



4-20-2018

Disclosing an Eating Disorder: A Situational Analysis of Online Accounts

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Recommended APA Citation

Williams, E. P., Russell-Mayhew, S., & Ireland, A. (2018). Disclosing an Eating Disorder: A Situational Analysis of Online Accounts. *The Qualitative Report*, 23(4), 914-931. Retrieved from <https://nsuworks.nova.edu/tqr/vol23/iss4/14>

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Abstract

Disclosing a mental illness can be difficult, especially for those affected by eating disorders. Individuals impacted by eating disorders often worry that disclosing their situation may lead to fear, judgment, and stigmatization. Online eating disorder communities have become increasingly popular, hosting thousands of users worldwide, and may be safe places for individuals with eating disorders to communicate and connect. In this postmodern study, we utilized situational analysis to examine online accounts on publically accessible websites where individuals discussed disclosing eating disorders. Situational Analysis utilizes illustrative mapping techniques to demonstrate the complexity of the situation of inquiry, allowing researchers to highlight heterogeneities. Our findings demonstrated (a) the fight that frequently occurs after an eating disorder disclosure, (b) the notion that eating disorders are a monstrous issue, and (c) stigmatization one experiences after disclosing and when considering to disclose. This study has potential to inform educational recommendations given to the public about disclosures and stigma in regard to eating disorders, as well as earlier identification and treatment outcomes for individuals with eating disorders.

Keywords

Eating Disorders, Situational Analysis, Disclosure, Social Media

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Disclosing an Eating Disorder: A Situational Analysis of Online Accounts

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Disclosing a mental illness can be difficult, especially for those affected by eating disorders. Individuals impacted by eating disorders often worry that disclosing their situation may lead to fear, judgment, and stigmatization. Online eating disorder communities have become increasingly popular, hosting thousands of users worldwide, and may be safe places for individuals with eating disorders to communicate and connect. In this postmodern study, we utilized situational analysis to examine online accounts on publically accessible websites where individuals discussed disclosing eating disorders. Situational Analysis utilizes illustrative mapping techniques to demonstrate the complexity of the situation of inquiry, allowing researchers to highlight heterogeneities. Our findings demonstrated (a) the fight that frequently occurs after an eating disorder disclosure, (b) the notion that eating disorders are a monstrous issue, and (c) stigmatization one experiences after disclosing and when considering to disclose. This study has potential to inform educational recommendations given to the public about disclosures and stigma in regard to eating disorders, as well as earlier identification and treatment outcomes for individuals with eating disorders. Keywords: Eating Disorders, Situational Analysis, Disclosure, Social Media

Eating disorders are complex, multidimensional disturbances in eating and eating-related behaviours that interfere with functioning and health (von Ranson & Wallace, 2014). Eating disorders characteristically develop during adolescence and disproportionately affect females living in Western countries (von Ranson & Wallace, 2014). These disorders are commonly misunderstood by lay people (Ebneter & Latner, 2013; Roehrig & McLean, 2010), and have attracted substantial attention from the media (Saguy & Gruys, 2010), adding to the stigma and misunderstanding of those affected.

Individuals with eating disorders have reported that the general public do not understand eating disorders and often attribute the illnesses to vanity or emulating celebrities (Dimitropoulos, Freeman, Muskat, Domingo, & McCallum, 2016). Due to the stigma of having an eating disorder, individuals often attempt to conceal their eating disorder from those around them (Cachelin, Rebeck, Veisel, & Striegel-Moore, 2001; Hinshaw & Stier, 2008). The fear of judgment and anticipated discrimination contributes to decisions not to disclose an eating disorder and may also delay seeking treatment (El Badri & Mellsop, 2007).

Few studies have focused on the disclosure of eating disorders. The topic of disclosing an eating disorder is critical to study, because the choice to disclose has been considered an important gateway for individuals to access professional help (Gilbert et al., 2012). Researchers suggest that early diagnosis and referral are the best predictors of recovery from an eating disorder (Loeb & Le Grange, 2009), pointing to the importance of better understanding the disclosure process. For many individuals with eating disorders, they cannot begin recovery without inviting someone else into their experience (Rüsch, Gabbidon, Thornicroft, & Clement, 2014).

Given that little is known about the process or the experience of disclosing an eating disorder generally and that social media is playing an increasing role in the lives of young

people, this study sought to better understand how individuals with eating disorders describe their experiences of disclosing to others. In particular, this study examined the online narratives about disclosure (e.g., reasons for disclosure, responses to disclosure, and thoughts about how the disclosure was received by others) on websites specifically created by and for those with eating disorders. The research question guiding the study was “What are the tensions, differences, and positions in online narratives about eating disorder disclosures?”

Disclosing an eating disorder has been demonstrated to be difficult for the individual disclosing, and literature shows individuals with eating disorders are often hesitant to come forward to others (Becker, Grinspoon, Kilbanski, & Herzog, 1999). Thus, learning more about the disclosure experience is imperative to better serve individuals with eating disorders, by way of evidence-informed resources about disclosure and to better advise mental health professionals responding to and discussing the disclosure experience. Findings from this project are relevant to clinicians working with individuals with eating disorders and shed light on the hesitation to disclose a potentially shameful experience. Further, findings have important implications for the profession of counselling psychology and suggest the need for family-based therapy and offering increased psychological services over the Internet for those with eating disorders.

