

DISSERTATION

AM I UGLY OR DO I HAVE BDD?: PERSONAL DISCLOSURE AND SOCIAL SUPPORT ON A  
BODY DYSMORPHIC DISORDER ONLINE FORUM

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## ABSTRACT

### AM I UGLY OR DO I HAVE BDD?: PERSONAL DISCLOSURE AND SOCIAL SUPPORT ON A BODY DYSMORPHIC DISORDER ONLINE FORUM

The current study used an emergent research design that employed qualitative content analysis to understand how individuals with body dysmorphic disorder (BDD) communicate with their peers in an online support forum ([psychforum.com/body-dysmorphic-disorder](http://psychforum.com/body-dysmorphic-disorder)). The purpose was to explore (a) the communication activities on the forum, (b) the personal experiences with BDD disclosed by participants, (c) the categories of social support sought and shared, and (d) the social support provided and roles performed by the most frequent posters to the forum. The data sample consisted of 911 messages posted by 225 participants during 2012.

The primary communication activities on the forum were asking about other members' personal experiences and seeking support, disclosing personal experiences and providing support, engaging in conversations, and storytelling. Personal disclosures included appearance concerns (feeling ugly, depressed, guilty, ashamed, angry, and suicidal), compulsive behaviors (plastic surgery, mirror/photograph checking, and social comparison), the impact on one's personal life, and recovery from BDD (treatment, diagnosis, coping, and overcoming symptoms).

Social support sought and shared included informational, emotional, and social network support. Informational support topics included diagnosis, treatment, overcoming symptoms, and recovery. Emotional support took the form of empathy, caring/concern, gratitude, encouragement, sympathy, compliments, and validation. Social network support reinforced that people who understand the disorder were present on the forum and could provide companionship. Although not common, unsupportive comments (disagreement, disapproval, criticism/sarcasm, and flaming) were also present.

The five most frequent posters were emergent leaders whose supportive roles supplemented those of the two forum moderators. The most frequent poster was a male who played a lead role in providing

informational and social network support, along with four frequent female posters whose primary contribution was providing emotional support. The five emergent leaders and moderators also performed functional roles, including greeter, advocate, arbiter, mediator/harmonizer, corroborator/validator, information/opinion giver, evaluator/critic, and encourager/cheerleader, that were critical to the successful functioning of the forum.

The study discusses five key conclusions (themes) that offer valuable insight into how members communicated on the forum: (a) personal disclosure *facilitated* social support in initial posts and responses, (b) group members served primarily as *support providers* or *support seekers* whose behaviors were complementary and essential to the successful functioning of the forum, (c) contributions to the forum varied by *gender* with females providing more personal disclosure and social support than males, (d) the forum served as a *coping* mechanism where members shared coping strategies and coping assistance, and (e) the forum offered members *peer support* within an online community that supplemented the support received from other online and in-person sources.

The study underscores the growing importance of peer-to-peer communication and contributes to the limited research on online support groups for individuals coping with serious mental illness. As a result of this investigation, health communication scholars will have an increased understanding of why individuals with stigmatized health conditions turn to their peers to find the support they need online. In addition, this study provides BDD researchers and clinicians with an increased awareness about the resources and support needed by those suffering from the disorder.

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## CHAPTER 1: INTRODUCTION

Online health communication has been recognized as an increasingly important strategy used by individuals to find information and to connect with others who understand their condition (Fox, 2011a); those who engage in online communication can also serve as role models for coping. Indeed, Bandura's social cognitive theory (1986) stressed the importance of modeling in the adoption of new social practices and behavior patterns. Models can motivate, inform, and encourage new behaviors and competencies through demonstration or description. Interactive media can link individuals to social networks and community settings where they can find role models for behavioral change. These social networks can provide "personalized guidance, natural incentives, and social supports for desired changes" (Bandura, 2004, p. 150).

Social networks (offline and online) refer to connections and contacts with other people through membership in both primary and secondary groups (Thoits, 2011). Primary groups tend to be smaller in size, more informal, intimate, and enduring, such as family members, relatives, and friends. Secondary groups tend to be larger and interactions more formal (guided by rules and regulations); membership in such groups can be shorter or longer in duration, and knowledge about one another is less personal. Such distinctions between networks is similar to Granovetter's (1973, 1983) description of strong and weak ties, where tie strength depends upon the amount of time spent together, the emotional intensity of the relationship, the intimacy of mutual disclosure, and reciprocity of services (Thoits, 2011).

Primary groups are expected to provide greater social support (functions performed for the individual by others) and opportunities to share personal experiences due to the larger amount of time individuals spend together, the emotional intensity that characterizes the relationship, the depth and breadth of personal disclosure, and the greater reciprocity of services (Thoits, 2011). However, Goffman (1963) noted that individuals with stigmatized conditions are discredited by themselves and by others, and thus are no longer considered "normal" members of society (p. 5). They belong to a group of similar others who suffer from the same stigmatized condition (p. 112). Online forums offer individuals with

stigmatized conditions, such as mental health disorders, a secondary support group with whom they can share their most intimate feelings, thoughts, and experiences. Such a group of weak ties can offer greater support than an individual's family members and friends, who often lack firsthand knowledge of the health condition (Wright, Rains, & Banas, 2010).

Research has found that patients suffering from chronic health conditions use the Internet to gather information about diagnosis and treatment, and to interact with others who share their condition (Ransom, La Guardia, Woody, & Boyd, 2010; Whitlock, Powers, & Eckenrode, 2006). Although physical health conditions have been more widely studied, there is a growing body of research showing that online mental health groups also provide a wide variety of health benefits for users including reduced stress, increased positive coping, increased quality of life, increased self-efficacy in managing one's health problems, and reduced depression (Wright, Sparks, & O'Hair, 2013). Thus, studying online support groups specifically for individuals suffering from mental health disorders is an important area for health communication research. The current study explores the personal experiences and peer support that individuals seek and share within an online forum for body dysmorphic disorder (BDD).

### **Serious Mental Illness and BDD**

There has been growing concern about the impact of mental health disorders in the United States and around the world. In 2009, one in four adults in the United States suffered from a serious, diagnosable mental, behavioral, or emotional disorder (National Institutes of Mental Health [NIMH], 2011). These include schizophrenia, bipolar disorder, anxiety disorder, and depressive disorder. The U.S. Surgeon General reports that 10% of children and adolescents in the United States suffer from serious emotional and mental disorders that cause significant functional impairment in their day-to-day lives (National Alliance on Mental Illness, 2012). Mental illnesses cost Americans more than \$193 billion in lost earnings annually (NIMH, 2010). The World Health Organization (WHO) reported that serious mental illness comprises 4 of the 10 leading causes of disability in developed countries, including the United States, and by 2020 major depressive illness will be the leading cause of disability in the world for women and children (National Alliance on Mental Illness, 2012).

People with mental health disorders experience significant stressors such as illness management, isolation, and stigma, which elevate their risk of morbidity and mortality. Stigma in particular has been cited as one of the most serious and devastating psychosocial issues affecting the lives of people with serious mental illness (Chronister, Chou, & Liao, 2013). People with mental health disorders experience key characteristics of stigmatization including being officially labeled, set apart, associated with undesirable characteristics, and discriminated against. Stigma related to mental illness is considered to be one of the greatest obstacles to treatment according to WHO's World Health Report (Orel, 2007).

Stigma theory posits that the stigma associated with having a mental health disorder manifests via public stigma and internalized stigma (Corrigan, 1998, 2004). Public stigma refers to the negative beliefs, attitudes, and conceptions about mental illness held by the general population; internalized stigma (self-stigma) refers to the devaluation, shame, secrecy, and social withdrawal triggered by applying negative stereotypes about mental illness to oneself (Corrigan, 1998, 2004). Research suggests that public stigma leads to the development of internalized stigma (Conner, McKinnon, Ward, Reynolds, & Brown, 2015). A third type of stigma, referred to as stigma by association (Pryor, Reeder, & Monroe, 2012), entails the social and psychological reactions to people associated with a stigmatized person (family members and friends), as well as people's reactions to being associated with a stigmatized person.

Factors that have been found to protect against the internalization of stigma are coping (efforts to regulate one's response to stressful events and circumstances) along with social support. Coping and social support have received widespread empirical support for moderating or mediating the negative effects of stress on psychological outcomes across a wide variety of populations and stressor types (Chronister et al., 2013). Coping with the stigma of mental illness via social support can help people gain insight and ideas for action to address their stigma problems. In addition, peer support can assist them in considering new, more effective ways of confronting stigma by sharing their experiences, supporting one another, and rehearsing new ways to handle their stigma encounters (Dudley, 2000).

## **Body Dysmorphic Disorder**

There are a wide variety of anxiety-related mental health disorders, including obsessive-compulsive disorder (OCD), social phobia, and panic disorder. According to the National Institutes of Mental Health (2013), anxiety disorders are among the most common mental health disorders experienced by Americans. *The Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association, 2013) contains the most widely accepted nomenclature used by clinicians and researchers for the classification of mental health disorders. Body dysmorphic disorder (BDD) is classified in the *DSM-5* as an obsessive-compulsive spectrum disorder (OCSD) and is the focus of the current study.

BDD is an anxiety-related disorder characterized by a preoccupation with perceived defects or flaws in physical appearance that are not observable or appear slight to others; that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning; and the appearance preoccupations are not restricted to concerns with body fat or weight as in an eating disorder (American Psychiatric Association [APA], 2013). The disorder is classified further by patient insight levels: (a) good or fair insight: recognizes that BDD beliefs are definitely or probably not true, or that they may or may not be true; (b) poor insight: thinks BDD beliefs are probably true; and (c) delusional beliefs about appearance: completely convinced BDD beliefs are true (APA, 2013). Also, there is now the additional specification for the muscle dysmorphic form of BDD (the belief one's body build is too small or is insufficiently muscular). The previous classification of BDD in the *DSM-IV-TR* was as a somatoform disorder. Somatoform disorders are mental illnesses that cause bodily symptoms that cannot be traced back to any physical cause (Oyama, Paltoo, & Greengold, 2007).

BDD impacts from 1% to 2.4% of men and women in the United States (Koran, Abuiaoude, Large, & Serpe, 2008). This makes BDD as prevalent as eating disorders, which impact .9% of women and .3% of men (anorexia nervosa), and 1.5% of women and .5% of men (bulimia nervosa; Hudson, Hiripi, Pope, & Kessler, 2007). Sixteen percent of adult psychiatric hospital in-patients with symptoms of depression have been found to suffer from BDD (Conroy et al., 2008). Available evidence indicates that

approximately 80% of individuals with BDD experience lifetime suicidal ideation, and 24% to 28% have attempted suicide (Phillips, 2007). BDD affects women and men at an approximately equal rate (Phillips, 1996/2005).

According to Phillips, Didie, Feusner, and Wilhelm (2008), BDD exacts high costs in functioning and quality of life for patients, yet it often goes unrecognized. BDD can be present in individuals with symptoms of other disorders, including major depression, bipolar disorder, obsessive-compulsive disorder (OCD), social phobia, eating disorders, personality disorders, and substance abuse disorders. In making the diagnosis, clinicians must distinguish BDD from these other disorders, using questioning and diagnostic tests.

The etiology of BDD is unknown; possible causes include developmental, psychosocial, cognitive, behavioral, neuropsychological, and neurobiological factors (Feusner, Neziroglu, Wilhelm, Mancusi, & Bohon, 2010). Causes that have been linked to the onset of BDD symptoms include: childhood bullying (Wolke & Sapouna, 2008); childhood teasing about appearance and competency (Buhlmann, Cook, Fama, & Wilhelm, 2007); growing up in family with an emphasis on appearance (Rytina, 2008); perfectionist standards concerning appearance and exposure to high ideals of attractiveness and beauty in the mass media (Veale, Ennis, & Lamrou, 2002); a possible dysregulation of the serotonin system (Phillips, McElroy, Keck, Pope, & Hudson, 1993); and neurological disturbances that constitute a common genetic basis for disorders of the obsessive-compulsive spectrum (Allen & Hollander, 2004).

Symptoms of the disorder include obsessive thoughts and compulsive behaviors related to perceived appearance defects. About one-third of people with BDD think about their appearance flaws for one to three hours a day, nearly 40% for three to eight hours a day, and about a quarter for more than eight hours a day. Most people with BDD realize that they spend too much time thinking about their appearance, but for others, the thoughts are so much a part of their lives they think that everyone worries about their appearance for hours a day (Phillips, 2009, p. 57). However, the perceived flaws are usually

not visible to others, and most individuals with BDD are often considered to be quite attractive by societal standards (Phillips, 1996/2005).

BDD also contains compulsive behaviors related to the condition. These compulsions from most to least common are: camouflaging the perceived defect(s) with one's body, clothing, makeup, hand, hair and hats; comparing the disliked body part with others/scrutinizing the appearance of others (social comparison); checking one's appearance in mirrors and other reflective surfaces; seeking cosmetic treatments such as surgery and dermatology; engaging in excessive grooming; questioning others about the perceived flaw or convincing others that it is unattractive (reassurance seeking); touching the perceived flaw; excessively changing clothes; dieting; skin picking to improve appearance; tanning to improve the perceived flaw; and engaging in excessive exercise, including excessive weight lifting (Phillips, 2009, p. 68).

These obsessive appearance-related thoughts and compulsive behaviors cause individuals to undergo intense emotional and mental suffering. Some individuals become socially isolated as a result, unable to go out in public places for fear of exposing their perceived defect and ugliness to others. Due to the nature of the disorder, most sufferers have little self-awareness or insight that they have a psychological disorder, not a physical one. They may undergo multiple cosmetic surgery and dermatology treatments to approve their appearance, but are rarely pleased with the results, and often feel worse after the procedures (Sarwer & Crerand, 2008; Tignol, Biraben-Gotzamanis, Martin-Guehl, Grabot, & Aouizerate, 2007). Occasionally, people with BDD do surgery on themselves, with disastrous results. More than a quarter attempt suicide and others succeed in killing themselves. Often, they are young men and women who feel so hopeless about fixing their perceived defects, that suicide seems the only way to end their suffering (Phillips, 2007).

Lack of insight that they have a psychological disorder is one of the barriers to treatment for those with BDD (Marques, Weingarden, LeBlanc, & Wilhelm, 2011). Barriers to treatment include logistical and financial barriers, stigma, shame, discrimination, low treatment satisfaction, and misperceptions about treatment (Marques et al., 2011). In a study of 401 individuals with moderately severe symptoms

consistent with a diagnosis of BDD, only 30.5 % of the 401 had sought help from a psychiatrist, and 29.5% of the 401 from a psychologist. The authors explained the findings as due to multiple factors, including low knowledge of BDD, even among mental health professionals, which may prevent accurate diagnosis and treatment (Marques et al., 2011).

After a diagnosis of BDD is made, engaging the patient in treatment can be a challenge (Phillips et al., 2008). Clinicians use motivational interviewing, education, and cognitive-behavioral therapy (CBT) to treat patients (Phillips, 2005). CBT involves modification of intrusive thoughts of body dissatisfaction and overvalued beliefs about physical appearance; exposure to avoided body image situations; and elimination of body checking. Treatment for delusional or suicidal patients often requires both selective serotonin reuptake inhibitors and CBT therapy, which can be effective in improving the sufferer's symptoms (Phillips et al., 2008). Patients' communication with therapists has been studied primarily from the clinicians' viewpoint and will be covered in more detail in the following section. The role of social support for individuals with BDD has not been a primary focus of BDD research to date, although one study was found on the relationship between perceived social support and the severity of BDD symptoms (Marques, Weingarden, LeBlanc, Siev, & Wilhelm, 2011).

### **Communication about BDD**

Most communication about BDD is produced by mental health researchers and clinicians, and is targeted to other mental health professionals, the public, health care providers, and individuals with the disorder. Research on interpersonal and patient-provider communication about BDD is primarily from the clinicians' perspective about their clients (Phillips, 2009; Phillips et al., 2008; Veale & Neziroglu, 2010; Wilhelm, 2006). Researchers and clinicians have used mass media (books, magazines, television, radio, and the Internet) to provide resources for their patients, other health care providers, mental health professionals, the public, and individuals with BDD (Claiborn & Pedrick, 2002; Fisher, 2011; Phillips, 2005, 2009; Veale, 2009; Veale & Neziroglu, 2010; Wilhelm, 2006).

Articles about BDD in peer-reviewed journals focus upon etiology, symptoms, diagnosis and treatment, comorbidity with other disorders, and barriers to treatment (Buhlmann, 2011; Davey & Bishop,

2006; Feusner et al., 2010; Phillips et al., 2008). Articles targeted to dermatologists, plastic surgeons, and general practitioners focus on recognizing patients with BDD and referring them for effective treatment (Castle, Phillips, & Dufresne, 2004; Jesitus, 2007; Phillips & Dufresne, 2000; Sarwer, 2002; Slaughter & Sun, 1999; Wilson & Arpey, 2004). Magazine and newspaper articles about BDD targeted to the public often focus upon symptoms, how to recognize the disorder, and treatment options but are relatively few in number (Brody, 1997; Goddard, 2011).

Individuals diagnosed with BDD and comorbid disorders (such as major depression, OCD, and eating disorders) have written books about their experiences (Baughan, 2008; Westwood, 2007; Wolf, 2003). Many more individuals communicate with others using the Internet. Discussion forums related to BDD include Psychforms, OCD-UK, and BDD Central. Individuals with BDD also communicate with one another using Facebook and other social networking sites (Fisher, 2011). BDD patient-provider communication has been studied by researchers from a treatment perspective (Phillips, 2009; Phillips et al., 2008; Veale & Neziroglu, 2010; Wilhelm, 2006). The current study advances this literature by focusing on how individuals with symptoms of the disorder communicate with their peers online.

### **Purpose of the Study**

The purpose of the study was to understand how individuals with BDD communicate with their peers in an online mental health forum. The study extends previous research on social support and personal disclosure in online forums for physical and mental health disorders. The current research also integrates the concepts of personal disclosure and social support by examining (a) the communication activities that take place on the BDD forum, (b) the personal experiences related to BDD that are discussed on the forum, (c) the social support that is sought and shared by individuals on the forum, and (d) the support provided and roles played by the most frequent posters to the forum.

There have been relatively few studies on how individuals with serious mental illness communicate with their peers using online support forums (Bauer, Bauer, Spiessl, & Kagerbauer, 2013). Due to the growing use of online support groups by individuals with serious mental illness, this constitutes a gap in research that communication scholars can fill by studying how individuals with

mental health disorders, such as BDD, utilize online forums to seek and provide peer support. The current study adds to research on personal disclosure and social support by exploring the communication that takes place between individuals who post messages to an online support forum for BDD.

### **Background: Health Communication with Providers and Peers**

Individuals communicate about their health conditions using a variety of channels. These can include face-to-face communication as well as computer-mediated communication (CMC) using the Internet. According to the Pew Internet and American Life Project (Fox & Duggan, 2013), a majority of adults in the United States (70%) said they received health information, care, or support from a doctor or other health professional. Sixty percent of U.S. adults said they received information or support from family and friends, and 24% said they turned to others who have the same health condition for information or support. Though the majority of these interactions took place offline, more than half (59%) of those surveyed have used the Internet to look for information about health topics. Age and education levels influence who goes online to search for information. Adults between the ages of 18 and 49 with some college education were more likely to go online to search for health information than older adults and those without a college degree.

For most individuals in the U.S., contacting a healthcare provider is their first choice for receiving health-related information, support, and treatment (Fox, 2012). Patient-provider communication has been studied extensively in the fields of social psychology and health communication (Wright et al., 2013). Individuals also contact family members and friends for support and advice about their health concerns. Doing so can have both advantages and disadvantages for patients with mental health disorders.

In a study of 417 individuals with depression (Griffiths, Crisp, Barney, & Reid, 2011), 51% of the participants cited only the benefits in consulting family members or friends about their condition, and 39% cited both advantages and disadvantages. Benefits included the social support family members or friends provided, their background knowledge, the opportunity to offload the burden associated with depression to others, their personal attributes, their accessibility, and the opportunity to educate family and friends about the condition. Disadvantages included stigma, inappropriate support, lack of knowledge

about the condition, adverse impact on family members/friends, changes in one's relationship with family members or friends, unhelpful personal attributes, and unhelpful outcomes. Individuals who consult physicians for information, support, and treatment also face a variety of communication challenges. A brief discussion of Street's (2003) model of patient-provider communication and some relevant studies are provided below.

### **Patient-Provider Health Communication**

The medical encounter between the physician and patient is predicated on the understanding that the patient will bring his or her story of illness to the physician in order to receive a diagnosis and appropriate treatment (Hunter, 1991; Roter & McNeilis, 2003). As Hunter (1991) noted, in psychiatry the concept of the patient's symptomatic story is foundational, and whatever else may take place, the sharing of the patient's story of illness is an integral part of every medical encounter. This medicalization of the body, referred to by Mirivel (2008) in his study of a plastic surgery practice, takes the patient's story and constructs it in terms of a medical problem using medical vocabulary.

Street's (2003) ecological model for the study of communication in medical encounters focuses on the interaction between health care providers and patients as situated within and affected by a variety of social events, including an interpersonal context, organizational context (managed care), media context (Internet), political-legal context (malpractice and patient bills of rights), and a cultural context (race and ethnicity). The model places the interpersonal context as the one within which the consultation is most fundamentally embedded. According to Street (2003), what happens during the medical consultation between provider and patient depends upon the communicative actions that emerge directly from the participants' goals, linguistic skills, perceptions, emotions, and knowledge, as well as from the constraints and opportunities created by their partners' responses.

Cognitive-affective and cultural influences also guide how providers and patients communicate within medical encounters. Both health care providers and patients generally have a cognitive representation of the encounter that includes their goals, perceptions of the patient-physician relationship, expectations about what behaviors are appropriate, and expectations about how the encounter will

proceed (Street, 2003). Doctors often talk differently to patients based upon their findings about the patient's condition, the patient's age, gender and ethnicity. Power relationships in medical visits between patients and physicians are expressed through several key elements, such as the physical setting, who sets the agenda and goals for the visit, the role of patients' values, and the functional role assumed by the physician (Emanuel & Emanuel, 1992). Roter and McNeilis (2003) summarized the four relational styles in terms of patient and physician control: default (low control for both), paternalism (high for physician, low for patient), consumerism (high for patient, low for physician) and mutuality (shared control).

Street's (2003) ecological model of communication in medical contexts also includes the role of media, specifically the Internet, in patient-provider communication. CMC between patients and providers can help to facilitate treatment and access to healthcare (American Psychological Association, 2013). According to Street (2003), the Internet may also affect the physician-patient relationship by giving the patient a stronger sense of control in managing his or her health. Though many physicians are concerned about the quality of health information available on the Internet, others see the Internet as having a desirable effect on their interactions with clients (Street, 2003).

### **Peer-to-Peer Health Communication**

Peer-to-peer health communication refers to communication among patients and consumers through support groups, discussion boards, and online knowledge resources (such as Wikipedia) to exchange information, emotional and instrumental support, and to establish group norms and models (Ancker et al., 2009). According to the Pew Internet and American Life Project, most individuals report that these interactions take place offline. However 72% of Internet users (59% of U.S adults) have looked online for health information in the past year (Fox & Duggan, 2013). Thirty-five percent of U.S. adults said they have gone online to find out what medical condition they or someone else might have (Fox & Duggan, 2013), 24% of adults in the U.S. received information, care, or support from others with the same health condition, 26% read or watched someone else's experience about health or medical issues online, and 18% of Internet users went online to find others with health concerns similar to theirs (Fox, 2011a).

Blogs, personal websites, and discussion groups are important sources for peer information and support. Additional online resources include Usenet news groups, electronic mailing lists, real-time chat sessions, wikis (such as Wikipedia), content communities/media sharing sites (YouTube and podcasts), social networks (such as Facebook), and virtual worlds (such as Second Life). Individuals have been found to be selective about where they disclose health information in order to manage their online self-presentations (Newman, Lauterbach, Munson, Resnick, & Morris, 2011). Similar to Goffman's (1959) depiction of a front stage and back stage, Newman et al. (2011) likened Facebook to a front stage where participants communicated that they were positive, in control, and not struggling, while online forums were considered the backstage, where individuals could reveal their struggles and need for help in an anonymous setting.

According to Fox (2011a), people living with chronic and rare conditions were significantly more likely to go online to find others with similar health concerns (85% compared to 77% without a chronic condition). Women, non-Hispanic whites, younger adults, and those with higher levels of education and income were more likely than other demographic groups to gather health information online (Fox, 2012). About 41% percent of individuals who diagnosed themselves using the Internet went on to have their diagnosis confirmed by a clinician. The most commonly researched topics were specific diseases or conditions, treatments or procedures, and reviews about doctors or other health professionals (Fox & Duggan, 2013).

Internet users who have experienced a recent medical emergency, their own or someone else's, are also more likely than other Internet users to go online to try to find someone who shares their situation (23% compared to 16 %). Six percent of Internet users (4% of American adults) have posted comments, questions, or information about health or medical issues on a website of any kind, such as a health site or news site that allows comments and discussion. Four percent of Internet users (3% of American adults) have posted their experiences with a particular drug or medical treatment online (Fox, 2012).

Online forums (bulletin boards) such as Psychforums, offer many benefits to members, including 24 hour availability, selective participation in posting and responding to messages, anonymity and

privacy, immediate and/or delayed responding, and recording of transmissions (Burnett & Buerkle, 2004). Online support resources are not restricted by temporal and geographic limitations (Wright et al., 2013, p. 190). They offer 24-hour availability and enable individuals to access them at their convenience. These electronic bulletin boards originated with Usenet newsgroups in the 1980s. Most online bulletin boards work via asynchronous communication; participants post messages that are stored online for others to read, and individuals can log on and respond at different times (Walther & Boyd, 2002).

### **Motivations for Using Online Health Communication**

Uses and gratifications theory as formulated by Blumler and Katz (1974) has been used to study mass media for over 40 years. Uses and gratifications theory contends that audience members are not passive recipients of media messages, but are actively engaged in selecting media to fulfill various needs (Blumler & Katz, 1974). More recently, uses and gratifications theory was used to analyze people's use of legacy media (newspapers, magazines, radio, and television). Since then, the theory has been applied to new media such as cable television, cell phones, and the Internet (Anderson, 2011). Studies using interviews and surveys have found that participants have multiple motivations for using online support groups. These motivations include searching for help and information, sharing one's feelings with others, and receiving guidance and support (Buchanan & Coulson, 2007; Dholokia, Bagozzi, & Pearo, 2004).

Dholokia et al. (2004) found five primary motivations for participation in online communities: purposeful value (seeking and finding information); self-discovery (using social resources to obtain self-knowledge); interpersonal connectivity (contacting other people for social support and friendship); social enhancement (deriving value from one's status within a community); and entertainment (from interacting with others). Buchanan and Coulson (2007) found that the primary motivations for seeking peer communication in an online forum for dental anxiety were searching for help, sharing fears, feeling empowered by reading messages posted by others facing similar challenges, and receiving guidance, support and encouragement from others.

Motivations for communicating about one's health with peers online also include low satisfaction with one's healthcare provider, the desire for peer support, and wanting to learn about the experiences of

others living with the same condition (Millard & Fintak, 2002; Rodham, McCabe, & Blake, 2009). In a study of individuals who posted to a message board for Complex Regional Pain Syndrome (Rodham et al., 2009), those who used the site had few people locally to whom they could turn for support. Millard and Fintak (2002) found that patients who were more skeptical about healthcare, experienced problems with access to healthcare, and described themselves as being in poorer health were more likely to use the Internet as a source for health information.

Individuals with a stronger health orientation, as well as Internet broadband access and familiarity, were also found to be more likely to go online to search for health information (Dutta-Bergman, 2006; Rains, 2007). Fox (2011b) found that Internet users who had experienced a recent medical emergency or crisis, their own or someone else's, were more likely than other Internet users to go online to try to find someone who shared their situation. For individuals struggling with eating disorders and suicidal thoughts, motivations for visiting online communities included meeting people with similar conditions, getting information and advice, and receiving support from others (Kral, 2006).

People with stigmatized illnesses (such as anxiety and depression) are more likely to use the Internet to gather health information than those without a psychiatric stigmatized illness (Berger, Wagner, & Baker, 2005). Results from a study on a nationally representative sample of adults seeking mental health assistance (DeAndrea, 2015) indicated that the more participants reported social stigma, the more likely they were to seek support online rather than from an in-person support group or traditional treatment. As the reported number of logistical barriers to mental health treatment increased, a corresponding increase occurred in adults seeking online support rather than traditional treatment (DeAndrea, 2015).

People with serious mental illness face uncertainty about how to cope with the condition (Corrigan, 1998, 2004). They go online to reduce uncertainty, gather information, and seek support from others who understand their condition. Wright (1999) found that the most important strategies used for coping with divorce, alcoholism, eating disorders, and other stressful situations in online and offline

support groups were thinking about and gathering information about the problem, doing something to solve the problem, and seeking emotional support from others.

### **Significance of the Study**

People with mental health conditions such as BDD can feel socially isolated because of their limited knowledge about the disorder, and lack of contact with others who experience and understand BDD. Under these conditions, it may be difficult for individuals suffering from BDD to communicate with family members, friends, and physicians in order to receive the support and information they need. An online BDD forum offers individuals with concerns about the disorder an outlet for seeking and sharing social support and personal experiences with peers who understand the condition. This ready access to a secondary group of similar others can serve to ameliorate individuals' psychosocial distress, without the constraints or expenditure required of a face-to-face support group.

The current study was undertaken to better understand the communication that takes place between individuals who post messages to a mental health online support group. Understanding the peer support exchanged on the BDD forum can contribute to research on the importance of secondary networks for stigmatized individuals and specifically, for individuals suffering from BDD and related mental health disorders (such as OCD and social anxiety). As a result of this investigation, BDD researchers and clinicians will have an increased awareness about the resources and support needed by those suffering from the disorder. Health communication scholars will have a better understanding of why individuals turn to their peers to find the information and support they need to cope with the disorder, and about the communication that takes place on support forums for mental health conditions, such as BDD.

### **Dissertation Overview**

The dissertation is organized into five sections. Chapter 1 has identified the research problem, and the purpose, background, and significance of the study. Chapter 2 reviews previous research showing how personal disclosure and social support have been studied in online forums related to physical and mental health conditions. At the end of Chapter 2, the research questions are presented for the study. Chapter 3 discusses the qualitative content analysis methodology used to answer the research questions. In Chapter

4, the findings from the four research questions are reported, using quotations from participants to offer support for the researcher's interpretations. In Chapter 5, the implications of the findings are discussed as they provide an expanded understanding of the role of personal disclosure and peer support in online mental health forums, along with the study limitations and opportunities for further research.

## CHAPTER 2: LITERATURE REVIEW AND RESEARCH QUESTIONS

Individuals who have been diagnosed with BDD, or believe they have the disorder, may suffer from what Goffman (1963, p. 4) described as a “spoiled identity” because they are unable to meet the normative expectations of modern society in two important ways: first with “abominations of the body” (perceived ugliness), and second with “blemishes of individual character perceived as weak will” (mental illness). Individuals who endure public and self-stigma due to having a mental health disorder turn to both online and offline groups for social support. Online groups in particular enable individuals to find support that may be unavailable from family members and friends who do not have first-hand knowledge of the stigmatizing condition. As a result, individuals go online to share their personal experiences with others who can understand the condition.

### Personal Disclosure

Personal disclosure, also referred to as self-disclosure in the literature, has a long history in communication research. Cozby (1973), an early theorist of self-disclosure, defined the concept as “any information about himself [or herself] which Person A communicates verbally to Person B” (p. 73). Derlega, Metts, Petronio, and Margulis (1993) defined self-disclosure as what individuals verbally reveal about themselves to others, including their thoughts, feelings, and experiences (p. 1). More recently, Greene, Derlega, and Mathews (2006) defined the concept of self-disclosure as an “interaction between at least two individuals where one intends to deliberately divulge something personal to another” (p. 411). Self-disclosure is measured using three parameters; breadth, depth, and duration. Breadth is the quantity and variety of information disclosed, depth is the intimacy of information, and duration is the amount of time spent disclosing each item of information (Cozby, 1973).

Social penetration theory (Altman & Taylor, 1973) focuses on self-disclosure as the primary way that individuals develop close relationships. In developing personal relationships in an offline context, communication moves from relatively shallow, nonintimate levels to deeper, more personal levels. Altman and Taylor (1973) compared people to a multilayered onion, with each inner layer revealing

increasing levels of breadth and depth. Interpersonal closeness is predicted to proceed in a gradual and orderly fashion, from superficial to intimate levels of disclosure, motivated by current and projected future outcomes.

In contrast to the movement from less to more intimate self-disclosure that occurs when developing in-person relationships, Walther's (1992, 1996) social information processing theory seeks to explain how, over time, people using text-based CMC are able to form impressions of and relations with others online that achieve a similar level of development as offline communication. Social information processing theory (Walther, 2011) recognizes that text-based CMC is devoid of many nonverbal communication cues that accompany face-to-face communication, such as eye contact and body language, and assumes that individuals are motivated to develop interpersonal impressions and affinity regardless of the medium.

Research has shown that online communication can lead to high levels of self-disclosure. For example, Parks and Floyd (1996) concluded that disclosures by participants using CMC revealed moderate to high levels of breadth and depth. Tidwell and Walther (2002), in a study of Usenet groups, found that a common online support strategy was to disclose a very personal narrative and/or revelation of feelings and conclude with a question to find out if anyone else had similar experiences. The topics for the Usenet groups chosen for the study included a wide range of public health concerns, from abuse, divorce, and smoking cessation, to multiple physical and mental health disorders, including arthritis, anxiety, asthma, attention-deficit disorder, cancer, and depression.

One characteristic of CMC that encourages individuals to self-disclose online is the ability to write down one's thoughts and feelings without interruption by others. In the study by Walther and Boyd (2002) about the advantages offered by CMC support groups, one participant believed that online disclosure was "easier and healthier" because "the computer does not interrupt us during our story or questions, and we do not have a chance to interrupt the response" (p. 171). Anticipated social support is another important factor in encouraging individuals to make intimate disclosures online, because a person cannot receive support until the disclosure occurs. Anticipating and receiving support has been shown to

prompt intimate disclosures in a variety of mental health-related contexts, such as pro-anorexia forums (Chang & Bazarova, 2016; Haas, Irr, Jennings, & Wagner, 2011). Chang and Bazarova (2016) found that individuals disclosed negative feelings and behaviors in anticipation of receiving social support from other members.

Personal disclosure can take various forms, including personal information, brief anecdotes, and extended narratives, that are shared online in various message genres, such as personal websites, blogs, discussion boards, chats, and emails. Previous research on patterns of self-disclosure and social support in emails by adolescents (Tichon & Shapiro, 2003) found that self-disclosure was used to elicit support more frequently than direct requests for help. The pattern that emerged was that self-disclosure was used in initial emails to elicit support, in email responses to provide support (empathy and examples of coping), and then used by the person who initiated the email to provide reciprocal support (social companionship). Self-disclosure was used in 100% of the emotional/esteem responses and in 60% of the advice/informational support responses.

Arntson and Droge (1987) emphasized the importance of storytelling for mutual support. Storytelling enables people to regain a sense of control over their lives and is part of the process of making meaning from one's life experiences. Pennebaker and Seagal (1999) viewed the act of constructing stories as a natural human process that helps individuals to understand their experiences and to organize and remember events in a coherent fashion. This process gives individuals a sense of predictability and control over their lives, since once an experience has structure and meaning, it follows that the emotional effects of that experience become more manageable (p. 1243).

### **Social Support**

There is much research that gives credence to the idea that social support has measurable effects on physical and mental health (Berkman, 1984; Cassel, 1976; Cobb, 1976; Cohen & Wills, 1985). Social support has been defined as actions and behaviors that serve to assist a person in meeting personal goals or the demands of a particular situation, as well as information and resources from others that minimize the perception of threat and maximize actual and perceived mastery related to coping (Tolsdorf, 1976, p.

410). Outcomes of social support include self-acceptance, enhanced self-esteem, and fulfilling needs for intimacy, affection, and communication with others (Albrecht, 1987).

Social support as a communication phenomenon also can be defined as “verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one’s life experience” (Albrecht, 1987, p. 19). Communication is both a transactional and a symbolic activity. When one person communicates a supportive message to another, that behavior can affect both people’s feelings and cognitions. As the receiver gives feedback to the source about the message, both become sources and receivers. Meaning, however, does not reside in the intent of the creator or the messages exchanged, but in the perceptions of the participants. A message that is intended to be supportive may or may not be perceived as such by the receiver. Also, a message that is not intended to be supportive could be perceived that way by the receiver (Albrecht, 1987).

Burleson (2002) defined supportive communication as “specific lines of communicative behavior enacted by one party with the intent of helping another cope effectively with emotional distress” (p. 552). Burleson (1994) classified comforting messages using three levels based on the extent to which the feelings and perspective of the distressed other receives explicit acknowledgement, elaboration, and legitimation (p. 12). The lowest level reflects messages that either implicitly or explicitly deny the feelings and perspective of the distressed other (unsupportive). Messages that provide moderate levels of support contain an implicit recognition of the feelings and perspective of the distressed other (empathy, understanding). Comforting messages in the higher levels of the hierarchy require advanced cognitive abilities through which the others’ perspective can be recognized, internally represented, coordinated with other relevant perspectives, and incorporated within the person’s own understanding of the situation (Burleson, 1994, p. 13). These messages are more listener-centered, are more focused on evaluating the causes of the situation, are more accepting of the other person, and are meant to help the other person understand their situation.

Researchers have found that social support can provide buffer effects on stress as well as direct effects on individual well-being (Bambina, 2007; Berkman, 1984; Cassel, 1976; Cobb, 1976). Supportive relationships can aid recovery from illness, protect against clinical depression, reduce the risk of suicide, encourage behavioral commitment to prescribed medical regimens, and promote the use of community health services (Albrecht, 1987). Two theoretical perspectives seek to explain how social support affects health: the main effect hypothesis and the stress-buffering hypothesis (Cohen & Wills, 1985). Under the main effect hypothesis, having a social network can provide a sense of belonging, reassurance of worth, an opportunity for nurturing behavior, and access to new contacts and diverse information (Berkman, 1984). Social networks impact the overall physical and mental health states of an individual (Cohen & Wills, 1985).

The stress-buffering hypothesis suggests that the presence of adequate social support enhances an individual's ability to cope with stressful events (Cohen & Wills, 1985). Social support can affect how individuals appraise situations as either stressful or manageable. If people believe that their support system can provide resources or guidance, then they may not evaluate the situation as stressful. If the situation is viewed as stressful, social support can intervene and help to "buffer" the harmful physical and psychological effects resulting from stressful life events (Cohen & Wills, 1985).

Responding to others' requests by providing support and help can also have positive effects on the provider's health, such as feelings of belongingness, reduced stress and mortality, and the empowerment that comes from being useful to others (Chung, 2013). In the process of helping others, individuals also engage in self-reflection by "reappraising their own problems objectively and ultimately learn new coping skills and shift perspectives to a more positive light, which in turn leads to a reduction in levels of emotional distress" (Kim et al., 2012, p. 533)

### **Social Support by Males and Females**

There has been considerable research focused on differences between the social support provided by males versus females. Studies have found that men generally focus on gaining control through information-seeking, and that women tend toward emotional and community support (Herring, 1993;

Klemm, Hurst, Dearholt, & Trone, 1999; Seale, 2006). Klemm et al. (1999) found distinct differences in the types of CMC in cancer support groups across males and females. In the four categories of communication studied (information seeking/giving, encouragement/support, personal opinion, and personal experience), men were more likely to post messages providing information, and women were more likely to post messages displaying support/encouragement. Men have also been found to provide support that is more focused on tasks than on emotions, whereas women provide more emotional than informational support (Burleson, 2002).

Although most research shows that individuals do uphold male and female behavior stereotypes in online support groups, some studies have also provided evidence to the contrary. Flynn and Stana (2012) studied an online support group for men with eating disorders. Their study found that, contrary to previous research on social support and help seeking, men on the forum sought and shared personal disclosure and emotional support more often than informational support. Informational support, which was found to be the most frequent form of support by men in other research studies, occurred in only 11% of the messages (Flynn & Stana, 2012). Mo, Malik, and Coulson (2009) also found that men shared more emotional support and personal experiences on a support forum about infertility. Previous studies indicate that both men and women engage in supportive communication, though the type may vary, based on gender norms and the topic of the forum.

### **Categories of Social Support**

Social support behaviors have been classified using a variety of coding schemes. One of the most popular is the 5-category Social Support Behavior Code (SSBC) developed by Cutrona and Suhr (1992, 1994). The SSBC consists of informational support, tangible assistance, emotional support, network support, and esteem support (Cutrona & Suhr, 1992, p. 161). The SSBC was found to be applicable for studying communication behavior in online contexts by Braithwaite, Waldron, and Finn (1999). Since then, the SSBC has been widely used by researchers to identify themes in online forums for both physical and mental health conditions (Coulson, 2005; Flynn & Stana, 2012; McCormack & Coulson, 2009; Mo & Coulson, 2008; Walther & Boyd, 2002). Cutrona and Suhr (1994) also identified five negative

communication behaviors that can be considered forms of nonsupport. These have not been widely used for coding support in online forums: interrupting the other person, complaining (talking about one's own problems), offering criticism (blaming the other person), isolation (refusing to help the other person), and disagreement/disapproval (not agreeing with the other person).

Informational support and tangible assistance in the SSBC are behaviors intended to help another person solve or eliminate a problem causing stress (Cutrona & Suhr, 1992). Informational support includes advice/suggestions, referrals, situational appraisal, and teaching. Tangible assistance includes offers to provide needed goods and services, such as helping with tasks. Emotional support, social network support, and esteem support are efforts intended to comfort or console another person, without trying to solve the problem (Cutrona & Suhr, 1992). Emotional support includes expressions of caring, empathy/understanding, encouragement, prayer, and sympathy. Social network support provides a sense of belonging among people with similar interests (companions). Esteem support refers to expressions of regard for one's skills, abilities, and intrinsic value, such as compliments, validation, and relief from blame.

The three functions of social support identified by House and Kahn (1985) were emotional, informational, and instrumental (tangible) assistance. Emotional support refers to demonstrations of love, caring, esteem, value, encouragement, and sympathy. Informational support refers to advice intended to help a person solve problems, as well as appraisal support (feedback about the person's interpretation of a situation), and instrumental support (offering material or behavioral assistance). Similarity, Bambina (2007) classified online social support into three categories: emotional support, informational support, and companionship. Emotional or affective support included understanding/empathy, encouragement, validation, sympathy, and caring/concern. Informational support included advice, referrals, and teaching. The category of companionship included chatting, humor/teasing, and groupness (social network support).

## **Online versus Offline Support Groups**

### **Offline Support Groups**

A person's primary group of strong ties (Granovetter, 1973, 1983) including family members, friends, and significant others is usually expected to provide social support and assistance to help buffer stressful situations (Cobb, 1976; Thoits, 2011). They usually do this by expressing that they understand the reasons for the person's distress, and by offering information, advice, instrumental support, and encouragement (Thoits, 2011). Although primary group members intend these acts to be helpful, they can also be ineffective because the information and advice offered may seem too generic, inappropriate, or even misguided to the distressed person (Thoits, 2011). There are also costs in soliciting and accepting social support in personal relationships. According to Albrecht, Burleson, and Goldsmith (1994, p. 433), asking for help may make people "appear weak or less competent" and undesirable information may be disclosed while seeking support, which can result in stigmatization.

Secondary groups tend to be larger and participants' knowledge about one another is less personal. Work, volunteer, and religious organizations are examples of organized secondary groups (Thoits, 2011) Face-to-face support groups can also be considered secondary groups. These support groups have been in existence for hundreds of years in fraternal organizations, such as Freemasonry, but flourished in the middle of the 20<sup>th</sup> century with Alcoholics Anonymous and other 12 Step programs. These programs demonstrated that group support was essential in helping members recover from stressful situations and addictions (Barak, Boniel-Nissim, & Suler, 2008). These support groups were based on the simple premise that people who share similar difficulties may understand one another better than those who do not, and offer mutual emotional and pragmatic support (Thoits, 2011).

Individuals suffering from diverse physical and mental health problems join support groups to solve or cope with their personal problems or experiences (Borkman, 1999). When individuals suffer from a chronic and/or stigmatized condition, they may be prone to recurrent crises, and may seek mutual support from others who understand the condition. The essence of help in a mutual aid group is in the responses a person receives from and provides to other members. This supportive communication helps

individuals to reshape their personal narratives so they can help others while also helping themselves (Alcoholics Anonymous, 2001, pp. 89-103; Arminen, 2004).

### **Online Support Groups**

Online support groups became popular in the 1990s and presently Internet support groups have evolved into a social phenomenon that is estimated to be in the hundreds of thousands worldwide (Barak et al., 2008). Online support groups can operate through various Internet technologies, including email lists, chat rooms, or forums (bulletin board formats). Online forums have become the dominant technology, due to the many benefits they provide, including ease of access, asynchronous communication, the opportunity for archival search, emoticons and hyperlinks, and a user-friendly design (Meier, 2004).

Online support groups have become a prevalent source of information and support for individuals with numerous health conditions. Geographical dispersion allows those with physical restrictions the opportunity to participate (Braithwaite et al., 1999) and empowers those with rare or stigmatized conditions to find others who share their condition. Thus, individuals can meet and obtain support from a large network of people who come together to discuss specific health concerns.

**Advantages of online support groups.** Finn (1999), in a study of online self-help groups, found that such groups can provide mutual problem-solving, information sharing, expression of feelings, catharsis, mutual support, and empathy. Online support groups can also encourage patients to take responsibility for their own care. Most online support communities are available to anyone with a home computer and a modem, are often free, and sometimes provide moderators and/or volunteer health professionals who are experts on the condition in question (Burnett & Buerkle, 2004). Walther and Boyd (2002) found 12 advantages to participating in online groups compared to relying on family and friends for support: more candor (both less harsh and more forthright responses to problems), less negative judgment, reduced obligation to reciprocate support, less relational dependency, more immediate ability to seek support, greater expertise in the secondary network, stigma management, intimacy, access, uninterrupted composition, more expressive communication, and anonymity.

The anonymity and limited visual and nonverbal cues that text-based online support groups offer can help members to focus on the issues they have in common and lead to an increase in self-disclosure and affinity (Walther, 1996). Houston, Cooper, and Ford (2002) found that more than one third (37.9%) of participants with depression preferred an Internet support group over in-person counseling, and used their online experiences to supplement, rather than replace in-person depression care. The researchers concluded that a potential advantage to online support for people with depression is the freedom to discuss their concerns anonymously. One participant in the study stated:

I find online message boards to be a very supportive community in the absence of a “real” community support group. I am more likely to interact with the online community than I am with people face to face. This allows me to be honest and open about what is really going on with me. There are a lot of shame and self-esteem issues involved in depression, and the anonymity of the online message board is very effective in relieving some of the anxiety associated with “group therapy” or even individual therapy. I am not stating that it is a replacement for professional assistance, but it has been very supportive and helped motivate me to be more active in my own recovery program. (Houston et al., 2002, p. 2068)

The ability to reveal one’s true self on the Internet is facilitated by remaining anonymous in group-level interactions, since face-to-face interactions impose costs for disclosing negative aspects of oneself, such as disapproval from family members and friends (Bargh, McKenna, & Fitzsimons, 2002). Research on health-related online support groups indicates that individuals who use these groups tend to be satisfied with the support they receive, and they are often able to obtain more and better quality support than is possible from in-person networks (Wright et al., 2013). The preference for secondary support groups may be due to having access to diverse viewpoints not available within more intimate relationships, a reduced risk of stigma due to the anonymity offered, access to objective feedback from others, and fewer role obligations. Support expectations are generally less extensive and more easily reciprocated in secondary (weak-tie) networks than with family and friends (Wright et al., 2010).

**Disadvantages of online support groups.** Concerns about online health-related forums include the accuracy of information shared and the provision of unsupportive comments. Some medical information provided on Internet discussion boards may be unconventional, based on limited evidence, and/or not appropriate/erroneous (Culver, Gerr, & Frumkin, 1997). In a study of self-injury message

boards, Whitlock et al. (2006) found that online interventions offered essential social support for isolated adolescents. However, peer support could also normalize and encourage self-injurious and potentially lethal behaviors.

Members in online forums for physical health conditions (breast cancer, arthritis, and fibromyalgia) discussed several disempowering processes that take place on support forums. These included being unsure about the quality of the information offered, being confronted with negative sides of the disease, and being confronted with complainers (van Uden-Kraan, et al., 2008, van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009). Comparable results were found for members who participated in online support groups related to HIV/AIDS (Mo & Coulson, 2014). The disempowering processes included being unable to connect physically with others in the group, inappropriate behavior online, declining real life relationships, information overload, and misinformation.

Similarly, support was offered in a negative manner on discussion forums that promote disordered eating behaviors (pro-anorexia websites; Chang & Bazarova, 2016; Haas et al., 2011). Haas et al. (2011) found that pro-anorexia forum members encouraged negative or harmful behaviors, accepted self or other negative messages without correction from others, and co-constructed an enabling in-group used to combat stigma in their offline world. They labeled this type of support group an online negative enabling support group (ONESG). Chang and Bazarova (2016) analyzed messages posted to a pro-anorexia message board and found a pattern of negative responses to eating disorder-specific content in the messages, congruent with the type of support in the ONESG model.

**Participation in online groups.** Studies of online support groups have found that not all individuals participate at the same level; some are much more active in terms of sending and receiving messages. Studies comparing active members to *lurkers* (individuals who read but do not post messages) found that the positive effects of social support were weaker for lurkers than for active members (Mo & Coulson, 2010; van Uden-Kraan et al., 2008). A study of individuals living with HIV/AIDS (Mo & Coulson, 2010) found that compared to frequent posters, members who only read the messages scored lower in receiving support and useful information, and lower in satisfaction with group members. These

findings suggest that active participation leads to greater supportive benefits (van Uden-Kraan et al., 2008).

Individuals also differ in the type of support they exchange with other members, though less research has been done in this area. Bambina (2007) studied an online cancer forum using social network analysis, and qualitative and quantitative content analysis. She classified the support provided and received by the forum's 84 members according to their activity level and message content; the group consisted of 1 network star, 6 prime givers, 10 serious members, 15 moderate users, and 52 takers. She found that the most active members (the star, prime givers, and serious members) exchanged companionship, emotional, and informational support with one another, whereas the moderate users did not exchange companionship, and the takers only received informational support.

### **Research Questions**

The current study investigates how individuals communicate with their peers in an online forum for BDD ([psychforums.com/body-dysmorphic-disorder](http://psychforums.com/body-dysmorphic-disorder)). Based on the review of personal disclosure and social support above, this study addresses four research questions that explore the communication activities that take place on the forum, the personal experiences disclosed by participants, the social support that is sought and shared, and the support provided and roles performed by the most frequent posters on the forum.

#### **Communication Activities on the BDD Forum**

**RQ 1:** What communication activities take place on the BDD forum?

As a foundation for examining the subsequent research questions, the first research question addresses the communication activities that take place on the BDD online forum. Recognizing that various models of communication have been proposed, and communication can involve processes that incorporate transmission, ritual and/or the construction of meaning (Carey, 1989; Shannon & Weaver, 1949), this study focused on identifying specific key actions or identifiable acts used to initiate communication exchanges between participants on the forum. Previous studies, for example, have focused on how individuals use written text, such as email and message posts, to communicate online in

ways that are both similar to and different from face-to-face communication (Galegher, Sproull, & Kiesler, 1998; Sproull & Kiesler, 1986).

Galegher et al. (1998) studied online Usenet groups to understand the naturally occurring “talk” of group members. Posts in online groups were found to have similar conventions as in-person conversations; responses are usually directed to a particular person’s remarks or questions. These questions and answers are embedded primarily within personal experiences, and posts are typically short, coherent, and pointed (Galegher et al., 1998). Individuals in online groups can read messages and post new messages for anyone to read, thus there is fluidity in users’ roles where the writer can become a reader, and the reader a writer. There is also considerable fluidity in the topics posted, since the text in online groups is ever changing as new threads of conversation are built upon each person’s questions, statements, replies, and reactions to other posts.

