Out of the Clinic, Onto the Web: Narratives of Relapse during Eating Disorder Recovery on Reddit

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Abstract

With recovery rates cited from 0% to 92%, the conceptualization of eating disorder [ED] recovery remains murky within the field. An understudied component of recovery is the occurrence of relapse, which can be a determining factor of illness outcome. This study navigates the written expressions of relapse events from users of the social media site Reddit. The research aim is to explore users' narratives in relation to relapse triggers, the definition of relapse, the experience of relapse, and the support received by other users in the face of such written expressions". Through narrative and thematic analysis, individual posts will be explored to establish a greater understanding of how relapse is given meaning by those who experience it to construct a frame of reference for common relapse experiences. Posts with comments on eating disorder forums written between March 2022 and May 2022 will be extracted and then coded for sentiments, symptoms, and themes. I will discuss found commonalities in the lived experiences and how these insights can be used to better the conceptualization of relapse in ED recovery. I will also speak on how this data relates to current knowledge and practice in the eating disorder community and how health approaches can be adapted with greater awareness of sufferers' experiences. Lastly, I will comment on the use of social media as a means of expression in relation to mental health disorders, and if these forums are a tool or detriment to the delicate process of eating disorder recovery.

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1.1 – Eating Disorders: Definitions, Prevalence, and Outcomes

Diagnostic classification

The persistent symptoms of eating disorders go much deeper than ritual fasting or fad diets. Eating disorders are categorized by behavior and belief, with eight types listed in the Diagnostic and Statistical Manual V [DSM-V]. Each disorder is defined with specific diagnostic criteria that must be met in order to receive a said diagnosis (American Psychiatric Association [APA], 2013). The DSM-V first recognizes disorders such as pica, rumination disorder, and avoidant/restrictive intake disorder. However, as these disorders are most prevalent in early childhood and are less common, this thesis will focus on the five disorders that follow: anorexia nervosa, bulimia nervosa, binge eating disorder, other specified feeding or eating disorder, and unspecified feeding or eating disorder. The order in which these disorders are listed in the DSM is not significant in terms of classifications, prevalence, or severity, however, the last five disorders that are listed are often the ones in mind when discussing eating disorders in a clinical setting or within media.

Diagnosis of anorexia nervosa [AN] relies on having a "significantly low weight", though this is in relation to what the patient's own 'normal' weight range is (APA, 2013). Low weight must be paired with disordered eating caused by a fear of weight gain and body disturbance, with disorder severity marked by body mass index [BMI] (APA, 2013). Bulimia nervosa [BN] is listed next, which is described as bingeing with behaviors used to avoid gaining weight such as purging or laxatives (APA, 2013). The severity of BN is marked by the number of episodes of purging (APA, 2013). The following eating disorder is binge eating disorder [BED], which refers to binge eating with distress, and severity is measured by the number of binges per week (APA,

2013). These disorders are followed by two other disorder types: other specified feeding or eating disorder and unspecified feeding or eating disorder [often referred to as EDNOS]. The former includes subtypes of less severity, such as AN without weight loss or purging disorder, while the latter refers to disorders that do not meet all of the criteria or have atypical presentations but still cause psychological impairment (APA, 2013).

The age of onset for this second set of eating disorders is typically in early teen years or early adulthood (Makino, Tsuboi, & Dennerstein, 2004). The first three diagnoses (AN, BN, BED) typically define frequency and duration criteria for each disorder, and presentations of symptoms outside of those criteria are often diagnosed as EDNOS. For example, the diagnosis for bulimia nervosa cites that "the binge eating and inappropriate compensatory behaviors both occur, on average, at least once a week for 3 months" (APA, 2013). These criterions also correlate to severity markers of the disorders, where in the case of BN, an occurrence of one to three of the episodes mentioned above per week is mild, whereas eight to thirteen episodes per week is labeled as severe.

Prevalence

Prevalence rates of EDs vary depending on country and ethnicity, though recent meta-analysis estimates the prevalence of anorexia, bulimia, and binge eating disorder within a lifetime to be 0.89%, 1.41%, and 1.53% respectively when using DSM-V criteria (Qian et al., 2021). These statistics are pooled data from several worldwide epidemiological studies, so different populations may have higher or lower rates. EDNOS prevalence is estimated to be around 3.95%, signifying that ENDOS makes up the majority of eating disorder incidences (Galmiche, et al., 2019). Prevalence is generally higher among young people and females. While

epidemiological studies are useful for exemplifying trends among defined populations, it should be noted that these results are often an underestimation due to low rates of help-seeking and detection (van Eeden, van Hoeken, & Hoek, 2021). One literature review on ED rates between 2000 and 2018 presented the weighted mean of how many people will have an ED during their lifetime to be 8.4% (Marie et al., 2019). Sub-clinical eating disorders (or disturbed eating problems) are even more common, with one study reporting that up to 74.5% of the study population (women ages 25-45) felt as if weight and shape concerns disrupted their happiness and 31% had enacting in purging to control weight gain (Reba-Harrelson et al. 2009).

Eating disorders are often denoted as a symptom of Western culture, which is perhaps a reaction to the high rates of EDs in Europe, Australia, and the United States (Makino, Tsuboi, & Dennerstein, 2004). Though it should be noted that disability-adjusted life years for ED burden have increased at the highest rates in African, Middle Eastern, and Asian countries in the last years (Makino, Tsuboi, & Dennerstein, 2004). Some consider this to be from influences of Western media, however eating disorders in such countries often have differing presentations, such as anorexia without a weight-gaining phobia (Makino, Tsuboi, & Dennerstein, 2004).

Treatment and Outcomes

Recovery from eating disorders can be independent, meaning an individual takes steps towards recovery outside of a clinical setting, or recovery can occur with treatment. Eating disorder treatment is far from standardized, though many studies have highlighted certain factors that are often linked to more positive outcomes. Federici and Kaplan list these factors as “social support, motivation for change, developing an identity independent from the eating disorder and factors related to the therapeutic alliance” in their study on patient recovery narratives (2008).

Through meta-analysis, rates of treatment-seeking have been shown to be highly variable, from around 41% to as little as 8% (Hart et al., 2011). One study even cited a 0% prevalence of treatment-seeking among their population of female adolescents (Meyer, 2001). Recovery rates for eating disorders are equally varied, as researchers and medical professionals often define recovery by different criteria. Different classifications such as good versus poor recovery or full versus partial recovery make it difficult to provide an accurate estimate of recovery rates, and the presented rates ranged from 8% to 88% in one meta-analysis (Berkman, Lohr, & Bulik, 2007).

These issues within treatment availability and help-seeking unfortunately coincide with the high rates of mortality, especially when considering psychological disorders. Anorexia has the highest mortality rate among psychiatric disorders, with an estimated 5% (Agras, 2001). As a mental disorder that substantially affects the body, AN often coincides with osteoporosis, cardiovascular complications, impairment of cognitive function, and significantly decreased fertility (Agras, 2001). These symptoms can lead to eventual failures of organ systems, typically cardiovascular in nature. Mortality rates for bulimia have varied in reports, with the standardized mortality ratio [SMR]spanning from 1.9% to 3.9% (Smink, van Hoeken, & Hock, 2012). BN often causes irreversible dental issues, along with damage to the digestive system. Electrolyte imbalances are the most common cause of death with BN (Jáuregui-Garrido & Jáuregui-Lobera, 2012). Researchers have estimated binge eating disorder to have an SMR of 2.29 (Smink, van Hoeken, & Hock, 2012). The consequences of BED are closely intertwined with those of obesity, which increases the risk of cardiovascular disease and metabolic syndrome symptoms, though these can affect non-obese patients as well (Mitchell, 2016). Lastly is ENDOS, which accounts for the largest population of eating disorder sufferers. ENDOS has been reported to have an SMR between 1.9% and 5.2% (Smink, van Hoeken, & Hock, 2012). As ENDOS can include

symptoms and behaviors from all the other ED diagnoses, complications can be a combination of the ones mentioned above. As previously displayed, most statistics surrounding the prevalence and outcomes of eating disorders are presented in ranges, some with larger ranges than others. The variability surrounding eating disorder statistics may be attributed to underdiagnosis or varying follow-up periods during studies.

Diagnostic criteria, prevalence, and outcomes all provide important aspects for understanding eating disorders; however, these statistics and definitions do not describe the entire experience of having an eating disorder. Some researchers are calling for more open investigations into the understanding of eating disorders, where lived experiences are a central focus instead of pooled data on trends of the disorder or self-reported questionnaires relating to diagnostic framework (Patching & Lawler, 2008). Patient perspectives can assist in developing a more comprehensive framework of what eating disorders are and how individuals are affected by having an ED.

1.2 – Relapse in Eating Disorders

One common aspect of the experience of an eating disorder is the presence of relapse. Relapse is not an eating disorder-specific term, and different fields generally use relapse to describe an event of returning symptoms or behaviors after a period of improvement. For example, in reference to addiction, this could relate to once again drinking or gambling after a time of abstinence. Practitioners also use relapse in regard to disease, cancer, or mental health disorders. In the context of eating disorders, the definition of relapse is not always clear in current literature. Presently, researchers have failed to create a consensus on what relapse is and how it presents itself. Broadly defined, relapse is the reoccurrence of ED symptoms after a period of recovery or abstinence from certain behaviors. What further constitutes a relapse

remains a debated topic between researchers, clinicians, and patients, which illustrates a central issue in the conceptualization of ED relapse. Conceptualization refers to the process in which observations and experiences are brought together to create a coherent whole of one concept (Bardone et al., 2010). For relapse, conceptualization can include physical, behavioral, and psychological indicators or experiences.

The conceptualization of relapse has been shown to be varied across research. A meta-analysis completed by Berends, Boonstra, and van Elburg compiled the definitions of relapse used in anorexia nervosa published research, which resulted in a full spectrum of conceptualizations (2018). Out of the 16 selected research papers, six groups of researchers stated relapse required a return of full symptomology, while five referenced relapses in terms of any increase or return of ED behaviors (Berends, Boonstra, & van Elburg, 2018). Many researchers included weight as an indicator, though this too varied from a specific BMI to the percent of weight lost (Berends, Boonstra, & van Elburg, 2018). The periods in which relapse criteria must occur over as stated by each research group also ranged from one week to a one-year period (Berends, Boonstra, & van Elburg, 2018). As for bulimia nervosa, a meta-analysis of BN relapse highlighted similar issues. Bulimia relapse is mostly defined as a return of binging and purging episodes, however, the temporal aspect of symptom presence spanned from four weeks to eight months (Olmsted, Kaplan, & Rockert, 2005).

These research definitions tend to be criteria-heavy, as the goal of precisely defining relapse is to enable empirical examination of relapse prevalence or treatment efficacy. Clinicians or treatment specialists will sometimes use these strict definitions, though some healthcare professionals refer to relapse more broadly as a return to previous coping mechanisms. Patient definitions are typically explored more in qualitative research, though very few studies focused on relapse as a

central theme. For example, Federici and Kaplan completed a research study with the intention of exploring narratives of female patients regarding their personal experiences and views towards their illness after a period of recovery (2008). Among other insights, an observation from this study was that the weight-relapsed patients did not identify as relapsed and felt as though the research classifications did not represent their personal experience of their disorder (Frederici & Kaplan, 2008). What patients consider to be relapse was not discussed, and patient conceptualizations are infrequent in the literature. Some research on social media narratives of eating disorders has mentioned relapse being an important aspect of recovery that entailed negative events or setbacks (Goh et al., 2021, & Bohrer, Foy, & Jewell), though these studies did not present further descriptions of how relapse was defined.

The mixed consensus on relapse definitions has led to varied statistics in other research topics, such as studies on relapse timing and prevalence. Much of the current literature on relapse explores relapse as a specific outcome for one DSM eating disorder. A major focus in studies was mapping out relapse timing and rates. In a meta-analysis of studies dealing with AN, relapse rates ranged from 10.8% to 57.4% (Berends & van Elburg, 2018). Studies showed that relapse occurred at higher rates within the first year of discharge from treatment and risk continued for "up to two years" (Berends & van Elburg, 2018). According to Clausen, BN patients and ENDOS patients tended to have a better outcome than those with anorexia, which was shown in the results of their study with remission rates for AN, BN, and EDNOS patients being 37%, 53%, and 69% respectively (2006). It should be noted that these rates are determined using researcher definitions of relapse, and patients may or may not agree with being classified as relapsed.

Researchers have also investigated predictors of relapse alongside triggers. A predictor of relapse is generally thought of as either the degree of a trait a patient has, such as fear of weight gain or

body dysmorphia, or as the presence of related factors such as comorbidities (obsessive-compulsive disorder, depression, etc.). In the same meta-analysis that reviewed relapse rates, predictors of relapse were organized by statistical significance. Predictors with the greatest statistical significance were decreased motivation, the subtype of AN, "misperception of body", fear of weight gain, and higher amounts of checking behavior at admission into treatment, while also stating that relapse was more likely for those who 'partially recovered' (Keel et al., 2005). Worth noting is that these predictors are quantitatively assessed, where scores of behaviors are correlated with relapse rates. These predictors do not reflect what research participants view as their own personal obstacles. Relapse predictors are used to indicate individuals who may be at higher risk when encountering 'triggers', which commonly refers to "anything that activates, prompts, or maintains" eating disorder thoughts and behaviors (Wasson, 2003). Triggers are generally personal in nature, but qualitative research has shown that participants describe triggers as being able to be both positive or negative emotions [internal triggers], or environmental and relational triggers [external triggers] (Wasson, 2003).