Entrance into the Research

I (first author) am a white woman, currently undertaking my Doctorate in Philosophy in Counselling Psychology. At the time this research was conducted, I was a Master of Science (MSc) student. I entered into this research largely because of an experience that occurred during my undergraduate degree. I received a phone call and learned that a close family member had been concealing an eating disorder. This person was caught off guard, and through this discovery the remainder of the family was informed. News of my family member’s eating disorder came as a shock. The thoughts and feelings that the discovery of the eating disorder evoked in me in the days and weeks afterward inspired me to learn more about eating disorders and also the process of disclosing to others or being caught unintentionally.

I (second author) am a white female academic. I was the research supervisor for this MSc research project and came to the topic with extensive experience supervising graduate students in weight-related topics. I also entered this research as a woman who has had a troubled relationship with her body from early adolescence and with personal disclosure experiences related eating disorders.

I (third author) am a white female PhD Candidate in Counselling Psychology who was supervised in my mentorship of this research. I entered into the project as a graduate student with research experience related to both eating disorders and Situational Analysis. With an overall interest in weight-related topics, I shared interest in the disclosure experiences of those with eating disorders, particularly in the social construction of discourses related to stigmatization.

Taken together, the three of us collaborated on this research project, each offering different perspectives and lived experiences. As Clarke (2005) mentioned, all researchers coming to study a particular situation bring their own subjectivity, therefore, the different perspectives of the authors proved very helpful in thinking about alternate possibilities. As a result of generative conversations, the situational maps changed and were modified to account for various perspectives towards the situation.

Literature Review

Disclosure

Disclosure is the process of letting one's self be known to others (Corrigan & Rao, 2012). Since many physical and mental illnesses are concealable, individuals face the dilemma of sharing intimate details about themselves with others. Disclosure can lead to positive experiences including felt closeness with others and increased and strengthened social support (Chen, Lai, & Yang, 2013). However, disclosure may also result in negative outcomes including physical harm, rejection, and heightened trauma-related symptoms (Rüsch et al., 2014). Research demonstrates that choosing not to disclose may protect individuals from stigma and discrimination in the short term, however, those who intentionally conceal information have poor long-term outcomes, facing constant stress regarding others finding out (Brohan et al., 2012; Brohan et al., 2014).

Disclosing mental illness may be especially difficult given the lack of reciprocity involved in the information exchange. Robinson (2012) explained that typically, when information is shared between a dyad, the recipient of the disclosure offers information in return. However, in the case of disclosing mental illness, it is unlikely that the recipient of the disclosure will reveal a relatable experience (Robinson, 2012). Evidently, the decision to disclose mental illness, like an eating disorder, is a difficult decision.

Eating Disorders

Eating disorders develop due to an interplay of sociocultural, psychological, and biological factors (Striegel-Moore & Bulik, 2007; von Ranson & Wallace, 2014). Parallel to how a host of causes can lead to the development of an eating disorder, different discourses have arisen over the years in relation to these disorders. Two relevant positions include the medical model of eating disorders, and the discourse position of feminist scholars. These two groups differ in their conceptualization of eating disorders, with those ascribing to the medical model defining them as mental illness (American Psychiatric Association [APA], 2013), and those working from a feminist lens describing them as socially constructed products of society (Brown & Jasper, 1993). Though there is no question of severity and impact of eating disorders, beliefs about the development, maintenance, and treatment are contentious.

Disclosure and Eating Disorders

Individuals struggling with eating disorders are often hesitant to disclose they have a problem (Becker et al., 1999). Secrecy and concealment are common behaviours of individuals with eating disorders, as evidenced by clinician reports (Basile, 2004). Though the topic of disclosing an eating disorder represents an important area to better understand, literature on this topic is scarce.

From the limited research available, female high school students with eating disorders tended to score lower on measures of self disclosure (i.e., the Self Disclosure Questionnaire) compared to individuals not experiencing eating concerns (Le Grange, Tibbs, & Selibowitz, 1995). In the same study, female students with high levels of body and weight preoccupation scored lower on the Self Disclosure Questionnaire compared to classmates with less severe eating and body concerns (Le Grange et al., 1995). Similarly, Smart and Wegner (1999) demonstrated that among a female university sample, those who endorsed characteristics of eating disorders (i.e., terrified of gaining weight, use of laxatives or vomiting after eating) reported greater levels of secrecy about their eating patterns and attitudes toward food than

those without these eating characteristics. This tendency to under report and conceal may be related to experienced shame (Swan & Andrews, 2003), as researchers have found significant associations between general shame and the drive for thinness and bulimia nervosa (Sanftner, Barlow, Marschall, & Tangney, 1995).

In addition to literature suggesting greater concealment, patterns of disclosure among female college students self reporting eating and weight related concerns, as determined by the National Eating Disorders Screening Program, differed based on the disclosure targets (i.e., parents, friends, health professionals; Becker, Thomas, Franko, & Herzog, 2005). Friends were the group most likely to be the recipient of a disclosure (86%) while mental health professionals were the least likely group (35.6%). Participants also reported disclosing to a partner (56.5%) and to a parent (52.8%; Becker et al., 2005). In 2012, Gilbert et al. examined the disclosure process in relation to (a) the target of disclosure and help seeking, (b) the identity of the disclosure recipient, and (c) the autonomy to disclose (Gilbert et al., 2012). By retroactively studying a sample of females in treatment or recovery for eating disorders, researchers demonstrated that being older at the time of initial disclosure was significantly associated with help seeking and specialist treatment (Gilbert et al., 2012). Disclosing to a friend did not predict help seeking, and when someone else initiated the disclosure by asking questions or making comments about the symptoms and acted positively, help seeking was sought faster (Gilbert et al., 2012). Evidently the role that others play as the recipients of disclosure and how these recipients manage their responses is instrumental in the next steps an individual chooses to take regarding an eating disorder. However, little is known about the experiences of those who disclose an eating disorder. Given the increasing presence of social media (Al-Deen & Hendricks, 2011), it is important to examine disclosure experiences in a contemporary context.

