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Advice giving in online eating disorder forums : what clinical social workers need to know

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WHAT CLINICAL SOCIAL WORKERS NEED TO KNOW

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ABSTRACT

This qualitative, exploratory, descriptive study expanded the limited existing research on online eating disorder forums by examining the thematic content of advice giving on three different types of online eating disorder forums: 1) professional-operated, pro-recovery forums; 2) peer-operated, pro-recovery forums; and 3) peer-operated, pro-eating disorder forums. Additionally, the study sought to elucidate the comparative relationships amongst different forums between advice content, aims, and accuracy and key forum characteristics, such as forums' missions and methods of moderation. Two publicly available websites for each forum type were studied. From these, a total of 60 advice messages consisting of 91 advice units were collected, analyzed, and coded, resulting in 9 thematic topics: cognitive strategy/change, environmental/context change, behavioral change, medication/vitamins, getting more information, social support, professional help, support groups, and unclear. Professional-operated forums had the highest rate of recommendations for professional treatment, while users of pro-recovery and pro-eating disorder forums emphasized behavioral and cognitive changes. Increased moderation and a clear pro-recovery stance appear to negatively correlate with destructive advice. However, pro-eating disorder forums appear to vary greatly and may be less likely to endorse disordered eating behaviors than previously thought. Given the limited resources available for this study, further research is needed to increase the reliability and generalizability of its findings and examine forum users' response to advice giving in online eating disorder forums.

ACKNOWLEDGEMENTS

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CHAPTER I

Introduction

In the United States, at least 30 million people have suffered from a clinically significant eating disorder at some point during their lifetime, including anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), and other specified feeding or eating disorder (OSFED), formerly called eating disorder not otherwise specified (EDNOS) (Wade, T. D., Keski-Rahkonen A., & Hudson, J., 2011). Eating disorders affect individuals across gender (Lemberg, 1992; Levine & Harrison, 2009), racial, and ethnic groups (Hudson, Hiripi, Pope, & Kessler, 2007; Marques, Alegria, Becker, Chen, Fang, Chosak, & Diniz, 2011; Wade et al., 2011). Additionally, it is now well established that the rate of new cases of eating disorders has been steadily increasing since 1950 (Hudson et al., 2007; Streigel-Moore & Franko, 2003; Wade et al., 2011). Improved identification of and treatment for eating disorders along with greater numbers of individuals seeking services have also alerted researchers and healthcare professionals to the wide breadth of feeding-related symptoms, their duration, and frequency. This development has resulted in numerous changes with respect to eating disorders in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), including the relaxation of criteria for various diagnoses (Fairweather-Schmidt, A. K., & Wade, T. D., 2014).

Despite increased awareness of eating disorders, stigma remains prevalent (Crisp, 2005; Mond, Robertson-Smith, & Vetere, 2006; Pescosolido, Martin, Lang, & Olafsdottir, 2008; Russell, 2004) and can deter sufferers from disclosing their illness and seeking treatment. The

Internet offers valuable means of anonymously obtaining information, guidance, and emotional support. The increasing usage of electronic eating disorder support groups has attracted a modest but growing amount of scholarly attention within the fields of communication, psychology, social work, technology, healthcare, and sociology (Darcy & Dooley, 2007; Eichhorn, 2008; Flynn & Stana, 2012; Gleason, 1995; Keski-Rahkonen & Tozzi, 2005; Stommel, 2007; Stommel, 2009; Ransom, 2010; Walstrom, 2000; Wesemann & Grunwald, 2008; Winzelberg, 1997). Haas, Irr, Jennings, and Wagner (2010) identified advice as a common communication strategy amongst anorexia Online Negative Enabling Support Groups (ONESG) as well as two types of advice that occur. While Eichhorn (2008) and Flynn and Stana (2012) have identified advice giving as one of the primary forms of interaction in online support groups, studies have yet to analyze the content, range, and accuracy of this advice or how such advice in peer-operated forums compares with professional-moderated forums. Thus, this study sought to answer following research question: What do clinical social workers need to know in order to provide guidance to clients about advice giving in online eating disorder forums?

The selection of eating disorder discussion forums (i.e. websites through which users can view and respond to others' messages) for this study is intended to mirror the most common method by which individuals with eating disorders would approach finding an online support group. As comScore, Inc., identifies Google as the most popular search engine (Lella, 2014), users looking for online eating disorder communities are more likely to use Google in their search. Therefore, in order to identify the largest and most diverse sample, I used Google to conduct three searches using three key phrases: "eating disorder forums," "pro eating disorder forums," and "pro recovery eating disorder forums." As each of these searches yielded hundreds of thousands of results, I used a set of criteria to limit and categorize forums within the top 20

results for each search into three groups: pro-recovery eating disorder forums provided by an organization or professional(s), pro-recovery forums facilitated by peers, and pro-disorder forums. I then selected the two most popular forums from each of these categories and contacted forums with posted registration or participation policies relating to research. Once permission to access forums was obtained, I identified, recorded, and analyzed each message posted within a month-long period that contained advice as defined by Oxford dictionaries as "guidance or recommendations offered with regard to prudent action" (Oxford Dictionaries, n.d.). Due to the minimal forum usage, I had to expand the time frame to two months for one pro-recovery forum.

It is critical for social workers to be informed about the wide array of online resources that are easily accessible to clients and are being widely used by those with eating disorders. Given that eating disorders are so strongly characterized by shame and denial, it is highly likely that clients with eating disorders will have already encountered eating disorder websites and forums by the time they begin professional treatment. In order for clinicians adequately to support clients in making wise choices about what advice they heed and what information they accept, they must first understand the nature of the advice that is available.

CHAPTER II

Literature Review

This literature review is a presentation and discussion of the existing research related to the study's research question: What do clinical social workers need to know in order to provide guidance to clients about advice giving in online eating disorder forums? The first section will ground the reader with foundational knowledge regarding the types, characteristics, severity, and prevalence of eating disorders. Necessarily, I will address recent diagnostic changes concerning eating disorders in the DSM-5. Although an etiology remains unknown, efforts toward establishing a cohesive theory and identified risk factors will also be discussed in the first section. The second section will include an overview of treatments for eating disorders, an explanation for the lack of evidence-based approaches, as well as barriers to treatments and their challenges. In the third section, I will introduce the reader to the minimal available research on the relationship between eating disorders and the Internet, including eating disorder websites and forums. Finally, in the fourth section, I will summarize the reviewed research to explain the need for this study and its contributions.

The Who, What, and How of Eating Disorders

Eating disorders are serious, prevalent, non-discriminatory, and multi-faceted. Eating disorders, AN in particular, have the highest mortality rate of any other mental illness (Arcelus, Mithcell, Wales, & Nielsen, 2011); their symptoms, duration, and severity can lead to life-threatening consequences. This section will provide an overview of the criteria and health risks

for each of the following eating disorder diagnoses: anorexia nervosa, bulimia nervosa, binge eating disorder, and other specified feeding or eating disorder.

Anorexia nervosa (AN). AN is the obsessional pursuit of thinness characterized by: 1) restriction of caloric intake resulting in significantly low weight (in the context of the individual's age, sex, developmental trajectory, and physical health); 2) extreme fear of gaining weight/becoming fat or persistent behavior that interferes with this; and 3) maladaptive ways of experiencing one's body, exaggerated impact of weight/shape on self-worth, or denial of the dangerousness of one's low body weight (American Psychiatric Association, 2013). In addition to the more well-known symptoms of excessive dieting, fasting, and exercise, behaviors may also include binging, purging, or misuse of laxatives, diuretics, and enemas (American Psychiatric Association, 2013). As a result, serious medical conditions arise, such as abnormally slow heart rate and/or blood pressure, muscle loss/weakness, decreased bone density, fainting, fatigue, dry skin, and hair loss (National Association of Eating Disorders [NEDA], n.d.c). In fact, at least 20% of people diagnosed with AN prematurely die from these types of health complications or suicide (The Renfrew Center Foundation for Eating Disorders, 2003). For females with AN, ages 15-25, the mortality rate is 12 times higher than the rate of all other causes of death (Sullivan, 1995).

Bulimia nervosa (BN). Although professionals typically associate BN with low mortality risk, Crow, et al. (2009) discovered BN to have a mortality rate nearly as high as AN and the highest suicide rate of .9%. BN is characterized by recurrent episodes of binging and purging (whether by vomiting, misuse of laxatives or other medications, fasting, or excessive exercise) occurring at least once a week for 3 months (American Psychiatric Association, 2013). Like AN, body shape and weight influence one's self-evaluation disproportionately (American

Psychiatric Association, 2013). Compensatory behaviors can lead to a range of medical problems, including electrolyte imbalances, inflammation and/or rupture of the esophagus, potential for gastric rupture, tooth decay and/or staining, peptic ulcers, pancreatitis, and chronic irregular bowel movements (NEDA, n.d.c).

Binge eating disorder (BED). According to NEDA (n.d.a), BED affects 1 in every 35 adults in the U.S., or about 5 million women and 3 million men, more than either AN or BN.[1] As its name suggests, BED is characterized by recurrent episodes of binging, which involves eating an amount of food larger than what most people would eat within a similar period of time (within 2 hours) under similar circumstances (American Psychiatric Association, 2013). Additionally, one must experience a lack of control during the episode, report marked distress regarding binging, and engage in the behavior at least once per week for 3 months (American Psychiatric Association, 2013). BED is associated with eating very rapidly, feeling uncomfortably full, binging when not physically hungry, feeling disgusted/depressed/guilty afterward, and eating alone due to embarrassment (American Psychiatric Association, 2013). The excessive food intake can lead to high blood pressure, elevated triglyceride levels (contributing to heart disease), high cholesterol, Type II diabetes mellitus, and/or gall bladder disease (NEDA, n.d.c).

Eating disorder not otherwise specified (EDNOS) and other specified feeding or eating disorder (OSFED). As BED was not professionally recognized as a clinical disorder until the DSM-5 was published in 2013, studies referring to clients with EDNOS may also include those who would now meet criteria for BED. That said, Crow, et al. (2009) found EDNOS to have the highest mortality rate of all eating disorders at 5.2% with .5% due to suicide

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[1] Although NEDA cites other statistical information on its website, I was unable to verify this information in published research.

while BN and AN had 3.9% and 4.0% mortality rates respectively. Crow, et al.'s (2009) sample population may explain why such findings contradict other evidence that AN has the highest risk. While most previous research has focused on eating disorder patients in inpatient settings, Crow, et al.'s (2009) subjects were receiving outpatient treatment. At the facility where their study was conducted, more severely ill patients were commonly referred to the emergency department (Crow, et al., 2009). Thus, a lower mortality rate might be expected of a sample in which participants are generally more stable.

EDNOS is also one of the major changes that occurred in the DSM-5, which has renamed the category as Other Specified Feeding or Eating Disorder (OSFED).[2] As clients with OSFED may demonstrate a wide range of eating-related symptoms, duration, and severity without meeting the exact criteria for the other eating disorders, they may face any of the aforementioned medical issues.

Prevalence and populations. Considering the seriousness of eating disorders, their prevalence makes them a significant public health concern. At least 20 million women and 10 million men in the U.S. have had an eating disorder (Wade, et al., 2011) and the rates of new cases have been steadily increasing at least for at least the past 30 years (Hoek & van Hoeken, 2003; Hudson, Hiripi, Pope, & Kessler, 2007; Streigel-Moore & Franko, 2003; Wade et al., 2011). The incidence of anorexia in women ages 15-19 has been rising each decade at least since the 1930s while the incidence of bulimia in women ages 10-39 has tripled between 1988 and 1993 (Hoek & van Hoek, 2003).