By reviewing the topics that have been investigated the most in relation to eating disorder relapse, it is evident that the voice of patients or those with eating disorders is either missing from studies or incongruent with how researchers and clinicians operationalize relapse. In the literature, the event of relapse encompasses defined symptoms that can be influenced by predictors and triggers. Where clinical definitions of relapse provide clear, operationalized descriptions of what a relapse is, patient narratives work to 'flesh out' the conceptualization of relapse, adding the contextualization of a lived experience. In addition to symptoms or behaviors, patient narratives of relapse can be used to create a frame of reference for the experience of a

relapse event and the time leading up to it. Researchers have approached the inclusion of lived experiences through both clinical interviews and online media studies.

The benefit of online studies is the ability to have a more naturalistic approach to interpreting patient accounts. This type of methodology has increased in popularity as internet use expanded, and eating disorder researchers took to online ED discussion groups to find insights on lived experiences with the disorders. Relapse however often took a back seat. In Keski-Rahkonen & Tozzi study, 148 messages from an online ED discussion group were coded to match the five stages of recovery proposed by the transtheoretical model of change, with relapse being the fourth stage (2005). Out of all five stages of change, relapse had the fewest contributions after the results were organized, and most messages spoke of relapse from months prior (Keski-Rahkonen & Tozzi, 2005). It was proposed that the lack of relapse content was due to the shame associated with 'failing recovery' (Keski-Rahkonen & Tozzi, 2005). When mentioned, relapse content was paired with themes of disappointment and pseudo-recovery and user tone was often negative or ironic (Keski-Rahkonen & Tozzi, 2005). Another study was completed using Reddit as a research site, where the conceptualization of recovery was investigated, which included the presence of relapse (Bohrer, Foyer, & Jewel, 2019). In anonymous threads dedicated to EDs, many sufferers spoke about the existence of relapse within recovery, stating it is "a normal and oftentimes necessary part of the recovery process". Numerous commenters described recovery as a constant process, with contemplation being a key aspect of the journey during periods of debating between recovery and relapse (Bohrer, Foyer, & Jewel, 2019). From this, researchers emphasized the highly personal nature of EDs and advocated for personalized treatment goals over set measures required for remission (Bohrer, Foyer, & Jewel, 2019). While these studies introduced more patient perspectives to eating disorder research, recovery was explored much

more frequently than relapse. This has led to relapse, a common part of a lived experience with an eating disorder, to become missing from certain frames of reference for eating disorders.

1.3 – Introduction to Thesis Work: Narratives on Reddit

Using internet forums on Reddit as a research site, the proposed research aimed to uncover a "patient-first" conceptualization of relapse in ED, which included personally identified risk factors or triggers of relapse. Data on how sufferers express and navigate through their own perceived 'relapse' provided a greater understanding of the concept of relapse outside of the researcher-clinician lens. As shown in the discussed literature, definitions of phenomena are generally set by researchers or clinicians with less input from those who are experiencing the events. The narratives of individuals facing ED relapse should be voiced in conceptualization discussions as those individuals often know best how their disorder presents itself. Due to the use of internet forums, this study had the unique benefit of hearing from people in the moments of first relapsing, which differed from clinical interviews that often ask for reflections upon a prior or ongoing relapse. Additionally, the use of online data provided access to those with EDs that do not come from treatment centers, as well as gaining data without observation bias. By examining a large number of these narratives, we have both a basis for better, more informed treatment and a representation of the disorder to inform the public with – especially when individuals may be too anxious to share struggles in a formal research setting out of fear of judgment or repercussions.

The main methodology of the proposed study was narrative analysis via analysis of Reddit forum posts. The strength of narratives originates in the empowerment felt by those with illness when they are able to express what is happening to them as a person, not a medical subject. People are

more often able to process difficult experiences through storytelling, which is why patient narratives have had an important place in advocacy, policy-making, and qualitative research. While statistics and cost-benefit analyses are compelling tools for representing illness outcomes or treatment efficacy, the patient is often lost behind these numbers if a narrative is not included. The use of patient narratives in medical research was not always a popular practice. Healthcare innovation from narratives began with questioning the use of standardized medical descriptions of illness where patients diagnosed with a disease were grouped into one illness course (Greenhalgh, 2016). Howard Brody, a bioethicist and physician, spoke often about the imperative to combine both stories of illness and medicinal models (1998). Without both accounts, "we dehumanize the patient, fail to address him or her as an individual, and ultimately may very well increase the patient's suffering" (Brody, 1998).

The use of Reddit provided additional benefits to this study such as combating observer bias, where the presence of researchers can unintentionally influence results (American Psychological Association, 2023). For example, methods such as focus groups or interviews can lead to participants not feeling comfortable disclosing all information (Frederici & Kaplan, 2008). Social media sites however have become data-rich sources where narratives are shared with less thought of what is appropriate to say or what a researcher may want to hear. On Reddit, users are anonymized by posting under a chosen username and are not required to display any identifying information (i.e. age, gender, nationality). With this anonymity, users have the ability to candidly discuss eating disorders without fear of repercussions or judgment. This concept of disinhibition has been cited in previous research dealing with anonymous websites (Pinsonneault & Heppel, 1997; Suler, 2004; Mathew et al., 2018). Researchers found that anonymity aided community discussions surrounding stigmatized topics and increased the sharing of personal and sensitive

text (De Choudhury & De., 2014; Mathew et al., 2018). Additionally, online forums may have participants from outside of the clinical world, which is a valuable asset to ED research. Considering that only approximately half of anorexia nervosa cases are caught by the healthcare system, with an even smaller proportion receiving treatment, many ED sufferers likely go without diagnosis or contact with healthcare workers (Bulik et al., 2006). Online forum users can potentially represent the voices left unheard in the current body of ED literature that focuses on treatment-receiving patients.

In terms of the current study, narratives were defined as the text posts on Reddit in which community members construct their personal experiences of ED relapse. Patient narratives are a needed addition to the development of a meaningful operationalization of the term "relapse", which in term leads to a more holistic understanding of eating disorders. Beyond this, relapse narratives can assist in informing medical professionals and the public about how eating disorders severely impact the lifeworld of a sufferer. Eating disorders are often misunderstood, with many asking, "why don't they just stop?". The narratives collected in the current research helped exemplify that eating disorders are not a choice and that recovery is often an uphill battle. Themes of relapse were coded throughout each narrative and data analysis led to further insights on each topic approached within the literature review: conceptualization, triggers, overall experience, and important individual expressions of what living with an eating disorder means.

Chapter Two: Methods, Study Design, and Ethics

2.1 – Study Aims & Objectives

This study was designed to analyze how relapse is triggered, conceptualized, and experienced, as voiced by users of the social media website Reddit. This aim was addressed by examining narratives of relapse from community members of eating disorder forums on Reddit. While addressing how users conceptualize their relapses, user-defined causes of relapses can be examined, as well as how individuals explain the development of relapse. How community members discuss these issues also revealed degrees of hopefulness and self-agency and if community members believe relapse to be deliberate, accidental, or caused by an environmental trigger. Many people with EDs state that recovery is a constant choice (Bohrer, Foyer, & Jewel, 2019), so it was worth noting if relapse is regarded as the same by those who experience it.

A second aspect of this study was to summarize the emotions and sentiments expressed when discussing relapse, along with the thoughts and behaviors discussed by ED sufferers in relation to relapse, themselves, and their environment. Results correlating to these themes helped build a frame of reference for clinicians and provide concrete factors to include in a relapse definition. Lastly, there was an aim to determine the significance of relapse to each individual commenter. This was examined through how individuals relate relapse to their life and disorder outcomes. As relapse occurs within a disorder, it was important to summarize how community members discuss their relapse in relation to their entire experience of having an eating disorder. Lastly, the use of Reddit for eating disorder discussions and online research ethics were debated as I reflected upon the methodology of this study.

2.2 – Study Design

The study design of this research project was a social media site-based qualitative study that used narrative and thematic analysis to navigate written expressions of personal experiences surrounding the event of relapse. As a methodology, qualitative research strives to investigate meaning in "real-world conditions" (Yin, 2016). This is especially true for this research study as the voices of those who experience ED relapse were brought to the center of the discussion, rather than solely relying on clinically defined categories and descriptions. With an open-ended investigation on forums, narrative analysis allowed for the viewpoints of participants outside of pre-established questionnaires. In this sense, those who experience relapse were directing the conversation.

The data of this study was approached inductively, and the analysis was designed to reflect the perceptions of those with eating disorders without attempting to theorize secondary meanings or interpret unwritten motivations. Grounded theory was used in the analysis, where potential themes were identified after engagement with the data. Grounded theory supported the aims of this study as personal experiences were approached with an openness to any possible meaning rather than organizing narratives into pre-determined categories based on what I as a researcher believe to be important. Reflexivity as a researcher had an integral role in this process as I did not want my personal beliefs to shape the results, but rather wanted the voices of participants to guide this study.

2.3 – Study Site

To collect narratives of relapse in ED, I harvested posts from Reddit, a community-based social media website, or platform. Shown below is an example of how a post typically looks on a subreddit, followed by definitions of each aspect.

Figure 1

Subreddit: a group of forums in which users post content related to a specific topic. Subreddits are often referred to as a Reddit community. Subreddits are marked by 'r/'

User: Users are account holders on Reddit and have a displayed username. Users are referred to as community members when posting in a subreddit. Users are marked by 'u/'.

Post: a single post is a user-created text, image, video, or poll that includes a title and date stamp. Posts are created on a subreddit.

Comment: a response made to either the original post or to another comment

Thread: a post that has been commented on creates a thread. A thread refers to the posts and comments together, similar to a discussion.

Flair: a flair is a Reddit-based term for a tag on a post or thread. Flairs assist in marking posts by specific topics such as “Venting” or “Personal Story” so that users can be notified of what a post may contain before clicking on the post to see the entire post and thread.

Score: arrows on the side of each post mark the voting or ‘score’ that a Reddit post or comment has received, as calculated by the number of upvotes subtracted by the number of downvotes. Any user can vote on any post, but only one time.

On Reddit, users mainly interact within the subreddits/communities, so the site has a distinct forum-like format. Subreddits are typically dedicated to one topic, and a particular topic may have numerous subreddits that differ in ideology or focus points. For example, searching ‘eating disorders’ in the search bar at the top of the site displays results from subreddits described as pro-recovery, information-based communities to subreddits dedicated to healthy weight loss. Users can join subreddits and post within these communities via text, image, or video posts. Some subreddits have moderators and only allow approved posts whereas others allow unrestricted participation. Posts within a subreddit can be both commented on and voted upon, creating a ‘thread’. Voting is a community action that is applied to both posts and comments, where an ‘upvote’ is associated with opinions of agreeance, relevance, or high quality, and ‘downvotes’ are associated with dislike, uninterest, or poor quality. Voting is done by either clicking an up or down arrow that appears next to each post or comment, and posts or comments can be organized by the highest vote.

Reddit was chosen as internet forums were the desired form of communication to analyze for this study, and Reddit hosts fifty million daily active users with over 100,000 communities called subreddits, making it one of the largest sites for online communities (Reddit, 2023). Reddit forums were chosen as they typically include larger bodies of text when compared to content on Twitter or Instagram, which allows for more narrative analysis. Additionally, Reddit is a public platform with subreddits being accessible to any site visitor, so data harvesting via Reddit was less complicated than gathering data from private forums that have restricted view. For example, National Eating Disorder Association, the largest U.S.-based nonprofit for ED support and resources, hosts forums on their media site (Multi-Service Eating Disorder Association [MEDA], 2023) for community members to discuss topics. These forums require a membership to the website to view any forum and have an extensive list of community rules to protect members, including that posts should be "recovery-oriented" (MEDA, 2023). While these spaces are integral online support to many individuals, Reddit allows for a wider range of topics and sentiments to be shared, such as true feelings towards body weight or diet changes that may arise during relapse.

Due to the openness of discussion on Reddit, subreddit threads can house conversations on positive and negative experiences that are less censored and more accessible to the public. This makes Reddit suitable for more naturalistic investigations, though it should be emphasized that the use of Reddit in this study does not mean that Reddit is thought of to be the best place for ED social support compared to other forums. This study does include investigations on the uses of Reddit by community members, however, no conclusions were drawn on how Reddit compares to other forums or to progress in recovery.