Social Media

Social media is a term used to describe technologies designed to reach and influence mass audiences. Over the last 10 years, the number of individuals using social media has grown exponentially (Al-Deen & Hendricks, 2011). Since 2005, there has been a 78% increase in social media usage among those aged 18-29 in the United States (Perrin, 2015). In addition, in a Canadian university sample, 90% of first year females, and 86% of first year males utilized social media websites (Hargittai & Hsieh, 2010). Evidently, social media plays an enormous role in the lives of emerging and young adults.

Eating Disorder Websites

Social networking sites have become the major form of media by which people have created personal networks online (Lewis & Arbuthnott, 2014). Social networking sites have developed as salient platforms for individuals experiencing mental illness, specifically, for the purpose of connecting with others who share similar struggles (Whitlock, Powers, & Eckenrode, 2006). Of the thousands of social networking sites available, online communities have been created to support and foster connection for particular groups, for example, those with cancer, LGBTQ* communities, and for individuals identifying as having an eating disorder.

Individuals with eating disorders frequently use the internet to discuss and connect with others who understand their experience and struggle (Lewis & Arbuthnott, 2014). Currently, there are hundreds of online communities designed specifically to support those with eating disorders (Brotsky & Giles, 2007); fostering safe environments for users to share their experiences. Many of these online communities offer interactive components for members to

converse with each other, most commonly in the form of anonymous message boards and blogs (Brotsky & Giles, 2007).

Different types of eating disorder websites. Although the activities on many websites foster positive interactions, feelings of support, encouragement, and decreased isolation, online eating disorder communities may also be detrimental. Eating disorder websites are categorized either as pro-recovery or pro-eating disorder (pro-ED). Pro-recovery sites cater to individuals who wish to recover from an eating disorder, are in the process of recovering, or have recovered (Wilson, Peebles, Hardy, & Litt, 2006). Pro-recovery websites tend to discuss eating disorders as an illness, promote support and recovery, and are against material that encourages disordered eating behaviours (Chesley, Alberts, Klein, & Kreipe, 2003). Pro-recovery sites typically share the definitions of eating disorders, recognizing the associated behaviours and cognitions to be detrimental to physical and psychological health.

Alternatively, pro-ED websites promote eating disorder behaviours and attitudes as an alternative lifestyle to strive for (Lewis & Arbuthnott, 2014; Meenan, 2003), rather than as a disorder. Pro-ED sites offer weight loss tips, strategies for engaging successfully in destructive behaviour, and *thinspiration* messages (i.e., words or photos meant to inspire members to lose weight) intended to reinforce eating disorder behaviours (Chesley et al., 2003). Individuals drawn to pro-ED websites typically view their eating and attitudes as an accomplishment and consider restricting or purging behaviours as an act of successful self-control and personal choice.

There are clearly contrasting positions these websites take in regard to eating disorders either as an illness or lifestyle choice. Research indicates that individuals with eating disorders access both types of websites frequently (Lewis & Arbuthnott, 2012). In 2012, Lewis and Arbuthnott found that “pro-ED” had been searched 13 million times annually on Google, demonstrating the degree to which eating disorder websites are being utilized.

Potential benefits of eating disorder websites. Despite concerns associated with pro-ED websites, online eating disorder communities that connect individuals worldwide offer potential benefits. Individuals with eating disorders are socially stigmatized and often isolate themselves due to beliefs that others do not understand their circumstances (Lewis & Arbuthnott, 2014). In the online environment, individuals are offered the opportunity to share their experiences with others and gain mutual support in a judgment-free environment (Tierney, 2008). Further, the internet can be accessed at any time and from anywhere, therefore serving an important function of connecting individuals during times where in-person support might not be available. Wesemann and Grunwald (2008) found that 43% of new threads on an eating disorder forum were posted between 11:00PM and 5:00AM, a period in which face-to-face support is typically less available. Online communities can serve important functions for individuals living with an eating disorder.

Evidently, literature on eating disorders and disclosure illustrates the hesitancy and ambivalence individuals experience when considering coming out to others. Numerous factors can have great impact on one’s experience to share their eating disorder, and if and when that disclosure will occur and to whom. Considering those with eating disorders experience a great deal of stigma and due to the public’s misperceptions about what it means to have an eating disorder, how they develop, and are maintained (Dimitropoulos et al., 2016), it is not surprising that individuals seek to connect with others who understand these experiences first-hand. Hence, online communities specifically meant for individuals with eating disorders to connect are accessed millions of times each year (Lewis & Arbuthnott, 2012), and thus serve as a powerful support network for these individuals to discuss issues related to eating disorders that may be too difficult or risky to discuss with others in face-to-face settings.