Mutual help in support groups is an interactional process, based on personal experiences shared with others, in which “reciprocally narrated and shaped stories allow parties to reflect upon their identities to solve their problems” (Arminen, 2004, p. 320). Researchers have studied online mental health forums and found personal experiences within threads that appear to echo those in another participant’s posts (Giles & Newbold, 2013). The researchers referred to these empathetic responses as “second stories” (p. 486). The initial posters’ stories enabled other participants to demonstrate understanding and support by elaborating on and referring to features of previous stories in their posts.

### **Personal Disclosure on the BDD Forum**

**RQ2:** What personal experiences with BDD do individuals disclose on the forum?

The second research question focuses on the personal experiences that are disclosed on the BDD forum. Personal experiences disclosed on the forum include revelations about events in a person’s life, as well as their thoughts, behaviors, and emotions. Flynn and Stana (2012) found that participants in a male eating disorders forum shared more personal disclosure than emotional or informational support with one another. Common types of disclosures included their symptoms, behaviors, admissions of having an

eating disorder, the intent to seek (or admission of seeking) professional help, and sharing feelings about having the disorder.

Disclosing personal experiences has been found on forums for eating disorders (Haas et al., 2011; McCormack & Coulson, 2009), HIV/AIDS (Cousaris & Lui, 2009), and cancer (Coulson & Greenwood, 2012; Klemm et al., 1999). Barak and Gluck-Ofri (2007) categorized high levels of online self-disclosure into three categories: personal information (about one's traits, experiences, and behaviors); personal thoughts (about one's characteristics, physical appearance, health, and intimate ideas); and personal feelings (such as humiliation, agony, anxiety, fear, and pain).

Previous research has focused on personal disclosure in online support forums related to both physical and mental health conditions (Chung & Kim, 2008). The shame and embarrassment that individuals with stigmatized conditions feel can prevent them from communicating effectively with family members, significant others, and physicians. The anonymity offered by the BDD online support forum could help individuals to disclose personal experiences they may be reluctant to reveal to others offline. Individuals may be motivated to self-disclose online for a variety of reasons, including to engage in social comparison (Festinger, 1954), to display empathy (Giles & Newbold, 2013), and to elicit and provide support to other members (Tichon & Shapiro, 2003).

### **Social Support on the BDD Forum**

**RQ3:** What social support is sought and shared by individuals on the BDD forum?

The third research question focuses on the social support that takes place on the BDD support forum. Social support is defined as “communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one's life experience” (Albrecht, 1987, p. 19). Knowledge gained from informational support can provide a greater understanding of problems and possible solutions. Also, knowing that others have faced similar health issues can provide relief from personal blame, and renewed strength and determination (Bambina, 2007).

Barney, Griffiths, and Banfield (2011) studied the explicit and implicit information needs of people with depression on a depression support forum. Requests for information were coded as explicit needs, and reports of past or current problems were coded as evidence of implicit information needs. Six broad themes emerged related to informational needs: coping with depression; medication; professional treatment and services; understanding depression; disclosure and stigma; and comorbid mental health problems. Bambina (2007) found that the three types of support exchanged on an online cancer forum were companionship (network support), emotional, and informational support.

The study by van Uden-Kraan et al. (2008) found the participants encountered emotional support, recognition (by being with similar others) and informational support on three forums for physical health conditions. Participants felt that they received the support and information more quickly through the online group than if they had searched elsewhere. The information received on the forum was also valuable because it was understandable (not using medical terms) and tailored to their personal needs. Mo and Coulson (2008) studied messages posted to an HIV/AIDS online support forum and found that informational support was the most frequently provided type of support, followed by emotional support, and social network support.

### **Support Provided/Roles Performed by the Most Frequent Posters on the BDD Forum**

**RQ4:** What support is provided and what roles are performed by the most frequent posters on the BDD forum?

The fourth research question addresses both the support provided by the most frequent posters and the roles they performed on the BDD forum. As suggested in the literature about online forums, not all members participate at the same level, and people have different purposes for joining and being involved. Active members have been found to be more engaged with one another (Bambina, 2007) and enjoy higher satisfaction with their online experience (Mo & Coulson, 2008). Frequent posters are also more concerned about the group's ability to help other members (van Uden-Kraan et al., 2008). Active members who participated in support groups for patients with breast cancer, arthritis, and fibromyalgia (van Uden-Kraan et al., 2008, van Uden-Kraan et al., 2009) felt empowered by exchanging information,

encountering emotional support, finding recognition, sharing personal experiences, and helping others. In a study of a pro-recovery forum for eating disordered behavior (Aardoom, Dingemans, Boogaard, & Van Furth, 2014), the empowering processes most often reported by active members were exchanging information, finding recognition, and sharing personal experiences.

Other research pertaining to online social support found that most of the companionship, emotional, and informational support was exchanged by a small number of active participants (Bambina 2007). Providing social support to others can have both beneficial and detrimental effects for the support giver, depending upon the type of support offered. Companionship, which involves building positive emotions in other people by showing closeness, warmth, and inclusion, is associated with lower depressive symptoms. In contrast, listening to other people's worries and soothing people who are sad, angry and in conflict, has been associated with an increase in depressive symptoms for the provider (Strazdins & Broom, 2007).

### CHAPTER 3: METHODOLOGY

The current study used an emergent research design to study online health communication on the BDD forum. An emergent design allows the research process to unfold as the study progresses and is recommended by Lincoln and Guba (1985) for studying phenomena using naturalistic inquiry. Lincoln and Guba (1985) outlined guidelines for researchers when using qualitative research methods. The guidelines implemented by the current study were the use of a natural setting, having a human researcher as the instrument for analysis, the tacit (intuitive, felt) knowledge of the researcher during data analysis, purposive sampling techniques, an emergent research design, idiographic interpretation (looking at the particulars of the case), and special criteria used to determine trustworthiness of the research findings.

In this study, the natural setting was an online discussion forum and the data were messages posted to the forum. The researcher used her own tacit knowledge as well as previous research to understand the message content posted by participants to the online forum. Studying communication artifacts posted to an online support forum for BDD was guided by the researcher's personal experience with having BDD for more than 20 years (see Appendix A). The researcher's personal experience in seeking support provided the guiding line of inquiry for the study. Further, the researcher's background as a website designer and knowledge of online communication led to the Internet as a viable and important context for inquiry regarding individuals' communication about BDD.

Qualitative content analysis was used because it allows the researcher to make inferences about *naturally occurring, ordinary events in natural settings* (Miles & Huberman, 1994, p. 10) by recognizing patterns and themes in the data (Hsieh-Fang & Shannon, 2005). There are two main approaches toward qualitative content analysis: deductive and inductive (Berg, 2001; Mayring, 2000). Assigning codes (specifically defined categories) to the data is part of both approaches (Hsieh-Fang & Shannon, 2005). Deductive qualitative content analysis starts with a conceptual framework derived from theory and/or previous studies to develop categories, which can be helpful at the inception stage of data analysis (Berg, 2001; Corbin & Strauss, 2008; Mayring, 2000). In the inductive approach, categories are derived from the

data using the constant comparative method (Glaser & Strauss, 1967). The researcher combined deductive and inductive approaches when developing the categories and subcategories for the study.

Purposive sampling techniques were used to select all messages threads with replies posted to the forum in 2012. This was the most recent year when data were collected and the year with the most user activity since the forum began in 2006. Finally, the study used the trustworthiness criteria recommended by Lincoln and Guba (1985) to replace the conventional (positivist) criteria of internal and external validity, reliability, and objectivity. The following criteria are considered to be consistent with the axioms and procedures used in naturalistic inquiry (Lincoln & Guba, 1985, p. 42): credibility (instead of internal reliability), transferability (instead of external validity), dependability (instead of reliability), and confirmability (to replace objectivity).

The research design for the current study evolved based on the interaction of the researcher with the data and on feedback received from the researcher's dissertation committee. According to Lincoln and Guba (1985), the research design for a naturalistic inquiry needs to be emergent rather than pre-ordinate because what is learned during the study is not fully predictable as it is based on the interaction between the researcher and context (data and site). The research questions for the current study were refined as new findings emerged during the data analysis. Initially the focus was on describing the content of the messages posted to the forum (Research Question 2 and Research Question 3). As a result of identifying five individuals who participated more frequently than other members, Research Question 4 was created to focus the study more fully on the support they provided and the roles they performed.

After presenting the first draft of the findings to the dissertation committee, the researcher received feedback that more information was needed about how individuals communicated on the forum, in addition to the findings about what content the messages contained. As a result, a new research question was created to focus on communication activities on the forum, which was designated as Research Question 1. Additional data analysis was then conducted on the messages that were exchanged within the threads and on the messages that contained personal narratives (stories).

First, the chapter outlines the advantages and disadvantages of studying online communication in a natural setting, then the research site and artifact selection are described, followed by the data collection and analysis techniques. Next, the qualitative content analysis procedures are described, followed by the process used to analyze the most frequent posters, message exchanges (conversations), and personal stories. Finally, in keeping with the custom of qualitative research, the processes used to ensure trustworthiness are discussed, followed by the researcher's reflexivity statement, and ethical considerations for the study.

### **Studying Online Communication in a Natural Setting**

The Internet provides important information about individuals' communication in a natural setting without the researcher's interference (Bargh & McKenna, 2004). Further, qualitative inquiry in Internet research "exploits the fact that most online communication takes place through textual channels...which provide a vehicle for studying different psychological and sociological issues" (Barak & Miron, 2005, p. 508). Researchers consider the Internet to be a legitimate social context that enables observation and understanding of online discussants' communication (Pfeil & Zaphiris, 2010). The fact that CMC is mostly text-based means that text is often the only available data to use when investigating online communication.

These online texts can be considered "personal documents." Personal documents are defined as "any self-revealing record that intentionally or unintentionally yields information regarding the structure, dynamics, and functioning of the author's mental life" (Allport, 1951, p. xii). He noted that people write personal documents for reasons ranging from exhibitionism, to a desire for order and personal perspective, relief from tension, for therapy, monetary gain, fulfilling an assignment, social re-incorporation, scientific interest, literary delight, hope for public service, and hope for literary immortality (p. 178). Allport (1951) indicated that personal documents have an important role in social and psychological research.

One advantage to studying online messages is that, in most cases, the entire conversation can be retrieved and saved easily. The researcher can download and investigate all available data. However, this

can also be viewed as a restriction, since the researcher cannot observe the individuals who contribute to an online forum and review the written text according to the personal context of the contributors (Pfeil & Zaphiris, 2010). Studying only the online messages that have been posted overlooks the many forum users who lurk, meaning they may read the posts and use the forums, without posting messages (Burnett & Buerkle, 2004).

Anonymity in CMC presents another challenge for Internet researchers. Individuals log into online discussion forums with a freely chosen user name (screen name) and usually neither the other participants nor the moderators (if any) know their offline identity. This makes it difficult to identify demographic characteristics of participants, including their gender, age, and location, unless the information is contained within the message content (Flynn & Stana, 2012). An advantage is that anonymity can lead to a higher degree of self-disclosure (Pfeil & Zaphiris, 2010; Walther, 2011) than would be available to researchers offline.

Studies indicate that online verbal expressions can be considered authentic, honest, and reflect the “true self” (Bargh et al., 2002). Some researchers have studied people who harmed members of their online community by spreading lies (Feldman, 2000). However, many researchers believe that such cases of dishonesty are rare exceptions and individuals who post in online communities build an environment of honesty and trust (Pfeil & Zaphiris, 2010). The fact that dishonesty can take place in online forums represents a challenge for researchers and needs to be kept in mind when conducting Internet research. Studying the patterns of online users in the community can help to indicate if a user is telling the truth, but it is often impossible to completely resolve whether participants are being honest in their messages (Pfeil & Zaphiris, 2010).

## **Data Collection**

### **Research Site**

The Psychology and Mental Health Forum site related to BDD served as the research site for the study ([psychforums.com/body-dysmorphic-disorder](http://psychforums.com/body-dysmorphic-disorder)). The forum owner is listed as Coignet Allen in France. The site was started in 2002 and held the Alexa rank of 21,382 in the United States in July 2015.

The site received more than 28,000 page views daily (Alexa.com, 2015). Psychforums.com offers online support forums for a multitude of mental health topics, including the following: Abuse, Anxiety, Developmental, Cognitive, Dissociative, Eating, Factitious, Impulse-Control, Mood, Personality, Psychotic, Sexual, Sleep, Somatoform, Addictions, Therapy, and General Health. The BDD support forum is listed under Somatoform disorders ([psychforums.com/body-dysmorphic-disorder](http://psychforums.com/body-dysmorphic-disorder)).

Psychforums.com was chosen from among several forums offering online support for BDD that were found by searching in the Google, Yahoo, and Bing search engines. The search terms used for the searches included bdd online forums, bdd online discussions, bdd online chat, bdd forum, bdd online forum uk, and bdd support forums. All the sites were public, since there was no need to register on the site to view the messages posted on the forums. The top three sites listed in Google in June 2012 were Psychforums (801 topics), BDD Central (10,423 topics), and OCD-UK (245 topics).

BDD Central (BDDCentral.com), founded by Britney Brimhall, was the site with the most messages and was frequently listed as a resource by clinicians in their books (Claiborn & Pedrick, 2002; Phillips, 1996/2005, 2009; Veale, 2009; Veale & Neziroglu, 2010; Wilhelm, 2006). BDD Central had been the first choice as the research site for the study. However, on September 28, 2012, the site was no longer available on the Internet, due to the founder losing control of the domain name. Therefore, Psychforums.com was selected as the alternative site for the research study, since the forum contained the second largest number of message topics (801).

The Psychforums.com BDD support forum contains message posts that participants create using a chosen screen name (pseudonym). Individuals must sign into the forum as a member in order to post an initial message, and other people must sign into the site to post replies to the message topic. The initial message and the replies create a thread of messages related to the same topic. The messages posted to the forum are organized according to the most recent reply to a posted message topic. The discussion threads can also be viewed according to author, and in ascending and descending order. The length of each message thread varies depending upon the number of participants.

The posts remain on the site for years and as a result, archives dating back to 2005 are available for viewing. Because the messages remain in place for some time, people can view and reply to the discussion threads whenever they want. The forums are actively moderated by volunteers and have rules for use. These include an extensive list of considerations for participants, including not posting personal images, actual names or any identifying information within the content of message posts, due to the public nature of the forums. The volunteer moderators screen messages from new members and remove or edit content deemed harmful or in violation of the forum rules ([psychforums.com/forum-rules](http://psychforums.com/forum-rules)). The moderators are members who have been on the site for at least six months and have been active in providing support to other members.

### **Artifact Sample Selection**

The data corpus contained 280 initial message posts and 3,728 replies (4,008 total messages). One of the message threads was subsequently removed by the moderators due to being a duplicate post, thus the final number of topics for the study was 279. Purposive sampling (Coyne, 1997) was used to select all initial posts and up to the first three replies from the 279 threads in order to reduce the number of posts from 4,008 to 937. Three replies were selected due to being the median number of replies: half of the threads had fewer than three replies and half had more than three replies. Some of the messages could not be coded because the content had been edited or removed by the moderators, or the messages contained only images and no text (see Appendix B coding guide rules). As a result, the total number of messages coded for the study was 911. This represents 279 initial messages and 632 replies.

## **Data Analysis**

### **Qualitative Content Analysis**

The data analysis process initially focused on coding the content in the messages related to the concepts of personal disclosure and social support. The qualitative content analysis followed the steps outlined by Zhuang and Wildemuth (2009): prepare the texts for analysis; define the unit of analysis; develop categories and a coding scheme using a coding manual; test the coding scheme on a sample of text; code the remaining texts by adding new themes and concepts to the coding manual; assess the

coding consistency; draw conclusions from the coded data by making inferences; and report the methods and findings, striving for a balance between description and interpretation.

### **Text Preparation**

The texts were prepared by transferring the message threads for the study from the online forum into Microsoft Word documents. The 279 message threads were copied and pasted into sequentially numbered documents, ordered from January to December, 2012. In order to keep the messages in context, each of the message threads was saved as a separate electronic document. The documents were stored on the researcher's computer and backed up for safekeeping using a cloud computing service. The documents were then imported into the MAXQDA 11 data analysis software for coding.

### **Unit of Analysis**

The unit of analysis in the study was each discrete topic or idea within a message post. According to Pfeil and Zaphiris (2010), one way to code data in a qualitative content analysis is by using the message as the unit of analysis. This is a common technique when studying online discussion forums since each topic thread contain clearly distinct message units. However, the disadvantage of using the entire message as the unit of analysis is that multiple meanings within each message can be lost (Pfeil & Zaphiris, 2010). Therefore, each unit of analysis consisted of a single, discrete idea (topic) found within the data (Strauss & Corbin, 1990).

Coding by discrete topics allows the content to be coded at any structural level, such as a sentence, paragraph, and multiple paragraphs within the message (Henri, 1991). Thus the unit of analysis in the study could be one sentence, multiple sentences, and multiple paragraphs within the same message, but could not be larger than the entire message. The unit of analysis is referred to as a *comment* in the text (and as a *coding unit* in the coding guide) to add clarity and readability to the research results.

The comments that contained similar ideas were grouped together into categories. These categories were then grouped together into the themes (concepts) that emerged from the data. A theme is defined as a pattern found within the data that “at a minimum describes and organizes the possible observations and at maximum interprets aspects of the phenomenon. A theme may be identified at the

manifest level (directly observable in the information) or at the latent level (underlying the phenomenon)” (Boyatzis, 1998, p. 4). A theme can represent the same idea using different words or phrases but representing the same meaning.

### **Development of the Coding Scheme for the BDD Forum**

**Development of the first set of codes.** The development of the codes and categories for the content analysis was an iterative process that took place in multiple stages. A precondition of qualitative content analysis is that the primary researcher is familiar with the raw data that are being analyzed. In terms of discussion board postings, this means that the researcher needs to read through a sample of the posts several times in order to capture the overall context and get an overview of the dataset (Pfeil & Zaphiris, 2010). In the first step of the data analysis and coding process, the primary researcher read through a randomly selected sample containing approximately 11% (101) of the 911 messages selected for the study.

After becoming familiar with the data in the sample, the researcher then began the content coding process. The researcher highlighted important key words and phrases and made notes in the margins of the Word documents. This enabled the researcher to quickly skim the message threads and immerse herself in the data before coding the messages using the MAXQDA program. During all phases of coding, the researcher kept detailed coding notes (memos) outlining the coding process. These notes enabled her to refine and further characterize the codes and the relationships between them using the constant comparative process (Glaser & Strauss, 1967). The first set of codes for the coding guide was developed at this point, along with definitions and examples. The researcher also received feedback on the initial coding guide from her advisor and two committee members.

Coding for the personal disclosure categories was an inductive process because existing coding schemes for personal disclosure in online health forums (Coursaris & Lui, 2009; Flynn & Stana, 2012; McCormack & Coulson, 2009) did not adequately capture the personal experiences expressed by BDD forum members in the study. A deductive approach was used for coding social support by referring to the categories in the SSBC (Cutrona & Suhr, 1992, 1994). The SSBC is a standardized measure of social

support that has been used in previous research to study online forums (Braithwaite et al., 1999; Coulson & Greenwood, 2012; Coursaris & Liu, 2009; Mo & Coulson, 2008), making it possible to compare results across studies and build a more accurate picture of online behavior. The SSBC (Cutrona & Suhr, 1992) has also been divided into 23 subcategories and thus provides a complex and detailed measure of social support (Smedley, Coulson, Gavin, Rodham, & Watts, 2015). Ten of the 23 subcategories from the SSBC (Cutrona & Suhr, 1992) were adapted for use with the BDD forum coding scheme.

**Refinement and testing of the coding scheme.** The initial set of codes for personal disclosure and social support was then added to the MAXQDA 11 program where further refinement of the coding scheme took place. This process included adding message classification codes to identify the type of message (initial post or reply) within each thread and the name and gender of the message poster. Descriptions and examples of the message classification codes are provided in Table 3.1.

Table 3.1

*Message Classification Coding Scheme*

Classification Code	Description	Examples
Thread ID number	Each message thread is labeled with a unique identification number	1, 2, 3...297
Message type	The first message in the thread is the initial post and subsequent messages are labeled as replies	Initial post, Reply
Poster name	The name of the poster provided at the beginning of the message under the title	Roger, Kathy, Fran
Poster gender	Use context cues to identify the gender of the person posting the message, including the poster's name, self-identified gender (girl, guy), and role (mother, brother, etc.)	Male, Female, Undetermined

The researcher also continued to analyze the message content using the software and as a result, the category of tangible assistance adapted from the SSBC (Cutrona & Suhr, 1992) was removed from the coding scheme. Tangible assistance was removed because there was only one example where a member offered to provide needed goods (a list of literary resources) to another person on the forum; this was coded as informational support (resources). This is consistent with other studies of online support groups, where tangible (instrumental) assistance was only been found in small quantities or not at all (Bambina, 2007; Braithwaite et al., 1999; Tichon & Shapiro, 2003).

Throughout this coding process, the researcher searched for varied and discrete meanings among the codes. Newly discovered topics were then compared with those previously found in the message posts. Through this constant comparison process, the researcher was able to discover similarities among topics and group them together under higher, more abstract concepts referred to as “categories” (Strauss & Corbin, 1990). These categories were then developed into a coding guide that was applied to the data (see Appendix B).

Mayring (2000) recommended that a formative check (test) be conducted after 10% to 50% of the data has been coded, and that a summative test be conducted after all the data has been coded. The current study employed two intercoder reliability tests during the coding process and one test at the end. Two coders participated in the three rounds of testing; the first coder assisted with the first reliability test and the second coder with the second and third tests. The first coder had a master’s degree in Technical Communication from Colorado State University, and the second coder was a doctoral candidate from the department of Journalism and Technical Communication at Colorado State University.

The first reliability test took place after the initial coding scheme and guide were developed by the primary researcher. The content categories were kept mutually exclusive, since this is required for intercoder reliability testing using Cohen’s (1960) kappa. This coefficient is an appropriate test to determine reliability agreement by adjusting for chance agreement between two coders when working with nominal-level data (Neuendorf, 2002). Ellis (1994) indicated that correlation coefficients exceeding .75 to .80 demonstrate high reliability.

The first training consisted of the primary researcher and both coders reviewing the coding guide instructions, categories, definitions, and examples. Then multiple practice runs were conducted using another sample of threads purposefully selected from the study. During this process, the two coders offered suggestions for improving the coding guide categories and instructions. After the first coder was comfortable with the coding scheme and process, the primary researcher and first coder worked independently to code 13% of the messages randomly selected from the sample (119 messages).

After further refinements were made to the coding scheme based on the results from the first test, another reliability test was conducted with the second coder. The second coder was trained using the same techniques as those for the first coder. The messages from the first round of testing were used to train the second coder. The second reliability test was conducted using 11% of the messages randomly selected from the sample (102 messages). Some of the personal disclosure categories with lower kappa results were dropped from the coding scheme (such as personal disclosure topics) and new categories were added (symptom-related personal disclosure). Based on the low number of comments that could be coded as esteem support, this category was collapsed into emotional support.

The coding scheme for the second round of testing included seeking and sharing personal disclosure and social support. There were far more comments that could be coded as sharing (providing) than as seeking (requesting) support and personal experiences. This finding is similar to other studies of online forums where instances of seeking support (Bambina, 2007) and personal experiences (Flynn & Stana, 2012) were far fewer than for offering support and personal experiences. Asking for help (direct requests) can be difficult because an individual may feel vulnerable and needy when doing so (Bambina, 2007).

Distinguishing direct requests from rhetorical questions and indirect requests (statements of uncertainty, doubt, or curiosity) was difficult for the second coder and researcher to do adequately. As a result, the seeking and sharing subcategories were collapsed into the main categories for personal disclosure (symptom-related and recovery-related) and social support (informational, emotional, and

social network). Collapsing codes (variables) into fewer and better-defined categories is one of the options offered by Neuendorf (2002) for variables that do not achieve an acceptable level of agreement.

As a result of collapsing the codes for seeking and sharing into the main categories, the two personal disclosure categories had an acceptable level of agreement, but the three social support categories were still low (kappas from .40 to .65). A third test of the coding categories for social support was conducted after further refinements were made to the coding guide. The third test took place after the remaining messages (approximately 400) were coded by the primary researcher. This test was conducted on a randomly selected sample of 109 messages (12%) not used for previous testing or training sessions. The final Cohen’s kappa results are shown in Table 3.2.

Table 3.2

*Final Intercoder Main Category Reliability Measures*

Category	Cohen’s kappa
Gender	.75
Symptom-related disclosure	.90
Recovery-related disclosure	.81
Informational support	.84
Emotional support	.80
Social network support	.80
Unsupportive comments	1.00

Gender was a message classification code but was tested for reliability due to the latent nature of the variable. The poster’s gender was not provided on the forum, so message context cues were used to determine the poster’s gender. The .75 kappa occurred due to the second coder choosing “undetermined” for the poster’s gender more frequently than the primary researcher. The kappa results for the two personal disclosure categories were high (symptom-related was .90 and recovery-related was .81). The social support kappa statistics were also high: informational support was .84, emotional support was .80, and social network support was .80. The kappa statistic of 1.0 for social network support was reached because both the primary researcher and coder agreed on the one instance found during the testing

process. After an acceptable level of agreement was reached for each of the main categories, the primary researcher reviewed all the content codes for accuracy and consistency with the final coding scheme.

**Final coding scheme used for content analysis.** The final main categories and subcategories are provided in the coding guide (see Appendix B) and listed in Tables 3.3 and 3.4. The category of personal disclosure contains symptom-related personal disclosure and recovery-related personal disclosure (Table 3.3). Personal disclosure was defined for the study as the personal experiences that individuals share with others, including their likes/dislikes, feelings, thoughts, and behaviors (Derlega et al., 1993). Personal facts and information about the person, including demographic data (such as age, gender, and location) were not coded as personal experiences in the study.

Table 3.3

*Final Personal Disclosure Coding Scheme*

Category	Description	Codes
Symptom-related personal disclosure: Appearance-related	Feelings, thoughts, and behaviors related to person's perceived appearance flaws/ugliness	Hating one's face, nose, body, etc. Feeling ugly, suicidal, angry, etc. Social comparison, plastic surgery, appearance checking
Symptom-related personal disclosure: BDD-related (other than appearance)	Experiences related to the impact of BDD symptoms on person's social life, causes for disorder	Social isolation, parents as causes for disorder, relationship/dating problems, job/career problems
Recovery-related personal disclosure	Experiences with diagnosis and treatment of BDD symptoms, overcoming symptoms	Self-diagnosis, diagnosis by others Clinical treatment (therapy, CBT, medication), self-help and coping strategies, barriers, benefits

Symptom-related disclosures include appearance-related feelings, thoughts, and behaviors about a person's perceived ugliness and appearance flaws, and experiences related to the impact of having BDD on friends/family, on one's job/career, including causes for the disorder. Recovery-related disclosures include experiences with BDD diagnosis and treatment. Diagnosis could be by one's self or by others, such as physicians, family members, and friends. BDD treatment includes clinical treatment (therapy,

CBT, medication), self-help and coping strategies, barriers to getting effective treatment, benefits of treatment, and success stories (overcoming symptoms).

Under social support, there are three main categories: informational support, emotional support (containing esteem support), and social network support (Table 3.4). Informational support includes topics about treatment, diagnosis, coping, and recovery (coded as BDD-related), and appearance-related concerns such as whether one's perceived appearance flaws are real. Emotional support includes expressions of empathy, caring/concern, thanks/gratitude, encouragement, sympathy, compliments and validation. Social network support includes references to the forum (or other forums/social networking sites) as a place where people interact with and help similar others.

The descriptions for informational support, emotional support, and social network support were adapted from the SSBC (Cutrona & Suhr, 1992, 1994), along with the codes for advice (informational support), empathy, sympathy, compliment, encouragement, validation (emotional support), and presence and companionship (social network support). All other codes were derived inductively from the data during the data analysis process.

Unsupportive comments expressing disagreement/disapproval and criticism of other forum members (including sarcasm and flaming) were also present on the forum. Unsupportive comments are expressions of disagreement, disapproval, or criticism that either implicitly or explicitly deny the feelings and perspective of the recipient. These unsupportive comments serve as negative cases and indicate that, even though most of the communication on the forum was supportive, there were exceptions. Sarcastic comments were offered in a post when one member disagreed with another's opinions: "So i thank you very much kind sir, your post is actually quite ENLIGHTENING." Flaming comments included insults directed at other members: "Well, he said I am SO EXTREMELY UGLY that even surgery wouldn't help me..."

Table 3.4

*Final Social Support Coding Scheme*

Category	Description	Codes
Informational support	Advice and opinions directed to others on the forum about actions to take or taken to help the person solve a problem causing stress. Includes referrals to resources (clinicians, books) and teaching about BDD.	BDD-related (other than appearance): Diagnosis, treatment, self-help and coping strategies, overcoming symptoms Appearance-related: Plastic surgery and cosmetic procedures, perceived flaws and ugliness
Emotional support	Expressions of caring, concern, empathy, and sympathy directed to others on the forum meant to comfort or console another person without trying to solve the problem. Includes positive feedback that expresses belief in a person's abilities and capabilities (esteem support).	Empathy: Expresses understanding for recipient's situation, has similar feelings Caring/concern: Asks about the recipient's situation, offers or seeks help Thanks/gratitude: Expresses appreciation to the recipient for help or assistance Sympathy: Expresses sorry or regret for the recipient's situation Compliment: Offers praise and says positive things about the recipient Encouragement: Provides the recipient with hope and confidence Validation: Expresses agreement with the recipient's perspective
Social network support	References about the BDD forum as a community of people with similar interests and concerns, directed to others on the forum. Includes references to the forum as a place where people interact with and help similar others.	Presence: Refers to the forum as a place where people with similar interests and concerns come to interact Companionship: Reminds the recipient that there are others on the forum who are available to help (you are not alone!)
Unsupportive comments	Comments that either implicitly or explicitly deny the feelings and perspective of the recipient	Disagreement/disapproval: Expresses an opposing opinion from the recipient Criticism: Expresses negative judgements, including sarcasm and flaming

**Coding and Analyzing Messages in the Software**

The messages were coded in the software using both the classification codes and the content codes. An example showing how a message was coded is shown below (Figure 3.1). The message thread contains two messages: the initial post and one reply. The classification codes for the thread title and

message type were added first, starting with the initial post followed by each subsequent reply. After that, the poster's name and gender were coded for each of the messages in the thread. Colors were added to the codes in the software to make them easier to recognize (see Appendix C).

**Message thread title** [title]

**Message type-Initial post**

**Poster name** [ name]

**Gender** [female]

**Recovery disclosure-Diagnosis:** Hi my names [name] im 18, i've been told by psychiatrists in passing that i have body dysmorphic disorder, but never properly diagnosed. **Symptom disclosure-Appearance:** I have all the symptoms, i skin pick, i cant stand how i look, i find it hard to function/sleep/have healthy relationships/feel good about myself, i am obsessive on my faults, i have zero self esteem, i hate my face but cant stop looking in mirrors to try and see how i can disguise and fix, i have suffered from bullemia and annorexia due to how i feel about myself, and i just make myself feel sick, i cant stand being in my body or being who i am, i constantly compare myself to others and its ruining my life

**Informational support-Diagnosis:** i need to get diagnosed, if i definatly am suffering from it which only a doctor can tell me, really soon, because its having an impact on my studying and relationships and enjoyment of life. But i dont know how to get diagnosed? Do you walk into a doctors surgery and tell them you think you have it, or tell them your symptoms and see what they say, or do you go to a doctor at all? please help me know what to do, im getting to the end of being able to cope with how i feel, its too constant and its destroying my confidence and my ability to enjoy life

**Message type-Reply**

**Poster name** [name]

**Gender** [female]

Hi [name],

**Emotional support-Sympathy:** I'm sorry you are going through this. **Emotional support-**

**Encouragement:** I think it's great that you want to get help for it, that is an achievement in it's self

**Informational support-Diagnosis:** You should make an appointment with your GP and discus it with him/her. Tell them that you think you have BDD and why you think that. You could maybe write down how you feel and take it with you, that way if you find it hard to talk about it you can just hand it over to your doctor.

**Emotional support-Caring/concern:** Good luck, and let me know how you get on

**Poster name** [name]

*Figure 3.1* Example of coding messages in the software.

After the classification codes were applied to each of the messages in the thread, the researcher read through all of the messages multiple times and applied the content codes to each message in sequence, starting with the initial post followed by each reply. In the example provided (Figure 3.1), the first message in the thread (initial post) contains two personal disclosure comments (recovery-related and

appearance-related), and one informational support comment (diagnosis). The reply contains three comments coded as emotional support (sympathy, encouragement, and caring/concern) and one informational support comment (diagnosis).

Relationships between categories and codes were explored in the software by using data retrieval commands such as “Intersection/set” to access all text segments coded with overlapping classifications. For example, the codes for *companionship-provided* and *Roger* were retrieved to discover how many and what types of companionship comments Roger offered to other members. In this way, the researcher was able to identify individuals (by name and by gender) who posted the most comments in the messages coded for the study.

Thus, the software was used to make comparisons, model connections, and conduct further data analysis in order to discover relationships between categories and subcategories in the data. The MAXQDA 11 program was also used to create reports for each category, including frequency of occurrence. After the frequency of categories was calculated in MAXQDA 11, the statistical results were exported into an Excel spreadsheet for further analysis. Using a combination of data analysis techniques enabled the researcher to examine themes and patterns within the message threads and interpret the findings using both quotes from the participants and descriptive statistics.

According to Miles and Huberman (1994), counting occurrences of codes and categories is helpful for several reasons: to rapidly see patterns in a large batch of data; to verify a hunch or hypothesis; and to keep the researcher “analytically honest, protecting against bias” (p. 253). Summarizing the data in quantitative terms helps to inform the final step in the data analysis, making sense of the themes and categories identified (Zhuang & Wildemuth, 2011).

### **Additional Data Analysis**

After the coding and analysis for the personal disclosure and social support categories were completed (RQ2 and RQ3), additional analysis was undertaken to understand how individuals communicated in messages posted to the BDD forum. Research Question 1 focused on the communication activities that took place on the BDD forum within the message threads. Additional data

analysis was conducted to determine how many initial posts received replies (260) and if the original poster replied to other members. The researcher reviewed each of the 260 threads to determine how the original posters responded to other members' comments.

Further data analysis was also undertaken to determine if any of the comments coded as personal disclosure could be considered stories or second stories. First, the researcher found a definition for written narratives from a public health study (Thompson & Kreuter, 2014). Then the researcher reviewed all of the personal disclosure comments in order to determine if they contained an identifiable beginning, middle, and end that provided information about the scene, characters, and conflict, and concluded with a resolution to the conflict. Based on these criteria, 23 stories were identified in the study. Most of the stories were filled with personal struggles related to BDD symptoms and concluded with the poster finding the forum and asking for help. However, one story contained a narrative about recovering from BDD, and another story was identified as a second story that echoed the ideas in the first story posted in the thread.

Research Question 4 focused on the most frequent posters on the forum and the functional roles they performed based on the content of the messages. Because the names of the posters were coded in the software, the researcher was able to easily identify five members who posted the most messages. Further analysis revealed that these same five individuals (who were not forum moderators) posted more comments containing social support than other members.

When developing the themes (five conclusions) in the discussion, additional analysis was conducted using an Excel spreadsheet to record the content found in the initial posts and replies in each message thread. Messages posted by the less frequent posters (members who posted 30 or fewer messages) were analyzed in order to compare their contributions to those of the most frequent posters. In addition, there was an off-topic thread (titled "Off-topic") that contained more than 1,500 messages. The researcher analyzed the first 200 posts to determine if members other than Roger and Kathy exchanged messages in the thread.

## **Trustworthiness Criteria for Qualitative Research**

The researcher used the four trustworthiness criteria for qualitative research recommended by Lincoln and Guba (1985) to assure the quality of the results: credibility, transferability, dependability, and confirmability. Credibility evaluates whether the research findings represent plausible information drawn from the participants' original data. Transferability refers to whether or not research findings are transferable to other settings and contexts. Dependability refers to the consistency with which the research is carried out, and if the process is logical, traceable, and clearly documented regarding the methods used. Confirmability is a measure of how well the study findings are supported by the data collected (Lincoln & Guba, 1985).

Techniques used to establish credibility for the study were prolonged engagement, peer debriefing, and negative case analysis. The researcher spent more than two years studying the online BDD forum and revisited the site multiple times during those two years in order to thoroughly understand the context of the forum. Peer debriefing is the process of exposing oneself to a disinterested peer for the purpose of exploring aspects of the inquiry that might otherwise remain implicit within the researcher's mind (Lincoln & Guba, 1985). Debriefing sessions also provide an opportunity for catharsis in order to clear the mind of emotions and feelings that may impede the research process.

The researcher relied upon several debriefers during the study, including the primary researcher's dissertation advisor and other graduate students. The advisor asked hard questions about methods, meanings, and interpretations, and provided informational support during the research and writing process. Other graduate students, including the coders for the study, provided emotional support during the more stressful parts of the reliability coding process and offered feedback on the coding guide. Negative case analysis was used to refine the concepts and categories during the inquiry due to disconfirming evidence found in the form of unsupportive comments. The categories were revised until all cases fit by eliminating all outliers and exceptions (Creswell, 2007; Lincoln & Guba, 1985; Miles & Huberman, 1994; Patton, 2000).

Transferability of the findings can be determined by the reader based upon the researcher providing rich, thick description about the setting, the participants, and the context (Creswell, 2007; Denzin, 2000; Lincoln & Guba, 1985). The current study described the messages, the forum, and other contextual information in detail, using examples and quotations from participants. This detailed description enables readers to determine whether the findings can be transferred due to shared characteristics with other settings and participants (Creswell, 2007, p. 209).

Dependability and confirmability were established by creating an audit trail based on research memoranda that can be used to evaluate the study methods. Dependability was also established by independent analysis of the data using two trained coders and three rounds of reliability testing. Confirmability was further established by the researcher's disclosure about her background, perspective, beliefs, and values briefly within research manuscripts (Creswell, 2007). Following is the primary researcher's reflective statement summarizing her background, her tacit knowledge of BDD, her professional and academic qualifications, and reasons for undertaking the study.

### **Researcher Reflexivity**

My story as an individual suffering from BDD for 20 years, my recognition that it was a psychological disorder, my experiences in seeking and receiving treatment (both pharmacological and psychological), and my gradual recovery from BDD (see Appendix A) have motivated me to discover how I can contribute my skills and knowledge to educating others about the disorder. In addition, my strong desire to increase awareness about the disorder has led to my research on health communication topics in general, and BDD in particular. My research focus seeks to understand how individuals with mental health conditions, such as BDD, use online forums to communicate with others suffering from similar conditions, in order to find the advice, support, and information they need to recover.

My qualifications include more than five years of academic research experience specializing in qualitative methodology and theory. I have taken graduate courses at Colorado State University in Health Communication, Qualitative Methods in Communication Research, Communication and IT, Communicating in the Clinic, and Content Analysis. My professional qualifications for conducting this

study include more than 10 years as a website designer, Internet marketing specialist, content manager, usability consultant, and information design architect for corporations, small businesses, and nonprofit organizations in Colorado. I have also taught college courses on the history of the Internet, Internet marketing, and website design. My tacit knowledge of BDD, my 10 years of experience as an Internet specialist, and the graduate courses I have taken at CSU make me highly qualified to conduct this research study.

### **Ethical Considerations**

A key question when considering the ethical guidelines to use for the study is whether or not the online discussion forum, PsychForums.com, is considered to be a public or private online support forum (Barker & Swiss, 2011). There are multiple indications that messages are publically available for viewing. First, under the Forum Rules, there is a link to a privacy policy page that states, in part:

The Forums at PsychForums.com are open to all and do not require registration. However, some people choose to register of their own free will. These individuals are solely responsible for the release of their private information on this public forum...Note that all the forums and blogs are accessible by search engines and will therefore be publicly referenced. (Psychforums.com privacy policy, para. 1)

According to the Colorado State University Institutional Review Board (IRB) guidelines for human subjects research, sites that are considered “fully public” are not considered human subjects research and therefore do not require IRB approval. Fully public sites are defined as those that any Internet user can access and search without a required login or username, and where there is a general understanding that the information posted within such a site is public (Barker & Swiss, 2011). The online forum, Psychforums.com, clearly states that the information posted to their forums and blogs is public and can be indexed by search engines. Therefore, IRB approval was not required for the study.

In Herring’s view (2004), both the researchers and the participants of an online community are responsible for the protection of the participants’ privacy. Participants of online communities have the responsibility to declare their online community clearly as public or private. Researchers need to consider the protection of participants’ privacy, even if the material is publicly accessible. Part of protecting participants’ privacy includes protecting their online identity. Therefore, the researcher changed the

screen names used on the site to pseudonyms, and removed any private information that could identify individuals along with the days, times, and titles of messages (Pfeil & Zaphiris, 2010).

### **Reporting the Research Results**

Participants' own words are used to illustrate the themes found in messages posted to the forum. These "personal documents" provide information about the "structure, dynamics, and functioning of the author's mental life" (Allport, 1951, p. xii). Participants' quotations were retained in their original form, including typographical, grammatical, and/or spelling errors. Each quotation is identified by the poster's gender (Female, Male, and Undetermined). Quotations by the original poster (OP) in the thread and forum moderators (moderator) are further identified. When more than one message reply is provided in the example, messages are labeled as 2, 3, and 4 as applicable to signify the order in which the posts appeared in the thread (Giles & Newbold, 2013). Pseudonyms are used for the five most frequent posters when reporting the results from the fourth research question.

## CHAPTER 4: RESULTS

This study investigated the communication activities on the BDD forum by focusing on the conversations that occurred in the message threads, on the content of the messages, and on the posts by the five most active members. This chapter first describes the study artifacts, and then reviews the findings from the four research questions. The research questions focused on the messages exchanged by participants, the personal experiences they disclosed, the types of social support sought and shared, and the support provided by the most frequent posters. The findings from the study are presented using quotations from the participants, along with descriptive statistics.

There were 911 messages coded for the study, including 279 initial message posts and 632 replies (mean of 2.3 replies per initial post). A total of 2,278 comments were coded in the study; 857 were labeled as personal disclosure and 1,421 were labeled as social support. The frequency data include both seeking and sharing personal disclosure and social support (summarized in Appendix Table D1). The same message often contained both social support and personal disclosure. However, more initial posts contained personal disclosure, and more replies contained social support (Table D2).

Overall, a total of 225 unique forum members contributed posts to the 279 threads and 911 messages coded for the study. Of those members, 99 were coded as female (44%), 74 were coded as male (33%), and for 52, their gender could not be determined (23%). The number of posts per participant varied widely. Most members (72.4%) posted only one or two messages in the study, similar to studies of online forums for cancer (Bambina, 2007) and eating disorders (McCormack & Coulson, 2009). For the five most frequent posters analyzed for Research Question 4, however, the number of total posts ranged from 46 to 103 messages. Forty-five messages were considered the cutoff for a poster to be classified among the most active; the next highest number of posts per individual was 30.

Members' other demographic characteristics were unknown unless they were provided within the messages. Members visited the site from multiple countries including the United States, the United

Kingdom, India, Canada, and Malaysia. The age range of members who disclosed their age was from 15 to 52 years old. Most members who disclosed their age were in their early twenties to mid-forties.

### **RQ1: Communication Activities on the BDD Forum**

Research Question 1 examined the primary communication activities that took place on the BDD forum. These communication activities on the forum can be summarized as (a) members asking about others' BDD experiences and seeking support, (b) members discussing their experiences with BDD and providing support, (c) conversations in which members exchanged messages, and (d) telling personal stories. Details about the BDD-related personal experiences that were discussed on the forum will be presented in the research findings for RQ2, and the types of support sought and shared on the forum will be discussed in the findings for RQ3.

#### **Asking about Others' Personal Experiences and Seeking Support**

Individuals in the study asked about others' experiences with BDD and sought support (help, advice, and opinions) from other members. These queries or requests could be direct (in the form of a question) or indirect, when individuals expressed uncertainty, doubt, or curiosity within their personal disclosures. The inquiries seeking advice and opinions represented classic examples of information seeking – an idea that has received wide attention in the communication literature in connection with uncertainty reduction (Berger & Calabrese, 1974) and media use (Blumler & Katz, 1974).

Sharing personal experiences and support occurred more frequently than seeking personal experiences and support. There were 136 comments seeking the personal experiences of others, compared to 721 disclosure comments, and 260 comments seeking support, compared to 1161 providing support. These findings are similar to previous research (Bambina, 2007; Barney et al., 2011; Flynn & Stana, 2012; McCormack & Coulson, 2009) where seeking personal experiences and support were much less frequent than sharing support and experiences with others.

**Asking about others' personal experiences.** Direct questions in initial posts were asked in order to compare one's experiences to others, such as when one member wanted to find out if anyone else had trouble being assertive: "Anyone else here have people using or walking over you because of your

insecurities (or because you are scared of not being liked)?" Comparing one's experiences to those of others has been found to be a common activity on support forums for chronic illness and cancer (Bellizzi, Blank, & Oakes, 2006; Dibb & Yardley, 2006), and is done primarily for information seeking purposes.

Requests could also be made indirectly by indicating that members wanted to talk to others who could understand what they were going through: "Hello, I just found this website because I am at a low point right now and want to talk to people who understand..." Uncertainty reduction theory (Berger & Calabrese, 1975) stated that uncertainty leads to information-seeking behavior, as people are motivated to monitor others' behavior in social situations and engage in a variety of strategies to find more out about others. These communication strategies include asking questions about the other person or disclosing personal experiences to encourage others to self-disclose (Berger, 1979; Berger & Calabrese, 1975).

Introducing oneself to the forum by disclosing personal experiences and then asking if anyone had similar experiences was a common communication strategy used on the BDD forum, as shown in the following example:

**Female 1-OP (original poster):** I'm totally new to this forum. I found it through google searches on BDD, and thought it would be a good way to contact others who suffer from this disorder. I guess I just really would love to hear some of your stories, personal experiences, and habits all related to BDD.

Direct questions about another person's experiences in the replies were generally asked to find out more information about the person when offering help and advice. The moderator in the example below expressed concern about a male poster who was suicidal. She wanted to find out if he had seen a therapist for help: "[Name], are you getting support from a therapist at all? To help with the panic attacks now and to tackle the other aspects of your face that you're unhappy with?"

**Seeking help and support.** Individuals on the forum asked for help and support from other members. Many of the requests seeking help were direct; individuals discussed feeling lonely, ugly, or suicidal, and wanted to know that they were not alone, as shown in the following post by a female member: "Hi, I'm new here and just looking for some help and support. Knowing I'm not a complete freak and the only one that has these thoughts." Other members asked questions seeking help and support.

A female member posted a message during a panic attack and asked others for help because she was feeling suicidal:

**Female 1-OP:** Is anyone up or can someone talk to me? I'm laying in bed, but I cant sleep and I am having a panic attack...I ate some stuff today that will probably make me gain a lot of weight and my mind is racing about everything..I feel so disgusting and worthless I dont want to be here anymore. Someone please help me. I dont know what to do anymore. I just want everything to disappear.

**Seeking advice and opinions.** Participants also posted messages to seek advice and opinions from other members. Advice was focused on actions that individuals could take; opinions were judgments that did not necessitate taking action. Requests for advice were usually direct and asked before or after sharing one's personal experiences. A common question on the forum was about how to cope with BDD symptoms: "Should I see a professional? Speak to family? Or is there another self help way of approaching this?" When inquiries were indirect, the poster expressed uncertainty or doubt about his or her options: "I can't decide if I should just take medication or just attempt to get counselling without the meds."

The most striking example of seeking opinions on the forum was when individuals asked about their perceived appearance flaws. Members asked for others' opinions on their appearance despite not being able to post personal images on the site. The site's policy was summarized by one of the moderators in the directions for all members to follow:

**Undetermined-moderator 1:** Due to the potentially triggering nature, sharing personal pictures is not allowed on this forum. We hope this will help you concentrate less on your physical appearance and more on your behavior and feelings, assisting your recovery.

The visual anonymity offered by the BDD forum did not prevent individuals from asking others about whether or not their perceived appearance flaws were real. This was one of the most common appearance-related questions on the forum. In the following post, a female member asked others to tell her if her hands were too small for her body. In order to overcome not being able to post a photograph of herself, she instead included the size of her hands and her height:

**Female 1-OP:** Hey everyone, I'm new here, but to make a long story short, for several years now I have had this complex about my hands. I have received the occasional comment about how

small my hands are. I know they are small, but I am also a petite woman at 5'1. I measured my hand and it is about 6 inches. That is an inch shorter than the average woman's hand in America, but I am below average height.

After introducing herself to the forum and sharing her hand and body proportions, the poster then asked others if her hands were in the "normal" range, based on the measurements she had provided:

So I'm wondering... are my hands in the "normal" range of small, or are they... freakish? I feel so depressed over it, I have been suicidal and I just can't face living life feeling like I have "midget hands" or something.... I guess I can't attach a picture, which would be helpful, but hopefully you can get an idea from the measurement I gave.

Another common question on the forum was focused on whether or not the person posting the message was ugly or had BDD: "Do I have BDD? Or am I just a truly ugly girl who can't accept that she's ugly?" These types of questions are considered to be harmful for those with the disorder, since replies that the person looks fine, normal, or attractive rarely help, and will often cause the person to ask more appearance-related questions (Phillips, 1996/2005). However, in prior work exploring self- and other-diagnosis in user-led mental health online communities (Giles & Newbold, 2011), asking for or about a diagnosis was considered beneficial because doing so enabled members to establish that they belonged to the online community.

### **Sharing Personal Experiences and Support**

Individuals also came to the forum to share their personal experiences with BDD, and provided help, advice, and opinions to other forum members. Information sharing in the form of advice, opinions, and personal knowledge has been increasingly recognized as important in the diffusion of mass mediated messages (Katz & Lazarsfeld, 1955) and in promotional communication (Hallahan, 2013). Connecting to other people with similar issues can create feelings of belonging, which then becomes the reason for remaining part of the group, and for providing support to others (Tanis, 2008).

**Sharing personal experiences.** Personal experiences were often provided in the initial posts to introduce members to others on the forum. Some of these personal introductions could be extensive in both breadth and depth (700 or more words). Alternatively, other self-introductions could be brief, such as

when a member introduced herself and her social anxiety symptoms, before going on to describe her current struggles with BDD:

**Female 1-OP:** So some background about myself—I've been suffering very bad anxiety since 15. I am 22 now. It never really bothered me because my safety zone was home--my anxiety symptoms usually disappeared when I was at home. Okay, so moving on to problems I am having now!

Galegher et al. (1998) found that most of the personal narratives in Usenet groups were short, coherent, and pointed. This is similar to most of the self-introductions in the study messages, which were brief and focused. However, similar to Walther and Boyd's (2002) findings that online self-disclosures can be extensive in both breadth and depth, some of the personal introductions posted on the BDD forum were also longer (more than 1,000 words) and contained extensive details about the person's background and experiences.

Whereas personal experiences in initial posts served to introduce new members to others on the forum, disclosures posted in the replies helped people relate their experiences to those of others, and to indicate that they either agreed or disagreed with the advice they were given. In the following example, the female poster replied to another member by expressing that she had similar experiences with feeling ugly:

**Female 2:** hi i am sooooo tired of being ugly too. so very tired of it. and its hard a lot of times, when i have to look in a mirror or see a picture of myself and i just really dont want to look at it (my image) anymore. i feel like my soul belongs in a different body, a pretty one.

Sharing similar experiences in replies to members' initial posts is typical in mental health forums because doing so establishes that the person is in no way abnormal and that she or he also suffers from the same condition. Thus, sharing similar experiences fulfils the primary function of the online forum by providing empathy and establishing the normative nature of the experience (Giles & Newbold, 2013).

Another member used his experiences to provide evidence about why advice offered by another poster was not helpful, since he had already read the books that were suggested. He then went on to describe his personal coping strategies, which were not to care about others' opinions:

**Male 2-OP:** I have both the books you mentioned and it didn't do much comfort me other than show me all the other types of bdd that are out there. I did read the book "At Face Value" which

was pretty good as it dealt with a guy that had facially disfiguring cancer and I could relate more to it. The best I can do I guess is just try to not give a \$#%^ about what other people think. I hope some day, I have the emotional strength it takes to be that kind of guy.

The poster above replied to another member by rejecting his advice to read books on BDD. He related more to a story about a person who was facially disfigured due to having cancer. Distancing oneself from others with the same condition is a common coping technique for individuals who feel stigmatized by having a mental health disorder (Chronister et al., 2013).