2.4 – Study Population & Sampling Methods

Rather than seeking out individual Reddit users, predefined groups of individual posts organized into subreddits were used as a data source for this study. Subreddits provided a population composed of Reddit users who were actively engaging in discussions surrounding eating disorders. This means that the research population was solely defined by Reddit users who posted on the chosen subreddits, and no considerations for demographics were made, aside from the Reddit policy mandating that users must be thirteen years of age or older. There were no confirmed diagnoses among the population, as the research design did not call for medical history. Therefore, this population includes Reddit users who suffer from various eating disorders and symptoms.

Data was sought from three eating disorder-related threads: *r/EDAnonymous* (75.3K members), *r/fuckeatingdisorders* (24.9k members), and *r/eating_disorder*s (14.3 k members). These threads were chosen based on the number of community members, with all threads ranking in the top five populated communities in non-specified eating disorder subreddits. These three threads also allow posts without moderator approval first, though moderators can delete posts that violate community guidelines. There exist more populous communities dedicated to one specific disorder; however, those were not examined as this study aims to collect data on eating disorders in general. Additionally, the second most popular community "r/EatingDisorders" with 65.3k users was not used for this research. This community has a strict "questions only, recovery-focused" policy on posts, and all posts must be approved by a moderator. These restrictions would interfere with the objective of finding 'disinhibited' narratives, so communities that allowed posts without moderator approval were chosen instead.

2.5 – Data Collection Methods

In order to harvest data in a secure and automatic fashion, I used Python to interact with the Reddit public data. Python is a free programming system in which code can be written to extract data from other sources. The code for data harvesting on Reddit along with a guide is publicly available on GitHub and will be provided in the appendix of the research. Using Python allows the collection of data from particular months or with certain keywords on subreddits and organizes the posts into tables for easy assessment. I collected all posts containing the words: "relapse", "relapsing", "relapsed", "relapses, and "recurrence" on the chosen threads from March 2022 – May 2022. These keywords may have limited the data if individuals use other terms to refer to relapse, however, the use of these keywords helped ensure narratives are focused on what community members refer to as relapse, rather than recovery obstacles or triggers that do not result in relapse. This time frame was selected to create a manageable data corpus with time-current posts that have most likely been seen and commented upon by community members. It was ultimately decided to only use the first month of data, March 2022, as the number of posts collected in this month alone exceeded 100.

The collected data included a post ID that replaced the username, the title of the post, the body of text in the post, the score of the post (equal to upvotes minus downvotes), and the number of and text content of comments. Because I did not extract posts with images or videos, the appearance of a post is not of importance as all posts shared the same format.

Data harvesting occurred with the use of Educloud, which is a platform that acts as a remote desktop in which projects can be completed with assistance from pre-downloaded applications. The code written in Python acted as instructions for the computer on how to harvest data via

interfaces that provide access to such data, typically being an Application Programming Interface (API). As the code on Python enabled the computer to interact with Reddit's API, data was copied from the chosen parameters of subreddits and exported into a file on the desktop of my project's Educloud. The extracted data was formatted into a CSV file, which formatted data into tables that are separated by values. For this study, each data point (post) was sorted into a row and the columns within the row included post ID, title of the post, text content of the post, post score, and number of comments. To clean the data, posts that had no text content were deleted and each post was exported to a singular Word document for easier analysis.

2.6 – Data Analysis

Data was engaged with through a thematic and content analysis with a grounded perspective. While it is recognized that no two people experience a disorder in the same manner, I aimed to connect narratives through common concepts and shared sentiments. This method allowed for a flexible interpretation that is led by the data. I approached this research having completed a prior literature review, and the literature review was meant to provide a 'theoretical sensitivity' in which I was able to have knowledge on the concept of relapse without preconceived hypotheses of what the data will reveal (Glaser, 1978). Thematic analysis also allowed for the inclusion of a large data set of diverse accounts that can be represented in the details of themes.

Analysis was originally planned to be done through NVIVO, a qualitative analysis service. However ethical restrictions (see 2.7 – Ethical Considerations) required the use of Educloud, which did have access to NVIVO or other fitting qualitative analysis services. Therefore, the data remained on a Word document, with each post being a separate body of text. Themes were found

through coding the data, which is the process of identifying keywords or phrases in the body of text that describe a phenomenon or phrases by possible themes. Each data set was examined and coded first by finding words or phrases related to what is already known about relapse such as symptom reoccurrence or emotional distress. While applying initial codes, inductive coding was used to capture newly identified concepts or sentiments. By doing this, I hoped to provide a balanced interpretation of the data, where predetermined factors did dominate analysis and grounded theory could remain central to the investigation. For an example of coding, a portion of text stating "relapse is making me feel guilty" would be coded as relapse-related emotions, which related to the aim of how relapse is experienced by an individual.

The results of this study were organized through several major categories such as relapse, pre-relapse, emotions towards self, emotions towards relapse, and the environment in which an individual exists within. These results were created from two stages of coding: initial and secondary. After these results were coded with these initial codes, the data was read through again and organized into subcategories. Some initial codes were not relevant to the study objectives, so those themes were not present in this secondary coding process. Secondary coding instead focused on triggers or pathways to relapse, personal experiences of relapse, the conceptualization of relapse, and how relapse affects the individual and their outlook. These themes were based on the data itself, as the aims of the study were edited to include topics that were emphasized within the narratives, such as triggers.

While the use of direct, searchable text from the data corpus cannot be included in the thesis, the data was represented in several sections through the rephrasing of texts or a summary of a discussed situation. It is recognized that the direct "voices" of individuals being represented cannot be present in the results of this study, however it is my hope that the discussions and

rephrased examples surrounding the results in addition to data graphics provided a meaningful representation of these narratives.

2.7 – Ethical Considerations

Several ethical considerations were necessary for this research project. This research project was conducted in Norway, so ethical guidelines were sought from the Norwegian Centre for Research Data (NSD), a government-owned organization that manages, archives, and assesses data to ensure the ethical and safe handling of research data. When processing personal data in Norway, researchers must notify NSD so that a data management plan can be created. The assessment for this research study was completed by Dr. Simon Gogl, the senior advisor at the Data Protection Services for Research within NSD. A data protection impact assessment (DPIA) was created by Dr. Gogl to evaluate how the processing of data would be carried out in regard to: "processing special categories of personal data about health or information of a more personal character, limited possibility for data subjects to exercise their rights, and the processing of personal data about vulnerable individuals." (DPIA – Appendix E)

All ethical considerations were written in the DPIA, which was approved both by NSD, represented by Dr. Gogl, and the University of Oslo, represented by Are Evju, the data handler officer. Restrictions were suggested to protect and secure data alongside study participants. Firstly, restrictions concerning the processing of data were suggested in the DPIA to ensure the protection of sensitive information. The suggested restrictions were that data was to be harvested from Python+Reddit onto an external server called EDUCloud, where posts from all threads will be combined into one data corpus. Because the study will be completed using a publicly accessible website, all data is in turn publicly available. However, Dr. Gogl emphasized within

the DPIA that Reddit has a degree of expected anonymity, so no direct, searchable quotes or usernames should be used in the completed research paper. While users of Reddit publish material on a public forum that they can see has no restrictions to viewership, certain threads such as those dealing with disorders or more personal topics can be thought of to be more anonymous or viewed as a tight-knit community. Furthermore, with subreddits labeled in a manner like "r/EDAnonymous", it is difficult to discern whether or not community members are comfortable with anyone viewing their posts outside of that forum. It was therefore agreed upon that the re-identification of any post will be made impossible through the use of paraphrasing and rewording. This is to ensure that users are still protected, especially as consent has been exempted for this study.

In order to address the issue of consent, information about this project was made available on each ED thread that had been planned to collect from, as seen in the appendixes (information letter). This notification letter was included in the DPIA to address the exemptions for consent as informed consent was not required before harvesting the data from Reddit even though individual information was processed. In summary, the letter acted as an explanation to community members what the purpose of the study was, how their data would be protected, and whom to contact if they wished to withdraw their posts from the data set. Dr. Gogl also considered the data to deal with sensitive health information, so the accessing of the data was restricted to those directly involved in the research, being me and my two thesis advisors, Lasse Bang and Daniel Münster. The data could only be accessed through the use of the EDUCloud server; however, this server can be used on a personal laptop. The data was stored on the Educloud server until May 3rd, 2023.

During the data collection period of this study, one thread that had been selected was removed from the data corpus. A moderator of this thread reached out expressing concern about the integrity of having a completely anonymous support group being compromised. After conversing with the moderator about the aim of the research study, promises of complete anonymity, and providing direct contact information for the data protection officers, the moderator did not feel comfortable having any information from their group included in this project. We came to the agreement that I would only use data if I individually messaged a community member, and I was banned from the thread to ensure I could no longer post information within it. In accordance with my DPIA, I would still be within ethical clearance to process data from this specific thread, but I deleted all of the collected data from this thread out of respect for this particular community. It is worth noting however that before my information post was deleted, several members commented in support of the research and asked to be sent the finalized thesis, so the viewpoint of this moderator may not have reflected the opinion of every community member.

Chapter Three: Findings and Results

The results of this section reflect a coded analysis of 145 individual posts across two eating disorder-related subreddits. Data was organized to address triggers, pathways to relapse, relapse definitions, personal experiences of relapse, and finally, how relapse affects outlook. The timeline of relapse is reflected by this organization and follows along with how community members typically wrote a post when narrating a relapse event. Although the data included vital insights on topics other than relapse such as treatment, recovery, and etiology, the results section of this thesis focuses on relapse in order to remain concise and true to the study objectives.

3.1 – Triggers of Relapse

"The pressures of my ED thoughts and urges are too strong to resist anymore…"

Similar to studies in the etiology of the onset of an ED, the cause for relapse is not a clear, singular answer. One highly discussed catalyst for relapse within the dataset was a trigger. Triggers are viewed as unwelcomed stimuli that adversely impact the mental state of an individual, 'triggering' negative emotions and feelings. In terms of relapse, many individuals cited specific triggers that pushed them into relapse, while other users narrated past events that stood out in their memory in regard to relapse.

Triggers for relapse can be unique to an individual, as in a specific food, place, or person, but these triggers often fall into common categories that can be used to explain shared relapse triggers. Common relapse triggers have been cited in various research, and information about triggers can be found on many eating disorder informational websites such as National Eating Disorder Association. Triggers stated within the data varied from being an object, a discussion,

an event, or stress due to being in a particular environment. Due to the design of this research study, the reasoning behind a certain event being negatively impactful was not always able to be determined. For example, one user discussed how having a visit from their family triggered them. While one could propose the actual trigger came from a conversation or the pressures of hosting company, these conclusions are not drawn in order to present results that are grounded within the data. What was typically expressed was that being in a certain environment caused stress due to expectations and norms.

Listed below are the common triggers found throughout the results:

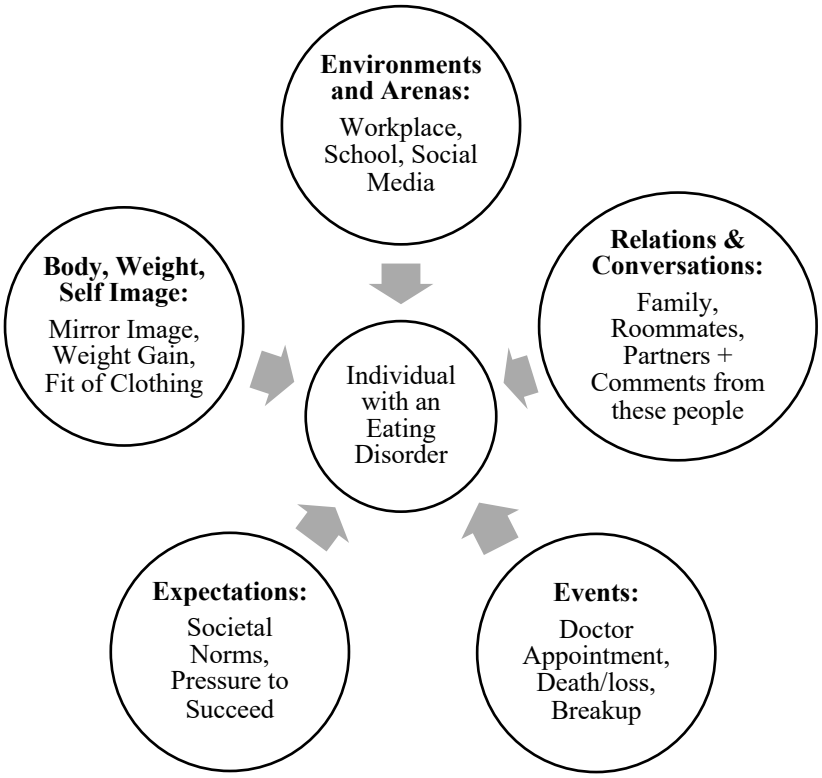

Figure 2

As shown above, triggers were discussed as general stress from the pressures of studies or work, or triggers were specific and often difficult to avoid, such as one's mirror image. The most

mentioned trigger in the data was interactions with family members. This included negative comments made by family members or family members who participated in dieting or encouraged weight loss. One occurrence worth mentioning was the several members who wrote about the concept of 'one comment' sticking in their minds. Numerous individuals wrote about a particular statement from the past that they were unable to forget. These posts included narratives of an individual feeling the need to restrict or purge again due to a friend or relative stating "you look curvy today", or other such comments that they would continue to reflect upon in the future. Other triggers were related to daily or overall stress that occurred within a particular environment. Community members narrated how pressures to get good grades or perform well at work contributed to stress levels, and therefore receiving a bad grade or poor performance report at work became an impactful negative trigger for relapse. Another common trigger was being weighed at a doctor's appointment, especially appointments not related to eating disorder treatment. As discussed earlier, some individuals made progress in ending eating disorder behaviors until a weight threshold was met, so many community members stated that they refrained from scales to avoid this.