The Current Study

We chose a qualitative method for the current study because we wanted to better understand the human experience of disclosing an eating disorder. We were not interested in quantifying the phenomenon. The qualitative method we have chosen for this project emphasizes the significance of being transparent regarding researcher positionality. The method also considers reflexivity to be of utmost importance during analytic inquiry. Situational Analysis (Clarke, 2005) is a postmodern, qualitative method that stresses the complexity of the focus of the project, also referred to as the “situation of inquiry.” This method contests approaches that reduce the situation down to the most salient or endorsed positions, and instead opens up the situation of inquiry to include marginalized perspectives and groups that are traditionally silenced by more positivist research (Clarke, 2005). Situational Analysis seeks to represent the complexity of a topic of focus by highlighting tensions, differences, elements, relationships, and silences that make up the situation of inquiry.

It was important to find a research method and a way of conceptualizing the situation of inquiry that would represent and acknowledge complexity without reducing information in order to make it seem neat and easy to understand. With this in mind, we searched for a method that would welcome nuances and help me to illustrate the situation as a complicated experience, just as how real life actually is: messy and complex.

Data Collection

Collecting information from publicly available websites has been widely used in past research, especially among researchers studying online eating disorder support groups and pro-ED websites (Bates, 2015; Brotsky & Giles, 2007; Giles, 2006; Harshbarger et al., 2009; Keller, Rosenthal, & Rosenthal, 2005; Lyons, Mehl, & Penebaker, 2006; Wolf, Theis, & Kordy, 2013). Inclusion criteria for websites to be considered for data collection were: (a) discussion on or related to disclosing an eating disorder; (b) at least five original posts discussing the disclosure of an eating disorder; (c) publically accessible, not requiring a username or password to review content; and (d) content must be in English. Search terms on the internet included: pro ana, pro anorexia, pro mia, pro bulimia, pro eating disorder, eating disorder support group, online eating disorder support, eating disorder recovery, and online recovery for eating disorders. Websites requiring a password and username were excluded and thus the study did not require research ethics review as all data was collected from publically available websites (Conjoint Faculties Research Ethics Board [CFREB], 2015).

After applying inclusion criteria, 11 potential websites were identified and used in data collection, including three pro-ED websites and eight eating disorder support websites. Analyzing data from both pro-ED and eating disorder support websites allowed us to understand the broader picture and the various discourses existing among individuals reporting disclosing an eating disorder. Within these 11 websites, 200+ original blog postings and replies were extracted for analysis. Following inclusion criteria, posts were selected if they included discussion on or related to disclosing an eating disorder (e.g., coming out to parents, getting caught, how not to get caught, factors preventing disclosure). Once collected, data was uploaded to NVivo computer software for analysis. NVivo allows for the collection, organization, and analysis of various types of qualitative information and enabled me to structure and visually portray the data in an organized manner. NVivo does not assign codes or analyze information itself, however, asking questions of the data was simplified using the features of this software. NVivo has been used to assist researchers using SA previously (e.g., Reisenhofer & Seibold, 2013; Smith et al., 2014).

Method of Inquiry: Situational Analysis

The voices of individuals with eating disorders are difficult to hear among the perspectives of health professionals and the mandates of treatment programs, therefore we sought to find a method that would enable these voices to be acknowledged. It was important to find a research method and a way of conceptualizing the situation of inquiry that would represent and acknowledge complexity. Before collecting data, we had hypothesized that our findings would represent varied experiences. We wanted to utilize a method that did not silence some voices and perspectives in favor of others that are traditionally privileged. With this in mind, we selected a method that would welcome nuances and illustrate the situation as a messy and complex experience.

Situational Analysis (SA) is a method, developed by Adele Clarke (2003, 2005) who wished to transform Grounded Theory (GT; Glaser & Strauss, 1967) into a postmodern adaptation capable of illustrating differences, variations, and multiplicities with greater postmodern finesse. Clarke (2005) contested GT's universal grand narratives, and instead developed an approach that explicitly mapped and represented complexity and untidiness. Clarke (2003, 2005, 2015) viewed Glaser and Strauss' (1967) GT as preserving the positivism and scientism of the 1950s and 1960s, and additionally proposed that Glaser and Strauss's GT was comprised of positivist "recalcitrancies" (2005, p. 11) requiring modification. Central to GT was the constant attempt to represent data in authentic ways, portraying truthful illustrations of perspectives, positions, intentions, and interpretations of research participants. For this reason, we selected SA over GT. We believe that life and the phenomenon that we study are complex and nuanced. We sought a method that would (a) capture differences rather than similarities, and (b) honor voices and experiences that represent various levels of power. Therefore, SA does not consider a point that is mentioned 50 times to be of greater significance than a point that was mentioned five times. Thus, we were interested in studying not just the positions or voices that hold the most power and therefore are heard the loudest, but rather a method that creates a space for all to be heard.

Situational Mapping and Analysis

Differences in a situation are highlighted with SA through the use of mapping processes that make contrasting positions explicit. Situational Analysis is comprised of three "analytic exercises" (p. 83) designed to promote deep examination of the data: (a) situational maps, (b) social worlds/arenas maps, and (c) positional maps (Clarke, 2005). These distinctive mapping techniques encourage new ways of thinking about data with the intention of opening up the data to provoke further analysis (Clarke, 2005).

