

# "Hunger Hurts but Starving Works:" Characterizing the Presentation of Eating Disorders Online

Jessica A. Pater

Georgia Institute of  
Technology  
Atlanta, GA  
pater@gatech.edu

Oliver L. Haimson

University of  
California, Irvine  
Irvine, CA  
ohaimson@uci.edu

Nazanin Andalibi

Drexel University  
Philadelphia, PA  
naz@drexel.edu

Elizabeth D. Mynatt

Georgia Institute of  
Technology  
Atlanta, GA  
mynatt@cc.gatech.edu

## ABSTRACT

Within the CSCW community, little has been done to systematically analyze online eating disorder (ED) user generated content. In this paper, we present the results of a cross-platform content analysis of ED-related posts. We analyze the way that hashtags are used in ad-hoc ED-focused networks and present a comprehensive corpus of ED-terminology that frequently accompanies ED activities online. We provide exemplars of the types of ED-related content found online. Through this characterization of activities, we draw attention to the increasingly important role that these platforms play and how they are used and misappropriated for negative health purposes. We also outline specific challenges associated with researching these types of networks online. CAUTION: This paper includes media that could potentially be a trigger to those dealing with an eating disorder or with other self-injury illnesses. Please use caution when reading, printing, or disseminating this paper.

## Author Keywords

Anorexia nervosa; bulimia nervosa; eating disorder; ED; self-injury; self-harm; social media; online communities; content analysis; EDNOS; OSFED; behavioral health; social networking; Twitter; Tumblr; Instagram

## ACM Classification Keywords

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## INTRODUCTION

Eating disorders are not a new phenomenon. One of the earliest documented Western cases was in the late 1370's. It was reported Saint Catherine of Siena was accustomed to rigorous nutritional abstinence, confessing she was unable to eat due to an 'illness' that would not let her consume food, with the exception of her daily Holy Communion [37]. Eating disorders, while once viewed as an undesirable

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behavior or behaviors associated with religious rite and rituals, are now seen as treatable medical illnesses, most commonly expressed as Anorexia Nervosa or Bulimia Nervosa [58]. Both of these diseases, as well as eating disorders not otherwise specified (EDNOS), are characterized by a clinically unhealthy relationship to food, which manifests in a variety of behaviors and activities.

It is estimated that between 10 million [61] and 20 million [52] people suffer from a clinically significant eating disorder in the United States. Despite the commonality of these health issues, eating disorders continue to be ignored and overlooked at the state and national levels [59]. Healthcare professionals and politicians have begun to recognize the impact of eating disorders on the populace as a growing public health threat [59]. Anorexia has the highest mortality rate of any psychiatric disorder [2]. A woman 15-24 years old with anorexia is 12 times more likely to die than a women without anorexia, and the frequency of suicide is 75 times greater than a young woman without an eating disorder [49].

Marginalized communities and those with lifestyles that are not mainstream, and commonly labeled "alternative," have often found refuge online [21,31,53]. The CSCW community has a long and rich history of examining online spaces that support niche or marginalized communities [15,30,55]. As early as 2001, popular news outlets began reporting on the presence of the alternative communities of anorexic people online [41]. With increasing access to new media platforms, individuals with eating disorders no longer needed to meet up with other individuals with ED through clinics and at hospitals, but instead were able to establish and support thriving pro- <insert eating disorder or issue of choice> communities online [3]. Given the preponderance of coordinated, online activity, in this work we attempt to analyze the cooperative and computer-mediated activities taking place within this population. While this online activity is sometimes described as "communities [40]," we take a more conservative stance and characterize collections of user content as "networks" within and across media platforms [22,35].

In this paper we explore the dynamic relationships between eating disorder (ED) networks within multiple social media platforms. We present the results of a cross-platform

content analysis of eating disorder-related posts and characterize these activities based on associated hashtags and media. To achieve these goals, we focus on several key questions: 1) How is ED content organized within social media platforms 2) How do ED posters represent themselves in different online spaces and what, if any, similarities exist across platforms and 3) While this analysis is based on the presentation of eating disorders, what other health issues are self-disclosed in conjunction with ED?

Our work makes several contributions to the CSCW community:

1. We create a platform-independent corpus of terminology commonly used within ED networks.
2. We contextualize the presence of ED presentations online through a multi-platform content analysis of publicly posted content.
3. We highlight the co-occurrence of other behavioral, mental and emotional issues found in conjunction with presentations of ED online.
4. We articulate several challenges associated with this research domain.

**CAUTION:** This paper includes media that could potentially be a trigger to those dealing with an eating disorder or with other self-injury illnesses. Please use caution when reading, printing, or disseminating this paper

## RELATED WORK

### Eating Disorders

Eating disorders are a group of psychiatric disorders where a patient becomes obsessed with food intake, weight, and perceived body image (both internal and external) [56]. While Anorexia Nervosa and Bulimia Nervosa are the two of the most popularly known eating disorders, they are not the most common ED-related illnesses – the most common is “eating disorders not otherwise specified” or EDNOS [48] which was recently reclassified as OSFED or Other Specified Feeding and Eating Disorders [60]. Regardless of classification, all eating disorders are defined by three key characteristics [17,60]:

1. A disturbance of eating habits or weight-control behaviors
2. A clinically significant impairment of physical health or psychosocial functioning
3. The behavioral disturbance is not secondary to any general medical disorder or to any other psychiatric condition

The motivations driving these behaviors are often complex to unpack – yet at its core, they focus on individuals who view nutrition and the process of eating as a mechanism to solve or camouflage problems that seem insurmountable or insoluble [7] or a way of dealing with levels of self-worth [62]. While these diseases share commonalities, they also have distinguishing characteristics specific to the individual illnesses. Below we briefly describe the three classifications

of eating disorders – Anorexia Nervosa, Bulimia Nervosa, and EDNOS – and detail their defining characteristics.