In addition to the external triggers mentioned, internal triggers were equally discussed. As mentioned in the literature review, internal triggers are factors related to the internal world or one's mental and emotional environment. Negative feelings of worth and loneliness were commonly discussed internal triggers, where users narrated how relapse followed periods of feeling as if they "couldn't do anything right" or how "no one would care if I was sick or not". Triggering emotions were not necessarily related to eating either. Feeling a loss of control over one's surrounding or abilities was a major theme related to internal triggers. Often narrated were

how external triggers connected to internal triggers, where a low grade in school led to feelings of low self-worth.

Most triggers mentioned throughout the dataset were influential in the catalyst function, as described by those who narrated relapses beginning after encountering a trigger. Triggers can also impact the course of a relapse in a maintenance function. For example, several community members discussed moments when they changed their mindset and behaviors to begin a shift out of recovery and into relapse. This led to several important narratives about triggers that kept individuals in a relapse event when they had intentions of making progress in recovery. The most common obstacle that users discussed having when having begun the recovery process from a relapse was being told by a professional that they needed to track their food, weight, or calorie intake when they sought help. From what community members contributed, it was understood by these individuals that the measurements or amounts were being used by their healthcare professionals as a way to ensure they were getting proper amounts of nutrition. Having to track these amounts themselves however triggered several users into a restriction mindset once again, and they discussed the difficulty in seeing number amounts relating to their food intake or weight.

From the results, we can see that triggers can range from individual situations, such as the tension between family relations, to triggers more associated with ED symptoms, such as weight gain. Triggers spanned across several arenas and influenced individuals in different manners, as some triggers set an initial relapse and other triggers increased behaviors within a relapse. Overall, it seemed as if identifying triggers was viewed as important to many individuals, and several noted distress if they were unable to detect what caused them to want to relapse again.

3.2 – Different Pathways to Relapse

"I just wanted to diet…like normal girls…"

Environmental triggers were not the only discussed driving force toward a relapse. A common theme found within the data was the experience of a pathway to relapse, which users related to a period before they realized relapse occurred, the manner through which small-scale actions led to a fully symptomatic relapse, or certain thresholds being surpassed that led to decisions to relapse. These pathways to relapse relate back to predictors of relapse found in research, although participants rarely used clinical descriptions of traits or emotions they experienced.

The first category found in the results was a 'dieting to relapse' path. This collection of experiences was united by users discussing how their relapse occurred from enacting in certain disordered eating habits, though these users specified not wanting to fully relapse. Several posts mentioned how a relapse began "accidentally" after dieting. One user in particular stated that they had simply wanted to reduce processed foods and sugary drinks, but this diet led to them cutting out almost all foods. Another individual stated how dieting for them did not result in restriction, but it did result in them thinking about how having anorexia could be helpful in their diet goals. An additional post narrated the want to lose a few pounds due to a self-weigh-in, yet the author of the post stated they were unable to revert back to a healthy amount of food intake after their weight decreased. These experiences differ from those who wanted to 'purposefully relapse' as these users did not intend to end their recovery, but rather wanted to lose a few pounds or eat 'healthier'. Similarly expressed was the want to exercise without relapsing. Some community members began work-out routines such as weight training and then added more

hours in the gym which increased their want to restrict. Others wished to run again or exercise as a hobby but related that it either could in the future or has in the past turned into “an obsession”.

A second group of users described similar experiences of wanting to maintain a certain personal health standard, however, these community members described an intention to relapse. Many considered themselves to be in the recovery and intended to continue progress unless their ‘threshold’ was reached, meaning a weight or calorie range. For example, some users stated that they were at a ‘healthy’ weight [defined by them] and planned to continue recovery unless they gained more weight. Another individual wrote about how they would continue eating as long as their calories remained in a certain range, while a different community member had a similar mentality with their BMI. One narration of relapse described their relapses to be self-triggered, and how relapse was something they chose for when their weight would reach a certain number. Others referred to relapse cycles that began once a ‘limit was reached’. These narratives all revolved around both intentional steps toward recovery and intentional relapse based on a weight number or calorie range.

A final group of individuals who narrated personal pathways to relapse was those who described relapses to be approaching, though these relapse events were not connected to small-form ED behaviors or maintaining specific weight or calorie ranges. These individuals instead wrote about how they could feel themselves “slipping” again into relapse, and a few asked for advice on how to avoid a relapse during this phase. One user expressed how everything in their life was a “perfect storm for a relapse” and sensed one occurring soon, with another person describing how one situation put them in a similar feeling of everything aligning for a relapse to occur. Others described the experience of ED thoughts and urges increasing to a point where they feared they

would relapse. A common phrase used to explain this phenomenon was a "spiral into …." followed by specific ED thoughts or behaviors such as body dysmorphia.

Some individuals seemed to be very self-aware of what symptoms were indicators of relapse for themselves. One user who stated that their disorder revolved around binge-eating/purging (B/P) explained how a relapse approaching felt like the want and constant thought of binging while starting to watch videos relating to food or having "small bites" of sweets. This is similar to a user who explained how counting calories for one day greatly increased their urge to relapse as they were "enticed to keep up their efforts". Lastly, a few individuals mentioned that relapse approaching usually began with looking at 'thinspirations' (a term for inspirational content showing slim body types) or pro-ana sites (websites promoting anorexia) once again.

While these feelings could be related to triggers or stressors within one's life, the theme of feeling a relapse approaching could also be independent and spontaneous. For one particular user, they described having a positive outlook towards their life and body image, but that suddenly they felt as if they had relapsed overnight. They described an inability to label the reason for the return of their food obsession after being in recovery for years. Another individual narrated the same confusion, not comprehending why they were relapsing when they have no issues with their current weight. A third community member brought up their experience with spontaneous relapse, stating that even though they often relapse around a certain time of year (didn't discuss why), this time they were relapsing when their life was stable, and at a time of year when they are normally in recovery. This user also cited an acceptance of their current body, adding to the confusion of being in relapse. Furthermore, there were a few individuals who mentioned having been in recovery for years when suddenly a relapse occurred without a trigger. From the results, an explanation was not provided why this phenomenon of spontaneous

relapses occurred, though dieting or restriction was noted to negatively impact recovery even if the intention to relapse is lacking.

3.3 – Relapse Conceptualization

Following the pathways and triggers of a relapse leads to the event of relapse itself. While the prior factors describe indicators, predictors, or risk factors of a relapse, the conceptualization of relapse is addressed through numerous user-generated descriptions and terms used for relapse and reflects upon how participants label and define an event of relapse. Many users wrote about the severity, specific behaviors, and emotions they had during a relapse. Relating to conceptualization, several community members provided their own definition or description of what a relapse was to them. In order to maintain anonymity, the following diagram was created using either singular words that appeared in numerous posts or phrases created to summarize a description of reoccurring types of relapse definitions.

Categorization of Relapse	Examples from Text
involving a specific symptom	relapse with strict restriction, relapse with daily purging, counting calories again, etc.
defined by weight-loss	quickly lost X lbs, lost a significant amount of weight in X weeks, etc.
defined as a coping mechanism	relapsed to deal with stress, needed to soothe myself, tool to fix body issues, etc.
defined as a return to a previous condition	back here again, slipped back into my ED, spiraling into old habits, etc.
Singular event	overate tonight and relapsed, threw up lunch, didn't eat dinner

Figure 3

Differing Relapse Conceptualizations

One of the most frequent conceptualizations of relapse was stating to have relapsed with respect to one specific ED behavior. This could be restriction, calorie counting, bingeing, purging, etcetera. The return of just one of these behaviors is what numerous users defined as having 'relapsed'. Some would note that they for example relapsed 'without binging this time', while others spoke about how all of their prior ED behaviors returned. Many individuals

conceptualized their relapse as a period of rapid weight loss. Another common occurrence was the use of other phrases to define a relapse such as a downward spiral, a loop/cycle, a rabbit hole, a sinking/slipping/sliding feeling, or a return to old habits or a previous mental state. A few members even mentioned not knowing whether or not to categorize their recent experiences as a relapse. For example, one stated that they thought they were relapsing, but they were not sure, as their weight was the same as prior to when they began restricting again. As for the temporal aspect of relapse conceptualization, mixed results were found. Some users referred to a single binge/purge event or a few days of having difficulty eating as a relapse, while other users described a relapse that they had been in for weeks or months. The least frequent conceptualization was the use of the word relapse to describe a singular event, such as skipping one dinner.

Aside from having variations in the definition of one relapse event, users also often used severity markers for their own relapse events past and present that were self-generated based on personal criteria. A frequent expression on the forums was the concept of major versus minor relapses. Some users mentioned having each a major or minor relapse in the past, while others described a current relapse as particularly 'worse than ever' due to an increase in symptoms. For example, one individual explained this concept by stating how they went from calorie counting with maintaining regular meals to then only having one meal per day as their relapse got 'worse'. Another explained how during the relapse they were currently experiencing when posting, they could not eat any food without vomiting, which was a new extreme for them. A few other community members simply stated that their relapse or ED symptoms were worse without providing a comparison.

Besides minor versus major relapse, there was also a premise of “semi” versus “full” relapse and the concept of “relapsing more”. Users did not always explain what they meant by those terms and with the current research design, it is not a possibility to provide an example of how users conceptualized “semi-relapse”, though one user did mention intermittent fasting as not “fully" relapsing and several others used terms ranging from mini and slight to full-blown and complete relapse. As for an increase in the severity of a relapse, a few community members mentioned a certain trigger that made them want to ‘relapse even more’ by beginning to enact in more ED behaviors like purging or fasting for longer periods of time. These results on defining relapse encompass the numerous different ways in which community members defined and labeled their events of relapse. Overall, the data collected in this study exemplifies the individuality of relapse conceptualization as community members defined relapses not by specific DSM criteria or academic citations, but rather by their personal experiences. Each narration of a relapse event presented insight into what relapse means to one person with an ED and how relapse influenced that person.

3.4 – Experiences of Relapse

“My ED has brought so much destruction to my life and body…. I’m trapped in this cycle with no control.”

As discussed in the methods section of this thesis, the aim of this study was not only to investigate personal definitions of relapse but also to go one step further and navigate narratives of the lived experience of a relapse event. Community members discussed their experiences throughout relapse in multiple ways, from their regard towards their relapse to emotions towards themselves and their agency. The results diverged in a few themes such as those who wanted a

relapse compared to those who felt a sense of failure for relapsing. Many users were in-between these two camps or had conflicting emotions in regard to their relapse. It is important to consider how this section is not representative of all people who have an ED, but rather representative of users of these forums. Below is a chart with paraphrases of common expressions regarding relapse:

	Positive Emotions	Conflicted Emotions	Negative Emotions
Regarding Relapse	*"happy to be losing weight again"* *"helps me to feel confident"* *"gives me a sense of comfort"* *"love the feeling of emptiness"*	*"hate that I am happy to be restricting"* *"why does this make me feel safe"* *"it's so sad that I feel successful losing weight"*	*"disappointed that I'm doing this to myself again"* *"this is so scary and I want it to stop"* *"how can I escape this horrible cycle"*

Figure 4

Differing Regards Towards Relapse

Only a few community members spoke in an explicitly positive way about relapse, whether that meant that they were content with the resulting weight loss or that they wanted to continue relapsing and did not want to recover. This is most likely due to the forums that were used in this study specifically stating that they should not be used to endorse ED behaviors or cognitions, such as what is commonly done on "pro-ana" or "pro-mia" websites (pro-anorexia or pro-bulimia, movements that support eating disorders). This means that there are likely fewer individuals who would discuss having an eating disorder in a positive manner in the results, however, there were some individuals who described a relapse as something that was beneficial to them.

Some examples of positive reflections on relapse from the results were how one user mentioned how a particular relapse feels different than usual as it is resulting in weight loss, but the individual stated how they were content with the process and will be able to stop once they reach their lower weight goal. Another community member described how they would use relapse to lose weight if their weight threshold was surpassed, but they struggled to define whether or not this was a healthy system even though they regarded relapse with optimism. Others relayed that they were not ready to recover and hope that their relapse is not discovered by family members or friends, which displayed an acceptance of relapse. Lastly, one user noted that they prefer relapse to the discomfort they were experiencing during recovery and decided to quit recovery due to this.