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[2] For the sake of clarity, I use the diagnosis EDNOS when the study being discussed or cited also uses that term. In all other cases, I use OSFED to reflect the most up-to-date diagnoses and criteria as they are defined in the DSM-5.

Not only are eating disorders more prevalent than previously believed, we are finding that they affect more populations regardless of gender, age, race, and ethnicity. In review of epidemiologic studies of BED, Striegel-Moore and Franko (2003) found that several studies reported no significant gender differences between the rates of BED among women and men, although one study found that women were significantly more likely to meet criteria for BED. This may be due, as another study revealed, to men's decreased likelihood to report discomfort about their binge eating (Lewinsohn, Seeley, Moerk, & Striegel-Moore, 2002; Striegel-Moore & Franko, 2003).[3] Additionally, eating disorders' reputation as a women's issue likely discourages men from disclosing and/or seeking professional help, suggesting that the overall percentage of men suffering with eating disorders may be much greater than studies have yet shown. In their first nationally representative study of eating disorders in the United States, Hudson, et al. (2007) found that one-fourth if AN and BN sufferers identified as male.

Another recent study also challenges the stereotype that eating disorder sufferers are exclusively adolescent, White women. While the onset of eating disorders does most often occur during adolescence or young adulthood, the number of midlife adults reporting for treatment is on the rise (Ackard, Richter, Egan, & Cronemeyer, 2014). Furthermore, with the exception of AN (which remains more common among Non-Hispanic Whites), eating disorders affect people at similar rates across race and ethnicity (Hudson et al., 2007; Wade et al., 2011). The bias amongst healthcare professionals on this matter has likely contributed to the under diagnosis of eating disorders in non-White populations.

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[3] Although numerous eating disorder organizations' websites state that 40% of BED suffers are men, I was unable to verify this with published research.

It is important to note that it remains very difficult to conduct methodologically sound, large-scale studies on the prevalence of eating disorders (Smink, van Hoeken, & Hoek, 2012). In a review of prevalence studies (limited to articles published in English), Smink, van Hoeken, and Hoek (2012) underscored the major challenges, including: patients' tendency to deny/conceal their illness and avoid professional help (leading to costly and ineffective studies); the need to use psychiatric case registers or hospital records, an approach that underestimates the occurrence of eating disorders as general practitioners do not detect all cases or refer them to hospital or mental health care; and the possibility that difference in rates over time actually reflects improved diagnostic skills/tools and increased public awareness contributing to earlier identification and increased availability of treatment services. Thus, the results of studies on rates of incidence often vary and results more likely than not underestimate the prevalence of eating disorders across populations.

Etiology. In an overarching review and update on clinical progress toward understanding and addressing eating disorders, Grave (2011) observed that we have yet to develop a unifying causal model. Nonetheless, studies suggest that genetic, biological, and environmental factors play significant roles. One study found relatives of probands with eating disorders to have a 10-fold lifetime risk of having eating disorders than relatives of controls without eating disorders (Bulik & Tozzi, 2004a). Twin studies have also estimated that genetic factors account for 50-83% of the variance in AN, BN, and BED (Bulik, Slof-Op't Landt, van Furth, & Sullivan, 2007; Bulik & Tozzi, 2004b; Javaras, 2008). Various studies on biological functions have observed that neuro-circuitry disturbances in the brain frequently persist after recovery, suggesting that some disturbances may predate the onset of the disorders and could, perhaps, predispose individuals to the development of disordered eating problems (Grave, 2011). A range of environmental factors

is also likely to contribute to the development of eating disorders (Grave, 2011). Some of these factors can begin at the time of conception, including mothers' exposure to stress during pregnancy, birth complications/trauma, and related injuries (Grave, 2011). Prospective studies and community-based case-control studies have also yielded a number of risk factors, including general harmful experiences, e.g. neglect, physical and sexual abuse, and dysfunctional parenting (Grave, 2011). Harmful experiences related to food and weight are also likely to contribute to the development of eating disorders, including childhood and parental obesity, family dieting, critical comments about eating/shape from family and/or others, recreational and occupational pressure to be thin (Grave, 2011).

While the media does not directly cause eating disorders, media is ubiquitous in Western culture and can play a profound role in the development of disordered eating behaviors. Bryant and Oliver (2009), Smolak and Levine (1996), and Thompson, et al. (1999) highlight how substantial media messages are "augmented or buffered by messages from family, friends, teachers, and coaches" (Bryant & Oliver, 2009, p. 493). Such messages include: "1) the paramount importance of being attractive; 2) the pre-eminence of thinness for attractiveness and the demonstration of control; and 3) the value of technologies and products such as diets and drugs for achieving beauty ideals" (Bryant and Oliver, 2009, pp. 492-493). While only about 5% of American women are underweight, over 30% of women in character roles on television are underweight (Bryant & Oliver, 2009). Meanwhile, 2% of men in the U.S. are underweight and 12% of male television characters are underweight (Bryant & Oliver, 2009). Thus, throughout their development, "girls and boys have no trouble finding the raw material for maladaptive but entirely normative thin-as-normal and thin-as-ideal schemata," leaving them highly susceptible

to damaging self-scrutiny which can so easily evolve into restrictive and/or compensatory behaviors (Bryant & Oliver, 2009, p. 493).

Changes in the DSM-5. The increased prevalence, identification, and public awareness of eating disorders resulted in special attention being given to eating disorders in the DSM-5, in which several important changes have been made (APA, 2013). A couple of these alterations have already been mentioned. BED has been added to the "threshold eating disorders (TED)" formerly including only AN, BN, and purging disorder (PD), a validating addition for sufferers of BED who felt that its absence in the DSM minimized its seriousness (Fairweather-Schmidt & Wade, 2014, p. 524). Criteria for TEDs have also been relaxed and given dimensionality so as to decrease the number of cases that would otherwise fall under EDNOS, now known as OSFED. This revision was intended to be one of the clinical improvements for eating disorders in the DSM-5 (Fairweather-Schmidt and Wade, 2014). The DSM-5 also includes clarification of "the expected course, and treatment options over time becoming achievable when patterns of symptomatology change are recognized and definable" (Fairweather-Schmidt and Wade, 2014, pp. 524-525). However, two studies of DSM-5 eating disorders in young people up to 20 years old suggest that OSFED still represents 15%-40% of cases, suggesting that, perhaps, the manual does not make meaningful distinctions between TED and OSFED diagnoses regarding risk and impairment factors (Fairweather-Schmidt and Wade, 2014).

In sum, eating disorders are serious, life-threatening conditions that affect people across race, gender, ethnicity, and age groups. To the extent that prevalence studies have been possible, we have learned that eating disorders occur at high and increasing rates at least since the 1930s, with onset most commonly occurring during adolescence. Although a unifying causal model for understanding the etiology of eating disorders has not yet been developed, numerous genetic,

biological, and environmental factors have been identified as strongly influencing the their development.

Treatment

Despite the prevalence and high mortality rates of eating disorders, funds for further research and the development of effective, high quality treatment programs have lagged behind the investment in other physical, developmental, and mental health conditions. While treatment for eating disorders generally favors behavioral, skills-based approaches, no singular methodology has been found to consistently result in high rates of long-term recovery. Clients, particularly those in residential treatment programs, may engage in various interventions at the inpatient, residential, partial hospital, intensive outpatient, and outpatient levels, such as: support groups, individual therapy, family therapy, medication management, and nutrition counseling. The following section will provide an overview of the most common treatment methodologies for eating disorders and the major challenges that obstruct clients' access to clinical support.

Cognitive Behavioral Therapy (CBT). CBT has been the primary focus of treatment development for eating disorders (Crow & Petersen, 2009). CBT broadly refers to therapeutic techniques that focus on the relationships between cognitions, affect, and behavior. One of the challenges of synthesizing the findings of CBT effectiveness studies is the significant variance with which it can be practiced. Some examples of the numerous approaches to CBT include Rational Emotive Behavior Therapy, Rational Behavior Therapy, Rational Living Therapy, Cognitive Therapy, and Dialectic Behavior Therapy (National Association of Cognitive-Behavioral Therapists, n.d.). Nonetheless, CBT is generally recommended for 1-2 years with clients who require substantial weight gain and 1 year for others (Crow & Petersen, 2009). The National Collaborating Centre for Mental Health (2004) in the United Kingdom awarded CBT

with an "A" for the treatment of BN for its strong evidence base. In a systematic review of CBT trials, the National Collaborating Centre for Mental Health (2004) also confirmed that although CBT results in faster reduction of disordered eating behaviors, Interpersonal Psychotherapy (IPT) and CBT are equally efficacious in the long term. Thus far, Fairburn, et al. (2009) is one of the few if not the first to study and demonstrate the effectiveness of CBT as a treatment for EDNOS (Crow & Petersen, 2009). However, the effectiveness of CBT is less clear as an intervention for AN (Crow & Petersen, 2009). While the treatment appears to increase engagement and persistence for individuals with AN, most studies find that there is symptom reduction without full recovery (Wilson, Grilo, & Vitousek, 2007).

Dialectical behavior therapy (DBT). DBT is an empirically supported model of CBT originally developed by Marsha Linehan for individuals with borderline personality disorder (BPD) and chronic self-harm and/or suicidal behaviors (Linehan, et al., 1992; Linehan, 1993; Linehan, et al., 2006). In outpatient therapy, standard DBT includes four modes of treatment: weekly individual psychotherapy, group skills training, therapist consultation team meetings, and 24-hour daily telephone access to coaching (Bankoff, et al., 2012). Designed to target problem behaviors resulting from emotion regulation, DBT provides adaptive affect regulation skills with special attention to treatment interfering behaviors (e.g. absences, dropout; Bankoff, et al., 2012). As such, it has been adapted for numerous psychiatric problems including eating disorders due to the association of eating pathology with emotion dysregulation and the conceptualization of disordered eating behaviors as maladaptive attempts to regulate emotions (Bankoff, et al., 2012; McCabe, et al., 2004).

In a systematic literature review of peer-reviewed publications on the application of DBT for eating disorders, Bankoff, et al. (2012) identified 13 empirical studies on the efficacy of

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modified DBT treatment for AN, BN, BED, and EDNOS. All of the studies demonstrated significant reduction of disordered eating behaviors as well as improvements in mood and treatment retention, suggesting that DBT may be more tolerable than other interventions (Bankoff, et al., 2012). The results may also indicate that DBT successfully addresses treatment interfering behaviors particularly for those with comorbid disorders (Bankoff, et al., 2012). Five of six studies also demonstrated significant reduction of symptoms at follow-up (Bankoff, et al., 2012). While relapses and new eating disorder behaviors did develop at follow-up for some individuals who had been symptom-free at the end of treatment, this occurred at approximately the same rate as other evidence-based practices (Bankoff, et al., 2012). Although DBT was more effective than no treatment in two of two studies, no studies were found comparing DBT to other evidence-based treatments for eating disorders (e.g. CBT, IPT; Bankoff, et al., 2012). Furthermore, there was not adequate support for the theory that improvements in emotion regulation decreases in disordered eating behaviors (Bankoff, et al., 2012). The authors ultimately concluded that more research is needed (Bankoff, et al., 2012).