### Anorexia Nervosa

Anorexia Nervosa has four essential diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM) [60]:

1. Refusal to maintain body weight over minimum expected for age and height
2. Intense fear of gaining weight
3. Disturbance in the experience of body weight and shape, undue influence of weight and shape on self-evaluation, or denial of seriousness of low body weight
4. Amenorrhea (irregular menstruation cycles)

### Bulimia Nervosa

Bulimia Nervosa also has four essential diagnostic criteria outlined in the DSM [60]:

1. Recurrent episodes of binge eating and an awareness of loss of control during the binging
2. Recurrent inappropriate compensatory behavior to prevent weight gain (e.g., self-induced vomiting, laxatives, excessive exercise or fasting)
3. Self evaluation unduly influenced by body shape and weight
4. Binge-eating and compensatory behaviors occurring twice a week for three months

### OSFED – The New EDNOS

Under the new edition of the DSM, EDNOS was changed to OSFED as mentioned earlier. For the purpose of this paper we used EDNOS, the more commonly used term in the mainstream ED-related vocabulary. EDNOS is a category of eating disorders that does not meet criteria for either Anorexia or Bulimia. OSFED has six criteria outlined in the DSM [60]:

1. For females, all criteria for Anorexia Nervosa are met except that the individual has a regular menstruation cycle
2. All the criteria for Anorexia Nervosa are met except that, despite significant weight loss, the individual’s current weight is in the normal range.
3. All the criteria for Bulimia Nervosa are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for a duration of less than 3 months.
4. The regular use of inappropriate compensatory behavior by an individual of normal body weight after eating small amounts of food (e.g., self-induced vomiting after eating small amounts of food)
5. Repeatedly chewing and spitting out, but not swallowing, large amounts of food.
6. Binge-eating disorder: recurrent episodes of binge eating not characteristically typified in Bulimia Nervosa.

OSFED should not be perceived as a less serious or less severe eating disorder. On the contrary, the only reason

there is delineation between OSFED and Anorexia or Bulimia is based on the presentation seen with the eating disorder [48]. The classifications have nothing to do with severity or potential impacts of the illness on the individual.

### **Eating Disorders Online**

Individuals grappling with behaviors and activities outlined above utilize the Internet to connect and collaborate in the sharing of best practices [20], sharing inspirational media known to the network as *thinspiration* [18], and connecting with others to support their activities in a non-judgmental manner [3]. Interactions on these platforms encourage the sharing of knowledge, attitudes, and behaviors for the disorder with the broader network to amplify the destructive impact they have on themselves [4,18]. These networks can utilize different technologies including bulletin boards, static websites, blogs, groups on social network sites, email listservs [3], or more recently through hashtags within social media platforms as an informal, ad-hoc network [8]. While a majority of literature classifies these groups of individuals as *communities*, we will refer to them as *networks* or *support networks* as to not conflate these groups with the CSCW definitions of community. We use the term *support networks* not as a traditional support group seeking health, but a network supporting the actions associated with the disease

Support networks that support eating disorder activities and behaviors construct social norms and customary patterns that govern the group members' activities and perceptions of reality as reflected through the collective voice [11]. Fleming et al. describe their analysis of these groups through socially constructed approaches [18]. This perspective allows a focus on the exchanging of knowledge and practice through collaborative dialogue [51]. This constructivist approach to identity and network formation is critical in understanding how such a decentralized and fluid community maintains norms and a sense of presence in spite of hurdles like community censorship and decentralization across multiple platforms.

### **Social Support**

One of the most seductive charms of these groups that sustain and perpetuate eating disorders, especially those online, are the support mechanisms put in place that sustain existing members while attracting new ones. Social support theory offers a theoretical lens that is useful in understanding ED networks. The theory posits that influencers in an individual's life can provide positive social encounters and discussions that will result in changes in behavior [13]. In typical social health literature, this support is positive in nature and focused on using peer support through parents, teachers, or friends [32] to encourage behavior change that is both positive and sustained.

A contrast arises between social support's expected outcome in traditional contexts – positive impact on an individual's ability to cope with stress [13] – and its role in

ED networks. For someone with an eating disorder, not being in complete control of caloric intake and management is a primary source of stress [14]. Social support within the lens of an eating disorder network or group means trying to inspire yourself and others to be the “best anorexic” or “best bulimic” person you can be [42].

### **Self-Presentation**

Online spaces allow people suffering from various issues such as depression [44], sexual abuse [34], and eating disorders [54] the ability to self-disclose aspects of personal identity or behaviors associated with issues while at the same time seeking support for them. For example, participants of suicide-focused Internet forums often situate their participation as not just a “cry for help” but as part of their identity [24]. Online forums allow these identities to be tried out, expressed, and validated [24]. To engender what they hope is seen as an authentic self-presentation, participants often consider audiences when constructing their narratives about depression and how and when it started [27,28]. The use of these online forums for sharing has also been viewed as a type of identity performance; for example, in the context of self-harm, the self-harmed body becomes a site of intersecting discourses [45].

These presentations often take place in online spaces not specifically dedicated nor designed for such sensitive disclosures. Andalibi et al. looked into depression-related images and captions on Instagram and found that people often disclose personal narratives and stories, negative affect, and self-appearance concerns, and seek social contact [1]. In the context of expressions of loneliness, Kirvan-Swaine et al. found that Twitter expressions of loneliness included temporal bounding of loneliness (enduring vs. transient), the inclusion of context (social, physical, romantic, and/or somatic), and explicit interactivity within the expression (e.g. requesting engagement) [26].

### **PROJECT GOALS**

The goal of this project is to understand the various presentations of eating disorders across several popular social media platforms. While people do not fully exhibit the entire range of their ED-related activities through their online presentation, the insights obtained by analyzing the activities and behaviors that are shared on social media provide a rich contextualization and understanding into an often-overlooked population.

### **METHODS**

In this study, we chose to investigate ED activities within the popular social media platforms Twitter, Instagram, and Tumblr. These sites were chosen based on their pervasive use within the 13-24 age demographic [39]. To achieve our research objective of characterizing ED support networks online, we first did an investigative search across platforms to establish an ED-based dictionary of terms. We then collected posts and established a codebook for both the hashtags associated with the posts as well as a codebook for

the embedded media. Image 1 highlights a typical artifact that we collected. Each post included a combination of a piece of media (video, image, gif), post text, and hashtags.

### Development of the Dictionary

To begin, we researched the terminology associated with #bonespiration #thinspo #thinspiration #goals #ednos #chest #legs #gap #ribs #anamia



**Image 1. Exemplar post from dataset**

general eating disorders and, more specifically, with Anorexia and Bulimia. Based on a review of the literature [46] and popular online eating disorder forums, we established an initial set of search terms,  $T_i$  (see Table 1).