Situational Maps

We began analyses by identifying the most important human and nonhuman elements (e.g., technologies, material things, specialized information) that made up the situation of inquiry. The primary goal of situational mapping was to broadly lay out the site of inquiry and the elements that comprise it, regardless of how peripheral they appeared to be (Clarke, 2015).

Abstract and messy situational maps. Situational maps aim to illustrate: Who and what make up the situation? What matters in the situation? What factors or actors make a difference to the situation? (Clarke, 2005). In the initial stage of situational mapping, we created abstract/messy situational maps that served as illustrations depicting all influential analytic human, nonhuman, symbolic, discourses, concepts, sites of debate, and material elements comprising the situation in an unordered format. Next, we organized our maps into

an ordered/working version, allowing categories to be listed neatly. Elements are typically organized into categories including individual human elements, political economic elements, silent/implicated elements, and discursive elements (Clarke, 2015). In this version, the same elements from the abstract/messy map appeared, however the organization of categories allowed for easier viewing of elements making up the situation. We continued to work on our situational maps until “analytic sufficiency” (Clarke, 2005, p. 28) had been met, or until there was an extended period since major changes had been made. Analytic sufficiency refers to a point in the analysis/mapping process when no additional information can add any further properties to understanding the topic of inquiry (Glaser & Stauss, 1967).

Relational analysis. Once the ordered situational maps were complete, we began to ask questions of our work and started to look at relations among elements of the inquiry. Systematically, relationships between each element and all others are considered. Lines were used to connect related concepts, and also to describe the nature of relationships. Relational analysis mapping helped us in deciding which stories to tell, and what relations to pursue in future mapping sessions.

Social Worlds/Arenas Maps

The second stage of mapping focused on better understanding social groups and collective action involved in situations (Clarke, 2005). Social worlds are defined as “universes of discourse” (Strauss, 1987), in which individuals come together or act as a group for the purpose of a particular issue. Many social worlds may be found inside arenas, as arenas in our project served to identify common themes of interest. This stage of mapping was concerned with the level of social action and how individuals become committed to specific social worlds by their participation in certain activities.

Positional Maps

The last mapping process offered a visual representation of major positions within the situation of interest. At a micro-level, positional mapping lays out the major positions taken on issues, absence of positions, silences, or differences of positions with regard to a particular controversy or situation (den Outer et al., 2013). Clarke (2005, 2015) stressed that positional maps are not representations of individuals, institutions, or groups, but instead positions in discourses. During positional mapping, we located positions of controversy, areas of tension, and heterogeneity, and displayed these dimensionally across two axes. Basic and contested issues were located across the map allowing us to view various positions evident in the data. Positions were depicted as they appeared within the data and taken up in the discourse. Further, positional mapping allowed us to illustrate silences within the situation.

Findings

We employed SA to better understand the online narratives of disclosing an eating disorder by recognizing the human actors, materials, privileged knowledge, positions, tensions, discursive elements in the situation of inquiry, and the relationships between these elements. Situational maps and illustrations were used as analytic exercises to simply us to think more deeply and move around the data (Clarke, 2005). Given these multiple stages of analysis and mapping techniques, we elected to present several key findings from our analytic endeavors. Rather than presenting each analytic exercise, which contain many sites of tension, difference, debate, actors, et cetera, we chose to illustrate three findings in the form of a project map, as it is more user friendly and less overwhelming for audiences to digest. The following findings

were chosen for presentation because through analytic exercises we found these points were the most contested, intensely argued, most heated sources of debate. Further, through mapping it was evident there was polarity and tension between these issues, and an obvious amount of strength and intensity, demonstrated through strong language and use of examples by participants. Moreover, these findings respond to significant issues highlighted in the literature such as the stigma associated with eating disorders (Dimitropoulos et al., 2016), divergent definitions of eating disorders (APA, 2013; Brown & Jasper, 1993), and the severity of eating disorders (Khalsa, Portnoff, McCurdy-McKinnon, & Feusner, 2017).