Acceptance and commitment therapy (ACT). ACT is an understudied treatment for eating disorders that shows some promise (Juarascio, et al., 2012). As "one of several novel acceptance-based models of CBT that emphasize changing behaviors rather than altering internal experiences," (Juarascio, et al., 2012, p. 461), ACT has been consistently shown in meta-analyses to be more effective than control conditions and at least as good as other empirically supported treatments such as CBT or behavioral therapy (BT) (Hayes, Luoma, Bond, Masuda, & Lillis, 2006; Powers, Zum Vorde Sive Vording, & Emmelkamp, 2009). Juarascio, et al. (2012) make a strong theoretical case for the use of ACT with clients diagnosed with eating disorders. ACT targets important maintenance factors (e.g. high experiential avoidance, poor experiential

awareness, lack of motivation) that tend to be heightened for eating disorder patients but are left unaddressed by other treatment models (Juarascio, et al., 2012). In a pilot study to test the efficacy of ACT-based group therapy for eating disorders in a residential setting, Juarascio, et al. (2012) added ACT to the normal treatment regimen for more than 100 women with AN, BN, and EDNOS and compared outcomes with those of women who proceeded with treatment as usual (TAU). Juarascio, et al. (2012) found that both groups showed significant decreases in eating pathology, but 38% of the ACT group was within normative range post-treatment compared to only 17% of the TAU group. Additionally, 18% of the TAU group was rehospitalized within 6 months of treatment while just 3.5% of the ACT group was rehospitalized (Juarascio, et al., 2012). In sum, Juarascio, et al.'s (2012) findings suggest that ACT is a viable form of treatment for eating disorders that warrants more outcome research.

Family-Based Therapy (FBT). Although not as frequently studied as CBT, FBT has been gaining evidence base as a treatment for eating disorders (Couturier, Kimber, Szatmari, 2013). FBT remains the most extensively studied treatment for specifically for AN (Wilson, Grilo, & Vitousek 2007) and is the American Psychological Association's recommended practice (Couturier, et al., 2013). More specifically known as Maudsley Family Therapy, FBT consists of "outpatient, intensive treatment using the family as the primary resource to renourish the affected child or adolescent" and involves 9-12 months of treatment with a therapist and physician (Couturier, Kimber, & Szatmari, 2013, p. 3; Lock, le Grange, Agras, & Dare, 2001). Couturier, Kimber, & Szatmari (2013) performed a meta-analysis of FBT efficacy studies with adolescent target populations and allocation concealment as strict inclusion criteria (amongst others). The 3 highest quality studies in the review revealed FBT to be no more successful for symptom reduction at the end of treatment than individual therapy (Courturier, Kimber, & Szatmari,

2013). However, FBT achieved significant higher remission rates at 6-12 month follow-up (Courturier, Kimber, & Szatmari, 2013). Subjects with AN and BN experienced similar results (Courturier, Kimber, & Szatmari, 2013). As to why FBT may be more effective in the long term, the authors note that participants in FBT continue to have their parents' support after treatment has ended and continue to make gains while those without FBT struggle when direct therapeutic support is removed leading to relapse (Courturier, Kimber, & Szatmari, 2013). In a review of treatment studies for AN, Wilson, Grilo, & Vitousek (2007) identified corroborating results; FBT was slightly more effective or had equal efficacy as other treatments in comparative studies. The National Institute for Clinical Excellence (NICE) in the United Kingdom is credited with performing the most thorough and rigorous evaluation of eating disorder treatment (Wilson, Grilo, & Vitousek 2007). Through a stringent grading process of assessing treatment studies for strength of evidence, NICE (2004) awarded a "B" to FBT while all other treatments for AN received a "C" due to the paucity of research (Wilson, Grilo, & Vitousek 2007).

Interpersonal Therapy (IPT). IPT is a treatment approach that focuses on addressing the client's interpersonal difficulties. Although it was originally developed for depression, it has become a leading evidence-based treatment for eating disordered clients who feature binge eating as a symptom (Murphy, Straebler, Basden, Cooper, & Fairburn, 2012). Interpersonal difficulties for these clients may predate the eating disorder or develop as a consequence (Murphy, et al., 2012). Social withdrawal, a common feature, can occur due to low self-esteem and as an attempt to avoid others' scrutiny of pathological behaviors (Murphy, et al., 2012). As previously noted, two randomized controlled trials of IPT for the treatment of BN have been conducted (Murphy, et al., 2012). In one study comparing IPT, CBT, and BT, CBT was found to be more effective in the short-term, but equally effective as IPT at an 8-month follow-up as IPT

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participants continued to improve (Fairburn, et al., 1991; Fairburn, Jones, Peveler, Hope, & O'Connor, 1993). Six years later, the 72% of IPT participants no longer met DSM-4 criteria for an eating disorder (Fairburn, et al., 1995). These findings were replicated in a second, larger study comparing IPT and CBT (Agras, Walsh, Fairburn, Wilson, & Kraemer, 2000).

Only one limited study compared IPT, CBT, and non-specific supportive clinical management for AN and found that IPT was least effective in the short-term (McIntosh, et al., 2005). However, similar to IPT for BN, at long-term follow-up 6-7 years after treatment, IPT participants were found to have continued to improve, resulting in no significant long-term outcome differences amongst the three groups (McIntosh, et al., 2005). Two main studies on IPT for EDNOS have focused on clients suffering from binge eating who are also overweight (Murphy, et al., 2012). In both studies (Wifley, et al., 2002; Wilson, Wifley, Agras, & Bryson, 2010), IPT resulted in marked improvement but was not more or less successful than other treatments, including CBT, guided cognitive-behavioral self-help, behavioral weight loss treatment. However, Wilson, et al. (2010) found that IPT and guided cognitive-behavioral self-help were significantly more effective than behavioral weight loss treatment for eliminating binge behaviors. As such, current research indicates that IPT is a viable alternative to CBT as the leading recommended treatment for BN and BED, but is not effective for the treatment of AN. More research is needed on outcomes of IPT for other forms of OSFED.

Medication. Pharmacotherapy is frequently used to treat eating disorders in conjunction with other available forms of treatment. However, Mitchell, Roerig, and Steffen's (2013) recent review of biological therapies for BN, BED, and AN yielded only modest evidence of its efficacy, including few studies of child and adolescents and many mixed results. For BN there are few pharmacotherapy double-blind randomized controlled trials, most of which are trials of

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antidepressants, especially selective serotonin reuptake inhibitors (SSRIs) (Mitchell, Roerig, & Steffen, 2013). Of the SSRIs, fluoxetine is the only medication indicated by the Food and Drug Administration for treatment of BN (Mitchell, Roerig, & Steffen, 2013). Unfortunately, full remission rates are often not reported and abstinence from BN behaviors is not frequently discussed (Mitchell, Roerig, & Steffen, 2013). One review of 24 studies comparing fluoxetine to a placebo for the treatment of BN did include an abstinence rate of more than 20%, but this result is not promising (Bacaltchuk, 2003). Maintenance medications have also been studied but have yielded results that are either poor or difficult to interpret due to significantly high attrition (Mitchell, Roerig, & Steffen, 2013). While there are a variety of studies examining combination therapy, it was only administered in one trial that resulted in significantly better outcomes compared to single medication treatment (Walsh, et al., 1997).

Conducting a review of pharmacotherapy of BED is less straightforward due to the recent formalization of its diagnostic criteria in the DSM-5. Mitchell, Roerig, and Steffen (2013) note that there have been a number of trials for obesity and this has often included individuals with BED; thus, their discussion on the pharmacotherapy of BED largely focuses on the effects of drugs on weight loss. Although pharmacotherapy has only achieved very minimal weight loss, binge eating symptoms appeared responsive to several drugs (Mitchell, Roerig, & Steffen, 2013). Finally, the review yielded very few studies on pharmacotherapy for AN compared to BN and BED (Mitchell, Roerig, & Steffen, 2013). Those that were controlled generally presented poor effectiveness (Mitchell, Roerig, & Steffen, 2013). The historical trials of TCAs and antipsychotics and the more recent trials of SSRIs and second-generation antipsychotics generally yielded mixed results while the latter group led to mostly negative results (Mitchell, Roerig, & Steffen, 2013). At this time, psychotherapeutic methodologies remain the most

promising form of treatment for eating disorders, and more high quality studies are needed to assess outcomes for the use of pharmacotherapy.

Nutrition counseling. Although nutrition counseling is used as an adjunctive resource in many eating disorder treatment facilities it does not have a strong evidence base as a stand-alone intervention. In one study comparing nutrition counseling with CBT, Serfaty, Turkington, Heap, Ledsham, and Jolley (1999) failed to obtain results due to the 100% attrition rate in the nutrition counseling group (although nearly all of the subjects in the CBT group completed treatment). In another similar comparative study, Pike, Walsh, Vitousek, Wilson, and Bauer (2003) found nutrition counseling to be less effective for participation, positive outcomes, and relapse prevention than CBT. The paucity of research on nutrition counseling for eating disorders is highlighted in Rocks, Pelly, and Wilkinson's (2014) survey of Australian dieticians in which 94% of participants reported that the available evidence for the nutritional treatment of AN is "insufficient or only somewhat sufficient to guide practice" (p. 100). Consequently, dieticians' interventions were shown to vary (Rocks, Pelly, & Wilkinson, 2014).

Literature in the field of nutritional research emphasizes the importance of multidisciplinary approaches to the treatment of eating disorders. Given the severity of potential health consequences for eating disorder sufferers, physical stabilization through nutrition management is essential, particularly in inpatient and partial hospital settings in which patients are at significant risk (Rock, 1999; Rock & Curran-Celentano, 1996). For AN, weight restoration is the primary goal of nutrition management, but that alone does not result in recovery (Rock, 1999). Rather, it is essential that patients concurrently receive intensive psychotherapy with mental health professionals (Rock, 1999). The same is true for those with BN and EDNOS. For BN, the primary goal for nutrition management is to normalize typically very chaotic eating

patterns and discontinue purging behavior (Rock, 1999). As the symptoms, weight, and nutritional needs of patients with EDNOS can greatly vary, nutritional intervention can also vary based on the specific needs of the patient. Although patients in this category who present for treatment tend to be overweight and seek medical attention for that reason (Rock, 1999).

Barriers and challenges to treatment. As one can see, one of the main challenges of treatments for eating disorders is the array of only moderately effective options, many of which are in need of higher quality studies. Not only are the treatment options less than ideal in terms of their effectiveness, their availability and affordability vary greatly depending on one's geographic location, insurance, and economic standing. Such barriers in addition to eating disorders sufferers' characteristic ambivalence toward treatment have led only 1 in 10 of those with clinically significant symptoms to receive treatment (South Carolina Department of Mental Health, n.d.). Furthermore, only about 20% of girls and women who have accessed care for their eating disorders get the intensity of treatment they need to prevent relapse (South Carolina Department of Mental Health, n.d.). Despite exhibiting similar rates of eating disorders, Latina, Asian, and African American individuals in the United States with a lifetime history of any eating disorder are significantly less likely to receive mental health treatment than non-Latino whites (Marques, et al., 2011). This is a trend that is also generally true for other mental illnesses amongst racial minorities, strongly indicating that there are particular treatment barriers for people of color (Marques, et al., 2011). Such barriers can vary depending on the particular identities, communities, and family history of any particular individual. Some common obstacles for people of color may include lack of racial representation at mental health facilities (which tend to be primarily white), lack of transportation and financial access due to intersecting structural forces of racism as it manifests in the U.S., covert and or covert experiences of racism

in previous health or mental health treatment, (for immigrants) fear of deportation, lack of treatment in one's native language, general distrust of whites/institutions, and/or cultural stigma or alternative understanding of mental illness and how to treat/manage it.

