). Instead, the degree to which respondents differ from the source population is crucial in evaluating the representativeness of a survey. Non-response bias refers to the systematic errors that occur when reasons for study participation are correlated with the phenomenon of interest in the study. Therefore, the goal of a representativeness analysis is to assess whether the reasons for which respondents participate in a survey are also associated with the outcome.

A representativeness analysis was performed in Study II, using external data sources to compare respondents with the full population, as recommended by Johnson and Wislar (2012). The total study sample was compared with the source population, i.e., women aged 18-60 in the county of Östergötland, regarding the demographic characteristics available from existing Swedish population statistics (age, level of education completed, employment status, and profession), and a similar distribution between the study sample and the source population was found. However, even though the demographic data available did not differ substantially between the respondents and the source population, we cannot know whether

they differed regarding appearance concerns, which is of course what we would really like to assess to evaluate non-response bias. According to Galea and Tracy (2007), individuals are much more likely to take part in a study that is concerned with an issue which is essential to the participants' lives (for example, studies of the relation between cellular phone use and cancer have reported participation rates of 90% or higher). One could therefore argue that women with appearance concerns would be more inclined to participate in Study II, and the rates of appearance concerns obtained would, thus, be falsely high.

Contrary to this argument and relevant to Study II, when it comes to studies concerning socially unacceptable behaviour (e.g., smoking, alcohol, or drug use) or undesirable conditions, affected individuals are often underrepresented (Galea and Tracy, 2007). For example, studies concerned with eating disorders have been shown to underrepresent individuals with these disorders (Beglin and Fairburn, 1992; Mond et al., 2004). Due to similarities between eating disorders and BDD, this phenomenon may also occur with individuals with BDD. Speculatively, individuals who are seriously ill with BDD may not manage to participate in a questionnaire study or even bother to read their mail; aspects that would further contribute to an underestimation of the BDD prevalence.

In summary, the low response rate in Study II may have affected the sample representativeness and the prevalence rate found in Study II may be an underestimation of that in the source population.

5.2.7. Generalizability (Studies I-III)

The prevalence of BDD was estimated in the largest population-based sample to date. Random sampling was used to increase the representativeness of the results. Regarding sample representativeness, there may be an underestimation of the self-reported BDD prevalence rate in Study II. An advantage of Study II compared to previous population-based studies of corresponding sizes is the use of a validated questionnaire to estimate BDD prevalence. The BDDQ was validated in a sub-sample of Study II, albeit with a different prevalence of positive BDD screening. The PPV of 71% indicates that the prevalence of BDD is lower than the 2.1% (95% CI 1.7-2.7) as assessed by the BDDQ and is estimated at 1.5% (95% CI 1.1-2.0). There are no reasons to suspect that women in the county of Östergötland differ from Swedish women in general regarding appearance concerns. Therefore, the results are assumed to be generalizable to Swedish women. Moreover, the similar self-report prevalence rates found in all larger population-based studies indicate a comparable prevalence of BDD across other Western countries (Sweden, Germany and the US).

In Study III, the response rate was high (81%) and the sample size was the largest to date used to assess BDD prevalence in general dermatology patients. The prevalence of respondents screening positive for BDD was twice as high in female dermatology patients than in the general female population, 4.9% (95% CI 3.2-7.4), which indicates that BDD is more common in dermatology patients. Some dermatology patients who screened positive for BDD did not qualify for a BDD diagnosis because of noticeable appearance 'flaws'. Therefore the proportion of respondents with positive BDD screening qualifying for a BDD diagnosis in

dermatology patients may be lower than that in the general population. Nevertheless, the results of Study III can be interpreted as demonstrating the frequent occurrence of features of BDD in dermatology patients. These results are assumed to be generalizable to female patients in Swedish tertiary (hospital) dermatology clinics, while higher BDD prevalence may be found in private dermatology clinics, where more cosmetic treatments are offered.

5.2.8. Trustworthiness (Study IV)

The aim of Study IV was not to generalize but to gain a deeper understanding of BDD. In qualitative studies, instead of concepts such as validity, reliability and generalizability, the quality of research is judged by other criteria that depend on the theoretical orientation of the study (Patton, 2002). In ID, as in Naturalistic Inquiry, studies are judged by their trustworthiness. Trustworthiness involves credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985). In addition, the findings of ID studies ideally ought to have application potential, in the sense that they should be meaningful for clinicians and contribute to assessment and/or interventional strategies (Thorne et al., 2004).