**Providing help and support.** Members also posted statements meant to help alleviate others' symptoms and suffering. For example, when individuals revealed they wanted to commit suicide, participants usually responded by providing hope and reasons to keep living, as shown in the following statement: "Never give up on you, you are a human being and just doing the best with the knowledge you have, keep going, the days become brighter I promise you." Many members indicated that they appreciated the help and advice that was provided on the forum:

**Male 1-OP:** I would like to say that this is the first time I have tried seeking advice/help from total strangers. I discovered this forum while browsing another website and was astonished by just how big and helpful this community is.

**Offering advice and opinions.** Members also shared advice with others on the forum. Most replies containing advice were offered after individuals shared their debilitating appearance-related symptoms in initial posts. For example, one male poster responded to another's negative BDD experiences by advising the person to get clinical treatment:

**Male 2:** Get treatment. Even if you don't believe me about the way you look, you still recognize that you have a disorder and the distress caused by BDD is unbearable. At least get that distress dealt with. There is no reason you need to suffer through that.

Offering advice and help in response to others' problems with BDD was a common activity on the forum, and advice could be offered even when not directly sought by the original poster. This pattern of offering unsolicited advice in response to personal disclosures was also found on a mental health forum for individuals suffering from bipolar disorder (Vayreda & Antaki, 2009).

Sharing one's opinions also occurred in the initial posts and in the replies. Personal opinions were defined as judgments about the actions, ideas, and beliefs posted by others. One member, who was

convinced he was ugly rather than suffering from BDD, believed that there was one objective standard for beauty. As a result, he replied to the member who wanted to know if she was truly ugly or had BDD by telling her that if she lacked beautiful features, then she was indeed ugly:

**Male 2:** Beauty and ugliness are pretty objective. They basically come down to a few factors: 1. Symmetry 2. Proportion 3. Sexual Dimorphism 4. Coloring (e.g. smooth, even skin or healthy red lips) 5. Low body fat. If you have all of these, you're seen as beautiful. The fewer you have, the uglier you are.

Many posters, like the male above, believed that they did not measure up to societal standards for physical beauty. They believed that only two appearance standards existed: beauty or ugliness. This type of black or white thinking is typical of individuals with BDD (Phillips, 2009). Believing that there is one objective standard of beauty to which one does not measure up is a demonstration of internalized stigma. Internalized stigma is the devaluation, shame, secrecy, and withdrawal triggered by applying negative stereotypes to oneself (Corrigan, 1998).

### **Conversations on the Forum**

Conversations on the forum were evident when one person posted an initial message and other members replied to the original poster and/or other members within the same thread. Most of the initial posts (97.9%) received at least one reply, with the median number being 3 replies per post. Members shared their personal experiences in the initial posts (80.6%); 225 of the 279 threads began with members' BDD-related experiences. In contrast, most of the advice, opinions, and help were posted in the replies, when members responded to questions posed by others (80.4%); 508 of the 632 replies contained statements offering advice, opinions, and help. Only 19 initial posts did not receive any replies; some of these initial messages offered unsolicited advice, opinions and/or help, and in others, members did not clearly ask for help or advice from others.

The conversational nature of the forum was readily apparent in the fact that there were 107 message threads in the study where the original poster (OP) responded to other members (38.4% of the 279 message threads) within the first three replies (others might have responded in subsequent replies not coded in the study). Most of the replies by the original posters were by female members (64 females, 34

males, 9 undetermined gender) and contained answers to others' questions and/or more personal experiences with BDD. Sometimes the original poster also continued the conversation by asking a follow-up question, or expressing gratitude to those who had responded. In 31 of the message replies (27.4%), the original poster thanked other members, as shown in the following example:

**Female 3-OP:** Thank you so much! Logically I know I should go to a doctor about it, I have a lot of symptoms of hypochondriasis that my friends are telling me to see someone about as well, so I suppose I can talk about both when I'm there. I meant to do it today when I was at the doctor for something different, but I got too nervous!

Other posters acknowledged the advice they received and then asked for more advice, sometimes on a different topic. In the following message, the original poster thanked the person for her response, acknowledged that she would use the treatment advice she had received, and then asked for relationship advice:

**Female 3-OP:** Thanks for responding to my post. I will mention it to my therapist next time I go, since this really is a big time waster for me.

I have a question. What do you do if people in your life are unknowingly making you feel bad/self-conscious about your looks? I have dark blond hair, and even when I was younger I remember wishing to be a brunette like the majority of my family. So since I think brown hair is prettier, I already was dabbling in dyeing my hair and stuff. But then I started dating my boyfriend, and he says he thinks brunettes are hotter than blondes. Even though he's said I'm not blond (I disagree, my hair is too light to classify as brown), I still feel like I'm not the girl he'd like to have and I'm not pretty enough for him. I'd like to tell him to not say things like that, but I'll just sound oversensitive. So what do I do about stuff like that?

Most of the replies posted by members were received in a positive manner by the original posters. However, some original posters disagreed with the opinions and advice they received from other members, especially related to their appearance. This occurred when the person posting the message did not believe that his or her perceptions were distorted. The original poster below took issue with another person's assessment that his nose obsession was caused by neurological defects in his brain:

**Male 4-OP:** thanks for your comment again.  
I agree with most of what you are saying. Defect in visual processing does take a large part in BDD but it seems that there is indeed a mild deformation of my nose. . . . I don't think what I am seeing is unrealistic. I could understand that you guys may really have the neurological part in it but for me it would be very tiny to even non-existent.

Disagreements between posters could also arise when one person believed that the advice given by others was not appropriate. Some forum members provided advice that would be considered unhelpful for people with BDD, such as ways to improve one's appearance using steroids, plastic surgery, and dermatological procedures. For example, on the topic of how to deal with being rejected by women, one male poster recommended taking steroids and going to the gym as a solution. A third male poster replied to both the initial and second posters by discouraging the use of steroids:

**Male 3:** That is awful advise to give somebody. If a woman says she does not like a guy who takes steroids then she means it. Taking steroids will NOT make you appear more manly and it won't boost your confidence.  
My advise is, don't take [Male 2's] advise.  
[Male 2], you come across very shallow with every thin[g] you have said.

According to BDD clinicians and researchers, attempts to improve a person's physical features are rarely helpful in alleviating BDD symptoms, and can cause symptoms to worsen (Phillips, 2009). Fortunately, when posters gave poor advice to others, either the forum moderators or other members would offer advice that was more in line with professional clinicians and therapists. For instance, in the previous example, another male suggested that the original poster get clinical treatment to help his symptoms: "Go to a doctor, tell them you have BDD. Its not easy to do but you will never regret it once you finally take that step." Thus, the BDD forum differed from pro-anorexia forums (Haas et al., 2011), where members primarily reinforce rather than discourage harmful behaviors.

Many researchers of online forums and chat rooms contend that they facilitate dialogue, not merely individual monologues (Bambina, 2007; Flynn & Stana, 2012; Giles & Newbold, 2013; Savolainen, 2011). Conversations were evident on the BDD forum where all but 19 of the message threads contained replies, and about one-third were by the original posters within the first three replies. The original posters primarily responded to other members by sharing their personal experiences, and offering gratitude for the advice and help they received. These findings that the forum primarily contained helpful replies to others' posts, rather than statements that reinforced others' poor advice or negative comments, is in line with studies for both physical and mental health conditions (Bambina, 2007; Flynn & Stana, 2012; Mo & Coulson, 2008).

## **Telling Personal Stories**

Beyond self-introductions and sharing personal experiences in the form of anecdotes, participants also shared their personal stories with other members on the forum. These personal stories formed naturally-occurring narratives that contained characters, a conflict, and a beginning, middle, and conclusion. A narrative has been defined as “any cohesive and coherent story with an identifiable beginning, middle, and end that provides information about the scene, characters, and conflict; raises unanswered questions or unresolved conflict; and provides resolution” (Thompson & Kreuter, 2014, p. 1). Twenty-three personal narratives were identified in the study, and one of the narratives was considered a second story that echoed the ideas in the previous post. Few studies have researched naturally-occurring narratives in forum conversations (Giles & Newbold, 2013), most health communication studies focus on the impact of constructed narratives within media campaigns (Kim, Bigman, Leader, Lerman, & Cappella, 2012; Slater & Rouner, 2002).

Twenty-one members (16 females and 5 males) posted personal stories on the forum. Most of these “storytellers” posted between 1 to 14 messages coded for the study. However, one of the storytellers posted 46 messages; she was one of the five most frequent posters in the study (see RQ4). The storytellers posted narratives that contained past events, characters (including family members and significant others), and conflict situations that concluded with their seeking or providing support to others.

Based on the content of the posts, there were three primary reasons that storytellers came to the forum to post messages: first, they came to share their stories in an anonymous setting without fear of being stigmatized; second, they came to seek help and advice from others who understood their struggles; and third, they came to help others by sharing their stories about recovery from BDD. The veil of anonymity on the forum enabled storytellers to reveal their most intimate feelings without the stigma of sharing them with friends and loved ones. This was especially important for individuals in the study since family members and friends often could not understand the reasons why they felt ugly, when they often looked objectively attractive.

**Introducing the scene and conflict.** The storytellers typically started their narratives by introducing themselves and/or describing the story scene and conflict. For all but one storyteller, who posted a story about his recovery, the conflict involved the suffering caused by their BDD symptoms. In the following two examples, the female storytellers started their narratives by revealing that they were alone and struggling with negative emotions:

**Female 1-OP:** I'm new and have not posted in this forum before. First off, my sympathy to anyone who has or may have BDD. I'm sending you all good thoughts.

I think I have Body Dysmorphic Disorder. I am at the point where it is making me think about killing myself. If my family or friends knew what I was thinking they would hit the roof.

**Female 1-OP:** Hello, I just found this website because I am at a low point right now and want to talk to people who understand... My boyfriend is out of the apartment for the weekend so I have spent a good amount of this time just staring in the mirror and recording video after video of myself. . . I can't stop crying, I feel like I'm going to throw up. And I have to be to work in less than 2 hours, I'm scared to know how that's going to go with me being so emotional.

The two storytellers above also introduced the conflict situation: the first person was thinking about killing herself, and the second was depressed and worried about her emotional state. In addition, they set the scene for the stories: the first poster was alone in her suffering because she had not shared her suicidal thoughts with family members and friends; and the second was alone because her boyfriend was out of the house for the weekend.

**Describing the characters.** Most of the storytellers cast themselves as the protagonists, with parents, friends, and peers at work or school as the antagonists. The exception was one male poster who told a story about his girlfriend with BDD, and asked members for help and advice. The other storytellers revealed that family members either did not understand their condition, or contributed to their symptoms.

One storyteller attributed her body image disorder to comments from her father about her weight:

**Female 1-OP:** I had an eating disorder when I was 16, and ended up extremely sick. My dad encouraged it by telling me "You'd be so much prettier if you weren't so chubby" and similar things. And when I finally started losing a ton of weight (I was 125 originally mind you) My dad would tell me how I was so pretty etc. The positive attention caused me to continue and get worse.

Significant others provided support that was well-meaning but ineffective for relieving appearance concerns. One poster's boyfriend advised her to get help for bipolar disorder: "My boyfriend has told me many times that he thinks that I'm bipolar because of the extremes which my mood changes between. Of course, he couldn't possibly understand why my mood changes."

**Resolving the conflict.** For most storytellers, the resolution to the conflict they described was posting to the forum and asking for help from others who understood their concerns. One of the frequent posters wanted to know who she could turn to when she feeling suicidal, since she did not want to burden her boyfriend and her friends did not know about her condition:

**Female 1-OP:** I have no friend who knows about my BDD, I cannot take the load out, I am exploding. Where should I turn in emergencies like this?? I was seriously scared today of my mental health. I am preparing for a long sleep now, and avoiding all contact what so ever with talking to boyfriend again tonight. I must straighten my suicidal mind up!! \$#%^!!! . . . Come to think of it, this was the reason I joined the forum in the first place. I was at bottom of frustrations. But its different today, today its like I have realized there is....no....way....out..... Pretty please, anyone give some hope..?

Thirteen of the 21 storytellers ended their posts by expressing how distressed they were, verging on suicidal. The moderators, most frequent posters, and other members responded by offering advice, sympathy, and empathy for their struggles. The most frequent poster responded to the previous storyteller's plea by suggesting that she get some sleep and tell a friend or family member about her condition. Another poster suggested that writing down her thoughts could be beneficial, especially on the forum where "everyone understands your struggles." In response, the female storyteller thanked them both and wished them good night:

**Female 4-OP:** Really thank you for taking the time to reply and trying to give some relief, I dont think as you say that any friend could in the end possible relate. Wish you both a good night..

**Recovery from BDD story.** One of the male storytellers posted a narrative about his hair loss obsession 2 months after he started therapy; later he posted another story discussing his recovery after 6 months of therapy. The story started with his past struggles, described how he had had a mental breakdown, went to therapy, and was overcoming the symptoms of BDD with medication and clinical treatment. He concluded his story by confirming that the positive outcome had been worth the effort:

**Male 1-OP:** So, what do i think of the treatment i received? It worked. I still take medication everyday but i haven't been to my therapist in over a month, and for a long time, i was going less and less, because i didn't need to. Still some minor, lingering symptoms but i don't feel like i have BDD anymore. I am happy and calm and this is the best my life has been for years. It isn't easy but even if it had taken 10 years, it would have been worth it.

The male storyteller above used the forum to document his struggles but also his success with therapy. He could have served as a positive role model, thus increasing the chances that other members might also seek clinical treatment. One of the strengths of narratives is their ability to engage audiences; research has found that compared with predominantly informational methods of presentation, narratives can lead to stronger emotional reactions, greater identification with the person sharing the messages, and increased engagement (Thompson & Kreuter, 2014).

**Second story.** There was one second story identified in the study, which is defined as a personal story that follows another story in a sequence in order to demonstrate empathy and understanding with the first storyteller. Second stories “echo” previous stories by referring to and elaborating features of earlier stories (Giles & Newbold, 2013, p. 486). The second story posted to the forum echoed another member's desire to be “the most beautiful woman in the world” for her boyfriend:

**Female 2:** Your text really struck a cord with me, because you've expressed very well what it's like. Isn't it weird how a person, probably on the other side of the world, can express exactly how you feel yourself?

I have the same problem in my relationship right now (it's my first and I'm 24). With wanting to be the most beautiful girl in the world / for my boyfriend, completely crashing down as soon as you see a beautiful women leaving you feeling completely worthless, and the porn thing. The problem is my boyfriend is quite a good looking guy with lots of money, who's had a model ex (6ft tall, blonde, skinny) and who once told me that my body wash't up to scratch (weighing 114 pounds).

The female poster then described her most recent issue with her boyfriend; she had asked him to help her by giving her compliments but he had refused, so they had gotten into a “big fight.” She continued the story by disclosing that her boyfriend also liked to watch porn. This was a problem because it impacted her self-esteem:

And then the porn thing, I sorta get it, I really do, when it applies to other people. I would never tell another women that it's because there is something wrong with her, for him it's probably just a form of foreplay. But when my boyfriend does it it makes me feel so \$#%^ about myself. Because the women in those movies are not beautiful, they're trashy and usually not even fit. But

then again, he has cheated on me with a prostitute once (as I know of, could be many more times). Even though, at that time, I has sex with him up to 6 times a day whenever we met, all just to please him and make him not stray (my father destroyed my family and left me after having cheated on my mother, and after that didn't want any contact with me).

She ended her story by complimenting the previous poster on her ability to express herself, and noted that she valued intelligence in other people, but could not see value in her own intelligence. This self-deprecating comment concluded her narrative about herself and her adulterous boyfriend:

I don't really know what to say to you, just that you're obviously very intelligent being able to express yourself the way you've done. And I know that it seems that in this world that counts for nothing, but for some people it does. For me it does. Just not when it comes to myself.

About half of the message replies in the study contained personal experiences that echoed those of the original poster (41.3%). However, only one poster in the current study shared a second story that formed a narrative, containing a conflict, characters, and a conclusion. This finding indicates that exchanging personal experiences is a common activity in online forums, but sharing naturally-occurring narratives is rare. Recovery groups, such as Alcoholics Anonymous, use second stories to reinforce that members share the same struggles (Sacks, 1992). In online forums, posting experiences that echo those of other members may serve the same purpose, without requiring a narrative format to be effective.

Narrative researchers argue that there is value in studying the "small stories" that people share about their daily experiences (recent events) in naturally occurring conversations (Bamberg, 2011; Georgakopoulou, 2006). These small stories are contrasted to "big stories" or life narratives that are commonly elicited through research interviews. Small stories are considered valuable to study because they help people to form a self-identity, and in the case of the forum, they reinforced that individuals shared common experiences with other members.

### **Summary of Findings about Communication Activities on the BDD Forum**

The primary communication activities on the BDD forum were (a) asking about the personal experiences of others and seeking support, (b) sharing one's own personal experiences and providing support (c) engaging in conversations, and (d) telling personal stories. The communication strategies employed by individuals included asking direct questions to solicit others' experiences, help, advice, and

opinions, as well as seeking help and advice indirectly by expressing uncertainty and doubt. Participants also shared personal experiences, help, advice, and opinions with other members. Sharing personal experiences can also be considered a way to indirectly seek support from others (Bambina, 2007; Eichhorn, 2008; Tichon & Shapiro, 2003).

Participants' motivations for posting to the forum were usually not disclosed. However, thirteen members included information about why they posted messages in their self-introductions. One member wanted to contact others with BDD: "I'm totally new to this forum. I found it through google searches on BDD, and thought it would be a good way to contact others who suffer from this disorder." Another member indicated that she had been lurking for a while and decided to post a message on her journey towards recovery: "After reading this forum for a while I feel strong enough to reveal my problems although i'm ashamed of it as well."

Dholokia et al. (2004) found five primary motivations for consumer participation in online communities: purposeful value; self-discovery; maintaining interpersonal connectivity; social enhancement; and entertainment. Individuals who posted to the BDD forum did so to find others who understood their experiences and to seek and share support. Thus, the motivations for posting to the forum include purposeful value (seeking and sharing others' experiences), for self-discovery in terms of writing down one's experiences and comparing one's experiences with those of others, and for maintaining interpersonal connectivity by seeking and sharing support with other members.

The current study also adds to research on naturally-occurring narratives in online support forums, since the stories identified in the study adhere to the definition of a narrative provided by Thompson and Kreuter (2014). Personal narratives are differentiated from personal anecdotes, which do not have a narrative structure. The storytellers in the study shared their struggles with BDD and their desire to overcome symptoms in order to feel normal again. The members who posted stories about trying to recover and about overcoming BDD symptoms could have served as positive role models for change (Thoits, 2011) since they were actively engaged in coping with the disorder.

## **RQ2: Personal Experiences Disclosed about BDD on the Forum**

Research Question 2 asked what personal experiences with BDD individuals disclose on the forum. Personal experiences include a person's feelings, thoughts, and behaviors about oneself and life events (Derlega et al., 1993) that they self-disclose to others. Three-quarters (76.9%) of the messages posted to the forum contained members' personal experiences with BDD symptoms, including feelings of self-hatred and shame. The personal experiences requested and disclosed on the forum were focused on three broad areas: peoples' appearance-related feelings, thoughts, and behaviors (impact on self); BDD symptoms and social relationships (impact on family, friends, dating/relationships, job/career); and recovery from BDD (diagnosis, treatment, coping, overcoming symptoms). Comments about one's appearance were more prevalent in the study (360) than those about the impact of symptoms on one's social relationships (197), and about recovery from BDD (300). The results for the symptom-related comments are presented first (appearance-related concerns, behaviors, and impact on personal life) in order of prevalence, followed by the recovery-related comments (diagnosis, treatment, self-help and coping strategies).

### **Appearance-related Disclosure**

Most individuals in the study were extremely preoccupied with perceived defects or flaws in their physical appearance. Forum members often disclosed feeling ugly and expressed dislike or hatred either towards their overall appearance, their face and/or body, or particular features. This finding aligns with the key characteristic of the disorder, which is classified by a preoccupation with appearance flaws that cause clinically significant distress and impairment in social situations (APA, 2013). Similar expressions of self-loathing (focused primarily on weight) were present on pro-anorexia sites that encourage disordered eating behaviors (Chang & Bazarova, 2016; Haas et al., 2011).

**Appearance-related concerns.** The most common appearance-related concerns disclosed in the study, in order of prevalence, were about one's face, facial features (head, skin, nose, jaw, teeth, and hair), being generally ugly, and one's body shape and size. Individuals described feeling ashamed, angry, and

suicidal about their appearance, seeking or having plastic surgery to fix perceived appearance flaws, and behaviors such as mirror checking, reassurance seeking, and social comparison.

Feeling ugly and hating one's appearance. Members frequently disclosed feeling ugly and hating their appearance. The belief that they were ugly and/or physically disfigured resulted in participants feeling anxious, depressed, and ashamed about their appearance. The following female poster believed that she was ugly, and as a result, that she would never have a boyfriend. She was obsessed with looking in mirrors and wanting to change herself because she felt inadequate. These thoughts resulted in her feeling "sick" and depressed about her condition:

**Female 1-OP:** Hello everyone i suffer with BDD. I am a very ugly looking person and feel that i will never have a boyfriend as i look so horrible. I am a young person from London. I always feel inadaqaute and whatever i do is not good enough and i always have to keep looking at mirrors etc not because i am happy with my image it is that i am unhappy and want to change myself all of the time. I just feel so sick with these thoughts.

The obsessive thoughts that are characteristics of BDD do not have to be focused on specific facial features or body parts (Phillips, 2009). The perceptions of ugliness can be all consuming and result in feelings of hatred for one's overall physical appearance.

One female poster could not name any one thing she hated about herself, since she hated everything, and listed all her perceived flaws. The parts of her body she wanted to fix could change from "week to week." This illustrates how persistent and pervasive BDD thoughts can be. As a result, she felt that life had "passed her by" and she had nothing to look forward to:

**Female 2:** For me I hate everything about myself. I'm ugly and weird looking. I couldn't even begin to list everything I would change it really is everything. I do get more obsessive about certain parts but it can shift and change week on week. For me I hate my nose. It's wonky and to the side. I hate my hairline, it's too high and weird. I would like a hair transplant. I would like laser on my skin as it's awful with spots and broken veins. I would like an eyebrow lift as I don't like my eyebrows. I'd like filler in my eyebags, round my mouth and in my lips. I'd also like lipo on my jaw and a chin implant. At my most extreme point I also wanted jaw implants and cheek implants but I've got past this now. I hate my boobs as my nipples are too low so I'd want an uplift. I would like liposuction on my legs as well. I hate my legs, i have broken veins, stretch marks and short fat legs. I'm absolutely obsessed with wrinkles around my eyes and as I'm getting older i'm petrified of ageing. I currently have 7 eye creams that I use numerous times a day. I'm afraid of smiling and am obsessed with lighting. I can't even watch certain programmes on tv as it triggers my obsessions. I feel life has passed me by and there is nothing to look forward to.

Like the two female posters above, individuals in the study often expressed feelings of self-hatred and shame due to perceiving themselves as ugly or physically unattractive. However, some posters were not convinced they were ugly, but felt that people judged them on their appearance. Thus, their perceptions of their body were based on how they believed others viewed them.

In the following example, a female poster was convinced that people were calling her ugly in public. She asked others on the forum if they had similar experiences and wanted them to explain why this occurred:

**Female 1-OP:** Does this happen to you where people will say you are ugly in public? It has happened to me several times in my life. I don't even find myself that ugly, why would this happen to me? The thing that upsets me the most is when little kids say it because I know they really mean it. Adults say it to me too and sometimes pretty girls will laugh at me like they feel bad for me. I get so angry but that makes people even happier. Does this happen to anyone else? Does anyone have any idea as to why this would happen to someone? Trust me, i'm not THAT ugly. It has taken its toll on my self-esteem and my gender life - but that's another story.

The uncertainty about why people were calling her ugly in public caused the female poster above to seek answers from other members. She was hoping to find other members who shared her same experiences, or could tell her why it was happening. Asking questions and/or disclosing personal experiences to encourage others to share information (Berger, 1979; Berger & Calabrese, 1975) is a common method that individuals use in order to reduce uncertainty about a situation or another person.

The desire to find others who could understand one's appearance concerns was one of the primary reasons that individuals posted messages to the forum. Another question that a male poster had was why the thought of being ugly distressed people on the forum so much. The reasons given by participants revolved around wanting to be loved and accepted, rather than rejected by other members in society:

**Male 1-OP:** I am interested to hear what it is about being ugly that distresses people so much. I am not saying anyone here is ugly, but that is what we fear. What is it about being ugly that distresses you so much?

**Male 2:** The fear of being embarrassed or outcast, I think the fear of somebody seeing your flaws which you try to hide, that would be the worst kind of distress.

**Female 3:** i am trying to figure that out as well. being ugly to me, means being un wanted, unloveable. For me, I put so much emphasis on looks, and my looks put all the weight on my

worth. I feel like because I'm ugly I have no importance in this world and that I won't be successful. Yet at the same time, the rational part of me knows that isn't true. Looks aren't everything. Ugly or beautiful, everyone is important and beautiful in their own way. I think a lot of people with BDD, including myself just think that in order to be happy, we have to be beautiful. It's a vicious cycle.

**Undetermined 4:** OK, well my BDD was spurred by very chronic bullying which started about 5 or 6 years ago (I'm 15 now). I suppose the prospect of being ugly distresses me so much simply because of the fear of rejection, (like the bullying).

Many individuals in the study, such as the posters above, feared being rejected due to their perceived ugliness. These feelings could have been caused by the social stigma placed on individuals with physical deformities. Stigma has been defined as an attribute that is deeply discrediting to a person's social identity (Goffman, 1963). Participants in the study with BDD symptoms believed that their appearance was disfigured in some way and thus feared rejection by "normal" members of society.

Appearance concerns affected both men and women in the study, including feeling ugly and hating one's perceived appearance flaws. According to BDD researchers, some concerns tend to be more prevalent in males compared to females, such as fear about hair loss (Phillips, 2005). This was evident in the study when male forum members specifically addressed concerns related to hair loss. The following male poster knew that his thoughts about balding were irrational, but he was unable to extinguish them. He was in therapy for BDD, so had awareness that his perceptions were not true, yet he was still worried about losing his hair. He believed that the reflection he saw in the mirror was accurate because the mirror "can't" lie:

**Male 2:** My BDD involves hair loss. This has been going on since I was 15 years ago, I'm 25 now. Even though hair loss in ones mid-teens is extremely rare, even though my hair hasn't seemed to change at all in the past decade, even though everyone I know says that I am not going bald, even though I have been to a doctor who said I show no signs of hair loss, even though I have been diagnosed with BDD and told that I have severe perceptual distortions, it is still hard for me to believe that I am not losing my hair most days. Because what I see in the mirror is reality. How can it not be? I know what I see, the mirror can't lie.

The thoughts about losing his hair caused him extreme anxiety, despite the fact that most of the time he and others did not perceive that his appearance had changed. This example indicates that although people with BDD can acknowledge that their thoughts are irrational, that knowledge does not stop the thoughts

from occurring (Phillips, 1996/2005). Thus, having good insight (APA, 2013) that a person has BDD symptoms does not by itself help a person overcome them.

Body appearance obsessions (size, shape, weight, height) afflict both men and women with BDD (Phillips, 2005). Individuals may feel they are too fat or may be concerned about looking too thin. One of the male participants lost weight and felt better about himself, but thought his head looked too large for his body as a result. He disclosed his concerns and then asked if others on the forum had similar experiences and how they had coped:

**Male 1-OP:** The problem is, even if I in a way feel better about myself and think my body looks better, I don't feel like everything adds up. I feel very weird now when I look at myself and like something is wrong. I don't know if this is just because it takes time to get used to it? One thing I've been thinking is that my head vs my body looks odd now, I have a pretty big head and so I feel it looks weird on a smaller frame than when I was bigger overall.

I want to know if other people here has been through some similar experience when losing weight and how it turned out for you, was it a temporary issue with getting used to your new looks or has it caused problems for you ever since? How did you cope with it?

Another female poster had also lost weight and had a "perfect BMI" yet was still obsessed about her appearance. She received lots of compliments about her body, but felt anxious because she still had terrible self-confidence, and constantly talked about her concerns with her friends, family, and boyfriend. This caused her more anxiety because she was afraid that they did not understand her behavior and thought she was looking for attention. She started the post by asking for others to share their stories and experiences related to BDD:

**Female 1-OP:** I guess I just really would love to hear some of your stories, personal experiences, and habits all related to BDD.

I'm a 20 year old girl who really has nothing she should be complaining about at all (and this just makes me feel even more selfish for feeling so terrible at times). I guess I should start by saying I was bullied throughout all of my school years for my weight. After leaving school, I lost it all. Now I have a perfect BMI, receive many compliments from people, yet I still have.. just plain awful self-confidence. ☹ . . . I can't go five minutes without thinking about my weight, I always talk about it to my friends, family and boyfriend (this causes me more anxiety sometimes just because I'm afraid they don't understand and think I'm looking for attention), I feel severe guilt for eating anything I deem as bad food and I work out obsessively.

Like the female poster above, other people in the study were also afraid that family members and friends would think they were seeking attention if they continually talked about their appearance concerns.

People with BDD may fear that seeking assurances from others will be mistaken for vanity, and so do not disclose the real reasons behind their concerns to family and friends (Phillips, 2009). In these situations, one's secondary group (Thoits, 2011) may be able to provide better support due to sharing similar appearance concerns.

**Feelings of guilt, anger, and acceptance.** As shown in the previous examples, feeling ugly and being obsessed with perceived appearance flaws caused individuals to feel extreme self-hatred, shame, depression, and anxiety. Other notable responses were guilt about being the cause of one's flaws, anger at being rejected by others, and acceptance of one's ugliness as a blessing from God.

A young man felt extreme guilt because he had tried to fix moles on his face with a commercial product that left "4 large noticeable scars" instead. He recalled getting advice from a dermatologist to leave the moles alone, but had persisted and now experienced "thoughts of extreme guilt" about what he had done. He had spent "a couple thousand dollars at a plastic surgeon" trying to remove the scars. The guilt and regret about his actions left him suicidal and depressed more than 2 years later:

**Male 1-OP:** Before I decided to do this, I had gone to a dermatologist to remove them [moles]. She told me not to do it, that it was not worth it, that the scars could look worse; her words have been echoing in my mind ever since. So, I put this cream on all 4 moles (all on the right side of my face, except 1 on the tip of my nose) because the dermatologist would not do it herself. Needless to say, the cream left 4 large red craters on my face. After that, people just stared at my face (especially family) wondering what the hell happened. My mother even at one point told me I ruined a "beautiful" face. Since then, I have spent a couple thousand dollars at a plastic surgeon, trying to remove my mistakes. Not a day goes by when I'm not kicking myself for what i've done;

Other participants who felt they were ugly as a result of their fate, rather than their actions, responded with anger and frustration. The desire to vent one's negative feelings without asking for support did occur in some messages coded for the study. For example, venting emotions is considered to be a common coping strategy for individuals suffering from stressful situations (Lazarus & Folkman, 1984). Venting one's emotions has been found to result in both positive and negative adaptive outcomes (Wright & Rains, 2014). For women in a breast cancer online support group, venting anger and sadness resulted in less depression and a higher quality of life after six months of participation, whereas expressing anxiety had the opposite effect (Lieberman & Goldstein, 2006).

In the following example, the female poster used all caps to emphasize the extreme frustration and anger she felt about her fate, and her horror at the “monster” staring back at her in the mirror:

**Female 1-OP:** I am ugly, I am hideous, SO STOP LYING!  
If I wasn't men would at least give me a glance.  
If I wasn't people wouldn't look at me with that horror look on their face.  
If I wasn't I wouldn't see These DARK , DARK PURPLE RINGS AROUND MY EYES THAT  
MAKE ME APPEAR TO BE DEADLY OR SERIOUSLY ILL!  
If I wasn't I would be desired by men . Or at least Lusted after.  
I would have friends.  
I wouldn't see what I see in the mirror.  
A monster staring back!  
SO BEFORE YOU TRY TO MAKE ME FEEL BETTER BY TELLING ME I'M NOT UGLY...  
spare me.  
Because I already Know I am.

The female poster above did not receive any replies to her message during the study. Angry posts or posts without a clear request for help were often ignored or engendered few replies from forum members. This example indicates that even among the “in-group” of weak ties (Granovetter, 1973, 1983) on the forum, there were accepted social norms that guided when support would be provided or withheld from other members. This is consistent with findings that turn-taking in conversations generally requires a question to be the stimulus for a response (Sacks, Schegloff, & Jefferson, 1978). The female poster clearly indicated that she believed she was ugly and did not ask for help, leaving forum members with few options to help ease her suffering.

Rather than lashing out in anger and frustration at her fate, one of the participants tried to accept her perceived ugliness as a blessing from God:

**Female 2:** well.....i am trying to learn to wear my ugliness as a badge of honor, which is extremely hard to do, but i definatly think God made me ugly because he wanted to bless my **soul**. not my outer body which will rot someday, but my soul. i wish that all “ugly people” would be able to “wear their ugliness as a badge of honor”.

She was deeply religious and compared herself to Jesus, who was also one of the “ugly people,” and a social outcast:

God thought i was special enough to be ugly like Jesus was, and to learn the life lessons that many beautiful people will never figure out (like how to treat other people regardless of how they look, like how badly it hurts to be judged on something you can't control, like how it feels to be a social outcast). ooooooh yes i think that God loves ugly people, God loves an underdog.

The female poster above identified herself as a “social outcast” due to her belief that she was ugly, but she choose to accept her fate as a blessing from God. Acceptance of one’s stigmatizing condition as a “blessing in disguise” is another coping strategy that people may use (Goffman, 1963): “He may also see the trials he has suffered as a blessing in disguise, especially because of what it is felt that suffering can teach one about life and people” (p. 11). However, for some individuals in the study, their suffering was too great to accept or ignore. The desire to alleviate their negative thoughts and feelings led some individuals in the study to consider suicide as a last, desperate solution to end their suffering.

**Suicidality.** The desire to ends one’s suffering by committing suicide was a reoccurring theme in messages coded for the study. This finding reflects the high rate of suicidality found in people with BDD symptoms. Available evidence indicates that approximately 80% of individuals with BDD experience lifetime suicidal ideation and 24% to 28% have attempted suicide (Phillips, 2007). The desire to commit suicide was fueled by a range of emotions including shame, depression, guilt, and anger. Shame was based on feeling that it was wrong or selfish to be so focused on one’s appearance. This is referred to as the “double whammy” of BDD: people not only have distressing thoughts they cannot control, but they also berate themselves for having those thoughts (Phillips, 2009, p. 61).

The “double whammy” of hating oneself both for one’s perceived flaws and for being so focused on them can make it almost impossible for those with BDD to disclose their deepest fears to others, such as family and friends. One female participant felt like an “idiot” for hating herself due to her appearance flaws, and the same time, admitted that she felt too ugly to live:

**Female 1-OP:** I hate the way I look, and I am starting to hate myself for looking this way. I don’t hide away all the time. Although sometimes I do. I will lie to my friends and say I’m not around when they want to meet up, because I can’t handle what seeing them does to my self-esteem on a given day. Whenever I see them, however I might be feeling that day, my self-esteem will always shoot down 100% because I am reminded that they are beautiful, I am ugly, and that is how it will always be. I rue the day I joined Facebook, because now my stupid face and body are there for the world to see. I feel like an idiot for saying what I have just said, because I have studied psychology, philosophy and education in quite a bit of detail, and I know that there is so much more to our existence than what we look like. I am going to die someday, so why am I wasting my life feeling like this? The problem is that I feel too ugly to live.

A male forum member disclosed that thinking about his kids kept him from committing suicide. His greatest fear was that he was obsessed with his appearance and was also physically ugly. He felt self-loathing, hatred, and suicidal about his looks, interspersed with periods of acceptance. He ended his post by sharing his “love and support” with others who were also dealing with self-image issues:

**Male 1-OP:** I definitely have suicidal thoughts quite a bit. That is scary. Most of the time it is thinking about seeing my kids the next day that keeps me going. [...] I oscillate between hatred/self-loathing/suicidal thoughts and getting by acceptance. Never better than that. Stress exacerbates the problem. Of course, my fear is that yes, I am obsessed with my looks but I am also \*right\* about my appearance. you can be both you know and that is my greatest fear. My love and support to anybody else dealing with these self image issues. Most of the participants who had plastic surgery were dismayed and suicidal due to the results. In

the first example, a male forum member disclosed that he would never forgive himself for getting plastic surgery to trim his jawline. The outcome left him more distressed about his appearance. He wanted to get a second procedure to fix the first, and planned to kill himself if that failed. He felt that the surgery had left him uglier than before:

**Male 1-OP:** I feel like I will never forgive myself. I've been told I'm attractive my entire life. But I obsess over certain features on my face that I hated. My nose, my flat cheeks, my jawline. I impulsively decided to get a plastic surgery procedure to trim my jawline. Yes, I cut off my freaking bones. And I really regret it. I used to have a strong, defined jawline. Now it's weak and uneven with a droopy chin. I look like I aged 10 years. I don't know how I will ever forgive myself. I am going to try to get reconstructive surgery next month. If I can't improve it, I have planned to kill myself in the next few years. I will probably drive my car off a cliff and pretend it was an accident, and give all my assets to my mom. I can't imagine living with this face anymore. This face I destroyed. I was born with it, I could accept it. But because I paid \$\$\$\$\$ to alter it and ruined it, it now looks unnatural and weird and NOT ME. I don't think I can ever accept it. I wake up every day wanting to die. I look in the mirror and have panic attacks. The only way out is to end my life. I'd rather be dead than live with this ugly face I butchered.

Another member responded and echoed the concerns of the original poster about wanting to get a second procedure to fix the results from the first surgery. These types of responses were considered to be second stories by Giles and Newbold (2013). She was also suicidal and believed that the plastic surgery had left her face unrecognizable. Both her mother and psychologist recommended that she not get a second surgery but she could not “get her life back on track” after the first surgery and hated the results:

**Female 2:** oh my gosh me too I'm feeling the same way - I got a nose job and I hate it so much. It's not me anymore in the mirror. I can't deal with this change and I think about suicide every day. I did not know that I should not have done this but when I think back, I see all the signs for someone who should not have plastic surgery. I don't know how to deal with it and all the advice I get is to move on and accept it but when I look in the mirror I just can't. I don't feel like myself even when I'm not looking in the mirror because when people look at me now I'm wondering what they see. It's so strange and horrible. I can't get my life back on track. I want a revision so bad but my mom said I should not and my psychologist said that will not make me happy and they sound like they are right but I can't be happy with this.

Both of the previous participants were dismayed at the results of their plastic surgery because the image they saw in the mirror was now unrecognizable. The second member's post expressed empathy and understanding with the suicidal feelings of the original poster. This is one of the disadvantages of online support groups; members often reinforce negative feelings and behaviors shared by others. In a similar manner, individuals in studies of pro-anorexia (Haas et al., 2011) and self-harm websites (Whitlock et al., 2006) disclosed potentially injurious behavior that was echoed by other members; therefore these members served as models for risky health behaviors.

**Compulsive BDD behaviors.** The desire to change one's appearance using cosmetic surgery was commonly disclosed on the forum, along with other BDD-related behaviors, such as checking one's appearance in mirrors and photographs, questioning others about perceived flaws (reassurance seeking), and comparing one's appearance to others (social comparison). According to Goffman (1963), another way that individuals with a physical deformity (or in the case of BDD, a perceived physical deformity) try to cope with their condition is by having plastic surgery to correct the defect.

**Plastic surgery.** Some members on the forum endorsed having cosmetic surgery as a way of feeling better about their appearance, despite the poor outcomes expressed by the posters above. However, forum moderators and others reminded people that plastic surgery was not recommended by professionals to fix their appearance concerns. BDD researchers have found that even when surgery is successful and individuals feel better about one part of their body, the image obsession moves to a different body part or parts (Sarwer & Crerand, 2008). This was the concern expressed by a one of the frequent posters who had contemplated fixing his nose with surgery:

**Male 2:** i think about surgery often, but i've been regularly told that it won't achieve anything, one way or another i will scrutinise something else. It's the nature of the business and i had a think about it the other day, if i fixed my nose i would probably move onto my ears or something even though i have very little issue with them right now.

Other study participants wanted to find out if having surgery would help ease their BDD-related thoughts and feelings. In the following example, a male poster wanted to know if anyone on the forum had plastic surgery and liked the results, or had surgery and was "LESS" upset with how they looked. Another member replied that he had had multiple procedures and did not feel worse about his appearance. However, he still believed that he was "dog ugly" and admitted that the surgeries had not helped his BDD:

**Male 1-OP:** My question is: has anyone EVER had surgery with BDD and liked the results? Scratch that, has anyone ever had surgery with BDD and been unhappy with the results/preoccupied with something else but overall LESS upset with how they look?

**Male 2:** I guess the best way to put it is that I have, for , 50 flaws that I feel make me god awful ugly. So I try to go down my list and correct each one. And yes, I have had extensive cosmetic surgery to correct many of my flaws with great success. Do I still have bdd after all the surgeries and procedures and alterations? Yes. Why? Because I may have only eliminated 20 or so defects off my list, so I still believe I am dog ugly, but not as severe as before my "transformation". I do not feel my surgeries have worsened my bdd.

Another poster also responded and warned that she had gotten a rhinoplasty procedure that made her feel worse about her appearance. She had wanted to be "beautiful naturally" but getting the surgery had dropped her self-esteem, which was why she joined the forum. She realized in hindsight that plastic surgery could not make anyone more beautiful:

**Female 3:** No, I got a rhinoplasty in November and its made my face worse. I'm disgusted with plastic surgery. In fact, the rhinoplasty has dropped my self-esteem 10-fold and that's why I'm on here. I remember being insecure, but the plastic surgery has made me so much more insecure. I was hoping to become more beautiful naturally, as I seemed to be doing in my late 20's but it seems to be going backwards again, i'm 32. Plastic surgery can't make anyone beautiful, I never saw that before, it just isn't possible.

Despite their attempts to fix their perceived flaws with plastic surgery, most participants ended up feeling worse after the procedure(s). Another compulsive behavior that can leave people with BDD symptoms feeling trapped in their perceived ugliness is the habit of checking mirrors and photographs to find out if one's appearance has changed for better or worse since the last encounter.

**Mirror and photograph checking.** Individuals in the study often had a love-hate relationship with mirrors and photographs. They reported spending hours studying their reflection in mirrors and obsessing about their perceived defects. The key reason was their belief that the mirror “doesn’t lie,” so even if they liked some aspects of their appearance, looking in mirrors caused them to see their “true” ugliness. Studying one’s image in mirrors and other reflective surfaces is a common BDD-related behavior: researchers have found that 87% of people with BDD undertake this behavior (Phillips, 2009).

The following examples illustrate the mirror obsession/mirror avoidance cycle that some individuals with BDD undertake, and the ritual of comparing one’s image in mirrors and photographs. The original poster asked if anyone else on the forum had trouble knowing what they “really” looked like. She felt that she did not “look human” in photographs but could look pretty in mirrors:

**Female 1-OP:** Does anyone else on this forum almost have trouble knowing what they really look like? There are days I can look in the mirror and look pretty, and then have my photo taken and see the photo and look grotesque. . . I want to cry every time I see a photo of myself next to a friend and I realize that I don’t even look human. It is so confusing to me, like every day I look different, but the way I look is so fragile that if the weather is off or if I eat something heavy my appearance completely changes. And then there is the fact that I look completely different depending on the mirror I am looking into.

In contrast to the poster above, who felt she looked pretty in mirrors, another female responded that she hated looking at her reflection in the mirror. Doing so caused her to spiral into a manic depressive episode that would leave her sobbing all day long about her body and her life in general. She was caught between not wanting to be seen in public due to her appearance, yet felt even worse if she stayed inside all day:

**Female 2:** I also have phases of ‘mirror obsession’ and ‘mirror avoidance.’ I have periods where I deliberately don’t look in mirrors or any reflective surface because I know I’ll be sucked into that whole cycle of mirror checking, and I can’t take it. But of course sometimes I’ll catch sight of myself, be really shocked by how ugly my body is (or legs, in particular) and it’ll send me spiralling into ‘manic depressive’ episodes where I’m just sobbing all day long about how I look, the pain of living in this body, and usually my life in general and how \$#%^ it is, for instance being too afraid to leave the house, yet feeling even more depressed if I stay in all day).

The mirror often became a trap that caught individuals’ attention for hours at a time. Another trap was becoming obsessed with how their image could change in photographs compared to mirrors or other reflective surfaces. The uncertainty caused by the difference between their perceived appearance in

mirrors and photographs caused some individuals to ask family members and friends to confirm whether they were truly ugly, or if their perceived flaws were real. This behavior is referred to as reassurance-seeking in the BDD literature (Phillips, 2009).

**Reassurance-seeking behaviors.** Reassurance seeking about one's appearance is one of the compulsive behaviors characteristic of the disorder. However, providing assurance that the person looks fine rarely helps and often leads to more reassurance-seeking behavior (Phillips, 2009). Participants in the study seemed unable to reconcile the image in the mirror with the kind words they received from family members and friends. As a result, like the following male poster, people came to the forum to "get some advice from people who have experienced this as no-one else I know can comprehend what I am going through right now."

Most loved ones confirmed that members looked pretty, handsome, and even beautiful. Unfortunately, such responses were often met with disbelief; people thought others were lying in order to make them feel better. Forum members wanted to believe what they were told but their reflections in mirrors seemed to confirm their ugliness. One of the female participants on the forum expressed the disbelief she felt when her boyfriend and others told her she looked pretty:

**Female 1-OP:** I believe that I am ugly, fat and revolting, and will never be anything more than that. People tell me I am pretty. My boyfriend (god help him) tells me I am beautiful every day. He might as well be telling me the sky is red, not blue - it means absolutely nothing to me. Every time someone tells me I look nice, or I am pretty, I want to punch them, kick them, scream at them and call them liars, because I know it isn't true.

Reassurance-seeking questions by individuals with BDD are asked in an attempt to reduce doubt, uncertainty, and anxiety about their appearance concerns. Many people with BDD never disclose their appearance concerns, but about half (54%) frequently question others about how they look (Phillips, 2009). People who posted to the forum often valued the advice and opinions of their peers over feedback from their family and friends, because the answers provided by primary group members seemed inappropriate or even dishonest.

Another male participant spent hours looking at his face in the mirror and told his parents how he felt about his appearance. They responded that he was a “good-looking lad” yet he believed they had lied to make him feel better:

**Male 1-OP:** I now spend most of my time either looking in the mirror, looking at pictures of myself and trying to pick out flaws or looking up surgical corrections on the internet. My parents have noticed this and I have told them about the way I feel but they just do not believe that I can feel this way and say things like “but your a good looking lad”. I of course think that they are saying this just to make me feel better.

In the same message, he disclosed that a plastic surgeon had also assured him his face looked fine and that he did not need surgery:

I felt so bad the other week that I booked a consultation with a plastic surgeon who’s exact words were “I cannot find a problem and your face is actually more symmetrical than most peoples”. Get this though, I actually convinced myself that he was lying for a period of time. I CONVINCED myself that a professional who’s main job is to identify and correct anomalies in the face was lying to me to make me feel better. Then I thought to myself, what would he have to gain from lying. He is a complete stranger to me who would obviously benefit from the identification of a facial problem or defect as I would pay him to correct it. But instead, he actually advised against surgery.

After expressing incredulity at his own disbelief about the surgeon’s diagnosis, the poster confessed that he did feel better for 2 days, but looking in the mirror made him feel ugly again:

This made me feel good for maybe 2 days. As always though, I am always 1 look in the mirror or 1 less than friendly remark from someone (that doesn’t even have to have anything to do with my looks) to make me start feeling ugly again.

As shown by the examples above, telling individuals with BDD that they look fine does not alleviate their negative feelings about their appearance. Instead, comments that the person looks fine can result in further reassurance-seeking behavior. Even after his parents told him he was good-looking, the male poster above wanted to get feedback from a plastic surgeon. However, neither the assurances from his parents nor the plastic surgeon had lasting results.

**Social comparison.** Another behavior that can have harmful effects on people with BDD is comparing one’s appearance unfavorably to those of others, such as models and actors. According to Festinger (1954), individuals in an achievement-oriented culture tend to compare their abilities to someone they believe to be slightly superior (upward social comparison) for motivational purposes.

However, this upward social comparison can also take place on other dimensions, such as a person's physical appearance (Wheeler & Miyake, 1992). Social comparison to others who are viewed as superior can either be motivational (for people with high self-esteem) or can cause them to feel worse (for people with low self-esteem; Wheeler & Miyake, 1992).

Upward social comparison on appearance often left individuals on the forum feeling worse about their perceived appearance flaws. Social comparison by study participants took place with media images such as models and actors, with friends, and with other forum members. One of the participants on the forum eloquently described the pain and suffering that resulted from engaging in upward social comparison:

**Female 1-OP:** I feel like crying all the time. I see so many beautiful, beautiful girls around me everywhere I go, and I will never ever ever be as beautiful or thin as them. One of my closest friends is beautiful. She has perfect skin, perfect teeth, and a perfect body. She is everything I will never ever be. She is successful too, in her career. I feel it is her looks that have made her that way, because I am also well-qualified and experienced, yet I never seem to succeed, career-wise. I feel that the way I look is dragging every other part of my life down with it.

Male as well as female posters compared themselves to others' appearance and this caused one male poster to feel suicidal as a result. He compared his appearance to actors and other men when he was out in public with his girlfriend. As a result, he was convinced that he would never achieve their level of physical attractiveness, which was extremely important to him. Despite having a girlfriend, he wanted to get plastic surgery to fix his entire body:

**Male 1-OP:** I have suicidal thoughts if i see an attractive male actor i could never achieve the level of psychical attractiveness, i want to try to be over obsessed about my looks...then i think its not worth it because i can never achieve this and proceed to eat a mass of food.I won't see any movie with my girlfriend with an attractice lead or male in general of any kind.I can't go to the beach or river because of other guys without their shirts off and my girl complains about not doing anything fun, i don't think she fully understands.I want plastic surgery really bad,but im afriad and its so expensive it would probably put me in debt.I don't want to live with these facts anymore, its not just one part of my body. It's ALL of it.

Posts could also contain comparisons to other forum members, despite photographs and images of oneself not being allowed on the site. As a matter of policy, forum moderators did not allow members to post personal images due to privacy concerns and the potentially harmful behaviors that doing so could

trigger in others. However, despite the moderators' best intentions, members compared their disliked appearance features to those of other members.

The following examples demonstrate that people assumed others' features were more attractive, based only on their verbal description. Comparing one's appearance to others took place despite the visual anonymity offered by the text-based interactions on the forum. A female poster disclosed that she had a bump on her nose and wanted to know if others on the forum had the same problem. Another member offered to "swap" noses with her, due to wanting a larger nose:

**Female 1-OP:** Oh man...I've got a serious problem with my nose. Does anybody else? I want to feel better about it, and my counsellor says I'm pretty and I know most people think I am, but I don't. I almost don't want to not think its ugly because I feel like I'd be tricking myself because I know I have a bump on my nose when I turn to the side. Even if it was a little bit smaller I'd be happy.

**Undetermined 2:** I'll swap you your nose for my nose. I have a small nose and frequently wish it was bigger.

The drive for social comparison was so strong that one member compared herself to another female poster who was experiencing suicidal thoughts. The initial poster expressed hatred for her body and a desire to end her life, without directly asking for support from others on the forum. Another member declared that her body and face looked worse, without having any physical basis for comparison:

**Female 1-OP:** I feel like I am falling down a pit and screaming but no one can hear me. I hate my body so much.. I don't want to be in it anymore. I want this pain to end. I just want to die.

**Female 2:** my body looks worse than yours. ever since i was 10 i never wore anything that is not long sleeve or close to long sleeve and ETC you don't know how it is like to unable to wear any kind of cloth except super baggy ones also even though my body looks terrible it's second problem, first problem is with my cursed face

Research has shown that upward social comparison contributes to the maintenance of BDD symptoms through individuals' compulsive need to compare their body parts with those of others, often concluding that they are less attractive (Phillips, 2009). Many BDD patients report collecting magazine pictures, videotapes of particular media celebrities, or photographs of themselves at an earlier age to compare their appearance (Neziroglu et al., 2008). Comparing is one of the most common BDD behaviors; 88% of individuals with BDD engage in social comparison (Phillips, 2009).