While purely positive sentiments towards relapse were uncommon, many users felt torn between relapse and recovery. Written below are rephrases of narratives describing the conflicting feelings between wanting to recover and wanting to relapse:

"I feel stuck between recovery and restriction as there is no point in recovering when I'm not underweight, but I still want to stop having an ED."

"Neither recovery nor relapse has significance to me as I have no one to share either with."

"I don't want to relapse, but I don't want anyone to see me with the weight I've gained in recovery."

A frequently expressed sentiment was the feeling of a person wanting to 'escape' relapse while simultaneously being unsure if they actually want to recover. There were mixed notions on whether or not the individual felt in control of this choice, but the feeling of being split between these two disorder outcome paths was shared among many. Several of the narratives highlighted how relapse and recovery are both physically and psychologically difficult processes which was the driving factor in their confliction. For example, one user mentioned that due to finding out their exact weight, they feel extreme fear towards their weight gain and want to relapse while also noting that they did not wish to renter their ED cycle. Another individual mentioned how their discomfort in feeling full made them want to restrict again, but that they are exhausted of their ED making them feel this way. The mentioning of discomfort in recovery was commonplace, yet it was generally discussed by users who still were attempting to either avoid or end relapse.

While not every user who was divided between recovery and relapse gave reasoning for their feelings on the matter, many individuals commented on how relapse provided them with a sense of comfort or control. Listed below are rephrases of several different narratives which illustrate this concept:

"All of this [referring to a triggering event] just makes me want to relapse to gain control over something and to soothe myself."

"I miss the feelings of relapse where you felt as if you were accomplishing your goals."

"Those first moments of relapse were so comforting to me, just like a familiar friend…as it progressed, it started consuming my entire life and I need to recover again."

Something mentioned throughout several posts was the enjoyment of physical sensations brought on by relapse, such as feeling lighter, but in contrast to those who viewed a relapse positively, these users felt upset about enjoying these feelings or hatred towards their need to lose weight. There were also a few individuals who felt successful when weight loss was evident but were angered that this was a part of relapse that they still felt satisfaction from. So, while there were many community members who enjoyed aspects of relapse, the majority of them were self-reflective enough to realize that being comforted by relapse was not their desired outcome for their future.

Aside from those who expressed having some positive reactions toward relapse, other community members clearly stated their fear or disappointment towards a relapse event. Many users who narrated their negative experiences in relapse discussed relapse as if it were something to climb out of or a horrible cycle that they wanted to leave. A few individuals expressed this by

stating their regret about enacting in ED behaviors again, while others discussed their fears of being in a relapse and their desire to end it. One user went as far as to equate their relapse to their ultimate lowest moment with their mental health. Several posts contained statements in which the author questions why they were doing this [relapse] to themselves. Individuals in this camp commonly described the duration of a relapse to be painful mentally and physically, especially for those who needed to wait to receive treatment. Some spoke out about how the physical symptoms had been especially frightening to them and how they became worried about damage to their body. A few community members also wrote about how they missed life prior to relapse when meals were enjoyed without care, exemplifying the pressure of ED symptoms during a relapse. Other relapse experiences were described less but labeled with words such as "horrible, consuming, extreme, worse than ever…" and so on. As illustrated by the narratives above, many of those who experience relapse either view their relapse as something they wish they could escape from, or fear being trapped within.

A final expression towards relapse to note was a few users feeling as if progress had been ruined by relapsing, or that they had "thrown away" any efforts made during recovery. This expression relates back to how some users felt it difficult to bring the cognitive tools and treatment practices of recovery into a period of relapse. By viewing relapse as a negation of previous recovery, users implied that relapse is not a part of recovery but a failure of recovery. The loss of control within relapse or the presence of relapse led to other strong emotions for some community members. With relapse being regarded as a return of ED thoughts or behaviors, some users shared feelings of personal failure when they went from being in recovery to relapsing. One user in particular questioned if they should be angry towards themselves for letting their mental health decrease and later felt guilty for not recovering when they were in a safe environment. Another user who

attempted to diet but ended up relapsing referred to themselves as “stupid”. One user wrote about how they feel horrible for relapsing as it makes them feel like they have let themselves down, along with their treatment professional. All these narratives bring about a discussion on self-responsibility and fault within eating disorders and ED recovery. While some members viewed their relapse as a result of their so-called incompetence or lack of thought, others felt as if they were personally responsible for allowing triggers to negatively influence them.

Control in Relation to Relapse

One specific feeling that was highly present in the results was a ‘loss of control’, as mentioned in relation to internal triggers. While a loss of control in regard to one’s surroundings helped explain an influence on relapse, loss of control in regard to behaviors within a relapse was another phenomenon that many users experienced. When writing about relapse and its relation to poor self-agency, users often either described an inability to end a relapse event, or how they felt as if their experience with their ED was a constant negative cycle. Listed below are rephrases of some of the narratives that illustrated this:

“I reached my goal weight but feel as if I cannot stop restricting…I’m fearful that I will continue down this “hole” of relapse.”

“Relapsing is “blacking out” … [describing how they once again enacted in binging and purging behavior.”

Commonly mentioned alongside these narratives were how a person was unhappy to be relapsing, but they stated that they could not stop or that they do not know how to get to a stage of recovery. Many individuals described the maintenance of a relapse event to be completely out

of their control, and it was as if their eating disorder was steering the way. Some described the experience as similar to feelings of falling or slipping without a way to control their path. Similarly, many individuals stated that they wanted to recover, but ended up relapsing due to the urges being too strong. Another issue centering on control was how some users described an inability to act in any way other than extreme. For example, one user felt like they could not regulate their eating habits in terms of either overeating or restricting. For them, it felt like a middle ground is impossible to reach. These narratives can be grouped together by a theme of a lacking belief in personal agency, or the feeling of control being lost after a period of being in control. For many, it seemed that pressures built up continuously until it became unbearable, or that recovering from relapse was more difficult than expected.

3.5 – Effects of a Relapse Event on Disorder Outlook

Each relapse experience narrated by Reddit users was often described to influence their outlook on the future. Many users of the threads wrote candidly about their conception of their eating disorder and how they viewed their future with the disorder, which was often influenced by the presence of relapses. Many users mentioned how recovery and relapse felt like an ongoing cycle for them. One user in particular highlighted how having an ED meant having a constant interaction with that of which you fear or feel out of control with: food and your body. This is an aspect of eating disorders that makes avoiding relapse particularly more difficult as a person cannot easily avoid the triggers of food or appearance. Many of the posts included users discussing how much of their focus and worry surrounded the necessary part of daily life: consuming food. Others acknowledged how their mental health revolved completely around body image and weight. A few users showed concern that ED symptoms would endure across their lifetime, and some in relapse questioned if any amount of weight loss would ever be enough

to satisfy them. One common belief found in the text was that a person would never feel attractive at a higher weight than what they are or were during a relapse.

Many community members acknowledged that having certain symptoms of an ED is something that they will always have to deal with. One individual wrote how the reoccurrence of ED thoughts was inevitable even after experiencing long periods of recovery. Recovery as a stable state was not something that all users agreed existed. One user described how the lack of social support or friendship in their life makes them feel as if recovery is pointless, so they have no choice but to allow their ED to take control of their existence. A few narrated a struggle with finding a life outside of their disorder as so much of their prior focus was on their weight or food intake. Furthermore, a couple of members admitted to feeling as if they will never recover or "do better" due to relapse reoccurring. These results were grouped together to illustrate the connection between relapse and the entire experience of an eating disorder, and how a very common belief is that symptoms will continue to resurface. In addition, many narrations displayed blurred lines between recovery and relapse due to this belief of a cycle.

There were also several people who did not want to recover from a relapse due to their beliefs in body dissatisfaction or other symptoms never being able to go away. When discussing this disbelief in recovery, the community members shared how they were not able to see a future without their ED or without disliking their bodies. Multiple events of relapse were often mentioned in these cases, where a few users mentioned that attempts of recovery always resulted in relapse. Within these discussions were narratives of how tiring it is to be in recovery or how uncomfortable recovery is, so relapse was a "better alternative".

Ultimately the results of this study can be summarized as relapse being an individual experience that can bring forward strong emotions about both the self and the future. Definitions of relapse were marked with ambiguity and there was a distinct variation among personal regards towards a relapse event. How this data relates to what is already known about relapse will be discussed in the following section as each theme will be once again examined in regard to significant insights and notable contributions.

Chapter Four: Discussion

4.1 – The Individuality of Relapse Definitions

As reflected in the results section of relapse, individuals experiencing eating disorder relapse narrated their own experiences in manners more complex than the current strict definitions found throughout the research. Definitions of relapse found in research are generally composed of both weight or BMI criteria and a temporal component. For example, in a one-year follow-up study by Carter, relapse was defined as "BMI less than or equal to 17.5 for 3 consecutive months or at least one episode of BP behavior for 3 consecutive months" (Carter et al., 2004). However, the results of the current study showed conceptualizations that ranged from a day of symptoms to months of rapid weight loss, highlighting a major theme of ambiguity. This variance and uncertainty about what relapse is that was shown within the forums exemplifies a failure in the current conceptualization of the term, and how having multiple definitions from research can lead to ED sufferers having difficulties recognizing relapse in their life. As shown by this study, a strict relapse definition in the style of "one size fits all" fails to address the struggles and needs of numerous individuals.

The definitions of relapse from study participants also reveal how little clinical language is used in discussions of experiences with an eating disorder. Reddit users seldom used terms such as partial relapse or partial remission and instead described relapses in comparison to their own past experiences. Individuals were able to assess the severity of their own relapse by discussing changes from a previous relapse, such as new behaviors that they previously did not struggle with. Users also expressed points where they knew their relapse was out of their control, demonstrating a gauge of relapses that could differ from person to person. This again

differentiates from research models of relapse, where terms such as “minor, major, less severe, worse than ever, etc.” are absent and different categorizations of relapse are seldom used.

While a strict categorization system assists in the ability of clinicians to have a framework for diagnosis, using only clinical definitions in discussions surrounding eating disorders and relapse takes away from the experiential viewpoint of having an eating disorder (Patching & Lawler, 2008). Without patient narratives, relapse is equated to episodes and weight loss without the rich descriptions of ED urges taking over or relapse severity increasing with an inability to gain control. Using the results of this study and similar studies that include patient narratives can push forward the conceptualization of relapse into definitions that are clearer to individuals while still encompassing various possible experiences.

4.2 – The Vague Lines Between Recovery and Relapse

It is evident that the conceptualization of relapse is often individual and strays from strict clinical criteria. Certain pathways to relapse further complicate this as the community members in the current study often viewed the stages of relapse, recovery, and in-between as being more fluid than medical categorization. As presented, certain users discussed relapse as voluntary or as ‘pre-loaded’ after being in a period of recovery. This was often in either the beginning stages of recovery or after a threshold of weight or calories was reached, set by the individual. These occurrences made it difficult to differentiate between who is in recovery and who has relapsed. Additionally, the presence of planned relapse negates certain definitions of recovery, as the symptoms of fearing weight gain or body changes are still present. Short periods of recovery before relapse coincide with the same issue. Many community members described having abstained from certain behaviors with a sense of self-pride, though they still struggled with

others. For them, this was a process of recovery. However, by medical standards, these individuals were not to be considered as 'recovered', but rather in partial remission/recovery or subsyndromal phase (Steinglass et al., 2020). All these terms make the course of eating disorders overmedicalized and confusing to sufferers.

For example, researchers in several studies classified recovery as being symptom-free for eight or more weeks (Keel et al., 2005, Richard et al. 2005, Strober et al., 1997). Relapse was then defined as a full return of symptoms after recovery or remission (Keel et al., 2005, Richard et al., 2005). Partial remission adds a further distinction of requiring a reduction of symptoms to either a subclinical level or the presence of symptoms without having full diagnostic criteria (Berends, Boonstra, & van Elburg, 2018). Based on these clinical categorizations, patients who are in self-proclaimed recovery would have never in fact been considered to recover, which in turn would mean they were not relapsing but were rather still experiencing an eating disorder in its initial course or in a subclinical phase. This is because in the eyes of many researchers, relapse can only occur after recovery. Yet in this study, most Reddit users narrated experiences with categorizations that did not fit this model.

Even those who were clinically defined as recovered felt differently. To many, the exhaustion of ED thoughts made them feel closer to relapse than recovery, even if they were defined as weight-restored and not enacting in ED behaviors. Numerous community members narrated how even outside of a clinically defined relapse they struggled with the cognitive side of their ED, such as constant anxiety towards eating. This was a shared concern in prior literature, as researchers illustrated how overall well-being was a vital, yet often unaddressed component of recovery (Bardone et al., 2010). This suggests that the conceptualizations of relapse and recovery should be re-evaluated together to fully ensure a clear framework that matches patient experiences and

clinical assessments. It is understood that diverse perceptions could complicate processes such as allocating treatment, so medical categorizations may still be beneficial in certain aspects. However, more informed care can take place with more knowledge about those diverse perceptions.