Using the  $T_i$  corpus, we conducted an initial search of 50 posts for each term on Twitter, Tumblr, and Instagram – the platforms analyzed for this study – yielding a dataset of 800 posts. This dataset had fewer posts than anticipated for several reasons. The hashtag convention within ED communities does not use hyphens, thus we removed “proana” and “pro-mia” from use. In addition, Instagram has blocked the terms “proana” and “promia” from use. The hashtag “proED” was also removed due to a lack of use by ED support networks – this hashtag is widely used by the higher education community. Because of these limitations, we collected no data on the “proed,” “pro-anas,” and “promias” tags nor did we collect data from Instagram using the “proana” or “promia” tags.

Using this set of 800 posts, we identified the most relevant

	Search Terms
Initial Search Terms $T_i$	anorexia, proana, pro-ana, bulimia, promia, pro-mia, eating disorder, proED
Refined Search Terms $T_r$	anorexia, proana, bulimia, promia, eating disorder, anamia, proanamia, EDNOS, thinspo, thinspiration, thinspo***, thinsperation*

\* Due to the filtering used by Instagram, these terms were used in the final search.

**Table 1. Initial search terms ( $T_i$ ) and refined search terms ( $T_r$ ).**

search terms for each site and then compared across

platforms. Because each platform has different policies and technical affordances, conducting a one-to-one comparison would not be a truly fair representation of the prevalence of the hashtags within that platform. Several terms were added to the initial corpus based on this analysis (See Table 1) to create our revised corpus,  $T_r$ .

### Data Collection

Using the search terms within the  $T_r$  corpus, we collected data between April 27 and May 8, 2015 from Twitter, Tumblr, and Instagram. We collected only public posts in the English language. We also gathered all hashtags attached to the post, the body of text associated with the post, and any attached media (image, video, gif). We noticed that several posts were repeated across platforms both formally (e.g., linking to an Instagram post on a Tweet) and informally (e.g., similar images and language being used by different account names on different platforms). To deal with this potential cross sampling, we chose to randomly sample the data for our final data pool. While this strategy does not eliminate the potential for cross sampling, it diminishes the likelihood of cross sampling within our data. In total, we analyzed 575 posts.

### Codebook – Hashtag Analysis

We created a small classification codebook for the hashtags. We again employed an inductive approach to analyze the 6705 total hashtags collected from the posts in our dataset, of which 1182 were unique. While some of these codes are similar to the media analysis (see below), some are unique. We used the following categories:

Anorexia	General ED	Recovery
Body	Identity	Self-Injury
Bulimia	Inspiration	Social Support
Depression/Sadness	Mental Health	Suicide/Death
Fitness	Other	Weight
Food	Post Composition	

We used these as an organizational framing for terminology corpus presented later in this paper (see Table 5).

### Codebook – Media Analysis

We used an inductive approach to analyze the 575 posts within our dataset. A team of three researchers independently open coded a randomized 7% sample (40 posts) of media attached to collected posts. We coded for general themes. Next, we met as a group to discuss themes and further refine the coding taxonomy. The team reached an inter-rater reliability of 86%. Table 2 below depicts the final codebook used for this analysis.

### FINDINGS

The data collected in this research focused on two main components – hashtags and media. We analyze specific hashtags and their presence across platforms, synthesize these terms into a corpus, provide a categorization of the corpus, and detail temporal trends associated with certain terms. Next, our media analysis resulted in categorization of the media associated with the posts, and highlighted the

Parent Code	Child Codes
Body Part	arm(s), back, breast/chest, collarbone(s), face/head, full body, hands, legs, ribs/stomach, thighs
Image Attribute	black and white, color, drawing, food/beverage, individual, group, image other
Mood	angry, artistic, happy, inspirational, instructional, neutral, painful, provocative, sad/depressed, selfhate, suicidal, supportive
Text	candid, inspiration-disease, inspiration, recovery, no text
Identification	identifiable, unidentifiable
Focus	informational, neutral, pro-disease, pro-recovery

**Table 2. Media Codebook**

interplay between images and their associated text and hashtag(s). Findings uncover important social engineering practices that users employ to circumvent censorship on social media platforms. Finally, we analyzed the different health-related issues that users self-disclosed in our dataset.

### Hashtag Analysis

We analyze the presence of hashtags used in ED-related social media content, and provide a corpus and categorization of these hashtags. A total of 6705 hashtags were attached to the 575 posts in our data set. On average, there were 11.7 tags attached to each post ( $SD = 9.0$ ; range 1-33). Table 3 below highlights the breakdown of these numbers per platform, since there are differences between each with respect to the affordances of each site.

### Categorical Definitions

The categories that evolved for this part of the analysis were derived from the hashtags associated with each of the posts in our dataset. Below is a brief generalization for each category. The full eating disorder corpus organized from this data can be found in Table 4.

	Total Hashtags	Avg. tag/post	Std. Dev.	Range
Tumblr	3433	20.2	7.9	2-33
Instagram	1939	12.3	8.1	1-30
Twitter	1333	5.42	3.9	1-18

**Table 3. Hashtag analysis**

It should be noted that several terms found within certain categories are used by other categories as well – for example, terminology associated with the struggle associated with the disease like “warrior,” “fighter,” and “soldier” occurred in both pro-disease and pro-recovery categories. For purposes of this categorization schema, we focused on the ED component attached to the tag.

Table 4 highlights and defines the categories used to set up the ED vocabulary corpus (Table 5). Previous analysis of ED activities online have analyzed categories associated

with thinspiration, recovery, control, perceived harm [4], and social support [46]. Our analysis includes other mental illnesses as well as an explicit, more detailed analysis of the specific eating disorders Anorexia and Bulimia.

**Anorexia** (15.0%): All terms associated specifically with Anorexia are captured in this category. More specifically, all terms contain some form of “ana” within the term.

**Bulimia** (9.5%): All terms associated specifically with Bulimia are captured in this category. Unlike Anorexia, this category also includes central behaviors and activities crucial to the disease of bulimia like binging and purging.

**General Eating Disorders (ED)** (8.9%): Disease-focused eating disorder tags not captured through the Anorexia or Bulimia categories. These ranged from more formal classifications to activities that comprise these specific activities.

**Body** (4.0%): This category encompasses all terms associated with anatomical parts of the human body.

**Depression/Sadness** (4.0%): Emotional terms associated with sadness, depression, or behaviors associated with these sentiments. These sentiments could be reflective of oneself, the community, or the world.