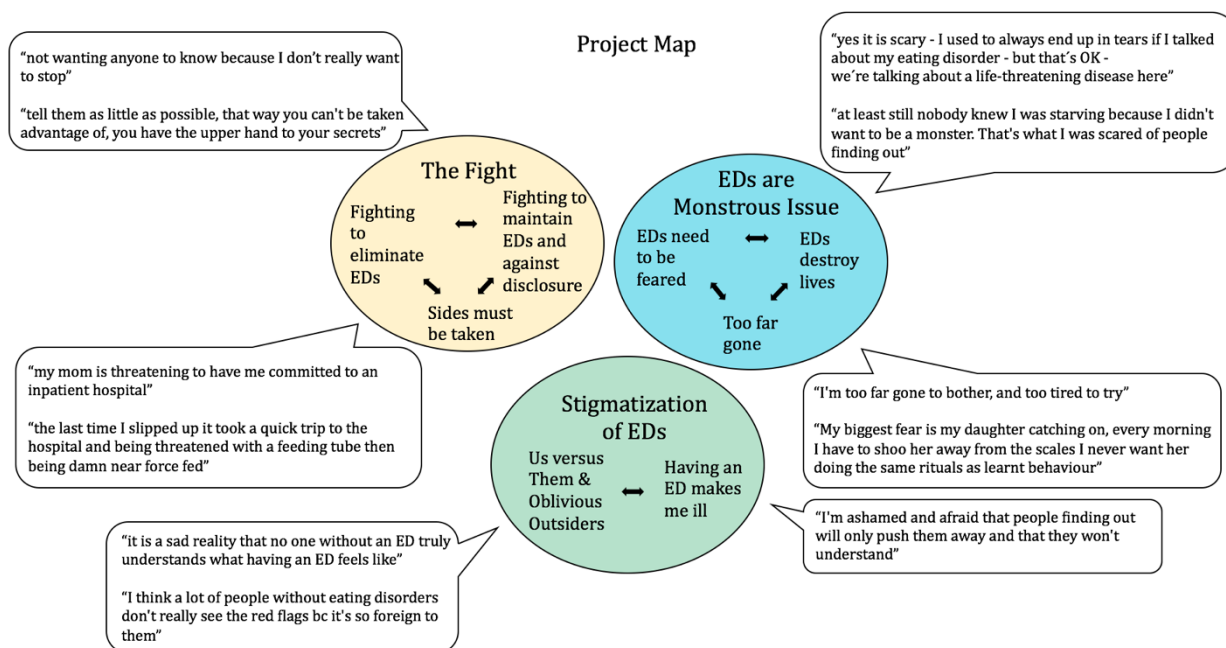


Figure 1. Project Map.

Project Map

Project maps are based on the three types of situational maps and are created with the purpose to “travel well” (Clarke, 2005, p. 137). A project map is a way of presenting findings. Quotations from participants have been included to further demonstrate participants’ perspectives and first-hand accounts of the disclosure experience. A SA project map is meant to allow for flexible knowledge dissemination and is an efficient way to share results with a broad audience (e.g., academic journals, eating disorder experts, individuals with eating disorders). This project map is comprised of positions that appeared during analytic exercises and points to (a) the fight that frequently occurs after an eating disorder disclosure, (b) the notion that eating disorders are a monstrous issue, and (c) stigmatization one experiences after disclosing and when considering to disclose.

The Fight

The yellow circle in the project map illustrates the multiple issues and pieces of evidence from the online data that suggest disclosing an eating disorder is considered somewhat of a fight. Not only is an eating disorder seen as something to be battled, but those involved must also take sides, fighting to eliminate the eating disorder or fighting to maintain it. The experience of those with an eating disorder being forced into treatment was often visible within

the online data. One participant stated, “I am currently being threatened to go to residential at the hospital.” Another participant said:

My mom is threatening to have me committed to an inpatient hospital (the same one I went to when I was 17). I just had a conversation with her and it ended with her yelling at me and saying she's going to call 911 and have me taken to the psych hospital. I honestly cannot take her threats and yelling anymore... I've tried telling her that threatening me is unhelpful. But truthfully, I'm scared she will actually commit me...I am an adult now, but can she still force me into inpatient against my will?

In both of the above quotations, the participants were referring to family members who were *threatening* treatment, and according to the data this appears to be a common occurrence. Not only do families have to take sides but hospitals and treatment facilities also take a side; to eradicate the eating disorder whether the individual with the eating disorder wants this or not. The sides different groups take against an eating disorder are often not subtle and agendas are pursued forcefully. One participant described her experience at the hospital “the last time I slipped up it took a quick trip to the hospital and being threatened with a feeding tube then being damn near force fed.” From past experiences of either feeling threatened or being admitted to health centers, individuals with eating disorders have learned that others (e.g., medical staff, families) have decided to fight against the eating disorder and do so physically and forcefully.

Eating Disorders Are a Monstrous Issue

The positions within the blue circle on the project map are intended to demonstrate that social and discursive forces, such as the use of language, add to the perceived severity and fear of eating disorders. Participants communicating online frequently used terms including *battle* and *fight* to describe their relationship with their eating disorder, and also referred to themselves as *monsters*. One participant stated “at least still nobody knew I was starving because I didn’t want to be a monster. That’s what I was scared of people finding out,” evidently pointing to how the individual saw themselves in relation to the struggle. Calling oneself a monster and being fearful of others learning of one’s eating disorder was echoed by several individuals communicating online, and points to the use of language (e.g., monster) and how it is perpetuating this position. Another person online stated “I’m scared the therapist will think I’m being ridiculous. It’s not that easy of a battle, and I’m scared that he or she will write me off.”

Not only did individuals communicating online refer to themselves as monsters, but they also characterized the eating disorder itself as a bigger monster compared to other mental illnesses. Participants communicated these messages in several ways. First, participants used language, referring to their eating disorders as life threatening, medical disorders, “...we’re talking about a life-threatening disease here.” This dominant discourse referring to the fatality of eating disorders fuels people’s fear and contributes to the position that eating disorders are a monstrous issue. Second, best practice for eating disorder treatment typically involves a team of professionals (de Amusquibar, 2000; Luzier, Sondike, Linton, & Mizes, 2012), all contributing a different specialty to the recovery process including medical doctors, psychiatrists, psychologists, nurses, and nutritionists. The idea that eating disorder treatment requires a team rather than a single professional also adds to the fear that eating disorders are a bigger monster than other mental illnesses.

Further, during online discussions regarding the desire to disclose, some participants endorsed the belief that they were *too far gone* to conceal their eating disorder anymore.

Demonstrating that eating disorders can become extreme both physiologically but also emotionally, one participant stated, “I used to lie to my parents a lot, but then my problems just became so prominent that I couldn't hide them anymore so I've just stopped caring.” When eating disorders are referred to as *constant battles* and those experiencing them are referred to as *monsters*, it reinforces the notion that eating disorders are powerful enough to destroy lives.