Screening. Unfortunately, adolescent patients rarely present to their primary care doctor with a complaint an eating disorder, leaving it up to the doctor and other professionals in their lives to properly screen for disordered eating problems (Rome, et al., 2003). Rather, patients are more likely to report physical symptoms such as fatigue, headaches, dizziness, amenorrhea, or heartburn (Rome, et al., 2003). Often, it is a concerned parent, coach, or school nurse who will end up referring a child or adolescent for treatment (Rome, et al., 2003). Although general practitioners are recommended to have a low threshold for suspicion, eating disorders frequently go undetected, as physicians do not typically use the screening tools available to them (Rome, et al., 2003). Even when/if individuals are referred for treatment, a plethora of challenges await them.

Cost. As the best approaches to eating disorders involve multidisciplinary teams, different phases of treatment, and often multiple providers, the cost of services can skyrocket (Rome, et al., 2003). According to the South Carolina Department of Mental Health (n.d. need better source), treatment for eating disorders in the U.S. can range from $500 to $2,000 daily while the average cost for one month of inpatient treatment is $30,000 (South Carolina Department of Mental Health, n.d.). For outpatient treatment, from therapy to medical monitoring, the cumulative costs of care can easily reach $100,000 or more (South Carolina Department of Mental Health, n.d.). Clearly, the expenses for treatment are prohibitive for many families, leading many to settle with inadequate services.

Health insurance. There are three main reasons why health insurance companies do not adequately cover such costs: eligibility, scope of benefits, and reimbursement (i.e. copayment and deductibles) (Rome, et al., 2003). Thankfully, some of these obstacles have been addressed with the implementation of the Affordable Care Act. Previously, eligibility for children and adolescents was an even greater issue because insurance companies could deny coverage due to pre-existing conditions (U.S. Department of Health and Human Services, 2014). For plans in which children are included, young adults are now also able to remain covered by their parents' plan until age 26 (U.S. Department of Health and Human Services, 2014).

Nonetheless, insurance companies have drawn arbitrary lines between psychiatric and medical benefits for pecuniary reasons, and coverage for eating disorder treatment has been notoriously minimal (Rome, et al., 2003). Although the Affordable Care Act requires mental health and substance abuse treatment to be included in all "essential benefits packages" with coverage comparable to medical health services, it is left to the states' discretion as to which DSM diagnoses are included (U.S. Department of Health and Human Services, 2014). In an assessment of all states' and the District of Columbia's parity laws for eating disorders, the National Women's Law Center (2010) found that only 10 states require coverage for anorexia and bulimia on the same basis as other mental illnesses. Moreover, 23 states had no policy to protect those with eating disorders (National Women's Law Center, 2010). Thus, although individuals are estimated to need at least 3 to 6 months of inpatient care, health insurance companies often refuse to cover the cost (South Carolina Department of Mental Health, n.d.).

Finally, while "lifetime limits on most benefits are banned" under the Affordable Care Act (U.S. Department of Health and Human Services, 2014), limits may and often are imposed on eating disorder treatment (Rome, et al., 2003). Copayments and deductibles can quickly

accumulate regardless of coverage and may be incredibly high in the case of hospitalization

(Rome, et al., 2003). As Rome, et al. (2003) note, "An indirect way in which this limit setting

affects the care of patients with eating disorders is a structure of inequitable payment for

different types of care, emphasizing rewards for technical procedures rather than anticipatory

guidance or counseling" (p. 106). Inadequate care in the earlier stages of an eating disorder can

also result in further medical costs later on when complications such as osteoporosis ensue

(Rome, et al., 2003). Furthermore, an added concern for those with eating disorders and their

families is the more subtle impact of low reimbursement rates for clinicians' psychological

services, which could potentially lead to fewer qualified providers, at least for young people

(Rome, et al., 2003).

Ambivalence toward treatment. In study after study of eating disorder treatments,

authors speculate about the difficulty of achieving full recovery and sustained remission for

sufferers. Many comment on the inherent, challenging characteristics of eating disorders. For

example, eating disorders are commonly understood to be highly ego-syntonic which strongly

contributes to individuals' ambivalence toward treatment, particularly treatment that seeks to

directly address disordered eating behaviors and thoughts (Fairburn, 2008; Vanderlinden, 2008).

Indeed, one may view eating disorder symptoms as defenses from upsetting internal experiences

such as rejection, imperfection, failure, vulnerability, and intimacy (Hayes & Pankey, 2002;

Keyser, Sharma, Pastelak, Wirth-Granlund, Testa, & Alloy, 2009; Paxton & Diggens, 1997;

Serpell, 1999). Furthermore, the negative effects of malnutrition on cognitive and emotional

processes can exacerbate poor judgment regarding health, self-care, and the prioritization of

different aspects of daily life (Keys, Brozek, Henschel, Mickelsen, & Taylor, 1950).

Rather than view diagnosed individuals as valuing their eating disorders, Turner, Tatham, Lant, Mountford, and Waller (2014) argue that eating disorder symptoms are actually safety behaviors that decrease anxiety in the short term, a notion supported by the substantial rates of comorbidity between eating disorders and anxiety disorders (Kaye, Bulik, Thornton, Barbarich, & Masters, 2004). From this perspective, individuals are likely still very reluctant to seek treatment as the prospect of giving up the disordered behaviors could have terrifying consequences. In studies on biological treatments, Mitchell, Roerig, and Steffen (2013) also suggest that adverse medication side effects and patients' limited understanding (if any) of the rationale for their prescriptions likely contribute to high dropout rates.

Stigma. In addition to the ambivalence toward treatment, which is a function of eating disorders, stigma may further discourage sufferers from disclosing and pursuing support. Sadly, ample research has shown the public's tendency to stigmatize individuals diagnosed with mental illnesses through "identification, separation, attribution of undesirable characteristics and discrimination" (Mond, Robertson-Smith, & Vetere, 2006, p. 519; Link & Phelan, 2001). Stigma toward psychotic disorders, anxiety disorders, and mood disorders have been thoroughly studied; however, little attention has been given to lay attitudes toward people diagnosed with eating disorders (Mond, Robertson-Smith, & Vetere, 2006). The media's reinforcement of the desirability of eating disorders by associating them with fame, thinness, and beauty may be contributing to this lack of research (Striegel-Moore & Franko, 2003). Furthermore, eating disorders are not typically perceived as dangerous or unpredictable in the same way as other stereotyped disorders, such as schizophrenia (Mond, Robertson-Smith, & Vetere, 2006; Link, Struening, Rahav, Phelan, & Nuttbrook, 1997). The prioritized attention given to diagnoses perceived to be more dangerous, traumatic, or widespread is reflected the National Institutes' of

Health allocation of funds for research. While about $81 research dollars were spent on individuals affected by schizophrenia in 2011, a mere $0.93 was spent on individuals affected by eating disorders (NEDA, n.d.b).

Health care and mental health professionals are not immune to stigma. Indeed there has been growing concern amongst advocates for the mentally ill that "climate and culture of treatment setting often have unintended, stigmatized influences, including the absence of hopeful messages from providers" (Kelly, 2006; Pescosolido, 2006; Pescosolido, Martin, Lang, & Olafsdottir, 2008, p. 436). Given eating disorders reputation for being very difficult to treat, it is not unlikely that one would encounter the latter. Thus, whether individuals encounter stigma amongst lay people, within a professional setting, or both, it is reasonable to believe that those with disordered eating behaviors are likely to explore alternative, anonymous means of getting support and information, such as online.

In sum, available treatments and their accessibility currently leave much to be desired. Of the primary therapeutic interventions currently being practiced, including CBT, DBT, ACT, FBT, and IPT, CBT maintains the strongest evidence base for BN followed by IPT. However, DBT and ACT demonstrate tentatively promising results for the treatment of numerous eating disorders though additional research is needed. FBT remains the only evidence-based, recommended practice for AN but still only yields modest rates of recovery outcomes. Psychopharmatherapy and nutrition counseling for eating disorders typically occur in coordination with psychotherapy and are ineffective as stand-alone treatments. Despite the prevalence and severity of eating disorders, extensive external and internal barriers to accessing treatment persist. Screening processes continue to be inconsistent and insufficient. Despite parity improvements thanks to the Affordable Care Act, coverage for eating disorder treatment can still

vary greatly from state to state while primary and secondary costs are often prohibitive. On the individual level, deep-seated ambivalence toward treatment contributes to ongoing secrecy. Avoidance of professional support is also exacerbated by pervasive stigma that minimizes the physical and emotional damage wrought by eating disorders. Given these circumstances, it is understandable for eating disorder sufferers to feel overwhelmed, discouraged, and unsure. Thus, the virtual and anonymous world of the Internet presents an easily accessible, "safe" source of information and emotional support.

Eating Disorders and the Internet

The primary, easily accessible, and obvious means of obtaining support and information anonymously is the Internet. For those with eating disorders, the prospect of disclosing their maladaptive behaviors can be incredibly intimidating. First, individuals may be uncertain of whether their experience constitutes a clinically significant problem that merits attention and treatment. Second, they may be convinced by self-deprecating thought processes that they do not deserve help. Third, they may be reluctant to disclose their disorder knowing that doing so is likely to result in increased monitoring and/or pressure to change behaviors that, despite their destructiveness, may still be: 1) sources of comfort, 2) coping mechanisms, or 3) perceived as effectively progressing them toward a particular goal (e.g. weight loss/maintenance). Thus, individuals with disordered eating may turn to the Web in order to answer questions and allay some of their anxieties. However, many individuals may also turn to the Internet to find communities of support and sources of information that may help them perpetuate their disorder and learn additional maladaptive behaviors. Mounting concerns for this latter aspect of eating disorder-related material online have prompted a minimal but growing body of research on the

controversial relationship between eating disorders and the Internet, which commonly manifest as websites, blogs, social networking venues, and forums.

        Pro-eating disorder (pro-ED) content. There are at least as many websites promoting eating disorders as there are websites promoting recovery on the Internet. The term "pro-ana community" is now typically used to refer to the nomadic group of websites created by and for (typically young) people with eating disorders (Giles, 2006, p. 464; Pollack, 2003). Although it has been estimated to include at least 400 pro-ED sites, their names and Uniform Resource Locators (URLs) are ever shifting, as they become targets of criticism and are often shut down by hosts (Atkins, 2002). The name "ana" itself has also become a point of contention on pro-ED sites where identity negotiation can frequently play out (Giles, 2006). Harshbarger, Ahlers-Schmidt, Mayans, Mayans, and Hawkins (2009) describe pro-ana (i.e. pro-anorexia) sites as venues for "anas" to find support typically through sharing experiences and offering encouragement. They can include a range of content, such as instruction for starting and maintaining AN as well as motivational material (e.g. photos of thin models or site users, poetry, song lyrics about eating disorder conditions) (Mulveen & Hempworth, 2006; Norris, et al., 2006). While forums (i.e. online spaces in which users can anonymously exchange messages) sometimes include eating disorder "tips and tricks," there are often a number of more innocuous threads regarding common adolescent concerns (e.g. school, crushes), which may be reflective of the typical user population (Giles, 2006). Norris, Boydell, Pinhas, and Katzman (2006) supported this conclusion when they found site administrators to be largely female adolescents, younger than 18 years in some cases.

        Within the past 15 years, several studies analyzing the content of pro-ED sites have observed that anorexia, amongst other eating disorders, is often presented as a lifestyle choice

rather than an illness (Dias, 2003; Giles, 2006; Haas, Irr, Jennings, & Wagner, 2011; Lipczynka, 2007). Consequently, parents, health professionals, eating disorder support groups, and the media have condemned such sites as potential triggers that generally encourage eating disorders (Giles, 2006). The backlash has lead many hosts to shut down sites promoting pathological behaviors, such as Tumblr (a blog hosting service) did in 2012 (Ryan, 2012). While critics may have a more wholesale sinister view of these sites and their users, however, Brotsky and Giles (2007) observed (covertly) that there is not a consistent standpoint amongst participants in a pro-ana community. Rather, participation is more so about reassurance and the comfort of belonging to safe group of people with shared experience (Brotsky & Giles, 2007).