Despite the visual anonymity offered by the forum, individuals were driven to compare themselves to other members. This behavior could be explained by the hyperpersonal model of communication, where the receiver reads a selectively self-presented message by the sender, and responds in a way that reciprocates and reinforces the other's online personae (Walther, 2011). Previous studies have found that individuals compare their health condition to those of others in online forums (Bellizzi et al., 2006; Bunde, Suls, Martin, & Barnett; 2006). This finding adds to research on social comparison online by demonstrating that upward social comparison on appearance can occur based only on cues within another person's written self-description.

### **BDD Symptoms and Social Relationships**

BDD appearance-related symptoms disclosed by individuals in the study included feelings of self-hatred, depression, social anxiety, suicidality, and behaviors such as mirror-checking, reassurance seeking, and social comparison. Participants also disclosed that family members either caused their BDD symptoms or were affected by their appearance concerns and behaviors. Relationships with friends were also impacted due to the social anxiety people felt about having their perceived flaws seen in public. Dating was also difficult for study participants due to men and women feeling too ugly to be attractive to the opposite sex. Choosing a career where the person would need to be on stage, or holding down a job that required interactions with other people, were also obstacles faced by individuals in the study.

These findings reflect the considerable evidence that BDD-related thoughts and behaviors often become barriers to living a normal life. The appearance concerns characteristic of the disorder can make it extremely difficult for individuals to maintain relationships with family members, friends, and significant others. In cases where symptoms are severe, people with BDD may be unable to attend work or school, due to the social anxiety they feel about being seen in public (Wilhelm, 2006). As a result, they become socially isolated, which is one of the reasons why posting to the forum was helpful for members.

**Family members and BDD.** Both men and women on the forum shared personal experiences about the role that family members had in contributing to their BDD symptoms, and the impact their symptoms had on their relationships with family members. As a result, the secondary group (Thoits,

2011) provided by the forum enabled individuals to disclose the impact the disorder had on their primary, in-person groups. In the following example, a female poster revealed that her mother was diagnosed with borderline personality disorder and was also extremely focused on her appearance. As a result, the poster believed that her mother had contributed to her BDD symptoms:

**Female 1-OP:** I don't know how much of my BDD is genetic or as a result of my upbringing, probably both. My mother was diagnosed with Borderline Personality Disorder when I was little and also kind of displayed fears about her appearance, much like I do. She was also very beautiful and had very high standards about how I should look. I was a very beautiful child and was put into beauty pageants and modeled for several toy companies but, for some reason, when I turned 13 my face completely changed and people started telling me I was ugly.

One of the male participants on the forum blamed his father for his obsession with losing this hair. Ten years later, he clearly remembered the insensitive comment that his father had made about him going bald when he was 16 years old:

**Male 2:** I had really bad BDD related to hair loss for about 10 years now. My dad told me I was going bald when I was 16 and I never was able to shake that moment. Of course that is nearly unheard of and I have the same amount of hair today, which is the same amount I have always had, so my dad is an idiot but that didn't stop me from losing my mind.

Parents with BDD were concerned that their image-related obsessions, behaviors, and perceived flaws would either be passed on to their children or were interfering with the parents' ability to be good caretakers. One father in the study felt guilty because his symptoms were causing him to be a poor role model for this son. He described the shame, anger, and depression he felt about his perceived flaw, as well as the dichotomy between his outward appearance (a big strong tough guy) and his inner self (a weak pathetic excuse of a man). He was too ashamed about one of his "features" to name it even within the anonymity of the forum:

**Male 1-OP:** Hi everyone don't want to say my name, I am 26 I have a lovely little son but I'm so wrapped up in my own fudged up world it's got to a point where i can't have fun with him or do what a normal dad should do for his son. I love him to bits but the majority of my Time Is spent looking in the mirror or feeling bitter and angry or depressed etc.....

He then went on to ask himself and others, rhetorically:

What kind of a roll model am i? I Rarely go out and when I do it's only because I have to. I am so deeply upset and hurt by my self image I don't want to do anything or go out or have fun because all I think about is what people think of me. I am very ashamed of one of my features that I don't want to share it... But I'm even more ashamed of the fact that I am no role model to my son. I am

kind of a big strong tough guy on the outside but on the inside i am weak perfect excuse of a man, whether my obsession with my physical defect is imagined or real the point is I should be a Man and not let it bother me because it's not fair for my son.

A similar message was posted by a mother who was contemplating suicide due to her symptoms not improving after having plastic surgery and years of clinical treatment. She was worried that her depression and appearance obsessions were having a negative impact on her daughter, but knew that committing suicide would leave her daughter without a mother. This is another example of the “double whammy” of BDD (Phillips, 2009), where individuals feel guilty about the impact their behavior has on others, while also being depressed about their perceived flaws:

**Female 1-OP:** I have had bdd for almost 17 years and I cant take it anymore. Had plastic surgery and wasted most of my life as I find no joy in anything as im so convinced I look ugly. I have an amazing daughter but I can see that im starting to transfer my insecurities on to her...this kills me more than anything and honestly feel like she will be better off if im not around. I so badly cannot do this anymore....the depression is too much to handle....after trying cbt and ssris for years I cant see any way out. Im planning my next surgery but I know it probably wont make me happy,.im losing hope and im terrified for my daughter...i believe that if im alive I will mentally scar her as im so troubled...or I will take my life and she will have no mummy at all.

Although some members reported being able to share their struggles with their family members, others confided that doing so was not helpful because they wanted to project an outward appearance of being strong, capable, and normal, like the father above. According to Albrecht et al. (1994), there are costs in soliciting and accepting social support in personal relationships, since asking for help may make people appear weak or less competent, and thus result in stigmatization. As a result, some individuals (like the parents above) chose to disclose their shame and despair on the forum, where they could remain anonymous and keep their feelings hidden from their children.

**Impact on friends, dating, and intimate relationships.** Due to the shame and embarrassment many individuals in the study felt about their perceived ugliness, they cancelled plans with significant others and friends to avoid being seen in public. However, they were often reluctant to disclose the reasons for their anti-social behavior to others. The following example is from a male poster whose friends were confused and upset by his avoidance behavior. He felt guilty and asked forum members how

he should respond. Another poster empathized with his predicament and confessed that she also avoided telling her friends about her BDD symptoms:

**Male 1-OP:** But for now, I'm having a lot of problems with my friends. I sometimes make plans with them that I can't then make, because ... I don't know how better to say it than I don't look good enough to go out. Some of my friends are like, 'oh I haven't seen you, try and come' My best friend however, I tell her I can't come out and she replies with something like, why???

**Female 2:** I'm kind of in the same boat, my friends are like that too and it sucks. Do your friends know about BDD? Mine don't and I'm constantly making up new excuses but my friends are at their limit and they get really annoyed with me now I'm slowly losing them all, I have only one true friend and my boyfriend, they are the only people I like to be with, so I'm not complaining because for me that's enough but it's hard to try and make excuses and stuff to not socialise with other people.

Another example of the impact that BDD can have on one's life and relationship was expressed at length by a female poster who suffered from multiple symptoms, including depression and an eating disorder. She was not able to stay in school or attend work due to the severity of her BDD symptoms. One part of her realized that she was a "good looking girl" but her desire to look "perfect" caused her to spend hours putting on makeup only to cancel plans at the last minute. Her boyfriend (bf) dismissed her concerns so she turned to BDD forum members for advice:

**Female 1-OP:** Now at 26 yrs old I'm still struggling ...I cancel most things ...nights out..dinner..birthdays...lunches...anything really..because it takes me hours to get ready and I end up crying and panicking and hating myself. One part of me knows I'm a good-looking girl and another part of me can't stop thinking about all my flaws. I feel the need to be perfect in every way and because I can't be ..I can't leave my house. I'm so depressed and sad and have nobody to talk to about it..my bf just thinks I'm being a baby but he doesn't get how severe this is. job opportunities...school opportunities...social opportunities..all ruined by this. . . Everyone sees this perfect person and thinks I'm so lucky for my life and my looks but nobody knows how much I hate everything inside and just am done with it all.... I can't spend the rest of my life like this and I don't know what to do.

Men on the forum tended to feel distressed due to not being able to attract women for dating and sexual relationships. Female posters were most concerned about the impact their behaviors had on significant others. The following male poster liked everything about his body but felt trapped and helpless by his ugly face. Having an ugly face distressed him because not being handsome made him unattractive to women. He metaphorically compared his image with the portrait described in *The Picture of Dorian*

*Gray* (Wilde, 1993), where the protagonist remains youthful and attractive, while his portrait grows ever more hideous and grotesque with age:

**Male 1-OP:** I love life. I really do. I love everything about myself except for one thing tho. My face. It is the one thing I can't change and feel trapped in. All my other imperfections I accept. I am 6'4" tall and muscular. I have sculpted my body into a Greek statue of fitness. I am smart, funny and passionate.

But my face is the one thing I can't change and can't seem to accept. And it's killing me. To get by, I have avoided looking at my face in pictures. When I have to look in the mirror, I take out my contacts or dim the lights. I have gotten by like this for years. It has enabled me to project confidence and function.

But one look at a picture or glance in a mirror, and it's like the story of Dorian Gray...my confidence shrivels and I realize I've been living a lie, I'm also a guy, which makes it hard. Men don't talk about this stuff.

He was keenly aware that women (in his opinion) are more attracted to a man's face than to his body, and felt that strong facial features provided physical capital (Shilling, 1993) that he would never have. Even having a body like a "Greek statue of fitness" and being "smart, funny and passionate" did not minimize the importance he placed on his face. Being handsome was more important to him than being wealthy or powerful, and though he appeared strong and muscular to himself and others, he felt helpless because he could not change his face, hide it, or work out and make it better:

But all my life, I've been hyper aware of the importance of male handsomeness in today's society. And by that, I mean facial handsomeness. It doesn't seem to matter that I have a great body or am tall or am funny or smart....I've observed that initial female attraction seems to be heavily influenced by male facial attractiveness. This is not a swipe at women, I LOVE and respect women, and harbor zero blame on women. I think it's just nature.

I think men and women are both visual when it comes to attraction. But from my observations, animal magnetism when it comes to female sexual selection on a purely visual basis seems to revolve around a mans face more than his body. Otherwise every guy pumping iron at the gym would be considered hot...which obviously isn't true. Men however seem to look at a womans body more. Meaning a woman with an average face will still be considered hot by a majority of men on a visual basis based on her body.

Money or power might make average or even ugly men more attractive....but that knowledge has never brought me any solace. No Matter how much money I had, I'd still know I was ugly. It really sucks. My face is like a prison I can't escape. I can't change it. I can't hide it. I can't work out and make it better. I am stuck with what Ive got....and it's the most helpless feeling in the world.

Unlike other males on the forum, this poster did not view plastic surgery as an option to fix his face. He believed that his body was malleable and could be improved through a regiment of weight lifting (Pope, Phillips, & Olivardia, 2000; Thompson, Keinberg, Altabe, & Tantleff-Dunn, 1999), but that his facial features were permanent and ugly. Another aspect of this message that is significant is the poster's intense desire to be attractive to women. As he noted, most of the time men don't talk about their appearance insecurities with other men. Posting a message to the forum enabled him to confess to other members why he felt inadequate as a man without needing to reveal his true identity. His feelings were similar to another male poster who expressed hatred for his weak jawline because he wanted to be sexually attractive to women:

**Male 1-OP:** Anyway, I've thought about all this stuff for years. Why do I do this? What is the real core belief driving my BDD? I don't hate my jawline because of my jawline. I hate it because of what it symbolizes: that I am not sexually attractive to women. That I am not one of those men that women look at and feel sexually attracted to. I have no idea why that is such a huge deal to me but it is. And that's really the core of my BDD: a feeling that my ugly, dorky face makes me a valueless pariah in the sexual marketplace. Those are the truly painful emotions underneath it all.

A female poster also felt she had an ugly face and spent hours every morning applying makeup. She had not let her boyfriend see her without her "mask" during their four year relationship. She was worried that her boyfriend would leave her due to her ugly face and BDD behaviors, but was also exhausted from constantly having to wear makeup to hide her perceived flaws:

**Female 1-OP:** I think my biggest fear is to lose my fantastic boyfriend because of my problems, or that he will agree with me that I do look ugly without makeup. Or that people will go around saying how can that handsome guy be together with that ugly girl. My boyfriend has during these 4,5 years together never seen me completely without makeup, although I have revealed an eye or eyebrow for him once in a while. Not even him saying he prefers me to have less make up, or that he will love me no matter how I look, is it changing the way I feel.

Not all members who posted to the forum suffered from BDD symptoms. Two male posters wanted to learn how to help their girlfriends with BDD and asked others to share their experiences. One poster's girlfriend had recently ended their relationship "for no reason" and later confessed to him that she felt like a "crazy" person due to her BDD symptoms. Female members responded by describing their own experiences with BDD symptoms, including how ugly and worthless they felt:

**Male 1-OP:** My girlfriend has been recently diagnosed with BDD. She has recently started thinking that she is no good for me from what I understand about 4/5 days ago she broke up with me for no reason. Just out of the blue after calming her down and discussing it with her I found out the above reason she thought I could do better and didnt want to go out with a ‘crazy’, ‘mad’ women etc. . . Tonight she broke up with me again this led me to google (wikipedia was no help) but i did find this forum. How can i comfort her and make her understand how much I love her and want to be with her?

Can anyone help me with how they felt having suffered/suffering with BDD? or even people who are in the same shoes as me?

The second poster confessed that she felt like a “crazy mad woman” who would never let anyone get close to her:

**Female 2:** I thought I’d tell you what it’s like for me and mabey that will give you some insight as to how your girlfriend is feeling.

I constantly think about how unattractive I am, how worthless I am and it doesn’t matter how many times people try to tell me differently, I don’t believe them. I think they are just saying it because they feel bad for me.

When I look in the mirror it makes me want to scream, and cry.

You said crazy mad woman,that’s also howi feel! And I can’t ever imagine anyone wanting to be with me, I never let anyone get close.

The third poster feared that men who wanted to date her were not trustworthy because she did not believe they could be attracted to her:

**Female 3:** I don’t know when you have written it but i will reply. I was diagnosed as BDD last year. I can understand her. I have a worse situation. I cannot love anyone, beacause I don’t believe men. I think they are teasing with me or they are waiting something else like abusing sexually so I hate men who want to date me. I didn’t have a serious relationship and I am 24.

The impact of having BDD and related conditions, such as social anxiety and depression, can make it difficult for those with the disorder to get or stay in personal relationships. The individuals in the study often complained about having problems in their primary relationships with friends and significant others. They chose to reveal their ‘true selves’ with other members, since face-to-face interactions can impose costs for disclosing negative aspects of oneself, such as disapproval from family members and friends (Bargh et al., 2002).

**Impact on job/career.** Both male and female posters to the forum also exchanged experiences about the impact that BDD had on their career and job aspirations. One of the most frequent posters asked

others on the forum to disclose if their symptoms impacted their career plans. Her ambitions had changed from wanting to be a surgeon to a psychiatrist so she could help others with BDD:

**Female 1-OP:** I was curious to see to what extent “feeling ugly” can impair us to reach our goals and ambitions in life. I see myself as a very ambitious person and has always been. I believe there is nothing I cannot do. Unfortunately the last couple of years my condition of feeling ashamed of my looks have impaired me to live fully my capabilities, realized that it affects my daily life too much, so I had to cut down on some of those highest ambitions.

Another frequent poster replied that she also had changed her career plans and no longer wanted to be a dancer due to her appearance concerns:

**Female 2:** Mine have changed! I wanted to be a dancer, I went to a dance school and I loved it! But it became too hard for me to perform in front of people, I got distracted from what I was doing because I was so concerned about how I looked! I cut down on my time spent in class because I felt so uncomfortable in front of all the other people there. So at 16 I quit and I don't really dance anymore. But I don't really mind to be honest, I think if it didn't work out then it wasn't meant to be.

A male forum member disclosed that his appearance concerns had impacted his ability to advance in his career. He compared himself to his friend who had made millions by starting his own company.

This example shows that upward social comparison (Wheeler & Miyake, 1992) by members could take place on aspects other than appearance, such as career success, status, and income. The male poster asked if others on the forum had been able to fulfill their job/career potential despite having BDD image concerns:

**Male 1-OP:** Is there anyone here who is able to fulfill their potential when it comes to jobs/career opportunities despite BDD/image concerns or does it prevent you from even working at all? I ask because I read about an old friend from school who I was in the same classes as back in high school, he was quite a bit cleverer than me I admit but he has his own consulting company now which has made him a millionaire. I however have had to just settle for a very basic office job doing admin work because I don't have the confidence due to my image issues to do things where attention is on me. I get so self-conscious when eyes are on me, fearing being seen/judged as ugly/unattractive.

The previous quotes taken from male and female posters to the forum reveal that BDD poses a challenge to those with the disorder, in terms of the struggles they go through to cope with symptoms and communicate with others in their primary support group. The BDD forum may be their only resource to disclose feelings of ugliness and shame, and share their experiences with BDD symptoms and how the disorder impacts their lives, careers, and personal relationships.

## **Recovery from BDD**

Individuals in the study expressed the desire to recover from the disorder and to live a normal life. Recovery from a mental health disorder is defined as “A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential” (Substance Abuse and Mental Health Administration, 2011, para. 3). The first step for many was diagnosing themselves with a mental health disorder for which they could receive support from their peers on the BDD forum. Other members disclosed that they had received a clinical diagnosis while they were in treatment for BDD symptoms or for comorbid disorders, such as depression and social anxiety. Three members disclosed that they had been diagnosed by family members or friends.

Many participants expressed the desire to receive clinical treatment, but had experienced barriers to getting effective treatment, such as low knowledge levels among clinicians about how to recognize and treat the disorder. As a result, they sought and shared coping techniques that did not require professional support, such as journaling, exercise, and thinking positive thoughts. Some forum members were in the process of receiving clinical treatment, and shared their experiences with treatment options, including the benefits they received. Two forum members, who were recovering from the disorder, revealed their condition publically, one by posting information about BDD to Facebook and another by writing a book, in order to raise awareness and encourage others to seek help.

**Diagnosis by self, friends, and family members.** The most frequent type of diagnosis on the forum was self-diagnosis; more than 43 participants disclosed that they diagnosed themselves with BDD by searching for information on the Internet, reading the list of BDD symptoms posted on the site, or by reading others’ experiences on the forum. Members discussed their BDD diagnosis when introducing themselves to others on the forum, in order to find others who shared their symptoms. Disclosing symptoms also signaled to other members that the poster could be considered part of the “in-group” (Goffman, 1963) of stigmatized individuals on the forum.

One way that individuals diagnosed themselves with BDD was by doing Internet research. The female poster quoted below introduced herself to the forum by verifying that she belonged on the BDD

forum due to her symptoms. She confessed that her insecurities appeared “completely irrational” to everyone she knew, and wanted to meet “nice and interesting” people on the forum:

**Female 1-OP:** I have never been diagnosed with BDD but after conducting a lot of research I do believe that I suffer from it and that I have for quite some time. I’m not going to go too far into detail in this post as it’s a simple introduction post but I do have several insecurities that seem completely irrational to everybody else. . . . I would love to meet some nice and interesting people who I can talk to and relate to.

Getting diagnosed with BDD or self-diagnosing oneself with the disorder was important to forum members. A BDD diagnosis verified that members belonged on the forum, and could help to explain their irrational feelings, thoughts, and behaviors. Giles and Newbold (2011) note that members of online support communities place importance on diagnostic criteria to form a group identity. Part of the appeal of having a mental health diagnosis lies in its ability to explain behaviors that would otherwise leave individuals open to blame and personal accountability (Giles & Newbold, 2011). The young woman above diagnosed herself with BDD, and disclosed that she had done so when she joined the forum, in order to find others who shared her symptoms.

Some members expressed uncertainty as to whether or not they had BDD. As a result, they compared their symptoms to those found on the BDD support forum, or other websites, such as Wikipedia. The first male poster had many BDD symptoms but had not been clinically diagnosed. He was housebound and felt alienated from his family, which is one of the reasons that individuals used the BDD forum to connect with their peers:

**Male 1-OP:** I’m unsure if I have body dysmorphic disorder or not. I have the majority, if not all of the symptoms posted in the General Information topic on here. I haven’t been to the doctors to get myself diagnosed because well let’s be honest, it’s a little bit embarrassing. But I know this the time that I should say something because it’s literally taken over my life, completely. I’m pretty much housebound now (Haven’t left my house for 3 or so months now) My relationship with my family has deteriorated and virtually non existent now.

A female poster disclosed that she had used Google to find information related to her symptoms. She wanted to be “almost sure” she had BDD before seeking treatment, to prevent herself from being embarrassed and wasting the clinician’s time:

**Female 1-OP:** I Googled some of my symptoms (which I know you're not really supposed to do), and I found loads of stuff on BDD, but I'm reluctant to go to the doctor about it until I'm almost sure, as I don't want to embarrass myself or waste their time.

Some individuals diagnosed themselves after reading others' personal stories and experiences with BDD posted to the forum. Empathizing with others and discovering that they shared similar thoughts, feelings, and experiences helped members confirm that they were also experiencing BDD symptoms. Thus, members could serve as role models (Thoits, 2011) for others who wanted to confirm that they had BDD. One forum member expressed relief knowing that she was not alone since she was too ashamed about her appearance obsessions to share her feelings with those closest to her:

**Female 1-OP:** I have not been diagnosed with BDD, but reading about peoples stories, I believe that it is the closest to what I am experiencing in my life, that I have yet encountered. And it feels somewhat of a relief knowing that it is not just me feeling like this.

Three participants in the study explained that they had diagnosed themselves after being told by friends or a family member that they might have BDD. One female participant had a friend with an eating disorder (ED) who diagnosed her with BDD after she confessed to feeling ugly. As a result, she used Google to find information about symptoms, which led to her self-diagnosis:

**Female 1-OP:** I am new here but I thought I would introduce with a thread. I am 41 years old and I have NEVER thought about this disorder. I am very much into fitness and know a few people with ED but I never fell into that. I was talking to a friend of mine struggling with an ED and I told her, "well I'm having a harder time getting down to the weight I want and I can't look in the mirror. I think I look bulky and I just look ugly." She says "Oh right so just regular BDD". Like this is a normal thing? She is not a psychologist mind you but google is right? So I google BDD and low and behold my symptoms are all there mirror avoidance, hatred of photos of myself, panic disorder, low self esteem, obsessive thoughts about my body. Everything I had gone through most of life was there!

The previous examples indicate that finding an in-group of similar others (Goffman, 1963) can provide relief and enable individuals to diagnose themselves with BDD. Self-diagnosis can lead to increased self-efficacy and favorable outcome expectations for treatment and recovery. This is because the knowledge that one has a recognized and treatable mental health condition is often preferable to feeling "trapped in an ugly face" or that one is "too ugly to live."

**Clinical diagnosis and treatment.** Only 30 of the 225 participants in the study (13.3%) disclosed that they had received a clinical diagnosis for BDD. Receiving a clinical diagnosis meant that

individuals had to seek out a mental health professional and confess their feelings of ugliness. Some members were already undergoing treatment for related disorders but felt too ashamed to talk about their appearance concerns to their doctors. The primary fear individuals had was that clinicians would confirm their ugliness, rather than providing a diagnosis for BDD. One male poster was relieved when his clinician casually diagnosed him with BDD:

**Male 2:** I had had BDD for 10 years before I finally decided I had to tell someone. I told them thinking I'd be laughed at. The Clinical Psychologist I "confessed" to, said (very casually) "Oh, that....you think like that because you have BDD."

Another member had been diagnosed with BDD but was still convinced she was ugly: "In the past couple of weeks i've discovered that i have BDD, clinical depression and social anxiety disorder. I know I have BDD, but I AM genuinely UGLY."

Many individuals wanted to receive clinical diagnosis and treatment, but found disclosing their symptoms difficult due to the shame they felt and fears about being laughed at or being called ugly. The barriers to finding and receiving effective treatment were topics frequently disclosed on the forum. One female poster had been diagnosed with BDD, and could get free counseling sessions from her campus therapist, yet disclosed that she was terrified that the clinician would either dismiss her concerns or tell her she was ugly:

**Female 1-OP:** So, I found out my campus gives students 10 free therapy sessions a year...and after that it is all sliding scale (which, based on my income, would make my copays very, very cheap.) I am planning to go but I am truly SCARED. I was diagnosed, sure, but I am scared that this person will laugh at me if I tell her my diagnosis...as if he or she would assume I am fishing for complements, or that they would tell me I am simply unattractive and trying to obtain something I will never have. I know this is crazy but I am absolutely terrified.

The poor outcome expectations about treatment that participants expressed in their posts suggested they were reluctant to seek professional treatment. As a result, they came to the forum to express their concerns and get help. According to Bandura (2004), two determinants of effective health practices include individuals' expectations about the costs and benefits of health behaviors, and the perceived facilitators and impediments to the changes they seek. One of the social impediments that

forum members encountered was low knowledge levels by physicians and clinicians about how to recognize and treat the disorder.

Participants complained that clinicians either tried to minimize their fears by assuring them they looked fine (in a patronizing manner) or lacked knowledge about how to treat BDD. Some female posters were told that they looked “pretty” or “attractive” by their doctors or clinicians. The original poster below asked others on the forum if this happened to them and if this helped, since it never helped her:

**Female 1-OP:** What does your therapist say when you explain your issues? All I get is “you’re attractive, there’s nothing to worry about” or when I try to explain what people have said to me or done to me they say “why do you care about looks so much?” or “maybe that person is having a bad day” or something. It NEVER helps me. Does it help you?

Another poster replied that she was seeing a university counselor for depression but had never been diagnosed with BDD because doctors told her she was good looking:

**Female 2:** I was seeing a counsellor at my university for 3 years and she suspected I have BDD..i never got diagnosed by a doctor mostly because anytime I’d say I was sad they’d say “well you must not be sad about how you look” and then go on to list physical traits of mine and say im good looking. so yes, id say I have BDD.

A male poster similarly shared his negative experience with the doctor he went to for help, since the doctor did not know about BDD and referred him to a specialist:

**Male 2:** Well the doctor was a moron. Wasn’t even aware of the condition! He was clueless, he told me he had never heard of it and just made me feel like a bit of an idiot. It took a lot of courage to go in there and just talk face to face about it to someone. I told him how hard it is for the sufferer and how much emotional anxiety and constant negative thoughts weight on the mind. He has refered me to a specialist. Hopefully this person will have some knowledge and isn’t a complete demoralising moron. I am not done fighting.

The fear, shame, and stigma felt by those with BDD, reinforced by clinicians’ lack of knowledge about the disorder, were the most common barriers experienced by individuals in the study. These results are consistent with studies by BDD researchers (Marques, Weingarden, LeBlanc, & Wilhelm, 2011) and on a forum for people with depression (Barney et al., 2011), where barriers included logistical and financial barriers, stigma, shame, discrimination, low treatment satisfaction, and misperceptions about treatment. Forum members also discussed other barriers to seeking effective treatment. These included

the cost of therapy, lack of health insurance, and desire to seek dermatological and cosmetic treatments to fix one's perceived appearance flaws. One member expressed her preference for dermatology treatments because of the high cost of clinical therapy:

**Female 1-OP:** worse of all, my parents don't understand the pains i go through... i've had guy friends who commented about my body hair and it was so embarrassing... & they don't even wanna pay for waxing and laser... i have to save up for my own \$\$\$\$ to get it done. plus i'm still schooling so its impossible for me to work full time to save up enough \$\$, school starts next month and i've only earned \$500 so far which i've spent on nicer clothes and hair.... a therapist is kinda out of the question, went to one before and it was so expensive!!!! \$100 for one session, just to talk to the therapist and draw about how i feel?!?!? THATS CRAZY.

Group therapy with individuals who did not suffer from BDD was an obstacle faced by another forum member. Therapy had been helpful when she attended groups for general unhappiness with life and becoming more assertive. However, the current group she was attending was focused on "General Anxiety Disorder" and she felt out of place. As a result, she felt more comfortable sharing her concerns with forum members since they could understand what she was going through:

**Female 1-OP:** I didn't go to group last week and I honestly don't plan on going back. I [attended] a couple of group therapies before and made a lot of progress. One was for general unhappiness with life and the other was for helping with assertiveness. I just feel out of place at the one I'm at now. I want to let people know about my issues, but I feel like things are moving too fast. I posted on here because I feel like at least people on this board will understand what I'm going through. I fear that people at group will tell me I have nothing to worry about. I'm not strong enough to face that possibility.

Not all disclosures posted about recovery from BDD described barriers to receiving effective diagnosis and treatment. Six individuals shared positive results with cognitive-behavioral therapy and medication. For one participant, who was suffering from multiple conditions including depression, medication had helped to control her obsessive thoughts:

**Female 2:** For me BDD died down in my early 20's but has now come back with a vengeance. I'm 27 and have had BDD since I was 17. I also suffer from depression and body focussed repetitive behaviours. I find stress does it make it worse as well. I'm going through a particularly tough point in my life and it's really worsened my BDD. I'm currently on 100mg of sertraline and have had counselling. I'm now starting CBT which I hope will help a bit. I'm resigned to the fact I can't be cured but that the illness can be managed. Since I've gone on a high dosage of SSRI's it has helped my obsessive thoughts which is good as I can now function day to day whereas before I got to the point where I wasn't functioning or thinking clearly and rationally.

**Self-help and coping strategies.** Many forum members wanted to feel “normal” again, freed from their debilitating thoughts and behaviors. As a result, they developed their own coping strategies for managing and overcoming BDD symptoms. These included positive thinking, taking steps to counter obsessive thoughts and behaviors, reading self-help books, meditation, exercise, and journaling. Positive thinking and exercise helped one forum member to overcome negative thoughts related to the disorder. The person shared coping strategies and then asked members to share some of theirs:

**Undetermined 1-OP:** I was thinking it would be good to share tips/strategies/ideas how to lessen the symptoms of BDD. For me, constantly telling myself, “No one thinks I am as ugly as I think I am” helps me put things in perspective sometimes. We are our own worst enemy. When I start obsessing, I try to exercise because it kills two birds with one stone—takes my mind off obsessing and makes me feel like I am doing something to change my despicable appearance. Does anyone else have coping mechanisms they could share?

A male poster started another thread by sharing the methods he used to cope with his BDD symptoms. He then asked if others had tried his system, which was similar to exposure therapy in clinical treatment. Exposure therapy involves having a person face situations that he or she would otherwise avoid, in order to help the person become habituated and feel more comfortable (Phillips, 2009):

**Male 1-OP:** My way to cope with this is to make me get used to the feeling of being ugly. The actions include not caring about how you look, not dressing up properly, not making your hair properly while still going out as usual, trying to look at the mirror as much as possible of course. With all of these in place, you would feel very hopeless, probably like the most serious depression state you could get. . . . It may last for a week or so. After that, you would not be depressed anymore because you have already reached the final stage- the true acceptance. For those who have tried this method, please let me know if it works for you.

Unfortunately, no one responded to this person’s post about using exposure therapy to overcome symptoms. The reason could be that this form of treatment can increase anxiety levels and so might have been viewed as too difficult by forum members. Rather than facing her negative thoughts directly, another poster knew that her perceptions were not accurate, and so focused on doing something fun instead of having a miserable day, thus distracting herself from her negative emotions:

**Female 2:** Basically, whenever I feel an avalanche of negative emotions building up, I pause and remember that I know it’s only my perception tricking me, and it isn’t how things truly are. So now instead of having a really miserable day, crying for hours and contemplating killing myself, I literally just decide to do something fun to distract myself while my mood gets back in balance. It may sound weird, but “training” myself that way really worked for me. I learned that “BDD attacks” or whatever you want to call them, aren’t real. They’re not how I truly perceive things.

Distracting oneself from negative feelings and thoughts is considered to be an emotion-focused avoidance coping strategy (Lazarus & Folkman, 1984). Although this type of disengaged coping strategy is generally believed to be maladaptive (Wright & Rains, 2014), the female poster above used this technique to effectively make herself feel better, even if it did not result in her overcoming symptoms of the disorder.

**Overcoming BDD symptoms.** Some forum members were in the process of overcoming BDD symptoms and recovering from BDD; they were transitioning from being members of a stigmatized “in-group” with a mental health disorder to becoming “normal” members of society (Goffman, 1963). Two forum members choose to reveal their condition publicly; the first by using social media (Facebook) and the second by publishing a book about his experiences with BDD. Their goals were to help raise awareness about BDD among the public and their friends and family members. For the following participant, posting information about BDD on her Facebook page meant revealing her condition to her primary group. She was proud about doing so since she no longer blamed herself for her condition. She was also passionate about starting a “revolution” meant to raise awareness about BDD:

**Female 1-OP:** For the past week a passion has grown in me, to try to start a revolution within spreading this knowledge and understanding. I just did a massive difficult thing!!!!!!! I shared a page on my facebook about BDD, and also wrote some short information of how common and under-diagnosed it is, but very disabling. Linked to a couple of pages to find more info, to be able to understand and support a family member/friend. . . . Im exited and scared, but mostly proud that I took this decision and went though with it.

An entry in Wikipedia led the second member down a path of self-diagnosis and treatment for BDD. Finding out he was not alone and that millions of Americans also had BDD had caused a “piano sized weight” to come off his back. His goal was to start an “awareness campaign” to help people not only realize they may have BDD, but to seek treatment if they did. His ultimate goal was to “have support groups on every college campus” throughout the country:

**Male 1-OP:** I sought counseling at school in Miami and subsequently wrote a book about living with BDD. I plan to use a portion of the proceeds to start a counseling center for people with BDD. My ultimate goal is to have support groups on every college campus and in other settings like 12 step programs have throughout the country. . . . I still have only told a few people, but with the publication of my book I am ready to come out with my story. I want to help fellow

BDD sufferers and know that all of my pain and suffering can serve some greater purpose. I want to start an awareness campaign to help people not only realize they may have BDD, but to seek treatment when they do.

Another member responded by sharing similar BDD-related symptoms and complimenting him on his achievement:

**Female 2:** Thanks for sharing this. It's a truly great thing you're doing, spreading awareness of a not-well-known (yet probably very common) disorder, and helping people who are suffering/those who may not be able to attribute any kind of 'label' to their severe body image issue. . . . That extract was excellent and really well written. It's nice to know someone else experiences almost exactly what you do when they look in the mirror.

Disclosing that a person had BDD on the forum could provide a sense of relief and empowerment, since doing so enabled one to join a secondary group of similar others. The two individuals above were even more courageous because they revealed their BDD symptoms publicly without the veil of anonymity provided by the online forum. They could have served as "exemplary others" (Thoits, 2011, p. 154) who offered hope to those still struggling with BDD.

### **Summary of Findings about Personal Experiences Disclosed on the Forum**

The personal experiences disclosed on the forum were focused primarily on peoples' appearance-related concerns and behaviors, the impact that these symptoms had on their social relationships, and their efforts to overcome BDD symptoms with diagnosis, treatment, and self-help. Most disclosures were about the impact their appearance concerns and behaviors had on their own lives, and the least common types of disclosure were about diagnosis, treatment, self-help, and recovery. This finding indicates that most individuals who posted personal experiences to the forum were still struggling with BDD symptoms, and few had successfully overcome the disorder. Thus, the forum was used more by individuals who wanted to share their problems with BDD symptoms, and less by those who had received clinical treatment and recovered from the disorder.

As shown by these examples, men and women shared similar appearance-related concerns, though men focused more on hair loss and not being attractive to the opposite sex. This was different from most of the women, who focused on the impact their BDD symptoms had on their primary relationships. Both male and female posters also disclosed that their primary group members were unable

to understand the reasons for their appearance-related concerns and behaviors, since they were often considered attractive by friends and family members.

As a result, individuals came to the forum to find others who could understand their personal experiences with BDD symptoms. The experiences of other members was used by some participants as a means to self-diagnose themselves with BDD. The experiences they shared about clinical treatment and plastic surgery could have been used as reinforcement to either seek or avoid similar treatments. The anonymity offered by the forum enabled individuals to reveal their “true selves” online (Turkle, 1995), which was often hidden or not revealed to those in their primary support group.

### **RQ3: Social Support Sought and Shared on the BDD Forum**

Research Question 3 asked what social support is sought and shared by individuals on the BDD forum. Messages in the study contained both personal disclosures and social support; fully three-quarters of the messages coded for the study contained social support (76.8%). As identified in the preliminary readings of the posts used to create the coding guide, the final analysis confirmed that members sought and shared three types of social support: informational, emotional, and social network support, but also exchanged some unsupportive comments. Five members, one male and four females, posted the highest number of messages containing social support. They are referred to as the most frequent posters in the results and their supportive roles are discussed in more detail in RQ4.

Of all three forums of support, informational support was the most common form of support sought and shared in the study, followed by emotional support. Informational support in the current study included advice and opinions about treatment, diagnosis, coping (self-help) and recovery, as well as plastic surgery and appearance concerns. Emotional support included expressions of empathy, caring/concern, sympathy, gratitude, compliments, and validation/agreement with other members. Social network support was the least common form of support. Social network support included references to the forum as an online community with similar others (companions) who understood the disorder. The three categories of social support were adapted from the SSBC (Cutrona & Suhr, 1992), along with codes for advice, empathy, sympathy, compliments, validation, presence, and companions.

## **Informational Support**

Individuals in the study primarily sought and shared information about treatment, diagnosis, coping, and recovery rather than about their appearance concerns. Interestingly, in contrast to the RQ2 themes, BDD-related comments were more prevalent than comments related to one's appearance concerns and behaviors. There were 336 BDD-related comments, compared to 209 appearance-related comments. The finding that informational support was the most common form of social support coded for the study is consistent with other studies of online groups (Barney et al., 2011; Burnett, 2000; Coursaris & Lui, 2009; Mo & Coulson, 2008).

**Information about clinical treatment.** Information about clinical treatment for BDD was the most common support topic sought and shared on the forum. Clinical treatment included cognitive-behavioral therapy (CBT) and medication. CBT involves exposing individuals to situations they would otherwise avoid in order to eliminate body checking behaviors (Phillips et al., 2008). Some individuals expressed doubts about whether therapy would be effective since they were convinced they were ugly and had visible appearance flaws. One male poster feared that treatment would make him delusional by forcing him to accept his flaws:

**Male 1-OP:** I had 2 assessments with a BDD expert and she is taking me on as a patient next week. I am 1000% convinced that my perception is not flawed and that I see things accurately. What is the point of doing this treatment? Is it to make me feel okay and accept myself this way? Is it to make me delusional? If that is the case then they should just stop lying and tell me to accept myself from the start. I'm sorry for sounding frustrated I just needed a place to vent and get some advice.

If the person posting the message was "1000% convinced" that his perception was not flawed, he could have been suffering from the delusional form of BDD, which means that a person is convinced that his or her appearance beliefs are true. According to the *DSM-5* classification for BDD, a person's beliefs are considered delusional if the person is convinced that perceived appearance flaws are real (APA, 2013). Thus, the poster's fear about treatment was based on the "delusional" belief that his perceived flaws were real. One of the frequent female posters responded by expressing sympathy for his plight,

advised him to get therapy, and welcomed him to the forum. In response, the original poster simply repeated his fears about treatment:

**Female 2:** I'm sorry your having a hard time at the moment.  
I think you should stick with the therapy, try it out and see how it goes.  
You are very welcome to come here and vent and we will try to give you advice if we can.

**Male 3-OP:** What's the point of treatment if it's the truth? To make me feel less bothered by it?  
If that's the case I rather not be made delusional. You know?

The female poster replied again and asked him to consider the possibility that his beliefs about his appearance were not true, and as a result, that therapy could help him. She confessed that she would “give anything” to become more accepting of her own flaws in order to live a normal, happy life:

**Female 4:** But what if it's not the truth? I'm not saying you are wrong at all, but what if you are? And if that's the case this could really help you. And don't you want to be happy? If this makes you happy and less concerned about it, wouldn't that be worth it? To be able to live a normal happy life and not have to bother about it. I would give anything to have that!! I understand that you don't want to be made delusional, but what if it's not about being made delusional but about becoming accepting of it?

As shown in the example above, individuals on the forum advised others to get treatment for BDD. The most common advice was to get treatment from a clinician familiar with the disorder. Moderators and members encouraged individuals to seek professional help for diagnosis and treatment. However, studies by BDD researchers (Marques, Weingarden, LeBlanc, & Wilhelm, 2011) have shown that clinicians often lack knowledge about how to recognize and treat the condition. Thus, despite their best intentions, the advice shared by members may have been hard for the recipients to execute.

Members were more specific when they sought and shared experiential information about treatment options, such as medication (SSRIs) and cognitive behavioral therapy (CBT), which are designed to help alleviate BDD symptoms. One of the male posters revealed his fear about going to the doctor for treatment and asked others to share their experiences with CBT: “Has anyone ever tried CBT for their body [dysmorphic] disorder and what was it like? Did it help? Are my fears unfounded (or more likely being caused by my disorder)?”

Some members who were prescribed medication sought advice about whether or not they should follow the treatment program recommended by their doctors. Similar questions about medication dosage

and effectiveness were also evident on forums for a variety of physical and mental health conditions (van Berkel, Lambooi, & Hegger, 2015). Other members, like the female poster below, asked for advice on how to get a prescription since she believed medication could help alleviate her symptoms. The BDD forum was helpful when it served as a gateway for individuals who wanted to get treatment but were unsure about what actions to take:

**Female 1-OP:** I have finally decided to get help. I have anxiety and OCD problems along with my BDD. I think medication would be the best thing for me. How do I go about getting it? Can I just go in to a therapist, explain my problems and why I feel medication would be best for me, and they would diagnose me and I can get the medication from there? I doubt it is that simple. What are your experiences with medication? Do you feel medicine would be the best thing for someone like me? I feel like I have way too many problems that would take more than therapy to fix.

One of the frequent posters responded and advised her to seek professional help and follow the treatment regime outlined by the doctor. The original poster's desire to get medication encouraged the female member to also ask her psychiatrist for a prescription, despite being off medication for two years. This example demonstrates that the desire expressed by one member to use medication could motivate another member to also take action:

**Female 2:** Listen to your psychiatrist about how long for you should use the medicine and stay by those indications and the dosages, do not make the mistake I did and stop when you feel better. I stopped after 6 months and got worse. Haven't had meds now for approx. 2 years, but I think any day I will go and ask the lady for another round.

The most frequent male poster also responded and provided information about treatment options for BDD. He urged the original poster to discuss her concerns with her therapist since "everyone is different" and some people need CBT, medication, or a combination of both. The original poster replied that both responses had helped her and she now looked forward to finally getting help:

**Male 3:** Many people say that the best form of treatment for BDD is a combination of cognitive behavioural therapy and serotonin re-uptake inhibitors and then once treatment with CBT has finished you may not need the meds after it. Everybody is different though however and some people can tackle it with just CBT or psychotherapy and others may require medication or both, there's no right or wrong way but it would definitely be advisable to make it a discussion point with your therapist because with their 1-to-1 interaction with you they will be in a much better position to offer you concrete advice.

**Female 4-OP:** Your responses really helped a lot and make me look forward to finally getting help. Luckily I have seen the therapist before so I will be comfortable talking with her.

Members also used their own experiences to guide others toward appropriate treatment options. One college student was afraid to approach the campus therapist for help. Two members replied and encouraged her to get treatment. However, a father cautioned her against using a campus therapist, based on his daughter's experiences. His daughter went to the campus therapist for help with her OCD symptoms, which resulted in her being committed to a psychiatric ward and expelled from school. He suggested that the poster seek treatment off campus, and offered to provide her with more information:

**Male 2:** Not to be a naysayer, but I have a lot of experience with a campus mental health center and would advise you to be very cautious about seeking assistance at yours. We encouraged our daughter who was struggling with OCD to seek counseling at her campus mental center. . . In our case, my daughter was unnecessarily and involuntarily committed her to a psych ward and then subsequently denied enrollment and housing. Ultimately, her enrollment was reinstated, but she declined to return.

There's a lot about this issue on the internet. I'll try to find some links that may be helpful. I understand how it may be appealing to utilize the campus resource, but it can be problematic. What about getting some insurance coverage through the college? Do you think it's a possibility?

Questions about medication and treatment were also frequent topics on an online support forum for individuals with depression (Barney et al., 2011). The researchers found that individuals reported difficulties obtaining professional help and had concerns about the unavailability of services. Bambina (2007) looked at seeking and sharing information about cancer on an online forum. She found that experiential information was a common form of informational support, as shown by the following example: "I went to a naturopath for this and you buy the enzymes through his office (depends) or through a health food store" (p. 48).

Members rarely asked others for factual information about BDD, such as the location of treatment centers. One poster did ask members where to find BDD treatment centers in Canada: "Is there any treatment centres in Canada? I live in Ottawa Ontario Canada and cannot find anyone in Canada that is specialised in BDD." There were no responses to this person's inquiry about where to find treatment centers. One possible reason is that knowledge about where to find help for BDD is low among individuals with the disorder.

**Information about a BDD diagnosis.** Experiential knowledge could be helpful when answering members' questions about treatment for BDD symptoms. However, experiential knowledge was often not

adequate for confirming whether or not individuals on the forum had BDD. About 20% of the study participants had diagnosed themselves with BDD using Internet searches or others' personal experiences posted on the forum. Some members had received a clinical diagnosis but wanted other members to provide a second opinion to complement the professional diagnosis. Seeking a second opinion from forum members is not a common activity on support forums for physical and mental health conditions, though questions about a clinical diagnosis are common (Barney et al., 2011).

In the following example, a poster asked if she fit the description of a person with BDD. She had done research to find out if the tentative BDD diagnosis provided by her therapist was accurate. She wanted other members to confirm that she belonged on the BDD forum and was in the right place to get the help she needed:

**Female 1-OP:** In late July 2012 I started seeing a councillor and it is only then that I was told I might have Body Dismorphic Disorder. I'm not sure if I do or not, but having read up on it now I certainly relate to a lot of it. The problem I know have is how to even begin to get through this? Do I sound like someone with BDD? Am I in the right place?

Questions from members about whether or not they had BDD were common, even after they received a clinical diagnosis for the disorder. This was due to their conviction that they were indeed ugly, and receiving the BDD diagnosis did not seem to contradict this belief. This uncertainty motivated people on the forum to engage in a variety of strategies to gain knowledge about BDD, such as asking questions or disclosing personal experiences to encourage others to share information (Berger, 1979; Berger & Calabrese, 1975).

A female poster copied symptoms from the BDD description in Wikipedia and wanted forum members to tell her if she had BDD or not:

**Female 1-OP:** Could you help me? Tell me if you think I have BDD or not. I copied over some symptoms of BDD from Wikipedia to help me out. These are all symptoms that I show. I took out all the symptoms that I don't show.

Another member wanted to know if she could have BDD if she was genuinely ugly. She had been given a tentative BDD diagnosis but disagreed with the therapist because she thought others were responding negatively to her "strange" facial features:

**Female 1-OP:** After years of therapy I've had BDD as a working diagnosis. They still don't know if it is BDD or not.

I don't think it's BDD. The things that fit are that I cover up my face, afraid of social interactions and generally depressed because of my appearance.

However the things that don't fit are, I don't actually think I am ugly. Yet I keep getting negative reactions from people, I've had strangers comment on my 'strange' facial features. I am a girl yet have a heavy jawline, but I never thought it was a problem until I started getting all these comments. It never used to be a problem before. Also I am not delusional, people actually say these things. And I think, if I am genuinely ugly then how can I have BDD?

One of the most frequent posters on the forum replied by instructing her that BDD is a psychological disorder and suggested that she try to diagnose herself, since only she would know if the symptoms matched her experiences:

**Male 2:** Body dysmorphia is every bit psychological.

You don't always have to think you're ugly I guess although the vast majority of BDD sufferers think they are ugly at least 60% of the time.

If a therapist thinks you may have BDD it's worth looking it up seeing how it fits with you, because at the end of the day only you will truly know if it is, what everyone else says is opinion.

Other posters wanted to get a clinical diagnosis for BDD but didn't know how to do so. This lack of knowledge was prevalent in the messages posted to the forum. This finding is similar to the information needs of people who posted to an online depression forum (Barney et al., 2011). Individuals on the depression forum were often confused due to receiving different diagnoses for the disorder. The male poster below wanted to get a professional diagnosis but did not understand where to go for help:

**Male 1-OP:** I need to get diagnosed, if I definitely am suffering from it which only a doctor can tell me, really soon, because it's having an impact on my studying and relationships and enjoyment of life. But I don't know how to get diagnosed? Do you walk into a doctor's surgery and tell them you think you have it, or tell them your symptoms and see what they say, or do you go to a doctor at all?

One of the frequent posters advised him to go to his doctor for a diagnosis. She also suggested that he write down his symptoms beforehand if he found it too difficult to talk about his feelings at the appointment:

**Female 2:** You should make an appointment with your GP and discuss it with him/her. Tell them that you think you have BDD and why you think that. You could maybe write down how you feel and take it with you, that way if you find it hard to talk about it you can just hand it over to your doctor.

Most members and the moderators who responded to these requests stated that they were unable to provide a diagnosis on the forum. They referred individuals to medical professionals for diagnosis and treatment. These referrals could have encouraged participants to seek help from clinicians familiar with treating the disorder. Letting members know that their symptoms were related to having BDD could have increased their insight that they had a diagnosable mental health disorder, rather than being as ugly or physically disfigured as they believed.

On two occasions, forum members responded by providing reasons why they thought that the person did or did not have the disorder. However, this was rare and most individuals were referred to professionals for a diagnosis, as shown in the following example:

**Female 2:** I would say don't focus on whether you have BDD or OCD because it might cause you to stress more. Everybody experiences this differently and varying intensities. My advice would be, if you would like to live without worrying about being ugly or not, you should find a nice psychologist. Everybody experiences body worries but it's when it starts to take over and cause you distress it becomes a problem.

Receiving an accurate diagnosis for BDD is critical for getting effective treatment for the disorder (Phillips, 2009). The individuals who responded to members' requests recommended that they seek out clinicians for an accurate diagnosis. The advice individuals received on the forum could have facilitated their pathway to diagnosis and treatment for BDD. Studies of online support groups have found that one of the empowering outcomes for participants was an increase in their help seeking behavior (Aardoom et al., 2014; Mo & Coulson, 2008) and motivation to seek therapeutic treatment (Kral, 2006).

**Information about self-help techniques.** Many individuals in the study wanted to find out how to cope with and effectively manage their BDD symptoms. Some sought help through therapy, while others wanted to help themselves, either as an alternative to seeking therapy or in addition to clinical treatment. The recommendations offered by forum members included a variety of self-help techniques, including self-acceptance, posting messages to the forum, mandala therapy, engaging in enjoyable activities/hobbies, meditation, and not comparing oneself to media images of celebrities and models. Self-acceptance was one choice among many for coping with BDD symptoms. A male poster quoted an

American monk and writer (Chodron Pema) when offering advice about self-acceptance and transformation:

**Male 2:** Although self-improvement can have temporary results, lasting change occurs only when we honor ourselves by approaching our imperfections with kindness, compassion, and patience. It is only when we begin to relax with ourselves, instead of relaxing our body, that acceptance becomes a transformative process.

One of the moderators suggested that a hobby or something the person felt passionate about could be used as a distraction from BDD symptoms. Reflecting on her personal experiences, she disclosed that the forum had given her a feeling of belonging and being good at something, which increased her self-esteem:

**Female-moderator 2:** People here say that it helps to have something you're passionate about that has nothing to do with the way you look. Do you have anything like that? It could help with your self esteem a lot. I have this forum, for [example] and it gave me a feeling of belonging and of being good at something especially when I first started posting here. It could be any kind of hobby that's not related to looks, really.

**Information about recovery.** Individuals also had questions about whether or not recovery from BDD was possible. The desire to feel "normal" and overcome BDD symptoms was a goal for most forum members. One person was extremely persistent in trying to find out if BDD could be "cured" and he posted this question multiple times on the forum. Two members, including one of the frequent posters, responded by assuring him that recovery is possible:

**Undetermined 1:** Yesterday I read BDD can't be cured...  
So, can it be cured?  
I mean, can it be cured like it hasn't happened ever? I'm not talking about easing up the symptoms...  
Or do I have to take medicine for the rest of my life?