The Stigmatization of Eating Disorders

The green circle of the project map illustrates the positions that contributed to experience of stigma related to having an eating disorder and disclosing this to others. The “us versus them” discourse apparent in the data and presented in the project map acknowledges how individuals with eating disorders feel when others (e.g., parents, families, friends, partners, doctors) do not appear to understand their eating disorder. One participant said, “you are right: it is a sad reality that no one without an ED truly understands what having an ED feels like.” Some participants communicating online expressed frustration when opening up to others and being met with responses that demonstrated others’ perceived misunderstanding of their experience. Further, participants reported feeling like even medical professionals did not understand what having an eating disorder was like, “my doctor, who is aware of my past with anorexia and current issue with bulimia...offered me prescription diet pills *sigh* I'm tired of trying to educate my doctors.” Unfortunately, it appears that once participants have built up the courage to ask for help they are occasionally met with offensive or uninformed responses, reinforcing the notion that they are misunderstood and alone to deal with their disorder. These beliefs of being alone in their experiences, and being different than others without eating disorders, adds to the stigmatization of eating disorders and leads individuals to further conceal their struggles.

In summary, the project map illustrates salient issues that together make up our broad understanding of the complexity of disclosing an eating disorder. As is evident from this project map, better understanding the disclosure process of eating disorders is a controversial issue. The experiences of participants ranged so greatly that it seems difficult to draw just a few conclusions from the data. For this reason, we have presented the broad hot button issues that comprise this situation of inquiry, and by doing so highlight the complicated nature of disclosing an eating disorder.

Discussion

The Fight for and against Eating Disorders

Individuals communicating online often spoke about being fearful that others would take their eating disorder away, whether that be through treatment or others keeping a closer eye. Many participants communicating online mentioned the stress within their families after they had disclosed their eating disorder. The noted fight for and against the eating disorders resulted in tensions between family members, as evidenced from participants’ online communication. Further, participants wrote about the need to keep their eating disorder concealed, so that no one could take it away from them through methods such as treatment or more watchful eyes from family members.

The literature presents numerous treatment options available to decrease eating disorder behaviours and cognitions. One such piece of literature refers to the roles families play in the draining recovery process. Brown (2011) recounted personal experiences of feeling helpless and passive in the recovery process of her daughter’s struggle with anorexia nervosa. Brown positioned a parent’s role to a child with an eating disorder akin to being “locked in a kind of

mortal combat with someone we could not and did not want to understand” (2011, p. 457). This arguably severe use of language paints a picture of a tense situation where parents want to take action against the eating disorder that is taking hold of a child. Conversely, Brown (2011) also acknowledged a contrasting position that described some individuals with eating disorders as insisting nothing is wrong and they are in fact healthy. The insistence of health and denial that anything is wrong, according to Brown (2011), leads to a treatment process marked by a challenging trajectory often resulting in parents and children taking opposing sides. This struggle was also reflected in this research. Participants frequently mentioned family members, particularly parents to be hyper vigilant towards body shape, food, and meal times and acting as food enforcers, leading to tensions. Multiple participants made reference to the “food police” and explained that family members often reminded individuals with eating disorders that there needed to be a change in caloric consumption or treatment would be the next alternative.

Eating Disorders as a Monstrous Issue

Discourses about fearing eating disorders were present within the data. Words including *battle*, *fight*, and *monster* were used online to describe the personal experiences of those with eating disorders. Individuals in the online forums communicated that eating disorders were a bigger, scarier issue compared to other mental illnesses. The importance of how language is used when describing an eating disorder has also been taken up in related research (Malson et al., 2011).

Researchers curious about the role that language plays in constructing meaning, making sense of eating disorders and recovery, conducted interviews with 39 individuals hospitalized for anorexia nervosa and bulimia nervosa (Malson et al., 2011). When inquiring about recovery, participants frequently mentioned that imagining themselves recovered from an eating disorder was “impossible” (Malson et al., 2011). The inability to even imagine oneself as recovered points to the self-constructions of participants involved in the research but is also echoed in the cultural discourses regarding eating disorders prevalent within Western society. Malson and colleagues (2011) described the common experience of body dissatisfaction in Western societies, especially for females, and indicated that imagining a time when participants might expect to be free from these concerns seemed unlikely. Individuals interviewed also described having an eating disorder as “wasting your life” and one participant indicated it “feels as if I’ve been asleep for four years” (Malson et al., 2011, p. 31). Malson and colleagues used discourse analysis and suggested that individuals feared missing out on important life events and were also concerned about their eating disorder taking over their lives and potentially enjoyable moments in the future. Participants in Malson et al.’s (2011) study used language similar to, if not the same as, the participants in the current study used. For example, one individual described her experience with her eating disorder as a “constant battle” (Malson et al., 2011, p. 29). Participants in our study also used *battle* and *monster* to describe their experiences with eating disorders. The fact that individuals are referring to their experiences of living with eating disorders as *battles* and *fight*s reinforces the notion that we must be fearful and suggests that eating disorders are powerful enough to destroy lives.