To increase credibility, the analysis of each interview transcript was confirmed by a co-analysers (last author in Study IV). Throughout the analysis, the analysing authors had on-going discussions, and reached consensus on themes and sub-themes. Quotes of the interviewees were also used to increase the credibility of the findings. Triangulation (i.e., using two or more methods to study a phenomenon) is recommended in ID as a means of increasing credibility and confirmability, and ideally, multiple data collection strategies should be used (Thorne, 2008). In Study IV, individual interviews were considered the best method to address the aims. Telephone interviews were used as a supplement to face-to-face interviews for practical reasons; however, the option of a telephone interview, may have contributed to more seriously ill patients agreeing to participation. 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 and to increasing the transferability of the findings. BDD patients with comorbidities were not excluded from participation and it is possible that attributes of comorbid disorders have influenced the study results. To prevent the results reflecting comorbid conditions, during the interviews and the analysis, the specific focus was on the participants' experiences of BDD. Furthermore, comorbidities are common in patients with BDD, as described above, and therefore, including patients with comorbidities probably makes the results more characteristic of people with BDD.

Instead of aiming to eliminate all bias, as is desirable in quantitative research methods, qualitative researchers must account for the influence of subjective bias upon their findings (Thorne et al., 1997). In Study IV, the author's reflections emerging during and after the interviews were recorded and written down as a means to account for subjective bias. Discussions and reflections with co-authors as the interviews were read and listened through also contributed to raising the awareness of my pre-understanding. Sometimes, the

co-analysed prevented me from jumping to premature conclusions influenced by my knowledge of BDD.

The descriptions of living with the disorder are likely to be similar in other individuals with BDD, and the study also contributes by indicating some implications for health care professionals, as outlined below. Nevertheless, most of the patients were already on a waiting list for treatment and these patients were aware of their diagnosis, even if some were not convinced. BDD sufferers who have not yet been diagnosed and who do not recognize that they suffer from a psychiatric disorder may have different experiences of BDD. Many patients declined participation or could not be contacted, a phenomenon that may be a reflection of the nature of the disorder, since BDD sufferers are secretive, avoid social situations and may even be housebound. Therefore, patients who did not agree to participation may have been more seriously ill and, if so, they may have more negative experiences of BDD.

5.2.9. The researcher's role

As a physician trained mainly in positivistic reasoning it has been an eye-opener to engage in qualitative research (and to partake in qualitative method courses). Before initiating Study IV my prejudices related to qualitative methods included that these are more subjective and therefore less valid than quantitative methods. Moreover, it was a challenge to conduct an inductive analysis, not knowing exactly what to look for, and what to 'measure'. Admittedly, I chose a method where I did not have to 'go in blank' (i.e., bracketing prior knowledge) as is desired in many other qualitative methods, but instead I was allowed to use the framework of knowledge about BDD to formulate research questions and create an interview guide (Thorne et al., 2004). During the months of interviewing and analysing the interviews, I found myself living with the BDD patients' descriptions of living with the disorder. I was highly affected by all the stories of the impact BDD had on the participants' lives, and I became more than an objective bystander. But then again, objectivity is not desired in qualitative research, where researcher and 'research object' are supposed to interact and influence each other (Lincoln and Guba, 1985).

Something I have come to understand during my PhD studies is that quantitative methods also include elements of subjectivity, and merely by defining concepts to be investigated, positivist researchers risk being unsuccessful in their pursuit of objectivity (Polit and Beck, 2008).

Throughout the discussions in the cover story it is evident that I see some limitations and possible bias in the findings of this thesis. From more obvious sources of subjective bias such as performing the SCID interviews (Study I) and the qualitative interviews (Study IV) or choosing what cut-off values to use (Studies II and III), to wider aspects of subjective impact such as choosing research questions and research methods, I have influenced the results of this thesis.

To this end, albeit with some limitations, I believe that the results of this thesis are valid and can be useful.

6. IMPLICATIONS

6.1. CONSIDERATIONS FOR FUTURE RESEARCH

Further research is needed to complement the findings in these first studies estimating BDD prevalence rates in Sweden. The prevalence of BDD in Swedish men is as yet unknown and needs to be assessed. There is also a need to assess the occurrence of BDD in private dermatology clinics, and cosmetic surgery clinics, where the prevalence of BDD is supposedly higher than in Swedish tertiary (hospital) dermatology clinics, in which appearance-enhancing treatments such as fillers, minor surgery, threads, and Botox, are not performed.