**Female 2:** Where did you read BDD can't be cured? That is just untrue. BDD can be healed and you can also help heal yourself. You don't have to take medicine unless you want to. You can't change the past so no you can't forget that you had BDD. Would be nice, but life is just not like that.  
If you put the time and effort into healing yourself you can be happy again.

**Male 3:** To my understanding it can be cured, the best way i've heard is through cognitive behavioural therapy which is basically a rewriting of your thought patterns. There are some that say CBT and use of Serotonin re-uptake inhibitors are the best combination although i've refrained from using any medication so far as a matter of personal principle.

The participant who posted asking whether or not BDD could be cured was looking for hope that he could recover from the disorder. The responses he received from forum members could have encouraged him to seek treatment for his symptoms by increasing his positive outcome expectations. Thus, positive feedback and encouragement from other members could have helped individuals to increase their self-efficacy and motivation to seek treatment. This outcome is explained by the role of social influence, when similar others in one's reference group serve as role models for health behavior (Thoits, 2011).

**Information about BDD resources.** Some individuals specifically requested resources for more information about BDD. Forum members responded by recommending books and websites about BDD and self-help body image books. In the following example, the original poster confessed that she had become "obsessed" with researching BDD since her diagnosis. She wanted members to direct her to additional reading, such as books, websites, and "good forums" for more information:

**Female 1-OP:** So I just now found this site and so far have found some interesting information. I was diagnosed with BDD a little over a month ago. I have Googled BDD only God knows how many times and I still feel like I am not fully informed. Every site I see says basically the same thing! I know the symptoms and everything, but I feel like I am still not getting all the info I can. (I have kinda been obsessed with researching it ever since my diagnosis, lol.) I just feel like there HAS to be more to this. Something so severe and debilitating cannot be that simple! Can anyone refer me to some good reading, on the web or books? Maybe link me to some good forums?

A female member recommended that she talk to a therapist first, and then referred her to books about BDD, including *The Broken Mirror* (Phillips, 2005) and *Body Dysmorphic Disorder. The Broken Mirror* (Phillips, 2005) is considered a seminal work on BDD. The second reference could be the updated, shorter edition titled *Understanding Body Dysmorphic Disorder* (Phillips, 2009):

**Female 2:** I always suggest talking to a therapist first, but if you can't do that, read as much as you can online about BDD. Check your local library or bookstore for books on BDD (two I always recommend are "The Broken Mirror" and "Body Dismorphic Disorder"). If you have a couple dollars to buy them I recommend doing that because I find it really helpful to be able to go back and reference those books whenever I need to, I prefer to have them on hand. I'm no professional, that's just what has helped me over the years.

Another member recommended a self-help guide for overcoming body image problems (including BDD):

**Undetermined 3:** I'm new here was hoping to join the bdd central but it appears to have gone off line but anyway, I am currently reciving CBT for my BDD and I was recommended a book by

my therapist which I bought straightaway and it's so far very useful , it is from a series called Over Coming. So overcoming body image problems including bdd, self help guide with CBT techniques by David Veale, Rob Willson and Alex Clarke, not sure If you can get it on a kindle though...

Individuals in the study were unsure where to get treatment for BDD and if treatment would work for them. People were also uncertain as to whether or not they had BDD. Thus, new members asked existing members for a diagnosis or to confirm a previous diagnosis. Asking for a diagnosis from other members has also been found on a depression forum (Giles & Newbold, 2011) and was used to establish that individuals belonged to the online depression community.

**Information about causes and symptoms.** Individuals in the study did not specifically ask for information about what caused BDD. Most members who disclosed having BDD symptoms put the responsibility on family members and friends, due to rude comments or teasing by others. Participants offered possible causes for the disorder based on their own experiences, supplemented by articles and books about BDD. Possible causes for BDD included dysfunctions in the brain, distorted self-perceptions, and low self-esteem due to getting teased and bullied during childhood. These are all considered possible causes for BDD by researchers, though the exact cause of the disorder is unknown (Feusner et al., 2010).

One of the members on the forum used scientific terms when teaching another member about neurological causes for BDD:

**Male 2:** Research has shown that aspect of BDD is due to neurological abnormalities. The human visual system has links to a structure in the brain called the amygdala. The amygdala is responsible for processing fear responses. The link to the visual system allows us to tell when something we are seeing is a threat. The problem with those of us who have BDD is that whole system is overactive. We process too much visual information as threatening and since we are fixated on our looks, everything we see in the mirror or in photos of ourselves, seems frightening, even when it objectively isn't. That is why we can see extremely minor details and feel that they are overwhelmingly horrible.

The previous explanation provided valuable medical knowledge about the neurological causes for BDD. However, one of the reasons that individuals find online forums valuable is reading easy-to-understand information in plain language from one's peers (van Uden-Kraan et al., 2008). The same member used less technical language in another reply when comparing abnormal visual processing in BDD to "hearing voices" in schizophrenia:

**Male 2:** This condition is so tricky and so deeply ingrained and so severe that it really is impossible for most of us to see ourselves accurately, even for a brief moment. Your perception of your own reflection, just like mine, and just like everyone else here is probably completely f\*\*\*ed up. The reason is neurological. Your brain is lying to you. This is the case with all of us. Virtually everyone with BDD has abnormal visual processing in the brain. In many ways it is completely different from people without the condition. Just as the brain of someone with schizophrenia perceives voices that aren't there, the brains of people with BDD perceive deformities that aren't there.

The member above, who had concerns about losing his hair, had been in therapy for BDD. That could account for his extensive knowledge about possible causes for BDD and awareness that his perceptions were not accurate. Another poster attributed low self-esteem as a possible explanation for why a female member was convinced that her hands were too small for her body:

**Undetermined 2:** It could be that for reasons that began either in your childhood or earlier life, you have developed a sense of low self esteem and have fixated on your hands in order to explain your low self esteem. I am sure that your hands are fine, but this doesn't really help or take away your feelings of low self esteem. Finding out where these feelings began can really help as it sounds to me that somewhere along the way you forgot how to love yourself. Therapy can help you to find the patterns, where these feelings originated, and how they impact upon you today. You may need to explore what your childhood was like, how you related to those close to you, and how they related to you.

One member explained to a poster who suffered from an eating disorder that childhood bullying could affect a person's self-confidence and behavior later in life. Bullying has been found to be a contributing factor in the development of BDD symptoms (Feusner et al., 2010). The male poster described the outcome of bullying and its impact on a person's self-esteem:

**Male 2:** Being bullied has a terrible effect on many people, I myself received so many put downs, called names, ridiculed, etc about my appearance - and it has a huge impact on one's life. Your problem is very logical, you were hurt so badly by people's judgements of you, you were made to feel worthless, inadequate, shameful, that you weren't good enough, etc. It absolutely batters our ego, our ego is crushed, we feel worthless, not good enough, shameful, worthless, etc. It is only natural as a result you aimed to perfect the part of you that you were judged negatively for - your weight and you have managed it.

Some individuals wanted to know if their obsessive thoughts and compulsive behaviors were symptoms of BDD. Responses by forum members were usually helpful in terms of teaching that BDD could cause distorted self-perception and compulsive behaviors. The following reply was posted by a male forum member who instructed the person about BDD, assured him he was in "good company" on the forum, and encouraged him to seek professional help:

**Male 2:** Fortunately, the symptoms of BDD are now being understood by the most of the medical profession and no-one's going to laugh at you, cart you away or lock you up – but they may not recognise how serious it is by looking at you—you will have to tell them how terrible it gets.

Do a few Searches using the search facility above and see what good company you're amongst. Try and write down those fears...give them a voice and just see how common they are. Hopefully, you'll then be able to pluck up the courage to seek some professional help and support.

Sharing information about BDD symptoms and causes was done primarily by members who were in treatment for BDD. These individuals used what they had learned about their symptoms from clinicians and from doing research to teach others on the forum about possible causes for their BDD symptoms.

**Information about plastic surgery.** Some members wanted to get cosmetic surgery to fix their perceived flaws, despite the disappointing results disclosed by others. Their desire to have cosmetic surgery was countered by concerns and worries that they would no longer recognize themselves, or would look worse after surgery. As a result, individuals sought information about the benefits of surgery and if it was helpful for alleviating BDD symptoms. In the following example, one member wanted to get surgery to fix his/her nose:

**Undetermined 1-OP:** So, I'm very focused on a certain flaw; a bump in my nose. I told someone my worries about it and they said there's nothing there, and mentioned BDD. But the thing is, I have evidence proving it is there. I can feel it, and it seems as though I've inherited it, so how can I be imagining it if it's so obvious it's really there? I want a rhinoplasty and nobody is listening to me..

Two other members shared their belief that surgery could be helpful if the person's life was "being destroyed" by fixating on the perceived flaw:

**Female 2:** I believe that if you indeed think your nose does not make the best of your face, you could have a rhinoplasty. Think long before you do one, and choose the right type of surgery. I know people may disagree and say that we need to accept this fact, but I disagree. For us who have been good looking and lived years being treated in a certain NORMAL way, will be miserable after "the change of appearance".

**Male 3:** I personally think surgery is not necessary because I find nobody ugly and will always say no you really don't need that you look fine. But for people like us who fixate too much on them to a level that their lives are literally being destroyed—surgery can be a very affective cure, of course speaking from personal experience.

One of the forum moderators also responded to the original poster. She pointed out that even if the flaw did exist, focusing on the bump could be related to BDD. The moderator cautioned against getting plastic

surgery, and recommended that the person get advice from a therapist, since she could not confirm the BDD diagnosis on the forum:

**Female-moderator 4:** Even if it is there, maybe you worrying about it [bump in the nose] and obsessing over it might be a sign of BDD or traits, thought I couldn't tell you for sure and we're not professionals here. You could talk to a psych about this and see what they think and ask them to help you. Surgery is not how you treat BDD, the "obsession" just moves to another part of the body and it goes on forever with no therapy.

Despite the poor experiences with plastic surgery disclosed by members, most believed that surgery could help fix perceived flaws. However, four of the most frequent posters and the two moderators countered this advice and reminded people that surgery was not helpful in relieving symptoms for those with the disorder. In this way, the poor advice offered by some members was corrected by others who were either in therapy, or given the task of moderating the forum. This is consistent with previous findings that when misinformation was posted on support forums, others intervened (van Uden-Kraan et al., 2008).

**Information about appearance concerns.** Despite the visual anonymity offered by the BDD forum, most appearance-related information was focused on finding out if a person's perceived flaws were real and if the person was ugly or not. The cognitive dissonance (Festinger, 1962) caused by individuals seeing themselves as ugly in mirrors, photographs and/or videos, and yet being told they looked fine by significant others, led them to question forum members about their appearance. Reassurance seeking on the forum consisted of direct requests for information about one's perceived appearance flaws, and indirect requests for opinions about the body part or facial areas of concern.

One member asked a direct question about his perceived ugliness in his initial post. The message began with a lengthy self-introduction (almost 1,500 words) that included his childhood experiences and how his appearance changed in mirrors, pictures, and videos. He was currently in therapy and on antidepressants, but did not believe he had BDD, because he saw a distorted image in more than just mirrors. As a result, he wanted to know why the left side of his face looked so much better than the right, and if he really was ugly:

**Male 1-OP:** And the problem is am I really ugly? I mean the video says the truth right? if somebody has bdd he sees himself wrong in the mirror but not in the pictures and video right? So why do I look different in them too? I look good in some of them, I look terrible in some, I look like a nice kind guy who I am in one and I look like a stupid manly guy in another one. I feel I look old in some of them and I look younger than my age in some other (people used to think im younger than my brother who is 4 years younger than me but last time i had this compliment it was a year ago) What is this? Am I going completely insane?

Forum members also engaged in more indirect forms of information seeking by asking others about appearance flaws of concern to them. One of the most frequent posters started a thread by asking if other people found women with excessive body hair disgusting. Two other members, including another of the most frequent posters, responded that they did not. The frequent poster who responded insisted that she would not find excessive body hair disgusting but other people who were “vain and ignorant” might be judgmental.

**Female 1-OP:** If you saw a woman and she had a really hairy face and arms and legs. Would you think she was disgusting?

**Female 2:** No, I definatley wouldn't. But some people out there are cruel and judgmental and if something is different to what THEY think is right then to them it's not socially acceptable. What I'm trying to say is vain, ignorant people may judge you. But there are alot of people who I'm sure wouldn't. If you are ok with it then don't change it. But if it really bothers you there is loads you can do to change it.

The second member was similarly reassuring and provided an example of a female co-worker who had a “really hairy face” but was not perceived as disgusting:

**Undetermined 3:** I used to work with someone who had a really hairy face, it was blonde fine hair I'd never see someone quite like it before, but no I did not find it disgusting.

The original poster responded to both members thanking them for their positive perspective. She also confessed that she was obsessed with her hair/skin and was relieved to know that neither person would be “repulsed” by her appearance. Their replies seemed to console her despite neither member being able to provide feedback on her actual physical appearance:

**Female-OP 4:** [Female 2] Thank you for the positive perspective. You may already realize I'm obsessed with hair/skin. Hair removal is also an issue for me but I won't bore you with details. All I know is, medical and social standards are not matched. This is a real point of stress for me.

[Undetermined 3] Thanks for your perspective, I certainly need it. Very interesting your first reaction was not repulsed, as my BDD would have me believe.

Individuals usually responded to requests about another's appearance by assuring the person that the perceived defects were probably unnoticeable to others, instructing the person that such thoughts were related to BDD symptoms, and advising the person to get help from a therapist. One of the frequent posters responded to another member by explaining that his appearance obsession was related to having BDD:

**Female 2:** It is clear that this is an obsession of yours to find out "am I ugly, average/normal or good looking?" And the fact that your family does NOT see the flaw that you see points towards BDD. But your family is not lying. Not either can we EVER know what each individual of this planet thinks of our looks, since it is so different what people see as beautiful.

She also pointed out that, even if he could learn what he "really" looked like to others, he might still be worried about why some people did not find him attractive:

And even IF you KNEW, you would probably still be preoccupied about WHY doesnt ALL of them think you look good, and how will I know who I got a chance with or not? And shall we all then wear labels that tells other people what we find attractive? And even if 90% of the population thinks you are beautiful/handsome, you will probably still take offense from those who dont, that gives you an uninterested or disgusted look. Do you see how this problem just cant get solved by thinking like this?

Other members suggested that therapy would be helpful for people who wanted to know if they were ugly or not. The original poster in the following exchange believed that his left side looked better in both mirrors and photographs. However, his parents told him he was wrong and that it was his imagination. Unsatisfied with this response from his primary group members, the male poster wanted forum members to tell him if he was ugly or not:

**Male 1-OP:** Another problem is that I look way way better from left both in mirror and camera. I can tell other people feel this by seeing them by corner of my eyes but still my parents tell me Im wrong and its only my imagination. All these makes me so confused ! Am I ugly or not just tell me please!

A female poster emphasized with his concerns about feeling ugly since she was also "terrified" that others would find her ugly. She advised him to get help, since many people (in her opinion) looked worse than they did and functioned well:

**Female 2:** I feel the same way. I get a lot of anxiety about facing the world, having people see me, and I am terrified of the thought that someone in the world may think I'm ugly. I think of a lot of situations in my mind where I'm looked at as ugly and worry they will happen. The solution to all of this is getting help. There are so many people in the world who are a lot worse looking than us and they function just fine.

As shown in the previous example, participants often made assumptions about one another's appearance, despite the visual anonymity offered by the BDD forum. Personal images were not allowed on the forum, but that did not prevent individuals from asking other members for feedback on their perceived appearance flaws and ugliness.

In the following example, a female poster also thought that one side of her face looked better than the other. She wanted to know if she had BDD or if she was a "truly ugly girl" who could not accept her ugliness:

**Female 1-OP:** I think only one side of my face looks good. The right side of my face looks smashed in and very ugly. I'm so confused. Do I have BDD? Or am I just a truly ugly girl who can't accept that she's ugly?

One member responded by providing her with masks showing "perfect physical proportions" to determine if she had facial flaws. Another person reassured the original poster that she was probably not as ugly as she thought, then provided a lengthy personal disclosure (about 1,000 words) outlining her own BDD experiences and suicidality. She ended the message by advising the original poster to take a self-test for BDD and to keep posting on the forum:

**Female 3:** I feel for you. I really do. I am sure that you aren't as ugly as you think you are. If only I could tell myself that. I have always been really good at giving other people advice, but when it comes to me.....Well, I feel like I am too ugly to live. . . . There is so much stuff online for you to research this topic. If you go to psychcentral there is a test you can take to see if you are suffering from BDD. It should not take the place of a therapist but it is an excellent site for information. All I can tell you is to keep posting here and listening to the feedback that you get. I am sure that someone will come up with some ideas here sooner or later.

In the previous thread, the person who replied and felt "too ugly to live" was herself suffering from experiences similar to the original poster. She was uncertain as to whether or not other members would be able to offer helpful advice, but believed it could happen if the other person kept "listening to the feedback" she received. The original poster thanked the others for their help and disclosed that her family did not suspect she had a mental health disorder because BDD is "pretty unknown."

Another female poster asked forum members why she had recently developed an obsession about her skin complexion, despite getting reassurances from “everyone” that she looked fine:

**Female 1-OP:** Why did I suddenly develop an obsession about my skin NOW when I was totally fine when I actually had pimples a few months ago?  
Will I be able to see myself with glowing skin again? Why am i being like this? Am I really seeing something wrong?  
I always ask everyone for reassurance and their answers are always the same...”Your mind is playing tricks on you...seriously you look the same...etc. etc.”

Forum members did not have access to images of the person who posted the message, but that did not prevent them from providing opinions about her symptoms and appearance. One of the forum moderators agreed that her mind was “playing tricks on her” based on the feedback she had received:

**Female-moderator 2:** Assuming you trust these people to be honest, or you’ve asked several people separately, then I would say that yes, your mind is playing tricks. It’s perhaps not that you’re seeing something that isn’t there, but your brain is interpreting what it sees differently to the other people. It’s focusing on the exact shade of your skin and over-emphasising it to an unhealthy colour.

Seeking assurances about one’s perceived appearance flaws from other forum members could also backfire. A male poster wanted forum members to look at pictures and tell him if his “big head” was hidden by his hair because he was too embarrassed to question family members. In response, another poster warned him that she might look at the pictures and confirm that his head really was big. She confessed that she wanted to ask others about her nose but was afraid they would confirm it was huge:

**Male 1-OP:** Because I’m too embarrassed to talk to a family member about this, I’m looking for someone kind, honest and with a deal of maturity who will look at pictures of me and tell me if I now look normal; and if so, why does having my hair the way it is hide my big head? Is it because it masks my forehead? My neck? I’m really confused and depressed, please help!

**Female 2:** I’d look at your pics, but what if your head really is big? would you be able to accept someone saying it is? I want people to look at my nose but i don’t know if I can truly accept someone saying “yes it definitely is huge” Think about it!!

Another female member received an affirmative response to questions about her perceived ugliness. The person who replied to her inquiries believed that he was ugly and wanted to convince other members they were as well:

**Female 1-OP:** But I guess my point is, it isn’t just my imagination. So many others have told me how ugly I am, that I must believe it’s true. So is it BDD, or not?

**Male 2:** From my experience, most attractive people are never told they are ugly and are constantly told they are beautiful. Ugly people, on the other hand, rarely receive comments on their appearance, but when they do, they don't always receive positive comments. In short, if you've been told you're ugly, you probably are. (Disclose: I've been called ugly many times and have never once been called anything better than "average looking.")

The answer provided by the male poster might appear to be unsupportive, since he was trying to convince the person that she actually was ugly, rather than having BDD. However, she validated his response by confirming that she was ugly, but still wanted to know if she could have BDD. He replied that if she had real flaws, she could not also have BDD:

**Female 3-OP:** So I am ugly. Fact. But does that eliminate the possibility of BDD?

**Male 4:** I would say so. I mean, you probably have the symptoms of BDD, but if these symptoms are due to *real* flaws, then I don't see how you could call it BDD. Being ugly is extremely painful, and it's natural to be upset over it and want to get surgery to fix it.

The poster's response that having appearance flaws meant a person could not also have BDD was misleading and false, according to the medically-accepted classification for the disorder. According to the *DSM-5*, BDD is classified as a preoccupation with flaws that *appear minor or are not observable to others* (APA, 2013). The male poster may or may have intended his response to be supportive, but the original poster seemed to agree with his assessment of her situation. Their exchange indicates that the meaning of supportive messages does not reside in the message content, but in the perceptions of the participants (Albrecht, 1987).

As shown by the examples above, seeking assurances about one's appearance concerns occurred despite the visual anonymity offered by the forum. Seeking information about one's perceived flaws from others is considered unhelpful for those with BDD symptoms (Phillips, 2009). The desire to find out if a person was truly ugly or had BDD was evident when individuals sought a diagnosis from other members. Asking about a diagnosis from peers has been found in other studies of mental health forums (Giles & Newbold, 2013) and is considered a way for participants to reduce uncertainty about their condition.

### **Emotional Support**

Individuals on the BDD forum also sought and shared emotional support with other members. The most common types of emotional support in the study were empathy/understanding and

caring/concern, due to being both sought and shared by study participants; there were 139 comments expressing empathy and 118 caring/concern comments.

**Empathy with members' experiences.** The most prevalent type of emotional support sought and shared on the forum was empathy. Empathy included statements that the person understood the recipient's situation (Cutrona & Suhr, 1992), shared similar feelings with the recipient, or could relate to the recipient's experiences. Empathy with others' problems included identifying with their appearance obsessions, feelings of general ugliness, and behaviors related to perceived defects.

Individuals often shared their personal experiences with BDD and then asked other members if they felt the same way or had similar experiences. For example, a male poster who was obsessed with "stretch marks" on his body wanted to know if others on the forum could relate to his experiences:

**Male 1-OP:** I was diagnosed with BDD a couple months ago. At first I didn't think I had it but now I'm certain I do. I am a 23 year old guy and for some reason I developed a ton of stretch marks. I hate my body because of them and whenever I see them I get angry. I get told I'm handsome and get looked at all the time, but all that goes through my head is "if only they knew what was under these clothes. I've never dated because of them even though I want to. I'm just sick and tired of these things ruining my life when they shouldn't be. I just thought it would be nice to hear others experiences and if there's anyone that can relate to me.

Another male replied that even though he did not have BDD, he could relate due to having third degree burns on his body. He empathized with the original poster's experiences, encouraged him to not focus on his flaws, and reminded him that he was not alone:

**Male 2:** Well, I can relate to the whole "whats under the clothes" thing and I'm 25 never dated or anything as well. I don't have BDD btw, but I have similar compulsive worries due to 3rd degree burns and dentures at 25 lol, so yeah I can't offer much experience advice considering I never really overcame anything yet so im in your boat but, keep your head up bud. I know your opinion on your body matters alot more to you then someone elses opinion that implies you look fine, I try not to focus on my flaws alot but its very hard to do so don't feel alone!

Members' responses could also reinforce others' negative thoughts about being ugly and hating their appearance. One male poster disclosed how much he hated his ugly face and felt that he would always be unattractive to women as a result. A female member responded by relating to his feelings of being ugly. She reminded him that they both had "as much value" as the most beautiful people in the world:

**Female 2:** hi i am soooooo tired of being ugly too. so very tired of it. and its hard a lot of times, when i have to look in a mirror or see a picture of myself and i just really dont want to look at it

(my image) anymore. i feel like my soul belongs in a different body, a pretty one. please remember you and i, we have every bit as much value as the most beautiful people in the world. they did nothing special or good to deserve being born with beauty and i did nothing “bad” to deserve being born without beauty.

Individuals on the forum who had received plastic surgery and were unhappy with the results often sought empathy from others. A female poster described the results of her rhinoplasty procedure and asked if anyone could understand her feelings. She felt that the surgery had made her face unrecognizable.

**Female 1-OP:** What a nightmare this year has been for me. I had low self-esteem before I got the rhinoplasty so I thought maybe it could make me feel better. HUGE mistake, I am so lost right now. I don't feel like the self i used to feel anymore. I am not strong anymore, I cry everyday. When i look in the mirror i don't recognize myself. Does anyone understand this?

The poster received a response from another member who also felt that she had ruined her face with plastic surgery: “I got rhinoplasty 5 days ago. And I feel the same. I have got drastic change on my face. Is it beautiful? surely not. It is the ugliest thing in the world.”

Individuals also empathized with other members' desire to commit suicide. In the following example, a forum member (undetermined gender) understood another's desire to commit suicide, since the person also planned to have a second surgery to fix the results from the first: “I understand, because I am also planning a surgery and if doesn't work out then I am planning to kill myself.” Thus, members with extremely harmful BDD behaviors could find others who shared their thoughts and feelings. This finding reflects studies of self-harm and pro-anorexia sites where peer support could encourage self-injurious and potentially lethal behaviors (Haas et al., 2011; Whitlock et al., 2006).

Individuals also responded with empathy by indicating how similar their problems were to those of other members. For example, many males in the study were distressed by the thought that their perceived flaws made them undesirable to women. One poster responded to another man's desire to have a stronger jawline so that he could be attractive to women:

**Male 2:** For a second I thought I wrote this. You and I have EXACTLY the same story. I have a problem with my jawline as well. This thread blew me away, because it captured the feelings I feel everyday as a man with a weak jawline....and how hard it is to cope with being unattractive to women...and society because of it. There is TREMENDOUS pressure on men to be HOT and attractive too.

Another example is when a female poster felt she was “literally” reading about her own experiences in another person’s post:

**Female 2:** Wow, reading this I literally felt like I was reading about myself. Im 22 too and I’m extremely pale, i have a huge nose, i have small weird eyes, my face is weird, wrinkles ( ☹ ) and im too short....I know how you feel, dont you wish you could just go to a bar like other people our age and feel normal?!?!?!? And the picture part, I hate it, I always make sure I’m facing the camera straight forward and I’ll go on facebook so much the next fews days just to check pictures that were tagged of me.

The close affinity that members felt with others’ experiences can be viewed from the hyperpersonal effects perspective of online text-based communication. Chat room and online forum participants have been observed making over-attributions of similarity when communicating with others under conditions of visual anonymity (Lea & Spears, 1992; Walther, 2011). In addition, reciprocating another person’s feelings and experiences can enhance one’s sense of belonging to the online group, which can buffer the negative effects of stress (Tanis, 2008).

**Caring/concern for other members.** Seeking and sharing caring/concern for one another’s suffering occurred almost as frequently as empathy/understanding in the study. Requests for caring and concern from others on the forum were made by asking for help, support, and guidance. Caring/concern requests were often made after disclosing BDD symptoms, without specifying what type of support was needed. In the example below, a male poster needed “someone” to help him. He wanted to talk honestly about his problems and get some perspective so he could return to his old self:

**Male 1-OP:** I don’t even know why I’m writing this. I just don’t know what to do anymore. I need someone to help me. I need someone to talk to honestly about my problems so I can perhaps see the whole thing from a different angle. I don’t want this to take over my life, I want to be the old me once again; the happy, enthusiastic, ambitious and sweet boy who made everyone laugh.

The desire to return to one’s “normal” self was common for individuals in the study. Members also posted messages asking for help when they were suicidal and alone, sometimes at night when there was no one else around to confide in. Online support groups offer advantages to those with stigmatized health conditions, since they provide access to support 24 hours a day, when professionals and primary group members might not be available to help (Burnett & Buerkle, 2004). For example, one female poster

wanted to talk to someone during the night while she was having a panic attack and contemplating suicide:

**Female 1-OP:** Is anyone up or can someone talk to me? I'm laying in bed, but I cant sleep and I am having a panic attack...

I ate some stuff today that will probably make me gain a lot of weight and my mind is racing about everything..I feel so disgusting and worthless I dont want to be here anymore. Someone please help me. I dont know what to do anymore. I just want everything to disappear..

One of the frequent posters responded showing concern for her condition: "Sorry i wasn't around when you typed this, are you alright?" The original poster was grateful for his reply: "I completely appreciate you replying, regardless of the time." Expressions of caring and concern were also provided to individuals who disclosed their intense suffering related to the disorder. One male poster responded to a female member who was feeling suicidal by offering to help her with "anything" she needed: "I really really wish you the best as you sound like a nice person and you don't deserve what you're going through. I really hope I've covered everything, but please if there is anything you'd like me to help with please ask."

Members expressed compassion by letting others know that they were not alone and that people cared about them: "How are you? I hope you're doing okay." One member offered to pray for the person in distress: "I'll keep you in my prayers." Caring/concern was also expressed by the most frequent posters and other members by sharing holiday greetings on Christmas day. These findings are consistent with research on support forums for cancer (Bambina, 2007), eating disorders (McCormack & Coulson, 2009), and HIV/AIDS (Mo & Coulson, 2008) where members created a supportive community by expressing caring/concern for others, including offers to pray for other members.

**Sharing gratitude, encouragement, sympathy, compliments, and validation.** Individuals' positive actions and ideas (both online and offline) were reinforced by other members on the forum. Comments providing gratitude, encouragement, sympathy, compliments, and validation were shared rather than sought; there were 97 thanks/gratitude comments; 72 encouragement comments; 61 sympathy comments; 46 compliment comments; and 26 validation/agreement comments.

Expressions of thanks/gratitude were shared both in initial message posts and in the replies. In initial posts, members offered thanks in anticipation of receiving help and advice (“Thanks in advance for your help”) and to others for taking time to read the message: “Thanks for reading this!” One female poster started her message by acknowledging that she had been reading the posts for a few weeks and was grateful for the advice given to others on the forum:

**Female 1-OP:** I’ve been reading the posts on here for a few weeks trying to sort myself out and you guys really seem to know what you’re talking about, I just want to say thanks for the advice i’ve picked up from the replys off the other posts.

Sharing stories about one’s suffering and asking for help could in itself be beneficial, as shown in the following post by a female member who disclosed her feelings of ugliness, despite getting positive feedback on her appearance. She asked members for help and was grateful to be able to write about her feelings on the forum:

**Female 1-OP:** i feel ugly and disgusting even though from what i hear i’m def. not. i just can’t believe it. i’ve been accused of fishing for compliments when i can’t get my hair right, or i think jeans don’t fit me perfectly right and i look decent otherwise. i’m just running out of options. i really wish i didn’t have these feelings about myself, i’m the only one who should pass judgement on myself and instead i’m relying on others and instead not believing a word they say. i really need some help and would be thankful for anyone that replies to this. wow. it feels good to get that all out. thank you all so much.

The female poster above reflected on her habit of relying on others for reassurance that she was not ugly. She knew that only she should judge herself and was grateful for the opportunity to express her feelings on the forum. She thanked other members in advance for their replies and help.

One male forum member posted his story of recovery from BDD specifically in order to encourage other people on the forum to get treatment and to provide a positive example that recovery from BDD was possible. He disclosed that being in group therapy for BDD had been difficult because he knew other people were scrutinizing his appearance. As a result, he found it helpful when he returned to the university and was around people who were “normal” in terms of not judging people on their looks. He ended his post by encouraging members to keep pushing towards recovery from BDD:

**Male 1:** The reason i wrote here was to create a perception for you all on what it’s like “post” BDD. I know alot of you won’t believe it’s possible to reach this level, but i urge you to keep pushing and pushing... I want you to know it’s possible. I’ve done stupid things, lost friends

family and partners cus of my BDD fuelled behaviour. I know what it's like, but i urge you to keep going, you will get there, and when you do you'll feel complete. That feeling of completeness is so much more than anything you might be looking for. Remember don't compete with others... compete with yourself and you shall set yourself free.

Two members expressed gratitude for his great post. They found it inspiring and motivating, and were glad to know that beating BDD was possible:

**Female 2:** Thanks for your post ☺ it's really inspiring and motivating. It's great to hear from someone who is beating BDD! I often wonder if it is truly beatable, but you prove that it is.

**Female 3:** I thank you also for this great post. What you've put here is very encouraging. I think you've hit the nail on the head focussing on management rather than cure. I'm come to realize the same in regards to my own Bdd—questing for complete freedom from it I've found to be futile at best, counterproductive and damaging at worst.

The original poster responded to both members by thanking them for replying to his message. He addressed each of them personally and further encouraged them to keep fighting because they could also beat the disorder:

**Male 4-OP:** Thank you [Female 2] for finding my post inspiring:) It is indeed beatable and i hope you beat it soon for you deserve alot more in you're life than what BDD brings you. It will be hard and it's always a mode you can slip back into. But I promise you though it is beatable, and you will beat it, keep going and hold your head high, avoid all the traps BDD puts you into, and you'll feel free.

Thank you [Female 3] also for your response. You're absolutely right focus on managing the BDD and it'll become so minimal that you won't notice it being there at all. Then the trick is to become so unconcerned with appearance (even more than the average person on the street) that a relapse becomes very small probability wise.

Expressions of sympathy were usually provided in response to others' personal experiences related to BDD. Sympathetic comments contained expressions of sorrow or regret for the recipient's situation (Cutrona & Suhr, 1992). One poster responded with sympathy to another member who was rejected by his girlfriend after revealing he had BDD: "I'm sorry to hear about your experience..." One of the most frequent posters expressed sympathy for a female poster who was struggling with BDD symptoms: "I'm sorry you are struggling, and I'm glad you've already found the forum helpful."

Compliments were offered to members for their use of effective coping strategies. Compliments contained positive words and praise for the recipient (Cutrona & Suhr, 1992). One person suggested a

“forgetting box” to put away negative feelings and thoughts that she experienced due to her BDD symptoms. Another member complimented her on this coping technique:

**Male 2:** If your point is what i think it is then it’s a good one. Yeh it is a lot easier to remember the bad things that happen in your life rather than the easier ones, it’s a psychological way of making sure it doesn’t happen to you again by keeping it in the mind.  
Your ‘forgetting box’ is a good idea, if it works for you then that’s fantastic.

In response to a female poster who was trying to accept her ugliness as a blessing from God, another member complimented her on each part of her message:

**Male 2:** That’s a beautiful thing you write. Why does it have to be ugly? Why aren’t you just unique in who you are?. . . The way you see yourself, in leaps and bounds. That’s awesome in your ability to do that. If only more people thought like this, I think the world would be filled with a lot less depression, self-persecution, and otherwise. . . You’re a positive role-model for diveristy of character and being. . . That’s just grand.

Members encouraged others to post messages on the forum, to seek treatment, and to keep fighting despite feeling suicidal. Comments containing encouragement sought to instill hope and confidence in the recipient (Cutrona & Suhr, 1992). One female member offered words of encouragement to another person who was brave enough to disclose his/her feelings on the forum, and provided hope for overcoming BDD:

**Female 2:** The good news is you are talking about it! It can be the hardest thing just to post on here. Just know there are so many options for you. So many things out there you can benefit from, loads of people that can and will love and support you, so don’t lose hope, you can overcome this ☺ keep posting if you want I’m here pretty often.

Another member responded to a female poster who was contemplating suicide by empathizing with her feelings of self-hatred. She offered reasons for hope, and encouraged her to continue fighting the disorder:

**Female 2:** And I know how it is to hate something that is yourself so much that you want to die. It comes in waves and we need to survive those days hun, we can, we are so many fighting here with the same thing, a self-disgust! Stay with us and fight. Shared pain is half pain! Give me some some right now. . . Hang in there, dont give up, you are very strong! <3

Members also shared emotional support by validating another person’s ideas and opinions. Validation comments expressed agreement with the recipient’s perspective (Cutrona & Suhr, 1992). As shown below, one poster agreed with another that he needed to focus on thoughts other than his jawline.

He wanted the person who replied to his post to know that he still struggled with BDD symptoms every day:

**Male 2:** You are right - I have to focus on other things besides my jawline. I'm actually a lot better about this than I used to be but I still have problems with it, obviously. I wrote the OP when I was feeling particularly bad. It's a struggle each day.

In another post, a member announced that she was finally starting CBT treatment after years of "muddling" through various medications and therapists. She was concerned because she was "feeling okay" and did not know what to expect from the treatment. A moderator responded that she had also received CBT treatment, and that it had helped, but was not a "magic wand." She agreed that having reservations about treatment was understandable:

**Female-moderator 2:** I definitely agree with the wait and see, though. I did a brief course of CBT for stress and anxiety and it was very helpful. But not a magic wand. I'd hope it'll help you in places, but I think you're right to have a few reservations and not to go in expecting a miracle.

In summary, members sought and shared empathy and caring/concern with others on the forum. They also provided compliments, sympathy, encouragement, gratitude and validation for others' opinions and advice. The most frequent posters, moderators, and forum members helped to make the BDD forum a supportive place by providing almost as much emotional as informational support to participants. Emotional support was found to be the predominant type of support on forums for cancer (Bambina, 2007) and male eating disorders (Flynn & Stana, 2012). These findings indicate that online forums are valuable due to the support they provide individuals suffering from serious mental and physical conditions which may be unavailable from their friends or family members.

### **Social Network Support**

The third type of support sought and shared in the study was social network support. Social network support contained two subcategories; references by members about being part of an online community (being present) and comments about the forum as a place to find similar others (companions) who understood the disorder. Social network support occurred less frequently on the forum than informational or emotional support. This finding is similar to other studies of online forums for HIV/AIDS and cancer (Coulson & Greenwood, 2012; Coursaris & Lui, 2009; Mo & Coulson, 2008)

where social network support was less prominent than informational or emotional support. There were 130 comments about being present on the forum, and 55 comments about finding similar others (companions). Most of the social network support comments were provided by the most frequent posters to the forum, and will be discussed in more detail in RQ4.

**Being present on the BDD forum.** Members and moderators welcomed new members to the forum and praised the forum as a supportive place for individuals with BDD. In the following example, the original poster announced that she was recently diagnosed with BDD. No one in her primary group of friends and family members knew about the diagnosis and she was too afraid to tell them. She was seeking other members who would be willing to “group chat” or help her:

**Female 1-OP:** I was recently diagnosed with body dysmorphic disorder. I’ve had it for almost two years now, and I have no idea how to cope with it. No one knows, and I’m too afraid to tell anyone besides my doctor. I just need a friend and some strategies to suppress my anxiety. I’m a runner, I have a happy heart and soul, but a depressed mind. I’m creative and funny.. But I’m just hideous. Does anyone have an iPhone where we can group chat? Or is anyone willing just to help me..?

As suggested in RQ2, the BDD forum was a place where individuals could share their personal experiences with others who understood the disorder. Reading about others’ problems on the forum could help members get some perspective on their own difficulties, as shown in the following example. A new member found the forum on his/her search for a BDD cure because CBT did not seem to be working. The person posted to the forum to get some perspective on his/her problems:

**Undetermined 1-OP:** Have been feeling pretty crap recently and found this forum on my google-cure adventures. I’ve come to the conclusion that CBT isn’t working, and I’ve got to accept that I’m never going to feel better...I guess posting here is an attempt at getting some perspective as things are never as bad as I convince myself!

One of the moderators replied that she hoped the forum would enable the person to get some perspective and feel better: “I’m glad you’ve found the forum, [name]! And perhaps “getting perspective” will turn out to be an alternative way to feel better.”

Another new member was not sure if he had BDD or not but he had many of the symptoms. In his message he revealed that the condition had put a “terrific strain” on his relationship with his family since he couldn’t leave the house, had dropped out of school, and could not hold down a job. He concluded his

post by expressing his appreciation at finding others who felt the same way he did: “Thank you for reading. It can get extremely lonely at times so it’s nice to know there are others out there who feel the same, and that you’re not completely alone.” The moderator and a member responded by encouraging him to post to the forum and congratulated him on having the courage to discuss his symptoms online:

**Female-moderator 2:** You could read through this forum a bit if you like, see if it helps, and post here too.

**Male 3:** Congratulations on posting by the way, it can be hard for people to discuss these kind of things and you’ve come to the right place the people on this forum are fantastic.

Members encouraged others to keep posting to the forum to get advice and help, and offered to support new members. One poster (undetermined gender) responded to a female member who felt she was ugly and that other people were making negative comments about her looks. The person let her know that BDD forum members were available to listen and help her:

**Undetermined 2:** I think it’s great that you posted this and are talking through it, it’s hard to write about our experiences. Feel free to keep posting about your thoughts, feelings and experiences. We’ll do our best to listen and support you.

**Finding similar others/companions.** The ability to disclose one’s feelings to others who understood the disorder and shared similar experiences was of great importance to many who posted to the forum. Finding other people who shared one’s “crazy or weird” behavior, such as on a depression forum (Giles & Newbold, 2011, p. 423), could provide validation that a person’s behavior was “normal.” A female poster revealed that her high school friends could not understand how serious her condition was, so she hoped to connect with people on the forum for mutual support:

**Female 1-OP:** The most difficult part of this is dealing with it in the high school setting. I compare myself to everyone. The few friends I have are all very confident and outspoken, and it often feels like no one understands how real and serious this is to me—which is why I found this forum. I really hope I can meet someone to correspond with and provide mutual support to. I need to talk about this with someone who understands. Nothing is working or helping.

Another female member was having a rough time and wanted use the forum to meet other people with BDD. She was afraid to talk to other people because they might think she was “crazy” or mistake her appearance concerns for being vain and shallow:

**Female 1-OP:** I am hoping that this forum will help. I have never met a person with BDD, and I have trouble talking about my feelings about my appearance to other people because I am scared that they will misunderstand, think I am crazy, or think I am shallow or into myself. Sorry for the rant, having a little bit of a rough day.

The BDD forum also extended the support offered by other social network sites and online forums, including BDD Central and Facebook. Some of the previous BDD Central members posted messages to the BDD forum in order to foster a sense of community with other members. The following two messages were posted by former BDD Central members to resurrect popular topics from that site:

**Male 1-OP:** Almost feels a bit disrespectful to BDDCentral making this [thread] but seen as though it was such a popular thread on there, and entertaining at times (seagull talk ☺ ) hopefully it will make things seem a bit familiarish in the meantime. Well it's here anyway.

**Male 1-OP:** We used to have a drawing thread in BDDcentral, so we could insitute a similar one here too ☺ You can post your creative artwork for others to see.

Another BDD forum member posted a message inviting people to visit her college's "Beat BDD" Facebook page that had been created to raise awareness about the disorder. She invited members to visit the page so they could feel less alone:

**Female 1-OP:** I just wanted to share our Beat BDD Facebook page with all of you. It started as a small project dedicated to my friend's uncle who struggled with BDD, but turned into a campus-wide campaign. We worked hard trying to spread the word about this highly unnoticed illness. Below is an event we did to spread awareness and an animation I made to help others develop a greater understanding of BDD. I know that sometimes it can seem lonely, and so we created a Facebook page filled with positive energy and a place for others to connect with another. Our group has disbanded after graduating college, but we hope to keep up this site in hopes of further spreading BDD awareness.

Posting to the online forum was also helpful for people who were experiencing negative feelings and needed to express them. One of the reasons given by a female member was that simply writing down one's negative thoughts could be therapeutic, even when the person was not ready to share them "with the world." Another advantage given was that everyone on the forum understands one another's struggles with BDD symptoms. The poster disclosed that she had tried to explain the situation to her friends, but they could not understand the reasons for her appearance concerns:

**Female 2:** From my experience, the best thing to do in those moments is exactly this: post here. Simply writing down negative thoughts can be very therapeutic, even when you're not willing to share them with the world.

More importantly, everyone here understands your struggles. That isn't the case with people who don't have BDD symptoms. I've attempted to explain my situation to close friends in the past, and they just don't understand. Which isn't to say they aren't caring and supportive, but they can't understand why I'm having those thoughts in the first place. There's nothing rational about BDD, and I think you need to feel those symptoms in order to truly understand how terrifying it can be.

The poster above noted the importance of sharing one's experiences with others who could understand the disorder. The process of sharing one's experiences and writing them down has been shown to increase individual empowerment and a sense of control over one's situation, reflecting the direct effect of social support on a person's well-being (Barak et al., 2008; Diamond, 2000). In addition, the poster's recommendation to write down negative feelings on the forum, as an alternative to sharing them "with the world" stresses the importance of online anonymity. Houston et al. (2002) found that more than one third (37.9%) of participants with depression preferred an Internet support group over in-person counseling, because the online group gave them the freedom to discuss their concerns anonymously.

One male poster came to the forum because he believed he had BDD and the symptoms had kept him socially isolated to the point that he no longer had a relationship with his family or loved ones. He introduced himself as a way of becoming a member of the online community:

**Male 1-OP:** Okay, so this is the second time I'm writing this, the first one didn't appear in the forums?!?! Anyway, I've been reading these forums now for a while but only now did I even contemplate creating an account and saying something so I'll just tell you a little about me, that's how these things work, right? I'm a 20year old male from the UK...

A female member responded to his post by confirming that his symptoms did appear to be caused by BDD, and encouraged him to get diagnosed by a therapist. She then praised the forum as a place where he could share his feelings with others who understood what he was experiencing:

**Female 2:** I think that one of the key things that every BDDer needs is someone to talk to, someone to understand them. Hence the forum. Feel free to share anything. At the previous forum I was at it really helped me ... being able to share very private matters with other people who understood me.

Participants in the study felt supported by being part of an online community and by encountering similar others (companions) who could understand their concerns. This finding is similar to other studies of online support groups where individuals felt empowered and supported by becoming members of an

online community filled with similar others (Bambina, 2007; Coulson & Greenwood, 2012; Coursaris & Lui, 2009; van Uden-Kraan et al., 2008, van Uden-Kraan et al., 2009).

### **Unsupportive Comments**

Although they did not occur frequently on the forum, members made comments that could be considered unsupportive. Unsupportive comments contained expressions of disagreement/disapproval with another person's opinions and advice, sarcasm/criticism directed toward other members, and comments that were considered offensive or hurtful (flaming). Burleson (2002) classified the lowest level of comforting messages as those that either implicitly or explicitly deny the feelings and perspective of the distressed other. There were 17 disapprove/disagree comments and 7 sarcasm/criticism comments.

The unsupportive comments posted in 24 of the messages account for only 1.1% of all the comments coded for the study. This finding indicates that on the BDD forum there were not many unsupportive comments compared to the many supportive comments sought and shared. Unsupportive comments by individuals in the study occurred when members disagreed with one another's advice, opinions, or ideas. The subject of beauty and attractiveness was a common theme in messages coded for the study. One of the most frequent posters believed that beauty is subjective, thus everyone had the potential to be beautiful:

**Female 1-OP:** I was just thinking that I find the thing that really bothers me about beauty is the subjectiveness. I think that's what gets me ... Maybe I don't have a strong enough positive opinion on my looks which allows other people OPINIONS (NOT FACTS) to determine how I feel. I should probably tell myself every single day that I am beautiful.

The poster's opinion that beauty is subjective differed from other members who believed that beauty is objective and that there is one socially accepted ideal for men and women. One member pointed out that Angelina Jolie is considered beautiful by many people. In her opinion, people who did not believe the actress was beautiful were jealous, or tired of the "hype" around her beauty:

**Female 2:** I think there is SOME objectiveness in beauty. I seen you mention Angelina Jolie in your other post, I think she is beautiful too and I don't believe people that say she is not. I think most people that say she is not are either jealous or just tired of the hype about her beauty. I think this is beautiful and I think most people would agree about her face being beautiful, and if they say no I think its her style or something else that they hate.

The second person to respond believed that beauty is “very objective.” His opinion was that people who told each other ‘beauty is in the eye of the beholder’ were ugly people who wanted to make each other feel better.

The same male poster also offered an unsupportive comment to another member who dissuaded him from getting plastic surgery. He felt it was “insulting” to tell ugly people they should not get plastic surgery, since being ugly resulted in a person having a lower quality of life:

**Male 2:** So if you were born with a receding chin, a huge nose, severe facial asymmetry, flat cheekbones, and dumbo ears, you should just accept that? You should somehow come to terms with being ugly and the misery it entails?

Well, I could never accept that. I could never accept a lower quality of life just because through pure chance I ended up with genes for ugly features. I want to be physically attractive and happy, and I will get all surgery I need to fix my inherited flaws.

Telling ugly people to just accept their terrible fate is incredibly insulting. It’s basically saying they should be content with a lower quality of life.

The same forum member believed that he and others were actually as ugly as they felt. However, he did make an exception for one female poster who he referred to as “pretty” when she sent him her photograph. However, when another female member did the same, she was met with a very different response. He reinforced her belief that she was indeed ugly, and also suggested that she commit suicide as a solution to end her suffering. She was so devastated by his response that she posted a message asking if others on the forum had experienced the same outcome:

**Female 1-OP:** Well, he said I am SO EXTREMELY UGLY that even surgery wouldn’t help me so I’m doomed to stay ugly forever. . . .[Name] even said that I was spoiled for thinking I had the right to be pretty. It has really made me feel like crap. Even the tiniest bit of self confidence I had left is gone now. All the random strangers that used to call me ugly were right. I am not going to commit suicide like he suggested, but I sure hate my life right now. And most of all the harsh society that values looks over personality, most of the time.

One of the frequent posters responded to her message by criticizing the male poster: “That’s one crazy mothafacka that [name] and his genuine help. I am sorry that you had to read those arse words of his.” These messages indicate that not all support offered on the forum was meant to enhance others’ well-being. The unsupportive comments on the BDD forum are similar to those found on other mental health forums (Burnett & Buerkle, 2004), where members disagreed with one another and posted insulting messages (flaming).

## **Summary of Findings about Social Support Sought and Shared on the Forum**

The forum provided a way for individuals to both seek and share support from their peers. The informational support provided on the forum was primarily beneficial for members who were seeking to overcome their BDD symptoms. When individuals asked about BDD diagnosis and treatment, most members and the forum moderators recommended that people seek out a therapist who specialized in treating BDD, and shared their experiences with CBT and medication. The advice to seek professional treatment is supported by BDD researchers and clinicians since many individuals require therapy, medication, or a combination of both to overcome BDD symptoms (Phillips et al., 2008).

Gaining knowledge through the exchange of information that is perceived to be relevant, credible, reliable, and that increases an individual's ability and opportunities to make informed personal decisions can lead to individual empowerment (Barak et al., 2008; van Udeen-Kraan et al., 2008). This has been found to be one of the primary benefits of participating in online support groups (Buchanan & Coulson, 2007; Chung, 2013). This was the positive aspect of seeking informational support from others on the forum; they could provide advice and opinions tailored to each member's specific needs based on personal experience. Studies on empowerment in online groups (Barak et al., 2008; van Uden-Kraan et al., 2008) have found that the information received in these groups is viewed as valuable because it is often tailored to each person's particular needs.

Individuals also came to the forum for emotional and social network support due to the fear and stigma they felt about disclosing their symptoms and appearance concerns to friends and family members within their primary support group. Forum members sought and shared empathy and caring/concern with other members, and shared gratitude, sympathy, compliments, encouragement, and validation for their feelings and experiences. Buchanan and Coulson (2007) found that the primary motivations for seeking peer support in an dental anxiety online forum were searching for help, sharing fears, feeling empowered by reading messages posted by others facing similar challenges, and receiving guidance, support, and encouragement from others.

Overall, the social network support offered on the BDD forum was positive in terms of reassuring others they were not alone in their suffering, and that there was a secondary group of similar others who could provide the support they needed to help overcome BDD symptoms. Many individuals who suffer from stigmatized physical or mental health conditions find that participating in support groups (both online and offline) reduces feelings of loneliness and social isolation. Being part of a secondary network of similar others provides participants with a sense of belonging, affiliation, and social cohesion, which translates into feelings of empowerment (Barak et al., 2008).

#### **RQ4: Support Provided and Roles Performed by the Most Frequent Posters**

As outlined in Chapter 2 and demonstrated in the RQ1 results, participation levels on the forum varied widely among members. Research Question 4 asked what support is provided and what roles are played by the most frequent posters on the forum. The BDD forum included 5 participants during 2012 who could be classified as the most frequent posters. Each posted 45 or more messages (up to 103), while the next most active participant posted only 30 messages. One of the frequent posters was male; four were female. In order to better understand the support they provided and the roles they played, it is first helpful to briefly profile each using the personal disclosures they provided during the year. Then the social support they provided and the roles they played on the forum are described and interpreted using examples for support. Finally, communication exchanges by four of the most frequent posters illustrate how they formed a circle of strong ties (Granovetter, 1973, 1983) within the secondary support group on the BDD forum.

#### **Profiles of the Most Frequent Posters**

Roger joined the forum as a member in March, 2012. He did not post a self-introduction and instead shared his experiences with BDD in replies to other members. Roger disclosed that he was 23 years old and lived in Great Britain. He had to drop out of university due to his BDD symptoms, and was committed to overcoming the disorder using CBT. In one thread, he disclosed that his obsessions were primarily focused on his facial hair, nose, and balding:

**Roger 2:** As for my story i'll make it as brief as i can, had BDD since i was about 14,15 or 16 although i didn't know about it until i was about 20 (i'm 23 now). My problem areas are nose, skin and hair which are all the top 3 areas of concern although my hair concern is probably more around facial hair than anything else.