Despite the efforts to suppress pro-ED sites, they remain easily found, presumably because they are in high demand and the support is much needed (Gavin, Rodham, & Poyer, 2008). Indeed, one study showed 41% of adolescent eating disorder patients visited pro-ED sites, 35.5% visited pro-recovery sites, and 25% visited both sites (Wilson, Peebles, Hardy, & Litt, 2006). Ninety-six percent of pro-ED site users along with 46.4% of pro-recovery site visitors learned new weight loss or purging skills (Wilson, Peebles, Hardy, & Litt, 2006). Although site users' health outcomes did not differ from nonusers, they reported a longer duration of illness, less time spent on school, and more hospitalizations than nonusers, suggesting that eating disorder site usage whether pro-ED or pro-REC may have a negative impact on patients' lives (Wilson, Peebles, Hardy, & Litt, 2006). In a qualitative study of reasons why individuals enter and continue to engage with pro-ED websites, Peebles, et al. (2012) found that motives included: lack of outside social support; stress; depression; feeling like family, friends, and/or providers did not understand or empathize with them; and feeling alone. Although participants minimized or ignored dangers of disordered eating and/or using the pro-ED websites, they listed several

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benefits including feeling like they could be themselves, reduced isolation, and increased coping and support (Peebles, et al., 2012).

Yeshua-Katz and Martins (2012) added a much-needed exploratory, qualitative study to the extant research on the pro-ana community by directly investigating pro-ana bloggers' personal perspectives on the motivations, benefits, and drawbacks of blogging about a stigmatized mental illness. Thirty-three interviews from 7 different countries revealed that pro-ana blogging both alleviates and triggers anxiety (Yeshua-Katz & Martins, 2012). Participants reported that the primary benefits of blogging were social support, means of coping, and self-expression (Yeshua-Katz & Martins, 2012). On the other hand, bloggers remained fearful that their eating disorder and blog would somehow be exposed and/or encourage disordered eating. Unlike other extant research (Dias, 2003; Giles, 2006; Haas, Irr, Jennings, & Wagner, 2011; Lipczynka, 2007), only 3 of the 33 subjects in Yeshua-Katz and Martins' (2012) study described their eating disorder as a lifestyle. Rather, most bloggers defined it as a mental illness, suggesting that most people with eating disorders may mainly be trying to cope as opposed to purposely engaging in dangerous behaviors (Yeshua-Katz & Martins, 2012). While others have found pro-ana websites to share weight loss and concealment tips, only 5 bloggers mentioned this as sources of motivation for writing their blogs (Yeshua-Katz & Martins, 2012). Moreover, bloggers in this study provided disclaimers warning users about the content and ignored or blocked posts for tricks (Yeshua-Katz & Martins, 2012).

Yeshua-Katz and Martins (2012) consider two possible explanations for the differences in their findings compared to previous research on pro-ana communities: 1) bloggers who agreed to participate in the study may have been more aware of public criticism and therefore wanted to counteract such views by providing an alternative narrative; and 2) all previous studies were

based on content analysis alone. The authors further argue that the "moral panic" about pro-ana websites may not be appropriate given the grossly under-researched, poor treatment and support available (Yeshua-Katz & Martins, 2012, p. 506). Thus, Yeshua-Katz and Martins (2012) suggest, "Efforts to censor an outlet for a group who cope with a mental illness that has no effective treatment might not be the right step. Instead, efforts should be concentrated in providing more comprehensive online resources for information about effective treatment." (p. 507).

Of the extant research available, I was only able to identify one study explicitly including online, pro-ED support groups. Haas, Irr, Jennings, and Wagner (2011) used grounded theory to explore how communication strategies function to co-create pro-ana support in online forums, blogs, and personal webpages, all of which allowed users to exchange anonymous messages. Their findings, which included 4 main themes and 8 communication strategies, shed light on a new type of online community, coined Online Negative Enabling Support Group (ONESG) (Haas, Irr, Jennings, & Wagner, 2011). The 4 themes were named: co-constructing an ana personal identity, self-loathing ana, advising ana, and group ana encouragement. The themes' corresponding communication strategies all involved forms of self-disclosure, e.g. disclosures of weight loss tips and managing 'non-anas' in social situations (Haas, Irr, Jennings, & Wagner, 2011).

Pro-recovery (pro-REC) content. Compared to the approximately 500 pro-ana sites identified by Chelsey, Alberts, Klein, and Kreipe (2003), pro-REC and professional eating disorder sites represent a small portion of eating disorder-related information available on the web, yielding only 100 and 30 sites respectively. There is a corresponding gap in the research; while numerous studies have analyzed the content of pro-ED sites, and, to a lesser extent, the

motivations of their users, only four have explicitly addressed pro-REC resources (Chelsey, et al., 2003; Stommel, 2007; Wesemann & Grunwald, 2008; Wilson, Peebles, Hardy, & Litt, 2006). Thus, the available knowledge on pro-REC sites, forums, and support groups is minimal.

Based on the few existing studies, there appear to be some key differences as well as a significant amount overlap between pro-REC and pro-ED sites in terms of their content. Contrary, perhaps, to what one might expect, pro-ana sites tend to be more organized and comprehensive than pro-REC sites (Chelsey, et al., 2003). More intuitive is the finding that, unlike users of pro-ana sites, pro-REC site users "overwhelmingly presented introspective first person viewpoints on AN and had little nutritional advice" (Chelsey, Alberts, Klein, & Kreipe, 2003, p. 124). In a content analysis study of a German, pro-REC forum, Stommel (2007) highlighted the importance of nicknames as identity signifiers connected to users' stage of recovery. In another German pro-recovery forum for BN, Wesemann and Grunwald (2008) analyzed almost 15,000 posts to uncover underlying structural types and quantitative comparison of communication threads. Interestingly, although problem-oriented threads were most numerous, metacommunication threads received the most postings, which included discussions on how to address issues such as pro-ED messages (Wesemann & Grunwald, 2008). The latter suggests that, although the site was pro-recovery and unmoderated, pro-disorder content emerged and lay participants took the initiative to stop it.

Other studies on online forums, often referred to as electronic support groups (ESGs), merely *imply* that the sites are pro-REC oriented, such as when the forum provider is maintained by a private clinic or professional(s) (Johnsen, Rosenvinge, & Gammon, 2002; Keski-Rahkonen & Tozzi, 2005) or pro-ED material is absent from the forum content discussed (Darcy & Dooley, 2007; Flynn & Stana, 2012; Gleason, 1995; Walstrom, 2000). In Johnsen, Rosenvinge, and

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Gammon's (2002) comparative analysis of three different types of forums, they found the eating disorder group to be the only one with a "destructive dimension" amongst main posts which, in turn, appeared to lead to a promulgation of "destructive" or "negative" topic threads (p. 445-456). Like many self-proclaimed pro-ED sites, the forum was closed for this reason but was reopened with the supervision of two professionals specializing in eating disorders (Johnsen, Rosenvinge, & Gammon, 2002). In her discourse analysis of 490 postings to the top 5 Yahoo! eating disorder ESGs, Eichhorn (2008) also cites examples of informational support (i.e. advice), the most common form of support exchanged, that is outside standards of care. As these ESGs were not clearly identified as pro-ED or pro-REC, such examples further suggest the grey area that exists on the pro-REC/pro-ED spectrum in which many forums reside despite their self-identified status as "support groups."

As Ransom (2010) observes in her study on the information and support exchanged in an one eating disorder forum, the supervision and mission of the forum—whether it is moderated by professionals or peers, unmoderated, pro-REC, or pro-ED—could play a role in forums' challenges and therapeutic value. Although Ransom (2010) explains how adaptive and maladaptive behaviors are both encouraged in this case, she does not identify whether the forum has a particular orientation toward or away from recovery. Nor does the author explain the types of advice or information that is communicated. Though Flynn and Stana (2012) further this area of research by identifying types of support exchanged by men in a UK-based ESG for eating disorders, they also neglect to characterize the forum explicitly as pro-REC or not and argue for the need of professionals to moderate forums. Although their focus of the study was not the types or accuracy of advice, it did emerge as a prominent category worthy of further study, particularly in light of the unknown reliability of advice provided on ESGs for eating disorders. Gleason

(1995) echoes the need for intervention if/when necessary in her report on the experimental development of a college ESG for food, eating, and body image (although that did not end up being necessary in that case).

Thus, as has been discussed, the Internet provides a plethora of online resources for eating disorder sufferers that can range from staunch, pro-ED communities replete with "tips and tricks" to pro-REC forums monitored regularly by trained professionals. The extensive number of pro-ED sites reflects the pervasive stigma surrounding eating disorders, the tremendous need of eating disorder sufferers for understanding and belonging, and the failure of traditional treatment providers to be accessible, relatable, nonjudgmental, and attuned to the individuals' respective stage of change.

Summary

In conclusion, the development of a unifying causal model and effective treatments for eating disorders has not been able to keep up with their rise in prevalence amongst populations across gender, race, ethnicity, and age. Although some treatments maintain a stronger evidence base and are more effective than others, high rates of long-term recovery outcomes remain elusive. Given the plethora of intrapersonal, interpersonal, and systemic challenges to professional treatment and the shortcomings of interventions once accessed, it is small wonder that eating disordered individuals very frequently seek support, understanding, and information online. Electronic support groups in the form of online eating disorder forums that satisfy those needs have become controversial targets of public criticism as they range from strictly pro-REC, professionally moderated forums to amorphous, un-moderated, pro-ED forums operated by peers.

Despite eating disorder forums' tremendous popularity and their potential to influence users along the continuum of harm to recovery-oriented support, only a handful of studies have examined online eating disorder forums. As such there is an important need for additional research on this web-based communication. Specifically, it is critical for social workers interacting with eating disordered clients to be aware of the information and advice that is directly exchanged and to what extent it affirms or undermines professional treatment. While Eichhorn (2008) and Flynn and Stana (2012) have identified advice giving as one of the primary forms of interaction in online support groups, studies have yet to include a substantial analysis of the advice content (Haas, et al., 2011), its accuracy (Winzelberg, 1997), or its orientation toward maladaptive or healthy ways of being. Furthermore, it is unclear based on existing research how types of advice differs amongst difference types of forums, limiting the extent to which clinicians can inform clients about the risks and/or benefits of different online resources. The role of professionals and other types of moderation can inform future efforts toward the creation of alternative sources of support and interventions that are safe and accessible for eating disorders sufferers.

CHAPTER III

Methodology

This qualitative, exploratory, descriptive study employed a covert, complete observation approach to answer the research question: What do clinical social workers need to know in order to provide guidance to clients about advice giving in online eating disorder forums? This method was appropriate for several reasons. First, given the very limited research available on eating disorder forum communication and the lack of analysis specifically on advice giving, it is more fitting to apply inductive rather than deductive reasoning. Second, the formalized presence of a researcher in this context would significantly influence and likely inhibit the flow and content of anonymous communication amongst eating disorder sufferers. As social workers need to know the advice being exchanged in clients' natural environments, less direct access to this information (e.g. through secondary reports of online advice giving in a focus group) would be less valid, and arguably less clinically helpful.