The methodological shortcomings in this thesis may be better addressed in future studies to increase the quality of research. Studies based on diagnostic interviews could be used to overcome the limitations of using self-report questionnaires to assess BDD prevalence. If a self-report questionnaire, e.g. the BDDQ, is used to estimate BDD prevalence, it is recommended that the validity properties of the questionnaire be assessed in the specific setting examined. To improve the accuracy of the validation, it is preferable that two experienced psychiatrists or clinical psychologists conduct diagnostic interviews to assess inter-rater reliability. In future studies, the occurrence of repetitive behaviours (as included in the DSM-5 criteria for BDD) should be included in the assessment of BDD. To increase response rates in self-report surveys, the application of multiple contacts, using procedures with mixed-mode sequencing (e.g. web-mode combined with a follow-up letter), monetary incentives, and personalized communication can be recommended (Edwards et al., 2002; Van Horn et al., 2009; Israel, 2013).

Another suggestion for future research is to include measurements of clinical severity in surveys of BDD. The BDDQ (and the DSM) do not separate mild from moderate or severe forms of the disorder. It has been suggested that to increase the clinical utility of results, epidemiological surveys of psychiatric disorders should go beyond dichotomous diagnostic distinctions to include dimensional measures of clinical severity (Regier, 2000). Such an approach could help direct clinical interventions and treatment strategies for individuals with BDD. For example, a Swedish study has suggested ICBT to be an accessible and effective treatment for individuals with mild to moderate BDD (Enander et al., 2016).

Most importantly, since the findings of this thesis indicate that BDD is relatively common, more research needs to be directed at detecting BDD and finding effective treatment strategies. In addition to further research regarding psychotherapeutic and psychopharmacological treatments, educational programs about BDD directed at both mental health care professionals and non-psychiatric health care professionals (especially general practitioners, dermatologists and plastic surgeons), and routes of referral need to be developed.

6.2. CLINICAL IMPLICATIONS

The importance of an increased recognition of BDD

BDD appears to be relatively prevalent in Swedish women but at the same time under-recognized by health care professionals. When outlining recommendations for the health care system it is essential to consider the substantial emotional distress and psychosocial impairment associated with BDD. In addition to the personal suffering of people with BDD when the disorder remains untreated, there are increased costs for society associated with decreased school attendance, a decreased capacity to work, and comorbid conditions, as observed in previous research (Grant et al. 2005) and confirmed by the findings in Study IV.

Therefore, it is crucial to increase the recognition of BDD among health care providers and to offer adequate treatment.

In this thesis, the prevalence of self-reported BDD was more than twice as high in dermatology patients as in the general population of women, and therefore it is especially important for dermatologists to be aware of symptoms of BDD. Mental health professionals, general practitioners, dermatologists and plastic surgeons are probably the most likely health care professionals to encounter individuals with BDD (Phillips et al., 2001).

Because only a minority of suicidal individuals seek psychotherapeutic or psychiatric care (Picardi, 2013), non-psychiatric health care professionals play an important role in recognizing suicidal ideation and preventing suicidal behaviours in patients with BDD. The BDD patients in Study IV had experienced that knowledge regarding BDD was limited or non-existent among health care professionals. A majority of the participants 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. This further emphasizes the importance of recognizing features of BDD.

Detection: 'How do your appearance concerns affect your life?'

Thus, in patients seeking help for physical appearance concerns, even if visible anomalies (e.g., dermatologic symptoms) are mild, it is important to assess the consequences of the patients' concerns. If the appearance concerns are excessive in relation to the perceived flaw, and cause clinically significant distress or impairment, BDD should be included in differential diagnostic considerations. However, what constitutes only 'slight' appearance flaws is subjective. It is likely that dermatologists or cosmetic surgeons may notice even minor 'defects', because they are trained to be observant regarding details (and deviations) in physical appearance. Because it is difficult to evaluate if the concerns are 'markedly excessive' in a patient with a 'slight' physical anomaly, it is important to emphasize the need and benefitting from treatment-aspect of a psychiatric diagnosis. However, if physicians are not even aware of the BDD diagnosis, they may not enquire into the magnitude and the consequences of the concerns and may, thus, fail to detect this highly distressing disorder. The BDDQ can be used as a screening instrument to assess how appearance concerns affect the

patients' lives. Nevertheless, I believe that only one question may suffice to capture suspicion of a BDD diagnosis, 'How do your appearance concerns affect your life?'