4.3 – Triggers and their Influence: The Cycle of Recovery and Relapse

A more fluid interaction between recovery and relapse also coincides with a central theme of 'delicate recovery' and the switch to relapse often being out of one's control that many individuals expressed. The pathways to relapse that correlated with triggers and environmental pressures illustrated how for many, pressures of life would build up until one trigger set them into relapse. Additionally, some triggers are difficult to avoid, especially for adolescents who live with their family and attend school as many noted triggering comments from family members or peers as well as pressure to succeed in academic settings. Research has already shown that individuals with eating disorders were victims of negative comments at higher rates than healthy controls, and associations were found between teasing and ED symptoms (Lie, Rø, & Bang, 2018). These studies indicated that appearance-related teasing prior to the onset of an ED was significantly common (Lie, Rø, & Bang, 2018). In other research, results evidenced how parental attitudes toward weight loss are often transferred to adolescents and are likely to influence the onset of an ED (Marcos et al., 2012). The most cited influence type in reference to family members was an encouragement to diet (Marcos et al., 2012). In the current study, many users described how these risk factors were also relevant for inciting relapse.

Having treatment that addresses this psychological side of EDs could assist individuals in finding coping mechanisms for unavoidable triggers such as peers and family. Additionally, the

narratives within this study can help educate family members and schools on how certain discussions can become catalysts for ED relapse. Worth exploring further is how to create and maintain environments that foster support and recovery within a family or school arena when it is evident how influential triggers within these arenas can be on a relapse event.

Aside from environmental and relational triggers, the main trigger of eating disorders often remained food. Having interactions with food, menus, calorie labels, etc. was a major cause of stress for individuals and often a maintaining factor for relapse. The most difficult aspect of this phenomenon is that food cannot be avoided in order to live. While interventions can target family relations or peer relations at school, food cannot be removed from the equation. Many users noted this and expressed strong desires to be able to be non-reactionary towards food. Addressing how to manage life with these triggers has been left out of certain treatments, which Reddit users discussed as well. Meta-analysis on treatment of AN illustrates how patients with AN frequently treated in medical units that are not specialized to deal with eating disorders. Because of this, weight restoration is often the focus of in-patient treatment, and psychological treatment is more likely to occur in specialized units or after hospital discharge (Guarda, 2007). While this is steadily evolving as more research presents the benefits of cognitive therapy and skills training when paired with weight restoration (Guarda, 2007, Linardon et. al, 2017), the results of this study show that many individuals still feel as if learning to cope with triggers is an unmet need.

4.4 – How the Experience of Relapse Affects an Individual

Unavoidable triggers and societal pressure coincide with many of the strong emotions that individuals described surrounding relapse. Beyond the broadening of classifications and definitions of relapse, the current research also provided rich narratives on how relapse is experienced and how individuals form meaning around having an event of relapse, whether that be towards themselves or their disorder outcome. Relapse to an individual is not just a return of symptoms; relapse also marked themes of hopelessness, failure, and confliction to many Reddit users. As expressed in the results, the existence of stable recovery was not believed to exist by numerous community members. This hopelessness was almost always connected to an event of relapse. Having a relapse led to commonly shared sentiments that life would continue to always be like this, with relapses into restricting or binging and purging. This was especially relevant for users who had been optimistic in working towards recovery or had been recovered for long periods of time. Relapse events also negatively impacted disorder outlook and motivation as many felt that relapses were inevitable, and the uncomfortableness of recovery is not worth experiencing. While this study is not longitudinal, there is evidence of long-lasting eating disorder patients who had similar expressions of hopelessness, where the increased duration of illness (10 years) led to only 23% believing in an ability to progress toward recovery (Noordenbos et al., 2002).

In addition to more negative outlooks, relapse events often influenced self-value. Numerous posts included sentiments of failure when an individual relapsed. This was either in relation to ‘wasted’ recovery efforts or feeling an inability to cope with triggers. The sentiment of self-describing words was often more negative, with users referring to themselves as “stupid” or “a let-down”. It became evident that relapse was a source of shame for many, and the presence of

relapse affected confidence in recovery as well as self-assessed agency in relation to coping with triggers. Furthermore, relapse was seldom viewed as being a part of recovery which is echoed in the research-provided stages of an eating disorder (Steinglass et al., 2020). Shame has often been researched in relation to ED behaviors, where beliefs of "insufficient self-control" and "failure to achieve" were significantly more frequent in a study population of bulimic women when compared to a control (Waller, Ohanian, & Osman, 2000). These beliefs were related to the onset and initial course of EDs, though from the results of this study, it can be seen how relapse may trigger these beliefs in a different manner. While initial ED behaviors were proposed to be a reaction to feelings of shame, this study reveals how those who fall into relapse can feel shame for re-enacting in behaviors after a period of progress (Waller et al., 2000)

The shame and failure surrounding relapse may be related to the stigma surrounding relapse, or due to relapse being defined outside of recovery. If a relapse is constantly discussed as a failure of recovery rather than a process within recovery, many individuals with eating disorders could become even less motivated to recover, as seen in several narratives. It should therefore be a priority to normalize the experience of relapse and ensure ED sufferers that although relapse can be an obstacle in recovery, relapse does not equate to a waste of previous efforts.

4.5 – Discussion of Study Site: Reddit as Social Support

All of the results from this study were from Reddit, so it is worth discussing how Reddit worked as a medium for conversations about eating disorder relapse. The main uses of Reddit during relapse were categorized as advice seeking, ranting, relating to others, and asking for insight on experiences. Many users clearly stated their purpose for using Reddit to discuss relapse and exemplified how Reddit became a tool in the experience of an eating disorder. Reddit

uses a system of tags for posts, so many of the posts within the dataset were identified by having been self-tagged as a "relapse" post. Other times users stated the purpose of their post within their text, such as advice-seeking or ranting.

Many people on the ED threads posted their experiences of relapse while also asking for advice on the situation. Advice seeking was commonly related to how to avoid a relapse or how to deal with triggers. This type of community engagement could be highly beneficial as users tend to be able to relate more to other community members within the thread as those using these threads have cognitive processes that may be similar when compared to a person who has not experienced an ED. This engagement also seemed useful for those individuals who sought advice on how to avoid or cope with triggers as those who commented had been through similar experiences. Another commonly announced use for the threads was to rant or vent about a situation. This went along with users who simply wanted their issues to be heard by an audience. Some seemed to be doing this as a way to admit to their reality, as several individuals stated somewhere in their post lines such as "I think this is finally it" when referring to relapse.

A third use of the ED threads was to relate to others or to ask if anyone else experienced what the original poster had experienced. The abbreviation "DAE" ("does anyone else") was used widely throughout the threads to signify these discussions. The contents of 'DAE' posts typically included a narrative of a situation that the OP was concerned about, such as bloating or extreme hunger, and then they would ask if anyone else experienced this. Others would ask if any community members had similar experiences with triggers or relapses. These posts were often written in a manner in which they were asking for the normalization of their experience, as shown with language such as "am I the only one", or "is it weird that…". These discussions

often led to users feeling less stigma or less abnormality in their ED experiences, which is an indicator of Reddit being a positive source of social support.

Despite having several benefits, recovery-based forums on Reddit can still be sites of detrimental interactions. Although forums were moderated to remove any pro-ED content, certain topics may not actually be assisting in the well-being of users. For example, some users discussed their body image in an extremely negative manner, which was often tagged as a "rant". These posts are viewed as being part of recovery because users agreed that recovery can lead to uncomfortable feelings toward appearance. However, negative body talk has been linked to an increase in appearance checking and body comparisons (Mills & Fuller-Tyszkiewicz, 2018), and engagement in these discussions can increase body dissatisfaction (Mills & Fuller-Tyszkiewicz, 2016). So while the use of Reddit may be beneficial in decreasing relapse stigma, ED sufferers should remain cautious of using the platform.

4.6 – Discussion of Methods: Strengths and Limitations

The strengths of this study reflect the strengths of online and qualitative research. Many of the benefits of this study correlate directly with the arguments for qualitative research, such as being able to collect data in a naturalistic manner, where research participants are frequently more candid and expressive about current, ongoing issues. The use of the chosen methods accomplished the goal of gaining insight into lived experiences from a patient perspective that was unintrusive and resulted in narratives that were directed by those writing the Reddit posts, rather than being responses to researcher-developed questions. This meant that the results of the study were based on what was important to the individuals, which was a fundamental objective.

In addition, the use of Reddit allowed for a large amount of data to be quickly collected. Data collection took less than an hour and was automated through the process of Python. While this method does require programming knowledge, there are several online resources that provide explanations of how to use Python along with code templates. This study did use keywords to search for relapse-related data, so it is possible that narratives were missed in the collection period if the keywords were not used within the post. However, this limitation was compensated with a large number of posts that fully saturated each theme.

With gaining excess data, there were certain drawbacks. As mentioned by Smedley and Coulson in a guide for online research, harvesting online data can also lead to "data overload" (2018). This was experienced in this study as the first allocated month from which data was harvested yielded more than the expected total amount of posts. This led to the decision being made to only include the first month of data, which was more than enough to saturate all the concepts and themes discussed later in this thesis. It was however still difficult to sort through which sections of text were important for the purpose of this thesis as the data spanned over seventy pages of text.

Another drawback to automated data collection is the inability to gain disorder history or discuss topics further with study participants. This could be done by reaching out to Reddit users and asking through informed consent to discuss data further, though this would take away from the naturalistic approach that data harvesting offers. This limitation extends to the inability to confirm diagnosis validation, demographic information, or sincerity of posts. As Reddit forums do not require any validated background information, it cannot be determined that each post reflects a real, lived experience.

There is however a large discussion around the validity and usefulness of such research designs, as researchers do not directly interact with data subjects. It is difficult to validate narratives and to view phenomena from a timeline perspective, as community members do not often share their background or history within one particular post. In terms of representation, it should also be noted that internet access is not accessible to all, so data cannot be purely representational of a population (Smedley & Coulson, 2018). In the case of this study, this is especially true for the part of the population that does not use Reddit. Additionally, if sociodemographics are important, these can be hard to obtain from a text post. While age and gender were not considered in this study, the use of online forums does restrict the types of analysis that could be done with the harvested data. The representational limitations arising from the chosen method of collecting online forum narratives can be applied to research occurring within a clinical setting as well, however collecting a high number of narratives can provide more diverse results. Overall, the current study fits well as complementary data to quantitative research.

4.7 – Ethics & Online Data

This particular study design raises important ethical considerations for future research projects as the internet becomes a more often used source for health data. As discussed in the methods section, the use of online public data has several benefits that should not be overlooked. Yet there remain concerns on how to ethically obtain data. The main question to be asked is if the public posting of data gives implicit consent for that data to be used by any viewer and if is it ethical to use public data for research. Reddit clearly states that all data is public, however as evidenced by a subreddit asking to be removed from my study, not all Reddit users agree that their data should be used in research or in other settings. In the case of that particular subreddit, it

was the moderator that asked for the data to be deleted, so this also brings to question whether a moderator should be able to speak on the interests of an entire group.

In general, the ethical conflicts met in this study exemplify how ethics surrounding public data need clearer guidelines so that online social network users are protected and feel safe, while researchers are aware of the proper steps to take when wanting to use online social network data. Approaches from other researchers have been suggested in regard to message boards, where 'open' versus 'closed' message boards have two separate guidelines (Rodham & Gavin, 2006). Rodham and Gavin argue that open message boards are public domain, so data collection does not require consent, however; the presentation of data should not lead to the ability to identify any individual (2006). While this argument may be in line with ethical boundaries, it cannot be determined whether or not Reddit community members post with the acknowledgment that their words would be used and analyzed in the research, even if they remain aware of Reddit being a public space. Having a researcher analyze personal thoughts could be viewed as invasive to some.

A solution to some of these debates could be the implementation of online healthcare social networks that provide a secure site for discussion, as opposed to the current use of public forums for users that do not wish for their posts to be seen or used by those outside of the online community. It may also be important for social media sites to be clearer on who can access their data, especially when it comes to data harvesting. Lastly, future online researchers should keep in mind the 'perceived anonymity' of their research site as guidelines for online research are in development. By creating a more open dialogue on how online platforms can share data, alongside having informed consideration for online community members, we as researchers can

ensure that participants are protected while significant contributions to topics can still be obtained.

Conclusions and Further Directions

Throughout this thesis, I intended to represent the narrative of individuals suffering from eating disorders in a raw and honest manner, while protecting the community that provided the data. Through the reading of over a hundred posts, I was able to, in a sense, be alongside these individuals as they experienced extremely trying episodes of mental health. The honesty presented within these forums revealed how difficult the lived experiences of relapse in eating disorders can be, and some posts were emotionally challenging to read in themselves. The narratives collected from Reddit exemplified how truly individual an experience of an eating disorder can be, which in turn can be extremely isolating. To combat that feeling, many users engaged in Reddit to find a community in which they either received support, advice, or an audience.

The first chapters of this thesis tackled the conception of this study, from methods to theoretical frameworks, and 'what is already known' about eating disorders and relapse was presented. Through discussions of prior research, it became evident that there was a lacking consensus on what eating disorder relapse and recovery should be defined as, along with an absence of larger amounts of patient narratives. This gap in knowledge led to the creation of this study, which aimed to further conceptualize eating disorder relapse, explore how relapse can be triggered, and bring forth personal experiences with relapse.