Sample

As comScore, Inc., identifies Google as the most popular search engine (Lella, 2014), users looking for online eating disorder communities are most likely to use Google in their search. Therefore, in order to identify the largest and most diverse sample, I used Google to conduct three separate searches using three key phrases: "eating disorder forums," "pro eating disorder forums," and "pro recovery eating disorder forums." As each of these searches yielded hundreds of thousands of results, I employed a set of inclusion criteria to ensure the sample's

feasibility and relevance to the research question. First, selected websites had to include a forum, that is, a digital space in which members (otherwise referred to as users or participants) have the capacity to post their own messages as well as view and respond to others' posts. Second, at least one thread within the forum had to be specifically about eating disorders as indicated by the thread title or the initial message that began the thread. Third, the forum had to be functioning and active at the time of data collection. Lastly, the identified forum (and thread) had to be specifically for disordered eating sufferers (as opposed to families, friends, or partners of those with disordered eating behaviors).

I evaluated and selected websites from the top 20 results for each separate search based on the inclusionary criteria and then categorized into three groups: pro-REC (recovery) eating disorder forums provided/facilitated by organizations/professionals, pro-REC forums facilitated by peers, and pro- ED (eating disorder) forums. I then selected two forums with the most participants from each category. Through consultation with the Smith College School for Social Work Human Subjects Review committee, I was able to ensure that the following steps for obtaining permission to access and collect data from forums were in accordance with the Federal Human Subjects Review Guidelines. For forums with posted registration or participation policies relating to research and/or threads accessible only to registered members, I contacted the appropriate representative with the email included in Appendix A describing my study, intentions, ethical considerations, and ethical safeguards to preserve the anonymity of the site and its participants. It was not necessary for me to contact forums whose messages were all in the public domain and who did not have posted policies relating to research or privacy. Obtaining informed consent from all forum participants was not feasible and would have disrupted the natural interactions occurring in online forums. Furthermore, abstaining from

seeking informed consent from subjects who post in publicly available web spaces is consistent with established online communication research (Eichhorn, 2008; Flynn and Stana, 2012; Keski-Rahkonen & Tozzi, 2005; Stommel, 2007; Walstrom, 2000; Winzelberg, 1997). As will be described in more detail, any and all identifying information of users, sites, and forums were disguised to protect the anonymity of participants.

Once permission to access the selected forums was given, I identified and recorded the first 10 messages posted on each website [Sept. 1st], 2014 to [Oct. 31st], 2014 that contained *advice* as defined by Oxford dictionaries as "guidance or recommendations offered with regard to prudent action" (Oxford Dictionaries, n.d.). Advice-giving messages posted before or after the designated month were beyond the scope of this study given the limited resources and only one rater available. Thus, the resulting 60 posts functioned as the units of analysis.

Given the anonymous nature of forum communication, one of the limitations of this method was the impossibility of gathering the demographic information of forum users. While utilizing Google, the most popular search engine, to identify websites increased the likelihood of a diverse sample, it did not, by any means, ensure it. Furthermore, the study was limited to forums conducted in English and the nature of the study automatically limited the sample to participants with the economic and/or geographic capacity to access a computer and the Internet.

Ethics and Safeguards

Anonymity and confidentiality were assured in the study. Data was recorded without any identifying information from each respective forum into a Microsoft Excel spreadsheet where it was organized and coded. Each forum was given an identifier, e.g. PRPeerModerated1, PROrgModerated1, PDPeerModerated1 (i.e. "PR" for pro-recovery, "PD" for pro-disorder).

Forum users whose posts were included as data in the study also remained anonymous and were given identifiers, e.g. PRPmember1, PROmember2, PDPmember3.

Any identifying information that appeared in advice giving posts was excluded or disguised with pseudonyms as the messages were recorded. Therefore, as I collected data, the only location of identifying information remained in the original post on the website. Nonetheless, as an added precaution any Word document or Excel sheet that included data was encrypted with a password that only I, the investigator, knew. No direct quotes were included in the final paper as this could potentially be used to search and identify sites, forums, or users.

Given the safeguards employed to protect participants' anonymity, the study posed no risks to participants. However, as discussed in Chapter II, the naturally occurring content available within forums can pose potential risks to users (e.g. "tips and tricks" for concealing eating disorders from others). As there was no informed consent and my presence in the forums was covert, it was not appropriate for me to provide referral resources to participants which would be disruptive to the supportive environment and, by extension, to the study. On the other hand, users may indirectly benefit from the study while some may benefit from it directly. Site facilitators who requested a copy of this thesis may or may not choose to make it directly available to forum members. Members for whom this is the case and who proceed to read the final report may gain a greater understanding of advice giving on online eating disorder forums and, in turn, use this knowledge to inform how they engage with similar sites. Users who may never encounter this study may still benefit indirectly through their providers, particularly clinical social workers. With the dissemination of this research, professionals and potentially families, peers, and friends of those with disordered eating behaviors will be better able to guide and support sufferers by directing them to accurate, reliable resources.

Data Collection

Methods for data analysis and storage were informed by the U.S. Department's of Health and Human Services Guidelines for Responsible Data Management in Scientific Research (U.S. Department of Health and Human Services, n.d.). I received a letter of approval from the Smith College School for Social Work Human Subjects Review Committee before proceeding with data collection (Appendix B). Using the complete observation method, I was able to collect data as it was naturally occurring in its environment without the limiting influence of an investigator's presence or simulated setting. The data was, however, vulnerable to my subjective interpretation and positionality as an individual who has been personally affected by eating disorders but remains an outsider of online forums. In an effort to increase objectivity and minimize bias, I regularly consulted with my thesis advisor and actively engaged in self-reflection.

As the units of analysis for this study included up to 10 individual advice giving messages for 6 separate eating disorder forums, the data was qualitative. During the designated 1-month period, each forum was regularly monitored. As each new message was posted, I evaluated it for the presence of advice, which typically required me to read previous posts if it was in response to another message in order to understand the context. Those messages that included advice were copied into a Microsoft Excel sheet where I immediately assigned it identifiers for the forum and user as well as removed any identifying information in the content (e.g. geographic location, proper nouns, age). Once I recorded the goal total of 60 messages, I ended data collection and proceeded with analysis. Due to the absence of a published instrument for assessing advice relating to disordered eating, I developed and applied a set of guiding questions and categories to code and analyze collected messages. These questions, which are aimed to asses the dependability of advice, included: 1) What type of advice (instrumental,

informational, or other) is being provided? 2) Is the advice accurate/consistent with evidence-based research? 3) Does the advice promote disordered eating, healthy behaviors, or neither? In the effort to strive for content and construct validity, I collaborated with my thesis advisor to pilot these questions on a sample data.

CHAPTER IV

Findings

Studies on pro-recovery and pro-disorder sites have explored members/creators' identity formation (Giles, 2006; Lyons, Mehl, Pennebaker, 2006; Stommel, 2007), stages of participation (Stommel, 2009), clinical characteristics of users (Darcy & Dooley, 2007), and thematic content/types of communication (Brotsky & Giles, 2006; Eichhorn, 2008; Flynn & Stana, 2012; Gleason, 1995; Johnsen, Rosenvinge, Gammon, 2002; Winzelberg, 1997; Juarascio, Shoaib, & Timko 2010; Keski-Rahkonen & Tozzi, 2005; Kral, Murero, Rice, 2006; Ransom, La Guardia, Woody, Boyd, 2010; Walstrom, 2000; Wesemann & Grunwald, 2008). While Eichhorn (2008) and Flynn and Stana (2012) have identified advice giving as one of the primary forms of interaction in online eating disorder support groups, studies have yet to analyze the content, range, and accuracy of this advice or how such advice in peer-operated forums compares with professional-moderated forums. Thus, this exploratory, qualitative study sought to answer the following research question through content analysis: What do clinical social workers need to know in order to provide guidance to clients about advice giving in online eating disorder forums?

Nine topical categories emerged from the content analysis: cognitive strategy/change, environmental/context change, behavior change, medication/vitamins, getting more information, social support, professional help, support groups, and unclear. For messages containing more than one unit of advice, I coded each unit separately. Consequently, the sum total of coded

advice was 91 units, exceeding the 60 advice messages originally collected. Ten messages were collected from 6 different online eating disorder forums: 2 PROrgOp forums, 2 PRPeerOp forums, and 2 PDPeerOp forums.

As one of the purposes of this study was to ascertain differences amongst various types of forums, I have organized the specific findings according to each of the three identified forum types in the following order: 1) PROrgOp forums, 2) PRPeerOp forums and 3) PDPeerOp forums. I introduce the data with a brief description of the forums' structure, the frequency of advice giving, and any relevant observations or differences between the two forums within that category. Then, I report prevalence of each advice topic in descending order for that same pair of forums. To protect the confidentiality of users, no direct quotes are used. Rather, I have integrated composite examples to illustrate topics and ideas.

PROrgOp Forums

Although both PROrgOp forums were being actively used at the time of data collection, the frequency of advice giving varied greatly between the two. I was easily able to collect 10 advice giving posts within 4 days for one forum. For the other forum, however, I had to expand my sample frame to include October 2014 in order to gather a sufficient number of messages. This appeared to be reflective of the forums' respective overall usage. Compared to the peer-operated forums, neither PROrgOp forum was very popular; each had less than 5000 total messages. Although moderators or site operators generated basic categories for discussion on their main page, members had the power to create their own threads within such categories.

Recommendations to seek out professional help constituted the vast majority of given advice at 36.84% for PROrgOp forums. Users made suggestions such as "talk to your therapist," "see a nutritionist," or "find a residential treatment center." The next most common type of

advice was for behavior change at 18.42% closely followed by cognitive strategy or change at 15.80%. Advice to change one's behavior included statements such as "stop restricting," "don't count calories," "be honest with your provider," or "ask for help." Messages recommending that users use a cognitive strategy or change their way of thinking were suggestions such as "journal about the reasons you want to recover," "reframe the way you think about the situation in a positive way," or "remember why purging does not work." Members advised others to pursue social support (10.53%) and seek out more information (7.89%) at nearly the same rates. Social support messages included advice such as "have a friend go with you to the doctor" or "you should talk to kskn9488 about this," while messages to seek out more information suggested that users "look at the provided links for more information about the risks of bulimia" or "use a search engine to learn more about the starve/binge cycle." Environmental/context change (5.26%) and support group (5.26%) recommendations both occurred minimally. Examples of environmental/context change messages were: "decrease your work hours to reduce stress" or "look for an office with cheaper rent to save money." There was no advice that was unclear or addressed the topics of medications or vitamins.

PRPeerOp Forums

The PRPeerOp forums were more actively used than the PROrgOp forums, with 10 advice messages being collected within just 5 days for one of the forums. While the other forum's advice messages were collected from a span of 26 days, the structure of the forum was so expansive that it was difficult to ensure that I was not missing advice messages in other threads. Both forums had an extensive history of use with hundreds of thousands of posts, significantly more than PROrgOp forums.

Overall, there was less variety regarding advice topics compared to the PROrgOp forums. Of the 25 identified advice units, the majority addressed behavior changes at 40.00%, such as "choose recovery," "eat regularly," "get more sleep," "take vitamins." The second most common type of advice involved cognitive strategies/changes at 24.00%, such as "use rational counterstatements if you're afraid of the scale," "remember the deadly consequences of not eating," and "see the positive in the situation." Medication/vitamins (16.00%) and professional help (16.00%) were equally common. The former included statements such as "use Nature Made for your vitamins," "Nexium works for acid reflux," while the latter suggested options like "see your doctor about that gastrointestinal problem" or "find a higher level of care". There was no advice in the PRPeerOp forums that recommended environmental/context changes, getting more information, or additional social support. There were no unclear advice units.