**Fitness** (0.9%): Activity terms focused on the act of physical exertion or identity makers of a fit person/group.

**Food** (3.4%): Food and beverage-related terminology as well as diets and terms associated with feelings linked to deprivation of food.

**Identity** (3.3%): Identity tags ranged from internal perceptions of self, to classifications of being, to characterizations of identity.

**Inspiration** (7.4%): Terms associated with disease-specific support and other forms of empowerment.

**Mental Health** (3.3%): Co-occurrences with other mental health illnesses like bipolar and anxiety in addition to general mental health terms and health status.

**Recovery/Treatment** (5.1%): Classifications of professional and non-professional assistance or help in battling eating related issue.

**Self-Injury** (7.1%): Self-injury or self-harm terms associated with self-mutilation and tools used for these activities.

**Social Support** (1.7%): Support for eating disorder behaviors from the support network online. Some might seem counter-intuitive because they focus on using terms like bully and shame to support them when they falter in maintaining characteristics of the disease.

**Suicide/Death** (5.2%): Explicit and implicit suicidal ideation and the tools used for the acts. Also included feelings associated with death.

**Weight** (7.6%): Direct individual weights, perceptions of weight, and the process of losing/gaining weight are included in this category.

**Table 4. Hashtag categories**

<b>Category</b>	<b>Associated Terms – Direct Eating Disorder Terminology</b>
Anorexia	anorexia, ana, annie, anne, anasoldier, anafighter(s), anacarefree; anawarrior(s); anorexic, anorecia, anorectic, anoressia, anorexia nervosa, anorexia nervosa, anorexianerv, anorexix, anorexique; antiana, braziliananorexic; proana, proana, proanamia, proanna, proanorexia, wannabeana, wannaberexia, , anabuddy, anatip(s),
Bulimia	antimia, binge(ing), bulimia, bulimianervosa, bulimiaprobs, bulimic, bulimique, bulimirexia, bulimix, bulmia, mia, promia, purge, vomit, vomiting, bulemia
General Eating Disorders	adultswithed, anamia, bingeeating, bingeeatingdisorder, bodycheck, compulsiveeating, eatingdisorder(s), ED(s), edfamily, edbuddy, edcommunity, edfam, edfighter(s), ednos, edproblems, edprobs, edrelapse, edstory, edstruggles, lax, laxative, menwithed, orthorexia, proed; relapse, secret_society123, secretsociety123, beated, eatingdisorderrecovery, edfree2015, ednosrecovery, edrecovery, edsoldier(s), edtreatment, edwarrior(s), waisttraining
<b>Associated Terms – Supporting Eating Disorder Terminology</b>	
Body Parts	arms, blade(s), body, bones, chestbones, collarbone(s), flatbelly, flatstomach, foot, hip, hipbone(s), legs, ribcage, ribs, stomach, thigh, thighgap(s), thygap, tummy
Depression/ Sadness	alone, broken, cry(ing), dark(ness), deb, depression, depress, depressed, depressive, depressing, depressin, disappear, disgusting, down, emotional, empty, failure, friendless; giveup, hate, heartbreak; hopeless, hurt, helpme, igitup, ihatemyself, iwanttodisappear, loneliness, lonely, lost, numb, pain, painful, sad(ness), selfhate, tear(s), tired, unhappy, unloved, upset, worthless, dfighter,
Fitness	10/5K, crunch, fitnotthin, fit, fitfam, fitness, squats, workout
Food	Calories, abcdiet, anadiet, anafood, breakfast, cleaneating, diet(s), donteat, eat, eatclean, eatforabs, eat4abs, edfood, fast(ing), food, foodie, foodisfuel, healthyeating, healthyeats, healthyrecipe, highcarb; lowcal; mono; monodiet; myfood; notfood; nutrition; restrict; skinnygirldiet; starvation; starve(ing); sugarfree; vegan; veganrecovery; zerosugar; yummy
Identity	beautiful; blithe; bohemian; boy; emo; fangirl/boy; fairy; failure; (i'm)fine; gorgeous; grunge; hipster; homosexual; loser; me; model; notme; pale; pathetic; perfect(ion); pig; pretty; pregnant; proud; relatable; runaway; stupid; tats; tattoo; teen; trash; ugly; useless; vintage;
Inspiration	bodyempowerment; bodypositive; bonespo; bonespoo; bonespiration; comments; fitspiration; fitspo; gymspo; legspo; inspiration; keepfighting; motivation(s); mythinspo; promiathinspo; thinspo; thinspiration; thinspo; thinspoo; thinspooo; thinspos; thynspo; thynspoo; fatspo; jawlinespiration; killmethinspo; naturalthinspo; thinspire
Mental Health	abuse; anxiety; anxietyattack; anxious; bd; bdp; bipolar; bipolar disorder; borderlinepersonality; borderlinepersonalitydisorder; crazy; disorder; inpatient; insane; insecure; insomnia; mental; mentaldisorder; mentalillness; mentalhealth; ocd; outpatient; panic; panicattack; panicdisorder; paranoa; psycho; psychosis; psychotic; psychward; psychopath; ptsd; schizophrenia; sick; social anxiety; trauma; voices
Recovery/ Treatment	fightana, fightanorexia, beatana, beatanorexia Anorexiarecovery, antiproana empowered; education; effyourbeautystandards; expectations; love; meditation; trigger; triggerwarning; tw; battle; beatobesity, bodygoals, boobsnotbones, choicebehappy, eatittobeatit, eattogrow, eattolive, eattonourish, eattorecover, faith, fight(er), gethelp, goals, happy(ness), health(y), hope, journey, life, nourishnotpunish, positive(ity), progress, prorecovery, recover(y), strongnotskinny, success, warrior, beatinganorexia, bingeeatingrecovery, bulimiarecovery, bingefree
Self-injury	blood, bruises, burn(ing), cat, catscratch, cut(s), cutting, cutter, deepcuts, hurt, razor, scar(s), scarred, scratching, selfharm(ing), selfharmmm, selfharmmmm, selfharmmmmm, selfinjury
Social Support	bodyshaming, breathe, bullied, bullying, challenged, competition, dontgiveup, Icare, itgetsbetter, peersupport, rantstaystrong, reachout, staysafe, staystrong, staythin, togetherwecan
Suicide/Death	dead, deadinside, death, demon; die, done, drowning, dying, gun, hanged, imtiredofliving, iwanttodie, kill, killme, killmyself, knife, letgo, noonewouldnotice, overdose, pill(s), sue, suicidal, suicide, wannadie
Weight	bbw, beskinny, chunky, fat, fatty, fatwhale, huge, loseweight, obesity, scale(s), sizezero, skinny, size0, size00, thin, Massive; thin15, thyn, toofat, tiny, weight, weightgain, weightloss, whale

Table 5. Eating Disorder-related terminology corpus

Based on the categorizations derived from the tags, Table 5 displays the full corpus of Eating Disorder hashtags found within our dataset. The corpus is divided into direct eating disorder tags and activities or states of being that support eating disorders. Unlike other studies focused on online eating disorder websites [4,6,18,46], we present the full range of lexical variations associated with the posts in our dataset. To our knowledge, this is the largest and most diverse terminology corpus focused on eating disorder behaviors and activities within the health and social computing domains.