Much of this thesis was formed by the data, rather than from preconceived categories. This was my intention as I wanted to have a thesis that begin with the individuals who were affected by the disorders I was discussing. I therefore had flexible research objectives, mainly aiming to understand the multi-faceted experience of relapse through the lens of a sufferer. In the results

section, the analyzed data was used to show how much variation there was in how relapse is experienced by the individual, beginning with triggers and ending with disorder outlook. In comparison to ED literature, individuals with eating disturbances tended to have less strict guidelines for what constituted a relapse, though users included more emotionally charged labels and also had degrees of severity that were not always present in previous research. Aside from relapse conceptualizations, many community members were extremely honest and self-reflective with how they regarded their relapses. Users were divided among things such as if a relapse was spontaneous or triggered as well as if each person wanted to relapse, felt comfort by relapse, or feared being within a relapse. These complex emotions surrounding relapse often resulted in self-doubt or shame when a person could not escape their relapse, or hopelessness toward future recovery.

The main outcome of the results was that patient narratives are often not reflected in clinical research or definitions, even though the narratives from ED sufferers provide key insights on triggers, emotional states, and disorder outlook related to relapse. Through the investigation of patient narratives, many aspects of the medicalization of eating disorders can be approached and innovated, so that relapse is conceptualized in a manner that is consistent with narrations of relapse events. In addition, information on triggers and disorder outlook can help inform both treatment and prevention practices.

This thesis tackled relapse from several different directions, and I sincerely hope that the individuals who have been through relapse will be a part of any future discussions on how to tackle this obstacle of recovery. As shown by the hundreds of posts collected for this thesis, ED sufferers have much to say about their own experiences with their disorders and their conceptualizations should not be overlooked. Further research can include larger numbers of

participants in order to ensure truly informed practices are created with representative data, as well as more qualitative investigations on phenomena within the course of an eating disorder. By shifting the focus to the individual, we as researchers can ensure that our contributions serve as advocacy for those who experience the disorder.

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Appendix A: Python Code

**** : personal information

```
import praw
from psaw import PushshiftAPI
import time
import pandas as pd
import datetime as dt

def log_action(action):
        print(action)
        return

api = PushshiftAPI()

reddit = praw.Reddit(
        client_id = '**********',
        client_secret = '*********',
        username = "relapseresearchstudy",
        password = "*********",
        user_agent = "my agent"
   )

base_dir = '*********

subreddits = ['EDAnonymous', 'fuckeatingdisorders', 'eating_disorders']
start_year = 2022
end_year = 2022

start_month = 3
end_month = 5

key_words = ['relapse','relapsing','relapsed','relapses','recurrence']

for month in range(start_month, end_month+1):
        action = '[month]: ' + str(month) + '\n'
        log_action(action)

        dirpath = base_dir + str(month)
        if not os.path.exists(dirpath):
                os.makedirs(dirpath)

        # timestamps that define window of posts
        ts_after = int(dt.datetime(2022, month, 1).timestamp())
        ts_before = int(dt.datetime(2022, month+1, 1).timestamp())
```

```
for subreddit in subreddits:
	start_time = time.time()

	action = '[Subreddit]: ' + subreddit
	log_action(action)

	subreddit_dirpath = dirpath + '/' + subreddit
	if os.path.exists(subredditdirpath):
		continue
	else:
		os.makedirs(subredditdirpath)

	submissions_csv_path = str(month) + '_' + subreddit + '_submissions.csv'

	submissions_dict = {
		'id' : [],
		'url' : [],
		'title' : [],
		'score' : [],
		'num_comments' : [],
		'created_utc' : [],
		'selftext' : [],
	}

	gen = api.search_submissions(
		q = 'relapse + relapsing + relapsed + relapses + recurrence',
		after = ts_after,
		before = ts_before,
		filter = ['id'],
		subreddit = subreddit,
		limit = 100
	)

	for submission_psaw in gen:
		submission_id = submission_psaw.d_['id']

		submission_praw = reddit.submission(id = submission_id)
		submissions_dict['id'].append(submission_praw.id)
		submissions_dict['url'].append(submission_praw.url)
		submissions_dict['title'].append(submission_praw.title)
		submissions_dict['score'].append(submission_praw.score)

submissions_dict['num_comments'].append(submission_praw.num_comments)
		submissions_dict['created_utc'].append(submission_praw.created_utc)
		submissions_dict['selftext'].append(submission_praw.selftext)
```

```
                        submission_comments_csv_path = str(month) + '_' + subreddit +
'_submission_' + submission_id + '_comments.csv'
                        submission_comments_dict = {
                                'comment_id' : [],
                                'comment_parent_id' : [],
                                'comment_body' : [],
                                'comment_link_id' : [],
                        }

                        # extend the comment tree all the way
                        submission_praw.comments.replace_more(limit = None)
                        # for each comment in flattened comment tree
                        for comment in submission_praw.comments.list():
                                submission_comments_dict["comment_id"].append(comment.id)

        submission_comments_dict["comment_parent_id"].append(comment.parent_id)

        submission_comments_dict["comment_body"].append(comment.body)

        submission_comments_dict["comment_link_id"].append(comment.link_id)

                        # for each submission save separate csv comment file
                        pd.DataFrame(submission_comments_dict.to_csv(subreddit_dirpath + '/' +
submission_comments_csv_path, index=False))

                pd.DataFrame(submissions_dict).to_csv(subreddit_dirpath + '/' +
submissions_csv_path, index = False)


                action = f"\t\t[Info] Found submissions:
{pd.DataFrame(submissions_dict).shape[0]}"
                log_action(action)

                action = f"\t\t[Info] Elapsed time: {time.time() - start_time: .2f}s"
                log_action(action)
```

Appendix B: UiO Ethic Board Recommendations

Faculty of Medicine

University of Oslo

Marisa Koster

Date: 12.06.2022

Statement from the Program Ethical Committee

The Program Ethical Committee have processed your application, number 21464321, about your project *"Out of the Clinic, Onto the Web: Narratives of Relapse during Eating Disorder Recovery on Reddit"*

The committee believe that your project does not fall under the Norwegian Health Research Law (helseforskningsloven and forskningsetikkloven) hence you do not need to apply for approval from the Regional Committees for Medical and Health Research Ethic (REC). However, person sensitive information might be collected and therefore you need to submit your protocol to the Norwegian Centre for Research Data (NSD) for review and approval.

Supervisors for **Marisa Koster's** master project are:

- **Daniel Münster** - Institue of Health and Society, UiO
- **Lasse Bang-** Norwegian- Institute of Public Health Sincerely yours

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Appendix C: NSD Notification Form

Project description
This study aims to navigate the written expressions of relapse events from users of the social media site Reddit, using the internet to involve persons with eating concerns both engaged in and outside of treatment. Through narrative and thematic analysis, individual posts will be explored to establish an understanding of how relapse is given meaning by sufferers. Posts with comments on eating disorder forums written between March 2022 and May 2022 will be extracted and then coded for sentiments, symptoms, and themes. I will discuss found commonalities in the lived experiences and how these insights can be used to better the conceptualization of relapse in ED recovery. I will also speak on how this data relates to current knowledge and practice in the eating disorder community and how health approaches can be adapted with the greater awareness. Lastly, I will if forums are tool or detriment to the delicate process of eating disorder recovery by analyzing the content of the comments.

If the collected personal data will be used for other purposes, please describe
Not applicable

Explain why it is necessary to process personal data in the project
The text used is necessary for textual analysis of eating disorder narratives found on social media. In order to directly analysis how users express relapse online, I will need the exact text and language used. Using the text posts also allows for the inclusion of a large data set of diverse accounts. The proposed research will add to eating disorder knowledge and contribute to the limited qualitative ED relapse research. The analyzed data will shed light on the ambiguity of ED relapse while providing a "patient-first" conceptualization of the term relapse. This conceptualization can be fused with medical definitions of relapse to provide a comprehensive classification that reflects both patient perspectives and professional input. After processing and analyzing, all data included in the written research paper will be fully anonymous and not searchable.

Project description
MarisaKoster-Protocol .docx
Type of project
Student project, Master's thesis

Contact information, student
Marisa Koster, marisajkoster@gmail.com, tlf: +4740160539

Data controller

Data controller (institution responsible for the project)
Universitetet i Oslo / Det medisinske fakultet / Institutt for helse og samfunn

Project leader (academic employee/supervisor or PhD candidate)
Daniel Münster , daniel.munster@medisin.uio.no, tlf: +4722850550

Will the responsibility of the data controller be shared with other institutions (joint data controllers)?
No

Sample 1

Describe the sample
Users of Reddit that have posted in the selected Reddit threads: r/EDAnonymous (75.3K members), r/fuckeatingdisorders (24.9k members), and r/eating_disorders (14.3 k members) from March 2022 to May 2022.

Describe how you will recruit or select the sample
All posts will be collected from the stated Reddit threads in the proposal from March 2022 to May 2022 via data harvesting.

Age
13 - 100

Are any of these groups included in the sample?

- Patients or ill people

Personal data relating to sample 1

- Other data that can identify a person
- Health data

How will you collect data relating to sample 1?
Social media – open forum
Legal basis for processing general categories of personal data
A task in the public interest or in the exercise of official authority (General Data Protection Regulation art. 6 nr .1 e)

Explain your choice of legal basis
Because Reddit is an anonymous website, data collected will only relate to a username and profile without any identifying information. Usernames will be removed upon data collection and replaced with number codes to reduce risk. Additionally, no searchable text will be used in the written research paper. The experiment aims to collect observations without researcher bias in hopes of gaining insight into a dangerous health disorder and the use of social media is in order to collect large amounts of data. All data is readily available online and does not require any membership to search and read all posts on public threads. For these reasons, I do not believe that informed consent is necessary and processing of this data should be allowed.

Legal basis for processing special categories of personal data

Archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes (General Data Protection Regulation art. 9 nr. 2 j)

Explain your choice of legal basis
I am processing data on eating disorder experiences in able to better inform health care practices which lies within public and scientific interests.

Information for sample 1

Will you inform the sample about the processing of their personal data?
Yes

How?
Written information (on paper or electronically)

Information letter
information_letter-2 (1).doc

Third Persons

Will you be processing data relating to third persons?
No

Documentation

How can data subjects get access to their personal data or have their personal data corrected or deleted?
Data subjects will not be personally identifiable by the collected data and the data being used is currently visible to all online. An explanation of the research will be posted on each thread that data is being harvested from to allow any user to delete their data by contacting me. The information states that only public data is being collected and all will be anonymized within the final research paper.

Total number of data subjects in the project
100-999

Approvals

Will you obtain any of the following approvals or permits for the project?
n/a

Processing

Where will the personal data be processed?

- A computer belonging to the data controller

Who will be processing/have access to the collected personal data?

- Student (student project)
- Project leader

Will the collected personal data be transferred/made available to a third country or international organisation outside the EU/EEA?
No

Information Security

Will directly identifiable data be stored separately from the rest of the collected data (e.g. in a scrambling key)?
Yes

Which technical and practical measures will be used to secure the personal data?

- Personal data will be anonymized as soon as no longer needed
- Restricted access
- Multi-factor authentication

Duration of processing

Project period
15.08.2022 - 01.06.2023

What happens to the data at the end of the project?
Personal data will be anonymized (deleting or rewriting identifiable data)

Which anonymization measures will be taken?

- Personally identifiable information will be removed, re-written or categorized
- The identification key will be deleted

Will the data subjects be identifiable (directly or indirectly) in the thesis/publications from the project?
No

Additional information

Other attachments
SGO DPIA 900792 til godkjenning version 2.docx

Appendix D: Information Letter

Notification of the Research Project

"Out of the Clinic, Onto the Web: Narratives of Relapse during Eating Disorder Recovery on Reddit?"

This is a notice about participation in a research project where the main purpose is to collect and analyse narratives of relapse in eating disorders. In this letter we will give you information about the purpose of the project and how data on this website will be used within the project.

Purpose of the project

This study aims to navigate the written expressions of relapse events from users of the social media site Reddit, using the internet to involve persons with eating concerns both engaged in and outside of treatment. Through narrative and thematic analysis, individual posts will be explored to establish a greater understanding of how relapse is given meaning by those who experience it. By comparing narratives, we aim to better the understanding of relapse in ED recovery and discuss how this data relates to current knowledge and practice in the eating disorder community and how health approaches can be adapted with greater awareness of sufferers' experiences.

This study is being completed as a master thesis for the University of Oslo within the program of International Community Health.

Who is responsible for the research project?
The University of Oslo is the institution responsible for the project.

Where and why is this data being collected?
Data will be collected from three eating disorder related threads: *r/EDAnonymous* (75.3K members), *r/fuckeatingdisorders* (24.9k members), and *r/eating_disorder*s (14.3 k members). These threads were chosen based off the number of community members, with all threads ranking in the top five communities in non-specified eating disorder subreddits and due to the lack of moderator-approved posts.