PDPeerOp Forums

The two PDPeerOp forums used for data collection were different in structure. One was organized similarly to the forums in other categories with a list of topics or threads in response to which others could post comments. It also had over a million posts, more than any other forum used for this study. The other was a space in which users posted messages more like journal entries and were less likely to solicit advice. Nonetheless, other users would respond with comments and recommendations. For the first forum, users provided advice rapidly and I collected ten messages in the span of just two days. On the other hand, advice messages for the second forum were collected over the course of 20 days and one could not tell how many total messages have been shared over time.

Like the PRPeerOp forums, advice in pro-disorder forums most commonly included behavioral changes (44.83%) such as "recover," "drink a lot of water," "don't have sugary

foods," "don't exercise on an empty stomach," or "just get coffee." Cognitive strategies/changes (27.59%) were the second most common type of advice and included messages such as "think of all the implications before you tell someone about your eating disorder," "stop pressuring yourself to exercise so much," or "focus on what is beautiful about yourself." Professional help (10.34%) and social support (6.90%) made up a comparatively small proportion of advice messages, such as "talk to your therapist," "get a doctor's note to play sports," and "tell your boyfriend about your disorder." While the environmental/context change (e.g. "stay in school"), getting more information (e.g. "research EDNOS"), and unclear categories were composed of just one advice unit (3.45%) each. There were no recommendations regarding medications/vitamins or support groups.

Summary

Based on this study's findings, social workers should know that users of eating disorder forums are likely to encounter a range of advice that typically addresses the following topics: cognitive strategy/change, environmental/context change, behavior change, medication/vitamins, getting more information, social support, professional help, and support groups. Occasionally, advice is unclear, in which case users are left confused or open to generate their own interpretations. Recommendations for behavioral change (32.97%), the involvement of professional help (23.08%), and cognitive strategies or change (23.08%) comprised the vast majority of advice across all forums. However, users are more likely to encounter particular topics based on the type of forum they use. In PROrgOp forums, they are most likely to be advised to seek professional help. In pro-recovery and PDPeerOp forums, however, users are most likely to view suggestions to change their behaviors. The following chapter provides tentative interpretations of the data in the context of existing literature and expounds the

implications of these findings, including the possible risks and benefits of advice that varies in its

perceivable aims.

CHAPTER V

Discussion

This exploratory, qualitative study made some modest strides toward answering the following research question: What do clinical social workers need to know in order to provide guidance to clients about advice giving in online eating disorder forums? In the limited research available regarding online eating disorder websites, the attention has primarily focused on pro-disorder sites and their potential harmful effects. There have also been a number of studies broadly identifying themes and the types of communication exchanged on eating disorder forums, but without specific attention to advice giving or observable differences amongst forum types (i.e. pro-disorder forums, pro-recovery forums, professional-operated forums, peer-operated forums). The results of this study confirmed, as Eichhorn (2008) and Flynn and Stana (2012) found, that advice giving remains as one of the most popular forms of interaction in online eating disorder forums. The findings also furthered existing research by distinguishing between different kinds of advice and how advice giving varies across different forum types. Thus, clinical social workers may now better understand the types of information their eating disordered clients are likely to encounter on particular forums. The information contained in this study may also increase clinical social workers' ability to provide educated caveats about online forums to eating disordered clients, who are generally very likely to use them.

In this chapter, I will contextualize the study's findings by forum type using the research discussed in Chapter II. Discussion for each forum type will follow the same order as in Chapter

IV: 1) pro-recovery, professional/organization-operated (PROrgOp) forums, 2) pro-recovery, peer-operated (PRPeerOp) forums, and 3) pro-disorder, peer-operated (PDPeerOp) forums. Then, I will elaborate on the study's implications for social work practice and policy. A discussion of the study's strengths and limitations will follow. Finally, the chapter will conclude with recommendations for further research.

PROrgOp Forums

The lack of existing research on PROrgOp eating disorder forums and websites highlighted the need to include this type of forum in this study. There are several possible explanations for the focus on pro-ED sites. First, the controversial nature of pro-ED sites, their popularity, and their easily observed potential for harm compel investigative attention. By comparison, PROrgOp forums are minimally used and may be perceived as low-impact sources of support and information. Given their professional oversight, it is likely assumed that such forums are generally helpful to users or at least harmless. As such, PROrgOp websites and forums may be perceived as less important to study although organizations may conduct their own internal investigations.

It is intuitive that recommendations to seek out professional help were found to be the most popular type of advice on PROrgOp forums. The earlier professional intervention takes place, the greater the chance individuals have for recovery. The second and third most popular types of advice, recommendations for behavior and cognitive strategies and changes, are also consistent with the literature; meta-analytic reviews of eating disorder treatment studies indicate that CBT is the most highly recommended methodology for eating disorders and has the strongest evidence-base (Crow & Petersen, 2009; National Collaborating Centre for Mental Health, 2004).

The authors of several studies of PRPeerOp forums have suggested the need for professional moderation of eating disorder forums to monitor pro-disorder content (Flynn & Stana, 2012; Gleason, 1995). Indeed, all of the advice giving messages collected from PROrgOp forums unquestionably promoted recovery, a position most frequently and obviously expressed through advice encouraging users to seek professional support. The information in these advice messages, which often provided rationale for the guidance provided, was also consistent overall with eating disorder research. Only three comments had debatable content. Two oversimplified the connection between doctors' recommendations for patients to lose weight (by decreasing food intake and increasing exercise) and binging. Another comment defined eating disorders as symptoms of underlying problems, which is one way of conceptualizing eating disorders but not necessarily one that has achieved widespread professional consensus as a governing theory. Additional resources would be needed to undertake further research on this particular topic.

Nonetheless, the findings in this study suggest that PROrgOp forums overall offer treatment-focused, evidence-based advice embedded in accurate psychoeducation about eating disorders. While this may excite clinical social workers as a viable source of online, anonymous support for eating disorder sufferers, it may also explain why this category of forums is so little used compared to other forum types. Users who are very ambivalent about recovery or opposed to treatment may be unlikely to visit professional websites before visiting other types of peer-operated forums.

PRPeerOp Forums

Like PROrgOp forums, PRPeerOp forums are in the minority compared to pro-disorder forums and have attracted less scholarly attention (Chelsey, et al., 2003). The findings in this study support and challenge the limited existing research in this area.

As Wesemann and Grunwald (2008) observed in a German pro-recovery, un-moderated forum, problem-focused threads were numerous amongst the PRPeerOp forums used in this study. As the authors did not note, problem-focused messages also led to a plethora of solicited and unsolicited advice messages. The prevalence of advice found in this study does, however, correspond with Eichhorn's (2008) and Flynn and Stana's (2012) findings from their respective discourse analyses on PRPeerOp forums; "informational support," or advice, was identified as the most frequent type of communication exchanged in both women's and men's eating disorder forums (Eichhorn, 2008, p. 69). For the two PRPeerOp forums in this study, 10 advice messages were easily collected within the 30-day time frame.

With so much advice being exchanged, Flynn and Stana (2012) expressed concern about the possibility of inadvertent advice being shared and/or followed. Eichhorn (2008) further cited examples of advice with ambiguous aims and several other studies of PRPeerOp forums have also noted the contradictory presence of pro-disorder content (Johnsen, Rosenvinge, & Gammon, 2002; Ransom, 2010; Wesemann & Grunwald, 2008). However, this study's findings indicate that the negative enabling aspects of the "destructive dimension" of PRPeerOp forums may occur to a lesser extent than previously suggested (Johnsen, Rosenvinge, & Gammon, 2002, p. 445; Ransom, 2010; Wesemann & Grunwald, 2008). Of the 25 advice units collected, two sought to minimize harm through vitamin and supplement recommendations, but did not necessarily endorse recovery. Two other advice units had ambiguous aims, leaving 21 advice units or 84% of the advice content unambiguously pro-REC.

The presence of some, though minimal pro-ED content in the PRPeerOp forums suggests, as Ransom (2010) does in her study on the information and support exchanged in one eating disorder forum, that the supervision and mission of the forum play an important role in forums'

challenges and therapeutic value. Indeed, the forum studied by Johnsen, Rosenvinge, and

Gammon (2002) was closed for pro-ED content like many PDPeerOp forums and then reopened

with the supervision of two professionals specializing in eating disorders. Flynn and Stana

(2012) and Gleason (1995) also argue explicitly for the need of professionals to moderate

forums. The PRPeerOp forums in this study, however, were highly moderated and appeared to

have systematized the use of usernames and/or taglines; similar to the way Stommel (2007)

observed that German users' nicknames tended to reflect their stage of recovery, the PRPeerOp

forums in this study had specific names that indicated their level of experience in the forum.

Such a system could theoretically enable users to make somewhat informed judgments about the

viability of members' posts and advice.

Very little commentary has been published on advice content in eating disorder forums.

Chelsey, et al. (2003) found that pro-REC site users, unlike pro-ED site users, "overwhelmingly

presented introspective first person viewpoints on AN and had little nutritional advice" (p. 124).

Indeed, only 16.00% of advice units (4 units) contained nutrition related information in the

PRPeerOp forums. However, PDPeerOp forums only exceeded PRPeerOp forums slightly, with

17.24% (5 units) of advice units containing nutritional recommendations.

Though highly moderated and oriented toward health like PROrgOp forums, PRPeerOp

forums may have an advantage when it comes to reaching eating disordered users. Their

significant popularity compared to PROrgOp forums suggests that users may feel more

comfortable in online peer communities. Unlike PROrgOp forums, PRPeerOp forums' most

common types of advice were behavioral changes and cognitive strategies followed by

professional help. One could speculate that users may anticipate simply being told to see a

professional in PROrgOp forums. If so, a user would be more likely to enter a virtual setting in

which she expects to receive practical advice without feeling pressured to engage in treatment until she is ready.

PDPeerOp Forums

PDPeerOp forums remain alive and well despite ample public criticism which has led many hosts to shut down pro-ED sites (Ryan, 2012). The difficulty I encountered while searching for PDPeerOp forums was likely due to the limited search I conducted rather than a lack of subjects, for the popularity and usage of one PDPeerOp forum used in this study greatly exceeded the PROrgOp and PRPeerOp forums with well over several million posts. This was reflected in the rapid provision of advice; for one PDPeerOp forum, I was able to collect 10 advice units in the span of just two days. Why are PDPeerOp forums so highly utilized in light of general condemnation from the public? Women and men face a double-edged sword in Western culture; the media present extreme standards of thinness and fitness (most often through Photoshop editing), but denounce those who use extreme measures to achieve those standards. Although, celebrities suspected to have eating disorders still attract a kind of glorified fame which may add to the attractiveness of eating disorders, particularly for youth. As previously noted, Peebles, et al. (2012) found that additional motives to turn to anonymous, online resources include: lack of outside social support; stress; depression; feeling like family, friends, and/or providers did not understand or empathize with them; and feeling alone. For users seeking understanding and empathy but not yet recommendations for treatment, PDPeerOp forums present a more appealing source of support than PRPeerOp or PROrgOp forums.

This study's findings on advice messages support Brotsky and Giles' (2007) observation that the pro-ana community lacks a consistent standpoint on eating disorders. Although multiple other studies have observed that anorexia is often presented as a lifestyle choice on pro-ED

websites (Dias, 2003; Giles, 2006; Haas, et al., 2011; Lipczynka, 2007), the aims and views presented in advice giving messages within the two forums used for this study greatly varied. In fact, there were no pro-ED advice messages in the first PDPeeOrg forum. In line with Yeshua-Katz and Martins' (2012) study which found only 3 of the 33 pro-ana bloggers who described their eating disorder as a lifestyle, the majority of advice provided in the first forum unequivocally promoted recovery while one message promoted health and/or harm reduction and two messages had ambiguous aims.