Stigmatization of Eating Disorders and Disclosure

Experiencing and anticipating stigma prior to and after disclosing an eating disorder was a widely presented experience within the online data in this study. Participants frequently reported being fearful of what others would think and how others would respond after a disclosure. The experience of stigma in some instances was more intense when the recipients of disclosure placed blame and/or attributed the development of an eating disorder to personal

fault or choice. Reactions to disclosure were reported as particularly hurtful when (a) the recipients held negative beliefs about eating disorders, and (b) recipients believed that vanity and attention were the purposes of an eating disorder. These experiences are reflected in stigma research regarding eating disorders (Dimitropoulos et al., 2016).

Dimitropoulos and colleagues (2016) proposed that the general public believe individuals with eating disorders can simply (a) pull themselves out of it and (b) only have themselves to blame for their eating disorder. This research supported the notion that individuals with specific mental and physical illnesses are further stigmatized because of the blame attributed to their condition (Dimitropoulos et al., 2016). Nineteen qualitative interviews with females receiving intensive inpatient treatment for anorexia nervosa demonstrated that all participants believed that the general public did not view eating disorders as an illness (Dimitropoulos et al., 2016). Instead, participants used words like *crazy* or *weird* to describe how they believed the public viewed them (Dimitropoulos et al., 2016). The perception that the public did not consider eating disorders to be real illnesses often lead participants to conceal their eating disorders, due to fear of further stigmatization (Dimitropoulos et al., 2016). Further, participants expressed that the general public misjudged the causes of eating disorders, giving examples that the public believed that people with eating disorders had “simply a desire to emulate celebrities and models” and engaged in extreme practices for vanity (Dimitropoulos et al., 2016, p. 50). Taken together, the ignorance and/or misunderstanding that the general public has towards those with eating disorders plays a role in the stigma experience.

As demonstrated in our study, participants communicating online expressed concern, frustration, and even agitation when others around them were not able to understand what it was like to have an eating disorder. The notions of “us versus them” and “oblivious outsider” were demonstrated with examples about doctors prescribing diet pills to patients they knew had struggled with disordered eating, parents pushing quick fixes on a child who had disclosed an eating disorder, and frustrations surfacing when others did not notice unhealthy behaviours or weight loss. Some participants also made comments about health professionals not being able to understand what having an eating disorder was like if they had never personally experienced one.

In summary, given the variance in reported experiences, this study has implications for clinicians working with individuals diagnosed with an eating disorder. Not only must clinicians be prepared to address a variety of presenting concerns when working with individuals with eating disorders, they must also consider how and when to include families and other recipients of disclosure into the treatment. These individuals may very well be looking to take up arms against the eating disorder, hold stigmatizing attitudes about the eating disorder, or be an oblivious outsider about the eating disorder, all of which would add to the complexity of clinical practice.

Strengths and Limitations

There are both strengths and limitations to this study. First, to the best of our knowledge, this is the first project to use Situational Analysis when studying online communities. This speaks to the innovation of the current study, as it has not only added to the limited understandings of disclosing an eating disorder but has also introduced a new way of studying the experience. By using Situational Analysis, our research allowed positions that are traditionally silenced to be recognized.

Second, the participants communicating on online eating disorder communities represented many stakeholders involved in eating disorders from pro recovery to pro eating disorder perspectives. Online communities also included the perspectives and experiences of

those who recovered from an eating disorder. The multiple perspectives visible in the data offered numerous insights into the situation of inquiry.

Though our study had several notable strengths, it was not without its limitations. First, although online data was practical and simple to access, we could not directly ask participants with eating disorders our research question. In the absence of direct contact with the population of interest, we had to interpret already existing dialogues, looking for information that would help us better understand the situation.

Second, due to the nature of data collection and gathering information from anonymous websites, a major limitation to this project is that we do not know who our participants are. The majority of individuals communicating online included photos and screen names, however we cannot make assumptions about intersecting cultural identities from this limited information. The few characteristics we have about the sample include (a) English speaking, however English may be a second language, (b) access to a computer and internet, (c) many discussed receiving inpatient and outpatient treatment, possibly suggesting they live in countries with free healthcare or they/their families had financial means to cover these costs, and (d) in contrast, some individuals discussed the financial stress of treatment.

Research suggests that non-dominant populations and individuals belonging to stigmatized groups utilize anonymous online communities to a great extent (Berger, Wagner, & Baker, 2005; Willis, 2012). Online research methods and online communities are ideal locations for populations who may feel uncomfortable or not safe disclosing their identity in public arenas (Mann & Stewart, 2000). Mckenna and Bargh (2000) suggested that individuals feeling lonely, socially isolated, and struggling to form face-to-face relationships are more likely to develop relationships online. Internet communities may also be especially helpful for individuals who desire a high level of anonymity when discussing their identity, especially those with invisible stigmas (e.g., LGBTQ* populations, individuals with mental illness; Trau, Härtel, & Härtel, 2013).

To the best of our understanding, research about the experiences of recipients of eating disorder disclosure has not been conducted. In the future, interviewing recipients of disclosure could provide valuable understandings of the phenomenon that would not have been possible by simply interviewing the individual who disclosed. It seemed apparent from current literature on disclosure and based on our findings that the experience is a relational process, therefore including perspectives from all involved would enrich our current understanding

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Article Citation

Williams, E. P., Russell-Mayhew, S., & Ireland, A. (2018). Disclosing an eating disorder: A situational analysis of online accounts. *The Qualitative Report, 23*(4), 914-931. Retrieved from <https://nsuworks.nova.edu/tqr/vol23/iss4/14>