My treatment at the moment is Cognitive behavioural therapy and sheer bloody determination which at times i seriously lack but i'm doing ok for the most part.

Roger was experiencing BDD symptoms, was undergoing CBT treatment, and had read books about BDD by medical professionals, such as *The Broken Mirror* by Phillips (2005). Thus, he was one of the primary sources for BDD diagnosis and treatment information on the BDD forum.

Kathy joined the forum as a member in June, 2011. She did not post an introduction to other forum members in 2012, which could be due to her joining the forum in 2011. Kathy primarily disclosed her BDD-related symptoms in replies to other members as a way of sharing similar experiences:

**Kathy 2:** I get headaches like that too, also at the sides like my temples get very sore too. I get this when I have to go out and I'm around other people.

**Kathy 2:** I hate my skin to, I have disgusting spots which I pick and make worse ☹ by judgment do you mean from other people or yourself, or both? I don't smoke pot, I've tried it a few times but it just didn't stick. Self harming is my method of coping.

Mia became a forum member in November, 2011. Mia primarily disclosed her experiences as a way of expressing empathy and understanding with other members:

**Mia 2:** YUP..I KNOW HOW YOU FEEL!!!!!!!!!!!! every person in the world could say im pretty...but i know ill never be the prettiest and i know ill never think im pretty on the outside...it f\*\*\*ing sucks. but you know what??? one day when youre old...you'll look back and think...man i was pretty (i bet or at least i hope)

However, Mia also posted an initial message on one of her bad days complaining about how ugly she felt. She noted that talking about her BDD symptoms seemed to make her feel worse instead of better:

**Mia 1:** This morning has been a very bad morning for me. I find if I look in the mirror too long, especially without makeup, my mind goes insane. My face is such an ugly shape it makes me feel sick. and everyone always says I have nice lips but that's not true, the only reason they look nice is because i wear lip liner/ gloss and they look kind of big when I smile....

anyways..im getting to a point where I'm so sick of the ups and downs...and I feel like talking about it almost makes it worse...I've been extremely depressed before and talking helped me but I feel like talking about BDD just makes me think about it more. So I feel lonely and lost, like no matter how many people said I'm pretty it wouldn't matter because I'll never think I am.

Janet became a member in March, 2012, and posted her introduction upon joining the forum. She was undergoing therapy for her obsession with her skin. Janet was in therapy for the disorder, similar to Roger, but also smoked marijuana to cope with the symptoms:

**Janet 1-OP:** I finally plucked up the courage to join this forum. Baby steps baby steps. . . I have the worst skin in the world. With far too much hair. Its so disgusting that if anyone sees it, they are likely to recoil in disgust and possibly throw up. . . . I do rely heavily on marijuana to soothe me through the day, and tend to deny the fact I'm addicted. I'm determined to make progress with the help of my psychologist. Anyone else in this limbo stage? I'm getting help but the BDD is my world.

Mia, who also smoked "weed" to cope with BDD symptoms, shared her experiences with Janet:

**Mia 2:** I smoke a lot of weed too...like a lot lol. I don't know if it makes my BDD any better or worse...I certainly dont care about much except for food or sleeping when im high and I get very paranoid when I walk alone at night and stuff. Well maybe it makes it worse in the sense that I hate being in public high.  
Lol..man if I'm high and I see my eyebrows though...I go insane, I've lost an hour to waxing/plucking those badboys before without even noticing it.

Fran was the most recent member of the forum; she became a member in October, 2012. Fran was also one of the storytellers on the forum (see RQ1). She posted a lengthy self-introduction (approximately 1,200 words) in her initial post. She was a 28-year-old medical student struggling to cope with her BDD symptoms and had received treatment in the past. She described her mirror obsession, her thoughts about being ugly, and her constant use of makeup to disguise her flaws:

**Fran 1-OP:** I am 28. I have a very demanding life which had made me come to the very top of all my frustrations. I am a medical student in my last year. I have managed until now in a way i dont understand how it was possible.

I think I am ugly, since I can remember. Not in the way that i have a big nose or ears or so, but i think its the mix of them all, my fathers eyes, the eyebrows that are long gone (little left), and all the little small things...that together just created a nasty reflection in the mirror. I wear makeup ALL THE TIME. Also when I sleep. I wake up, first thing i do is check the mirror to know what the day will have in store for me. It is almost always a big dissapointment, sometimes a smaller dissapointment which may be corrected if lucky. Every morning, looking with fear and some hope into that mirror, as if i wait for my face to have changed all of the sudden over the night. This is very disabling, and inhibits greatly me from having a normal live like i want. People have commented on my make up, that i wear too much, wrong colour etc etc. I hate it and feel ashamed of that too, but if I could choose, Id rather have them speaking bad about my makeup then about how ugly I am.

Fran believed that she was a great person who could accomplish anything. However, her face did not seem to reflect all her good qualities:

Psychologists may want to related this ugly-feeling to a deeper personal insecurity, but I really must disagree, at least in my case. I am a very talented woman, on my “good days” i am the most social and fun person, and there is nothing I cannot do, I am VERY good at most sports, smart and intelligent in my studies, inventive, handy, loving and caring of humans and animals, and I think I am really a great person that can accomplish anything. I just wish my face would match all this. I just wish to be looking ok, to be able to fullfill my life. And my lovely boyfriends life.

Fran expressed both positive and negative feelings about herself in her introduction. There was a striking contrast between her positive image of herself as a person who is “very talented...social and fun . . . smart and intelligent . . . inventive, handy, loving and caring” with a “fantastic one in a million boyfriend” and the person she saw in the mirror every morning, who wore makeup “ALL THE TIME” to hide her perceived flaws. Fran’s desire to have a ‘normal’ life was shared by many posters on the forum, though most other members did not paint their lives in such glowing terms.

### **Support Provided by the Most Frequent Posters**

Roger, Kathy, Mia, Janet, and Fran provided more social support than any other posters in the study, including the two forum moderators (Ann and Rose). The five most active members can be considered the *emergent leaders* (Balkundi & Kilduff, 2006) on the BDD forum due to the number of messages they posted and the content of the messages. Studies of emergent leaders in virtual groups focus on how individuals become perceived as leaders over time due to group interaction (Butler, 2001; Sutanto, Tan, Battistini & Phang, 2011). Leadership is “the process of influencing others to understand and agree about what needs to be done and how it can be done effectively, and the process of facilitating individual and collective efforts to accomplish the shared objectives (Yukl, 2002, p. 7). The two forum moderators could be considered the appointed leaders on the forum. However, they posted fewer messages than the frequent posters; Ann posted 19 messages and Rose posted 25 messages.

The important contribution of the five most frequent posters is apparent when comparing the proportion of comments seeking and providing support compared to other members. Table 4.1 presents the social support sought and shared by the most frequent posters (5) compared to those who posted less frequently (220) by gender.

Table 4.1

*Social Support by Most and Less Frequent Posters by Gender*

Gender/Category	Most frequent poster comments		Less frequent poster comments		Total comments	
	Count	Percent	Count	Percent	Count	Percent
<b>Female</b>	<b>367 (n=4)</b>	<b>28.4%</b>	<b>450 (n=95)</b>	<b>34.9%</b>	<b>817</b>	<b>63.3%</b>
Emotional	181	14.0	174	13.5	355	27.5
Informational	133	10.3	220	17.0	353	27.3
Social Network	47	3.6	51	4.0	98	7.5
Unsupportive	6	0.5	5	0.4	11	0.9
<b>Male</b>	<b>189 (n=1)</b>	<b>14.6%</b>	<b>286 (n=73)</b>	<b>22.1%</b>	<b>475</b>	<b>36.7%</b>
Emotional	47	3.6	112	8.7	159	12.3
Informational	84	6.5	146	11.3	230	17.8
Social Network	53	4.1	21	1.6	74	5.7
Unsupportive	5	0.4	7	0.5	12	0.9
<b>Total</b>	<b>556</b>	<b>43.0%</b>	<b>736</b>	<b>57.0%</b>	<b>1,292</b>	<b>100.0%</b>

*Note:* Posters whose gender was undetermined are excluded from the results.

The four most frequent female posters provided fewer informational support comments than the 95 less frequent female posters (10.3% compared to 17%), but they posted similar amounts of emotional support comments (14% compared to 13.5%) and social network support comments (3.6% compared to 4%). Overall, the 73 males who posted less frequently provided more informational (11.3%) and emotional (8.7%) support than Roger; Roger, however, posted more social network support comments than all the other male posters in the study (4.1% compared to 1.6%). Both males and females provided comparable amounts of unsupportive comments (.9%)

The emergent and appointed leaders provided much more support than they requested, which contrasted to the less frequent posters who sought more support than they shared (Table 4.2). Only 9% of the social support comments by the forum leaders involved seeking social support, while 91% consisted of providing support to others. The five frequent posters and moderators accounted for fully 51% of the comments coded as providing social support but only 17% of the total requests for support. In contrast,

the less frequent posters in the study posted 82.3% of the comments seeking support and 49% offering support.

Table 4.2

*Social Support by the Most Frequent Posters & Moderators versus Other Posters*

Comment type	Most frequent posters & moderators (n=7)		Other posters (n=218)		All posters (N=225)	
	Count	Percent	Count	Percent	Count	Percent
<b>Requests (seeking)</b>	<b>46</b>	<b>9%</b>	<b>241</b>	<b>24.7%</b>	<b>260</b>	<b>18.3%</b>
Percent of all requests	17.7%		82.3%		100.0%	
<b>Provisions (sharing)</b>	<b>593</b>	<b>91%</b>	<b>568</b>	<b>75.3%</b>	<b>1161</b>	<b>81.7%</b>
Percent of all provisions	51%		49%		100.0%	
<b>Total</b>	<b>639</b>	<b>100.0%</b>	<b>782</b>	<b>100.0%</b>	<b>1,421</b>	<b>100.0%</b>

Bambina (2007) studied social network support on an online cancer forum and found that most of the supportive messages were provided by one female member and six other male and female members. She labeled the most active female member the “network star” and the six other members as “prime givers” on the forum (p. 123). Givers supplied one another and forum members with support, as opposed to the “takers,” who asked for support from other forum members. The top two percent of active posters (*super-posters*) on a financial forum (moneysavingexpert.com), like those on the BDD forum, also provided advice and support to other members (Graham & Wright, 2014).

**Informational support.** Roger in particular provided advice and opinions about overcoming BDD symptoms that focused primarily on getting professional diagnosis and treatment for the disorder. He recommended resources such as books about BDD (Phillips, 2005) and offered to provide assistance to members, as shown in the following post:

**Roger 2:** My advice to you would be that if you really think that you have BDD then to discuss with a mental health professional if you have access to one and explain to them exactly like you have here about how it pre-occupies you and they would certainly be in a better position than me to say whether or not you are.  
I’ve noticed you saying you haven’t read up on BDD, if you’d like i could write up a little

synopsis of it and what it's about for you or i could point you to a good book called 'the broken mirror' if you have access to a library and like reading.

He offered treatment advice, encouragement, and social network support to a female poster who disclosed that she had recently tried to commit suicide, but was not seeing a therapist for her symptoms:

**Roger 2:** Then may i suggest you see one please, if you go to your GP and tell them your symptoms and how it affects you they can put you onto CBT and they can help work with you to change your mindset.

A big part of BDD is perceptions if you believe yourself to be 'ugly' in some way have you not thought that it could be BDD causing a lot of it? Please don't be so quick to try and throw your life away, it's not a lost cause.

You have obviously come on here for a reason. Please keep in touch with us on here we will help however we can i swear it!

Roger provided more informational support about BDD (48 provisions) than all the other male posters, but less informational support about fixing/changing one's appearance (9 provisions). In the following message, he discussed the idealistic image that people in Great Britain have about Americans, and advised the female poster not to compare herself to images on the Internet:

**Roger 2:** One thing i'd like to pick up on is comparing yourself to people on the internet. It's not going to give a true reflection. When you google them in your looking for something in particular, in your case curvy bodies and your going to end up with pictures of people who are perceived to have amazing curves. Now i'm guessing your from the States and one thing that we over in Britain get is the idea that all Americans have perfect teeth, are muscular, slim and incredibly witty but that's just the side that society shows you. Just like with curves it's not a perfect all round picture of what i call 'reality' where in fact none of us are perfect and there are very few people in the world who can even claim to have what we seek. In fact even the 'perfect' people that are in the movies, magazines etc have their apparent non perfect features hidden. That i tell you is a crying shame. It makes them not look human and does nothing to the 99.999% of the population that has to feel like they need to look like these people.

Most of the appearance-related information sought on the forum was about whether or not to get plastic surgery. Roger dissuaded members from getting surgery and recommended clinical treatment to alleviate BDD symptoms. The reason Roger posted fewer comments than other males about getting plastic surgery could have been because he was receiving clinical treatment. Mental health professionals recommend CBT treatment and medication for alleviating BDD symptoms, and discourage people with BDD from getting plastic surgery to fix perceived flaws (Phillips, 2009).

The four female leaders, like Roger, provided advice and opinions about BDD diagnosis, treatment, and coping strategies, along with emotional and social network support. Kathy often

responded to individuals who were unsure if their feelings of ugliness and appearance obsessions meant that they had BDD. She and the other emergent leaders recommended that individuals get clinical treatment for the disorder and offered encouragement and hope about recovery. They also occasionally offered advice on improving one's appearance using makeup (Kathy), painting one's nails (Mia), and getting plastic surgery (Fran). Following are some examples of informational support posts offered by the emergent leaders on the forum:

**Kathy 2:** I'm sorry you are going through this. I think it's great that you want to get help for it, that is an achievement in it's self ☺

You should make an appointment with your GP and discuss it with him/her. Tell them that you think you have BDD and why you think that. You could maybe write down how you feel and take it with you, that way if you find it hard to talk about it you can just hand it over to your doctor. Good luck, and let me know how you get on ☺

Kathy started her post by offering sympathy and a compliment to the forum member. She then advised the person to make an appointment with her doctor, and to write down symptoms of the disorder to make communicating with the doctor easier. Mia responded to another poster and also advised the person get help for the disorder:

**Mia 2:** I'm not a psychiatrist or anything but a lot of young people are self conscience about how they look, however, if you're finding that these thoughts are consuming you then speaking to someone about it may help. Besides, if it really is BDD then getting help for it early will be way better than waiting.

Fran echoed Mia's advice about getting professional help early for BDD, because without treatment the symptoms can get worse. This is the advice offered by treatment specialists who caution individuals to avoid trying to cope with symptoms themselves, and instead to seek out qualified professionals for help (Phillips, 2009). Fran was a medical student and had undergone treatment for BDD, so her advice was based both on her medical education and personal experience:

**Fran 2:** Just to add, if you are dealing with BDD, then you are doing the right thing to go and seek up a psychiatrist asap, do not drag it out because it may become worse. There is treatment and management, but works best the earlier you start. As it sounds to me you are still able to go to parties, and to your work, so you are doing well compared to many BDD sufferers who are may not be able to leave their homes. Dont let it get that far. Take care of it now. You are very strong! Take care of it, many hugs.

Janet was also in treatment for her BDD symptoms and advised another poster to get help from a therapist who specialized in treating OCD spectrum disorders. Her knowledge that BDD was being classified as an OCD spectrum disorder, prior to the publication of the DSM-5 (American Psychiatric Association, 2013), indicates that she had either done research or been told by her therapist about the revised classification:

**Janet 2:** I would suggest instead of trying to find if you fit the symptoms list of BDD, just get straight to a therapist who is specializing in the OCD spectrum. You will get a much better diagnosis this way. It's also easy to fall into the trap of diagnosing yourself via the Internet, which can get very upsetting pretty fast. I think from your post you're very much on the right track back to health and happiness because you're actually acknowledging where you are in your life and the fact you want help, which is a big part of the whole process. You know you better than anyone else. You are also right with the fact you will have to fashion your own coping mechanisms eventually, despite using CBT/some kind of drug.

The emergent leaders on the forum were familiar with BDD treatment options from personal experience and/or from doing research on the disorder. This knowledge enabled them to provide advice that was in accordance with that of BDD researchers and treatment specialists, who also recommend that individuals seek clinical treatment for the disorder (Phillips, 2005). As evidenced in the above examples, the frequent posters also provided emotional support along with advice and opinions in their posts.

**Emotional support.** Each of the emergent leaders provided similar amounts of emotional support: Kathy (51 comments), Roger (47 comments), Janet (44 comments); Fran (43 comments) and Mia (37 comments), as shown in Appendix D3. They responded to individuals struggling with feelings of ugliness, loneliness, and suicidality by providing sympathy, caring/concern, empathy, and encouragement.

Roger's emotional support comments were focused on helping forum members overcome BDD symptoms. He posted comments that assured others that recovery from BDD was possible, and validated the positive coping strategies posted by others. He did not request any emotional support from other members, but did provide encouragement intermingled with advice about BDD. He posted a forum topic that encouraged other members to focus on their successful attempts to cope with BDD, and reminded them that perseverance helps in overcoming the disorder:

**Roger 1-OP:** Everybody starts from the beginning, you cannot expect to be a pro when you first start something. You will fail, you will hit the wall on occasions but you will get better and you will progress. Every pro started off exactly where you did. When you take up that new hobby or new coping technique just remember you will not master it immediately. Perseverance will get you there in the end.

Roger's provisions of encouragement and advice about BDD treatment are consistent with the leadership roles that emerged on a support forum for men with HIV/AIDS (Kodatt, Sherk, Williams, & Horvath, 2014). The most common leadership roles were men providing mentoring/feedback and encouragement to their peers. Mentoring was displayed when a member advised a person to engage in a specific behavior and encouragement provided motivational support.

The female supportive leaders often responded with empathy and understanding to individuals who felt suicidal and lonely. Kathy expressed sympathy with one poster who was afraid she would never date because she could not trust men to find her attractive and love her:

**Kathy 2:** I'm sorry you feel lonely. Its so hard to trust people, especially with our hearts but maybe if you give a little then the reward will be so much greater than the potential hurt. It's a risk that sometimes we have to take, I'm saying this and I know Im not able to do it but maybe you could give it a go! Take the plunge, go out and meet people. Everyone deserves to be happy and it's so sad that this illness is holding you back.

Mia responded to a poster who was complaining about her life and attributed childhood abuse to the onset of an eating disorder and her BDD symptoms. Mia empathized with the poster because she had also been through a rough childhood and blamed her problems on her appearance:

**Mia 2:** Stop being so hard on yourself!! You've made it through such hard times and you deserve to be nice to yourself and to love yourself. I've been through a hard child hood too and I think that my problems with how I look stems from it because whenever I'm sad or whenever anything goes wrong I think it's because I'm ugly. But we're survivors we're strong, resilient and that's what makes us beautiful.

Fran empathized with a poster who was experiencing suicidal thoughts. She admitted that she had suicidal thoughts as well, despite having friends and a boyfriend for support. Fran expressed her frustration with the forum because she wanted to be able to provide physical comfort to the poster in the form of a hug as well as emotional support. Being unable to connect physically with other members has been identified as one of the disempowering processes of online support forums (Mo & Coulson, 2008):

**Fran 2:** I'm just so sad to read this. Its absolutely devastating. I have also felt the same way, despite the fact that I have a few friends and a boyfriend to back me up. But I know those feelings so well... they come often, and you feel you are better off **gone**. In moments like these I wish that we lived close by so that we could meet and talk to each other, show that we are real people who understand and care and wont judge! And because I really feel the urge of going and hugging you now! I want to make you have hope, but I dont know what to say, I have the same damn curse. There is hope there is hope, there must be sweetie. Hugs to you, hugs for all the dumb people who missed the privilege to give you one.

Janet also responded to a poster who was experiencing suicidal feelings. She complimented the person on her strength and thanked her for posting a story to which others could relate. Janet then urged the poster to “never give up” and provided hope that her life would improve in the future:

**Janet 2:** My gosh. Do you know how amazing it is that you actually survived through all of that? You must have a strength you do not realize yet, because I read your story and it's clear you are a survivor. Congratulate yourself on making it this far in life despite it all. And thanks for posting your story so others like myself can also relate to you. . . Never give up on you, you are a human being and just doing the best with the knowledge you have, keep going, the days become brighter I promise you.

**Social network support.** Clearly the most notable difference among the most frequent posters was Roger's heavy engagement in social network support, representing 28% of all of his support-related comments. The most frequent female posters as a group had 12.9% of their comments focused on social network support, and the less frequent posters had even fewer (11.3% of posts by females and 7.3% of posts by males; Appendix D3). Roger welcomed new members, invited them to keep posting, and praised the forum as a place where they could receive help from others who understood the disorder:

**Roger 2:** Welcome to the forum. You have come to a good place to talk to other people who are in the same boat as you regarding BDD, there are a few regulars on here who are excellent contributors to this forum and we get a lot of people who come on every now and then too. Maybe you should post on here for a little bit you might strike some common ground with some people on here, and also you could be able to help people yourself.

Roger was dedicated to providing social network support to other members, especially new members displaced by the loss of BDD Central. He started a thread in September 2012, on the same day that BDD Central went offline, wanting to know the status of the defunct site. He specifically targeted his post to other BDD Central members:

**Roger 1-OP:** [Where has BDD Central gone?] Went to go on this morning and it's just disappeared, replaced by those webpages that link you to allsorts of rubbish. Don't know if there's any BDD Central users on here that can shed any light on the matter.

After facing the loss of BDD Central, Roger realized that he shared a common bond with other forum members. He viewed those on the BDD forum as his extended family. As a result, he no longer felt alone in his fight against the disorder:

**Roger 1-OP:** We all share something here. We all have a common ground. We all know what's it like to be like we are and that is something i don't even share with my friends, or people of my blood. And because of that, and with the loss of BDDCentral to ram this point home in my mind, i have realised one thing.

This one thing that makes us unique, makes us a family. As far as i'm concerned you are all my brothers, you are all my sisters. You are not alone, you never will be alone. I don't care if your a regular on here, a lost connection from BDDCentral or a passer by who has joined because they have discovered who they are, you are **all** family to me.

Roger was focused on making other members feel welcome since he felt that others suffering from BDD symptoms were like "family" to him. Active members in online forums can feel empowered by helping others; doing so can make them feel less alone in coping with their disease (van Uden-Kraan et al., 2008). Roger felt connected to other members who also suffered from BDD symptoms and reaching out to them made him feel less alone with the disorder.

Roger was also interested in helping members by gathering their personal experiences with BDD to share with others on the forum. He initiated several threads that asked members to share their experiences with overcoming BDD symptoms. Roger wanted people on the forum to record their thoughts in a journal for one month so that he could share their common occurrences and coping techniques:

**Roger 1-OP:** I will try to compile as much information i have gathered up to now (i know a lot but i'm still only 23) but would also like to add some case studies and here is where i would like some help.

I am wondering if for one month this November anybody who is willing would keep a journal of their thoughts/worries and issues each day and by the end we could round them up and make them available for any members that wanted to read them.

I'm still going through the vagueries in my mind but i think it would be a good idea so we could maybe work out some common occurences and techniques that help and what have you.

The other four emergent leaders also fostered social network support on the forum. Kathy, like Roger, often welcomed new members and praised the forum as a place where individuals could find others who understood the disorder:

**Kathy 2:** The forum is great, I love it! You should post some things in the [forum] just for fun bit, it's a great way to get to know people. At first I found it a bit daunting and I thought people wouldn't want me to post there but everyone here is so nice, it's a great little community. There are so many people going through the same or a similar thing so it's great to chat to people here as they understand.

Mia reached out to forum members by starting a new thread and confessed that she felt better knowing that she was not alone in her suffering. Roger replied that he and other forum members were available to help:

**Mia 1-OP:** anyways...I was so sad, and I thought of some of you guys on here and I actually felt better, not because you guys are suffering like me, but because I finally know that I'm not the only person who thinks they look like a monster... I'm not happy at all that you guys have BDD, I hope you all get better, but it made me feel some relief to know I'm not alone.

**Roger 2:** No problem chief, you probably didn't mean me but nonetheless we are all here for you. We're just a keyboard away.

Janet provided social network support by posting threads to connect with other members, and offered to read and reply to members who responded to her messages. In the following thread, she wanted to connect with other members to discover why they posted to the forum. She wanted to find a face-to-face support group to attend, but decided to join the BDD forum due to the lack of such a group in her area:

**Janet 1-OP:** It seems that one will post in this forum and get one or two replies and then the thread stops. Just want to say I'm going to check this forum every day and am willing to speak to anyone about why they've ended up here. I wish there was a group in my area I could go to and actually meet other people trying to manage BDD but I guess this will have to do for now.

Fran was initially pleased with finding the BDD forum. She was glad to be part of the forum because she could relate to others' suffering and so felt less alone. She wanted to create a chat on the forum so that she and others could more easily interact and form friendships:

**Fran 1-OP:** I was thinking about how nice it would have been to have a chat connected to this forum, so that one can speak live chat with other BDDers. I think one could easily get feed-back

and comfort and support. Don't know who would develop such a thing, and probably it would take a long time to implicate. But it would be a nice next step, and getting friends on here would be much easier.

She shared her personal experiences, both good and bad, about coping with the disorder. Fran posted an initial message in which she celebrated having a great day with many positive experiences. Only one person replied to her post, and he both praised her and expressed envy at her success: "I'm delighted for you, and (I don't know whether this is a feeling you'll recognise) a little bit jealous." Fran replied by agreeing with his feelings of envy, since she was also envious of her own success. She wanted to come back to the forum to keep re-reading the post as a reminder that good days were possible.

Fran also reached out to other members for support but did not always receive affirmative replies. As a result, one month after she joined the BDD forum she decided to leave, and posted a lengthy explanation for other members. She concluded her post by asking herself whether or not participating in the forum had made her feel better or worse, and if she had been able to help others. She then provided answers to her own questions, both of which were negative:

**Fran 1-OP:** In this forum though I have found it hard to relate to others, except in the beginning when I saw there were more with BDD. That's as far as it reached.

In the end we have two questions to ask:

1. Is my contribution here making other feeling better?
2. Is my membership here making ME feel better?

I think in my case both answers are NO. Therefore I have to go where I can do use.

I hope that this forum will continue to be a very useful page for those who seek support, comfort and answers. It was just now right for me, it kind of hurt me more than it helped. I was seeking a normality within this chaos. Just some understanding.

I hope that anyone at all has had any kind of use in what ever I have written, I have always good intentions, I really wanted to help.

One female member replied and advised Fran to keep her posts on the forum, to help her sort out her feelings:

**Female 2:** Also although we are facing the same problem BDD but due to our different environment and character and our different ways in solving things. We may disagree. So it may end up this forum is not helping you. What i would like to say is just hang on, don't be quick to delete your posts as now you are still facing problems. Just keep your posts as references to help you sort out your feelings.

Another member, who had also posted to BDD Central, provided reasons why positivity was not appreciated on the BDD forum and on mental health forums in general. She felt that people on the forum

were glad to know that they were not alone in their suffering, but tended to focus on their problems rather than on overcoming symptoms of the disorder:

**Female 3:** Your reasons for leaving are exactly the reasons I had for leaving BDD central forums: positivity doesn't seem to be welcome. I think that's just how forums for people with certain mental issues work. They serve as an outlet for people to be like "omg, I'm in the same sucky situation, I feel less alone now", but they don't focus enough on finding concrete solutions to get out of that paralyzing mindset. People who are enthusiastic and try to bring some positivity quickly get dragged down by everyone else's negativity.

The previous examples of social network support by Roger, Kathy, Mia, Janet, and Fran indicate that the most frequent posters wanted to reach out to other members to share support on the forum. However, Fran expressed her concern that the forum was not helping in her efforts to recover from the disorder, and that she did not feel supported by other members. Thus, her comments extended beyond merely lamenting the lack of optimism or an upbeat tone on the forum. Fran's comments indicate that the forum could either enhance or impede participants' ability to cope with symptoms and overcome the disorder. Her disappointment could also have been prompted by the unsupportive comments posted on the forum. The frequent posters reacted to unsupportive comments by criticizing other forum members and even the moderators.

The two designated moderators edited posts, responded to inquiries about forum rules and maintenance, and provided social support to members. The moderators were easily identified due to being listed on the forum as moderators/administrators and having a signature under their names that read: "I am sorry I am not on the forum as much as I used to be, if I do not reply to you quickly, please contact another moderator/supermod/admin as well." Ann did not disclose much about herself besides mentioning that she did not have BDD. Rose admitted that she had some BDD "traits" and shared these in her posts: "I've felt like I'd never be seen as attractive and that I'd always be alone too."

The two moderators, like the frequent posters, differed in the social support they offered to members. Ann primarily advised members to get clinical treatment, rather than trying to fix perceived appearance flaws with surgery: "I think it would be really valuable to explore therapy first... Your value as a human being does not revolve around how you look." She also provided information about forum

rules, such as reminders that personal images were not allowed on the site: “No pictures here, please. It’s really important to maintain anonymity.” Ann also greeted new members, encouraged them to keep posting, and offered compliments, validation, encouragement, and empathy.

Rose also focused more on providing informational support than on emotional or social network support. Most of her replies to members contained the same advice, specifically to get therapy and find a hobby that they enjoyed unrelated to their appearance: “You have to try and focus on something else that has nothing to do with your looks. People with BDD say that it’s helpful. You could get some therapy too.” Rose offered emotional support (empathy, caring/concern, compliments, and sympathy) to members, and started threads to encourage others to share their personal experiences: “In this thread, you can take some time to introduce yourself and meet the community.”

### **Group Roles Performed by the Most Frequent Posters**

Beyond being the primary providers of social support in the study, the most frequent posters assumed an important role as social network facilitators. These roles were not necessarily intentional, but emerged because of their knowledge, longevity and commitment to other members on the forum. Roles are defined as positions within a social structure to which are attached reciprocal sets of normative rights and obligations (Thoits, 2011, p. 148). The most frequent posters performed important roles that helped the BDD forum to thrive and serve the needs of its members. Their functional roles supplemented the official responsibilities of the two designated forum moderators, who were the appointed leaders on the forum.

On the BDD forum, the most frequent posters played a number of leadership roles, which can be identified based on their communication with each other and other members. Due to their functional roles, the frequent posters could have increased members’ engagement and served as the “nucleus” for the virtual community. The moderators also had a number of functional roles due to their communication with forum members. The functional roles of the frequent posters (emergent leaders) and forum moderators (appointed leaders) are shown in Table 4.3.

Roger could be considered the primary *information giver* (Benne & Sheats, 2007) or *opinion giver* on the BDD forum, due to his posting more informational support comments than any other member. He also served as the primary forum *greeter* and *advocate*. Roger felt that other members were like his extended family and so reached out to new members, welcomed them to forum, and encouraged

Table 4.3

*Group Roles Performed by the Emergent and Appointed Leaders on the Forum*

Group role	Frequent poster (moderator)	Example
<b>Advocate</b> Promoted the value of the forum	Roger, Kathy (Rose)	The forum is great, I love it!
<b>Arbiter</b> Offered judgments about the appropriateness of content or behavior	Roger, Kathy, Fran (Ann)	No pictures here, please. It's really important to maintain anonymity.
<b>Corroborator/Validator</b> Reinforced advice and opinions by other members	Roger, Kathy, Mia, Janet	Like the other two said, go see your doctor...
<b>Encourager/Cheerleader</b> Offered praise, understanding, and acceptance to members	Roger, Kathy, Mia, Janet, Fran (Ann, Rose)	Omg that's incredible! im so happy for you I hope you get a job at the end too.
<b>Expediter</b> Started threads to encourage member participation	Roger, Kathy (Rose)	In this thread, you can take some time to introduce yourself and meet the community.
<b>Evaluator/Critic</b> Pointed out problems, needed improvements in the forum	Kathy, Fran	To be honest I don't understand why the moderators haven't done anything about this!
<b>Forum Greeter</b> Welcomed new members	Roger, Kathy (Ann)	Welcome to the forum.
<b>Information/Opinion Giver</b> Provided advice and opinions meant to solve others' problems	Roger, Kathy, Mia, Janet, Fran (Ann, Rose)	You should make an appointment with your GP and discuss it with him/her.
<b>Mediator/Harmonizer</b> Intervened in disputes between members	Kathy	I'm not sure what your aim was in posting it, maybe you could clarify this?

them to keep posting. Roger also advised members to get clinical treatment and assured them that recovery from BDD was possible. He played the role of forum *arbiter* when he disagreed with the actions and opinions of other members. When members, such as the forum flamer, posted unsupportive comments Roger criticized the insensitive remarks and indicated that such communication would not be tolerated on the forum.

Kathy provided support that was similar to Roger's, in that she also served as a forum *greeter* and *advocate* by welcoming new members and praising the forum as a supportive community. She served as *mediator* when disputes arose between Fran and Roger, and tried to mitigate the negative comments posed by other members. She, like Roger, did not appreciate when others posted nasty comments on the forum; they both cared about making the forum a supportive place for those suffering from BDD. As a result, she criticized the moderators when they failed to keep the members from posting "nasty" comments.

Roger and Kathy served as forum *expeditors* (Benne & Sheats, 2007) when they started threads in order to encourage other members to post their personal experiences. Benne and Sheats (2007) described the *expediter* as a group member who attempts to keep communication channels open by encouraging or facilitating the participation of others. Kathy and Roger asked questions and started threads to encourage members to share their experiences. For example, Roger started a thread asking members to keep records of their personal experiences and post them to the forum for a book he planned on writing about BDD.

The most frequent posters also served as *encouragers* (Benne & Sheats, 2007) and *validators* when they agreed with and reinforced the advice and opinions provided by other members and one another. The encourager praises, agrees with, and accepts the contributions of other members. He/she indicates warmth and solidarity, offers commendation, praise, understanding, and acceptance of others' viewpoints, ideas, and suggestions (Benne & Sheats, 2007). Though many people came to the forum and complained about their problems, the most frequent posters tried to counter these by providing informational, emotional, and social network support to encourage members that overcoming BDD symptoms was possible with clinical treatment.

**Group roles performed by the forum moderators.** As shown in Table 4.2, the moderators also played a number of functional roles on the forum, based on their communication with other members. Rose served as a forum *advocate* when she disclosed that posting to the forum had been beneficial in raising her self-esteem: “I have this forum, for example and it gave me a feeling of belonging and of being good at something especially when I first started posting here.” She served as an *information/opinion giver* and *encourager* by posting messages encouraging members that they could overcome BDD symptoms using techniques such as self-help and therapy. She became an *expediter* when she posted messages asking members to share their personal stories and to offer thanks on the forum.

Ann served as the primary *arbiter* on the BDD forum when she reinforced the forum’s rules and regulations. She acted as a forum *greeter* and *information/opinion giver* when she welcomed new members and offered advice about getting clinical treatment in order to overcome BDD symptoms. She and Rose also offered emotional support and praise to members for posting to the forum. Ann and Rose fulfilled functional roles by providing social support to members, in addition to their appointed roles as forum moderators who edited posts and enforced forum rules.

### **Unsupportive Comments by the Most Frequent Posters**

Roger clearly felt a connection with other forum members; he welcomed new members to the forum, encouraged them to keep posting, and felt they were part of his extended family. His proactive stance led Roger to disagree with and criticize a male forum member who consistently portrayed himself and those on the forum as ugly and in need of plastic surgery (forum flamer). The forum flamer posted 14 messages; he was one of the most frequent male posters to the forum behind Roger. Although Roger was not the only member who responded, he was the most consistently critical of the other’s behavior. The forum flamer could be viewed as the *aggressor* of the group; the aggressor is the person who expresses disapproval for the values, acts, or feelings of others by attacking the group, or the problem the group is addressing (Benne & Sheats, 2007).

The forum flamer posted an initial thread conveying dismay that physicians insisted on diagnosing ugly people with BDD, rather than suggesting they get plastic surgery to fix their appearance

flaws: “I’m so sick of psychiatrists failing to distinguish between legitimate ugliness and imagined ugliness. By failing to make this distinction, they incorrectly diagnose thousands of people with BDD and end up making their lives worse.” He insisted that beauty is objective rather than subjective, so the only way to improve one’s self-esteem was by changing one’s appearance. The post itself can be considered unsupportive, since the author states that being ugly is a legitimate reason to commit suicide:

**Male 1-OP:** The fact of the matter is that beauty is overwhelmingly objective: It comes down to the symmetry of your facial halves and the proportions of your facial landmarks. That’s it -- there’s hardly any subjectivity involved in interpreting beauty.

I should also add that attractiveness plays an enormous role in determining the quality of one’s life (duh!). Therefore, people who are legitimately ugly have every reason to be distraught over their appearance. They have every reason to be depressed and -- depending on the severity of their ugliness -- suicidal. I firmly believe that in some cases of incorrigible ugliness, death is a realistic option.

What legitimately ugly people need is not counseling but surgery. Cosmetic surgery doesn’t perform miracles, but it can provide significant and objective improvements to one’s facial appearance. Someone with a wide, humped, crooked nose would probably benefit much more from a quality rhinoplasty than therapy. Unlike therapy, surgery treats the *problem* (unattractive facial features), not the *symptoms* (depression and anxiety over appearance).

So if you are readings this, I implore you: Be skeptical of BDD. If you are legitimately ugly, then your best option is to correct what is making you unattractive. If after correcting these problems you still believe you are ugly, then perhaps you should seek a counselor. But do NOT be lured by the comforting diagnosis of BDD, which seems to suggest that no one is ugly. That’s a fairy tale.

Kathy responded to his post by pointing out that the content might be upsetting to other members.

She asked him to clarify his intentions in posting the message and offered to provide support if needed:

**Kathy 2:** I don’t mean to be rude but I think your post is very insensitive. I’m not sure what your aim was in posting it, maybe you could clarify this? If you are looking for support then we are more than happy to help you out, but please remember there are people here who are dealing with some hard things and your post may be upsetting to some people.

Roger, unlike Kathy, did not attempt to be supportive in his reply to the forum flamer. Instead, he responded with criticism, sarcasm, and insisted that beauty is subjective rather than objective:

**Roger 3:** Hahaahaha I’m going to have some fun with you. First of all, this ugliness thing, it’s subjective not objective. You see the world has this wonderful way of making certain things attractive to different people. Some people like blonde hair others prefer dark, ginger etc. Some people prefer men with a bit of body hair others prefer their men clean shaven.

THERE IS NOBODY IN THIS WORLD THAT EVERYBODY THINKS IS BEAUTIFUL,

SIMILARLY THERE WILL BE NOBODY IN THIS WORLD THAT EVERYBODY IS NOT ATTRACTED TO.

Now i'm not sure where your going with your post, personally i think your out to get a few people upset, make them feel hopeless, but i'm going to wager that most people that read your post just like i have done will see what you have put as the type of crap some self obsessed jock would put up to troll people into replying and guess what? All your post is going to do is make people more determined to prove the likes of you wrong cos that's most definately what it's done to me!

So i thank you very much kind sir, your post is actually quite ENLIGHTENING.

Roger voiced strong opposition to the male poster's opinions about beauty being objective rather than subjective. His reply indicates that Roger felt responsible for guiding the behaviors of other members on and off the forum. He did this by greeting new members and welcoming them to the forum. He also advised members to seek professional diagnosis and treatment for their BDD symptoms, and encouraged them that recovery was possible. Finally, he clearly indicated that posting offensive comments telling members that they were ugly and needed plastic surgery would not be tolerated on the forum.

Among the four most frequent female posters, Mia and Janet did not provide unsupportive comments to other forum members. However, Kathy responded to unsupportive comments by criticizing other forum members and the moderators. She posted a message expressing her anger and frustration over the nasty tone of the comments. The forum was a place where she had felt comfortable expressing herself before the "nasty" comments were posted:

**Kathy 1-OP:** I just wanted to say that in all the time I've been here I've never seen this place so negative and with so many blunt and in my opinion nasty comments! This is supposed to be a place where we can come for support, to talk to others like our selves or even to meet new people and have a little fun! It's not a place to point out peoples flaws or to put them down!

In the last couple weeks I've never felt so down because of this forum! I normally can't wait to come here, to let my self be my self! No one knows about my problems and here is the only place I can freely talk about it.

Kathy expressed her frustration with the forum moderators for not having blocked the nasty comments.

She felt that the posts could cause others to hurt themselves since she had been put into a "bad place"

because of the negative messages:

To be honest I don't understand why the moderators haven't done anything about this!  
If you want to be horrible to some one then quite frankly piss off and do it somewhere else because I've had enough of this! How dare people come and behave like this, I hope you realise

your posts could be the fine line between someone severely hurting themselves or not! Because I know you've put me in a bad place! I've been working so hard to feel better and to not SH but coming here is making me feel worse now! Not better like it was before.  
Grow up!!!!!!!

Roger and the other emergent leaders posted messages to try to combat the negative comments that were posted to the forum. They wanted to ensure that the forum was a supportive place for all members. Kathy expressed frustration with the forum moderators since she wanted them to censor the forum flamer's offensive posts. The primary role of the forum moderators was to review and edit posts due to triggering content. However, they did not delete posts due to the forum rules against doing so: "Please understand that for technical reasons and in accordance with the rules of the forum we will be unable to accommodate requests to delete." The most frequent posters took on roles that supplemented the responsibilities of the moderators. As a result, their contributions were vital to the successful functioning of the forum.

### **Collaboration and Disagreement among the Frequent Posters**

Four of the most frequent posters, Roger, Kathy, Mia, and Janet, exchanged supportive messages with one another. In 12 message threads, three of the four replied to the same person and corroborated the advice and support offered by the others. Roger started an "off-topic" thread that had more than 1,500 replies. The first four messages were exchanges between Roger and Kathy in which Kathy complimented Roger for starting the thread and Roger explained that a similar thread had existed on the BDD Central website. Upon further analysis, the researcher found that the first 100 messages in the off-topic thread were exchanges between Roger and Kathy containing jokes, teasing, and topics related to everyday events, most of them unrelated to having BDD. The second 100 posts in the thread contained exchanges between Roger, Kathy, Mia, and Janet, again primarily about experiences unrelated to having BDD.

In addition to chatting with the other four on the forum, Mia commented that she was friends with Roger, Kathy, and Janet on Facebook. She posted an initial message in which she introduced herself to the forum and encouraged members to believe they were all beautiful. Mia explained that she had been away from the forum and missed interacting with three of the other frequent posters (Roger, Kathy, and

Janet). She assured them that she had not deleted them off her Facebook account, rather, she had deleted her Facebook page altogether:

**Mia 1-OP:** I just wanted to say that, especially to [Kathy] and [Roger] and [Janet] (i didn't delete you guys off facebook, i deleted it all together lol) but I wanted to say that everyone on here is beautiful, please stop obsessing about your flaws, everyone has flaws but the world is beautiful everyday you're here is a blessing and maybe you see this but you still can't stop thinking about how you look. . . Anyways, I love you all and I hope you're all ok.

In the following thread, Roger replied to a female forum member who wanted to know if she was ugly or had BDD. He began by welcoming her to the forum and asked where she learned about BDD. He then recommended she find a qualified CBT therapist and invited her to stay on the forum. He referred to himself and the other forum "regulars" who could speak to her if needed:

**Roger 2:** Welcome to the forum, where did you learn about BDD? A lot of what you have written down here is very synonomous with what most if not all of us are going through. I think the best advice anyone can give right now is that if you feel you can, go see a doctor. They can get you to counselling if it's affecting your life and qualified CBT therapists are very handy for BDD as a changing of a person's thought processes are one of the best solutions on the matter. Please feel free to stay on the forum for the meantime there are a few regulars on, myself included and speaking to people in the same boat as yourself is a really good start. Keep us updated.

Kathy and Mia replied to the original poster and validated Roger's recommendation that she find a qualified therapist. Kathy and Mia also provided network support by offering to talk to her at any time:

**Kathy 3:** I'm sorry your going through this!  
The advice I would give you is the [same] as what [Roger] said, the best thing you can do is go and speak to your doctor. It's a hard thing to do but it's also the best thing to do. And the forum is a great place, it's helped me out significantly over the past year. Like [Roger] said there are a few regulars who would be more than happy to help out you however they can.  
If you need anyone to chat to I'm always here,

**Mia 4:** Like the other two said, go see your doctor...but if I were you, I'd only tell them if you really trust them because they might just shut you down if they're not a good doctor and it could make you feel worse. But ya please get help before it gets worse.  
you can talk to me the others on here anytime!!

In the following thread, Janet shared her progress in overcoming BDD, and asked how others on the forum were coping with the disorder:

**Janet 1-OP:** Hey guys! Whats been going on? Long time no speak!  
How is everyone progressing with dealing with BDD and directly related symptoms like depression, anxieties, addictions etc?  
Im in a really good place right now. Feeling very open and accepting and generally everything is

just good on a very deep base level. Im going to start a course next month and hoping to get a job at the end of it. Im so excited at the prospect of getting back into the workforce. Anyway I hope you guys are going well with everything and even though I haven't been on here for a while I do think of you all and send you positive thoughts often ☺

Roger replied to her post with expressions of caring and encouragement: "It's good to hear from you again chief, a few of us were worried about ya, glad your doing fine now. ☺" Janet responded to Roger, confirmed that she was doing well, and asked how he was doing in return: "Glad to see you're still here! Yes I've been having huge breakthroughs!!! How are you though??"

Fran was one of the most frequent posters to the forum, despite having been a member for only one month. She came to the forum to help others and to get help for her BDD symptoms. Fran wanted to raise awareness about the disorder among her family, friends, and the public by posting information about BDD to her Facebook page. Roger did not approve of her actions; he believed that doing so only raised awareness among one's friends and family members, but had little effect on public knowledge about the disorder:

**Roger 2:** I don't agree though that force feeding information about BDD to other people on facebook is the right way to go about it though. People, in general, aren't interested in things that don't affect them or people in their circle and although your family, partner, friends etc might be interested most people will probably scoff at it. The main thing is that BDD is better known than it was 10 years ago, which is better than it was 10 years before it and that's the way to look at it i think.

Roger and Fran each had firm convictions about how to help individuals with BDD. Roger provided support to his extended "family" on the BDD forum. Fran wanted to raise awareness among her primary group members and the public about the disorder. As a result, they disagreed on how best to accomplish that objective. Fran, unlike Kathy, Mia, and Janet, did not seem to recognize Roger's status as the unofficial BDD forum leader, although she did appreciate his supportive responses to some of her posts. Roger had provided encouragement that she could recover from BDD: "there were a couple of regulars who posted on here back in the day when i started out and now they don't need the forum anymore because they have seen an improvement in their lifestyle."

Despite his help, Fran accused Roger of “giving up” and being selfish in terms of not teaching others about his condition. She believed that posting information to Facebook would raise public awareness about BDD, and added that the post had received a positive response:

**Fran 3-OP:** No offense, but it sounds a bit as giving up. And not seeing further than to your own self and that YOU dont need to explain YOURSELF. Just like any foundation wants to spread their knowledge about Breast cancer, Prostate cancer, Stroke or what ever it might be, I am doing my part on a subject which I am passionate about. You are entitled to your own opinion, but a “force feeding” of information to open peoples eyes, I think some years ago when you weren’t this laid back about your BDD, you might have appreciated it. (Just to add that the post had a positive response.)

In the same thread, Kathy came to Roger’s defense in her role as the forum *mediator*. She questioned Fran about why she was criticizing Roger, and then expressed admiration for his opinions:

**Kathy 4:** How does what [Roger] say sound like he is giving up? All he is saying is that for him it doesn’t matter what people think, if they know they know it doesn’t embarrass him or make him feel ashamed, and I think that’s great! I hope to be like that one day, because the only person in my life that actually really knows me and about bdd is my boyfriend, I can’t bear the thought of anyone knowing about it.

Kathy frequently responded to Roger’s posts with compliments and validation for his ideas. In a thread where he asked members to post their personality characteristics related to BDD, Kathy was the first person to respond. She enthusiastically told Roger that his idea was a good one and listed her personality traits. She then continued the conversation by asking Roger which personality traits he would choose to describe himself:

**Kathy 2:** This is a good idea [Roger]! I am 99% percent sure that BDD has shaped my personality in a positive way, although it has negative side effects on my personality too I think it’s made me way more compassionate and caring etc. What about you rather what 5 would you pick??

Based on their supportive communication with one another, Roger, Kathy, Mia, and Janet formed their own circle of strong ties within the BDD forum. Thoits (2011) characterized primary groups (strong tie networks) as consisting of members who are emotionally tied to one another and who are viewed as important or influential in one another’s lives (p. 146). Active members in online support groups contribute time, energy, and resources to provide benefits to themselves and other members. These benefits include information, influence, and social support, which form the basis of the group’s ability to

attract and retain members (Butler, 2001). These four members (Roger, Kathy, Mia, and Janet) formed a supportive group that extended beyond the BDD forum to being friends on Facebook. Their communication with one another indicates that they had formed a group of strong ties within the weak ties of the online forum. However, their supportive communication on the forum could have also made the group more welcoming for individuals seeking help for their BDD symptoms.

### **Summary of Findings about the Most Frequent Posters on the BDD Forum**

The emergent leaders on the BDD forum were one male (Roger) and four females (Kathy, Mia, Janet, and Fran). These five members and the two moderators provided support that helped make the forum a more welcoming and supportive place for other members. The most frequent posters each provided more informational, emotional, and social network support than any other members in the study. Overall, Roger's role was one of information giver and social network facilitator, and the four female posters focused on being the emotional caregivers on the forum.

Roger served multiple functional roles on the forum, including forum *greeter*, *information giver*, *arbiter*, and *encourager*. Kathy acted as the group *mediator* when conflicts arose on the forum. The prominence of four females as emotional support providers reinforces findings that women often provide more emotional support than men (Herring, 1993; Klemm et al., 1999; Seale, 2006). These four female posters could also be considered the "prime givers" (Bambina, 2007) on the BDD forum.

The five emergent leaders offered empathy and understanding to members; in addition, they offered support that was focused on evaluating the other person's situation and needs. Thus, the support they provided was on a higher level than most other members, whose messages focused as much on their own problems as those of the other person. Supportive messages that display empathy are considered to contain moderate levels of support, whereas listener-centered responses convey a higher level of emotional support (Burlison, 1994).

The most frequent posters and moderators wanted to make the forum a supportive place for those with symptoms of the disorder. They encouraged others to join and to post messages. They also responded frequently to others' posts in order to make others feel welcome and supported. Most members

posted 30 or fewer messages containing personal disclosures and seeking and/or sharing support. The most frequent posters distinguished themselves by posting messages focused primarily on providing support, thus they served as emergent leaders who made the forum a supportive online community for other members.

## CHAPTER 5: DISCUSSION

**Roger-moderator 1:** Please do realise you are not alone in this fight. Every person with BDD is a brother and sister in a battle to rid yourself of your own personal bully. It's a fight you can win but one that is easier with people standing behind you all the way. A common cause that unites all of us from all around the globe into a group of people determined to make a difference. We are the BDD family. (2014)

**Roger-moderator 1:** We want this forum to be a pleasant experience for all, where members can discuss their experience with BDD without the more unpleasant aspect of malicious intent from anyone who may have an agenda which does not involve the betterment of yourself and people around you. (2014)

Three years after the artifacts for this study were collected (covering calendar year 2012) the BDD discussion board on Psychforums.com continued to thrive. By 2015, more than 2,000 topic threads had been started (compared to 801 threads prior to 2012). Roger, the most frequent poster during the period of the study, was appointed the forum moderator in 2014. Among the five most frequent posters for the period, only Kathy continued to be an active member, and she emerged as the most frequent poster (2,508 posts by July 2015). She was joined by Maggie as the next most frequent poster—a mother whose son suffered from BDD—and who joined the forum in late 2012 (with 1,669 posts by July 2015).

Although various members came and went, the mission of the forum remained unchanged. In his new role as moderator, Roger summarized his vision for the forum in two posts in 2014 (see above): to help people cope with the torment of having BDD and to provide a safe place for people to discuss how to better their lives.

This chapter examines five key conclusions (themes) that emerged from the research and their implications for understanding mental health forums and other health-related discussion boards:

- Personal disclosure *facilitated* social support.
- Group members served primarily as *support seekers* or *support providers*.
- Contributions to the forum varied by *gender*.
- The forum served as a *coping* mechanism for members.
- The forum offered *peer support* within an online community.