The terms found within the corpus span from traditional terms like “anorexia” and “thinspiration” to more modified terms like “anorectic” and “thymspoo”. Table 6 highlights examples of these transitions from traditional to modified terms for Anorexia and Thinspiration. We noticed that the same evolutions took place regardless of the platform where the post originated. These shifts can be related to changes in moderation policies [10], technical affordances [25], and more traditional permutations represented through slang derivations [38]. While understanding the motivations behind these shifts is out of scope for this analysis, highlighting these patterns is an important contribution of characterizing ED-related social media behaviors and points to important future work.

Root	Traditional Terms	Modified Terms
Anorexia Terms	anorexia (34.1%) anorexianervosa (1.8%) anorexic (1.0%)	ana (27.9%) proana (11.1%) anamia (9.0%) anatip(s) (3.5%) anorectic (1.4%) anarexic (1.0%)
Thinspiration Terms	thinspiration (26.3%)	thymspoo (44.6%) thymspooo (1.6%) thinspooooo (13.8%) thinspire (0.5%) thymspoo (3.7%) thinspiration (6.4%)

Table 6. Examples of terminology variations

### Media Analysis

Here we describe the results of the analysis we conducted on the media components of the posts in our dataset. We begin by describing content analysis results and then present discussion of the archetypes that were deduced from our findings. These archetypes, while not exhaustive, are representative of ED support networks. Out of the 575 posts in our dataset, 553 had images - 22 of the Twitter posts in the dataset did not have a piece of media attached to the post.

#### Image Composition

We did a general analysis of image characteristics. Black and white images comprised 54.1% of our data set with the rest being comprised of color-saturated images. Table 7 below highlights the other image characteristics captured in the content analysis.

Drawing	3.8%
Food/Beverage	9.8%
Image of an individual	56.2%
Image of a group	3.3%
Other type of image	26.9%

Table 7. Image composition – general

In our dataset, 59.5% of the images contained one or more individuals. We coded these images for the types of body parts that were the focus or most prevalent. In total we coded for ten body parts. Overall, the posts averaged 1.70 body parts per image ( $SD = 1.22$ ). Table 8 highlights the percentage of images that had a prominent body part, taking into consideration that images could have more than one prominent body part represented.

Arm(s)	10.2%	Hands	4.2%
Back	5.1%	Head/Face	20.3%
Breast	18.6%	Legs	15.3%
Collarbone(s)	10.2%	Ribs/Stomach	39.8%
Full body	13.6%	Thigh(s)	22.0%

Table 8. Image composition – body parts

We analyzed images with one or more individuals for gender presentation and identifiability. These were coded as feminine (61.0%), masculine (5.9%), or unknown/other (33.1%). Image 2 below shows a representation of each of these categories. Regarding identifiability, 79.6% were unidentifiable, meaning there were not enough characteristics in-focus or present to give the coders a sense of the likeness of the individual.



Image 2. Examples of masculine, feminine, and other/unknown

#### Images with Text

Just over half, 54.1%, of images had text associated with the image. When we analyzed the text to better understand its purpose in association with the image, we identified three categories associated with the sentiments shared. Text that embodied sentiments supporting illness was found in 21.2% of the total dataset. For example, “Do not reward yourself with food...you’re not a dog” and “I wish my bones showed like this” exemplify sentiments shared that support behaviors associated with eating disorders. Text that embodied sentiments supporting recovery was found in 6.1% of the total dataset. “I ate so well today, I am so proud!” and “Repost to save a life – eating disorder hotline:

1-800-931-2237” represent text shared demonstrating recovery or support to transition into recovery. The third and last category of text embedded in images was candid statements. Examples from this category include “Easily forgotten because I don’t matter” and “I hate the feeling when you randomly feel depressed...there’s no warning, no apparent reason. It just happens.”

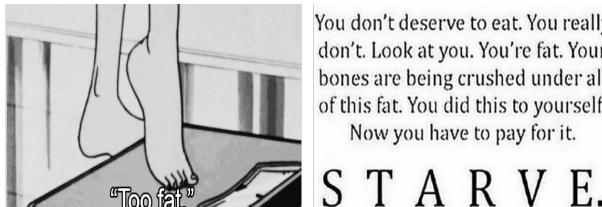
#### **Media Archetypes**

Our analysis of the media posted on these social platforms also identified certain archetypes related to ED posts. While all media did not fall into one of these foci, the following are representative of a majority of posts within our dataset.

#### *Thinspiration*

Posts in this category offer inspiration to both themselves (individual) as well as others within the network (others). Thinspiration or “thinspo” are media that encourage individuals to be as thin as possible. Image 3 is an example of thinspiration rated to activities or negative reinforcement.

Another category of thinspiration is images of individuals



**Image 3. Thinspiration images - activities**

and body parts to encourage individuals to strive for the “ideal” body type. This category includes “bonespiration” or “bonespo”, characterized by the ability to see as many of your bones through your skin as possible. Image 4 is an example of these types of media.



**Image 4. Thinspiration images – body.**

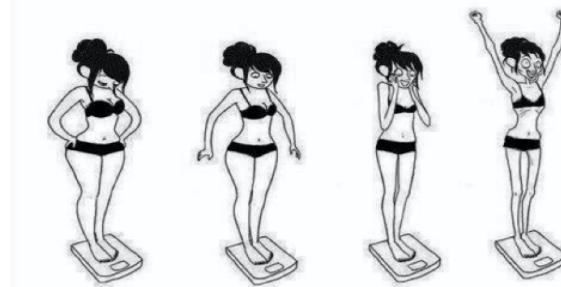
#### *ED journey*

Before-and-after compilations are a way for individuals to share progress and are likely used by the creator as motivation to “keep going” in their pursuit of the ideal body type. Media in this category focus on the journey associated with weight loss. Image 5 highlights the typical composition of these images – a before and after shot with some type of time annotation to denote duration of the

journey. Artistic depictions also highlight this journey as well as the corresponding emotions associated with reaching these different benchmarks (see Image 6).