Initial management of suspected BDD

To outline treatment recommendations for BDD is beyond the scope of this thesis. According to NICE guidelines, individuals with suspected or diagnosed BDD seeking cosmetic surgery or dermatologic treatment should be assessed by a mental health professional with specific expertise in the management of BDD (NCCMH, 2006). However, descriptions by participants in the qualitative study (IV) indicate that even in the mental health care field, knowledge of BDD appears to be limited, to the point of BDD patients having to enlighten health care professionals. These findings are supported by previous findings that BDD is an under-recognized disorder also in psychiatric settings (Zimmerman and Mattia, 1998; Grant et al., 2002). In Sweden, educational programs to increase awareness and knowledge of BDD need to be outlined and directed towards all clinicians who are likely to encounter these patients, and routes of referral need to be established.

Meanwhile, as first steps when suspecting that an individual may suffer from BDD, it is important not to dismiss their concerns as trivial or to only reassure them that dermatologic or cosmetic treatments are unnecessary (Phillips and Dufresne, 2000). Appearance-enhancing treatments should not be tried, because these may even exacerbate the psychological symptoms (Crerand et al., 2005). Instead, physicians are recommended to provide the patients with psycho-education about BDD, and thereafter to attempt to refer patients to a psychiatrist for treatment with an SRI, or to a psychotherapist trained in CBT for psychological treatment (Phillips and Dufresne, 2000; Veale and Bewley, 2015). Thus, the patients need to be made aware that they appear to have a body image problem known as BDD, which is a treatable condition that many people suffer from. Some patients may resist referral because they continue to believe that their problems are physical and not psychological. It is often fruitless to try to convince these patients that their beliefs are irrational. Referral may instead be motivated by focusing on how their concerns affect the patients' lives and the potential benefit of psychiatric-psychological treatment for symptoms of emotional distress and psychosocial impairment (Phillips and Dufresne, 2000).

7. CONCLUSION

This thesis includes the first studies to estimate prevalence of BDD in Sweden (Studies II and III). These studies are also the largest to date to report BDD prevalence rates in the general population and in dermatology patients.

In a population-based sample of 2 885 women, 2.1% (95% CI 1.7–2.7) screened positive for BDD by the BDDQ (Study II). This rate is comparable to the findings in large population-based samples in Germany and the US. An advantage of Study II compared to previous population-based studies of corresponding sizes is that the questionnaire used to estimate BDD prevalence was validated in the population examined. The BDDQ was validated against the SCID in a sub-sample of Study II, and displayed a high sensitivity (94%), a high specificity (90%) and likelihood ratio of 9.4, indicating that the questionnaire has good validity properties (Study I). The PPV of the BDDQ (71%) gave an estimated BDD prevalence of 1.5% (95% CI 1.1–2.0) in Swedish women.

The findings of Study III indicated that BDD is more common in dermatology patients. The prevalence of women screening positive for BDD by the BDDQ was twice as high in dermatology patients as in the general population, 4.9% (95% CI 3.2–7.4). The validity properties of the BDDQ could not be determined in the sample because so few respondents agreed to participate in a diagnostic interview. However, a few dermatology patients who screened positive for BDD did not qualify for a BDD diagnosis, because of noticeable appearance ‘flaws’. The results of Study III can be interpreted as demonstrating the frequent occurrence of features of BDD in dermatology patients. Thus, it is important for dermatologists to recognize these features.

The main finding in the qualitative study (IV) was that ideas of imprisonment and abnormality composed the entire experience of living with BDD. The 15 interviewees expressed a profound sense of their own ugliness that became a component of their identities; this feeling was associated with emotional distress, shame and disgust. They described symptoms of depression and anxiety, as well as suicidal behaviour, caused by their appearance concerns. Symptoms of depression and anxiety were quantified in Studies II and III and were significantly overrepresented in the women with positive BDD screening in both the population-based and the dermatology patient sample. In the dermatology patients with positive BDD screening, quality of life was severely impaired, as assessed by the DLQI. Study IV is the first qualitative study to add detailed descriptions of how the disorder restricts BDD patients’ lives.

In their struggle to be free from imprisonment, the BDD patients in Study IV had disappointing experiences of the health care system. Difficulty in accessing health care was quite common, although the participants had sought help repeatedly and desperately. In their experience, knowledge regarding BDD was limited or non-existent among health care professionals.

In summary, the main findings of this thesis indicate that BDD is relatively prevalent in Swedish women and yet it is an under-recognized disorder. Individuals with BDD suffer emotional distress and psychosocial impairment, and therefore it is important to increase awareness and knowledge of BDD among health care professionals to ensure that patients with BDD are recognized and can receive the appropriate care.

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