### **Personal Disclosure Facilitated Social Support**

As suggested by Roger's 2014 posts, the primary function of the forum was to provide social support to forum members. The forum accomplished this by offering individuals a place to anonymously disclose their personal experiences and to seek and share informational, emotional, and social network support. The findings from this study illustrated the central role that personal disclosure plays in online support forums and corroborates previous research that personal disclosure is used by individuals when eliciting, providing, and sharing social support in emails, another major online support tool (Tichon & Shapiro, 2003).

Personal disclosures in initial posts validated support seekers as legitimate members of the forum and provided a rationale that could be readily recognized by others for why support was being sought. The concepts of personal disclosure and social support were often inextricably linked on the forum. Indeed, revealing personal details about oneself was often a prerequisite for receiving support and thus helped the forum to function effectively. Individuals who post to online support forums must first indicate that they belong on the forum by demonstrating their affinity with other members. They can do this by sharing their problems in order to signal that they require assistance (Galegher et al., 1998). On the BDD forum, members accomplished this task by sharing their personal experiences, accompanied by direct and indirect requests for informational, emotional, and/or social network support.

Personal disclosures in initial posts also provided a way for posts to attract attention and engage members. The findings suggest social support was most likely to be provided when individuals revealed details about themselves. This might be explained as increased message processing involvement, wherein the presence of compelling personal information attracts attention, heightens arousal, and motivates forum members to process a post more thoroughly (MacInnis & Jaworski, 1989) by invoking thoughts about issues, values, actions, or perceptions about oneself that are relevant or important to the respondent (Johnson & Eagly, 1989; Petty & Cacioppo, 1986).

Personal disclosure also facilitated social support when members responded to others' posts. Dholokia et al. (2004) found five primary motivations for consumer participation in online communities:

purposeful value, self-discovery, maintaining interpersonal connectivity, social enhancement, and entertainment. Members posted personal experiences to reinforce their experiential knowledge when providing advice, for self-discovery by writing down their experiences and comparing their experiences with those of others (social comparison), and for maintaining interpersonal connectivity when seeking and sharing support with other members.

### Personal Disclosure and Social Support Patterns

This study identified eight patterns that illustrate how personal disclosure and social support were sought and provided in initial posts and replies on the BDD forum (Figure 5.1). The two predominant patterns contained personal disclosure in initial posts accompanied by an *explicit request* for support.

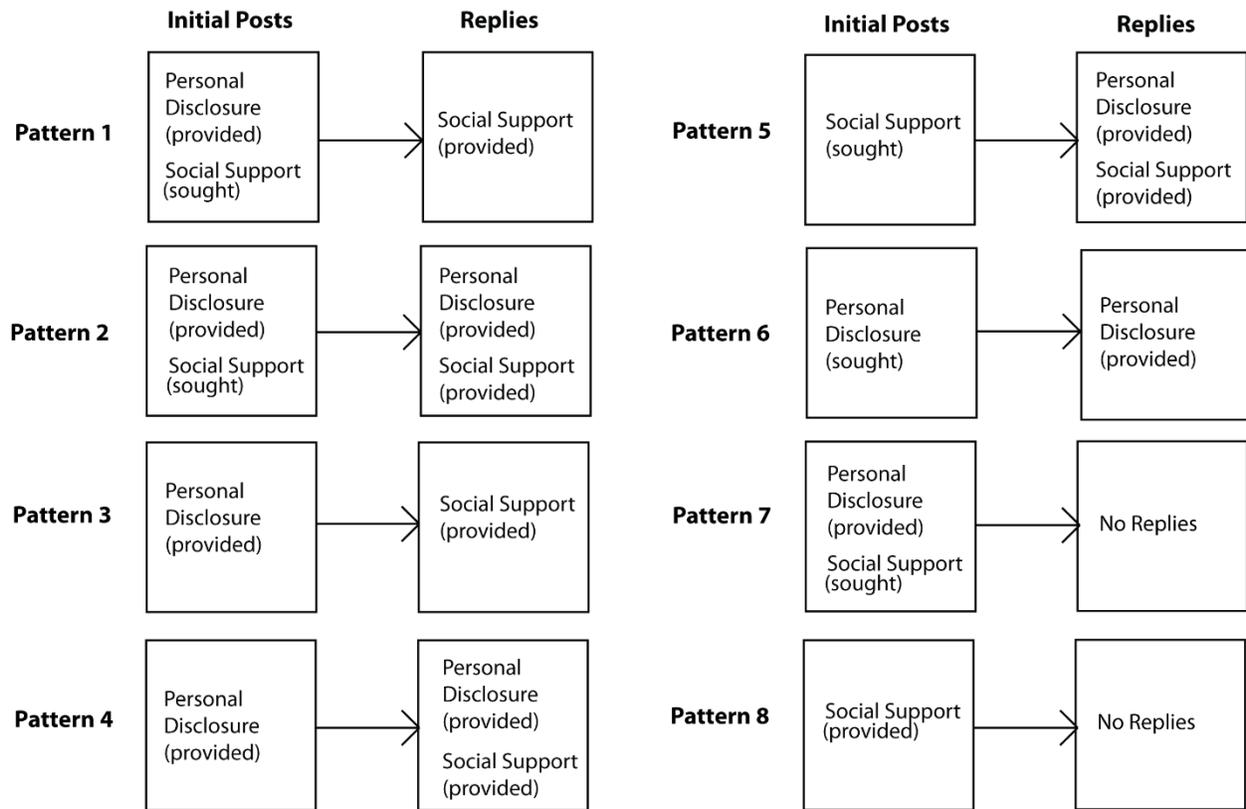


Figure 5.1 Personal disclosure and social support patterns.

These posts led to responses containing only social support (Pattern 1) or both social support and personal disclosure by the respondent (Pattern 2). There were also six less frequent patterns found in the study (Patterns 3 – 8). In two of these patterns, personal disclosure in an initial post could represent an

*implicit request* for support with replies offering social support (Pattern 3) or disclosing personal experiences in combination with emotional, informational, and/or social network support (Pattern 4). In the four other patterns, direct requests for social support were fulfilled and accompanied by personal disclosure by the respondent (Pattern 5), requests for personal disclosure were fulfilled (Pattern 6), initial posts containing personal disclosure and social support received no responses (Pattern 7), and initial posts offering social support received no responses (Pattern 8).

**Personal disclosure with explicit support requests.** The most prevalent patterns in the study involved individuals sharing their personal experiences in initial posts and then explicitly asking for support from other members. These two patterns occurred in 48% of the message threads analyzed for the study.

**Pattern 1:** Personal disclosure accompanied by support requests in initial posts often resulted in replies containing only social support. In these cases, responses primarily included advice, sympathy, and concern about the other person's situation. This pattern usually occurred when individuals posted their BDD symptoms and asked others for a diagnosis and/or treatment advice. For example, one of the storytellers posted an extended narrative about her appearance-related problems and being bullied in school. She then concluded her post by asking others if they thought she had BDD and for advice on how to get better: "I just want to know if any of you think i have bdd and if there's anything i can do to get better because i really do want to be normal again." In response, one of the moderators (Rose) concluded that she could have BDD, expressed empathy with her condition, offered advice on skin care and getting therapy, and then expressed concern by asking how she was doing:

**Female-moderator 1:** It sounds a bit like BDD because it just keeps moving from one area to the next, but maybe you've just had really bad luck with bullying. The same happened to me and it was awful. You might be getting that rash because you've been using those products for a long time but also because they might not be very good...But if it's BDD or traits, you do need to have therapy to help you deal with it. How are you doing?

**Pattern 2:** Complaints about a person's disliked body part(s), facial features, or ugliness were often accompanied by a question asking for people to share similar experiences, if others understood the person's situation (empathy), and/or for information about coping and treatment. Replies to these initial

posts often contained expressions of empathy followed by similar experiences, advice, and opinions. For example, one of the storytellers discussed his hair loss obsession and concluded his narrative by asking for advice: “If anyone has gone through this obsession before, your advice would be very much appreciated.” One of the respondents empathized with his hair loss obsessions, described the benefits he had received from therapy, and advised the person to get treatment:

**Male 2:** Right here, friend. I had really bad BDD related to hair loss for about 10 years now... I have tried everything over the past 10 years to treat this myself and nothing worked. Only getting help from my doctor and a psychologist has worked. And not just a little bit, I feel like my life has been transformed. Go to a doctor, tell them you have BDD. Its not easy to do but you will never regret it once you finally take that step.

There were a variety of reasons that individuals used personal disclosure to elicit support on the forum. Personal disclosure in initial posts resulted in others also disclosing their personal experiences in return, allowing the recipient to compare himself or herself to others. In addition, sharing similar experiences can offer an implicit acknowledgement of a common bond between the initial poster and the support provider (Tichon & Shapiro, 2003). This same pattern of sharing personal experiences while providing advice also occurred on a discussion board for women with cancer (Sillence, 2013). Almost half of the cancer study participants offered advice in conjunction with their treatment experiences.

In message responses, personal disclosure used in conjunction with personal advice and opinions was used to share experiential knowledge (knowledge based on the person’s experiences) that helped to reinforce one’s credibility on the topic. Experiential knowledge shared by similar others can be extremely helpful for distressed individuals who are coping with stressful situations. Similar others can serve as reference individuals against whom the distressed person can compare his or her situation and coping behaviors (Festinger, 1954; Thoits, 2011). Presenting one’s own experiences on the BDD forum served to reinforce that the person offering support was qualified to do so based upon his or her experiential knowledge.

**Personal disclosure as implicit support requests.** As suggested previously, participants did not need to directly ask for support in order to receive assistance from other members. Personal disclosure in initial posts could be used to elicit support and similar experiences without being accompanied by a direct

request (Patterns 3 and 4). These patterns occurred in 10% of the message threads analyzed for the study. Individuals vented negative feelings (anger, despair, shame, and depression) in initial posts and expressed uncertainty, doubt, or hopelessness about what to do or how to get help.

**Pattern 3:** Personal disclosure in an initial post often contained comments expressing uncertainty and doubt about whether the poster had BDD, embedded within a description of the person's compulsive appearance-related behaviors, as shown in the following example:

**Female 1:** I check my reflection at home compulsively multiple times a day, I bring a pocket mirror with me wherever I go. When I'm in a public place with reflective surfaces I avoid looking into them. When I do, I just want to cry because my skin looks terrible. I'm not sure if I have BDD. I am [so] excessively preoccupied with my appearance that it has become a problem.

When replying to these messages, the moderators and other members understood that the person posting the message wanted to know if he/she had BDD. The uncertainty expressed by individuals about whether or not they had BDD was often viewed as an implicit request for a diagnosis. This shared understanding indicates that the forum represented a high-context culture (Hall, 1976) where direct requests were not required in order to receive support. Most members replied to these posts with informational support, noting that they were unable to provide a diagnosis on the forum. As a result, responses usually contained advice to seek help from a doctor and/or psychologist:

**Female 2:** If it's a problem in your life and you feel bad about your looks and check your face in the mirror all the time, maybe you could talk to a doctor. You could ask your regular doctor where to find a psych who might be able to diagnose and treat you. Maybe counseling/therapy would be good.

As noted previously, the types of responses an initial post received generally depended upon the person responding to the message. When the support provider(s) who responded had good insight and knowledge about the disorder, replies usually contained informational support, rather than emotional support and similar experiences. Emotional support can be provided regardless of one's knowledge of the disorder, whereas advice was primarily used to guide others into taking specific actions. Members who advised others to seek professional treatment knew, often from personal experience, the benefits of receiving help from a clinician familiar with BDD.

**Pattern 4:** Personal disclosure about a person's problems could also be interpreted as a request for sympathy, empathy, and sharing similar experiences. For example, one member posted his story containing a detailed account of his BDD symptoms and suicidal thoughts: "I appreciate everybody sharing their story as it makes me feel less alone so I would like to share mine as well..." In response, another member expressed sympathy, offered information about BDD, and shared some of her problems:

**Female 2:** I'm sorry to hear you are going through such an awful time. BDD can go dormant for years and then reappear or it can be constant...For me BDD died down in my early 20's but has now come back with a vengeance. I'm 27 and have had BDD since I was 17. I also suffer from depression and body focussed repetitive behaviours. I find stress does it make it worse as well. I'm going through a particularly tough point in my life and it's really worsened my BDD.

In this instance, one person's desire to share his story prompted another member to share her experiences in response. This reciprocal sharing of personal experiences can reinforce for people that they are not alone; studies have shown that exchanging experiences tends to normalize them and helps people reduce the internalized stigma associated with having a mental health disorder (Chronister et al., 2013). The lack of an explicit request left the choice of response up to the participants. Some members interpreted these posts as requests for informational support, while others interpreted them as requests for emotional support, and so responded with empathy and by sharing similar experiences.

Members generally responded to stories about how others were successfully coping with BDD symptoms by sharing their experiences and providing emotional support in return. For example, when one member shared his positive experience with treatment, he received congratulations, encouragement, and others shared their experiences: "That's good to hear! I'm am fighting, fighting, fighting...I wont let it beat me!" These stories about recovery may have encouraged members to seek help for their BDD symptoms, since members who were successfully overcoming symptoms could have served as role models. Consistent with studies on individual empowerment in online forums (van Uden-Kraan et al., 2009), members who shared their personal experiences about recovery served as positive role models for change.

Soliciting social support by disclosing personal experiences is a common communication strategy found in studies of online conversations. In a study of e-mails by adolescents (Tichon & Shapiro, 2003),

self-disclosure was used in initial e-mails to elicit support, in e-mail responses to provide support (empathy and examples of coping), and then used by the person who initiated the e-mail to provide reciprocal support (social companionship). Asking for support directly can be difficult, and people with serious mental health illness who already feel stigmatized by their condition may risk further stigma and shame by directly seeking support after sharing their personal problems.

BDD forum members may have been concerned with *impression management* (Goffman, 1959; Tidwell & Walther, 2002), which has been suggested by previous researchers (Flynn & Stana, 2012; Tichon & Shapiro, 2003) as a reason that people do not directly ask for support. However, since many of the forum participants had already revealed deeply disturbing personal feelings, thoughts, and behaviors (such as suicidality), it could be that they, like the members who responded to their posts, did not believe a direct request was required in order to receive support. Offering unsolicited support (advice) in response to personal disclosures was also found on a mental health forum for individuals suffering from bipolar disorder (Vayreda & Antaki, 2009). This indicates that disclosing one's problems was understood to be an indirect request for support, and reinforced the behavioral norms of the group, which were to provide informational and emotional support to its members.

Two additional patterns containing initial posts and responses were identified in 11% of the message threads: direct requests for social support without personal disclosure (Pattern 5), and direct requests for personal disclosure without social support (Pattern 6). Two other notable patterns occurred in approximately 8% of the message threads when initial posts failed to receive any responses. Some initial posts provided personal disclosure and sought social support (Pattern 7) and other initial posts offered support (Pattern 8). Patterns containing only social support in initial posts and replies occurred in approximately 15% of the message threads coded for the study. However, these threads contained unsupportive comments or comments unrelated to having BDD, and therefore were not included in the patterns of personal disclosure and social support discussed in the chapter.

**Pattern 5: Explicit requests for social support without personal disclosure.** Pattern 5 occurred when members directly sought advice and opinions about their appearance and/or BDD symptoms to supplement information found on other sites and/or provided by primary group members and clinicians. These messages generated responses that contained both social support and personal disclosure. For example, one poster wanted to know if not getting orthodontic treatment at the right time could alter a person's looks permanently: "I have searched about this and haven't found any convincing answers yet, I have posted it on some ask doctor forums too but no answer... Do you guys know the answer to this question?" This pattern occurred frequently in conversations on the forum. Replies by other posters contained opinions and advice meant to answer the original poster's questions. In response, the original posters often expressed gratitude ("Thank you for your response."), and then disclosed why they asked the question, by sharing their personal experiences: "The reason I asked this is because...as I've said before in another topic I was a very good looking kid and teenager and now I hate myself." In these threads personal disclosure was used to facilitate social support by providing reasons for the person's reassurance-seeking behavior.

**Pattern 6: Explicit requests for personal disclosure.** Asking about others' experiences with BDD was done primarily for social comparison purposes (Festinger, 1954). Individuals shared their problems and then asked if anyone else had similar experiences. For example, one member put substantial effort into trying to look like a popular actress, and wanted to know if other people shared her obsession: "Is anyone else obsessed with wanting to look like a certain celebrity?" In response to her inquiry, two other posters named actresses who they believed were beautiful. Comparing one's experiences to those of others is important because individuals assess the validity of their own attitudes, beliefs, and behaviors against standards modeled by similar others in their reference group (Thoits, 2011). Finding that others had similar experiences may have helped people reduce their internal stigma by realizing that other people shared and understood their condition.

**Pattern 7: Personal disclosure and social support with no replies.** Another notable pattern was when initial posts containing personal disclosure and social support failed to receive any replies. No

definitive explanation can be offered as to why some of these posts failed to elicit responses, since they contained comments similar to those found in Patterns 1 and 2 above. For example, two members shared their BDD symptoms and asked others for a diagnosis, and another person complained that she looked “terrible” in her post. Some of these messages were posted at the end of December 2012, and may have received replies after the data for the study was collected.

Other messages contained requests for social network support that seemed to violate the anonymity offered by the forum. For example, one member wanted to find friends on the forum, but like Fran, did not find other members receptive to this request. The majority of members may not have wanted to convert these secondary group relationships into more intimate friendships. According to social penetration theory (Altman & Taylor, 1973), individuals develop close relationships by providing increasingly intimate forms of self-disclosure that move relationships from relatively shallow, nonintimate levels to deeper, more personal levels. Perhaps members wanted to keep their online and offline lives separate, and preferred the “weak ties” offered by the forum (Granovetter, 1973, 1983).

**Pattern 8: Social support provided with no replies.** A small number of initial posts may not have generated responses because members did not believe that a reply was needed. This pattern occurred when initial posts offered unsolicited help and advice, which countered the accepted norms of the forum. One post invited members to check out a “Beat BDD” Facebook page and another provided a technique for coping with BDD symptoms. Since these posts offered help but did not seek support, perhaps members did not believe a response was necessary.

#### **Group Members Served Primarily as Support Seekers or Support Providers**

As might be expected in an interactive, discursive environment composed of initial messages and replies, forum members engaged in two fundamental behaviors—support seeking and support sharing—more specifically, informational, emotional, and social network support. Theoretically, in an egalitarian and fully interactive forum, it would be expected that members played equal roles in supporting one another. Yet that has not been found in other studies of discussion boards and was not the case on the BDD forum. For example, similar to the most active members on the BDD forum, other frequent posters

have been referred to as *prime givers* (Bambina, 2007) and *super-posters* (Graham & Wright, 2014) in previous studies of online forums.

Members tended to fall into one or the other category on the forum, based on their level of participation, their personal experiences, and their knowledge about BDD. However, the roles of support seeker and provider were fluid, and not mutually exclusive, since the same person could engage in both activities. For example, Fran was one of the most frequent posters in the study, yet she engaged in both seeking and sharing social support, and many of the less frequent posters provided support to others. Importantly, these two behaviors were complementary and essential to the successful functioning of the forum.

### **Support Seekers**

Though both the more and less active members engaged in support seeking, the less active members as a group sought more support than they provided (RQ4). They could be considered the *information seekers*, *opinion seekers*, and *help-seekers* on the BDD forum. Indeed, information (advice), opinions, and help can be viewed as the primary forms of support on the forum. The *information seeker* asks for information or facts pertinent to the problem being discussed, the *opinion seeker* asks questions related to group values, and the *help-seeker* attempts to elicit sympathetic responses from other group members through expressions of insecurity or self-deprecation (Benne & Sheats, 2007). Participants served as *information seekers* when they sought advice related to diagnosis and treatment options, as *opinion seekers* when they asked for others' judgments about their perceived appearance flaws and ugliness, and *help-seekers* when they sought coping assistance from other members through expressions of uncertainty, self-doubt, and/or self-loathing.

The less frequent posters also took on some of the roles related to providing social support. They acted as *information/opinion givers* when they provided advice and opinions about perceived appearance flaws, diagnosis, and treatment options, *encouragers* when they offered emotional support to other members, *advocates* when they expressed gratitude for the comments posted to the forum, and *arbiters* when they disagreed with others' advice or opinions. However, unlike the frequent posters and

moderators, the less frequent posters rarely provided group support as *forum greeters*, *expeditors*, or *mediators*. This could be because they were not as invested in the forum as the moderators and frequent posters.

According to Butler (2001), active members contribute time, energy, and other resources that enable support groups to provide benefits for individuals. These benefits (information, influence, and social support) are the basis for the group's ability to attract and retain members. When individuals choose to actively participate in the group's communication, they are explicitly deciding to contribute their time, energy, attention, and knowledge. This is an investment of resources that less frequent posters may not be ready, willing, or able to make, and thus their roles remained primarily those of support seekers rather than support providers.

The support seekers could have been motivated to post to the forum due to their uncertainty about having BDD, shame about their perceived appearance flaws, and internalized stigma due to having symptoms of a mental health disorder. Thus, potential benefits of receiving support were reduction of uncertainty, stress, and the stigma associated with having a serious mental illness. Uncertainty reduction has been cited as a major motivation for information-seeking behavior (Berger & Calabrese, 1975). According to Thoits (2011), deliberately enacted support provided in response to a person's stressful circumstances validates and reinforces that others are available when needed, especially when the support is offered spontaneously.

### **Support Providers**

Many participants offered support to other members but, as outlined in the RQ4 results, the primary support providers on the forum were the five frequent posters. Their prominence as forum leaders emerged due to their active participation and greater knowledge and insight about BDD. The most active members and moderators demonstrated their dedication to the online community by being responsive when new messages were posted; they replied first in 134 of the 250 threads (54%) containing comments related to BDD, compared to the less responsive 220 members who replied first in 46% of the threads.

Active participation by members was important because the first respondents' comments often served as a guide to subsequent posters and could prompt initial posters to reply and continue the conversation.

The support providers offered advice and opinions based on their personal experience, knowledge, and insight about BDD. For example, when members wanted information about BDD treatment options, Roger and Fran recommended books by BDD experts and discussed their own experiences with treatment. When a female college student wanted to know if she should seek help from her campus therapist, one of the less frequent posters (a father whose daughter had experienced poor on-campus treatment) advised her against doing so.

A person's awareness about having BDD is referred to by clinicians and researchers as their level of *insight* (APA, 2013). Members with experiential knowledge of effective BDD treatment and good insight provided advice that was in accordance with BDD researchers and treatment specialists, such as using medication and CBT to treat the disorder rather than getting plastic surgery. As a result, these members sometimes disagreed with the advice and opinions offered by other members with lower insight levels or less knowledge about BDD symptoms and treatment.

For example, Roger and Kathy countered the opinion offered by another poster that beauty is objective and that ugly people should consider getting surgery rather than therapy. Their comments may have left some members, including the *forum flamer*, dissatisfied with the forum. One reason is that support seekers might equate receiving help with validation of their beliefs and behaviors. Thus, even the well-meaning replies by the frequent posters, moderators, and other members may not always have been interpreted as supportive. As noted by researchers such as Albrecht (1987), meaning does not reside in the intent of the creator or the messages exchanged, but in the interpretation of the recipient.

Members may have offered support because of the gratifications they received in return, such as a sense of belonging (social integration) and reassurance of worth (personal identify) when responding to other members. Offering support to others can provide a sense of belonging, reassurance of worth, and an opportunity for nurturing behavior (Cohen & Wills, 1985). Messages providing the requested support were often appreciated by many of the support seekers, as evident in their expressions of gratitude for the

advice and help they received. These responses may have further encouraged members to provide support, since doing so has been found to increase the feelings of empowerment that come from being helpful to others (Barak et al., 2008). The BDD forum was able to fulfill its function as an online support group due to the complimentary activities of the support seekers and support providers. The peer-based support offered by members served to supplement that provided by friends, family members, and significant others.

### **Contributions by Members Varied by Gender**

Contributions by forum members varied by gender, both in the number of messages they posted and the content of the messages. Female members were more active than male participants in posting messages, in sharing personal experiences, and in seeking and providing support; females posted almost twice as many messages as males during the study. Female posters contributed 57.1% of the messages, compared to 32.7% by the male posters (Table 5.1) This is surprising, since less than half of the forum members were identified as female (44%) compared to one-third identified as male (33%).

Table 5.1

#### *Summary of Messages by Participant Gender*

Gender	Number of posters	Number of messages	% of total messages
<b>Female</b>	<b>99</b>	<b>520</b>	<b>57.1%</b>
Most frequent poster(s)	4	204	22.4
All others	95	316	34.7
<b>Male</b>	<b>74</b>	<b>298</b>	<b>32.7%</b>
Most frequent poster	1	103	11.3
All others	73	195	21.4
<b>Undetermined</b>	<b>52</b>	<b>93</b>	<b>10.2%</b>
<b>Total</b>	<b>225</b>	<b>911</b>	<b>100.0%</b>

These findings indicate that each of the females posted more messages on average than the males; female members posted an average of five messages compared to an average of four messages per male

poster. This discrepancy cannot be accounted for due to the contributions of the frequent posters. Roger contributed 103 of the total number of 298 messages posted by the males (35%) whereas the four most frequent female posters contributed a total of 204 messages (39.3%) by the females. Thus, the percentage of their contributions were similar based on gender. Females also offered more comments containing personal disclosure (62.7% by females and 32.3% by males), social support (57.5% by females and 33.4% by males), stories (74% by females and 26% by males); females were also more reciprocal in conversations as original posters who replied to others in the threads (60% females and 31.7% males).

Overall, females in the study posted more messages sharing their personal experiences, and seeking and providing social support than did male posters. The differences in contributions by gender could have occurred for a number of reasons. First, women may have been more comfortable sharing the experiences, symptoms, and problems than were men. Some men could have been too embarrassed about their body image obsessions to disclose them to other members, even with the anonymity granted by the online forum. As one poster on the forum noted, men are not comfortable talking about their appearance problems: "I'm also a guy, which makes it hard. Men don't talk about this stuff." As a result, males may have felt more internal stigma than females and so were reluctant to disclose their problems on a public forum. Deaux and Major (1987) found that men and women act more in line with stereotypes when they believe they are being observed by an audience.

The different levels of participation between females and males may have been impacted by the types of support offered in the messages. Females on the BDD forum provided similar amounts of emotional and informational support, whereas males provided more informational than emotional support (RQ4). Since the females were inclined to offer both types of support, they may have been more responsive to the support seekers than were males. These findings contrast with those of previous studies showing that females provide more emotional support and males more informational support on mixed-gender forums (Herring, 1993; Klemm et al., 1999). However, in studies of online forums dominated by female members, like the BDD forum, researchers have found that females provide socio-emotional support (Seale, 2006) as well as informational support and tangible assistance (Bunde et al., 2006).

Similar to the BDD forum, women in a hysterectomy online support group offered primarily informational support rather than emotional support to other members (Bunde et al., 2006).

The males on the BDD forum provided more informational than emotional support, which is consistent with findings that males tend to focus more on sharing information than on providing emotional support online (Herring, 1993; Klemm et al., 1999). There were two notable exceptions to the findings that males provided less social network and emotional support than females on the forum. First, most of the social network support was provided by one male, who posted more messages than any other forum member. Roger greeted new members and encouraged them to keep posting in order to keep the forum vibrant and thriving. Second, two male storytellers posted narratives about successfully overcoming BDD symptoms as a form of emotional support, in order to provide hope, to provide encouragement, and to serve as positive role models for other members.

These findings suggest that males may uphold more traditional roles as providers of informational support on mixed-gender forums, but they can also provide more emotional than informational support on forums that are dominated by one gender. Males shared more emotional than informational support on a female-dominated breast cancer forum (Seale, 2006) and on a male-dominated eating disorder forum (Flynn & Stana, 2012). This study adds to previous research on mixed-gender online forums by finding that: (a) females offered both more emotional and informational support than did males, and (b) that males were motivated to provide social network support and act as role models for recovery on a forum dominated by females.

### **The Forum Served as a Coping Mechanism for Members**

The BDD forum facilitated personal disclosure and social support and therefore served as a valuable coping mechanism for members. Lazarus and Folkman (1984) defined coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 141). The authors viewed coping as a goal-directed, dynamic process that changes in response to the demands of a stressful encounter or event (Lazarus & Folkman, 1984). Individuals facing stigmatizing and stressful situations can attempt to

mitigate the negative psychological and social impact by employing a variety of coping strategies. Some strategies are focused on resolving the stressful relationship between the self and the environment (problem-focused), whereas other strategies seek to regulate negative emotions arising from the situation (emotion-focused; Carver, Scheier, & Weintraub, 1989).

People struggle to cope with health-related problems from the time they are aware of symptoms through resolution of the condition—a pattern described in the stages of change (transtheoretical) model as beginning with precontemplation and contemplation, followed by preparation, action, and maintenance (DiClemente & Prochaska, 1982). The forum served individuals who were in different stages of coping with the disorder; some members were uncertain whether they had BDD or were truly ugly, others wanted advice about treatment options, some were still struggling with symptoms despite receiving clinical treatment, three members had successfully overcome BDD symptoms, and two members wanted to help their girlfriends who had been diagnosed with BDD.

Importantly, forum members coped with symptoms of the disorder by seeking and providing support to other members. In many cases, successful coping represented the ultimate goal of support seeking and support sharing. Thoits (1986) conceptualized providing social support as coping assistance. Problem-focused coping assistance includes behaviors intended to help another person solve or eliminate a problem-causing stress, which is similar to informational support, whereas emotion-focused coping assistance is intended to comfort or console another person, similar to emotional and social network support. Participants used the forum to share their coping strategies and to provide coping assistance to other members.

Coping has been the focus of only a handful of studies regarding online health (Wright, 1999, Wright & Rains, 2014) and only one study devoted to mental illness. Chronister et al. (2013) identified five specific coping tactics employed by mental health patients to overcome stigma: educating and challenging coping (problem-focused coping), and withdrawal, distancing, and secrecy coping (emotion-focused coping). Notably, each of these coping strategies was evident in the BDD forum. The findings

from the BDD forum indicate that the problem-focused and emotion-focused strategies used by participants could have helped as well as hindered members' ability to effectively cope with the disorder.

Empirical findings from numerous coping contexts have consistently shown that problem-focused coping is predictive of positive adaptation while emotion-focused coping is predictive of negative adaptation, in part because individuals tend to use problem-focused coping when a situation is appraised as changeable and emotion-focused coping when a situation is assessed as unchangeable (Wright, 1999). Problem-focused coping strategies include seeking information, generating possible solutions to a problem, and taking actions to change the circumstances that are creating stress. Emotion-focused coping involves responses such as expressing one's emotions (venting), seeking emotional support from others, trying to avoid the source of stress, distracting oneself, and positive reappraisal (Lazarus & Folkman, 1984).

### **Emotion-focused Coping Strategies on the BDD Forum**

Emotion-focused coping strategies shared by forum members were self-acceptance, exercise, meditation, a forgetting box, mandala therapy, having other hobbies not related to one's appearance, telling oneself that BDD thoughts are not real and will pass, and accepting one's ugliness as a blessing from God (positive reappraisal). Kathy mentioned that having BDD had made her more compassionate and understanding, which is another form of positive reappraisal: "I am 99% percent sure that BDD has shaped my personality in a positive way." Another emotion-focused coping strategy used on the forum was venting negative emotions, such as anger, depression, shame, and guilt. The ability to disclose one's feelings and experiences to others who understood the disorder was of great importance to many who posted to the forum: "Sometimes you can feel so alone but it's great to know there are people out there that share the same problems as me, and have felt the same as me." In a study of participants in a cancer support group, venting negative emotions such as anger and sadness were shown to have beneficial outcomes six months after participation (Lieberman & Goldstein, 2006).

For many members, including the storytellers on the forum, writing about their problems and receiving support from others were important benefits of forum participation. Writing about one's

experiences can be useful for providing a sense of relief by exposing one's inner feelings, which can lead to emotional catharsis. Writing about difficult experiences has been found to decrease negative emotions and increase positive ones (Barak et al., 2008; Tichon & Shapiro, 2003). One female storyteller admitted that she felt better after sharing her story on the forum but could not reveal her experiences to anyone she knew: "I feel better for even having typed it out. But I can't ever, ever say that to anyone."

Reading about others' experiences and sharing similar experiences can lead to self-acceptance and a shared group identity, which is valuable for combating public and internalized stigma. For example, one member reassured another poster that even though her thoughts were not normal, they were shared by most participants on the forum: "Everyone here has the obsessions. It isn't normal but you certainly aren't alone and you certainly aren't a freak." Similar to online forums for individuals who self-harm (Whitlock et al., 2006) and engage in pro-anorexia behavior (Haas et al., 2011), forum members validated that BDD-related thoughts and behaviors were normal for those with the disorder. Doing so could have empowered individuals to seek help for their symptoms, rather than remaining silent and feeling isolated and alone.

Emotion-focused coping strategies shared on the forum that can be harmful for people with BDD, according to treatment specialists (Phillips, 2009; Phillips et al., 2008; Wilhelm, 2006), were upward social comparison, checking one's appearance in photographs and mirrors, asking others about perceived appearance flaws (reassurance seeking), and blaming others (such as parents) for BDD symptoms. These behaviors are considered harmful for individuals with BDD according to treatment professionals. Other coping strategies discussed on the forum that could have led to poor outcomes were withdrawal and secrecy coping. Withdrawal coping was evident when forum members avoided social situations with family and friends, and did not go to school or work. Fran and other forum members used secrecy coping when they concealed their perceived flaws with makeup and/or clothes, and refused to discuss the reasons for their behavior with friends, family, and significant others. According to the study by Chronister et al. (2013), participants who concealed their mental health history from friends, family, romantic partners, and employers in order to avoid rejection had higher levels of internalized stigma, and therefore experienced poorer mental health recovery.

Another avoidance coping strategy used by members was cognitive distancing. This was evident when members disavowed having BDD, despite posting messages to the forum. In distancing coping, individuals indicate that their problems are very different from people in the stigmatized group (Chronister et al., 2013). Distancing coping was used by members who were convinced that their perceived appearance flaws were real: “I don’t think what I am seeing is unrealistic. I could understand that you guys may really have the neurological part in it but for me it would be very tiny to even non-existent.” About half of the unsupportive comments were posted by members who used distancing coping strategies. One such member was the forum flamer, who believed that he was ugly, rather than having BDD. He posted messages that discredited BDD as a diagnosis and sought to convince other members that they were actually ugly: “Be skeptical of BDD. . . What legitimately ugly people need is not counseling but surgery.”

### **Problem-focused Coping Strategies on the BDD Forum**

Problem-focused strategies discussed on the forum included seeking information about symptoms, diagnosis, and treatment; generating possible solutions to one’s problems using self-help techniques; and taking action to change the situation by seeking and/or getting clinical diagnosis and treatment. Many members who posted to the forum wanted to get clinical treatment but were unable to find therapists who could effectively diagnose their BDD symptoms. As a result, some participants diagnosed themselves with BDD by comparing their experiences to those of other members. This is one of the surprising findings from the study, because the forum is labeled as a BDD forum, but not all posters had a BDD diagnosis. Thus, some members were able to increase their self-awareness that they had BDD (self-diagnosis) by comparing their own experiences to those of other members.

Fran and another storyteller on the forum used educating coping to let forum members and the public know about BDD and that recovery from the disorder was possible. Taking action by educating people about the disorder is considered to a valuable problem-focused coping strategy used to reduce internalized stigma (Chronister et al., 2013). Fran disclosed that she had posted information about BDD to her Facebook page, and one of the storytellers had written a book about his BDD experiences. Fran was

proud that she had made the effort, but Roger did not believe that “force feeding information about BDD to other people on facebook” was an effective strategy for helping people cope with BDD. Instead, he was committed to offering assistance to members by collecting their coping strategies and sharing them with other members in the form of a book, and taking action to combat unsupportive comments posted to the forum.

Roger and Kathy used challenging coping when they opposed the comments posted by the forum flamer, a strategy also referred to as confrontive coping (Lazarus, 1993). In challenging coping a person points out stigmatizing behavior; in confrontive coping individuals express anger to the person who caused the problem to get the person to change his or her behavior. On the BDD forum, the forum flamer made claims about people being ugly that could have increased their self-stigma; other members fought back by challenging his statements. Educating and challenging coping are considered to be empowering strategies for individuals with serious mental illness since they help to combat internalized and public stigma (Chronister et al., 2013).

Getting cosmetic surgery to fix one’s perceived flaws was an ineffective coping strategy discussed by forum members. Other ineffective coping strategies shared by members were getting dermatology treatments, dieting, body building, and contemplating suicide as a way to end one’s suffering. Seeking to improve one’s appearance with surgery and dermatology procedures was a popular strategy for members who believed that their appearance flaws were real. One reason for its popularity could have been because having cosmetic surgery is an accepted practice in modern society (Bordo, 2003; Shilling, 1993). There were more than 10 million surgical and nonsurgical procedures performed in 2014 in the United States, amounting to more than \$12 billion spent by Americans to improve their appearance (American Society for Aesthetic Plastic Surgery, 2016).

Most people on the forum who had received effective clinical treatment advised members to seek professional help and avoid getting plastic surgery. One such member quoted a respected BDD researcher and clinician (David Veale) to back up his advice that surgery was detrimental for individuals with BDD: “Even if patients are satisfied with cosmetic treatments, often the preoccupation moves to a different area

of the body, so that the handicap of the disorder remains.” According to Thoits (2011), coping assistance offered by people with firsthand experience can be more efficacious in guiding members’ behavior than that offered by well-intentioned but less informed members of the person’s primary support group.

### **The Forum Offered Peer Support within an Online Community**

The BDD forum offered members valuable peer support in an online community. Describing the forum as a supportive online community is important because doing so illuminates the potential advantages that such groups offer stigmatized individuals. The principal advantage that online groups offer participants is the opportunity to communicate with others who understand the disorder unbounded by geography. The BDD forum enabled members to expand their social network beyond the strong ties of their primary group to a peer-based support group online. According to Chronister et al. (2013), peer support is a central focus of current mental health treatment and appears to have the potential to increase the size and quality of a person’s support system.

The BDD forum can be considered a supportive online community based on the social support sought and shared by members. According to Rheingold (1993), virtual communities are “social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace” (p. 5). Baym (2010) conceptualized online communities based on five attributes: a sense of space (virtual place), shared practice (communication norms), shared social support, shared identities (group roles), and interpersonal relationships. All of these attributes are applicable to the BDD forum: the forum has a designated location in cyberspace; behavioral (influential) norms were enforced through the use of forum rules and regulations; members shared social support and took on roles as support seekers and providers; and the most frequent posters developed interpersonal relationships with one another. As with all communities, including geographic communities, the BDD online forum offered potential advantages and disadvantages to members compared to other offline and online sources of support.

## **Advantages for Forum Members**

Participants were able to expand their social network by joining the BDD forum and seeking and sharing personal experiences and support with their peers, along with coping strategies and coping assistance. The peer support provided on the forum had potential advantages over social support from other online and in-person sources. The BDD forum supplemented the support members received from their primary support group, social networking sites, and in-person therapy. The shame and stigma many individuals felt kept them from disclosing their feelings to those closest to them, including friends, family members, and significant others. As a result, they came to the forum to get the peer support they needed to help them cope with the disorder, and they were able to expand their social network as members of the BDD community.

There are benefits to being part of a supportive community consisting of people who share the same condition, because similar others have an in-depth understanding of the many dimensions and nuances of the stressful situation that family and friends may lack. This was evident on the BDD forum when participants encouraged one another to post because “everyone [here] understands your struggles,” and members agreed that even their friends could not relate to what they were going through: “I don’t think as you say that any friend could in the end possibly relate.” Being understood by another person can have direct effects on reducing an individual’s physiological and affective arousal, especially when friends and family members are unable to grasp the implications of the stressful situation (Thoits, 2011).

There has been little focus on the beneficial effects social support has on individuals with BDD symptoms. In fact, only one other study was found that corroborates the findings from the current study on the advantages that social support offers males and females who suffer from BDD symptoms. Marques, Weingarden, LeBlanc, Siev, & Wilhelm (2011) conducted an online survey of 400 men and women with symptoms of BDD and found that greater perceived support from family members, friends, and significant others was associated with less severe BDD symptoms. Social support from friends and significant others resulted in less severe symptoms in males, whereas support from family and friends resulted in less severe symptoms for females. BDD forum members who responded to others’ posts often

indicated that the peer support they received was valuable because it supplemented the support from family members, friends, and significant others. Thus, the forum filled a gap in support from primary group members, which could have led to a reduction in the severity of BDD symptoms.

Online communities that lack vibrant graphics, in-depth member profiles, self-starting videos, and personal photographs seem to be almost an anachronism in today's era of social networking sites. However, sharing one's problems with friends on Facebook is not common because individuals strive to project a positive self-image on the site and prefer to share their problems anonymously in online forums (Newman et al., 2011). Part of projecting a positive self-image on Facebook is choosing to upload flattering photographs of oneself to the site. However, members often lack control over which personal images are tagged and viewed. This lack of control was distressing to BDD forum participants who believed that they looked worse in their photographs than they did in person. Seeing images of themselves on Facebook could trigger harmful behaviors, such as obsessing about perceived appearance flaws and engaging in upward social comparison. Comparing one's appearance to other members' did occur on the BDD forum, but it was infrequent due to the fact that personal images were not allowed on the site.

Another advantage that the BDD forum offered individuals was that there were fewer barriers to receiving support compared to in-person treatment; members could retain their cloak of anonymity and still receive information, advice, and help. The barriers to seeking professional diagnosis and treatment mentioned in the study included the fear of being called ugly by clinicians, uncertainty about how to get help, being judged negatively by others, therapists' lack of knowledge about BDD, a waiting period required to receive treatment, and the cost of therapy. The BDD forum and other online support groups encourage members to take responsibility for their own care, since they are accessible anytime at no cost, and allow people to ask questions and seek support when needed.

Forum members shared the reasons that receiving in-person therapy could be difficult, including participating in face-to-face support groups. Some members were afraid of being judged negatively by clinicians or other patients. According to one participant who had been hospitalized with BDD: "In the early days when i was hospitalized and put into a BDD group, pretty much the whole group used to

analyze me and put me down physically!” Another patient believed that her therapist was judging her, so she was afraid to share her insecurities: “I also wanna say that I go to therapy but I normally don’t tell her much about myself while in it . . . I know that it’s a little strange to say, but I’m quite scared that she’s judging me for some reason.” Some participants found treatment to be expensive as well as ineffective, as shown by one member who was shocked at the cost: “a therapist is kinda out of the question, went to one before and it was so expensive!!!!”

As a result of encountering barriers to professional treatment, many participants turned to their peers on the forum for support that served to supplement offline support from mental health providers. Dickerson (1998) noted that self-help or mutual-help groups are among the most effective vehicles for fostering individual empowerment, especially in the context of mental health-related conditions. This is because support groups are directly associated with the three main attributes of individual empowerment: (a) reliance on self and peers (rather than on authoritative professionals), which contributes to a sense of personal competence; (b) voluntary participation and free choice, which contribute to feelings of self-determination; and (c) helping others and socially identifying with others, which contribute to perceptions of social engagement. The peer support on the forum may have fostered empowerment among participants, since they could rely on one another for support.

Online support groups, like the BDD forum, have been shown to foster individual empowerment through the exchange of information perceived to be relevant, credible, reliable; online support groups have also been shown to increase participants’ knowledge and ability to make informed personal decisions (Barak et al., 2008; van Udeen-Kraan et al., 2008). It is not only access and exposure to information that empowers people; it is the ability to share information with others. Both the receiver and provider of information are empowered, with the latter taking the role of guide, instructor, or helper. Also, individual decision-making is enhanced through discussions in an online support group because participants learn how to gather information, gain a better understanding of the nature of their distress, learn how to better cope with their condition, and learn from others’ experiences (Barak et al., 2008).

Participating in a dynamic group entails a process of creating interpersonal relationships. This increases social cohesiveness, thus legitimizing the expression of personal feelings. Expressing negative feelings can bring about a cathartic experience and emotional relief (Buchanan & Coulson, 2007). Sharing personal stories and reacting to the personal stories of others was often communicated within the BDD forum with much empathy, along with emotional reinforcements and support. Connecting to other people with similar issues can create feelings of belonging which become the reason for remaining part of the online group and for providing support to others (Tanis, 2008).

This mutual sharing and development of interpersonal relationships was evident when Roger, Kathy, Mia, and Janet greeted one another by name, validated one another's comments, and chatted in the "off-topic" thread that Roger started. These four members used the off-topic thread to create their own forum—a quasi-public place to deepen their relationships. Other members also shared personal experiences unrelated to having BDD that could have increased their affinity for one another, by sharing favorite movies, songs, and inspirational quotations. Similar instances of chatting, teasing, and off-topic posts were found in virtual communities (Burnett, 2000) and online support groups (Bambina, 2007; Finn, 1999; van Uden-Kraan et al., 2008). These off-topic conversations could have fulfilled members' entertainment needs by diverting attention away from their problems, and interpersonal needs by reinforcing their shared values and interests.

### **Disadvantages for Forum Members**

Despite the benefits offered by being part of a supportive online community, there were also potential disadvantages to posting messages on the forum, such as increased depression, poor advice from forum members, and incomplete information. First, posting messages could exacerbate one's BDD symptoms. For example, Mia reported that sharing her experiences made her feel less alone, but more obsessed with her appearance flaws: "this forum helped me a lot and made me feel like I wasn't alone, but it started consuming me and the more I came on here the more I thought about how ugly I am." For people with cognitive processing disorders, such as severe depression or posttraumatic stress syndrome (PTSD), writing about one's experiences was found to worsen symptoms (Gidron, Peri, Connolly, &

Shalev, 1996). According to social sharing of emotions theory (Rimé, Finkenauer, Luminet, Zech, & Philippot, 1998), sharing negative emotions and experiences is maladaptive when disclosers continue to ruminate on them. Continued rumination makes negative feelings more salient, thus intensifying stress, anxiety, shame, and other emotions associated with the experience (Chang & Bazarova, 2016).

Another disadvantage for members was that the support provided on the BDD forum was anecdotal and, as a result, could contain inaccurate or potentially harmful information, such as when forum members recommended plastic surgery as a strategy for alleviating BDD symptoms. On the BDD forum, knowledgeable support providers often countered the poor advice offered by other members and provided helpful alternatives. For example, when one male poster told another that he should take steroids in order to become more attractive to women, another member replied and criticized this advice: “That is awful advice to give somebody. If a woman says she does not like a guy who takes steroids then she means it. . . My advice is, don’t take [Male 2’s] advice.” This can be considered one of the benefits of online forums; harmful advice is usually corrected by other participants (van Uden-Kraan et al., 2008)

Because threads on discussion boards are presented in chronological rather than topical order, information on specific topics may be difficult to find. People who rely primarily on these online communities for advice and support run the risk of gaining inaccurate or incomplete information. As a result, individuals need to supplement the informational support provided by their peers with resources found on websites sponsored by hospitals, treatment centers, clinicians, and in the case of BDD, on the International OCD Foundation website.

The BDD forum facilitated peer-based support via personal disclosure, and members served as support seekers and support providers in order to help themselves and other members cope with BDD symptoms. Members shared coping strategies with their peers and offered coping assistance in the form of informational, emotional, and social network support. The support offered on the forum supplemented the support provided by primary group members and treatment professionals. Although the forum did have disadvantages for members, such as lack of factual information and the presence of unsupportive

comments from some members, overall the forum was a supportive online community for people suffering from this severe and under-recognized mental health disorder.

### **Limitations**

The current study extends previous research on peer communication in online health forums. The findings indicate that personal disclosure is used to facilitate social support in online forums, and that active members become emergent leaders whose supportive communication supplements the roles of the appointed forum moderators. Although the number of online forums for people with serious mental illness continues to increase, there are few studies that evaluate the types of help offered or the information shared among users of online self-help forums, according to health communication scholars (Bauer et al., 2013). Thus this study fills a gap in research on peer support in mental health forums and the value that such groups provide to stigmatized individuals.

There are a number of limitations in the present study that must be acknowledged. First, the study was based on messages posted to a single computer-mediated support forum during a one-year period. The extent to which these messages are representative of the BDD forum at other times or representative of similar forums is not known. Comparable results might have been obtained by studying BDD Central, the forum that was the original focus of the investigation. Further research would be beneficial to extend the analysis to multiple forums involving other mental health conditions.

Second, the high number of posters whose gender could not be determined (52) limits conclusions about the personal disclosure and social support provided by males versus females. Table 4.1 suggested that there were differences between the types of support offered by males and females on the forum. Additionally, findings indicated that females provided more personal disclosure and social support than males. However, since 23% of the posters could not be identified as male or female, extending these findings to all participants is not possible.

Third, the emphasis of this study was on examining personal disclosure and social support in messages. It is unknown whether or not such messages were interpreted by participants as being supportive, or in accordance with the broad categories identified in this analysis. The motivations that

individuals had for visiting and posting messages to the site also remains unknown, though some intentions could be deduced based on the message content. Interviews, participant observation, and/or surveys would be helpful to increase understanding of people's motivations for using the site and to determine if using the forum provided beneficial or detrimental outcomes.

Fourth, the study combined both deductive and inductive qualitative content analysis. The main strength of combining approaches is that existing concepts can be supported and extended (Hsieh-Fang & Shannon, 2005). However, adapting coding schemes developed in previous research, such as the categories of informational support, emotional support, and social network support from the SSBC (Cutrona & Suhr, 1992), can present challenges to naturalistic inquiry. Using categories from previous studies makes it more likely that one will find data that fit into the existing categories. The researcher strived to enhance the credibility of the findings by developing most of the codes inductively from the data and by using negative cases (such as unsupportive comments) to identify disconfirming evidence during the inquiry.

Fifth, obtaining adequate intercoder reliability for the categories of social support proved to be challenging, and required collapsing or eliminating two of the five social support categories found in previous coding schemes (Braithwaite et al., 1999; Cutrona & Suhr, 1992) since these did not occur frequently enough to be included in the coding guide. Esteem support was subsumed under emotional support, and tangible assistance was eliminated. These changes are similar to those by Bambina (2007) when she developed her coding scheme for an online cancer forum. Revising the original five support categories in the SSBC may have compromised the coding for the study because findings were limited to only the three most prominent types of support.

Finally, the researcher sought to strike a balance between conducting a study intended for health communication scholars that also addressed issues relevant to BDD researchers and clinicians. This entailed balancing the use of nomenclature that has specific meanings within the BDD community (such as *insight*, *reassurance seeking*, *obsessive thoughts*, and *compulsive behaviors*) with more general terms

that could be equally descriptive. The researcher did this in order for the study findings to add valuable contributions to theory and practice about peer-to-peer mental health communication for both audiences.

## **Implications and Further Research**

### **Implications for BDD Research and Practice**

For researchers and clinicians concerned with treating BDD patients, this study suggests that peer-to-peer communication via an online forum can be a valuable tool in helping individuals exchange personal experiences, and informational and emotional support. Peer-to-peer communication also provides members with problem-focused and emotion-focused coping assistance as well as social network support by others who understand the condition. Members on the BDD forum shared personal stories and anecdotes about their suffering and sought information about diagnosis, treatment, and coping with the disorder. The concerns expressed by people on the forum were similar to those of individuals who posted to forums for depression (Barney et al., 2011). For example, Barney et al. (2011) found that common themes expressed by people with depression despair and suicidal thoughts; difficulty coping with symptoms; lack of knowledge about treatment, medication, and how to access services; disclosing the condition to others, self-stigma (shame and blame), comorbid conditions, and the value placed on hearing about others' experiences with mental health problems.

The findings of this study and similar studies suggest that peer-based resources outlining self-help and coping skills would be valuable tools to post on websites about BDD and related mental health disorders that contain content created primarily by clinicians and researchers. Also, information that addresses typical concerns about therapy (diagnosis, CBT, medication) may encourage individuals to overcome the barriers to receiving treatment. The BDD forum also helped people to diagnose themselves and to learn about effective treatments for BDD. These findings indicate that by going online and sharing symptoms with their peers, individuals were able to diagnose themselves with the disorder. This could help to increase their self-awareness (insight) about having BDD, and encourage people to seek professional treatment.