**Image 5. Before and after shots**



**Image 6. Weight loss journey**

#### *Diet*

Foods and drinks are a central tenet for eating disorders in practice and in diagnosis. They are also used to evoke sentiments of social support and the sharing of best practices. Image 7 highlights the types of images in the dataset shared as part of a “balanced meal” or support to avoid consuming calories.



**Image 7. Diet/food related images**

#### *Mismatches*

For images within the mismatches archetype, the image and the associated hashtags are the antithesis of each other. This strategy could be implemented by the user to circumvent the censorship technologies employed by the social media platforms; it could be a strategy to impact large swathes of “wannabes” or those on the periphery of the network; or it could be an attempt to communicate actions and behaviors

to the network without using media that could potentially trigger or deeply affect other individuals.

If analysis only took place using the post text, void of the tags or images, some posts would show no indication of being a potential trigger. Image 8 was taken from Twitter. The associated post stated “Thank you for 100 followers. Lovely people!” The associated hashtags are “thinspo,” “ily,” “skinny,” “anamia,” and “ed.” There is clearly a mismatch between the tone of the post text and the hashtags associated with the post. While the hashtags and the media are synergistic, there is a definite mismatch with the attached post text. We saw many examples of these a certain number of followers or a post got a certain amount of likes.



**Image 8. Mismatch image 1**

Another example is taken from Instagram (Image 9). Again, there is a mismatch between the focus of the post text and the focus of the image and associated hashtags. The text of the post stated “Erg! I gotta pee again! (U didn’t need 2 know that, didyou?)”. This is less connected than the previous example. The hashtags associated with this post include “ana,” “anorexia,” “anorexic,” “skinny,” “thin,” “anamia,” “mia,” and “bulimia.” The post includes the text “Do not give up what you want the most for what you want at the moment.” Again, the hashtag and media are synergistic, yet the post text is an almost redirect from the content.



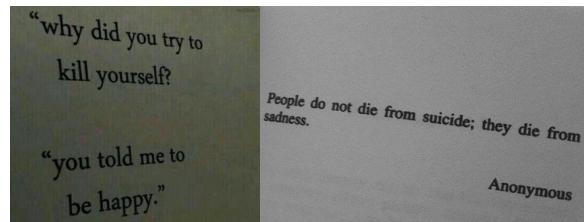
**Image 9. Mismatch image 2**

One explanation for these types of posts is an attempt by the poster to “beat the filter.” Instagram heavily moderates hashtags and content within its community. These types of posts serve as an example of the social engineering within the network in order to contribute content while evading

specific rules and norms within the platform. Another tactic to evade filters is tagging posts in the comments of the post instead of in the actual post itself. This is a relatively new phenomenon

#### *Suicidal Ideation*

Media representing suicidal ideation or expressions associated with death were present across all platforms. These images used varied types of presentation; use of quotes or written text was a particularly popular presentation style. Image 10 highlights these media types.



**Image 10. Text-based suicidal ideation media**

Another popular form of media associated with suicidal ideation or death is portrayal of the act of a death or showcase of a tool that one would use to cause death. Image 11 depicts examples of these presentations.



**Image 11. Suicidal ideation**

#### *Self-Harm*

Media representing self-injury behaviors such as cutting and bruising were also found in our dataset. These images (Image 12) were connected to sentiments of depression and selfhate.



**Image 12. Self-harm images**

#### **Other Mental Health Indicators**

Eating disorders do not happen in isolation of other behavioral, mental health or emotional health stressors or illnesses. Through the data analysis we found strong evidence supporting the idea that depression is a common mental health issue that is difficult, if not impossible, to decouple from the presentation of bulimia, anorexia, or EDNOS. Within the 575 posts, 40.6% of the posts reported a co-occurrence of Depression.

Depression was not the only mental or behavioral health issue uncovered through this analysis. Anxiety, Bipolar, PTSD, Borderline Personality Disorder, OCD, and Paranoia were the more popular of the co-occurring issues other than depression. Terms associated with behavioral and mental health issues – excluding depression – were found within 18.9% of all posts in our dataset.

### Summary of Results

In this work, we analyzed hashtags and media associated with ED-related posts on Tumblr, Instagram, and Twitter. We contribute a corpus and categorization of ED-related hashtags, a categorization of different archetypes of ED-related media, and analysis of the nuanced relationships between images, text, and hashtags. We also provide evidence of ED's co-occurrence with other health issues, such as depression, as disclosed by users on social media.

### DISCUSSION

The process of self-presentation of ED-related activities on social media platforms is not a simple, straightforward task. ED behaviors are actively censored on social media. Our results indicate that ED support networks use social engineering to circumvent the censorship. We then shift the discussion to focus on the relevance of our findings and typical mental health screening tools, highlighting the need for future work to connect and correlate these indicators. Finally we discuss the impacts that technology and electronic-based activities have on an individual's ED-related behaviors, understanding that these online behaviors represent real, and potentially deadly, health risks..

### Censorship

Content that is deemed “deviant”, “disruptive” or against community standards has a history of being censored, either by the platforms or the ISPs that host the material [6,46]. More recently, platforms have increasingly begun using sophisticated filtering algorithms and crowd-sourced content management (e.g., the reporting function on most social networks) to ensure that community standards and norms are upheld. Image 13 depicts the message that an individual receives if they search on a known “pro-ED” hashtag on Tumblr.

Members of ED networks and have raised concerns that the Pro-ana and Pro-mia communities are unjustly targeted in terms of censorship. Shade explored this tension, asking whether communities advocating instead for body acceptance for the overweight would be subject to the levels of censure that Pro-ana and Pro-mia communities currently manage [46]. Shade also argued that individuals are not forced to become members of these groups and share the same ideals, and questions whether public harm is actually taking place [42]. In response to these concerns of censorship, examples of social engineering have begun appearing within ED-related posts and we expand upon this further below.