The second PDPeerOp forum was more consistent with existing literature, which includes the finding that 96% of pro-ED site users along with 46.4% of pro-recovery site visitors learned new weight loss or purging skills (Wilson, et al., 2006). Most advice messages presented ambiguous aims in the second PDPeerOp forum (e.g. cognitive strategies that could be for moving beyond disordered thoughts or coping with them in order to maintain behaviors). An even number of the remaining messages promoted disordered thoughts/behaviors (e.g. tips for restricting around others) or promoted health but not necessarily recovery (e.g. affirming the removal of triggers for self-deprecating thoughts).

In their exploratory study of communication strategies in pro-ana online forums, blogs, and personal webpages, Haas, et al. (2011) identified "advising ana" as a major theme (p. 49). Advice only broke down into two categories: dieting concerns and managing social situations with "non-ana's" (Haas, et al., 2011, p. 49). However, the findings of this study indicate that there is more variety amongst advice giving messages in PDPeerOp forums; only 27.59% of the 29 advice units included content from Haas, et al.'s (2011) categories, including 2 posts with dieting suggestions and 6 posts with recommendations for dealing with "non-ana's" (e.g. going out to eat with a family member). Like PRPeerOp forums, the most common type of advice in

PDPeerOp both forums was behavioral change followed by cognitive changes/strategies, and professional help. As one might expect in PDPeerOp forums where users are less inclined to involve professionals, the first two categories were greater than in the PRPeerOp forums while recommendations for professional help were less frequent at only 10.34%.

Considering users' general youthfulness and the cognitive distortions that typically accompany disordered eating behaviors, one might expect a significant presence of inaccurate information on PDPeerOp forums. However, only two messages between both of the pro-ED forums contained questionable information; one suggested that you cannot begin recovery if you have any ambivalence about it while the other provided the number of calories for a particular serving of food that could, in reality, greatly vary.

Summary

In sum, this study contributed novel findings on advice giving in PROrgOp forums as well as supported and contradicted some aspects of existing research on PRPeerOp and PDPeerOp eating disorder forums. For the first time, it also compared the structure and advice giving of different types of forums, allowing me to observe that the popularity of eating disorder forums appears inversely related to the frequency of recommendations for professional help. This suggests that the majority of online eating disorder forum users are not yet prepared to hear treatment-focused advice and anticipate that this is the response they will receive when entering a PROrgOp forum. Hence, PRPeerOp and PDPeerOp forums highly utilized anonymous spaces in which users are more likely to encounter advice for cognitive and behavioral strategies they can implement themselves. In PRPeerOp forums, users have the opportunity to receive recovery-focused support and peer understanding without overwhelming pressure to engage in treatment. Though they lack professional input, these forums offer labels for moderators and users that

indicate their level of experience. Notably, depending on the PDPeerOp forum users access, they may be just as likely to receive recovery advice as in PRPeerOp or PROrgOp forums. In other PDPeerOp forums, however, they may primarily encounter advice including the "tips and tricks" commonly referred to in existing studies on online pro-ana communities.

Implications for Social Work Practice

Given that a high percentage of clients with eating disorders turn to online sources of support and information (Wilson, et al., 2006), it is important that clinical social workers be informed of users' motivations for joining online forums and the information they are likely to encounter there. Users encounter a range of advice depending on which type of forum they access. Although they are more likely than not to view advice with recovery and/or harm-reduction content with accurate information based on the forums included in this study, this could greatly vary from forum to forum. As pro-REC forum operators often note in their disclaimers, forums are not a substitute for professional treatment. However, clinical social workers can use this study's findings to have more informed, frank conversations with eating disordered clients about forums. If clients disclose that they have used or are using an online eating disorder forum, the therapist can have an idea of the kind of advice clients have viewed or received, guiding the therapist's further questioning and positioning her to more effectively counter pro-ED material and/or inaccurate information.

It is important that professionals and others in affected individuals' lives be informed and supported in intervening and educating their clients and loved ones. Critical analysis of online eating disorder forums, how they function for eating disordered clients, and how to address clients' use of them in treatment should be included in professional training for social workers who treat clients with eating disorders. Social work interns are also likely to need additional

supervision regarding the issues of online eating disorder forums, in which cases supervisors must also be prepared to have these conversations with students. Through professional development and family psychoeducational materials (e.g. through schools, primary care doctors' offices, treatment facilities), school staff and parents should be made aware of online eating disorder forums and their potential risks and benefits so that they can further support those with disordered eating behaviors in making healthy decisions for themselves regarding how or if they should utilize such resources.

The more frequent use of PRPeerOp and PDPeerOp forums imply the importance of anonymity, acceptance, and peer support to those suffering with eating disorders. The type(s) of forums clients are using may reflect their stage of change and current needs that are being left unmet, such as in treatment or in personal relationships. Therapists may then be able to make alternative suggestions for additional support. From a harm-reduction perspective, a therapist may choose to inform a client about the options of using specific PROrgOp or PRPeerOp forums instead of PDPeerOp forums, which pose greater risks. In this highly digital age, the option of getting 24/7 support through online forums may be very compelling for users, leaving eating disorder treatment providers with several questions: How can we make live, safe, anonymous support more accessible to clients? Is there a way that peers can be utilized beyond traditional in-person support groups considering the low recommendations for social support found in each forum type? How can we publicize and debunk popular types of ineffective, harmful eating-related advice? I will discuss the need for additional research to answer these questions and further explore disordered eating on the Internet in the final section of this paper.

Implications for Policy

  Policies that would mandate censorship of the Internet are unlikely to be supported or effective. However, public policy that could garner funds to increase public awareness about healthy eating and exercise behaviors particularly amongst youth could have a significant impact. Increased education and open discussion of eating disorders can begin to address the pervasive stigma that contributes so strongly to users' desire for anonymity. Given the near constant exposure of youth and people in general to thin-/fitness-obsessed messages in the media, a much greater effort must be invested in the promotion of positive body image and healthy eating and exercise behaviors. The stigmatization of eating disorders further isolates sufferers and encourages the pursuit of anonymous support, that is, the need for online eating disorder forums in the first place. This suggests, as eating disorder activist groups have argued, that prevention is an essential and underutilized intervention.

  The Eating Disorders Coalition (EDC) has been instrumental in advocating for eating disorder prevention programs on the federal level, although none of these bills have yet been passed. Amongst other initiatives, the Eating Disorders Awareness, Prevention, and Education Act of 2011 calls for increased awareness of eating disorders amongst parents and students as well as training for educators about prevention methods (EDC, n.d.). Another unsuccessful bill, the Promoting Healthy Eating Behaviors in Youth Act of 2002, would also provide funding for programs promoting healthy eating behaviors in youth (EDC, n.d.). Effective programming necessitates expansive, high quality research, and so the EDC has extensively advocated for the FREED Act (Federal Response to Eliminate Eating Disorders), a comprehensive bill that addresses and demands funding for treatment, education, prevention, and research (EDC, n.d.). The Truth in Advertising Act of 2014 would further require a regulatory framework through the

Federal Trade Commission for advertising that involves post-production editing techniques that drastically change the appearance (including the thinness) of the photographed people (EDC, n.d.). Such a bill could begin to address a major contributing factor to poor body image and unrealistic expectations for one's appearance, particularly amongst youth. Meanwhile, school-based workshops designed to actively develop a positive appreciation for and acceptance of one's body as early as elementary school could play a critical role in combatting environmental forces.

Strengths and Limitations

There are several strengths and limitations to this study. One of this study's strengths is its success in expanding the very limited existing knowledge about types of advice in online eating disorder forums. To my knowledge, it is also the first study to compare the content of different types of eating disorder forums. Given time and financial restrictions, however, I was only able to collect a very limited number of advice messages from each forum. The ten messages from each forum collected within a span of just 1-2 months are not necessarily representative of the advice generally exchanged within their respective forums. Furthermore, sufficient resources were not available to triangulate the data. Thus, my coding and categorizing of advice units, though reviewed by my thesis advisor, remained susceptible to my personal bias. My positionality as a white, middle class social work graduate student at a psychodynamic-focused institution will have certainly shaded, to some degree, my interpretation of the data as well as my methodological approach. Furthermore, my capacity to maintain objectivity will have been complicated by my strong motivation to engage in this specific area of research to supplement my social work education as well as deepen my understanding of the ways eating disorders have affected those in my personal life and could have been better treated and

prevented. Ideally, at least three more raters and a small team of researchers of diverse identities and backgrounds would have participated in the research process.

Recommendations for Future Research

There are numerous opportunities for future research in this area of study. With additional resources, I would have been able to increase the generalizability of this study's findings by including at least five forums from each category and collecting all advice messages posted over a period of 6 months. As the sole data analyst and coder, I also would have improved the reliability of the study's findings by having a team of at least five researchers collaboratively analyzing and coding the data. Although this study contributed to the pool of knowledge on advice giving in online eating disorder forums, we do not know forum users' responses to such advice. Nor do we really understand the roles and impact of moderators, who have such potential for shaping forums and influencing users' experience and exposure to information. Additional research in these areas is needed to better illuminate how eating disorder treatment providers and eating disorder organizations can create or promote health-oriented, peer supportive online services for eating disorder sufferers.

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Appendix A

Letter of Request for Permission to Access Forums and Collect Data

[Date]

Dear [name of organization/representative responsible for identified website/forum],

My name is Elizabeth Reali and I am a MSW candidate at the Smith College School for Social Work in Northampton, MA. I am contacting you to request your permission to access [name of forum] for research purposes. For my masters level thesis, *Advice Giving in Online Eating Disorder Forums: What Clinical Social Workers Need to Know*, I am conducting a modest study to increase clinical social workers' knowledge of online resources commonly used by those with disordered eating behaviors. Although the most prevalent form of support found on online eating disorder support groups is advice, we have not yet learned the range or reliability of this particular communication. Thus, participants' risk in participating in different types of forums is largely unknown. Demystifying this function of eating disorder forums will help clinicians make informed recommendations to clients regarding safe and accurate sources of information and support.

To be clear, my ethical responsibilities as a clinical social work student and the wellbeing of forum participants are of utmost importance. Therefore, although I would have to create a member account to view forum communication, I would not at any point post any messages or contact other users in any way. In the collection of data, which would entail the transcription of any message containing advice posted within a designated one month period, all identifying information would be disguised with pseudonyms (e.g. member1, facilitator2, OrgForum1) or excluded, including the name of the website/forum, participant usernames, pictures, and any personally identifying information in individual messages. No direct quotes would be included in the final paper, which will be completed by July 1, 2015 and made available to you upon request.

Available online support options related to eating disorders range from highly moderated, professional-facilitated forums to largely un-moderated, peer-facilitated forums and I hypothesize that forums funded and facilitated by established eating disorder recovery organizations are more reliable for users. Please support me in my efforts to demonstrate this for the health and safety of those with disordered eating behaviors. I am happy to discuss any additional questions or concerns and may be reached at ereali@smith.edu or XXX-XXX-XXXX.

Sincerely,

Elizabeth Reali, MSW Candidate
Smith College School for Social Work

Appendix B

Smith College School for Social Work Human Subjects Review Committee Letter of Approval

SMITH COLLEGE

School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950   F (413) 585-7994

December 9, 2014

Elizabeth Reali

Dear Liz,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Jean LaTerz, Research Advisor