The implications of the study findings are that online support forums offering visual anonymity could provide advantages over face-to-face support groups and social networking sites to help individuals with BDD receive social support from their peers. Online forums enable individuals with BDD to engage in reciprocal self-disclosure, reveal their “true selves” to others, and exchange informational, emotional, and social network support with peers who understand the disorder. The opportunity to interact with peers who share their experiences is important for individuals with mental health conditions, and the visual anonymity offered by text-based CMC could promote increased personal disclosure and affinity between individuals with BDD.

Despite the visual anonymity offered by the BDD online support forum, individuals still engaged in social comparison and reassurance-seeking behaviors about their appearance. Reassurance-seeking behavior about one’s appearance still occurred despite the fact that a person cannot reasonably expect to receive an accurate reply. Although the forum did not allow people to post personal photographs, some members nonetheless asked others whether their perceived flaws were real, or if they had BDD. Individuals on the forum who asked this question seemed to understand that having BDD causes perceptions of ugliness, but were unable to diagnose themselves with the disorder. This indicates that more online self-assessment tools are needed so that individuals can diagnose themselves with BDD.

Another implication for BDD mental health professionals is the need for having one or more therapists available to answer questions on support forums for mental health disorders. Moderators and members encouraged individuals to seek professional help for diagnosis and treatment, despite studies that show many therapists lack knowledge about how to diagnose and treat the disorder (Marques, Weingarden, LeBlanc, & Wilhelm, 2011). Thus, the advice shared by members may have been difficult for the recipients to execute. Clinicians familiar with treating BDD could offer information to members on where to find specialists in their area. Educated professionals familiar with treating BDD could answer members’ questions about diagnosis and treatment, draw attention to unhelpful communication behaviors (such as reassurance seeking and social comparison), and suggest beneficial ways of coping with the

disorder. Resources such as an “Ask the Clinician” thread could be provided as a way of supplementing the experiential knowledge offered by forum members.

More research about the level of awareness that people have about the disorder is needed. Researchers could survey college students, teenagers, and adults about their perceived and actual knowledge of BDD. Knowledge of eating disorders has been shown to be high among adults and adolescents (Hunt & Rothman, 2007; Smith, Pruitt, Mann, & Thelen, 1986). Clinicians and BDD researchers have acknowledged that the disorder is under-recognized by individuals with BDD, the public, and mental health professionals (Phillips et al., 2008). Studies that examine the levels of awareness that these different populations have about BDD would help inform mental health professionals about the educational resources needed by each group. As a result, information about the disorder could be tailored to meet the needs of individuals with higher and lower knowledge and insight levels.

As a result of the study findings, researchers and clinicians will have an increased awareness about the resources and support needed by those suffering from BDD and related mental health disorders., and a better understanding of why people turn to their peers to find the information and support they need to recover. This study, combined with other studies by mental health researchers, can help to inform clinicians and other treatment professionals about the value of online, peer-based support for individuals with serious mental illness, in particular those suffering from BDD.

### **Implications for Health Communication**

Many of the points outlined above pertaining to implications for BDD research and practice apply to health communication in general and mental health communication research in particular. Seeking and sharing personal experiences and social support are fundamental communication activities on support forums. However, consistently recognizing how individuals make requests and provisions has been challenging for health communication researchers. Some studies of online forums do not attempt to code social support separately from personal disclosure, while others do so by coding personal disclosures as indirect requests for support. The findings from the current study indicate that personal disclosure needs

to coded separately from social support when analyzing peer communication in online forums. By doing so, the various ways that personal disclosure is used to facilitate social support can be understood in more detail. The eight patterns outlined in the study demonstrate that personal disclosure is used both when seeking and providing social support, and is thus an integral component of the communication that takes place between peers online.

Another implication for health communication research is that peer-based communication supplements the support received from other online and in-personal sources. Members expressed gratitude that they could share their personal problems related to having the disorder with their peers on the forum and receive help, advice, and support in return. Studies have shown that online support group members appreciate having access to the experiential knowledge of their peers because the information they receive is often easy to understand and tailored to their needs (Barak et al., 2008). However, members of the BDD forum also shared their problems with family members, friends, and clinicians. This finding indicates that individuals with mental health conditions value information from their peers, from family members and friends, and from mental health professionals when coping with symptoms of the disorder. Important questions for further research could include how peer-based support and professional treatment work in terms of time order (e.g., do people use forums before or after seeking help from medical professionals), under what conditions people choose to seek support from a variety of sources, and whether using multiple sources is most effective for people when coping with BDD symptoms.

Despite the ever-growing popularity of Facebook, Instagram, and other social media sites as a research focus for health communication scholars (Walker, 2015; Wright et al., 2013), this study highlights the ongoing value of text-based communication, especially for individuals with mental health disorders. Further research could focus on how individuals with serious mental illness, including BDD, use a combination of online channels for support seeking and support providing, including forums, synchronous chats, websites, blogs, social networking sites (Facebook), virtual worlds (Second Life), and even chatbots on personal messaging apps. Researchers studying support forums for related mental health

conditions (OCD, social anxiety disorder, depression, eating disorders) could investigate what motivates individuals to use multiple communication channels.

More also needs to be known about how online and in-person support groups might work together for people suffering from mental health disorders. For certain mental health conditions, such as BDD, online support groups may be more beneficial than offline groups. Comparisons between in-person and online support groups could examine the conditions under which the two are complementary, or if individuals with mental health conditions prefer the anonymity and convenience offered by online support groups. In addition, interviews with forum participants could explore the benefits that forums provide to those who receive support, to those who lurk, and to those who offer support to others.

Future research could explore the extent to which coping strategies and coping assistance provided on the BDD forum are also provided in online communities for people with other stigmatizing health conditions. As a result, communication scholars may choose to refer to these online support groups as *communities of coping*, based on the coping strategies used by members. Informal workplace support groups have been referred to as *communities of coping* in organizational communication literature (Korczynski, 2003; Raz, 2007); however, this term has not been used to describe online communities for people coping with mental and physical health conditions.

As shown by the results from this study and other research on active members in online forums (Bambina, 2007; Graham & Wright, 2014), emergent leaders play a crucial role in providing support to other members on the forum. The leaders on the BDD forum participated in a wide variety of functional roles, including encouragers, information givers, and social network facilitators. More research is needed on the leadership roles of active posters in online communities to determine if they usually provide more social support than other members. If so, then the 2% of individuals who post the most messages could determine whether online forums are successful in helping individuals with serious mental illness get the support they need to cope with the disorder.

## **Conclusion**

Albrecht et al. (1994) suggest that researchers “should be especially interested in the features of situations, messages, interactions, relationships, and networks that can alleviate or reduce dilemmas” (p. 435). The basic dilemma facing individuals with BDD symptoms is that they may feel too stigmatized by their perceived appearance flaws and/or having a mental health disorder to reveal their suffering to others, and if they do, they often find little knowledge or understanding among family, friends, and even mental health professionals. Thus they turn to online support groups, like the Psychforums BDD site, to receive the peer support they so desperately need to help alleviate their suffering. These groups offer stigmatized individuals a supportive online community filled with similar others who can offer them the support they need to cope with BDD symptoms. The BDD forum enabled individuals who felt socially isolated and stigmatized by the disorder to discuss their problems, share coping strategies, and provide coping assistance to their peers. Overall, the BDD forum and related health forums are valuable because they provide a secondary group where members can receive peer-based support to help them cope with and recover from this often debilitating and under-recognized mental health condition.

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Content\_analysis.pdf

## APPENDIX A

### Researcher BDD Story

I remember starting to stare at myself in the mirror when I was 16 years old. Before then, I would spend most of my free time walking and reading outdoors, watching television, writing, or playing with my friends and pets. Then, after I turned 16 I became increasingly aware of my appearance, especially my face. I started wearing make-up and reading fashion magazines, and comparing my appearance to my peers and the models in the magazines. As a result, I found my appearance and facial features sadly lacking. My eyes were too small and close together, my nose too large, my forehead too short, and my chin too long. Also, though I was slender, my hips and thighs looked out of proportion to the rest of my body. I identified my body as ‘pear-shaped’ according to the fashion magazines I read.

It was not until I turned 18, during the summer before my freshman year at college, that I confessed to my mother how much I hated my appearance, especially my nose. I told her that I didn’t want to get married and have children, in case they ended up having my fat, ugly nose. I also told my mother that I had thoughts about committing suicide due to the fear of passing my defect to my children. Her response was to pay for plastic surgery (rhinoplasty) to have my nose “corrected” by making it thinner. After the surgery, I was horrified by the facial swelling and black eyes, and my mother had to cover the mirrors in the house while my nose healed. However, soon after the swelling went down I realized I still hated my nose, since my profile looked odd to me now. I never mentioned my displeasure with the results to my mother, since she clearly felt the surgery had been successful, and was pleased with my altered appearance. I felt terrible, still hated my appearance, and now felt guilty that the surgery had not made me feel better about myself.

Throughout college I was a good student, though I struggled with feelings of low self-esteem and mild depression. My grades enabled me to graduate cum laude, though I would have preferred summa or magna. After college, I managed an art gallery in Boston and found it extremely stressful being on my own for the first time. Soon after breaking up with my boyfriend, the stress and feeling emotionally

abandoned caused my symptoms to worsen. I spent hours in the morning and evening staring at my face in the mirror, looking at the pores in my nose, and picking at my skin. At one point, the picking caused a small facial scar. I remember collapsing on a stairway later that day in tears, devastated by the terrible mark I had caused, convinced it would never go away.

After I turned 30, I decided to move from Boston to Boulder, Colorado, where my brother and best friend lived. My mother, having been diagnosed with breast cancer at the age of 61, soon followed. She wanted to be close to her son and daughter during her illness. I went back to school to become a website designer, while my brother earned a law degree, got married, and settled down in Denver. My best friend became an ultra-runner and introduced me to the sport of long-distance running. Trail running and hiking in the Rocky Mountains helped to relieve the stress and anxiety I often felt upon waking. My appearance still preoccupied me, so being outdoors definitely helped to relieve my symptoms for a while. If I was not able to look at my face, I didn't obsess about my nose.

Meanwhile, my mother was struggling with the effects of a second mastectomy and chemotherapy. She became depressed and her doctor prescribed Prozac for the symptoms. The Prozac helped to relieve her depression and she became much more optimistic about her chances for survival. Her attention then turned to me and my depression, though she didn't know its cause. I had never again confessed to her how much I hated my appearance, or about the related symptoms of skin picking, comparison with others, or preoccupation with my nose. It surprised me that she noticed I was depressed. I had become so familiar with the constant state of anxiety about my appearance that it no longer was apparent to me.

My mother suggested that I get a prescription for Prozac since it had helped relieve her symptoms. I disliked the idea of taking prescription medication and so resisted her suggestions. Also, since I believed that I truly was ugly, I felt my negative feelings were justified. Then, one day while waiting in line at the grocery store, a magazine cover caught my attention. On the cover of the *SHAPE Magazine* (May, 1997) was a beautiful blond model in a bright blue bikini. As I scanned the headlines surrounding the model, I noticed an article titled, "Hate your looks? What it means when your mirror

lies.” The title caught my attention because my friends, past boyfriends, and family members had always insisted I looked fine to them, which contradicted what the mirror told me.

Inside the magazine was an article by Liz Brody about BDD (Brody, 1997). The article described the symptoms, possible causes, and treatment for the disorder. There was a five-item self-diagnosis questionnaire and a list of 10 common symptoms of the disorder, from the book by Katherine Phillips, *The Broken Mirror: Understanding and Treating Body Dysmorphic Disorder* (1996/2005). The article discussed effective treatments, both pharmacological and clinical, and noted that cosmetic surgery is often ineffective in treating symptoms of the disorder. Sufferers described feelings of shame and embarrassment that were incredibly familiar to me. Also, I was relieved to read that those with the disorder are often considered to be quite attractive, even while believing that they are ugly. This reassured me that my friends and family members were telling me the truth, rather than just trying to make me feel better by saying that I looked fine to them.

That article changed my life. Now I had a name for my symptoms. Now I knew that Prozac could help me. I felt empowered by the information, and for the first time in almost 20 years, had hope that I really was not as ugly as I imagined myself to be. That article provided me with the insight and information I needed to diagnose myself with the disorder. However, the realization that I was not really seeing myself the same way I appeared to others was shocking at first. I was both relieved and dismayed by the possibility that what I saw in the mirror was not what others saw when they looked at me. The stigma regarding having a mental health condition was less important to me than the stigma and shame that I felt regarding my perceived appearance defects. As a result, I referred myself for treatment.

The psychiatrist at the health maintenance organization (HMO) was not familiar with BDD so she diagnosed me with depression. She agreed to put me on Prozac, which fortunately is one of the medications shown to reduce symptoms of the disorder. I also entered therapy with a clinical psychologist at the HMO. The medication started to take effect after a few weeks, and my anxiety and preoccupation with my appearance slowly started to diminish. My mother was the first one to notice the change in my demeanor. She was delighted to see me smile and told me that I was becoming the young woman she

always imagined I could be. Sadly, my mother passed away shortly after I started treatment, when I was 34 years old.

After being on Prozac and in clinical treatment for two years, my symptoms improved. My anxiety about my ugliness dissipated and became manageable. I was no longer obsessing about my appearance and staring at my face in the mirror for hours every day. However, the psychiatrist at the HMO was convinced I was a 'lifer', that I would be on Prozac for the rest of my life. My desire not to be on prescription medication long term due to the side effects of Prozac prompted me to seek alternative treatments. As a result, I started practicing meditation and was able to slowly stop taking prescription medication to treat the BDD symptoms.

Now, 15 years after starting treatment, I consider myself to be recovered from the disorder. I no longer agonize about my appearance, and most of the time, I am at peace with how I look. My relationship with my body has improved. I now enjoy my physical self, and appreciate what I can do with my body, rather than only worrying about how it appears to others. I also understand that my self-worth is not dependent upon how I look. My psychological treatment involved coming to terms with childhood fears about abandonment and loss of love. Now I recognize that my feelings about my appearance originate inside me. That makes them manageable.

There are still difficult times when I struggle with symptoms, especially when I am stressed or anxious. I have adopted coping mechanisms to keep my symptoms under control, such as only having two mirrors in the house. Also, I put a clock in my bathroom to track the time I spend getting ready in the morning. If I find myself staring at my nose for more than five minutes, I leave the room. I still dislike my profile, and probably will never really like the way my nose looks. I have accepted that. That's okay. I am not my nose. As a result of my recovery from BDD, the quality of my life has improved dramatically. The focus of my life revolves around my family and friends, my relationship, and my passion for teaching college students. I now appreciate myself in ways that were impossible when I was obsessed with hating my appearance. The purpose of my dissertation study is to discover how individuals communicate on an online forum for BDD in order to receive the help and support they need to recover.

## APPENDIX B

### BDD Forum Study Message-Level Coding Guide

**Code Name:** Coder\_ID

**Code Label:** Identification number for each coder

1 = Eve Fisher (Lead Coder)

2 = (Doug)

3 = Caitlin

Important: Read the entire coding guide before starting to code messages for the study, including the BDD description, Social Support definitions, and Forum Moderator Posts provided in the Appendix. Clarify any questions with the Lead Coder before starting to code messages.

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### MESSAGE CLASSIFICATION CODES

The following codes are used to identify the thread ID, message ID, name of the person posting the message, and gender of the person posting the message.

**Code Name:** Thrd\_ID

**Code Label:** Message thread identification number

Each message thread (Microsoft Word document) is labeled with a unique identification number.

**Code Name:** Msg\_ID

**Code Label:** Message identification number

Each message thread may contain up to four messages (the initial post and up to three replies). The first message contains the title of the thread, in bold and underlined, at the top of the message. The replies to the initial message have “Re:” before the title. Code each message in the thread as follows:

1 = First message (initial post)

2 = Second message (first reply)

3 = Third message (second reply)

4 = Fourth message (third reply)

**Code Name: User\_name**

**Code Label: Name provided by the person posting the message**

The user name is listed at the beginning of the message under the title, with the word “by” in front of the name.

**Code Name: Gender**

**Code Label: Gender of the person posting the message**

Use one or more of the following cues to identify the gender of the person posting the message:

- Screen name: Female (lucyxx, jasmin, sweetmaryjane), Male (ThinManOneTwelve, Nick45)
- Person self-discloses his/her gender in the message (boy, girl, man, woman)
- Person self-identifies being a sister, aunt, brother, father, wife, husband, etc.
- References that the person is considered/wants to be “pretty” (female) or “handsome” (male)
- Comparisons made to others (female/male models, muscular men, pretty women, etc.)
- References/comparisons made by others replying to the message (he/she is a nice person)
- References to behaviors associated with gender (females-getting breasts enlarged, males-shaving face) Important: Applying makeup to hide flaws is done by both males and females
- Do not code gender based on references to having a boyfriend/girlfriend

Important: If there is no indication of the user’s gender in the message (or in the message replies), then choose unable to determine. Once the user’s gender has been determined, code each subsequent occurrence of the screen name with the same gender code.

1 = Male

2 = Female

3 = Unable to determine (undetermined)

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## **CONTENT/THEMATIC CODES**

The following codes are used to identify the content (thematic coding units) within the messages.

### **Instructions:**

1. Review the original thread in the Word document (when coding in the software).
2. Read the entire thread one or more times to review all the messages, starting with the title of the initial message. Then code the initial message, followed by each reply.
3. Code the message themes within the overall context of the message, the thread, and the BDD support forum. Also, consider how the themes would be coded for a face-to-face support group.

4. **Important:** Read the previous and following messages (when available) within a thread to help determine the themes present in each message. For example, if the initial post contains an emotional support request, do the replies contain emotional support provisions?
5. Code the themes at “face value” using the coding guide definitions, examples, and information about BDD in the appendix, rather than using your personal opinions/experiences.
6. Add comments in Microsoft Word (Review tab) to identify and label the thematic coding unit(s) within each message. Select the text and add a comment using the coding rules listed below.
7. Label each comment by choosing ONE of the thematic codes listed in the coding guide.
8. Label the comment using the Code Label and one of the examples from the list. For example: “Emotional support -provided.”
9. **Important:** Place a number in the coding sheet when a decision is made about the coding unit in a message. If a message cannot be coded (see rules below), put the coder ID, thread ID, message ID, user name, and gender data in the spreadsheet. Leave the thematic category codes empty. Do not skip any messages in the spreadsheet!
10. Review the coding to ensure that the coding sheet is filled out completely and accurately.

**Coding Rules:**

1. The thematic coding unit (theme) cannot be larger than one message.
2. The thematic coding unit cannot be smaller than one sentence (subject, verb, object).
3. Use sentences as the primary coding unit, and paragraphs if multiple sentences contain the same theme.
4. Sentences with missing punctuation can be coded (missing period at the end). Code sentences with two periods at the end as a complete sentence.
5. If a sentence contains more than one theme (separated by “and” “...” or commas), code the sentence based on the predominant (most frequent) theme. If there is no predominant theme in the sentence, code based on the predominate theme in the message and/or thread (title).
6. Each message may contain one or more thematic coding units (themes).
7. Emoticons are considered part of the thematic coding unit.

**Do not code the following:**

- Salutations and valedictions that are not complete sentences (hi everyone! Thanks guys, Be well)
- Message titles and signatures (repeated phrase at the end of the message above/below the user’s name) (Pfeil & Zaphiris, 2010).
- Duplicate messages (within the same thread), content copied from previous messages, messages with edited (missing) content, and messages containing only images (no text).
- Message length, time posted, signature image (if visible), number of posts by member, date joined, location, local time, blog.
- Sentences/paragraphs that do not contain one of the thematic codes listed in the coding guide.

**Requests and Provisions:**

The messages may contain requests and/or provisions for the personal disclosure and social support codes.

- Requests can be direct (questions, inquires) or indirect (statements of uncertainty, doubt, curiosity).
  - Provisions are usually (but not always) declarative sentences. Provisions seek to answer the questions or assumed requests of other people for personal disclosure and/or support.
  - Provisions can be solicited (in a message reply) or unsolicited (in an initial message).
  - Questions can also be rhetorical (asked and answered in the same post). Code rhetorical questions based on the content in the message (Aren't mirrors awful? I hate how I look in them.).
- 

### **Personal Disclosure Codes**

**Personal disclosures include information about one's likes/dislikes, thoughts, behaviors, feelings, experiences, and appearance concerns related to having BDD.** Refer to the description of BDD in the Appendix, and the examples provided within each category, to determine if the message contains personal disclosure related to having BDD.

Important: Personal disclosure has the person as the subject of the coding unit. Code personal disclosure related to sharing others' feelings as understanding/empathy. Code personal opinions where the subject is not the person as informational support (see examples below).

#### **Code Name: PI-Sympt**

#### **Code Label: Personal disclosure about appearance/BDD symptoms**

Requests and provisions for personal disclosure about BDD-related symptoms are focused on problems/issues related to having the disorder. Examples of BDD symptom-related personal disclosure include the following:

#### **Requests:**

- Appearance-related: body/ facial feature obsessions, compulsive behaviors (plastic surgery, mirror checking, etc.), mental and emotional suffering
  - What do you think is ugly about you? How do you cope with bad plastic surgery? Does anyone else have facial thirds that are not equal? How do you feel about your facial thirds? Does anyone else have a weak jawline? Do you like or hate mirrors? Is anyone else obsessed with wanting to look like a certain celebrity? Do you feel that the defect you see is your fault?
- BDD-related: causes (teasing, bullying, abuse), issues related to family/friends, impact on dating/relationships, impact on career/job, related conditions (OCD, eating disorders, depression, personality disorders)

- Were you abused as a child? I was curious to see to what extent feeling ugly can impair us from reaching our goals. Do your friends know about BDD? Does anyone else get headaches when they are stressed out? Does your BDD affect your job opportunities? Does anyone else have people walking over you because of your insecurities? Does your BDD prevent you from working?

**Provisions:**

- Appearance-related: body/ facial feature obsessions, compulsive behaviors (plastic surgery, mirror checking, etc.), mental and emotional suffering
  - Even if the [plastic] surgery doesn't work, at least I will have tried to fix my nose. I perceive myself as ugly. I hate my body so much...I just want to die. I am learning to wear my ugliness as a badge of honor, which is hard to do. I feel too ugly to live. I hate people who are richer, better-looking, or more successful than I am.
- BDD-related: causes (teasing, bullying, abuse), issues related to family/friends, impact on dating/relationships, impact on career/job, related conditions (OCD, eating disorders, depression, personality disorders, social anxiety, low self-esteem)
  - At 15 my father told me I was going bald. My girlfriend was recently diagnosed with BDD. I want to date someone good looking. I only date girls who have no appearance flaws. My friends don't understand why I cancel our plans. My obsession is making me a poor role model for my son/daughter. I am too ashamed about it to talk to my family. I am not good enough to be wanted by women. I have changed my career from wanting to be a surgeon. I've become bulimic and very depressed. I don't leave the house on my ugly days.

0 = Message does not contain BDD symptom-related personal disclosure

1 = Message contains BDD symptom-related personal disclosure

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**Code Name: PI-Rcvry**

**Code Label: Personal disclosure about BDD recovery**

BDD-related personal disclosure requests and provisions are focused on identifying and overcoming/trying to overcome the disorder. References to one's doctor/clinician/therapist, whether or not the treatment is helpful, can be coded as BDD recovery. Examples of BDD recovery-related personal disclosure include the following:

**Requests:**

- BDD diagnosis/self-diagnosis
  - Do you think you could have BDD? Have you asked your therapist if it's BDD?

- Clinical treatment (therapy, CBT, medication), self-help (coping, overcoming symptoms), success stories, disclosing condition to friends/family, benefits, barriers (do not include plastic surgery or medications listed in signature)
  - Did counseling help you to feel better? Have you ever had therapy? How did you recover from BDD? Is anyone else using an antipsychotic with BDD diagnosis? Does anyone have coping strategies they could share? Are you currently seeing a therapist? What measures are you taking to let your family know about BDD?

**Provisions:**

- BDD diagnosis (clinician, friends, family)/self-diagnosis
  - I was diagnosed as BDD last year. I have no diagnosis but a lot of these symptoms. I haven't been diagnosed yet probably because I haven't told my doctor. My friend told me I might have BDD. My therapist diagnosed me with BDD.
- Clinical treatment (therapy, CBT, medication), self-help (coping, overcoming symptoms), success stories, disclosing condition to friends/family, benefits, barriers (do not include plastic surgery or medications listed in signature)
  - We [my doctor and I] did CBT for about 1 hour, once a week. I have taken ssri's but they aren't working. I had BDD for 2-3 years and I recovered. The hardest part will be telling my parents. BDD has shaped my personality in a positive way. I think talking about [my symptoms] is helpful. My therapist didn't know about BDD. My doctor tells me I'm pretty. I am in treatment for anorexia and depression. I know this seems crazy but I am terrified [the therapist will tell me I'm ugly].

0 = Message does not contain BDD recovery-related personal disclosure

1 = Message contains BDD recovery-related personal disclosure

**Social Support Codes**

**Social Support includes emotional support, informational support, network support, and unsupportive comments directed to others on the forum.** Refer to the definitions provided in the Appendix for social support, and the definitions and examples provided within each category, to determine if the message contains social support.

**Emotional Support**

Determine whether a coding unit in the message contains emotional/esteem support. **Definitions:**

Emotional support is defined as expressions of caring, concern, empathy, and sympathy, meant to comfort

or console another person without trying to solve the problem. Esteem support is defined as positive feedback that expresses belief in a person's abilities and capabilities. Emotional and esteem support need to be directed to others on the forum.

Important: Code non-specific requests for help as emotional /esteem support (caring/concern).

**Code Name: SS\_Emot**

**Code Label: Emotional/esteem support**

Examples of emotional/esteem support include the following:

**Requests:**

- Caring/concern
  - I just need some help coping with it. I would appreciate any help. Help me please!
- Empathy/understanding (identify with, sympathize with, share feelings, relate to)
  - Can others relate to this? Is anyone else experiencing the same thing? Any of you feel like this? Do others feel your looks prevent you from dating attractive people?

**Provisions:**

- Caring/concern
  - My love and support to anyone else dealing with this. I hope you get better. How are you doing? Are you alright? Text me if you need to. Let me know how it goes. If you want anyone to talk to, feel free to pm me. I will keep you in my prayers. If you post here, I will be listening. Hugs to those who fight every day.
- Empathy/understanding (identify with, sympathize with, share feelings, relate to)
  - I understand what you are going through. I feel the same way. I know how you feel-I got a nose job and I hate it too. I felt the same way when I was younger. I also feel that I am not ugly, I just want perfect features. OMG this is me. I could have written this. Same here, I am genuinely ugly too. You just described me! I am also like this.
- Sympathy/apology
  - I am sorry that you're going through this. Sorry for the rant, I'm having a rough day.
- Thanks/gratitude/appreciation
  - Thank you for replying! Thank you in advance for your help.
- Encouragement
  - We can get over this with strength! Never give up. You can do it! It's terrible I know but there is light at the end of the tunnel. You will feel better in the future. You never know what the future holds, so don't assume it will be negative. You deserve to be happy. There is always hope for someone who is willing to try to overcome this disorder. Don't be silly, you don't sound pathetic. If you get treatment, you will get better! There is no reason to be embarrassed.
- Compliment

- I admire your enthusiasm. Good choices. That's a beautiful thing you write. That is a good idea! You are a worthy, loving, and lovely human being.
- Validation/agreement
  - I agree with you. I support that thought entirely.

0 = Message does not contain emotional/esteem support

1 = Message contains emotional/esteem support

### **Informational Support**

Determine whether a coding unit in the message contains informational support. **Definition:** Factual input (refer to the BDD information in the appendix), advice, and teaching, including actions to take or taken (what to do), in order to help another person solve a problem causing stress. Informational support also includes resources (websites, books, study participants, research studies). Informational support needs to be directed to others on the forum.

Important: Code personal opinions provided to others (solicited or unsolicited) as informational support when the person is not referring to himself/herself (see examples below).

**Code Name: SS\_Info**

**Code Label: Informational support**

Examples of informational support include the following:

**Requests:**

- BDD-related: causes, symptoms, problems/issues (dating, relationships), coping, diagnosis, treatment (medication, clinical therapy, self-help), recovery
  - Where do I go to get help? Are there any good self-help books for body image? How can I help my girlfriend with BDD? If anyone has gone through this obsession, your advice would be appreciated. Can BDD be cured? Where did you read that BDD can't be cured? Would college insurance pay for your treatment? Did you read the book about BDD? What was CBT like and did it help? Do I have BDD and if so, what can be done about it?
- Appearance-related: fixing/changing (makeup, dermatology, plastic surgery)
  - Does anyone know a good tip on how to make your fingers pretty? If women think beauty is a curse, why don't they disfigure themselves? Can you cancel the [plastic surgery] procedure?
- Appearance/behavior-related (reassurance-seeking):

- Should I get plastic surgery to fix my nose? I am looking for someone to tell me if I look normal. Are my hands too small for my body? So am I really ugly? Please tell me I'm not weird for being so obsessed about my nose. Do you judge people by what they look like? Am I ugly or do I have BDD? Am I vain to think about my appearance all the time? Is this normal for a girl?
- General/other
  - Forum rules, deleting messages, posting messages, getting blog approved, songs, movies, TV shows, inspirational/spiritual quotations, chakras, celebrities (with BDD)
  - Do you know about any celebrities with BDD? How do I delete my posts and cancel my account? Why did you post on this forum? Can I post photos on the forum?

**Provisions:**

- BDD-related: causes, symptoms, problems/issues (dating, relationships), coping, diagnosis (referrals), treatment (medication, clinical therapy, self-help), recovery
  - Here are some solutions to this. BDD can be healed and you can heal yourself. Yes, you can get better. Try mandala therapy. Here is a good book about body image. I would recommend that you get help from a therapist. Don't get stuck with a therapist you don't like. I know you would feel better if you had someone around to help. I don't think you have BDD. We can't diagnose you here. I suggest you ask a therapist if you have BDD.
- Appearance-related: fixing/changing (makeup, dermatology, plastic surgery)
  - I can give you some tips on painting your nails. There are several ways to lose weight. Go to your local dermatologist and make an appointment. Improve your looks and you will improve your confidence as well. Don't get plastic surgery, get HELP!
- Appearance/behavior-related (reassurance-seeking):
  - You are all beautiful so please stop obsessing about your looks. Please, there is no way your body could look worse than mine. I don't judge people by what they look like. You probably notice it more than other people. I did not find my coworker with a hairy face disgusting. If someone called you ugly, don't believe it! If you have been called ugly, then you probably are. I loved my ex-girlfriends small hands. I think that is normal. The mirror makes your face look asymmetrical.
- General /other
  - Forum rules, deleting messages, posting messages, getting blog approved, songs, movies, TV shows, inspirational/spiritual quotations, chakras, celebrities (with BDD)
  - I wish I could delete posts here, so I'll just change it. Here are some inspirational quotations that I like.

0 = Message does not contain informational support

1 = Message contains informational support

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## Community/Network Support

Determine whether a coding unit in the message contains community/network support. **Definition:**

Provides a sense of belonging among people with similar interests and concerns. Community/network support includes references to the forum as a place where people interact with and help similar others, including BDD Central\* and other social media sites.

Code references to posting threads on the forum, people being “here,” and that “we are available to help” as community support. References to similar others around the world can also be coded as community support (see example). Community support needs to be directed to others on the forum.

\*BDD Central is another forum where many people posted prior to it being taken offline in September 2012.

**Code Name:** SS\_Cmnty

**Code Label:** Community support

Examples of community support include the following:

### Requests:

- Presence/access/availability
  - Is there anyone else here from BDD Central? Where has BDD Central gone? I am new to this forum and would love to chat. I used to post on here every day and I just checked my last post was 2 months ago, and I’m trying to figure out what’s changed. I never thought I’d be seeking advice from an online forum, but here I am.
- Be with similar others
  - I am in need of friends who are in a similar situation. I thought I would never be able to connect with anonymous usernames giving me advice over the web, but I don’t really know where to turn anymore. I found this forum through google searches on BDD, and thought it would be a good way to contact others who suffer from this disorder. I posted on here because I feel like people on this board will understand what I’m going through.

### Provisions:

- Presence/access/availability
  - We are here for you! It’s nice to see you here. I am glad you found the forum! Hello to all the BDD Central people. Welcome to the forum, I hope you like it. We are all here for you. Please keep us informed about your progress. I went on this morning and BDD Central was gone. Here is a thread so we can get to know one another

better. I have not been here for a while. I have read a lot of your stories and been using this board for a while from an outsider's perspective. I am a new member of the forum. I have finally joined this forum. I want this thread to be about our victories.

- Be with similar others
  - It's great to find a community like this. This site is great you should stick around and talk to people as it can be a great support. There are a lot of people on here that will have similar stories to you. The people on this forum are fantastic. There are thousands of us all over the world in the same situation. I bet most people here have been teased about their looks. You are not alone! After reading this forum for a while I feel strong enough to reveal my problems but ashamed as well. I have this forum and it gave me a sense of belonging and of being good at something, especially when I first started posting here.

0 = Message does not contain community support

1 = Message contains community support

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### **Unsupportive Communication**

Determine whether the message contains unsupportive communication. **Definition:** Support that expresses disagreement, disapproval, and criticism of others, including resistance to the divergent viewpoints/opinions of others. Unsupportive comments need to be directed to others on the forum.

**Code Name:** SS\_Unspt

**Code Label:** Unsupportive communication

Examples of unsupportive comments are as follows:

- Disapproval/disagreement
  - I don't agree with you. I think that's disgusting. I don't think what I am seeing is unrealistic. No offense, but it sounds like you are giving up. x
- Sarcasm/criticism
  - What is wrong with you people? I now feel like crap so thank you! Your problem is you have no idea what you are talking about. I don't feel that positivity is appreciated on this forum.
- Opposing viewpoints/opinions
  - Appearance is definitely objective, not subjective. Being bisexual has NOTHING to do with wanting to be more feminine/masculine. Diagnosing ugly people with BDD is cruel.

0 = Message does not contain unsupportive comment(s)

1 = Message contains unsupportive comment(s)

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## Coding Guide Appendix

### Description of Body Dysmorphic Disorder (BDD)

#### BDD Causes

- There are a variety of possible causes linked to the onset of BDD, both biological and sociological. They include: childhood bullying (Wolke & Sapouna, 2008); childhood teasing about appearance and competency (Buhlmann et al., 2007); childhood maltreatment and abuse (emotional, physical, sexual) (Phillips, 2009); growing up in family with an emphasis put on appearance (Rytina, 2008); use of the brain's left side more in those with the disorder that results in their seeing the world differently (Choi, 2008); perfectionist standards concerning appearance and exposure to high ideals of attractiveness and beauty in the mass media (Veale, 2009); a possible dysregulation of the serotonin system (Phillips et al., 1995); and neurological disturbances that constitute a common genetic basis for disorders of the obsessive-compulsive spectrum (Allen & Hollander, 2004).

#### BDD Symptoms

- **Obsessive thoughts about appearance:** Obsessive thoughts about perceived appearance defects can be focused on one's body or on a specific body part/parts, including skin, hair, nose, height, weight, stomach, breasts/chest, eyes, thighs, teeth, legs, body build, ugly face, face shape/size, lips, buttocks, chin, eyebrows, hips, ears, arms, waist, genitals, cheek/cheekbones, calves, head shape/size, forehead, feet, hands, jaw, mouth, back, fingers, neck, shoulders, knees, toes, ankles, etc.
- About one-third of people with BDD think about their appearance flaws for one to three hours a day, nearly 40% for three to eight hours a day, and about a quarter for more than eight hours a day. Most people with BDD realize that they spend too much time thinking about their appearance, but for others, the thoughts are so much a part of their lives they think that everyone worries about their appearance for hours a day (Phillips, 2009, p. 57). However, the perceived flaws are usually not visible to others, and most individuals with BDD are often considered to be quite attractive by societal standards (Phillips, 2005).
- **Behaviors related to having BDD:** Compulsive behaviors in those with BDD, from most to least common are: camouflaging the perceived defect(s) with one's body, clothing, makeup (men and women), hand, hair and hats; comparing the disliked body part with others/scrutinizing the appearance of others (social comparison); checking one's appearance in mirrors and other reflective surfaces; seeking cosmetic treatments such as plastic surgery and dermatology; altering one's appearance by self-manipulation; engaging in excessive grooming; questioning or reassurance seeking (asking doctors and/or family members about the perceived flaw or convincing others that

it's unattractive); touching the perceived flaw; excessively changing clothes; dieting; skin picking to improve appearance; tanning to improve the perceived flaw; engaging in excessive exercise, including excessive weight lifting (Phillips, 2009, p. 68). These compulsive behaviors can become rituals, causing individuals to miss appointments with friends or family members, and unable to attend school, college, or work.

- Due to the nature of the disorder, most sufferers have little self-awareness, or insight, that they have a psychological disorder, not a physical one. They see themselves as ugly and disfigured, and so often use cosmetic surgery and dermatology treatments to approve their appearance. However, they are rarely pleased with the results, and often feel worse after the procedures (Tignol et al., 2007; Sarwer & Crerand, 2008). Occasionally, people with BDD do surgery on themselves, with disastrous results. Available evidence indicates that approximately 80% of individuals with BDD experience lifetime suicidal ideation and 24% to 28% have attempted suicide (Phillips, 2007). BDD affects women and men at an approximately equal rate (Phillips, 2005).
- **Reassurance-seeking:** Information seeking and reassurance seeking are not wholly separable, and it's more accurate to think about them existing on a continuum rather than as separate processes. Reassurance seekers often ask unanswerable questions or questions that their conversation partners cannot (or are not qualified to) answer (e.g., "Do you think I have BDD or am I just ugly?" "Is it normal to be angry all the time?"). They often know the answer they want to get in advance of asking the question and have a difficult time tolerating uncertain or ambiguous answers. Upon obtaining an answer, conclusions are typically deferred in hopes of understanding the issue more thoroughly later. Alternatively, action may be stalled in hopes that better or more accurate information might emerge in the future. As such, the decision making process is often time-consuming, stressful, frustrating, and non-productive. Moreover, the decision making process may be stopped and started multiple times due to OCD-related indecision (Seay, 2012).
- **Social comparison (appearance):** Comparing one's appearance to others' is a common BDD behavior; more than 90% of individuals with BDD engage in social comparison (Phillips, 2009). They frequently compare their "ugly" body part with the same body part on others, and often feel worse when they compare (Phillips, 2009). Many patients report compulsively collecting magazine pictures, videotapes of particular media celebrities, or photographs of themselves at an earlier age to compare their appearance (Neziroglu, Patel, & Veale, 2008). Neziroglu et al. (2008) found that individuals with BDD focus intently upon their own appearance and have a "felt" impression about how they appear to others from an observer perspective (p. 33). Individuals with BDD are often so excessively self-focused on adverse imagery, by comparing their unattractive body parts to those of more attractive others, that they are unable to make accurate observations about others' reactions to them. As a result, individuals with BDD maintain their perceptions that others are making negative evaluations about their appearance.
- **Emotional and mental suffering:** Individuals undergo intense emotional and mental suffering as a result of these obsessive thoughts and compulsive behaviors. Emotional suffering due to one's perceived appearance defects include feelings such as anger, depression, self-pity, shame, hatred, anxiety, disgust, suicidality, rejection, low self-esteem, and fear. Some individuals become socially isolated as a result, unable to go out in public places for fear of exposing their perceived defect and

ugliness to others. Depression and anxiety are common. Accidents and violent behavior can occur (Phillips, 2009).

### **BDD Diagnosis**

- The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) classifies BDD as an obsessive compulsive spectrum disorder (OCS). BDD can be present in individuals with symptoms of other disorders, including major/atypical depression, bipolar disorder, obsessive compulsive disorder (OCD), social phobia, eating disorders, substance abuse disorders, and personality disorders (borderline personality disorder). BDD can also manifest as a preoccupation with the size of one's muscles and body, called muscle dysmorphia. Muscle dysmorphia can lead to obsession with weight lifting and to steroid abuse (Davey & Bishop, 2006; Pope, Phillips, & Olivardia, 2000).
- The DSM-5 criteria for BDD are as follows: (a) "preoccupation with a perceived defect(s) or flaw(s) in physical appearance that is not observable or appears slight to others"; (b) "at some point during the course of the disorder, the person has performed repetitive behaviors (e.g., mirror checking, excessive grooming, skin picking, or reassurance seeking) or mental acts (e.g., comparing their appearance with that of others) in response to the appearance concerns"; (c) "The preoccupation causes clinically significant distress (for example, depressed mood, anxiety, shame) or impairment in social, occupational, or other important areas of functioning (for example, school, relationships, household); and (d) "the appearance preoccupations are not restricted to concerns with body fat or weight in an eating disorder" (<http://www.helpforbdd.org/about-bdd/diagnosing-bdd>).
- The other criteria includes patient insight levels: (a) good or fair insight (the individual recognizes that BDD (appearance defect) beliefs are definitely or probably not true, or that they may or may not be true); (b) poor insight (the individual thinks BDD beliefs are probably true); and (c) absent insight/delusional (the individual is completely convinced BDD beliefs are true) (APA, 2013). Also, the disorder can be classified as muscle dysmorphia: the belief that one's body build is too small or insufficiently muscular.

### **BDD Treatment**

- After a diagnosis of BDD has been made, treatment with selective serotonin reuptake inhibitors (SSRIs) and cognitive-behavioral therapy (CBT) can be effective in improving the sufferer's symptoms (Phillips et al., 2008). Clinicians also use motivational interviewing and psycho-education to treat patients (Phillips, 2005). Cognitive-behavior therapy involves modification of intrusive thoughts of body dissatisfaction and overvalued beliefs about physical appearance, exposure to avoided body image situations, and elimination of body checking. Treatment for delusional or suicidal patients often requires both selective serotonin reuptake inhibitors (SSRIs) and cognitive-behavior therapy.
- Because individuals with BDD often lack insight that they have a psychological, rather than a physical disorder, this constitutes one of the barriers to treatment for those with the disorder

(Marques et al., 2011) In a study of 401 individuals with moderately severe symptoms consistent with a diagnosis of BDD, only 30.5 % of the 401 had sought help from a psychiatrist, and 29.5% of the 401 from a psychologist. The authors explained the findings as due to multiple factors, including low public and professional knowledge of BDD, even among mental health professionals, which may prevent accurate diagnosis and treatment (Marques et al., 2011).

### **Definitions of Social Support**

- Social support has been defined as actions and behaviors that serve to assist a person in meeting personal goals or the demands of a particular situation, as well as information and resources from others that minimize the perception of threat and maximize actual and perceived mastery related to coping (Tolsdorf, 1976, p. 410). Functions of social support include self-acceptance, enhanced self-esteem, and fulfilling needs for intimacy, affection, and communication with others (Albrecht, 1987). Individuals request and provide social support in order to reduce uncertainty about their health conditions and to regain a sense of control (Albrecht, 1987).
- Social support as a communication phenomenon can be defined as “verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one’s life experience” (Albrecht, 1987, p. 19).

### **Psychforums.com Moderator Post: BDD Description**

#### Definition

BDD is a type of chronic mental illness in which you can’t stop thinking about a flaw with your appearance — a flaw either that is minor or that you imagine. But to you, your appearance seems so shameful and distressing that you don’t want to be seen by anyone. Body dysmorphic disorder has sometimes been called “imagined ugliness.”

When you have body dysmorphic disorder, you intensely obsess over your appearance and body image, often for many hours a day. You may seek out numerous cosmetic procedures to try to “fix” your perceived flaws but never are satisfied. Body dysmorphic disorder is also known as dysmorphophobia, or the fear of having a deformity.

#### Symptoms

##### **Signs and symptoms of body dysmorphic disorder include:**

- \* Preoccupation with your physical appearance
- \* Strong belief that you have an abnormality or defect in your appearance that makes you ugly
- \* Frequently examining yourself in the mirror or, conversely, avoiding mirrors altogether
- \* Believing that others take special notice of your appearance in a negative way
- \* Frequent cosmetic procedures with little satisfaction
- \* Excessive grooming, such as hair plucking
- \* Feeling extremely self-conscious
- \* Refusing to appear in pictures
- \* Skin picking
- \* Comparing your appearance with that of others
- \* Avoiding social situations
- \* Wearing excessive makeup or clothing to camouflage perceived flaws

**Body features you may obsess about include:**

- \* Nose
- \* Hair
- \* Skin
- \* Moles or freckles
- \* Acne and blemishes
- \* Baldness
- \* Breast size
- \* Muscle size
- \* Genitalia

The body feature you focus on may change over time. You may be so convinced about your perceived flaws that you become delusional, imagining something about your body that's not true, no matter how much someone tries to convince you otherwise.

**When to see a doctor**

Shame and embarrassment about your appearance may keep you from seeking treatment for body dysmorphic disorder. But if you have any signs or symptoms of body dysmorphic disorder, see your doctor, mental health provider or other health professional. Body dysmorphic disorder usually doesn't get better on its own, and if untreated, it may get worse over time and lead to suicidal thoughts and behavior.

**For more information click on the following link:** <http://www.mayoclinic.com/health/body-d... N=symptoms>

**Psychforums.com Moderator Post: Personal Pictures**

Due to the potentially triggering nature, sharing personal pictures is not allowed on this forum. We hope this will help you concentrate less on your physical appearance and more on your behavior and feelings, assisting your recovery.

If a member should approach you about sending them your picture, please report the post/pm by clicking the exclamation point icon at the top right of the message box. Any offers to critique another member's appearance will receive a warning.

I realize this all sound harsh and as a fellow BDD sufferer I do fully understand the allure of having other people "grade" your appearance; however, it's a dangerous, destructive impulse that only delays recovery and has no place on a support forum.

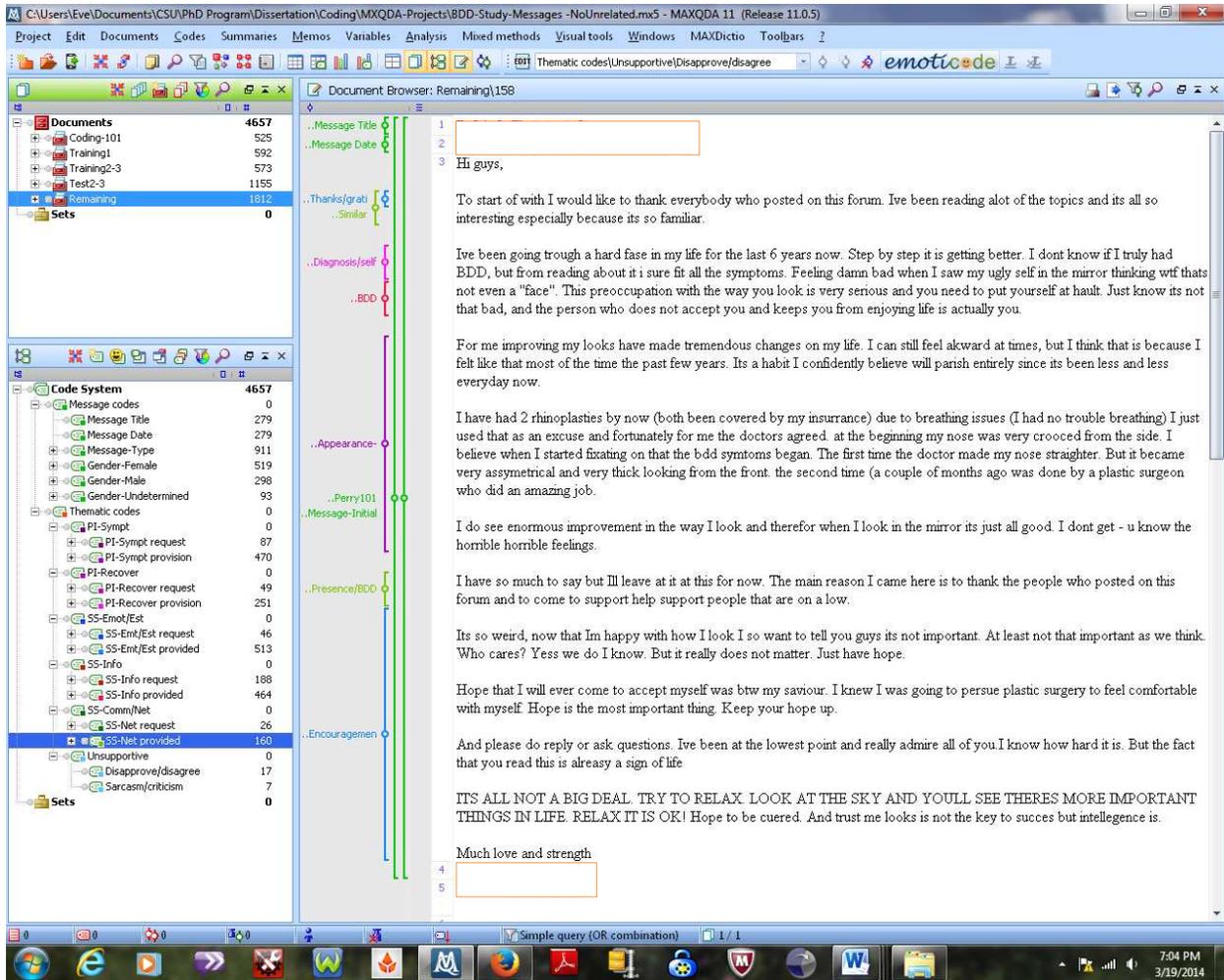
It's also important to note that people who critique others often have their own motivations for doing so, and those motivations can be driven by bad intentions.

Thank you for your cooperation.

Please keep safe.

# APPENDIX C

## Coding in MAXQDA 11 Screenshot



## APPENDIX D

### Descriptive Statistics Tables

Table D1

*Comment Frequencies for the Main Categories*

Category	Number of occurrences	Percent of total occurrences
<b>Personal Disclosure</b>	<b>857</b>	<b>37.6%</b>
Symptom-related	557	24.5
Recovery-related	300	13.2
<b>Social Support</b>	<b>1421</b>	<b>62.4%</b>
Emotional/esteem	559	24.5
Informational	652	28.6
Social Network	186	8.2
Unsupportive	24	1.1
<b>Total</b>	<b>2278</b>	<b>100.0%</b>

*Note.* Since messages may contain more than one comment, category counts do not add up to the total number of messages (N=911).

Table D2

*Comment Frequencies in Initial Posts and Replies*

Category	Number of occurrences	Percent of total occurrences
<b>Initial Post (279)</b>	<b>811</b>	<b>35.6%</b>
PD Symptom-related	281	12.3
PD Recovery-related	156	6.8
SS Emotional	104	4.6
SS Informational	202	8.9
SS Social Network	65	2.9
Unsupportive	3	0.1
<b>Reply (632)</b>	<b>1467</b>	<b>64.4%</b>
PD Symptom-related	276	12.1
PD Recovery-related	144	6.3
SS Emotional	455	20.0
SS Informational	450	19.8
SS Social Network	121	5.3
Unsupportive	21	0.9
<b>Total</b>	<b>2278</b>	<b>100.0%</b>

*Note.* Since messages may contain more than one topic/comment, category counts do not add up to the total number of messages (N=911). PD = Personal disclosures, SS = Social support

Table D3

*Most Frequent Poster Support Requests and Provisions*

Category	Requests (seeking)	Provisions (sharing)	Total		
<b>Roger</b>	<b>12</b>	<b>177</b>	<b>189</b>		
Emotional/esteem	0	47	47		
Informational	10	74	84		
Social Network	2	51	53		
Unsupportive	NA	5	5		
<b>Kathy</b>	<b>7</b>	<b>93</b>	<b>100</b>		
Emotional/esteem	2	51	53		
Informational	4	20	24		
Social Network	1	20	21		
Unsupportive	NA	2	2		
<b>Mia</b>	<b>10</b>	<b>77</b>	<b>87</b>		
Emotional/esteem	2	37	39		
Informational	7	32	39		
Social Network	1	8	9		
Unsupportive	NA	0	0		
<b>Janet</b>	<b>7</b>	<b>1421</b>	<b>86</b>	<b>817</b>	<b>9362.4</b>
Emotional/esteem	0	559	44	355	4424.5
Informational	6	652	34	353	4028.6
Social Network	1	186	8	98	9 8.2
Unsupportive	NA	24	0	11	0 1.1
<b>Fran</b>	<b>10</b>	<b>77</b>	<b>87</b>		
Emotional/esteem	3	43	46		
Informational	6	24	30		
Social Network	1	7	8		
Unsupportive	NA	3	3		
<b>Total</b>	<b>46</b>	<b>510</b>	<b>556</b>		
Percent	(9.0%)	(91.0%)	(100.0%)		