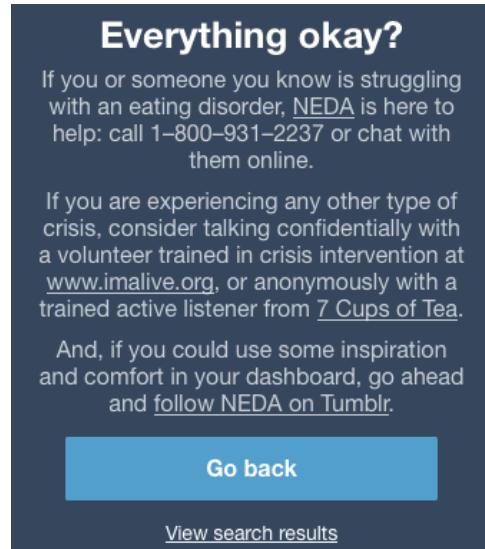


Image 13. Tumblr message that users receive when searching for pro-ED content

Putting aside the debate of whether ED is a public harm or not, even if we as a society decided censorship of these communities was appropriate, there is no national (US) or international enforceable legislation that could be effective in this domain [12]. Because the Internet is a global phenomenon, and does not belong to any one country or entity, the influence of legislation is immaterial. Even if all of these challenges were surmountable and treatment of ED via censorship was deemed a need within society, in the end these individuals, who are already dealing with physical, mental and behavioral health problems, would be further marginalized through the act of being labeled as criminals as well. This raises the question of how effective is censorship of these networks within these online platforms? And, potentially an even more important question, does this form of censorship do more harm than good for those struggling with these diseases? Future research is needed within this domain to tease out answers or indicators to these important questions.

### Social Engineering within the Network

In media and hashtag analysis, we uncovered initial pointers of social engineering within the network to circumvent platform regulations and norms. Within the corpus that we discussed previously (see Table 5) there are several lexical variations associated with the ED-specific terms. These types of classifications found within the support network are human nature – individuals will inevitably seek ways to classify things they care about even when the formal system of doing so is taken away [5]. While some of these modifications and evolutions can be explained through the evolution of slang derivations to the language [38], some modifications are not as easily explained. One potential explanation is the network's reaction to censorship. When a platform bans a hashtag, there is evidence [10] that there is an almost immediate

organic response via slight modifications to that term, i.e. “proana” and “proanaaa” or “thinspo” and “thinspoooo”.

Additionally, post composition was the other component where we witnessed members of the ED network socially engineering ways to overcome censorship. In Instagram data we witnessed a unique phenomenon that may attribute to this cause. Hashtags were not attached to the original post, yet were included in an immediate comment on the original post by the author. The Image 14 is a post from the dataset that exemplifies this activity.



**Image 14. Instagram post with hashtags included in an immediate comment rather than in the original text, as a potential example of social engineering**

Another example of social engineering to evade censorship was uncovered through our media analysis of the dataset. The idea of post text, hashtags, and media associated with the post representing a “mismatch” is intriguing because it raises an important question – why is this necessary? One explanation why a post author may deem mismatching necessary could be because they had previously been censored or had posts removed from the platform, and feel this method will keep them from being found.

Understanding the motivations behind such social engineering practices is not in the scope of this research, but is an interesting vein of inquiry moving forward as scholars continue to research these networks of individuals.

#### **Informing Diagnostic Tools**

When a patient presents with a health issue that signals a suspected eating disorder, a number of eating disorder-focused screeners can be employed while that individual is being triaged. Technology use, behaviors associated with technology use, and the role of online peer influence in ED behaviors are not assessed or even acknowledged by these diagnostic tools [19,57].

Social media ED behaviors are similar to the behaviors that ED screeners aim to uncover: information associated with diet, influences, and the journey to becoming thin are all assessed through these tools. These also represent half of the archetypes found within our media analysis. This connection represents just one indicator that a person’s

online presentation of ED behaviors and activities has relevance to and value for current in-practice diagnostics.

If the healthcare community is not rigorously assessing the level of interconnectedness between these offline and online pressures, recovery may be a more difficult process than it could be. By connecting and addressing issues ascertained through both online and offline ED support network participation, reductions in recidivism could potentially be realized because patients are better equipped to re-enter all aspects of society which encompasses both online and offline activities. How can our research profession help bridge this divide between the human-centered computing field and the mental and behavioral health providers? Developing social media-based ED-related heuristics that may allow for more holistic ED diagnosis and treatment, as we do in this paper, is a starting point.

Designing clinically based diagnostic tools directly into online communities could have real therapeutic and clinical value. Users that potentially present with these types of issues or those that are at risk for developing ED-related behaviors could be identified at the point of expression. However, if the current practice of censorship continues within online platforms, it could make realizing this type of design near impossible because of the social engineering techniques that continue to alter or change the presentation of the behaviors within the platforms in response to the censorship. This tension makes collaborations with healthcare providers and the development of enhanced diagnostic tools critical to effective interventions and treatment.

#### **Technological Influences on Behaviors**

The rapid development of ICT and personal computing technologies has exponentially increased the sheer numbers of people who are connected through online channels. We as researchers can learn from previous behavioral issues and how we as a society learned to negotiate technology and practice. Cyberbullying is a quintessential example of a how a traditional behavioral issue – bullying – witnessed changes in the presentation, penetration, and impact of associated activities because of the insertion of technology into the bullying process [9]. Prior to the introduction of new forms of bullying afforded by technological platforms, bullying had not traditionally been seen as a societal “problem,” and was instead accepted as a fundamental and normal aspect of childhood [29]. Other domains such as stalking [47], domestic partner abuse [16], and gaming addiction [36] have also shown evidence of increased severity and change in presentation after the introduction of technology.

The consequences of injecting technology into a behavioral issues such as bullying or ED have the potential to drastically change the scope and consequences of these activities due to several factors: the size of the audience increases, the ability to detach from the activity decreases,

and the artifacts from the activities persist online for those involved and others to re-digest at any given time. Initial research into these changes in the context of cyberbullying showed that technology-mediated activities potentially have more dire consequences than traditional presentations of those same activities [9].

Multiple strategies have been put in place to address cyberbullying: the development of anti-cyberbullying intervention prevention programs, mandatory reporting laws, and government-mandated protocols [23]. Other strategies have included creating public-private partnerships between the government and mobile phone providers like that seen with Vodafone and the NetSafe program in New Zealand. In this partnership, if an individual is found to be a repeat cyberbully, they can have their service temporarily interrupted or even have their accounts deactivated [63].