What does participation involve for you?

We will collect all posts containing the words: "relapse", "relapsing", "relapsed", "relapses, and "recurrence" on the chosen threads from **March 2022 – May 2022**. The collected data will include a post ID that replaces the username, the title of the post, the body of text in the post, the score of the post (equal to upvotes minus downvotes), and the number of and text content of comments. This data will be extracted onto an external hard drive, where posts from all threads will be combined into one data source. **This means that all that is being collected is the text within a post without the username.**

All data posts will be anonymized upon collection by replacing the username with a unique ID of randomized numbers. While the collected data will include the entire word post with comments, no posts will be used within the research project. **All text and comments will be paraphrased so that no posts are identifiable** within the research project.

Participation is voluntary

If you see this notice and wish for your data to be deleted from the data source, please send me a message and I will find your data and delete it from my data set.
All information collected from Reddit will be made anonymous. There will be no negative consequences for you if you chose not to participate or later decide to withdraw.

Your personal privacy – how we will store and use your personal data

We will only use your personal data for the purpose(s) specified in this information letter. We will process your personal data confidentially and in accordance with data protection legislation (the General Data Protection Regulation and Personal Data Act).

- *I, Marisa Koster, and my project leaders Daniel Münster, PhD and Lasse Bang, PhD will have access to the data. All data will be stored with the anonymous ID on posts.*

- *All data will be stored on a data server owned by the University of Oslo. This ensures that the data is protected and stored without access to any other users.*

What will happen to your personal data at the end of the research project?

The project is scheduled to end June 1st, 2023. All data will be erased on August 1st, 2023 to ensure time for the master examination.

Your rights

So long as you can be identified in the collected data, you have the right to:

- access the personal data that is being processed about you
- request that your personal data is deleted
- request that incorrect personal data about you is corrected/rectified
- receive a copy of your personal data (data portability), and
- send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data

What gives us the right to process your personal data?
We will process only data that is publicly available on the website of Reddit.

Based on an agreement with the University of Oslo, Data Protection Services has assessed that the processing of personal data in this project is in accordance with data protection legislation.

Where can I find out more?
If you have questions about the project, or want to exercise your rights, contact:

- The University of Oslo, Department of Community Medicine and Global Health via Daniel Münster by email: (daniel.munster@medisin.uio.no) or Marisa Koster by email (m.j.koster@studmed.uio.no)
- Our Data Protection Officer: Roger Markgraf-Bye, email: (personvernombud@uio.no)
- Data Protection Services, by email: (personverntjenester@sikt.no) or by telephone: +47 53 21 15 00.

Yours sincerely,

Project Leader (Researcher/supervisor)	Student (if applicable)
Daniel Münster	Marisa Koster

Appendix E: DPIA

Our ref.: 900792
Adviser: Simon Gogl
Date: 11.10.2022
Version: 2

Data Protection Impact Assessment

Project title: Out of the Clinic, Onto the Web: Narratives of Relapse during Eating Disorder Recovery on Reddit

Data controller: University of Oslo

Project leader: Daniel Münster / Marisa Koster (student)

Project number: 900792

Version History

Version	Changes	Changes in the document	Approval by data controller
Version 2	Personal data will be stored on UiO Educloud according to the recommendation from UiO's data protection officer	Section 5	The change has been approved by the data controller before the data collection started. Cf. dialogue in the project's notification form

About the Data Protection Impact Assessment (DPIA)

Data Protection Services has, together with the project leader and advisers of the data controller, prepared a draft of a DPIA on behalf of the institution. This draft contains:

1. A systematic description of the planned processing activities
2. An assessment of whether the processing activities are necessary and reasonable in relation to the processing purposes
3. An assessment of the risks to the rights and freedoms of data subjects
4. Measures that will manage these risks

We find that if the planned measures are implemented then the risks to the rights and freedoms of data subjects will be reduced to an acceptable level. In this way, the planned processing of personal data will comply with the General Data Protection Regulation, without the need for prior consultation with the Norwegian Data Protection Authority (DPA).

It is the data controller that ultimately decides whether the data protection impact assessment is satisfactory, and whether the risks are reduced to an acceptable level (allowing for the planned processing to be carried out) or whether it is necessary to consult the DPA (see part 6). The data controller should consult its data protection officer and consider any codes of conduct which may be relevant before making this decision. We hereby forward our assessment to our contact at the institution for approval. We ask that the final version of the DPIA is signed and uploaded in the notification form.

1 Background

Data Protection Services has reviewed the contents of the Notification Form. It is our assessment that the planned processing of personal data will involve a relatively high risk to the rights and freedoms of the data subjects. It is therefore necessary to carry out a data protection impact assessment (DPIA), cf. the General Data Protection Regulation art. 35 nr. 1.

It is necessary to carry out this assessment because the planned processing involves:

- Processing special categories of personal data about health or information of a more personal character
- Limited possibility for data subjects to exercise their rights
- Processing of personal data about vulnerable individuals

2 Purpose

The student describes the purpose of the data processing as follows:

This study aims to navigate the written expressions of relapse events from users of the social media site Reddit, using the internet to involve persons with eating concerns both engaged in and outside of treatment. Through narrative and thematic analysis, individual posts will be explored to establish an understanding of how relapse is given meaning by sufferers. Posts with comments on eating disorder (ED) forums written between March 2022 and May 2022 will be extracted and then coded for sentiments, symptoms, and themes. I will discuss found commonalities in the lived experiences and how these insights can be used to better the conceptualization of relapse in ED recovery. I will also speak on how this data relates to current knowledge and practice in the eating disorder community and how health approaches can be adapted with the greater awareness. Lastly, I will analyse if forums are tool or detriment to the delicate process of eating disorder recovery by analyzing the content of the comments.

2.1 Assessment of purpose limitation

Data Protection Services finds that the purpose is clearly defined, specific, explicit and considered reasonable for a research institution.

3 Data subjects

3.1 Data subjects, samples, recruitment and contact with the data subjects

The data subjects will be individuals that have been posting and commenting in the Reddit threads reddit.com/r/EDAnonymous (75.3K members), r/fuckeatingdisorders (24.9k members) and r/eating_disorders (14.3 k members) between March 2022 and May 2022. As the platform Reddit is open to users from the age of 13, it must be assumed that the data material will contain posts and comments of children and underage teenagers.

The student estimates that the downloaded data material will contain posts and comments of approximately 100 individuals.

Due to the sample size, the project will not be in direct contact with the data subjects. However, it will be possible to post information about the data collection in the threads.

3.2 Assessment of information and transparency

The data subjects will not receive individual information about, nor consent to, the processing of personal data. The challenges the GDPR's principle of information. However, the project will make information publicly available through a post/link in the threads that are harvested for data. The information provided will comply with Article 14, nr. 1-2.

Data Protection Services finds that an exemption from the data subjects' right to individual information can be made, cf. art. 14, nr. 5b.

3.3 Assessment of the data subjects' other rights and freedoms

The individual data subjects will have the right to exercise their rights of access, rectification, deletion, restriction and protest as long as they are identifiable in the dataset.

The data subjects can contact the student or project leader by e-mail, through the address provided in the publicly available information if they wish to exercise the above-mentioned rights.

4 Data sources, type and scope of personal data

The data will be collected from three threads on the online platform Reddit. The project will scrape all posts and comments from r/EDAnonymous (75.3K members), r/fuckeatingdisorders (24.9k members) and r/eating_disorders (14.3 k members) between March 2022 and May 2022. The threads are openly accessible and searchable and the overall expected publicness of posts and comments on the platform is relatively high.

The data will consist of a post ID that replaces the username, the title of the post, the body of text in the post, the score of the post (equal to upvotes minus downvotes), and the number of and text content of comments. Data will be harvested with the use of Python and usernames will be replaced with numbers during the harvesting of the posts.

Users on Reddit are usually not directly identifiable. However, it might be possible that users identify themselves through the content of their posts. Furthermore, it might be possible that the username is used on other platforms, too, which could help to identify an individual. The IP-address of the commenter/poster is known to Reddit.

Due to the topic of the research, the project will process special categories of personal data about heath (eating disorders).

Data subjects will not be identifiable in the publication. The student will rephrase posts and comments to make re-identification impossible.

4.1 Assessment of data minimisation

The project will collect data from a limited period (March to May 2022). Only indirectly identifiable data will be collected and does not aim to analyse/trace individual persons' experience. No personal data will be published, unless the data subject has given their consent.

We consider that personal data to be processed is adequate, relevant, necessary, and limited to what is necessary for the research purpose.

4.2 Assessment of data accuracy

The personal data will be obtained from posts and comments published by the data subjects. There is thus little reason to believe that the information is incorrect.

5 Data flow

- The researcher will collect all posts containing the words: "relapse", "relapsing", "relapsed", "relapses, and "recurrence" on the threads from Reddit named r/EDAnonymous (75.3K members), r/fuckeatingdisorders (24.9k members), and r/eating_disorders (14.3 k members) from the period of March 1st 2022 – May 31st 2022.
- Data will be harvested through the use of Python, which will extract the following: a post ID that replaces the username, the title of the post, the body of text in the post, the score of the post (equal to upvotes minus downvotes), and the number of and text content of comments. The data is organized into a table with each post and its comments being grouped into one table row.
- This data will be stored directly in UiO's Educloud, in a protected folder only accessible by the student and her supervisors (Dr. Lasse Bang and Dr. Daniel Münster). Data will not be sent or moved from to other storage solutions or devices.

5.1 Access to personal data

Only the student and the student's supervisor(s) at the University of Oslo will have access to the dataset.

5.2 Assessment of integrity and confidentiality

Our assessment is that the technical and organisational measures described above will provide adequate protection against unauthorized/illegal processing of personal data, as well as unintentional loss/destruction/damage of personal data.

6 Duration

The project will process personal data until 01.06.2023. After that, personal data will be deleted or anonymized.

6.1 Assessment of storage limitation

We consider the duration of the processing of personal data to be proportional to the research purposes.

7 Data Protection Services' overall assessment

Our assessment is that the project will handle the identified risks in an acceptable manner, and that personal privacy will thus be adequately safeguarded.

We emphasise that the project will process only indirectly identifiable personal data for a relatively short period of time. It will be rather unlikely that a data subject can in fact be identified in the material. Furthermore, we give weight to the fact that the material is published by the data subjects themselves on a platform with a high degree of expected publicness. However, we point out that some subreddits and threads within these subreddits can be quite small with few respondents, lowering the degree of expected publicness of a particular conversation. Moreover, in subreddits such as r/EDAnonymous, not all users might know that their posts are not completely anonymous.

We also emphasise that information about the project is publicly posted in the respective threads/subreddits.

7.1 Assessment of the risks to the rights and freedoms of data subjects

Data Protection services has identified the following risks to the rights and freedoms of the data subjects:

- Processing special categories of personal data about health or information of a more personal character
- Limited possibility for data subjects to exercise their rights
- Processing of personal data about vulnerable individuals (underage children and teenagers)

7.2 Planned measures to manage the risks

- The project processes personal data only for a relatively short period.
- Access to the material is limited to the student and her supervisor(s) at the data controlling institution
- The data subjects are not directly identifiable in the data material
- Information about the research project will be made available in the analysed subreddits.
- Quotes from the material will be paraphrased in the thesis to make identification impossible

7.3 Assessment of legal basis

The purpose of this research project is to establish an understanding of how relapse is given meaning by sufferers of eating disorders, how this data relates to current knowledge and practice in the eating disorder community, and how health approaches can be adapted with the greater awareness. Data Protection services finds that the public interest in the research is high and that the planned measures will reduce the risks for the data subjects to a large extent. Our assessment is that the public interest of this research clearly outweighs the risks to the rights, freedoms, and legitimate interests of the data subjects.

The project will process general categories of personal data on the legal basis that processing is necessary for the performance of a task carried out in the public interest, cf. the General Data Protection Regulation art. 6.1 e), and for scientific research purposes, cf. art. 6.3 b), cf. the Personal Data Act § 8.

The project will process special categories of personal data about health on the legal basis that processing is necessary for scientific research purposes, cf. art. 6.1 e), cf. art. 9.2 j), cf. the Personal Data Act §§ 8 and 9.

The processing is in accordance with appropriate safeguards for the rights and freedoms of the data subject, cf. art. 89.1.

7.4 Changes

If the envisaged processing of personal data is initiated on the basis of this DPIA and then the project is later changed, this might require a new or updated DPIA. It is the responsibility of the data controller to make sure that the project leader notifies such changes to us. In these cases, we will assist the data controller in assessing whether a new or updated DPIA is required, and if so, prepare a new/updated draft.

8 Advice and approval from the data controller

8.1 Advice from the data protection officer

8.2 Approval from the data controller

9 The following persons have been involved in the data protection impact assessment:

Name	Role/function	Institution
Simon Gogl	Senior advisor	Data Protection Services
Olav Rosness	Advisor	Data Protection Services
Marisa Koster	Student	UiO