While some of these interventions might not be applicable when appropriated for addressing online ED-networks, they represent an integral step - multiple stakeholders coming together to develop strategies for addressing the issues ED posters are at risk for harm to themselves while they are encouraging harm to members of their network. What is likely is that the pervasive access to online content is amplifying their reach and perhaps their offline, harmful behavior.

Much as technology has changed what it means to be bullied, we show in this work some of the ways that technologies, and the communities that form on technological platforms, mediate and potentially have changed what it means to have an eating disorder. We can learn from the evolution of bullying into cyberbullying and apply similar coping strategies to the online behaviors that support eating disorders. .

### **CHALLENGES IN RESEARCH**

Research in this domain faces several challenges. The challenges are not unique only to this vein of scholarship, yet apply to many other subfields that are concerned with attempts at making sense from people's digital footprints be it social media posts, technology utilization, or other facets of their digital lives.

Our research presented in this paper has several important limitations. Earlier in the paper, we discussed the changing nature of terminology. We can speculate as to motivations and drivers, but the methodology limits the understanding of the deeper cultural contexts. If we were to use a mixed methods approach and were able to interview individuals immersed in these communities, we could potentially have uncovered evidence as to why this phenomenon is taking place. Without this contextual validation, we are limited to our ability to speculate and conjecture correlations and causations related to what is driving these behavioral shifts.

The research team members are all outsiders to this community – no one self-disclosed to have issues associated with eating disorders or self-harm activities. In

addition, physicians, domain experts, and people who have survived any of these issues were not consulted in the analysis of this data. Future research in this direction should include these perspectives

### **Don't Take It at Face Value – Context is Important!**

On its own, analysis of hashtags was sometimes insufficient or misleading in relation to the tone and sentiment of an entire post. Terms within the Social Support, Inspiration, Identity, and Food/Eating categories in particular were not well-aligned with whether they supported disease, recovery, or neutral. Terms are shared between these communities with increasing frequency, and therefore many have become increasingly general in nature.

“I'm fine” or “bodypositive” are terms that we saw represented in both pro-disease and pro-recovery posts. Without the context of the associated media or post content one could deduce or categorize these as pro-recovery terms. In actuality, the terms are used both to justify the normalcy of the diseased behavior as well as signal representation of the recovery process.

Additionally, hashtag or individual post analysis often does not take into account responses from others (such as comments or retweets) and the social ecosystem that evolves around social media content. A post's social surroundings may uncover meaning that would be missed by looking at the post in isolation.

This observation calls into question what we can really learn from analyzing certain elements of online posts in isolation, not only in the context of ED populations, but in online media research more broadly. If we think of an individual post as a small ecosystem, then the sum of the individual parts of that post is greater than those individual elements. By only analyzing some parts, we are potentially incorrectly analyzing the intentions or actual presentations of the artifacts, and thus potentially misrepresenting marginalized online communities.

### **Hiding in Plain Sight**

In the early days of the Internet, eating disorder networks typically organized around bulletin boards, chat rooms, and specific websites [6,46]. These were public facing platforms that were characterized by group activities and organization. Therefore, it was much easier for these networks to be discovered and for their activities to be halted, which typically happened when the ISP shut down access to the webpage or the platforms; Yahoo!, for instance, could shut down certain chat rooms [46].

Social media platforms have moved the scope of network construction from the group to the individual. Instead of a formal chat room or bulletin board, ED network members use their personal social media feeds to connect with the, now distributed, ED support network(s). The uniting threads within a singular platform or across multiple platforms are hashtags. By moving to this organizational structure, these networks are able to “hide in plain sight” on

popular social media platforms like those analyzed in this study. This fluid, individualized presentation, can make researching these populations, and potentially deploying interventions, difficult.

### Ethical Considerations

When conducting research with marginalized online communities, we as researchers have attempted to keep in mind our own group memberships, identities, and potential lack of knowledge about that group's experiences, challenges, and values. We collected this data without user knowledge or consent – an accepted practice when dealing with public data. Thus, this research may misrepresent the behaviors, challenges, or identities of the study population, and our methods do not allow us to clarify potential misrepresentations. Additionally, the social media activity that we use for our analysis is unable to capture the many complexities and nuances of human behavior [43,50]. We note the ethical limitations of conducting this research without consent or input from the people who generated the data. Future research would benefit from a collaborative approach with members of online communities of interest.

In the abstract and introduction of this paper, we inserted “trigger warnings” for the reader; alerting them to the potential negative impacts that engaging with this paper might have on them. We feel this is a practice that those wanting to work in this domain, or other domains where readers might potentially be triggered or adversely affected by engaging with the content, should adopt.

All data that we collected for our analysis was public data. By definition (and as we have seen through practice), there is no consent for use required from those that post the data to public streams. There is a fundamental assumption to this practice – that those publishing to the public domain *understand* or have the *technical literacy* to fully comprehend the ramifications of this choice. We reached out to the account owners of all images used within this paper. We were intrigued to see if we were told not to use these images. We reached out to the 17 accounts from which these images were taken: 3 explicitly gave us permission to use them and 14 never responded. Because we were not explicitly told not to use media, we included all of them in this work.

The three researchers that coded this work often discussed coping mechanism used to ameliorate the impacts that immersing oneself into this type of data can have on an individual. While it is standard procedure for researchers in our field to protect the subjects within a research endeavor, it is far more rare to take into consideration the impact on the researcher(s) [33]. More discussions need to be had within our community as to what best practices and lessons learned could be shared by other disciplines that grapple with immersion into research areas that can negatively impact the researcher conducting the study.

### CONCLUSION

Eating disorders are not a new phenomenon and will continue to persist within the interconnected design of current popular social interactions. As social computing researchers, we will play an increasingly important role in understanding how the platforms and technologies that we create are used and misappropriated for negative health purposes. While it is not our role to design health interventions and treatment protocols, we can form new and stronger alliances with our peers in the mental and behavioral health fields to share insights that can help inform improved and more targeted interventions and treatments.

Through this analysis, we have analyzed the online, socially constructed presentations of eating disorders across several social media platforms. We found that irrespective of platform, there are salient trends within these support networks. We have distilled components of the communication patterns within the networks and created a platform-independent corpus of eating disorder related terminology. We have also highlighted remaining and new research questions with regards to the activities of this community, and the potential generalizability of this approach and the network trends to other behavioral health domains.

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